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# Universal Principles of Bioethics and Patient Rights in Saudi Arabia

Ahmed Abdulbasit Bukhari

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UNIVERSAL PRINCIPLES OF BIOETHICS AND PATIENT RIGHTS IN SAUDI ARABIA

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

Ahmed A. Bukhari, MBBS, MHMS

May 2017

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2017

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By

Ahmed A. Bukhari

Approved March 2, 2017

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Henk ten Have, MD, PhD  
Director, Center for Healthcare Ethics  
Professor of Healthcare Ethics  
(Dissertation/Project Chair)

---

Gerard Magill, PhD  
Vernon F. Gallagher Chair for  
Integration of Science, Theology,  
Philosophy and Law  
Professor of Healthcare Ethics  
(Committee Member)

---

Joris Gielen, PhD  
Center of Healthcare Ethics  
Assistant Professor of Healthcare Ethics  
(Committee Member)

---

Henk ten Have, MD, PhD  
Director, Center for Healthcare  
Professor of Healthcare Ethics  
(Center Director)

---

James Swindal, PhD  
Dean, McAnulty College and Graduate  
School of Liberal Arts  
Professor and Dean of McAnulty College  
(Dean)

## ABSTRACT

### UNIVERSAL PRINCIPLES OF BIOETHICS AND PATIENT RIGHTS IN SAUDI ARABIA

By

Ahmed A. Bukhari

May 2017

Dissertation supervised by Henk ten Have, MD, PhD

In order to keep pace with international bioethical practices, and with international bioethical declarations, this dissertation will investigate challenges facing patients' rights discourse in Saudi Arabia, and the adaptation of universal bioethics standards in the Saudi healthcare system. The role of religion and issues of human rights will be discussed further, given that religion and human rights affect patient's rights profoundly. Specifically, the divergence between religious dictations and the secular language of human rights principles will provide a distinctive perspective on patients' rights discourse, especially in a country such as Saudi Arabia where religion is integral to the national foundations, and where customs are vividly alive.

This dissertation will examine patients' rights as practiced in an international context in order to compare Saudi bioethics practices to other bioethics systems, while pinpointing the

strengths and limitations. In addition, Saudi practices concerning patient's rights are compared to the universal principles of bioethics, to show the variation between the existing and the desired ideal practices.

Furthermore, this dissertation will highlight the organizational and cultural challenges that decrease the possibility for the full adoption of patients' rights in Saudi hospitals in order to analyze the problems and formulate recommendations for future action.

This study carries with it presumed significance as one of a few analyses of patients' rights in one of the least studied countries in the field of bioethics, Saudi Arabia.

## DEDICATION

*To my family*

## ACKNOWLEDGEMENT

I would like to express my deepest gratitude to Doctor Henk ten Have, my dissertation advisor and teacher. Thank you for your patience, support and guidance through the years.

Also I would like to acknowledge other committee members Doctor Gerard Magill, and Doctor Joris Gielen. Thank you for your kind encouragements.

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## Chapter One: Introduction and Overview

International human rights have become a subject of global discourse in recent decades, especially in postmodernity, and almost all nations across the globe ascribe to degrees of the essences and principles of these rights. Roberto Andorno (2002) mentions, "... the current worldwide political consensus on the importance of protecting human rights."<sup>1</sup> Furthermore, Andrew Clapham (2007) asserts that, "playing the human rights card can be persuasive, sometimes even conclusive in contemporary decision making."<sup>2</sup> Thus, human rights and its fabricated principles are not passively acquired, and not peacefully pledged to communities of the world. In fact these rights were obtained forcefully, and went through difficult and long process of struggling labor. In reference to the Declaration of Human Rights of 1948, Jose Alves (2000) states that, "despite countries initially rejecting principles of this Declaration, eventually the nations changed their positions in response to the continuous demand of the people for their rights."<sup>3</sup>

Again, the vast consensus of the importance of protecting human rights is a direct result of fruitful and cooperative work of various international organizations, and humanitarian agencies such as The World Health Organization, the World Medical Association, and the United Nations Educational Scientific and Cultural Organization. However, the need to formulate binding laws to protect human rights is closely linked to international goals to prevent unethical biomedical activities in healthcare and research.

Principles of bioethics based on human rights statures are deemed vital to protect people's dignity and rights in medical and research settings. Roberto Andorno (2002) states:

Global challenges raised by biomedical advances require global responses. Some international organizations have made significant efforts over the last few years to establish common standards that can be regarded as the beginning of an international biomedical law. One of the main features of this new legal discipline is the integration of

its principles into a human rights framework.

Given the long history of its negligence in healthcare and research, the principles of modern patients' rights are relatively new and long overdue. The theoretical foundations of patient rights have been translated into numerous ethical principles, regulations, guidelines, and international declarations. This has helped in monitoring, regulating, and promoting the relationship between patients and healthcare providers on the basis of a mutual respect, articulating moral virtues, and guarding through codes and legal terms. Despite modern principles of bioethics articulating Western moral philosophies and specifically American ideologies,<sup>4</sup> these principles are also popular in non-western communities, and therefore have become internationally perceptible.

The enforcement of patients' rights in research and at patients' bedside is also relatively novel in many healthcare systems in many countries, due to the fact that these countries lack relevant bioethics infrastructure and the legislative and organizational power that is vital to protecting patients' rights. The absence of bioethics promoting logistics in some countries occurs due to lack of bioethics committees, lack or lenient bioethics laws, and even due to political or religious reservations.

In a similar fashion, standards that relate to patients' rights are implemented minimally or neglected in local healthcare settings due to ignorance of bioethics discourse; this can be due to individual acts, or due to complete organization culture mishaps. For instance, despite autonomy being a primary principle in bioethics that is discussed and protected by many international treaties, many providers in the Saudi Arabian healthcare sector and other countries fail to deliver services in accordance to best practices that preserve patient autonomy. Consequently, these healthcare systems fail to observe the universal bioethical standards.

Many internationally enacted bioethics principles aim to promote patients' rights, and assert the importance of respecting patient autonomy in accordance to the contemporary understanding of the inherited rights as well as the universality of these rights. However, when certain standards of the universal principles are applied in varying countries, they can conflict with local political and cultural norms; due to this conflict, these standards are deemed incompatible with indigenous cultures and political endeavors. For instance, in many non-industrialized communities people depend willingly or out of necessity on their families and tribal heads to deliver decisions regarding personal affairs; this is particularly the case when these people are faced with major issues, such as getting married or seeking extraordinary medical remedies.

In cultures where individualism is highly valued, such reliance on heads of families or the treating physician to deliver decisions on behalf of competent individuals is considered absurd. Out of context, this is the viewpoint because this decision making is considered an act of paternalism which contradicts the nature and principles of human rights of these cultures.

The issues of patients' rights in Saudi Arabia are not solely associated with the absence of the culture of bioethics, or lack of relevant laws, or even rejection of international laws. Rather, patients' rights as practiced in Saudi Arabian healthcare are a true manifestation of the dominant cultures of communitarianism and rise in accordance to the indigenous comprehension of the details of patients' rights. In addition, these rights as perceived in healthcare settings play into the rhythm of the existing Arabic culture and religion of Islam, which profoundly inspires the country's moral decisions, values, and choices as related to the healthcare system.

To elaborate on compatibility issues of patient's rights and culture, many countries have heated debates between intellectuals regarding the rejection or possible adaptation of the United Nations Educational, Scientific and Cultural Organization (UNESCO) Universal Declaration on

Bioethics and Human Rights in local settings. These debates are a segment of a broader discussion in relation to the application of principles of international human rights in non-western countries, in addition to the clash between different ideologies; this topic is discussed by Masudul Choudhury (2008) as related to the clash between Islam and liberalisms.

Many intellectuals argue that the international enacted principles and declarations articulate western philosophies, which resulted in the rejection of its essences for which it represents and the ideologies the principles are based on. Andrew Clapham (2007) states, “The historic development of the concept of human rights is often associated with the evolution of Western philosophical and political principles.”<sup>6</sup> Similar to Clapham’s (2007) argument, David Held (2013) denotes the wide influence of the western philosophies and their dominance: “Until recently, the west has, by and large, determined the rule of the game on the global stage. During the last century, Western countries presided over a shift in world power- from control via territory to control via the creation of governance structures created in the post 1945 era.”<sup>7</sup>

Therefore, the universality of bioethical standards and global principles of human rights are put into question and have been challenged frequently by intellectuals. The targeted populations for these international principles are diverse and distinctive. As presented by Almutairi (2015), “Each country has its own unique culture that defines the normative values of an individual or a group. This culture determines behavior that outlines all aspects of their lives.”<sup>8</sup>

In reference to Saudi Arabia, David Long (2005) states, “Western nationalist ideology did not hold much appeal for deeply conservative Saudi society, and bitterness at Western colonialism was never as strong among Saudis... in the words of King Faisal: We do not need to import forging traditions. We have a history and a glorious past.”<sup>9</sup> The statement from the Saudi King, which represents the country’s official outlook, holds a conservative position related to the

imitation and adoption of Western ideologies. These ideologies are perceived as paradoxical to the Saudi culture, and the religion of Islam.

Accordingly, and in reference to human rights and essences of bioethics, various Islamic countries have developed several patients' rights protocols. These protocols are considered compatible with the ideologies and religions of Saudi Arabia among those Islamic countries.

Interpretations of the principles of bioethics are congruent with common beliefs of locals, making it acceptable to the majority of Saudis. The universal recommendations related to bioethical activities advocate for a universal adoption of a unified set of principles, aiming to ensure that every person can receive adequate, standardized, and ethical care.

Patients' rights in the Saudi healthcare systems are derived from the dominant teachings of Islam, *Sharia*. Islamic traditional scripts and scholarly interpretations of the texts dominate Muslim's personal and public living endeavor. Similar healthcare ethics principles, which generally constitute the relationship between physicians and patients, are of no exception. Not only is religion persuasive at bedsides and in clinical settings; in fact, parochial cultural and traditional norms sway people's decisions tremendously.

In Saudi Arabia and many traditional countries, customs and traditions can be as influential as religion in determining a person's choices and rulings, including the choices made in illness and at healthcare facilities. Culture in Saudi Arabia and other developing countries prioritize needs of the community over individuals; as David Long (2005) states, "Despite the western influences introduced into the Kingdom since the early 1930s, social life still revolves around the home and family to a great degree."<sup>10</sup> Such practices demonstrate how these cultures are prone to overlook patients' rights in medical settings for the sake of culture and customs. Sachedina (2009) wrote, "Moreover, in Muslim world, like many developing world countries, medical practices continue to



remain essentially authoritarian and paternalist.”<sup>11</sup> This type of practice would consequently lead to abandonment of certain aspects related to standard of care customary to the universal principles of bioethics.

Traditions and customs most often conflict with the international regulations and universal guidelines. Therefore, a general consensus on what constitutes as best practice in ethics is challenging.

Challenges facing patients’ rights in Saudi hospitals can be described as cultural norms and affiliated ties such as the wide practices of paternalism, lack of confidentiality which is regarded as an “absolute requirement” by the World Medical Association (WMA) (1986),<sup>12</sup> and rights to autonomy. These challenges merge together to thwart efforts to improve bioethics in healthcare facilities. More precisely, challenges facing patients’ rights in the Saudi Arabian healthcare system are organizational and cultural in nature. Similar to the effects of culture and customs on bioethics, organizational challenges effect patients’ rights in Saudi hospitals and hinder the desired improvements and efficacy of care.

This study examines issues related to patients’ rights in the Saudi healthcare system; it also investigates the Saudi healthcare system and elaborates on the local practices of patients’ rights. In order to stay current with the existing bioethical practices and international bioethical declarations specifications, this dissertation investigates the hindrances to the adaptation of universal bioethics standards in Saudi Arabia. In addition, the role of religion and issues of human rights will be discussed, given that religious dimension and issues of human rights have a profound effect on patient’s rights.

The divergence between religious dictations and secular language related to human rights principles will provide a distinctive perspective on patients’ rights discourse; this is specifically the

case in a country such as Saudi Arabia where religion is integral to national foundations and cultural customs are vividly alive.

This dissertation elaborates on the examination of patients' rights as practiced in international contexts to better situate Saudi bioethics practices with other bioethics systems, while pinpointing the strengths and limitations of these practices. In addition, Saudi practices concerning patient's rights are compared to the universal principles of bioethics, to demonstrate the variation between the existing and the desired ideal practices.

Furthermore, this essay highlights organizational and cultural barriers that challenge the possibility for full implementation of patients' rights in Saudi hospitals. This analysis of the challenges and problem areas allows for formulation of recommendations for future action.

This study is significant due to its position as one of a few analyses of patients' rights in Saudi Arabia, one of the least studied countries in the field of bioethics.

Limitations in the majority of previous studies of the Saudi healthcare system and patient's rights in Saudi Arabia are tangible, as there are not many relevant literatures of qualitative and quantitative significance. Ultimately, patients' rights are an inherent part of human rights discourse; therefore, any debate on ethics and patients' rights must be presented within the context of human rights. The following are brief outlines of the contents of the dissertation chapters:

Chapter two is devoted to present Saudi Arabian cultural background, divided into three main sections; the first section includes a brief sketch of the country's history, geography, socio-politics, and healthcare system. The second section focuses on the history of modern medicine, which is typically known as the Western medicine in Saudi Arabia. This section provides organization through an overview of developmental milestones throughout history, beginning with the earliest records and ending with contemporary developments. The earliest records

include ancient Greek medicine in its role as a precursor to modern medicine, and then shifts focus to Islamic contributions to medical knowledge. The final section of this chapter recounts and elaborates on the history of biomedical ethics. It discusses times in biomedical experimentation that violated patient rights, yet are associated with progress in medical knowledge. Furthermore, this section introduces contemporary declarations and understandings of ethical principles, which are designed to safeguard patients in biomedical settings and protect their rights.

The first section of chapter three discusses two interrelated concepts and relationships. The first is between the principle of dignity and human rights and the second, between human rights and biomedical ethics as well patient's rights.

Together these concepts are the basis for discussion of the challenges faced due to the implementation of bioethics principles in different cultures. Various viewpoints are presented in order to represent perspectives of several Islamic states on international principles of human rights.

Subsequently, a discussion of global bioethics and multiculturalism serves as partial foundation for the dissertation to engage in an inquiry as to why an adaptation of universal bioethics principles in some countries is problematic.

A summary of patients' rights in a global context provides an overview of contemporary biomedical issues, which conflict with bioethical standards. The claim of universality for the principles of UNESCO's Universal Declaration on Bioethics and Human Rights is discussed thoroughly in order to assess the potential inclusion of its standards in the Saudi healthcare system.

Chapter four provides a link between the previous discussions of global human rights along with universal biomedical principles, in addition to the potential application of these principles in Saudi healthcare systems. This chapter elaborates on the role of religion in bioethics, and more precisely the significance of Islamic faith in determining the moral standards of biomedical work for Muslim patients and their families.

Islamic teachings are considered as cornerstone in the lives of Muslims, including people of Saudi Arabia. This is particularly the case when ethical dilemmas rise in healthcare settings such as in conception, controversial procedures, and end of life situations.

In relation to patient's rights in Saudi Arabia, this chapter elucidates possible cultural barriers related to the adaptation of universal bioethical principles in the Saudi healthcare systems.

Chapter five focuses on organizational obstacles that affect patients' rights adversely, as well as elaborates on healthcare organizational ethics which enable better medical ethics practice. The chapter also discusses the significance and effect of organizational culture to patients' rights. In order to examine the organizational produced barriers to proper application of patients' rights, this portion of the dissertation examines the lack of proper patient-doctor relationships, the barriers to vibrant channels of communication between foreign workers and locals, and the absence of unified and well defined policies aimed at protecting patients'.

The sixth chapter is dedicated to examining issues that generate challenges to bioethics in Saudi Arabian healthcare. For example, Fayeze et al.'s (2013) study in a Saudi hospital has determined which ethical problems occur most frequently there. The researchers state that the top three challenges to ethical concerns are confidentiality issues (36.3%), issues of informed consent (60.2%), and encroachment on patient autonomy (42.5%). This chapter evaluates, from a

philosophical perspective, the weaknesses related to bioethics that hinder proper implementation of universal standards of patients' rights in the Saudi healthcare system. The subsequent section that compares Saudi healthcare with that of other countries, primarily the United States, is supported by the following: a discussion of the role of informed consent in protecting patients' rights in healthcare settings, bedside paternalism, confidentiality, and vulnerability in health settings.

Chapter seven consists of two sections; the first section summarizes the position of Islamic bioethics in relation to Saudi culture and the perspectives and practices that occur in Saudi Arabian healthcare settings. This chapter concludes that Saudi culture and the Islamic religion must be considered in any collaborative communication or initiatives between the Saudi healthcare system and international ethics committees; this includes any efforts to implement principles of bioethics in local Saudi settings.

If international principles and standards encompass cross cultural matters and acknowledge and respect the cultural foundations of the targeted communities, these international principles are accepted by local communities. An awareness of the significance of individual cultures can pave the way to facilitate international collaboration in areas of human rights and bioethics.

Various scholars emphasize the importance of cultural features as principal components in modeling human personality and experience due to its relation to one of the core principles of UNESCO's Universal Declaration on Bioethics and Human Rights. Sachedina (2009) writes,

International bodies like WHO and UNESCO, which support local efforts in developing culturally sensitive bioethical curriculum, still appear to be unaware of the essentially religious nature of bioethical discourse in Muslim world and the need to engage religious ethics in the Muslim context to better serve the populations whose culture take religion more seriously.<sup>13</sup>

In relation to the topic of this dissertation, efforts to show respect for cultural instantiations of universal standards of bioethics would significantly reduce variations for implementation in Saudi Arabia and other healthcare systems worldwide.

Furthermore, this section of the chapter emphasizes the point that since Islam and the UNESCO Universal Declaration ascribe to commonly shared sets of moral virtues; the principles impeded in the declaration are virtually applicable in the Saudi healthcare setting. The second section of this chapter is devoted to formulating suggestions of how to handle inconsistency in applying international standards of bioethics to local Saudi healthcare institutions and facilities.

Beyond this, the section devises several practical recommendations that aim to promote ethical practices in healthcare and establish an effort for synching patients' rights in Saudi healthcare facilities with the international standards; this effort maintains a primary focus on the UNESCO Universal Declaration on Bioethics.

Saudi Arabia health care related issues are largely solicited through statistical figures and quantitative digits, which often circumvent ethics of care dimension and neglect qualitative and in depth analysis of patient's ethics affaires. Therefore, the approximation on patients' rights studies in Saudi Arabia enriches the discussion and contributes to the understanding of how Saudi bioethics are formulated and executed while contributing to the subject of biomedical ethics in Saudi Arabia.

In conclusion, this dissertation highlights the current realities of patients' rights in Saudi Arabia, through examining the cultural and organizational impediments which affect those rights in medical settings. However, this discussion in part attend to inquiry on the universality of biomedical ethics standards, as promoted by the UNESCO Universal Declaration on Bioethics and Human Rights, and determine its appropriateness in local healthcare systems such as in the

Kingdom of Saudi Arabia, as the universality of bioethics standards itself are questionable, especially in non-Western communities.

Notes:

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- 1 Roberto Andorno, "Biomedicine and international human rights law: In search of a global consensus," *Bulletin of the World Health Organization*, 80, no. 12 (2002): 959-962.
  - 2 Andrew Clapham, *Human Rights: A very short introduction* (Oxford: Oxford University Press, 2007), 1.
  - 3 Jose Alves, "The Declaration of Human Rights in Postmodernity," *Human Rights Quarterly* 22, no. 2 (2000): 478-500.
  - 4 Angele Alora and Josephine Lumitao. *Beyond a Western Bioethics: Voices from the Developing World* (Washington DC: Georgetown University Press, 2001), vii.
  - 5 Masudul Choudhury, "Islam Versus liberalism: Contrasting epistemological Inquires," *Journal of Social Economics* 35, no. 4 (2008): 239 – 268.
  - 6 Clapham, *Human Rights: A very short introduction*, 5.
  - 7 David Held, *Cosmopolitanism: Ideals and Realities* (Oxford: John Wiley & Sons, 2013), 1.
  - 8 Khalid Almutairi, "Culture and language differences as a barrier to provision of quality care by the health workforce in Saudi Arabia," *Saudi Medical Journal* 36, no. 4 (2015): 425-431.
  - 9 David Long, *Culture and Customs of Saudi Arabia* (United States: Greenwood Publishing Group, 2005), 4.
  - 10 David Long, *Culture and Customs of Saudi Arabia*, 64
  - 11 Abdul-Aziz Sachedina, *Islamic Biomedical Ethics: Principles and application* (New York: Oxford University Press, 2009), 13.
  - 12 Raanan Gillon, *Philosophical Medical Ethics* (New York: John Wiley & Sons, 1986), 106.
  - 13 Abdul-Aziz Sachedina, *Islamic Biomedical Ethics: Principles and application*, 10.

## **Chapter Two: Saudi Arabia, History of Medicine, and Bioethics**

Chapter two is presented to view the Saudi Arabian cultural and religious backgrounds that determine its specifications in social, religious, and in medical settings eventually. In addition, a brief history of medicine, and history of bioethics are offered to demonstrate the relation between both on one hand, and in the other, their relation to Islamic tradition.

This chapter is composed of three main sections; the first section includes a brief sketch of the country's history, geography, socio-politics, and healthcare system. The second section focuses on the history of modern medicine, which is typically known as the Western medicine in Saudi Arabia. This section provides organization through an overview of developmental milestones throughout history, beginning with the earliest records and ending with contemporary developments. The earliest records include ancient Greek medicine in its role as a precursor to modern medicine, and then shifts focus to Islamic contributions to medical knowledge. The final section of this chapter recounts and elaborates on the history of biomedical ethics. It discusses times in biomedical experimentation that violated patient rights, yet are associated with progress in medical knowledge. Furthermore, this section introduces contemporary declarations and understandings of ethical principles, which are designed to safeguard patients in biomedical settings and protect their rights.

### **2.1 Saudi Arabia: Geo-Socio Politics**

Western scholars, orientalist, and travelers have written about Saudi Arabia since its foundation on 1932 by King Abdul-Aziz bin Abdurrahman Al-Saud.<sup>1</sup> Prior to that date and long before the establishment of the modern kingdom, the Arabian peninsula has been exceptionally attractive for historians and anthropologists, for what it implies as the birthplace of Islamic



religion,<sup>2</sup> and origin of Arab clans.<sup>3</sup> These clans spread Islam and Arabic culture to the adjacent territories, and then to the entire world.

Scholars portray Saudi Arabia in relation to personal perceptions and impressions related to the Middle Eastern Arab country. Americans who worked in Aramco Oil Company during the 1940's to early 1980's may hold convictions about Saudi Arabia that differ to those who have visited the country more recently. That era that contemporized decades ago was marked by repaid social and economic developments in various aspects, which resulted in a huge transition especially related to cultural domain. For instance, Long (2005)<sup>4</sup> argues that during the last 70 to 80 years, the kingdom of Saudi Arabia has made massive social changes effecting the fabric of its social and cultural makeup; these social changes have been more extensive than what have has occurred during the entire known history of Saudi Arabia.<sup>5</sup> Long (2005) relates this social transition to the booming evolution in the country's wealth, which has been generated by oil production and sales.<sup>6</sup>

Long (2005) claims, "Saudis of all generations have taken quickly to Western popular culture,"<sup>7</sup> in reference to modern adaptation of contemporary western way of living which has become a dominant global modification shared by world populations. This view is also shared by Nevo (1998), who states, "Promotion of national identity based on several comprehensive components is essential in view of the ongoing process of Westernization, accelerated by increasing exposure of wider segments of Saudi society to foreign values and practices."<sup>8</sup>

An alternative perspective is offered by Lippman (2012)<sup>9</sup> who portrays Saudi Arabia as a traditional country trying to escape its traditional past for the sake of modernity.<sup>10</sup> Contrary to Lippmann's (2012) statement concerning the unsettling Saudi cultural and economic forces,<sup>11</sup> Gallagher (2002) renders Saudi Arabia as a country vying to keep its social, cultural, and

political norms intact while facing the transformative forces of modernity.<sup>12</sup>

While these statements represent the perspectives of their writers, it undoubtedly reveals that Saudi culture and societal fabric have significantly evolved in the last few decades. For example, large segments of the endogenous populations have abandoned the way of nomadic life,<sup>13</sup> to live in urbanized communities and modern cities.<sup>14</sup> Alyateem et al, (2015) states, “Over the past fifty years, these countries have moved rapidly from predominantly nomadic societies into societies where the infrastructure and systems found in modern technologically based countries have been put in place.”<sup>15</sup>

Similarly, Van Eijk (2010) writes, “The discovery of oil in the 1930s rapidly changed the country and forced the government to adapt and reform, but at the same time it wanted to hold onto its Islamic character and heritage.”<sup>16</sup>

All evaluative conclusions aside, Saudi Arabia is a Middle Eastern Islamic monarchy<sup>17</sup> that covers 2,149,690 square kilometers, or about 850,000 square miles,<sup>18</sup> most of which is deserted and uninhabited. The majority of the population lives in major cities scattered over the country vast area. The Kingdom of Saudi Arabia is located in center of Arabian Peninsula, surrounded by Yemen, Arabian Gulf, Jordan, Iraq, and the Red Sea. The country maintains a population of 27,752,316 people, twenty percent of the population being non-Saudis and eighty percent being of Arab lineage.<sup>19</sup> All citizens of the Kingdom are Muslims,<sup>20</sup> as stated in official denoted statement, and the majority of the population follows the Sunni congregation. Nevo (1998) wrote, “By definition, a non-Muslim cannot be a Saudi citizen.”<sup>21</sup>

One of the most transformative events in history of the Kingdom was the discovery of crude oil in the Eastern region in 1938. This discovery instantly made the country rich in energy, resources, and capital. Possessing a quarter of world’s oil reserves permitted the Saudis to

rapidly achieve a decent standard of living; the estimated GDP per capita is 31,300.<sup>22</sup> Nakov and Nuno, (2013) describe the economic status of the Saudi Arabia: "... the behavior of Saudi Arabia as that of a dominant producer with competitive fringe."<sup>23</sup> Consequentially, citizens of the Kingdom maintain one of the highest per capita incomes in the region.<sup>24</sup>

However, the significance of Saudi Arabia as a major player in world is not merely due to its role as one of the largest producer and supplier of crude oil for the last decades, and probably for several decades to come<sup>25</sup>. The importance of Saudi Arabia originates from its centrality to Islamic world<sup>26</sup> as the birthplace of Islam and the host of the holy mosques.<sup>27</sup> In addition, hundred thousands of devoted followers of Islam come to the Kingdom each year to preform religious sacraments known as *Uma rah* and *Hajj*.<sup>28</sup>

This position in the Islamic world motivates Saudis to teach and maintain Islamic studies in order to meet Muslims expectations as the custodian of the two holy mosques. This status also entitles Saudis to spread and export their ideologies outside of the Saudi Arabian borders as the "guardian of Islam."<sup>29</sup> Saudi clerics and theologians commonly known as *Muftis*<sup>30</sup>, *Qudies*<sup>31</sup>, *Fuquha*<sup>32</sup>, and *Ulama* <sup>33</sup> are influential and predominant to Muslims and Saudis specifically; these clerics and theologians preserve and contribute to Islamic traditions, as well as manage the spiritual affairs of Muslim followers across Islamic communities.

*Fatwa* is a form of Islamic verdict produced by Muslim clerics, which is regarded as binding law. This law articulates Islamic tradition texts and jurisprudence: "All laws and regulations are drafted then submitted to a commission of Ulama, or religious scholars, to ensure that they comply with the Islamic Sharia."<sup>34</sup> In addition, Babgi (2009) describes Islamic legal system as such: "Islamic law and the teaching of the Sunna... layout the foundation of the legal, civil, and penal systems of Saudi Arabia's constitution."<sup>35</sup>

To demonstrate *fatwa* production, an example follows: The Islamic jurisprudence council of Makkah in Saudi Arabia produces *fatwas* that cover wide range of social, religious, and bioethics topics that require contemporary, yet religious interpretations.<sup>36</sup> These *fatwas* are highly regarded and respected by Muslims around the world due to the prestigious position of the council of Makkah.

Islamic law has many sources including the *Quran*, *Sunna*,<sup>37</sup> and precedent exertions and tales of *Salaf* (companions of the Prophet Mohammed, and following religious clerks). Appealing to Islamic sources to obtain and consequently impose laws to regulate Muslim's affairs is central to Muslim communities. The civil and criminal judicial codes, as well codes of ethics demonstrate these Islamic sources of ruling. This dependency on religion to obtain contemporary ruling is customary in Saudi Arabia. In representation to the extent that Muslims are attached to old divine scripts, Butterworth (2012) indicates the importance of Islamic teachings in life of ordinary Muslims and how the daily dialogue occurring in the Middle East has rationalizing Quranic verses.<sup>38</sup>

Religion not only dictates and determines daily living activities<sup>39</sup> and the dimensions of Saudi's cultural norms,<sup>40</sup> but it also exerts a profound influence on Saudi's decisions in healthcare facilities. The medical sector in Saudi Arabia is regulated by and subject to Islamic laws, submission to Islamic ruling, and clerical interpretations of medical ethics are required. Even in scientific breakthrough, Islamic law legislators postulate verdicts to answer inquiries through *Fiqh* and in accordance to *Sharia*: "Muslim theologians, jurists, and healthcare workers have been addressing the challenges of modern biotechnology for years."<sup>41</sup> Otto (2010) wrote the following to represent the profound centrality of religion to these peoples' lives: "Common people used to consult the scholars, asking them what sharia' would prescribe in a particular

case.”<sup>42</sup> Alyousefi (2012) explicitly states the role of religion bedside: “Although religion plays a major role in every aspect of the life of a Muslim, for example, everyday life, activities during the time of illness ...”<sup>43</sup>

Consequently and due to the importance of religion in Saudi’s health affairs, various scholars advocate for inclusion of supplementary religious incentives in medical care settings; the scholars observe that the incorporation of religion promotes healing and provides answers for in accordance to the inclinations of people. For example, in the concluding remarks of a study related to expatriates nurses working in United Arab Emirates and Saudi Arabia, Alyateem et al. (2015) professes that, “Many of these nurses come from non-Islamic countries and have limited knowledge and understanding of Islamic principles and of the local UAE and KSA cultures, values, and functioning;” the researchers found that providers who are unfamiliar with Islamic traditions had to try to comprehend indigenous cultural norms and religion specifications of their patients in order to provide more appropriate care.<sup>44</sup>

## **2.2 Healthcare Systems in Saudi Arabia**

Topics related to bioethics and patient’s rights in Saudi Arabia are relatively scarce and limited in quantity. This can be linked to the contemporary nature of Saudi Arabian bioethical revisions and owed to the modernity of the Kingdom.<sup>45</sup> While Mohammed Mufti (2000) argues that, “Organized medical care began in the Kingdom in 1926”<sup>46</sup>, Almalki et al. (2011) claims that it happened a year earlier than Mufti’s date.<sup>47</sup>

However, healthcare ventures were only able to make transitional shifts in their operational capabilities in the mid-1940s when substantial economic developments were provoked by vast oil discoveries.<sup>48</sup> The tangible shifts in healthcare in Saudi Arabia occurred

between the 1980s and 1990s in the form of constructing new hospitals and modern clinics.<sup>49</sup> At the present time, the Saudi healthcare system has developed greatly, which has allowed citizens and visitors to obtain sophisticated services within Saudi healthcare system, as well as placing the national healthcare system 26<sup>th</sup> out of 190 countries on World Health Organization scale.<sup>50</sup>

Reflecting the United Kingdom national healthcare system,<sup>51</sup> healthcare in Saudi Arabia is universally delivered to all citizens and non-Saudi government employees free of charge.<sup>52</sup> These services cover all types of medical care such as emergency care, regular consultation visits, laboratory tests, radiological screening, medications, rehabilitation services, and home visits. In addition, Muslim pilgrimages visiting the holy places in the Kingdom throughout the year are eligible for similar privileges.<sup>53</sup>

In addition to for-profit, private hospitals, medical services are offered through various public and private vendors, regardless of being of primary, secondary, or tertiary echelons. For example, the Ministry of Health provides healthcare services to the public: “In the Kingdom of Saudi Arabia, healthcare is offered for free to Saudi citizens through more than 2000 primary healthcare centers and 420 hospitals.”<sup>54</sup>

In a similar fashion, the Ministry of Defense, Ministry of Education, government owned oil company (Aramco)<sup>55</sup>, Ministry of National Guard, Ministry of Interior, and many other private and public entities provide healthcare services for employees and their families. These services are provided through each entity’s owned hospitals and clinics<sup>56</sup> or through reimbursing insurance premiums.<sup>57 58 59</sup>

Like many other healthcare systems around the globe, the Saudi healthcare system faces various sets of challenges that complicate its ability to provide exceptional and efficient healthcare services. The most prominent challenges include the following: soaring healthcare

cost, lessening quality of provided services, increasing consumptions of healthcare services, and even the utilization abuses due to without charge care provisions.

Among these challenges is the state of biomedical ethics and patient rights in Saudi hospitals, given that many healthcare workforces are unaware of the appropriate management of ethics related concerns.<sup>60</sup> For instance, in a study by Alghanim (2012) concerning awareness of patient's rights among healthcare providers in Saudi Arabia, the author writes, "In summary, although patient rights are increasingly emphasized around the world, they are relatively lesser known in Saudi Arabia and are often recalled only when the health care providers make mistakes, which cause death or disability."<sup>61</sup> In a similar research study, El-Sobkey et al. (2014)<sup>62</sup> concludes that medical professions students studying in various healthcare programs in Saudi Arabian universities are oddly unaware of patient's bill of rights, either regarding its existence or its contents.<sup>63</sup>

Often, a Healthcare provider's unfamiliarity with healthcare ethics is provoked by the lack of clear and definitive policies dealing with medical ethics in Saudi healthcare systems<sup>64</sup>. This lack of definitive policies exasperates the issue of large numbers of healthcare workers with highly diverse backgrounds and cultural specifications;<sup>65</sup> these diverse cultural backgrounds habitually perceive and deal with ethical situations according to their preferences, values, attitudes, and grasps of ethics of biomedicine.<sup>66</sup> In a study review by Khalid Almutairi (2015), the author discusses the issue and stresses the problem of communication between patients and workers, and the lack of local cultural knowledge.<sup>67</sup>

Other issues that are currently challenging the Saudi healthcare system are the lack of national healthcare system<sup>68</sup>, insufficient funding, healthcare insurance, booming costs of care, privatization of public hospitals, and shortage of manpower in healthcare facilities. However, the

Saudi healthcare sector is trying to cope to overcome those challenges through insuring better quality of care,<sup>69</sup> applying different promising solutions, privatizing public hospitals, fee- for service, and introducing insurance to public healthcare systems.<sup>70</sup>

## **2.3 History of Medicine**

The purpose of summarizing medical history is to highlight key milestones in the history of medicine, thereby to portray medicine as continuously evolving scientific field. The discussion will range from the dawn of medical knowledge in ancient Greece until present times. This narration includes contributions made by Muslim physicians and Islamic civilization to modern medical endeavor; Albar and Chamsi-Pasha (2015) write “For several centuries, the world, and particularly Europe, has benefited from the great contributions made by Muslim physicians in the field of medicine.”<sup>71</sup> However, modern medicine is discussed with ethics of medical care, in order to link history of modern medicine and biomedical ethics, as both ventures are closely related, interconnected, and central to the topic at hand. Albert Jonsen (2003) writes, “...it seems however, that the work of healing and convictions about rights and wrong behavior have always been tightly linked.”<sup>72</sup>

### **2.3.1 Western Medicine and the Virtue of Healing**

Unlike many other economic, social, and human activities such as marketing, trades, sports, and engineering that are considered more clear-cut and pre-determined, Healthcare and its subsequent inquiries are complex, hard to comprehend, and even difficult to manage. In other words, Healthcare requires added flexibility to follow different treatment approaches in order to manage the things that may seem to correspond at first glance. Medical care requires devotion to



adapt principles of care and rather than applying fixed regulations and stagnant guidelines; Ruth Purtilo (2005) writes, “Caring, in the context of professional ethics, incorporates more than common ordinary dimensions of the notion of care.”<sup>73</sup>

Therefore, healthcare related problems around the globe are unique in the nature of presented problems, concerns, and on articulating moral scale by which it is judged and managed. For that reason, Gert, et al (2006) cites that traditional morality is not capable for managing all issues in healthcare settings, hence healthcare settings require philosophical ideals that refine, delicate, and look beyond standards of common morality.<sup>74</sup> It is argued that to develop a moral framework that can incorporate bioethics requires consideration of human weakness and healthcare system complexity.<sup>75</sup>

This urge to secure morality through incorporating ethics beyond standards of common morality is also supported by Nancy Jecker (1997), who states, “It would also be inaccurate to assume that bioethicists themselves always ascribe to a particular methodological approach. To the contrary, many do not consciously deploy one method; others deploy a variety of different methods.”<sup>76</sup>

In regards to the subject and in relation to Gert et al.’s (2006) position from common morality,<sup>77</sup> Beauchamp and Childress (1997)<sup>78</sup> label theory of common morality used in healthcare ethics as a pluralistic approach to ethical inquiries. This uses different yet widely recognized methods to explain ethical inquiries. This point validates bioethics as a unique discourse and represents its nature of how bioethical concerns need to reach beyond typical ethical questions.

While healthcare systems worldwide maintain different approaches to healthcare related questions, eventually all healthcare systems stumble upon similar obstacles. In comparison to

other aspects of human life activities, healthcare is more closely associated with ethical principles, moral standards, compassion, empathy, and devotion to humanistic professionalism<sup>79</sup>. This is due to the nature of dealing with human weakness and urgency in healthcare.

The “market characteristics” of medicine, which are a prominent aspect of the field in the 21st Century, did not exist prior to the 18th century.<sup>80</sup> Prior to the 18<sup>th</sup> century, the altruistic nature of medicine and its concomitant philosophy of healing dominated the scene. Medicine prior to the work of Hippocrates was associated with “prayers and rituals,”<sup>81</sup> rather of being based on science and rationality. In the *History of Medicine*, William Bynum (2008) writes in reference to that era:

The priest-physician is a common trope. Disease was widely assumed to be the result of divine displeasure, transgressions of various kinds, or magical forces. Diagnosis might involve prayer, interpreting animal entrails, or determining how the patient had transgressed. This mix of magico-religious medicine was also part of the Greek landscape during the Hippocratic period.<sup>82</sup>

Modern medicine as the world knows it has emerged through various important milestones and has developed tremendously in the last few decades. These developments are due to the advancements in medical technologies and other allied sciences, especially after the Second World War.<sup>83</sup>

Bynum (2008) claims that contemporary medicine is a lawful descendant of the ancient Hellenic medical knowledge: “Hippocratic medicine is holistic. The Hippocratic approach is always to the whole patient and the modern yearning for a holistic medicine finds a natural resting place there.”<sup>84</sup> This perspective supports Rosen’s (1993) claim that the establishment of rational medical knowledge started with Greek Healthcare. Somewhat distinct from its moral underpinnings, Western medicine began with the abstract concepts of health and illness as represented by Hippocrates’ four humors,<sup>85</sup> and *vix medicatrix naturae*. Within that framework,

healthcare advanced to Galen's era some five hundred years later, introducing experimentation into the art of healing.

The mid-17th century and 18<sup>th</sup> century marks the beginning of the enlightenment era.<sup>86</sup> The enlightenment era was especially noted in England and Germany as new hospitals were formed in order to reform medical practices for brighter horizons.<sup>87</sup> Kerr L. White (1991) describes this period: "The search began for fundamental and universal laws that governed the physical and natural worlds. A more rational approach to religious, social, economic, and political problems gradually emerged."<sup>88</sup> Thus, Thomas Sydenham (1624-1689), among others assisted in unconstrained medicine from the medieval sorcery and lengthy accompanied divination.<sup>89</sup> These qualitative and brilliant transitions transpired through establishment of foundations for scientific-based and clinically proven medical knowledge.

Across European states, new hospitals and medical schools have been made and existing ones have altered their curriculum to incorporate courses based in science and clinical observations.<sup>90</sup> Due to these changes, medicine has developed and transitioned into an era of computerized technology and modern machinery. These shifts in medical knowledge provoke moral inquires that did not exist previously. Some examples of contemporary issues include equal distribution and allocation of healthcare resources,<sup>91</sup> the ethics of genetics, enhancements, and prenatal and newborn genetic screening implications. <sup>92</sup>

Taking care of the underprivileged is a virtue rooted in one of humanity's finest moral traits, which urges people to care for each other and sanction them to sympathize with another's suffering and hardship.<sup>93</sup> Therefore, the concept of caring for patients in professional healthcare settings is based on genuine and commonly shared moral virtues. These virtues need to be stressed and reinforced by bioethics to indicate that healthcare ethics not only deal with

professional ethics and essences of common morality, but also delve further to insure better ethical practices. Beauchamp and Childress write in reference to ethics of care, “what physicians and nurses do... but also how they perform those actions.”<sup>94</sup>

The virtue of caring for others is not merely concerned with meeting the required standards of ethics in healthcare, but extends beyond minimum standards to attain additional quality-based services and better perspectives that reflect healthcare ethics values. Ghaly (2013) writes, “Contemporary bioethics should address the new pressing questions, and also develop new approaches.”<sup>95</sup> Therefore, the mission of medicine is humanistic at its core, and those who practice medicine are ethically obliged to care for those who need their services.

Healthcare providers have a moral obligation to treat patients in accordance to common morality and in adherence to the symbolic Hippocratic ethics,<sup>96</sup> which are regarded as the bases of healthcare professional code of ethics. This moral obligation of care for patients and the trust patients place in their physicians, distinguishes physicians from other professionals. This means that the trust in a physician’s moral characteristics is just as important as his professional’s skill and competence.

While medical codes of ethics base regulations on the essence and terminology of the classical Hippocratic Oath, this medical code of ethics constitutes the relationship between physicians and patients. Industrialization of medical care has imposed a new reality on this complicated bond. According to Lynch (2008), “... the past several decades have seen a major transition in the traditional relationship between doctor and patient.”<sup>97</sup>

New realism of healthcare services marked by increasing cost of care, subjected to forces of monetary profits, moved by legal regulations and social reform in modern days has forced the doctor-patient relationship to a new level of distrustful relation incentives and imperfection

collaboration.<sup>98</sup> There are various reasons for this shift in relationship; one factor is a growing self-awareness among individuals <sup>99</sup> as a result of western philosophical influences. These philosophical influences emphasize the significance of personal autonomy and human rights. Another factor is the emergence of conflicts of interest and of conscience in the healthcare industry. Despite the industrialization of medicine forcing a new reality on medical services, the original mission of medicine as a humanistic science remains intact. Physicians are therefore reminded of their obligations to patient wellbeing and are legally held responsible for these ethical concerns.

Childress and Siegler (2006) identify five models of relationship between physicians and patients; paternalism, partnerships, contract, friendship, and technical assistance.<sup>100</sup> These models describe the potential relationships between doctors and patients based on the terminology that describes the relation, and consequently describe the nature of these affairs in relation to bioethics.

### **2.3.2 Islamic Medicine and Arabic Culture**

Islamic medicine or forms of medicine practiced in Muslim communities are based in Greek medicine.<sup>101</sup> The medieval period in Islamic states were marked with a huge translation of Greek scientific and philosophical literatures into Arabic language<sup>102</sup> and then to Latin.<sup>103</sup> These efforts in translation enable Muslim scholars to view and study the work of precedent intellectuals and therefore contribute to their work. Pormann and Savage-Smith (2007) wrote, “One cannot appreciate the development of medical theory and practice in the Islamic medieval period without understanding its Greek antecedents.”<sup>104</sup>

Namely, medieval Muslim scientists such as Rhazes, Avicenna, Ibn Jani, Ibn Ridwan,

and Averroes contributed substantial bodies of knowledge to medicine,<sup>105</sup> for which theories and books are being studied and taught in Muslim states and European universities.<sup>106</sup> Ghaly (2013) states, “Rispler-Chaim argued, I claim that since there is an Islamic medicine which is based on Greek medicine but also on Qur’anic teachings and on the model set by the Prophet Muhammad in the Hadith,”<sup>107</sup>

A clear distinction needs to be made between Prophetic Medicine,<sup>108</sup> *Al-tibb-Al-nabawi*,<sup>109</sup> and the Hellenic originated medicine, “allopathic medicine”.<sup>110</sup> Prophetic Medicine represents complementary and alternative medicine that is widely practiced in Saudi Arabia and other Islamic countries.<sup>111</sup> The Hellenic originated medicine has been transferred to Arabia, translated from Greek to Arabic between the late 8th and 11th centuries,<sup>112</sup> and later to Latin in the thirteen century.<sup>113</sup>

Medical knowledge is based on texts of the *Quran* and the Prophet Mohammed’s *Hadith*, gathered and narrated by later Muslim scholars and clerics; this represents a collection of medical recommendations categorized under spiritual medicine, treatment practices, and preventive measurements known and practiced by the Prophet, his companions, and succeeding generations.<sup>114</sup> For instance, Fazulr Rahman (1987) writes, “Ibn Qayyium tells us that Prophetic Medicine deals with the overall principles while scientific medicine fills in the details.”<sup>115</sup> In addition, Albar (2002) claims that, “Islamic teachings carry a great deal of instructions for health promotion and disease prevention including hereditary and genetic disorders.”<sup>116</sup>

There is an additional form of Islamic medicine which is considered as a continuation of Greek medical legacy, and has been translated, added to, and practiced by many Muslim physicians such as Alkharizmi,<sup>117</sup> Rhazes,<sup>118</sup> Avicenna,<sup>119</sup> Averroes, Ibn Albaytar,<sup>120</sup> Albiruni, and others. Guy Attewell (2003) refers to it as, “Greco- Islamic medicine,” for which he

elaborates on: “The term Islamic medicine encompasses the traditions of medical theory, practice and literature that have been developed in Islamic cultural contexts and expressed most commonly in the languages of Islam.”<sup>121</sup>

In a similar fashion, Islamic biomedical ethics engage in ethical issues through theological channels, which represent the Islamic perspectives in accordance to *Sharia* law. Since the beginning of Islam, Muslim scholars have contributed to science through engaging scientific inquiries in pure scientific technique or through interpretation and examination of science through Islamic judicial assessments; this will show its suitability and fulfillments of Muslims’ religious requirements.

Albar and Chamsi-Pasha (2013) claim that Muslim physicians such as Alruhawi, the author of *Adab al-Tabib* Practical Ethics of the Physician, and Rhazes, the author of *Akhlaq al-Tabib* Medical Ethics, made substantial contributions to the science of bioethics. However, Sachedina (2009) argues that many scholars take Islamic bioethics as, “a subspecialty of applied Islamic jurisprudence,”<sup>122</sup> which only relate the bioethical discussion in Islamic contexts on permissibility or impermissibility of the medical act itself. This clearly steers away from the discussion of ontological dimensions and neglects the rationality of bioethical care beyond the decreed verdicts *fatwas*.

At this point, a distinction should be drawn between Arabic and Islamic cultures,<sup>123</sup> as the terms are used in conjunction with each other in various contexts and are almost synonymous in some old Western literature. Islam originated in Arabia approximately fifteen hundred years ago, though the majority of contemporary Muslims are non-Arabs.

Followers of Islamic faith come from diverse ethnic backgrounds<sup>124</sup> and have different cultural orientations.<sup>125</sup> In addition, Arabic ethnic backgrounds can be diverse in their religious

backgrounds in their definition and association with cultural specifications.<sup>126</sup> The purpose of this anthropologic discussion is to distinguish Saudi culture from other Arabic and neighboring cultural guidelines. Every Islamic community has its own practices, in addition to varying approaches to bioethical inquiry.

Godfrey Tangwa (2005) defines culture as, "...basically a way of life of a group of people, underpinned by adaptation to a common environment, similar ways of thinking and acting and doing, similar attitudes and expectations, similar ideas, beliefs and practices, etc."<sup>127</sup> Therefore, conclusions can be drawn from this holistic definition in regards to the Saudi culture which demonstrate the culture is a subdivision of Arabic culture. This is due to the shared common features within the Arabic world and the deep roots in Islam; these features mark culture and religion in Saudi Arabia as inseparable.

## **2.4 Biomedical Ethics**

Medical knowledge is in continuous need for scientific experimentation on humans for the purposes of developing new remedies, vaccines, prosthesis, and experimental organ transplantations. However, there are ethical considerations when experimenting on humans due to its potential of exposing people's to morbidity, mortality, or even for possible exploitation. Due to these potential risks, a significant number of immoral medical experiments and unethical clinical trials have occurred throughout the history, and therefore stained the work of many researchers. Subsequently, this led to the formulation of ethical codes and national and international declarations to regulate biomedical activities in order to help prevent unethical practices.

Biomedical ethics did not develop instantaneously or overnight; in fact, ethics of



medicine may be traced to the dawn of modern medicine and to the Hippocrates oath, which maintains the essence of bioethical values. On other hand, the old medical ethical standards are not sufficient enough to handle contemporary ethical issues occurring in healthcare.<sup>128</sup>

Biomedical ethics as a discipline is a branch of applied ethics philosophy<sup>129</sup> and has emerged from old medical ethics; old medical ethics are primarily concerned with the etiquette of physicians and the image of medical profession to be more concerned with the meta-ethics and normative ethics of moral inquires in healthcare settings. Therefore, bioethics has entered into new realm of organized scientific discipline with established journals, dedicated bioethics centers, workshops, and international conferences. Today, the Hasting center, Kennedy institute, and the society for health and human values are all dedicated to address biomedical ethics inquiries.<sup>130</sup>

George Khushf (2004) defines bioethics as, "...a large, interdisciplinary field, with contributions from philosophy, theology, literature, history, law, sociology, anthropology, and the diverse health professions."<sup>131</sup>

Biomedical ethics is a multi-disciplinary science that requires cooperative work between various disciplines to form a potent, integral system capable of addressing current and future moral inquires occurring in healthcare settings. David Steinberg (2007) writes, "Brandt, a historian of medicine, notes that bioethics is shaped by social and political conventions of the times."<sup>132</sup> This statement signifies the nature of bioethics as byproduct of social and political present environment, which reflect the convections and cultural norms of the society. Therefore, religious societies such as Saudi Arabia employ Islamic teachings in the forging of bioethical standards and convections; other more secular communities articulate primarily philosophical theories in bioethics.

### 2.4.1 History of Biomedical Ethics and the Unethical Practices of Biomedicine

According to Albert Jonsen (2007), “Bioethics appeared in the world of medicine in early 1970s”,<sup>133</sup> and Ten Have (2012) argues that history of bioethics as a new concept emerged to addresses issues related to the ethics of biomedicine starting with the innovation of the word bioethics, by Van Rensselaer Potter (1971),<sup>134</sup> in *Bioethics: Bridge to the Future*.<sup>135</sup> Ten Have (2012) also claims that Potter (1971) understood and used “bioethics” to tackle issues not precisely related to the modern concepts and current resolutions of bioethics as the world knows it today. Potter (1971) solicits an interdisciplinary scientific specialty that can address incoming future of biology in general: “...because of my conviction that bioethics must be based on modern concept of biology.”<sup>136</sup> Potter (1971) describes this domain as a discipline that should devote its essences to decrease the gap between man and ecology. This particular argument made by Potter is cited by Warren Thomas Reich (1994), “... for Potter a research oncologist the word bioethics had environmental and evolutionary significance, whereas Hellegers, the Dutch obstetrician/fetal physiologist/demographer who was instrumental in founding the Kennedy Institute of Ethics at Georgetown University with his Georgetown Colleges, used the term more selectively to apply to the ethics of medicine and biomedical research.”<sup>137</sup>

The development of the concept of bioethics has gone through various evolving stages as the concept of human rights. Both concepts have submitted to changes in ontological interpretations, and therefore have been applied in different practical contexts.

According to Daryl Pullman (2014), Pellegrino breaks down the evolvement of bioethics throughout the history into four stages. The first stage began with a quiescent period stretching from the time of Hippocrates to the 1960s, which marked the start of the second period which he called “principlism” when medicine became more associated with modern technology.<sup>138</sup>

The third stage is referred to as anti-principlism; Pellegrino claims that the questioning of the principle of bioethics by various philosophical traditions marked this stage. The fourth period is labeled as the crisis period; he argues that crisis results from the debate over the universality of bioethics principles, and the consensus over bioethics norms.<sup>139</sup>

According to Jonsen (2000), the ethics of medicine goes back to the Hellenic era, and Roman practices of ancient medicine; from this perspective, both Western medicine and the bioethics are bonded from the beginning, Pellegrino (1979) writes, “In the Greek era, philosophy and medicine were intimately interrelated. From their fruitful relationship came a medical system which went far beyond earlier empiricism and provided the requisite base for the evolution of scientific medicine.”<sup>140</sup>

While in recent times, and according to Sarah Ferber (2013) “Bioethics became more multidisciplinary in the 1990s, scholars of from arrange of academic fields began to pay greater heed to the role of language, narrative and rhetoric in the presentation and understanding of medical ethics issues.”<sup>141</sup>

However, bioethical discourse in postmodernity produces new queries regarding its legitimacy, efficiency, scope, rationality, and universality. For instance, many scholars including Tan Alora and Lumitao (2001) refuse the notion of internationalizing biomedical ethics.<sup>142</sup> Alora and Lumitao (2001) claim that moral value perspectives can be imposed on various communities by religious differences, political preferences, and cultural specifications.<sup>143</sup> This is supported by Chattopadhyay and De Vries (2013) in their article, *Respect for Cultural Diversity in Bioethics is an Ethical Imperatives*. Cheng-Tek Tai (2013), in a respectful manner, advocates for a collaborative form of western and eastern biomedical ethics in order to solve medical ethics issues without neglecting cultural specifications.<sup>144</sup>

In contrast, Ten Have and Gordijn (2011) argue that the UNESCO Declaration on Biomedical Ethics and Human Rights, which is regarded as the most comprehensive and recent internationally formulated bioethical principles, conveys multiple cultural norms in its principles. In addition, Tomislav Bracanovic (2011) argue that "...introducing the idea of respect for cultural diversity into bioethics encounters a series of conceptual and empirical constraints."<sup>145</sup> Bracanovic's (2011) viewpoint supports the idea of universality of bioethical principles as a unified ethical framework, and rejects the idea of incorporating various traditions and culture in formulating biomedical ethics principles.

As a result of globalization, internalization of laws, and advancements in telecommunications, many international declarations designed to engage global bioethical issues are predominantly based on western ethics.<sup>146</sup> Westernization of international law and prioritization of its principles occur due to biomedical ethics being spread throughout western countries to solve ethical dilemmas that arise from medical interventions and research occurring primarily in these countries. Therefore, international declarations naturally reflect occidental perspectives and moral philosophies, particularly European and North American philosophies.

This position is similar to Pollis and Schwab's (1979) *Human Rights: A Western Construct with limited Applicability*; this text provides the viewpoint that human rights are not universal and not valid to all communities. Bielefeldt (2000) argues that Pollis and Schwab, other prominent scholars such as Huntington, and Muslim scholars such as Mawdudi reject the idea of unified and universal human rights principles.<sup>147</sup>

Although medical research and practice have contributed to the wellbeing of humans through disease prevention, prolonging of life, as well as promotion of public health and overall standards of living, frequent and widely scattered incidences of unethical medical

experimentation still occur. Despite medical experimentation helping in the advancement of medical knowledge and scientific breakthroughs, unethical medical research trials produce horrific results which jeopardize the lives of thousands; these individuals can become victims of exploitation and greedy research practices.<sup>148</sup> In a clear violation of human rights and through an unnatural adaptation of paternalistic, utilitarian<sup>149</sup> social theories,<sup>150</sup> many researchers and politicians have allowed unethical research activities to occur by justifying through the weakest of logical reasoning.<sup>151</sup> Emanuel and Grady (2010) states, “Louis Lasagna, chair of the Department of Pharmacology and Toxicology at the University of Rochester, has taken the position that individuals could be sacrificed for the greater social good, asserting that the best protection for research participants has been the ethical standards of researchers.”<sup>152</sup> Furthermore, what caused unethical research activities to flourish in the past were false presumptions and misleading justifications asserted by the researchers involved in such experimentation. Those who had supported unethical research activities claim that scientific knowledge produced by research trials is precious, making the research objectives and procedures necessary to achieve the objectives, ethically justifiable. These researchers stated that although their work may neglect ethical requirements such as detailed information disclosure or informed consent, the anticipated outcomes will eventually help advance knowledge about a disease or drug, therefore allowing the vast majority of humanity to benefit from the outcomes which would justify overlooking some “technicalities.”

In response to these arguments, Callahan (2003) and others ask, “Was this research carried out by cold, cruel physicians? Not at all. For them the research imperative-the overriding importance of the relief of suffering or death of future victims of disease provided a clear justification for putting present subjects at risk.”<sup>153</sup> In fact, a number of unethical research trials

have occurred without any justification, which is usually presented by researchers; this could be due to the researchers being caught up in the objectivity of the research idea which causes them to be blind to issues such as ethics, or due to researchers intentionally exploiting certain human groups.<sup>154</sup> For example, during the World War II the Nazi regime held war prisoners in concentration camps and allowed physicians and scientists to perform degrading, torturous experiments on the prisoners.<sup>155</sup> Thousands of people died as a result of these experiments, and hundreds more suffered permanent disabilities.

Another infamous model of medical experimentation is the Japanese Imperial Army's experimentations on Chinese prisoners.<sup>156</sup> The Imperial Army, represented by its medical unit and affiliated departments, exposed thousands of Chinese prisoners to unethical trials; these trials were aimed primarily to train Japanese surgeons, develop biological weaponry, and conduct various biological research on human subjects.<sup>157</sup> Consequently, a significant number of prisoners died throughout those trials and those who survived suffered greatly, left with physical and mental damage.

Such experimentation occurred during wartime, driven by vengeance and ethnic abhorrence rather than scientific curiosity. William R. Lafleur has framed a theory of "war time conditions,"<sup>158</sup> by which he indicates that the mass of unethical experiments occur during peacetime.

Surprisingly, the majority of unethical trials occur in countries where human rights are valued and protected by enacted laws. For example in the United States and United Kingdom, many disastrous events of unethical trials have occurred in these countries regardless of the existence of protective laws. These unethical experiments are usually conducted upon vulnerable groups, for whom the majority of laws were enacted to protect against exploitation.

Guraya et al (2014) wrote, “In the early 1960s, most notably in the United States, instances of unethical medical research was reported over the volunteers, especially those who were vulnerable or terminally sick, were treated with obvious disrespect and exposed to significant risks of harm.”<sup>159</sup>

However, these misfortunate unethical trials have helped in the advancement of patients’ rights in healthcare as well as in research within these countries and other states.

In 1965, Henry Knowles Beecher<sup>160</sup> a Harvard professor and “Whistle-blower”<sup>161</sup> alarmed people and directed public attention toward the unethical activities occurring in American institutions.<sup>162</sup> In 1966 Beecher published an article in the *New England Journal of Medicine* summarizing the occurrence of twenty two unethical medical research studies.<sup>163</sup> As Beecher flagged the shocking reality of unethical experimentation practices, a number of these experimentations were simultaneously occurring on American soil. Unspecified numbers of people were used as objects for experimentation, without an informed decision, awareness of danger, and awareness of possible outcome of morbidity and mortality.

One of these studies is the Tuskegee Syphilis Experiment,<sup>164</sup> during which many black African Americans diagnosed with syphilis, “a highly contagious disease”<sup>165</sup> that is sexually transmitted, were denied existing therapeutic medications; this denial of treatment was meant to allow researchers the ability to study the course of the disease if left untreated. Many men who were treated with the placebo during the trial died horrifically, while others lost their minds and sight as a result of syphilis progression. Despite governmental agency supervision, the Tuskegee experiment illustrates the lack of ethics and accountability among researchers who ignored the code of ethics and basic morality, and were selfishly blinded by the potential research outcomes.

In a similar trial from 1954 onward, children at the Willow Brook Mental Institution, Staten Island, New York<sup>166</sup> were deliberately injected with hepatitis virus serum, in order to study hepatitis etiology and followed pathologies; this was meant to help researchers better understand the pharmacology of existing vaccines in order to better recommend future vaccines for the virus. As a result of this study, the children become infected with hepatitis and developed moderate to severe symptoms of the disease. There was no point throughout the experiment or afterward that the parents of those children who received the virus were informed. This study was under close supervision of the National Institute of Health (NIH)<sup>167</sup> and the *New England Journal of Medicine* published the outcomes; this demonstrates again the lack of ethical standards in medical systems including the United States. Additional trials lacking ethical consideration occurred under the supervision of respected universities and governmental committees, on land and overseas, include the AZT trial in Kenya, Uganda, and Thailand.<sup>168</sup> This represents and demonstrates how ethical standards of research activities can be overridden, dismissed, and ignored.

These reprehensible activities raised deep questions about the ethics of research and compelled the international community to enact and enforce standards, laws, and regulations to control biomedical activity. Spencer et al. (2000) writes, “In 1966 the Public Health Service mandated a local process of prior group review of any research project submitted for federal funding. Since 1974, there have been a series of federal legislative initiatives that require internal institutional oversight and protection for research subjects.”<sup>169</sup> However, the standard is summarized by Jonsen et al. (2010), “All states now have laws requiring informed consent for medical treatment, except in certain emergency situations.”<sup>170</sup>



## **2.4.2 Codes, Principles, and Declarations on Biomedical Ethics**

National and international laws<sup>171</sup> as well various national agencies have obliged healthcare workers and researchers to adopt better standards to promote safer practices.<sup>172</sup> These laws, regulations, and international declarations have been introduced and enforced to control biomedical practices worldwide, and to safeguard research activities against exploitative and abusive behaviors in medical and scientific ventures.

In contemporary times and in response to unethical activities practiced in biomedical settings and in research as detailed earlier, a series of international collaborative efforts resulted in enacting number of these codes and policies. Beginning with the Nuremberg Code of 1947,<sup>173</sup> formulated as an initial response to the horror of German concentrated camps of the WWII, and primarily attends to insure safe research passage. This was then followed by the 1964 Declaration of Helsinki,<sup>174</sup> the Belmont Report of 1978,<sup>175</sup> The UNESCO Universal Declaration on Bioethics and Human Rights,<sup>176</sup> and the work of various other subsequent national ethics commissions and committees in individual countries. This series of declarations and codes represent a keen interest on the part of the international community as well national agencies to promote human rights, and to elevate standards of biomedical ethics.

On other hand, concerned national agencies and some private entities have introduced different regulation to reflect governmental interest to promote patient's rights and safety in healthcare settings. Governmental agencies, which are assigned to control healthcare services and public health safety, formulate guidelines and policies that impose those regulations through strict laws.

Indeed, such regulations are mandatory to be monitored <sup>177</sup> and it is the responsibility of the healthcare organization to insure that these regulations are adopted and standardized in

various organization departments.<sup>178</sup> Noncompliance with governmental regulations, especially those regulations concerns patient safety and rights would subject healthcare organization to legal actions. For example, in the United States and in order to prevent medical error committed by inadequate medical training programs, the Accreditation Council for Graduate Medical Education ACGME has the authority to shut down any medical graduate programs in any healthcare organization for not complying with ACGME regulatory requirements.<sup>179</sup> Another example of governmental regulatory guidelines aimed to promote patient rights and decrease medical error incidences is the Joint Commission for Accreditation of Healthcare Organizations JCAHO<sup>180</sup> protocol known as the *Universal Protocol to Prevent Wrong Side and Wrong Patient Surgery.*<sup>181</sup> This protocol standardizes a set of precautionary regulations to prevent medical errors occurring in the operation room.

Even more, in 2006 the Joint Commission directed healthcare organization to adopt coded regulations aimed to prevent medical errors through improving communication standards in the healthcare organization, these regulations are known as the *Joint Commission National Patient Safety Goal.*<sup>182</sup>

Specific regulations are not firmly enforced by regulatory agencies but are highly recommended to be followed. Moreover, Healthcare Insurance Portability and Accountability Act HIPAA<sup>183</sup> developed certain measurements aiming to protect patient safety through protecting medical information and clinical data, and by unifying the international disease code, which used in correspondences between different healthcare organizations, which decreases the chance of medical error, and misinterpreting clinical data.

On the other hand, accreditation requirements and affiliation with various health care organizations require an enhancement in patient rights quality practices through encouraging

healthcare organizations to adopt and apply advance measurements in patient rights practices based mainly on best available guidelines and resources.

Further, a Prestigious affiliations with world class medical centers such as Mayo-clinic, Harvard Medical Center, and other medical associations plays a major role in promoting patients safety practices, and under market competition and under peer pressure forces various healthcare organization are obliged to provide excellent healthcare services, comparing to those institutions.

An example of accreditation role to promote patient rights is the Joint Commission<sup>184</sup>1995 code of organizational ethics which been introduced to promote ethical practices inside healthcare organization.<sup>185</sup> The Joint Commission as an accreditation agency known for promoting patient rights encouraged health care organizations to adopt and embrace ethical values, and by encouraging healthcare organizations to adopt ethics as standard requirements in developing organizational regulations, the Joint Commission set standards of quality healthcare work soaring above minimal governmental standards.

## **2.5 Conclusion**

This chapter inspects Saudi Healthcare systems and its components, as well present the historical, cultural, and social relevant backgrounds that affect the bioethics discourse in this country. Furthermore, the history of modern medicine and bioethics, were discussed while listing developmental milestones, and observing how codes and declarations of bioethics are developed, along with the surrounding circumstances that helped in shaping the current discourse of bioethics. Although, the international biomedical standards are considered to be “Universal” there are many scholars who oppose such claim of the universality of bioethics standards and describes it as a creation of western philosophy. This particular point was stressed in the

precedent discussion, through representing how western philosophies influence the contemporary bioethics discourse.

More even, precedent paragraphs revealed that Islam is a dominant religion in Saudi Arabia, which proven to be a major component of Saudis spiritual, moral and social life. Consequently, this reveals that Islam is a major determinant of patient's rights norms and bioethics standards in Saudi Arabian healthcare system.

Even more, previous discussions indicate that Muslim scientists and physicians especially in the medieval ages, has contributed to the body of medical knowledge and to bioethics discourse substantially; which infer that the current bioethics standards obtain its cumulative norms from the precedent collaboration exertion between Islam and western civilization.

Moreover, in the light of dissertation thesis, which reckon the following question of "How can patients' rights be better implemented in Saudi Arabia in order to achieve higher standards of ethical practices?" The precedent pages concluded that patient's rights in Saudi Arabia is closely associated with Islamic teachings and Arabic culture, yet, and due to Islamic contribution to cumulative knowledge of bioethics as stated earlier, current patient rights discourse in Saudi Arabia obtain its normative standards from the widely known bioethics principals, which emphasizes global normative values, such as respecting dignity, rights to autonomy, the importance of privacy among other bioethics fundamentals. However, and due to the centrality of Islam and Arabic culture to Saudi bioethics discourse, and to avoid any conflict that may occur between imported principles of bioethics, for example the UNESCO Declaration Bioethics and Human Rights, Islamic teachings and traditions must be incorporated while adapting such bioethics principles.

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### **Chapter Three: Human Dignity and the Universality of Bioethics**

The first segment of this chapter discusses two interwoven and widely discussed relationships that marked the contemporary era's social and political milieu. This discussion will support the viewpoint that these relationships helped in promoting moral incentives in numerous human activities and whereabouts.

The first relationship is the relationship between the principle of dignity and human rights. The second relationship is between human rights principles and discourse related to the rights of patients. Each of these relationships provides a foundation to discuss challenges confronting the implementation of the universal bioethics principles in healthcare systems, including the Saudi Arabian healthcare venture.

Numerous viewpoints concerning human rights will be discussed further to represent the existing voices of reservation in Muslim countries regarding the universality of human rights principles. Though these scholars may reflect their government's official standpoint, aspects of their reservations to adapt universal and internationally endorsed declarations of human rights principles in the local communities will be highlighted to better understand the concerns related to this issue. The Universal Declaration on Bioethics and Human Rights will then be discussed, revealing its theoretical appropriateness situated in healthcare systems as well as the universal applicability of its principles.

Global bioethics, cosmopolitanism, and multiculturalism will be discussed in relation to bioethics and international principles. This discussion will be supported through diverse scholarly perspectives and an associated analysis explaining the hesitations of some countries to adapt universal bioethical principles.

The reality of patients' rights will be summarized to provide an overview of contemporary biomedical issues in many countries concerning the universality of bioethical principles. Therefore, the claim of universality of the principles in UNESCO's *Universal Declaration on Bioethics and Human Rights* will be discussed thoroughly to assess the potential inclusion of these principles into the Saudi healthcare system.

### **3.1 Dignity and Human Rights**

In 2001, Wendy Austin writes, "Human rights may be the most globalized political value of our times."<sup>1</sup> Indeed, human rights discourse has had a profound impact on today's social and political environments worldwide. Due to globalization of trade, pop culture, and political ideologies, human rights are no longer restricted to specific ventures or regions. Therefore, human rights principles have been translated to numerous legal and moral principles that influence on a global scale. Typically there are areas of human undertakings, which are more influenced by human rights principles than others, and bioethics is a relevant example.

The emerging popularity of human rights as dominant philosophy in modern-day social and legal contexts is built upon a widely shared perception that humans are all equal and possess similar innate values; this perception concedes that all humans are entitled to rights and due duties.<sup>2</sup> This point is supported by Christian Erk (2011), who relates the popularity of human rights to the appealing influence of these rights, which is demonstrated by the extensive recognition of these rights among the international community; Erk (2011) states, "The worldwide acceptance of the idea of human rights is also reflected by the fact that all of the almost 200 states in the world have acknowledged the existence of human rights – either in their

constitutions and/or by means of ratification of one or more of the relevant treaties, declarations or covenants of international law.”<sup>3</sup>

To denote the significance of human rights principles and to exemplify its position in dictating laws aiming to prevent human rights violations, Lynn Hunt (2007) states in *Inventing Human Rights*, “We are most certain that a human right is at issue when we feel horrified by its violation.”<sup>4</sup> It can be inferred from Hunt’s statement that the responsibility of human rights is to preserve the existence of people as appreciated humans. Hunt also refers to the habitual thoughtfulness each person directs toward their personal rights in daily life, and how disturbed or frightened a person would be if these rights were violated.

Furthermore, Hunt argues that human rights are dependent on reasons and emotions for being self-evident; any rational being could appreciate principles of human rights as an assurance for political and social privileges, and would submit that these rights are intrinsically entitled to all human beings. Similar to Hunt’s position, Wendy Austin (2001) writes, “The central assumption of the rights paradigm is that every person can make certain claims based solely on their humanness.”<sup>6</sup>

According to Hunt (2007), there is no single definition of human rights that can be offered<sup>7</sup> due to the very nature of the concepts and principles; these concepts can be interpreted in different manners depending on the culture and political atmosphere, and therefore could be rationalized and weighted in accordance to specific circumstances. As human rights are labeled as inalienable rights possessed by all humans, this raises questions among scholars of whether human rights are absolute or acquired.

The inalienable nature of human rights can be rationalized through an adaptation of Terrance McConnell’s (2000) position concerning these rights; he states, “According to my

account, then, an inalienable right is such that the possessor's consent does not justify another in infringing that right, and that consent does not bring about any new obligations on the possessor. The possessors of inalienable rights lack the normative authority to effect such changes.”<sup>8</sup> Tom Beauchamp (2010) affirms the position that human rights are moral rights, not necessarily legal rights and therefore, human rights can only be justified from normative morality; consequently, human rights cannot be reduced relative to legal principle because legal laws are relative and prone to change in accordance to circumstances and events.<sup>9</sup>

The lack of a generally agreed definition of human rights is crucial to the value of human dignity, as explained by Andorno (2013): “As a matter of fact, defining dignity in a clear-cut terms would be as difficult as defining ‘freedom,’ ‘justice,’ ‘solidarity,’ or whatever other key social value (which by the way are never defined by law).”<sup>10</sup> However, a definition of human rights has been provided by Peter Baehr (1999) who writes, “Human rights are internationally agreed values, standards or rules regulating the conduct of state towards their own citizens and towards non-citizens.”<sup>11</sup>

At the same time, numerous scholars argue that principles of human rights are universal, and naturally inherited rights<sup>12</sup> to all humankind; this makes these principles appealing, acceptable and applicable in all human communities. In his work, *Are Human Rights Universal?*, Rex Martin (2013)<sup>13</sup> relates human rights in modern-day language to the old concept of the natural rights. The old concept of natural rights is also defined by John Finnis (2011) as a synonym to human rights; he writes, “Human, or natural rights are fundamental and general moral rights, particular or concrete moral rights.”<sup>14</sup> In addition, Roger Norman and Sarah Zaidi (2008) trace human rights incentives back to moral and religious roots, and determine universality of human rights in all communities, at all times.<sup>15</sup>



The preamble of the *Universal Declaration of Human Rights* states two important points. The first of these points is that human rights are fundamental, the second is that all human are entitled to these rights: “Whereas the peoples of the United Nations have in the Charter reaffirmed their faith in fundamental human rights, in the dignity and worth of the human person and in the equal rights of men and women and have determined to promote social progress and better standards of life in larger freedom.”<sup>16</sup>

Scholars often relate human rights to the stature of “Common morality”<sup>17</sup>, by which Beauchamp and Childress (2013)<sup>18</sup> foster this concept and appoint common morality as a foundation for prominent principles of bioethics.<sup>19</sup> Benjamin Bautz (2016) writes in reference to the principles of Beauchamp and Childress, and provides a comprehensive framework to engage bioethical inquires: “The argument they want to make is that because the four principles that serve as considered judgments are drawn from the common morality, they must embody genuine moral precepts.”<sup>20</sup> This relation of bioethical principles to common morality is also embraced by Gert, Culver, and Clouser (2006); these authors describe common morality, or common norms as the standards known and shared by most communities as they live according to moral rubrics stemmed from reasoning and human experiences: “Common morality only provides a framework for dealing with moral problems in a way that is acceptable to all impartial rational persons.”<sup>21</sup> Gert et al, also state, “Common morality, which is the framework for all justified moral systems, applies to venerable and fallible people. Its goal is to lessen the amount of harm suffered by those protected by it.”<sup>22</sup>

Regardless of global cultural diversity, humans that ascribe to common morality and live in accordance to virtues typically view human rights as natural rights; for example Lynn Hunt

(2007) writes, "...the use of this term is so familiar that there is almost no one who would not be convinced inside himself that the thing is obviously known to him."<sup>23</sup>

Human rights<sup>24</sup> as a political term with profound philosophical implications and explicit descriptions did not appear in European literature before the second half of the eighteenth century<sup>25</sup>; according to many scholars, the notion of human rights is far older than its contemporary definitions and philosophical narrations, concepts, and modern applications.

Common morality has inspired people to embrace virtues, goodness, and fairness while dealing with fellow humans for the entirety of human existence. Therefore, old essences of principles of human rights have inspired and obligated rational beings to appreciate the privileges they have, as well the rights of others through deep-rooted gratitude towards human rights; consequently, this enables humans to spontaneously recognize rights and denounce practices that contradict these rights.

Most human societies allocate common norms in social undertakings which then frame the community's collective moral stature; this inspires members of societies to act and behave within certain moral boundaries, regardless of convictions and cultural specifications.

While various cultures maintain convictions and practices unique to the culture and adapt their lifestyle "particular moralities"<sup>26</sup>; the majority of these convictions and customs originate from similar convictions and moral principles referred to as natural norms. For example, people around the world hold principles of justice, loving, fairness, respecting spousal bonds, respecting seniors, and other virtues, and embraces these principles by sanctioning laws and parameters to protect these principles.

As mentioned previously, prior to the eighteenth century human rights in its legal and philosophical concepts were not valued and persuasive as in today's literatures and practical

settings. Several historians and theorists such as Andrew Clapham (2007),<sup>27</sup> and Claudio Corradetti (2013),<sup>28</sup> and Peter Baehr (1999)<sup>29</sup> agree that the eighteenth century was a revolutionary period in which many moral concepts concerning human rights emerged, evolved, and introduced human rights principles to legal and social domains.

Inequality in the distribution of political vocations, social benefits, and assets, in addition to the infamous caste classifications in the past generated deep nuisances and spawned feelings of injustice among commoners; this was especially the case in European monarchies and in the newly discovered colonies in North America. These injustices were further fueled by economic hardships and political instability, and forced people to seek out their rights and achieve long deserved dignity. In reference to the *Human Rights Declaration* as an ideal end to centuries of negligence to human rights and the ensuing struggle for liberty, Francesca Klug (2015) writes, “The Declaration was not developed primarily as an intellectual idea, but was crafted out of the catastrophic events the drafters themselves had all just lived through or witnessed.”<sup>30</sup>

Scholars across Europe and the imperial colonies of North America began to develop and advocate for a new era of social and political equality. Soon enough, egalitarianism and social justice became common themes across borders. Consequently, a contemporary narration of man’s rights has evolved in social and political ventures, and a new term called ‘human rights’ has been developed.

When considering the history of human rights, Austin (2001) indicated that the oldest document that grasps the principles of human rights is the *Magna Carta* of 1215; the *Magna Carta* developed a constitution that promote rights of humans as “the natural rights”, and defined social obligations and political boundaries.<sup>31</sup> However, Klug (2015) disputed this theory as she claims that the *Magana Carta* does not precisely reflect the commoners’ interests; rather the

*Magna Carta* constituted its existing interests and distinct ranking and political boundaries among aristocrats. In addition, Klug (2015) traces back the existence of modern human rights discourse to the post-World War II era where human rights came about as a result to protect the rights of mankind.<sup>32</sup> Moreover, Christian Erk (2011) argues, “Far from being a modern idea, the concept of human rights has been constantly evolving throughout the history of humankind.”<sup>33</sup> Erk (2011) traces principles of human rights to the ancient code of Hammurabi, ancient Greek philosophers, and teaching of Confucius in Asia.<sup>34</sup>

In the same context, social philosophers, political reformers, revolutionists and social theorists brought the concept of natural rights to life in a modern expression of contemporary language. From that time and afterward, human rights have become increasingly focused on the discussion of political rights, social reform, civil rights,<sup>35</sup> and most recently biomedical ethics; Austin writes, “The use of human rights paradigm in the area of health ethics is relatively new.”<sup>36</sup>

As discussed previously, the definition of human rights and human dignity are often used interchangeably; Lynn Hunt (2007) supports this theory and argues that the definition of human rights is problematic, “...difficult to pin down because of their definition.”<sup>37</sup> In addition, Roberto Andorno (2009) that dignity does not have a particular definition: “This lack of definition has brought some bioethicists to argue that dignity is a simple slogan without any particular relevance.”<sup>38</sup> Further, Kay Aranda and Andrea Jones (2010), described dignity as “...vague, ambiguous and complex in its use...”<sup>39</sup>

These statements demonstrate the hurdles in understanding the definitions and basic concepts of human dignity and human rights. The lack of agreement upon a solid definition

makes it difficult to determine relevant ethical justifications, meaning, and practical applications in various contexts.<sup>40</sup>

The vagueness in definitions creates conflicts in assigning philosophical roles and related obligations, as it leads to failure in structuring common agreement. Scholarly claims that deem dignity or human rights as irrelevant also lack precise definitions. The barrier in establishing definitions does not doubt the values and principles, or the applicability in various settings. Many scholars offer definitions of human rights or “the rights of man”<sup>41</sup>, as they appreciate its meaning according to their perceptions and philosophical schools.

Descriptions of the stance of human rights in the United States initiated as the people of British colonies in New England began to fight for their independence. The concept of “free English man”<sup>42</sup>, which began in England, became a popular slogan in American British colonies; this motto enabled scholars including Thomas Jefferson to emphasize human rights in public and private speeches as well as correspondences, with a focus on encouraging perseverance in acquiring rights and secure liberty.<sup>43</sup>

Human rights have undergone extensive conceptual development that has been reflected in major civil reforms and political improvements. For example, as a consequence of the introduction of human rights in social and political ventures, the enslaved population fought for liberation from slavery, and commoners battled for national sovereignty; eventually the fourteenth amendment was added to the American constitution ending slavery.<sup>44</sup> After the revolution, the position of intolerance for suppressive actions and patronizing human rights was enforced,<sup>45</sup> at least in theory.

Social reform, under the influence of human rights, effectively changed fundamental societal norms and changed vernacular social and political beliefs; Hunt (2009) writes, “The old-

style patriarchal domination of husband over wives and father over children declined in the eighteenth century.”<sup>46</sup> Women began to actively seek out their own rights based in the essence of human rights, which addressed social stigmatization which had lasted for centuries.<sup>47</sup> Cyra Choudhury (2014) explains: “Internationally, as the domestic debates were unfolding, these decades saw the growth of transnational movements for human rights replacing socialist and nationalist movements.”<sup>48</sup> In addition, liberation movements began to incorporate ideologies of human rights which were followed by radical and extreme protective measurements; for example, in the United States there was a decree that outlawed swaddling of infants, as it was considered an act of aggression towards infants’ rights.<sup>49</sup>

After a long struggle, the endeavors of human rights developed throughout the years and become irreplaceable in many national and international conventions and treaties. The *Universal Declaration on Human Rights*, which is regarded as the ultimate international collaboration related to human rights, becomes a default agreement and standard declaration around the world. In addition, other declarations, conventions, and treaties regarding human rights acquire their terminology from the Declaration. According to Elizabeth Anker (2013) “It is hard to imagine a viable approach to social justice today that does not rely on the language of human rights. The proliferation of the many norms and ideals associated with human rights no doubt represents a hallmark achievement in international law, at the same time as it exemplifies the salutary repercussions of globalization.”<sup>50</sup>

The thirty articles of the *Universal Declaration on Human Rights* came into reality in 1948 (Winter & Prost, 2013), which has been referred to as the ultimate, most comprehensive, global, and well-publicized treaty. Even more, Klug (2015) refers to it as the ‘Magna Carta of all human rights principles’, while she characterizes the Declaration as a collective, post-war result

of all human experiences and not as specifically belonging to a singular Western origin as other scholars may describe.

Therefore, issues of human rights are no longer regarded as isolated or internal affairs of a state; countries and governments are deemed responsible to maintain and promote human rights in the communities. These countries and governments are held liable by the international community and the Human Rights Declaration principles in the case of human rights violation or breach within their borders.

As demonstrated previously, historical and philosophical notions formed human rights ideas and principles and scrutinized the associated affairs. The upcoming section will appraise the concept of human dignity, as it is perceived to be the foundational value of human rights discourse.

### **3.1.1 Dignity as Groundwork of Human Rights**

In further elaboration upon the issue of dignity and in representation of its association with human rights discourse, scholarly viewpoints will be scrutinized and contested. This ranges from arguments in support of linking human rights to dignity, to viewpoints that reject the inclusion of dignity in human rights endeavors.<sup>51</sup>

In a politico-legal context, *American Dignity and Healthcare Reform*, by Neomi Rao (2012) describes human dignity as the aptitude for moral agency and associates it with a state of minimum interference with matters of an individual. Rao's viewpoint mimics the Kantian theory of moral agency, which associates dignity to the capability to act morally.<sup>52</sup> In accordance to Rao's thesis, dignity is closely associated with individual rights; these individual rights are typically interpreted in classic, liberal thinking as freedom from state interference.<sup>53</sup>

Additionally, Rao describes the relation of dignity, autonomy, and values of liberty as overlapping,<sup>54</sup> as respect for dignity can be manifested through respect for the autonomy for individuals and free will and can be represented through promoting the values of social and political liberty standards. Jill Hernandez (2015) argues that dignity is inseparable from autonomy and from the basic rights designated to an autonomous individual.<sup>55</sup>

In the preamble of the *Universal Declaration on Human Rights*, respect for human dignity is cited and undoubtedly interpreted as an inalienable right designated for all human kind;<sup>56</sup> in the first article of the declaration, the term dignity is emphasized.<sup>57</sup> This term was not been chosen casually by the writer of the declaration, which suggests that the human right of dignity is valuable and capable of emphasizing the Declaration's principles because respecting human dignity captures the very essence of human rights disposition: "Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world,"<sup>58</sup> In addition, Yechiel Michael Barilan (2012) mentions that 157 of the countries that are members of the United Nations (UN), have made reference to human dignity within national constitutions.<sup>59</sup>

Rao (2012) described human dignity as a value that gives moral weight and philosophical justification to international conventions, which associate their standards with human rights. William Talbott (2014) writes, "It is a commonplace in the human rights literature that human rights are grounded in respect for human dignity."<sup>60</sup> In addition, Andrew Lustig (2013) states that human dignity is contemporary and thoroughly represented in international documents, declarations, conventions, and the bioethics field, because dignity is customary to and found as a common theme in a wide array of topics.<sup>61</sup>



To demonstrate the significance of dignity as valuable to all humans, there is a general agreement that suggests that the very nature of human beings makes them unique; this distinct nature is revealed when comparing humans, nature, and other un-human objects. Humans are able to perceive and comprehend moral values, and therefore enable them to act and behave appropriate due to their capability to think rationally, differentiate between harmful and beneficial actions, and act morally (in devotion to Kantianism<sup>62</sup>). George Kateb (2011) explains this point:

Only humanity can perform the three indispensable functions: keep the record of nature, understand nature, and appreciate it. The human species, alone among species on earth, can perform these services to nature on earth and beyond, and do so in part not for its own sake but for the sake of what is not itself. These services constitute the stewardship of nature.<sup>63</sup>

From this tradition, it can be concluded that human dignity distinguishes humans from other living species; therefore because of this unique nature, humans are entitled to distinctive insights and treatments. This unique nature is what makes human dignity important; it also verifies that dignity holds valid philosophical rationalization.

In relation to the previous argument, Andorno (2013) comments that human dignity as a moral concept, especially in Anglo-American contexts, assigns specific intrinsic rights to humans. This complements Donna Hicks' (2011) position which labels human dignity as a birthright, not an acquired value.<sup>64</sup> In addition, Andorno suggests that humans are not entitled to these innate rights due to being *homo sapiens*; Andorno claims that these rights are due to humans because of their intellectual abilities<sup>65</sup>. David Calhoun (2013) describes this concept as human exceptionalism; he relates human superiority to intellectual abilities in comparison to other forms of life.<sup>66</sup>

Kateb furthermore explains that "...human dignity has two components and both are

existential, not moral: the equal status of every human being and the stature of the human species.”<sup>67</sup> From these components, Kateb validates his hypothesis that species dignity is an intrinsic value assigned to humans and is deemed vital to human existence. This is reiterated by Lustig (2013) who relates this point of human superiority over other forms of nature to dignity as stated in the philosophical work Cicero.<sup>68</sup>

The basic notion of respect for human dignity rises from the acceptance of equality amongst all humans regardless of background, social status, or moral status. It can be inferred that no human can be distinguished as superior or inferior to another human, there is more to the equation according to Kateb: “All individuals are equal, no other species is equal to humanity. These are the two basic propositions that make up the concept of human dignity.”<sup>69</sup> This is also mentioned by Barilan (2012), who rationalizes the perspective of intrinsic value of human dignity on the basic belief that humans should be viewed as equals.<sup>70</sup> Through theological and religious reasoning, Barilan affirms the idea that dignity is justified, which is simpler than justifying dignity in secular thoughts. Barilan justifies these claims based on the origins of dignity and reliance on human dignity in conservative and religious ethical reasoning; this reliance makes the vindication of political and social theories based on dignity unappealing to secular scholars, especially those based on utilitarian and liberal concepts.<sup>71</sup>

In contrast, Hicks relates the significance of human dignity to peoples’ awareness and their own perception of being worthy of respect. Hicks connects dignity to the human mentality of what is respect worthy, and humans’ innate desire to be treated well and with respect.<sup>72</sup> This point is what contributes to the significance humans place on dignity and validates the notion behind recognizing dignity as an inalienable right.

Kateb stresses the critical role that the principle of respecting human dignity plays in affirming and assigning human rights as fundamental, moral value entitled to all humans; this includes those who do not respect dignity themselves: “I must try to show that the idea of human dignity adds something necessary to the theory of human rights, that though human history is a slaughter-bench, the scene of uninterrupted crimes and atrocities, human dignity must be affirmed, even the dignity of those who assault the dignity also, implausible as that notion may seem.”<sup>73</sup> This particular point is stressed by Hicks (2011) in the ‘ten essential elements for dignity’<sup>74</sup>; she argues that respecting others, treating them with dignity, acknowledging their wishes and choices are fundamental to dignity.<sup>75</sup> Hicks clarifies the distinction between unconditional respect of human dignity and condemning human wrongdoing; this judgment does not specifically take away from another human’s dignity.<sup>76</sup>

Kateb argues that respecting human dignity is central to human rights and crucial to deal with issues of a biomedical nature: “The requirement of respect for human dignity, which has been characterized as the cardinal principle of the legal norms relating to bioethics.”<sup>77</sup> The position of respecting human dignity in healthcare settings is consistent with the Kantian proposition that necessitates the respect for human dignity by regarding people as an end, never as a mean.<sup>78</sup>

Audrey Chapman (2015) mentions the four sources of dignity that were developed by Adam Schulman (2008) and published by the US President’s Council on Bioethics. These sources of dignity in bioethics are derived from the notion that dignity is worthy of honor because it’s special. The second source of dignity is because of the religious significance of humans. The third source is because the Kantian philosophy that holds all human equals and

respect worthy. Finally, Schulman justifies dignity based on the enacted international treaties, which regard dignity as a “supreme value”.<sup>79</sup>

Despite the controversial nature of human dignity as a concept and practical application,<sup>80</sup> due to different and inconsistent religious, legal, and cultural interpretations,<sup>81</sup> and scholarly rejections or reluctance to incorporate dignity into bioethics,<sup>82</sup> the principle of respecting human dignity remains universally appealing; it has been deemed intrinsic to the principles of human rights by numerous scholars: “The moral defense of rights has to be aided by the idea of human dignity.”<sup>83</sup>

The principles of human rights help to design rules to allow people to better understand the rights of others by setting practical and tangible standards beyond philosophical hypothesis and grim narrations. By affirming human dignity as a treasured virtue, communities can discern, comprehend, and confirm these rights, as well as enable people to observe their own inherited rights.

Actions that endanger the dignity of people would be considered an offense. It is clear, as Kateb elaborates, “Crimes against humanity are the most serious crimes against human dignity as well as the most serious crimes against morality embedded in human rights.”<sup>84</sup> Many of the unethical biomedical practices that occurred in research and hospital settings were as a result of the disregard for the principles of human rights and dignity. Therefore, human dignity as a principle when utilized in biomedical ventures would principally serve as a safety net against unethical medical conducts, Roberto Andorno states, “The notion of human dignity is beginning to be considered as the last barrier against the alteration of some basic characteristics of human species that might result from practices such as reproductive cloning or germ line

interventions.”<sup>85</sup> This particular point supports the claim that the idea of respect for human dignity is crucial and intrinsic to human existence.

Andorno therefore argues the role of human dignity as a condition in protecting humans from abuse in healthcare and research. Specific biomedical activities that include human beings do not specifically violate human rights, but these activities do violate human dignity. For example, cloning does not specifically infringe human rights because no harm occurs to anyone, including the person consenting to be cloned; under the doctrine of respecting dignity that is mentioned in the *Universal Declaration on the Genome and Human Rights*,<sup>86</sup> it is discouraged to utilize humans when conducting cloning experiments.<sup>87</sup>

Dignity in healthcare is an important value that enables judgment of the morality of medical interventions. For instance, Johnston et al. (2015) formulated a healthcare questionnaire to assess palliative care satisfaction based specifically on dignity, in order to provide a fundamental assessment to protect and promote morally oriented healthcare services.<sup>88</sup> Hernandez (2015) presented an example of a medical procedure referred to as physician assisted suicide, based solely on the assessment human dignity. Euthanasia and physician assisted suicide are widely performed in the Netherlands and other countries. These medical procedures are performed on terminally ill patients who do not meet the criteria of living with dignity. Many scholars have deemed these controversial practices unethical, but relevant arguments related to this issue are based on the notion that such procedures aim to preserve an individual’s dignity.<sup>89</sup> Buchini, Quattrin, and Zampieron (2014), argue that all policy and procedures protocols in healthcare systems mention human dignity as a fundamental value to be possessed by patients and extended to families.<sup>90</sup> The authors mention that dignity in healthcare supported with a new trend in medical care is referred to as patient centered care. Lustig (2013) elaborates that “The

success of dignity as a standard of specified rights and duties is obvious in the history of modern bioethics, particularly its emphasis on patients' rights to make treatment decisions free of the medical paternalism of an earlier era and in the protection of human research subjects."<sup>91</sup> These arguments developed from the point of healthcare represent the important role of dignity in ensuring moral healthcare practice.

To elaborate on the centrality of dignity to human rights principles, Roberto Andorno (2013) writes that after 1945 human rights discourse and relevant venues, as well the legal system of democratic states, are based on the notion that dignity is intrinsic to humanity and therefore people are inherited of certain rights.<sup>92</sup> While the UNESCO labels dignity as a minimal, fundamental right entitled to all humans. Andorno (2009) writes, "Whereas individual dignity refers to the idea that every human being has inherent worth, collective dignity is a derivative notion, which embodies the idea that the existence and integrity of humanity as such also has intrinsic worth and therefore also deserves to be protected"<sup>93</sup> In reference to the dignity embedded in the UNESCO Universal Declaration on Biomedicine and Human rights, Andorno (2009) elaborates further: "Thus, it is not surprising that the 2005 Universal Declaration on Bioethics and Human Rights, which formulates a set of norms to guide biomedical practice, assigns the first place to the principle of respect for 'human dignity, human rights and fundamental freedoms' (Article 3.1)"<sup>94</sup> Buijsen (2010) argues that all principles of human rights are formulated to protect human dignity,<sup>95</sup> In addition, Buijsen claims that human dignity is equivocal to human rights with all its possible metaphoric description such as being universal and interdependent.<sup>96</sup>

In relation to bioethical concerns, the value of dignity is persuasive at the bedside and in research settings; this point is mentioned by Andrew Lustig (2013) who views the presence of

dignity as crucial in George Bush's council on bioethical agendas and the work of bioethicists such as Leon Kass and Jim Childress.<sup>97</sup>

The statements made by various scholars on dignity or respect for human dignity is a major player in rationalizing the principles of human rights; respecting human dignity will support efforts made by the international community to promote human rights in all settings, including those regarding bioethics. Claims related to human dignity prove to lay the groundwork for the principles of human rights; there is a general consensus that human societies will recognize the importance and rationality of human dignity and rights, while upholding its respective principles.

### **3.1.2 Human Rights as an Ethical Basis for Biomedical Ethics**

Previously, dignity has been distinguished as intrinsic to humans, and therefore has been denoted as central to the groundwork for human rights principles; this section will elaborate on the other significant relationships. It has been concluded that human rights dictate bioethical standards and its normative, distinguishing principles. Respect for human dignity will be discussed as related to bioethical concerns due to the central nature of dignity to human rights principles; therefore the inclusion of dignity in this discussion is vital.

To elaborate on the role of human rights, the meta-philosophical meanings and practical intentions will be examined to reinforce the practicality of its principles in social and political settings, including the realm of bioethics. Angela De Stasi (2012) argues that human rights are essential not only to bioethics, but also to the international Biolaw, which constitutes the conduction of healthcare in general.<sup>98</sup> According to Revel (2009)<sup>99</sup>, standards of bioethics are formulated directly from human rights principles in this philosophy: respecting autonomy,

protecting vulnerable groups, committing no harm to patients, and preserving confidentiality.

Austin (2001) provides a statement related to the intrinsic nature of human rights in healthcare settings and bioethical principles, in addition to how human rights are intercepted and made applicable in practical settings: “Human rights violations can be inherent in the design and implementation of health policies.”<sup>100</sup> Austin (2001) writes in reference to Bartha Maria Knoppers, the chair of the Ethics Committee of the Human Genome Project, work *Human Rights and Genomics* (2000). That Knoppers considers bioethical standards as an extension of human rights principles, as she describes bioethics as the third generation of rights, which sanctions human rights in definite biomedical venues.<sup>101</sup>

Due to the centrality of human rights in healthcare and bioethics as a discipline, Austin also lists several international enacted codes and declarations aimed to stress the function of human rights in healthcare and in biomedical research settings. Among these is Article 25 of the *Universal Declaration of Human Rights*, Article 12 of the *International Covenant on Economic, Social and Cultural Rights*, the *World Health Constitution*, and many other important documents.<sup>102</sup>

In Renee Fox and Judith Swaze’s (2008) book, *Observing Bioethics*, the authors mention the likeness of bioethics in its contemporary form to the social theory of individualism; this forms a powerful social determinant of bioethics standards in Western traditions.<sup>103</sup> Individualism as a major factor of human rights principles, which constitutes individual rights and self-ruling, has its equal value in bioethics. Patients’ autonomy, respect of dignity, the right to confidentiality, the notion of informed consent and many other biomedical principles are founded upon human rights principles.



According to John-Stewart Gordon (2012) in *Human Rights in Bioethics-Theoretical and Applied*<sup>104</sup>, human rights in contemporary terms has developed through three phases, otherwise known as three generations. The first generation of human rights began in the eighteenth century and was mainly concerned with rights to “security, property and political participation”. The second generation of human rights began with the twentieth century; Gordon states that human rights were focused on “socio-economical rights, rights to welfare, education and leisure”. By the late twentieth century, Gordon associates human rights in its third phase to the following: “...rights to self-determination, the rights to clean environment, as well as the rights of indigenous minorities and group rights.”<sup>105</sup> Gordon clearly shows the different aspects of rights that emerged through decades and then formulated contemporary human rights principles. Human rights ideology has developed through the decades in close association with the historical circumstances of the time period.

Human rights as a practical principle is molded by the desire and willingness of people to live life according to their convictions that is free from government interference and other forms of social and political paternalism. Therefore, the term ‘human rights’ is synonymous with dignity and symbolizes the human desire for equality, respect, autonomy, and social justice. Principles of human rights cross paths with human events at all levels, beginning with shaping the basic rights entitled to humans, formulating social and cultural norms, and in constituting professional and legal codes that allow humans to live their desired life.

The theme of this section is to elaborate on the rule of human rights in establishing biomedical ethics norms and applied principles. Healthcare ethics is crucial to determine human social, physical, and psychological wellbeing in any community as a basic right to health. Without proper provision of health care and an absence of moral incentives in healthcare

ventures, nations cease to seek out basic moral rights and then these rights are prone to negligence and abuse.

George Annas and Wendy Mariner (2016) write, “Public Health ethics must be encompassed within a broader set of principles that define the power and limits of governmental institutions. These include human rights, health law, and even medical ethics.”<sup>106</sup> Annas and Mariner argue that public health ethics, a form of biomedical ethics concerned primarily with bioethical issues at the public level, provide a moral safety net for the public to ensure their human rights while dealing with public health matters.

Annas and Mariner (2016) also argue that human rights and medical ethics, “...were born simultaneously at the Nuremberg trials.” This statement denotes the interwoven relationship between bioethics and principles of human rights that initiated at the end of WWII to end violations of human rights in medical and in research settings<sup>107</sup>. Annas and Mariner mention that international treaties fabricated to protect human rights often share similar languages and lexicons with bioethics ideals; the authors discuss and conclude upon subjects that establish principles of biomedical ethics.<sup>108</sup>

The essence of the principles of biomedical ethics is derived from human rights principles as right to autonomy, protecting individual choices, refraining from harm, maintaining confidentiality and many other protective principles; these bioethical principles mimic the language and seeds of human rights principles, with specific focus on biomedical ventures.

John Arras and Elizabeth Fenton (2009) support the distinctive relationship between bioethics and human rights. In the essay, *Bioethics and Human Rights: Access to Health- Related Goods*, they argue that human rights are essential to bioethics because of the incorporation of widely recognized human rights, highly esteemed languages, and political schemas to develop

bioethical standards and norms. The authors also claim that the established art of bioethics can support the endeavors of human rights; this support comes from allowing the advocates for human rights and scholars of social science to advance from the long standing legacy of bioethics, as it articulates relevant philosophical and religious customs that reflect deep traditions.<sup>109</sup>

It can be inferred from scholarly statements that human rights and bioethics are dependent on each other, while the language and political weight of human rights allow the advancement and promotion of the biomedical ethics tradition; as a result, human rights are incorporated in many national and international declarations as well as global programs. There are numerous international treaties known to the international community that are detailed to variable extents and enforced at global level. Among these international treaties are the UNESCO Declaration on Bioethics and Human Rights, the UN Declaration on Human Genome and Human Rights, the Belmont report, the Nuremberg Code, and other international efforts that incorporate the language of human rights when dealing with general and specific biomedical issues. Gordon (2012) lists five points that describe the benefits of the human rights framework to bioethical matters, First is the powerful and moral language used by human rights, which contributes a legal and authoritative dimension to its principles. The second point is that the established legal framework of human rights had its own establishments and enforcing power through institutions such as the United Nations and Human Right Watch. The third point is the universality of human rights principles, which allows the establishment of universal moral norms for bioethics. The fourth point is the universal right to health derived from human rights principles, which can easily combine with bioethics standards. Finally, the fifth point is the

supportive norms of human rights such as right to autonomy and confidentiality, which are integrated in both ventures and form as an essential part of its philosophical grounding.

The relationship and theoretical association between bioethics and human rights has been previously highlighted. The current reality of this relationship will be revealed and the existing, fruitful collaboration between bioethics and human rights will be demonstrated on a global scale. According to Henk ten Have (2010)<sup>110</sup>, bioethical issues have become an international concern with global consequences; as a result, many international agencies have developed bioethical committees to extend the philosophical and regulatory agenda to medical and healthcare settings.

Among relevant international organizations is UNESCO, which developed the International Bioethics Committee (IBC) in 1993 to address issues related to bioethics in healthcare and in research settings. As a result, UNESCO has adopted an international declaration that covers theoretical and practical principles that aim to promote bioethics and human rights globally; this declaration is well known as *The UNESCO Universal Declaration on Bioethics and Human Rights*. A discussion related to the universality of the UNESCO Universal Declaration will be provided at length in a later section. The issue of human dignity in bioethics will be discussed further to enforce that the principles of human rights are the foundation of bioethics; human dignity is a vastly discussed topic in bioethical literature and is often contemplated as the groundwork for human rights.

According to Roberto Andorno (2013), dignity in healthcare has a dual function, "...as an overarching principle that serves as the ultimate foundation and guiding ideal of the legal norms relating to biomedicine; the other, as a standard for concrete health care decisions at the bedside."<sup>111</sup> He refers to the value of human dignity as the core principle in establishing bioethical principles and in determining decisions facing patients, family, and caregivers in

situations such as end of life decisions. In many international treaties related to biomedical work, such as the *UNESCO Universal Declaration on Bioethics and Human Rights*, there is a presence and great reference to the value of human dignity.

The *Declaration of Human Rights*, *Declaration of Helsinki*, and *Nuremberg Code* are all concerned with the wellbeing of humans and aim to protect human dignity; Ten Have and Jean proclaimed that the Charter of the United Nations precedent in adapting these principles earlier.

In reference to the *UNESCO Universal Declaration on Bioethics and Human Rights*, Henk ten Have and Michele Jean (2009) write, “The Declaration treats dignity as an inherent property of being human.”<sup>112</sup> This statement represents affirmation from the international community related to the importance of respecting human dignity as undisputed denominator in determining the morality of biomedical activities. Ten Have and Jean (2009) argue,

UNESCO is directed by its constitution, adopted in November 1945, affirming that the purpose of the organization is ... ‘to contribute to peace and security by promoting collaboration among the nations through education, science, and culture in order to further universal respect for justice, for the rule of law and for the human rights and fundamental freedoms.’<sup>113</sup>

The Declaration of the UNESCO presents a well formulated legal doctrine that is widely recognized internationally built upon the principles of human rights and respecting human dignity; this international acknowledgment is because the document is derived from a universal set of common and shared moral principles.

Despite the frequent appearance of the term ‘dignity’ in bioethical literature, there are many scholarly opinions that find the concept of human dignity in bioethical ventures challenging. Tranvag et al. (2015)<sup>114</sup>, ten Have and Jean (2009), and Matthew Jordan (2010) agrees that the term human dignity leads to confusion.<sup>115</sup> These authors contend that the concept of dignity in bioethics is controversial, ambiguous, and raises philosophical and practical

confusion.

There are other scholars that reject the inclusion of dignity into bioethical topics, principles, and reasoning. Andorno (2013) presents one of these objecting viewpoints; he refers to Ruth Macklin article in which she described dignity as a useless principle that can be simply replaced with the principle of autonomy.<sup>116</sup> Even more, and in reference to the US President's Council on Bioethics, Ruth Macklin (2003) has argued that "In the absence of criteria that can enable us to know just when dignity is violated, the concept remains hopelessly vague."<sup>117</sup> Steven Pinker (2008) articulates three points in rejection of dignity in bioethics due to its unreliable value. He stipulates that dignity is a relative concept that can fluctuate, dignity is fungible, and dignity can be harmful.<sup>118</sup> In addition, Stephen Dilley and Nathan Palpaut (2013) explain that dignity is elusive in concept and content, as the authors conclude, "...there is no such thing as human dignity."<sup>119</sup>

The main theme of the UNESCO Universal Declaration is represented in respecting the autonomy of people, respect for the privacy and dignity of people, and observing the rights of vulnerable individuals in biomedical settings. These human rights principles protect individuals from ethical exploitation and from being used as a means to an end in a medical setting; this demonstrates the centrality of human dignity as a crucial component in bioethical considerations.

### **3.1.3 The Universal Declaration on Human Rights and Islam**

The *Universal Declaration of Human Rights*<sup>120</sup>, formulated by the United Nations in 1948, is a modern manifestation of the rights of mankind. This declaration constitutes as an extension of ancient, deep-rooted values and moral stances within human consciousness. Social and political revolutions and liberation movements promoted the concept of the rights of

mankind; this therefore facilitated the discussion of human rights to the socio-political domain in various countries including the United States of America and the Republic of France. This is supported by Adamantia Pollis and Peter Schwab (1979) who argue that the roots of the *Declaration on Human Rights* can be traced back to the American, English, and French experience of human rights.<sup>121</sup> This is reinforced by John Wright (1979) who traces the origin of natural rights back to initiating contemporary human rights, to the American Bill of Rights, the English Petition of Rights of 1627, and to the French Declaration of the Rights of Man.<sup>122</sup>

In the eighteenth century, most countries were deeply impacted by social injustice and political disparity; the human rights movement initiated social reform and political transformations across Europe and North America. Lynn Hunt (2007) writes, “The Universal Declaration did not simply reaffirm the eighteenth-century notions of individual rights such as equality before law”<sup>123</sup>

Contemporary French social reformers forged the French Declaration of Human Rights based on the American idea of “human rights”; this then inspired the French uprising against the monarchy and Church. While in America, Marquise de Lafayette<sup>124</sup> and Thomas Jefferson wrote the draft of the *Declaration of the Rights of Man and of the Citizen*. These social and political reforms have changed the norms of the political and social realms, allowed for commoners to challenge authoritative symbols, and helped to shift theocratic communities to grasp secular ideologies.

According to Hunt (2007), Louis de Bonald accuses the French declaration of producing social mayhem: “The declaration encouraged people to neglect their duties and think only of their own individual desires.”<sup>125</sup> Hunt (2007) asserts de Bonald’s position, “The declaration of rights... represented the evil influence of Enlightenment philosophy and with it atheism,

Protestantism, and freemasonry, which lumped tighter.”<sup>126</sup> Similar objections and concerns did not take away from the forces of transformation, as social and political rectifications moved furiously throughout Europe and America.

Though human rights slowly progressed through the decades, all people including commoners eventually gained their rights; this enabled discriminated groups to gain long deserved social and political rights. For example, women initially gained rights through social acknowledgement; gradually women have become equal to men in rights and duties. This acknowledgement started with reform in marriage and inheritance laws; Lynn Hunt argues, “...women never gained equal political rights during the revolution. They did, however, gain equal inheritance rights and the right to divorce.”<sup>127</sup>

The *Universal Declaration on Human Rights* is considered fundamental in protecting people’s inalienable rights, with the goal of enforcing the culture of human rights as a social value to ensure justice and protect egalitarianism. There are many scholars that debate some of the principles and legal language of the Declaration, though there is a general consensus related to the significance of human rights in its abstract, moral formula. In addition, there are several positions that question the applicability of the Universal Declaration in different contexts. For this reason, these individuals thereby reject the assumption of universality as related to the Universal Declaration.

There are many scholars that criticize the Universal Declaration of being inherently Western-based and a derivative of Judeo-Christian religious and cultural inheritances. An example is Pollis and Schwab (1979) who write, “It is becoming increasingly evident that the western political philosophy upon which the Carter and the Declaration are based provides only one particular interpretation of human rights.”<sup>128</sup> This assertion is also made by David Plevak



(2013), who states that many scholars strongly agree that human rights principles are a collective result of three thousand years of Judeo-Christian religious and cultural traditions.<sup>129</sup> Heiner Bielefeldt (2000) quotes Picht (1980), who traces the idea of human rights to Stoicism; in addition, Bielefeldt (2000) recites Fikentscher (1987) who supports the idea of the Christian inauguration of human rights principles.<sup>130</sup>

Alison Renteln (2013) refers to contemporary human rights discourse as culturally biased, which raises concerns about its legitimacy.<sup>131</sup> These scholarly perspectives relate human rights principles to western civilization, which subsequently suggests that the *Declaration of Human Rights* is only appropriate for western countries.

There are other opinions based on the previous claims of western origination of human rights; these individuals deduce that the *Universal Declaration of Human Rights* in fact, is not universal and therefore is not relevant to non-western communities.

Patrick Emerton (2013) argues that for human rights discourse to be universally acceptable, certain standards of social, political, and economical requirements are mandatory for proper adaptation of this discourse.<sup>132</sup>

Rex Martin (2013) indicates five points that render the Universal Declaration lacking in universality; he states that no universal agreement exists on the declaration, the declaration addresses only organized societies, it considers social welfare a natural right, it addresses certain social and economic standards which are unrealistic, and the declaration addresses the rights of women as a specific rights.<sup>133</sup> Sam McFarland (2015) stresses a similar position that suggests variations in comprehension and adoption of human rights principles by cultures depending on culture, economy, and political environments.<sup>134</sup>

Pollis and Schwab (1979) conclude that since the Universal Declaration represents primarily Western philosophy, the document is not applicable in non-Western cultures due to ideological, developmental, and cultural differences.

Therefore, there are many Muslim scholars who express reservations related to particular articles in the Universal Declaration based on theological, political, and social reasoning. Abdul-Aziz Sachedina (2009) argues that internationally sanctioned treaties such as the Universal Declaration lack consideration for Muslim fundamentals and cultural specifications. The author asserts that many Muslims perceive the *Declaration of Human Rights* as an imperialistic tool with a treaty written with secular ideals that challenges religious tradition.<sup>135</sup> Yvonne Haddad (2011) describes the application of the western concept of human rights in Muslim societies as, “...the enduring legacy of colonialism and its effects.”<sup>136</sup> This perspective of the *Declaration of Human Rights* and other international treaties are popular amongst developing countries with a colonial past; many scholars perceive these international declarations as an extension of the imperial west, and ignorance of cultural relativism. For example, Sachedina (2009) claims the strict, secular foundation of the Universal Declaration is “epistemologically insufficient” in representing the inalienable nature of human rights.<sup>137</sup>

Abdullahi An Na'im (2012) asserts that avoiding cultural imperialism is important when applying the Declaration principles; the writer stipulates that cultural specifications should be carefully recognized through an “interdisciplinary” approach while enacting international treaties.<sup>138</sup> According to An Na'im (2012), this type of approach to human rights would provide a new approach to engage existing issues with collaborative contributions from different fields. Rather than focusing on contrasting viewpoints, the interdisciplinary approach focuses the epistemological nature of concerns to move beyond typical issues and topics raised by human

right discourse.<sup>139</sup> For example, the discipline of law cannot make conclusions beyond the legal implications and the details of human rights principles; meanwhile, engaging other disciplines through an interdisciplinary approach would strengthen human rights in theory and practice.<sup>140</sup>

Haddad (2011) argues that the concept of “western” human rights is an unfamiliar concept to Muslim traditions and religious legacy<sup>141</sup>; she also argues that some articles of the Universal Declaration on Human Rights conflict with Islamic laws (*Sharia*).

These perspectives that oppose the *Universal Declaration of Human Rights* and its cultural and religious incompatibility have resulted in the adaptation of these opinions by various countries. A number of countries have demanded from the UN General Assembly a revision of certain articles of the Universal Declaration to provide a more culturally sensitive interpretation; Pakistan and Saudi Arabia demonstrate reservations specifically on Article 18 of the Universal Declaration.<sup>142</sup> In a similar context, objections have been made by many countries to internationally enacted treaties protesting the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) Article 16, as it does not reflect the cultural views of all countries.<sup>143</sup>

David Littman (1999) illustrates the historical objections of Islamic countries, such as the Islamic Republic of Iran, against specific articles of the Universal Declaration.<sup>144</sup> According to Littman (1999), several countries such as Saudi Arabia, Iran, Pakistan, Afghanistan, Sudan, China, and India base objections of the Universal Declaration articles on the belief that the countries’ legislative and moral systems are traditional and diverge with articles in the Universal Declaration.<sup>145</sup>

There is a degree of flexibility in the acceptance of the Universal Declaration articles in Muslim countries; this is due to the religious teachings of those countries being clearly presented

and practiced daily.<sup>146</sup> Millions of Muslims emulate and incorporate the laws of the *Shari`a* in spiritual routines and the smallest details of daily tasks. Frank Vogel (2011) writes, “Shari‘a is the constitution of the state, the sole formal source of political legitimacy, and the law of the land or common law. It is avowed as the solitary source of binding norms for the civil and private spheres, shaping and justifying social, communal, and family mores as well as individual morality.”<sup>147</sup> This statement represents and supports the significance of the Shari‘a in determining interrelation communications between individuals in various settings as well their legal, civil, and religious duties.

Various and often contrasting interpretations of the articles of the Universal Declaration made by Muslim audiences demonstrate its compatibility and also incompatibility with Shari‘a laws. Accordingly, not every Muslim population experiences conflict and dilemma with the Universal Declaration articles.

The theologically and culturally based reservations that numerous Islamic countries experience have launched campaigns and initiatives to demonstrate the reservations they maintain through the UN to the international communities. A number of Islamic states have presented Universal Human Rights contracts based in agreement with Islam, such as *The Universal Islamic Declaration of Human Rights* (1981) and the *Cairo Declaration of Human Rights in Islam* (1990).

Several scholarly works have criticized such univocal and religion-based initiatives; the applicability and universality of such theologically based and culturally specific declarations have been questioned. For instance, Claudio Corradetti (2013) argues that religiously grounded arguments that address public issues fail to represent numerous, pluralistic viewpoints; more

importantly, the author asserts that a theological argument cannot have its canonical dialect translated into a universal and agreeable terminology.<sup>148</sup>

Dana Irina (2011) suggests that human rights discourse should consider cultural specifications that reflect various communities' endeavors; at the same time, the author affirms that populations should be protected from violent practices committed under cultural banners.<sup>149</sup>

Contemporary human rights discourse faces various challenges as represented previously. In elaborating upon the questions related to the universality of human rights and its relationship to Islamic tradition, the hypothetical question of universality of biomedical ethical principles will be addressed. The next section will highlight the current reality of global bioethics, while discussing global ethics, cosmopolitanism, and multiculturalism.

### **3.2 Global Ethics**

As demonstrated previously, there are many critiques of the Universal Declaration of Human Rights. One of these critiques notes the failure of the Universal Declaration to observe cultural relativism and, and the alleged information that the articles of this declaration do not distinguish the cultural specifications of various communities,<sup>150</sup> including those of Muslim countries.

This particular issue was addressed at the Vienna World Conference on Human Rights (1993) as countries contested the Universal Declaration on Human Rights.<sup>151</sup> The Asian Values Movement rejects the assertion of universality of human rights due to the occidental origin of its principles which does not complement Asian traditions.<sup>152</sup> The Universal Declaration is often unappealing to a great number of the targeted population due to the secular language of the declaration. According to Hans Küng (1997), the existing reality of globalization in post

modernity is that it requires a global set of moral norms and standards to allow global society a customary reference to adhere to conflicts arise. Heather Widdows (2011) states that increasing inter-dependence between countries in most aspects of life produce additional global problems, which require global solutions.<sup>153</sup>

Küng presents four theses concerning globalization and its impact on global ethics; this discussion reflects upon globalization as a prevailing certainty and the repercussions of this movement.

The four theories are as follows: globalization is unavoidable, globalization is ambivalent, globalization is incalculable, and globalization can be controlled rationally.<sup>154</sup>

Gerald Berthoud (2008) writes, “Globalization is seen as inevitable. It tends to impose itself on every one as being the result of a law of necessity.”<sup>155</sup> Carol Gould (2008) explains,

“Globalization in its universalizing dimension brings diverse cultures increasingly into contact with each other.”<sup>156</sup> In addition, Widdows describes ethics in relation to globalization:

“Globalization, and the political, technological and social changes and advances that accompany it, raise new dilemmas, and global ethics is a response to these.”<sup>157</sup>

The implications of the globalization in today’s world infer that local moral norms and isolated cultural practices are no longer specific to certain cultures; this is due to the interconnectedness of today’s economic, cultural, political, and social ventures. The emerging forces of globalization tend to pass judgment on cultural practices through internationally based common norms. Gould argues that current human rights discourse needs to be supplemented with values of empathy and solidarity to remain practical;<sup>158</sup> therefore, human rights and solidarity according to Gould will constitute as “key norms” of global ethics. Gould considers empathy and solidarity fundamental to global ethics, as these values facilitate other viewpoints

regarding global concerns; consequently, this promotes international cooperation, mutual cultural respect, and appreciation for other people's struggles which initiates supportive measures.<sup>159</sup>

Global ethics as a philosophical theory is inspired by theological inter-religious dialogues and has advanced structurally to take a form as a Declaration Toward a Global Ethic (1993), which is adapted by the Parliament of World Religions in Chicago;<sup>160</sup> global ethics are primarily concerned with ethical inquiries that ascend from globalization and its international consequences.<sup>161</sup>

Global ethics is an emerging practical theory <sup>162</sup> that fills in the gaps of global moral discourse produced by a reliance on the fixed legal standardization of moral stature; this is the case related to the authority of universal human rights principles and its reliance on articles that are unsuitable to various cultures. According to Gould, "global ethics is not simply a part of political philosophy, nor cannot be reduced to social and political norms. It also marks out a place for reflecting on the type of informal, interpersonal social relations that are required by globalization."<sup>163</sup> In reference to the limitation of human right universal discourse, Küng writes, "... just how difficult it is to drive a common ethic for humankind from the human rights which are proclaimed emerges from the fact that human rights are perceived very differently in some non-western societies."<sup>164</sup>

The theory of "global ethics" and subsequent sanctioned declarations are founded on Küng's original work "Global Ethics Project",<sup>165</sup> and Nigel Dowers (1998) "World Ethics"<sup>166</sup> and many others. The philosophy of global ethics attributes to the fact that humanity shares corresponding moral and ethical norms; this can serve as a framework for global ethics capable of resolving global issues. Küng explains, "Despite all the differences between cultures there are themes which appear in almost all cultural traditions and which could serve as the inspiration for

a global ethic.”<sup>167</sup>

From a global perspective<sup>168</sup>, when framed by international willingness and aided by multidisciplinary innervations,<sup>169</sup> would result in the formulation of practical solutions for global issues by concentrating on shared principles.

An Verlinden (2008) presents a similar perspective on the subject. Verlinden asserts that by vindicating the position of the universality of normative values, the approach to international relations from a global ethics perspective has pragmatic applications that strengthen cross-cultural relations, especially where other theoretical models fail to address international conflicts: “...global ethics is a new approach toward international relations.”<sup>170</sup> This is affirmed by Widdows, who assigns role to global ethics that stretch beyond the discussion of global issues to determine how these concerns are handled and examined, through morphological frameworks.<sup>171</sup>

Gould<sup>172</sup> stresses the distinction between international and global ethics, because global ethics is concerned with “newer” moral issues that emerge from globalization and human interconnectedness.<sup>173</sup> International ethics represent normative values and ethical virtues shared by many cultures; yet, numerous communities disapprove of its principles with rational critiques. This discrepancy is important to formulate an amalgamated viewpoint and common ground for discrepancy in meta-ethical terminologies that are vital while reflecting upon global issue; in addition, it will allow for a discussion of the prospect of universality of biomedical ethics.

As Gould describes, global ethics are concerned with normative issues related to global justice and social responsibility of corporations. However, <sup>174</sup>among global issues deserving of international attention and requiring immediate acts, is biomedical ethics as it counts as issues of international responsibility.



Many features of biomedical practice become global issues with subsequent and resonating global effects;<sup>175</sup> this includes issues such as biomedical tourism, the spread of endemics across international borders, human organ trafficking, and overseas pharmaceutical research and biomedical experimentation.

Globalization continues to become a reality and human rights discourse fails to provide practical resolutions to problems on a global scale, as many countries oppose its universal articles; it can be assumed that shared, common moral norms for the world's communities (based on global ethics theory) are important to address international issues, including bioethics venture. Widdows elaborates upon this issue:

Thus, global ethics is not theoretically impossible and may even be desirable, yet, if such an enterprise is to be successful then radical ethical rethinking is required. Without such thinking then the dangers of ethical imperialism are unlikely to be avoided and the charges of moral neo-colonialism proved true; not out of any great conspiracy, but simply because solutions will be found in an ad hoc manner, driven by practice without theoretical consultation and involvement.<sup>176</sup>

An adaptation of the global, ethical approach to international concerns is an additional model mentioned by Widdows to gather international consensus and formulate common ground for varying international perspectives to discuss global issues. The reality of bioethics on a global scale is not without flaws; as in many places around the world, the rights of patients and research participants can be neglected and rejected in local and international settings. The next section will discuss the current state of patients' rights in different circumstances as part of the globalization effect and will assess the feasibility of establishing a global ethical framework to resolve bioethics issues.

### 3.2.1 The State of Patients' Rights in Global Contexts

Cultural relativism and the concept of defending local customs both aim to protect individual cultures against the forces of globalization; this is an appealing concept to many, including scholars with varying philosophical theories. Absolute support for specific customs with no regard for potentially harmful and wrongful acts to patients is immoral and typically unlawful. This point is conveyed by Ian Holliday (2002), who explains that liberal traditionalists face problems that arise from addressing issues from controversial issues of cultural origin such as female circumcision; the moral philosophy of liberal theorists support cultural relativism while these harmful practices are still considered immoral and unacceptable to the majority of the population.<sup>177</sup>

In relation to bioethics, certain customs and medical practices are considered hazardous and degrading to humans; these customs are supported among commoners and intellectuals who justify these practices based upon respect for people's choices (autonomy) and preservation of cultural heritage. An example of this issue is the cultural tradition of genital mutilation in females; this practice has serious physiological and psychological implications, yet supporters of female circumcision maintain cultural relativism as a basis for its defense. Euthanasia is also a controversial medical procedure permitted by a few countries that often is justified on the basis of patients' right to autonomy, dignity, and self-ruling.

As illustrated previously, the relationships between medical practice, human rights, specific cultural acts, and the universality of human rights are problematic to address in every respect. These relationships and the resulting intellectual debates demonstrate the centrality of human rights principles in discussing global ethics concerns. In addition, such discussions result in an advocacy for human rights, which eventually lead to the enactment of laws and regulations

to help protect people in medical and in research settings, especially where harmful practices continues in the name of customs.

In countries where human rights are neglected, unethical medical and research practices develop naturally. Some known example is the unethical Romanian medical practice of “pronatalist” law that obliged women unwillingly to bare children under Ceausescu regime,<sup>178</sup> and the degrading medical services that occurred as a result of corrupted legal system in Zimbabwe under Mugabe’s ruling.<sup>179</sup> Similar practices inspired a study carried out by the Center for Research in Health Systems CISS, by Carlos Eduardo Pinzon-Florez et al. (2015), who assessed maternal and child mortality rate in relation to social determinants. Researchers concluded that corruption and democratization are significant markers of health status in general; therefore it was recommended that there be a reduction of corruption as a condition to elevate health status.<sup>180</sup>

Unprecedented innovations in technology and communication have facilitated international connectedness since the latter half of the twentieth century;<sup>181</sup> as this connection has peaked, medical tourism become accessible to thousands across the globe. Biller et al writes, “In 2004, the New York Times ran the story of Alberty Jose’ da Silva, who lived in a Brazilian slum and sold a kidney for \$6,000 to a woman from New York. The deal was arranged by Israeli brokers, the operation carried out in South Africa.”<sup>182</sup> This illustrates the reality of current medical services and how medicine has become more globally operational; as a result, medical procedures have been sanctioned as accessible to those that can afford the medical bill.

In addition, aided by convenient logistics, people living in remote areas around the globe now can access sophisticated medical services in most medical centers.

In addition, organ transplants, cosmetic surgeries, and locally banned medical services such as I.V.F and sex correction are among prominent examples of medical tourism. Another example of medical shopping is provided by Henk ten Have (2013) related to patients with degenerative diseases, namely those with Parkinson's disease, who travel to Russia to undergo unproven treatments in specialized stem cell clinics.<sup>183</sup>

An examination of trends in medical tourism sheds light on the extent and focus of global medical activity and highlights socio-economic effects of global medicine and its implications on varying societies. Such analysis will allow for deeper understanding of the current realities of biomedical ethics and patients' rights in global settings.

Medical tourism is not always free of coercion and exploitation. Many people that travel abroad to obtain medical services do so in order to bypass governmental restrictions on specific procedures such as IVF, abortion, Hymen repair, organ transplants. This in turn creates a black market demand for such demands; often these unregulated markets compromise the principles of human rights and jeopardize the rights of vulnerable groups through manipulation and coercion.

Many patients, especially those in need of organ transplants, travel to other countries in order to bypass waiting lists and quickly obtain procedures. In doing so, these patients violate national and international laws, in addition to risking their safety; this typically occurs when the countries that allow these procedures lack regulatory laws, civil advocacy groups, or demonstrate reluctance to impose regulation over medical practices and procedures due to limited resources or corruption.<sup>184</sup>

These circumstances can be clearly demonstrated in organ transplant practices; this represents the variation law application from country to country. Chadwick et al (2011) writes, "Accepted rules for transplantation and organ donation, for instance, vary among countries and

these different approaches have led to abuses such as organ trafficking and commodification of transplantation practices.”<sup>185</sup> These practices occur worldwide when financial incentives and individual benefits take precedence over morality, ethical laws, and the value of human rights.

Organ transplantation is regarded as one of the most desired medical procedures of medical tourism. Patients with renal failure travel extensively to countries known for providing organ vendors and related surgeries at low cost to obtain new kidneys. India,<sup>186</sup> which known to be the “Organ Bazaar,”<sup>187</sup> Iran,<sup>188</sup> China, Pakistan, and the Philippines,<sup>189</sup> are among the top countries for organ transplant surgeries.

The current realities of international biomedical research is not much different than the reality of medical procedures, as both share similar ethical concerns that require prompt biomedical ethical ruling and the application of international laws and regulations. In consideration of these issues of medical tourism and organ sale, typical concerns regarding exploitation, autonomy, and social justice becomes exceedingly complex.

While medical tourism usually aims to provide people with the means to become healthier by using approved and known remedies, biomedical research typically subject patients to procedures with uncertain outcomes which triggers additional ethical dilemmas.<sup>190</sup>

Biomedical research is an important tool for the advancement of knowledge related to disease etiology and potential cures: “...research is undertaken to produce new scientific knowledge.”<sup>191</sup> In addition, the research itself could produce adverse results different than the results originally anticipated. Many governments have enacted and enforced strict laws related to research to help protect people from being victimized in these settings. Unfortunately, not all political regimes share the same degree of support for biomedical ethics. Many countries, especially developing countries, do not strictly enforce regulations for biomedical research

activities due to lack of resources or complete absence of committees concerned with research and bioethics. <sup>192</sup>

An example of the reality of bioethics is the shift of research trials to settings, distant from the country of origin. To bypass strict regulations, avoid hefty law suites, and minimize operating costs, biomedical researchers have shifted research practices to various developing countries; in these countries, there are more lenient laws, which provide an appealing, lucrative research environment. <sup>193</sup>

This trend of shifting research operations has resulted in new ethical concerns; and these ethical concerns are so significant that it can sometimes outweigh the benefits that the hosting countries reap from the research. <sup>194</sup>

The benefits of global, biomedical research mandate its existence; as previously stated, research activities allow the advancement of knowledge related to illnesses and potential remedies. However, a balance between increasing knowledge and benefitting immediate stakeholders such as patients and communities involved in the research should be balanced, <sup>195</sup> as Ezekiel Emanuel (2008) notes that people's wellbeing is more important than gaining knowledge. <sup>196</sup>

The countries that host research activity benefit by providing logistical services to researchers and skilled professionals from the country are recruited to participate in the research trials which provides them state-of-the-art knowledge; the unskilled workers, citizens, and patients that are recruited for these studies benefit financially and gain access to otherwise unavailable medical services. For these reason and other various benefits, poorer countries seek out the foreign investment that global research requires.

Global biomedical research is not always beneficial for those involved; this type of research can potentially produce little to no positive advances due to the unethical practices occurring in global research ventures. Ethical concerns begin by questioning the objectives of research studies and the anticipated outcomes; in addition, issues related to conflict of interest are addressed. Throughout the recruitment phase, issues arise of informed consent, exploitation, ethical dilemmas related to the use of placebos and ineffective drugs in randomized control trials (RCT) due to issues of distribution of knowledge and continuity of medical care for the participants. These topics are controversial in ethical discussions and raise questions during research implementation.

In developed countries, biomedical and research practices are well controlled and heavily regulated. Due to the immature social and political environments in developing countries, this type of protection for patients and research participants are not typical. In addition, political corruption, underdeveloped healthcare infrastructure, and low standard of living are factors that give people in developing countries the incentive to become research subjects for presumed healthcare access or monetary compensation.<sup>197</sup> These factors permit off-shore researchers to conduct research studies freely and according to their terms. Many research groups practice according to their homeland standards while working in developing countries; the absence effective, local bioethical committees leave the regulation of ethical standards to personal interpretation and preference.

International laws that govern biomedical research are needed to protect research subjects from being used by giant, multinational research companies in the absence of local regulation. As represented by various agencies of the United Nations, the international community has formulated codes and declarations that have received international acceptance and recognition to

unify existing biomedical laws; the purpose of this unification is to establish binding, yet feasible international laws that regulate biomedical research in both developed and developing countries. Internationally formulated biomedical laws are deemed important to promote common morality in biomedical practices. According to Rizvi et al. (2011), the WHO demands that the Pakistan government controls organ transplantation, which has resulted in the enactment of a law referred to as the *Transplantation of Human Organs and Tissues Ordinance* (2007); due to this law, there has been a significant drop of illegal organ transplants occurring in the country.<sup>198</sup>

### **3.2.2 Multiculturalism**

As previously stated, the majority of human communities across the globe ascribe to common norms or dogma of acceptable behaviors that aim to promote goodness and prevent wrongdoing in the society. These norms are not specific to specific regions or societies because most human communities share similar moral principles. Becker (2002) suggests that western originated moralities have equivalent value in other cultures.<sup>199</sup>

One of these principles is the right to liberty and autonomy; this principle has been deemed crucial to humans as individuals and as cultural or ethnic groups. To elaborate on the concept of multiculturalism and its relationship with bioethics, the issue of autonomy will precede the discussion. David Zientek (2003) claims that there are significant differences in the implications of autonomy between Western and Eastern based on the findings of Angeles Alora and Josephine Lumitao from *Beyond a Western Bioethics: Voices from the Developing World* (2001).<sup>200</sup>

The notion behind respecting autonomy in biomedical settings is to protect people from compulsion to do something without consent that is against the person's beliefs and values.



Humans value autonomy because it allows people to pursue happiness and freedom; this implies that autonomy is multi-faceted and diverse. In this era, autonomy is expressed through a variety of channels such as freedom of thought, freedom of speech, and freedom of transportation which are socially and politically influential.

Respect for autonomy is a principle that creates boundaries and defines the relationship between people and societies. This principle enables people to live according to their convictions in a diverse society, aside from cultural differences and orientations.

Sovereignty is described by Freely as fulfilling human desire for liberty and intrinsic urgency to be heard and valued which can bring “irreplaceable satisfaction.”<sup>201</sup> The philosophical justification behind considering autonomy as a fundamental principle for human beings is that liberty, which is reflected through autonomy, is intrinsically valuable to humans.<sup>202</sup> Therefore, the principle of autonomy cannot be overridden or reduced in this era of globalization; unprecedented admiration for autonomy and an individualistic approach to living outweighs communitarianism and altruistic cultures.

Failure to recognize the value of autonomy disregards people’s right to liberty and autonomy, in addition of being immoral and jeopardizes human rights incentives.

Respect for autonomy is fundamentally important in social life because it allows people to express feelings, wishes, and expectations. This value for autonomy is applicable to social groups as well because social groups within a community act as an individual entity and demand for recognition, autonomy, and self-ruling.

Autonomy in healthcare and research settings is equally valuable to autonomy in political and social life. Respect for autonomy in healthcare and research settings is considered a first line of defense to protect patients and research participants from abuse through science. Patients and

research participants often lack sufficient knowledge of the medical or research process and limitations of choice, and therefore are prone to exploitative practices. Multiculturalism will provide an additional protective layer for patients by contextualizing social groups, typically by categorizing these groups as minorities or vulnerable to allow for increased consideration during these activities.

In respect to individual autonomy, multiculturalism is suggested to begin upholding varying cultures' specific rights to autonomy and self-determination.

The implications of multiculturalism are to respect individualism of culture specifications, defend local customs, and protect minor cultures against the forces of globalized ideologies;<sup>203</sup> therefore the effects of multiculturalism often clashes with universalism and demand for adapting contextualism.<sup>204</sup>

Multiculturalism is a theory frequently debated in global related discussions, and is valued by various philosophical schools, especially by multiculturalism theorists and traditional liberal thinkers. For instance, liberalism as a theory has gained a lot of global attentiveness in recent times; encirclements the idea of respecting individual cultures and its specifications, as culture demonstrates people's collective autonomous choosing, and symbolizes their liberty of thoughts transformed into beliefs and customs.<sup>205</sup>

The theory of multiculturalism in the realm of bioethics advocates for cultural relativism to be included in normative bioethical principles; this perspective is consistent with the argument that charges bioethics in its present form of lacking sensitivity towards other cultural specifications, and undermining ideological and social differences while ordaining bioethics discourse. Hence, these bioethical norms become the default standards in the contemporary settings. However, great considerations and suggestions are given to incorporate social sciences

while ordaining bioethical norms. This will allow the discipline of bioethics to become more culturally oriented, practically normative, and reflexive.<sup>206</sup>

What if certain habitual practices that are based on social science outcomes and defended for the sake of multiculturalism are harmful and malicious? Do claims of respecting group autonomy and multiculturalism make such practices morally permissible? Does the defense for local and isolated customs and promotion of cultural specification hold a legitimate and moral justification regardless of what is being defended, or could this position be used indirectly to support suppressive practices and to defend harmful customs?

Most human communities across the globe ascribe to common norms as principles that aim to promote goodness in the society and prevent wrongful actions; there are many isolated but frequent examples of suppressive customs and harmful practices throughout the world that are supported by the claim of cultural exception or religious doctrine. These practices endanger millions of peoples' lives and jeopardize their intrinsic dignity and universal human rights. The infamous custom of female genital mutilation demonstrates how customs and human rights clash in these settings. This custom is widely practiced in certain African and Middle Eastern countries,<sup>207</sup> and performed with religious and cultural justifications<sup>208</sup> in addition to the belief that mutilation of female genitals will decrease sexual temptations and sinful life.<sup>209</sup> The international communities, including local civil advocates, view such practices as a crime against human nature based on common logic, universal normative ethics, and reasonable judgments. To reduce such practices, international organizations have issued a "zero tolerance view" in 1997 to encourage countries to eliminate such procedures.<sup>210</sup>

Absolute support for multiculturalism and the rights of individual cultures and their customs with no refutation of wrongful acts is unacceptable on rational and ethical foundations and is not considered appropriate in today's modern societies.

Christian van den Anker (2008) explains that liberal theorists typically support individual rights and do not necessarily favor groups rights, as multiculturalism in liberal perspectives contradicts universality; therefore the multiculturalism claim will provide an opening for cultural and ethnic discriminations.<sup>211</sup> This point explains that the support of absolute multiculturalism is not precisely efficient when adapted in social and bioethics discourses, as multiculturalism does not hold practical solutions and justifiable arguments when harmful customs threaten people's health and rights. <sup>212</sup>

However, and since the concept of global ethics is an emerging philosophical theory that justifies its existence based on shared universal norms. The "Normative approach to international relations"<sup>213</sup> has a practical role that effects cross-cultural relations and aims to limit harmful practices occurring in different communities.

Even more, such practical applications are embodied in the UNESCO Universal Declaration on Bioethics and Human Rights.<sup>214</sup> The newly emerging concept of global ethics emerges from of the global necessity to formulate a path that will enable humanity to address the array of moral dilemmas that are the consequence of emerging technologies, new political ideologies, and contemporary social and economic realities.<sup>215</sup>

### **3.2.3 Cosmopolitanism**

Cosmopolitanism is an additional concept in global ethics that is essentially related to the discussions of human rights principles and bioethical standards; this concept is derived from the

Kantian absolutism theory<sup>216</sup> to address issues concerning global ethics.<sup>217</sup> According to Stan Van Hooft (2014), cosmopolitanism was first introduced to address concerns arising from dealing with “others” that can be strange neighbors, foreigners, or abstract cultures. Garrett Brown (2009) understands cosmopolitanism as a concept concerning global interconnectedness and world relations including the relation with ecology, social, political, and economical deterrents of the current era. According to Brown, cosmopolitanism is constantly evolving which means that this concept requires continuous examination and interpretation to cope with its dynamic nature.<sup>218</sup> Nikos Papastergiadis (2012) traces the terminology of cosmopolitanism back to the famous Socratic expression, “world’s citizen.”<sup>219</sup>

Van Hooft relates cosmopolitanism to the idea of the nature of human solidarity across the globe, which comes in a form of human equality and innate moral capability: “Cosmopolitanism is the view that the moral standing of all peoples and of each individual person around the globe is equal.”<sup>220</sup> Van Hooft views social classifications of humans based on ethnicity, religion, and cultural description as the roots for prejudice that contradict cosmopolitanism.<sup>221</sup>

Most importantly, Van Hooft perceives cosmopolitanism as a theory that proposes the idea of sharing the same set of morality and share the exact moral framework that could solve individual problems within the international community. Cosmopolitanism affirms formulaic problem solving, which is considered relevant to all humans and applicable across various cultures settings. However, to reflect on the subject of the universality of biomedical ethics, cosmopolitanism represents the possibility of introducing a unified framework to discuss moral topics at global scale. The demonstration of cosmopolitanism in relation to other global ethical ideologies provides additional support of the argument that holds global moral norms possible,

where therefore proves that global bioethics is not merely fiction. Martti Koskenniemi (2013) explains that cosmopolitanism can be a synonym or closely related to universalism and globalism.<sup>222</sup> This is mentioned by Magdalena Nowicka and Maria Rovisco (2009) as well, who assign practical roles to cosmopolitanism; the authors perceive that accepting cultural differences would sanction for global norm standardization and opposes ethnocentricity.<sup>223</sup>

In relation to Van Hooft's proposition, Ian Holliday (2002) suggests the adaptation of cosmopolitanism into bioethics as an ethical framework can be utilized as a foundational concept in formulating ethical standards; these standards will be capable of solving international biomedical ethical dilemmas without conflict to the theory of multiculturalism,<sup>224</sup> or by falling into the cyclical quarrel of respecting individual cultures.

Holliday argues that cosmopolitanism is important in negotiating ethical dilemmas that occur in global settings based on the universality of ethical principles. The globalization of biomedical ethical dilemmas permits the adoption of cosmopolitanism as practical framework capable of formulating a unified position regarding global bioethical issues.<sup>225</sup> Holliday also claims that any shared agreement developed through cosmopolitanism will be inherently cogent and convincing, therefore appealing to many individuals, cultures, and countries.<sup>226</sup>

Due to relevancy of these theories to bioethics as capable theories to address global bioethical issues, global ethic, multiculturalism, and cosmopolitanism has been addressed; as these concepts would contribute to the examination of the universality of bioethics principles, which is coming next.

### 3.3 Questioning the Universality of Bioethics: Is Biomedical Ethics Universal?

It is assumed that globalization and modernity plea for unified laws<sup>227</sup> and universal moral standards,<sup>228</sup> to allow for regulating different aspects of human activities, despite time and physical locations. However, not every community hesitates to accept regulations and laws produced by international organizations committees, as in the case of human rights articles. In addition, not every community demonstrates consensus on common morality and moral values essential to enforce such international standards in social fabrics and political systems.<sup>229</sup>

Such reservations to accept standards assumed to be universal occur naturally;<sup>230</sup> for example, there is a range of difference in interpreting international articles and prioritization of accommodations for ethical principles, or due to religious, cultural, or political incompatibility with those international treaties.

This will facilitate the discussion to determine the universality of biomedical ethics assumptions and examine the feasibility of universal bioethics principle's in various international healthcare settings, with consideration and concentration on the *UNESCO Universal Declaration on Human Rights and Bioethics*, as it is determined to be the most comprehensive set of normative ethical standards.

The principles of the *UNESCO Universal Declaration on Bioethics and Human Rights* sanction ethical guidance and a foundational framework that constitutes and regulates bioethical activities based on common moral principles derived from human rights values.<sup>231</sup> Moral principles such as respect for human autonomy through consent are stated in Article Six of the Declaration,<sup>232</sup> Justice, equity and fairness are protected in article Ten, non-maleficence and other values are adapted and presented throughout the declaration articles.

By reflecting on philosophical theories that provide input on universal values,<sup>233</sup> the international determination to promote human rights and protect human dignity represents international cooperation between countries. As mentioned, international laws that consider the ethics of biomedical practice began in response to the biomedical research practices during World War II; this resulted in an international campaign to develop and enact declarations concerning biomedical ethics and medical regulations. These collective international efforts resulted in formulating the *UNESCO Universal Declaration on Bioethics and Human Rights*, to continue the legacy of the work of previously formulated committees related to bioethics, such as the *Declaration of Helsinki* (1964),<sup>234</sup> *Nuremberg Code* (1947),<sup>235</sup> *The Council for International Organizations of Medical Science*,<sup>236</sup> and *The Belmont Report* (1970)<sup>237</sup>.

The UNESCO Universal Declaration mimics human rights discourse, which is regarded the most comprehensive form of human rights statement at the international level, and concentrates on promoting human rights and protecting human dignity in biomedical practices; Roberto Andorno (2009) writes, “The notion of human dignity is very frequently used by international human rights instruments”<sup>238</sup>

An understanding of the importance of collaborative works between countries allows the production of great results and encourages the unification of qualitative ethical standards; this therefore mandates and justifies the presence of such declaration for biomedical activities. Therefore, the principles of the *UNESCO Universal Declaration on Bioethics and Human Rights* are in sync with the human rights principles and other normative values that govern the missions of international organizations.

The history of the *Declaration on Bioethics* dates back to 1970, which accompanies the infancy of bioethics in its modern incarnation,<sup>239</sup> and comes to reflect on the growing interest of



the international community to formalize principles of bioethics that prove applicability in all healthcare settings.

The *UNESCO Universal Declaration on Bioethics and Human Rights* has gone through various phases of rigorous revisions, endless discussions, and several amendments prior to its official launch and adoption by the UNESCO countries. The International Bioethics Committee (IBC) has formulated the initial drafts of the *UNESCO Universal Declaration on Bioethics and Human Rights* and explained the principles embedded in the Declaration are morally relevant to the international community and universally feasible; a member states. Therefore, through its principles the *UNESCO Universal Declaration*<sup>240</sup> came to set norms and regulate biomedical activities in many countries.

Despite the demonstration of importance and significance of the *UNESCO Declaration*, there are scholarly critiques of the document's functionality and practicality in local settings. Opposing accounts that question the universality of the *UNESCO Declaration* are brought forward by numerous scholars.

Due to the close relation of bioethics to human rights discourse<sup>241</sup>, this discussion will begin with an analogy related to human rights discourse and opposing arguments that question the universality of bioethics. As mentioned previously, the universality of human rights has been questioned and contested rigorously; many quarrels between scholars have brought forth the debate of the universality and feasibility of human rights in varying communities. For instance Jack Donnelly (2007) rejects the assumption of the universality of various cultural behaviors and beliefs as well their ontology, which he describe as logically and politically not applicable.<sup>242</sup> This is based on belief that human rights principles are founded on occidental philosophes, which does not prove to be acceptable and compatible with other non-western cultures.

Many intellectuals from developing countries argue that current discourse related to human rights discourse represent specifically western philosophical perspectives on human rights and its implications. Some of these scholars perceive universal ethics as moral colonialism and new imperialism;<sup>243</sup> the scholars accuse western countries of imposing moral norms onto other cultures to continue the legacy of colonial past.<sup>244</sup>

These perceptions related to internationally enacted declarations can be extended to bioethics, as many bioethicists and scholars of social science reject the claim of universality of bioethics. John Arras and Elizabeth Fenton (2009) relate opposition of the universality of bioethics on the grounds that bioethical matters focus on the rights of individuals; this does not hold justifiable and valuable foundation to address bioethical issues in all communities. In Catharine Myser's (2003) article, *Differences from Somewhere: The Normativity of Whiteness in Bioethics in the United States*,<sup>245</sup> the author emphasizes the role of ethnicity in determining moral norms of bioethics in the United States. Through implicit and generalized dialect, Myser hints that the dominant white ethnicity in bioethical venture undermines the cultural innervation of other minorities and potential contributions to the field of bioethics in the US and abroad. This implies that bioethical principles are created by white ethicists; Myser's claims in conjunction with the initiation of contemporary bioethics in the United States demonstrate that current bioethical standards are univocal and culturally biased. This subsequently supports the occidental origination and westernization of bioethical principles. This is demonstrated by Subrata Chattopadhyay and Raymond De Vries (2013) who refer to Myser's (2011) writing: "Assembled in the North American socio- cultural context and using the raw materials of Western moral philosophy, bioethics developed with a "primarily Anglo-American cultural ethos."<sup>246</sup> Anita Ho (2016) also writes, "Whiteness is not necessarily about the skin color of

those who practice bioethics. Rather, it is first and foremost about the dominant cultural norms and ideologies that have come to determine how bioethics is practiced and what principles and contexts are considered relevant in the inquiry.”<sup>247</sup>

Chattopadhyay and De Vries quote Kazumasa Hoshino (1997), who accuses western bioethicists of imposing western embodied bioethics principles onto other cultures through the claim of moral universalism; the author argues that acknowledging such imposition of incompatible values is immoral.<sup>248</sup> Chattopadhyay and De Vries do not support moral universalism because the authors claim that adaptation of western-based moral norms in non-western contexts is “harmful.”<sup>249</sup> Godfrey Tangwa (1999) claims that western medical technologies and western moral values are exported to the world; as a result, Tangwa argues to exclude values from borrowed technologies, due to the irrelevant nature of western values in non-western cultures.<sup>250</sup>

Soren Holm and Bryn Williams-Jones (2006) conclude that in observable behaviors, global bioethics do not have common themes among different cultures; this is because topics that are relevant to certain cultures are not necessarily relevant to others which suggests inconsistency in perceptions of global bioethical issues. This study suggests that the absence of unity in bioethical topics among varying cultures which in turn, implies the absence of shared interests on a global scale; this supports the assumption of a lack of global consensus on bioethical standards.

According to opposing arguments of the universality of bioethics standards, finding common position in bioethics is not likely; <sup>251</sup> therefore, a unified set of principles is a hypothetical rhetoric doomed to fail. Even more, opposing views of the universality of bioethics present their arguments based on critiques of the philosophical foundations of bioethical

principles at its core. Principles of bioethics, as it constitutes various moral values in universal bioethics dialects (e.g. UNESCO Declaration on Bioethics), is subject to criticism and disapproval.

For instance, critiques of principlism come from different borders, ranging from opposing perspectives based on religion, to other philosophical oppositions such as the Universalist standpoints.<sup>252</sup> Maura Ryan (2004) also suggests that the perspectives of developing countries towards bioethics standards should be addressed and not only concentrating on philosophical debates within western contexts. These perspectives are required to be incorporated in the discussion, according to Ryan. This viewpoint is shared by Mary Rawlinson and Ann Donchin (2005), who argues that universal principles such as the UNESCO Declaration should not be based on shared norms, but should observe cultural differences which the authors claim the declaration lacks.<sup>253</sup>

An additional critique of international bioethics is related to the adaption of individualism as a fundamental, moral theory in constituting bioethical norms such as by respecting patients' autonomy, right to privacy, and confidentiality; these matters are considered debatable and relatively acceptable by different cultures.<sup>254</sup> Scholars including communitarians and multiculturalists regard the emphasis of international bioethics on individualism unsuitable in communities where social fabrics are stringent and families are actively involved in patients' affairs.

The *UNESCO Universal Declaration on Biomedical Ethics and Human Rights* is a model to formulate universal bioethical norms, as described critiques of bioethical universality address the UNESCO Declaration principles as well. One of the largest criticisms against the UNESCO Declaration is presented by Cheryl Cox Macpherson (2006); Macpherson described the

*UNESCO Universal Declaration* as controversial at the core from the beginning with drafting procedures and the selectivity in choosing contributors to the declaration. Macpherson argues that the IBC has excluded the “mainstream bioethicists” from making contributions in the articles. Macpherson also accuses the declaration of neglecting important topics of bioethics such as moral status of embryos; in addition, Macpherson claims that the IBC does not consider public and religious perspectives while developing the declaration articles.

However, Macpherson’s claims are short of critical reasoning as she mentioned that the IBC excluded the mainstream bioethicists as well ignored religious contribution to the draft of the declaration, while in fact and according to Ten Have and Jean (2008), the whole process of the drafting of the declaration; even prior to that, IBC has consulted a wide selection of ethicists arriving from 80 countries, representing the major world’s religions, and they have contributed in every stage in formulation of the UNESCO Universal Declaration.<sup>255</sup>

These accusations are shared with other scholars<sup>256</sup> such as David Benatar (2005), who suggest the problematic nature of universal bioethics and question its usefulness.<sup>257</sup>

The non-binding, legal tone of the declaration is also critiqued, as Mark Cherry (2009) argues that to promote health of any society, governments are obliged to fulfill the duty of advancing healthcare venture; the non-binding language of the declaration provides no model, scope, or presumed role for governments to follow while sanctioning biomedical related regulations at national level.<sup>258</sup> However, many scholars and writers fail to comprehend and grasp the ideas that give such normative instruments its supremacy. The declaration’s non-binding language does not reduce its significance as an extremely influential document with resonating, positive impacts on human wellbeing. In addition, the entirety of the UNESCO members accepts and adapts the declaration.<sup>259</sup>

Bioethical matters aim to protect human rights in medical settings and try to cumulate international strengths to promote patients' rights in global and individual biomedical settings. Scholars and philosophical theorists gain to support for the inclusion of bioethical values in global discussions to formulate unified, universal, and practical ideals to discuss bioethics disputes and constitute unified principles. The advantages of such collaboration will allow nations, especially those with inadequate bioethical infrastructures, to protect populations in medical and in research settings.<sup>260</sup>

The following scholarly statements will focus on the universality of bioethical matters through arguments made in support of the *UNESCO Universal Declaration on Bioethics and Human Rights*. This declaration symbolizes the ultimate representation of the product of international collaboration related to universal bioethical matters. Michael Kirby (2009) charges the *UNESCO Declaration on Bioethics and Human Rights* of being vague and written in complicated language in comparison to the *Universal Declaration on Human Rights*; additionally, the author asserts the crucial role that the UNESCO declaration plays in the advancement of the international community.<sup>261</sup>

Despite the emphasis on cultural diversity inclusion in the UNESCO deceleration articles,<sup>262</sup> majority of critiques made on universal bioethics focus on the lack of cultural sensitivity in determining global bioethical norms as well as the intended marginalization of different and important perspectives in the articles of the UNESCO declaration. For instance, Tomislav Bracanovic (2011) argues that the appeal to cultural relativity through rejection of universal bioethics principles is inconsistency and "misleading".<sup>263</sup> Bracanovic relates the claim of cultural diversity and the demand for inclusion of varying cultural norms to universal bioethics discourse based on two reasons. The first reason is the occidental origin of bioethics

principles, which does not appease proponents of cultural plurality and multiculturalists. The second reason is the false assumption that different cultures have different contributions to enrich bioethical discourse.

Bracanovic refutes these two reasons and argues that reliance on cultural plurality adds burdens to bioethics related to solving its dilemmas. Bracanovic argues that within any singular culture, there are many different contesting views; this is problematic to determine which perspective is truly representative of the culture. Bracanovic also states that since cultures are far older than bioethical dilemmas, given the contemporary nature of biotechnology and medical interventions, it is irrational to constitute modern principles in bioethics based on ancient customs. The author also proclaims that conveying higher normative status to cultures in determining modern and complex bioethical norms would harm the culture itself by assuming that culture is capable of providing relevant answers to bioethics inquires. Bracanovic suggests that the role of cultural plurality in bioethics is more problematic and impractical because every culture wants specific customs to be recognized and respected by the international community. This rejection of cultural relativism can be related to previously mentioned practices such as female genital cutting. Recognition of culture specifications will prove Bracanovic's claim that some cultural practices can harm people; in pure logic, such practices cannot be upheld through cultural plurality defenses.

In Ren Zong Qiu's *Biomedical Technology and Confucian Values*,<sup>264</sup> the author notes the variations between modern technological implications and the traditional Chinese philosophy of Confucius. Qiu argues that such conflict of traditional values with modernity, and between the old and the new can be seen when autonomy is assigned to patients instead of the traditional inclusion of families in determine their patient's affairs. Further, Qiu suggests the incorporation

of mutual dialogue between cultures to close the gaps in the determination of bioethics norms. These recommendations highlight the misperception of relativists and show the flaws of the incorporation of cultural relativism in bioethics; this strengthens the arguments advocating for principles of bioethics. This is noted by Henk ten Have and Bert Gordijn (2011) who charge those against universal bioethics on the grounds of cultural relativity of lacking descriptions of ethical problems without providing tangible solutions. Ten Have and Gordijn state that Adriana Petryna (2009) presents examples of bioethical problems across the globe lacks suggestions for solutions to these problems. Ten Have and Gordijn refute Chattopadhyay and De Vries (2008) claims of modern, normative bioethical principles being western born and morally imperialistic, bypassing other cultural perspectives. Ten Have and Gordijn argue that such accusation is irrelevant, since the body of knowledge is not specific to a certain culture and ignorance of others; this is such given that Arabic numbers are used by westerns and Arabs as obtained knowledge from other cultures, and have therefore contributed to science. This also refers to bioethics due to the global nature of technology and modern medical practices, which ultimately requires a global set of biomedical ethical standards that constitute bioethics normative principles.

Supporters of the UNESCO Universal Declaration defend the idea of universality of bioethics, as Henk ten Have and Bert Gordijn note, “Modern health care is universal, medicine is almost the same everywhere, and people have similar diseases. Why should bioethics be different?”<sup>265</sup> Therefore, different perspectives advocating for the *UNESCO Universal Declaration on Bioethics and Human Rights* will conclude this chapter. Roberto Andorno (2007) writes in reference to *UNESCO Declaration on Bioethics and Human Rights*:

...it is worth mentioning that this is the first international legal, though non-binding instrument that comprehensively deals with the linkage between human rights and



bioethics. Regardless of the weaknesses inherent to this kind of instrument, the very fact that virtually all states reached an agreement in this sensitive area is in itself a major achievement.<sup>266</sup>

Supporters of universal bioethics, such as Ten Have and Michele Jean, do not underestimate the potential contributions of varying cultures to bioethics; in fact, they call for the incorporation of different perspectives to bioethical venture to enrich discussions of contemporary ethical issues. For this reason, Ten Have and Jean write that for the UNESCO Declaration to be culturally sensitive, UNESCO has developed mechanisms to respect cultural perspectives as well as ensure that the articles are acceptable for those countries.<sup>267</sup> This is noted in article 3 of the declaration, which incorporates the idea of cultural diversity through precedence to individual preferences.<sup>268</sup> Michael Kirby (2009) argues that the scope of the UNESCO Universal Declaration supports cultural diversity and pluralism,<sup>269</sup> which thereby rejects accusations of the declaration of being univocal and biased.

### **3.4 Conclusion**

In conclusion, while globalization of ideas and goods become standard in this era, medical knowledge continues to become a global venture as medical tourism and medical research has become of global concerns. As mentioned earlier regarding the inevitable nature of globalization, the need for unified global bioethics to resolve global conflicts has become increasingly importance for the advancement of humanity. As demonstrated previously, there are numerous scholarly arguments that support or question the feasibility of universal bioethics in varying contexts based on contextualism, cosmopolitanism and multiculturalism. These theories have concluded that a need for more collaborations and unifications are required between countries to achieve better ethical standards.

However, and despite the accusations against the westernization of international principles and claims of the declaration's occidental origins, the *Universal Declaration on Human Rights* and *UNESCO Universal Declaration on Bioethics and Human Rights* among other international principles are considered significant contributions to the promotion of human rights and patients' rights around the globe. And despite the groundless accusations of the limitations of the Declaration articles due to the non-binding language, the *UNESCO Universal Declaration on Human Rights* has proved to provide a significant and crucial moral framework and practical guideline for bioethical venture as a whole. The Declaration also encourages healthcare systems around the world to adopt better practices.

However, and despite the accusations made against the UNESCO Universal declaration as being cultural and religion ignorant, and false allegations related to the lack of enactment and adoption by mainstream countries and scholars, these accusations have been refuted and rejected thoroughly. Even more, this elaboration on the UNESCO Universal Declaration demonstrates the strong foundations of the UNESCO Universal Declaration and represents the feasibility and the universality of the Declaration and bioethics norms in various international settings. In conclusion, the incorporation of the declaration's articles will result in the advancement of the rights of patients toward more positive, holistic healthcare across the world.

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## **Chapter Four: Cultural Concerns and Patients' Rights in Saudi Arabia**

This chapter will establish an essential link between the discussion in the previous chapter of the universality of international principles, with a specific focus on biomedical ethical principles represented by the *UNESCO Universal Declaration on Biomedical Ethics*, and the potential application of bioethical principles in the Saudi Arabian healthcare system.

This discussion will begin with an elaboration upon the role of religion in the determination of bioethical norms of any given community, including secular communities. This role examination will begin with an investigation of the different approaches to biomedicine that religions adopt, including three major world religions: Roman Catholicism to represent Christianity, Judaism, and Islam.

The chapter will focus specifically on the role of Islamic faith in the determination of normative principles and the shaping of Muslim perceptions related to contemporary issues in biomedical ethics. This discussion is crucial to understand bioethical discourse and its culture in Saudi Arabia, as Islamic teachings and traditions are central in the lives of most Saudi Arabians and other Muslims.<sup>1</sup> The majority of Saudi people are strict observers and followers of Islamic teachings in comparison to other Muslim countries that have secularly based legal and social systems. Many Arabian and Islamic countries apply moderate to strict separation of social, legal and religious spheres.

The separation between sacred practices and practiced ethics in areas concerning life and death interferes with the convictions of the communities; this includes issues such as abortion and the determination of the legal position of persistent vegetative state patients.

An important distinction will be made between religion and spirituality prior to the upcoming discussion of religion and bioethics. Harold G. Koenig (2006) provides a clear

explanation of the difference between religion and spirituality; this distinction will better demonstrate the role of religion in defining bioethical standards. Koenig describes spirituality as a complex human experience that occurs in any person, from any society despite being a follower of a specific religion.<sup>2</sup> Koenig describes religion as the following:

Religion usually relies on a set of scriptures or teachings that describe the meaning and purpose of the world, the individual's place in it, the responsibilities of individuals to one another, and the nature of life after death. Religion typically offers a moral code of conduct that is agreed upon by members of the community, who attempt to adhere to that code.<sup>3</sup>

Due to the negative implications of religion in some secular societies as a direct result of the secularization of social and legal discourse, many healthcare entities use the terms religion and spirituality interchangeably. Candy Brown (2015) notes that in modern hospitals and healthcare settings, the term 'spirituality' is favored as it is viewed as more acceptable over the term 'religion'. Brown describes the diminishing use of the term religion as a world in favor of spirituality to promote objectives of secularization.<sup>4</sup>

Religion is focused on providing a clear and binding reference for devotees to obey; meanwhile, spirituality does not require entailments, obligations, and does not promise canonical rewards or punishments. For example, Islamic mysticism (Sufism)<sup>5</sup> is a spiritual philosophy with diverse sub branches that provide specific guidance and spiritual practices to reach God's way; the significance of Sufism spirituality is that Sufism is not mandatory and majority of Muslims do not follow its practice. In addition, there are people that have unshakable beliefs in the practice of yoga as a spiritual approach to achieve higher locus, meanwhile yoga is not an established religious order.

Islamic religious teachings relevant to bioethics, and other deterrents of Muslim moral standards such as culture, and norms of biomedical ethics will be discussed; the majority of

Muslim scholars and religious clerks across varying school of thought perceive Islamic civilization and associated cultures as based on divine scripts and sacred teachings framing Muslim moral life. Due to the role of bioethics in sensitive topics concerning life and death, Islamic moral perspectives actively approach such matters to provide spiritual guidance to Muslim followers.

This chapter will discuss sources of Islamic law and the traditional foundations of Islamic moral reasoning; in addition, it will discuss the influence of Islamic jurisprudence upon ordinary Muslim susceptibility and sensibility of ethical issues concerning biomedical perspectives. The theological components of Islam as a proactive and organized religion do not constitute worship arrangements and communal rituals; instead, Islamic religion is composed of a magnitude of relationships occurring between Muslim individuals and their multilayer connections.

Islamic biomedical ethics will be demonstrated through a representative history of Islamic bioethics, sources of moral reasoning, and current states of affairs. Abdullah Daar and Binsumeit Alkhitamy (2001) write, “In Islam, bioethical decision-making is carried out within a framework of values derived from revelation and tradition. It is intimately linked to the broad ethical teachings of the Qur’an and the tradition of the Prophet Muhammad, and thus to the interpretation of Islamic law.”<sup>6</sup> This statement demonstrates varying sources of Islamic jurisprudences which are deemed by Muslims as binding, authoritative, and divine sources to obey and reflect upon. In addition, Islam is not only concerned with spiritual and legal aspects of Muslim’s affairs, it also describes Islamic-based guiding discourse in various human activities including medicine. Omar Hassan Kasule (2002)<sup>7</sup> suggests that in order to obtain maximum benefits of biomedicine and to avoid the materialistic pitfalls of current biomedical practices, the Islamic holistic approach to biomedicine provides a potent alternative and application that



fortifies patients' rights. Kasule mentions the existence of Islamic approach to biomedicine and demonstrates the centrality of religion to biomedical discourse and biomedical ethics.

It is necessary to elaborate upon the role of Islamic religion in determining bioethics norms when discussing patient's rights in Saudi Arabian healthcare systems. This elaboration is needed due to Islam being a major contributor to Saudi culture; in addition Saudi Arabia is a devoted theological based state and the birthplace of Islam fourteen centuries ago. Therefore, Islamic teachings are influential and persistent in Saudi Arabia. According to Mansoor Moaddel (2007),<sup>8</sup> a study conducted in 2001-2003 by the Pan- Arab Research Center involved a number of Islamic countries including the Kingdom of Saudi Arabia; this study has concluded that Saudis rank highest on the centrality of religion to individual identity, as Saudis associate themselves with religion before describing themselves as Saudi nationals. Moaddel writes, "Saudis consider religion as the most important element of their identity."<sup>9</sup> This demonstrates that the relationship between Saudis and Islam will certainly cast its influence on bioethical concerns. In addition, this represents the commitment to observing religious teachings of Islam as demonstrated by Saudis, which allows the observation of patients' rights within an Islamic, Saudi Arabian context.

Patients' rights in Islamic and Saudi Arabian health care system will be discussed to conclude similar and contrasting points with international bioethical principles. This discussion will expose the current reality of patients' rights culture in Saudi Arabia, which will contribute to the universality of biomedical ethics theory by reviewing peoples' perceptions of patient's rights in non-western communities such as the Kingdom of Saudi Arabia.

Discussing the culture of patients' rights in the Saudi healthcare system will identify and clarify the existing culturally-based impediments that limit the efficacy and potentiality of

adapting improved bioethical standards in local settings, namely the *UNESCO Universal Declaration on Biomedical Ethics and Human Rights*. This chapter will distinguish cultural obstacles of proper bearing of patients' rights and the religious charter that frames bioethics standards for Muslims, as many individuals including Saudis directly relate religious matters and customs. For instance, there are wide spread assumptions that a Muslim women's consent for medical procedures can be overruled by the judgement of her male acquaintance; therefore, many people falsely suppose that such practices rises from Islamic teachings whereas it's as a result of pure cultural derivation. Sachedina (2009) asserts that Muslim jurists (legislators) cannot conclude upon ethical, religious, or legal decisions independent from its cultural milieu.

This assertion demonstrates the validity of cultural customs in constituting legal and moral judgments including biomedical standards. This point signifies how culture and religion are independent from each other, which explains why such obstacles to patients' rights discourse in the Saudi healthcare system are misidentified as religious issues. Culture determinates and Islamic bioethics will be discussed in relation to one another, as both will be referred to interchangeably in the discussion of patients' right in Saudi Arabia.

#### **4.1 The Role of Religion in Bioethics**

While philosophical theorists try to provide comprehensive approaches to answering questions related to healthcare ethics, the three major monolithic religions provide perspectives based on biomedical ethics issues. Although Judaism, Christianity, and Islam share similar sources of divinity that deduce analogous ethical values,<sup>10</sup> these three major religions among other secular based moralities share similar values and principles that contribute to a shared outlook on biomedical ethics topics.<sup>11</sup> This shared understanding and broad agreement on issues

concerning ethical health practices is consistent with common natural laws which are widely recognized among human cultures and communities.<sup>12</sup> However, there are some exceptions in articulating these common norms as related to understanding stewardship and the meaning of life. For example, the ten commandments text to most Abrahamic religions such as do not kill, do not steal, love your neighbor and so on, are perceived as common virtues that are shared by all human communities committed to observe these moral values. The common norms that constitute higher principles and values, and determine the relationship between the members of the society have a deep tradition in Islam, Christianity, and in Judaic teachings.

As scientific advancements in biomedicine continue to advance the questioning related to the morality of controversial medical interventions such as IVF, cloning, genetics, euthanasia, and abortion. Around the globe people utilize moral beliefs, spirituality, and religious teaching<sup>13</sup> to reconcile and rationalize answers to controversial biomedical topics.<sup>14</sup>

The established institution of religion which has gathered millions of devoted followers is considered one of primitive sources of spiritual and moral guidance. Many major religions provide ethical guidance to believers across the globe; therefore, religion is a major determinant of normative ethics and is deeply involved in the discussion of the inevitability of biomedical ethics.

Along other secularly based philosophies, religion strives to provide legitimate answers for bioethical inquires. Religion provides a construct for people to base a determination of what is permissible and what is immoral. This is due to the shared assumption of the validity in religious teachings and ruling when defining norms and human morality of followers without further justifications. To demonstrate the deep devotion and belief in the authority of religion, Aasim Padela (2013) writes in reference to traditional Islamic ethical frameworks followed by

millions, “Islam employs a number of ethical frameworks to guide the more than 1.5 billion Muslim,”<sup>15</sup> This is an example of the vast influence religion plays as a moral compass in life of millions, which is applicable to Christianity, Judaism, Confucianism, Hinduism, and more.

The things that are deemed moral and permissible to religious perspectives will be justified and embraced by millions; meanwhile perspectives that conflict with tradition, especially religious heritage, are typically judged immoral and wrongful.

Theological justification is based on the delegation of bioethics standard authority and reasoning from divine normative principles, while secular ethics obtain its validity from common morality and other debated methodologies.<sup>16</sup>

The level of religious involvement and precedence of religion in biomedical inquiries and engagement in bioethical issues vary dependent on the specific faith<sup>17</sup> and the strict adherence and commitment demonstrated by followers towards their faith. This is dependent on the existence of relevant theological studies and allied infrastructures, both which facilitate the deliberation of biomedical ethics from religious perspectives.

For example, the Roman Catholic tradition has a long history of profound willingness to deliver Catholic perspectives on biomedical questions; the Second Vatican council provides an excellent example of such canonical involvement.

This leads to the examination of what bioethics is to religion and why religion considers bioethics in the first place. From a Christian perspective, Lisa Cahill (2005) relates the initial interest in bioethics to the narration of the miraculous work of the Christ as a healer and caregiver to the poor and sick. To continue the legacy of the Christ, the Christian church sustains this tradition and continues to provide care for the sick and poor; throughout the ages and to

recent times, Christian missionaries and churches around the world have established and managed healthcare facilities and hospitals as missionary work.<sup>18</sup>

In elaboration of the role of religion in regulating bioethical standards, David Kelly (2004) draws the connection between religion and biomedical inquiries, as Kelly affirms the religious rooting in contemporary biomedical normative values. Kelly and scholars believe that current bioethical discourse is not true to its religious heritage, though religion is the initiating force behind bioethical practice. In addition, Kelly and scholars claim that religions offer bioethics proven tools for moral rationalization and reasonable references proficient in allowing communal consensus.

Kelly has expanded further and charges individuals that relate contemporary biomedical ethics to secular philosophies as being self-conceded and ignorant of theology and contributions of theologians to bioethical ventures.<sup>19</sup>

While many scholars relate current bioethical norms to the Western creed of moral philosophy, Kelly traces the root and contributing source of Western bioethics to the Roman Catholic tradition.<sup>20</sup> In addition, Kelly claims that prior to the year 1960, the bioethical discussion was not appealing to people other than theologians; Candy Brown (2015) also mentions this, and proclaims that around this date American hospitals become more pluralistic and secular.<sup>21</sup>

To strengthen his argument concerning theological roots of bioethics, Kelly agrees with Nicanor Austriaco (2011)<sup>22</sup> who maintains that the principle of human dignity as a primitive value holds rational claim in bioethical inquiries; this is obtained from the Catholic theological understanding of the concept of redemption and creation.<sup>23</sup>

Christopher Tollefsen and Joseph Boyle (2004) support Kelly's argument concerning the

Christian origination of bioethical principles; the authors claim that secular bioethics have roots in teachings and theological work of St. Augustine, St. Thomas Aquinas, and other Christian theologians,<sup>24</sup> which is also supported by Nicanor Austriaco.<sup>25</sup>

In regards to the principles of biomedical ethics, Gilbert Meilaender (2013) claims that the appeal of moral norms such as autonomy, beneficence, non-maleficence, and justice are dependent on predetermined, human beliefs that originate from primary sources of moral justifications that manifest through religious dogmatism.<sup>26</sup> However, Meilaender refers primarily to the Christian perspective in regard to the principles of biomedical ethics, which is contested by secular scholars that rationalize principles of biomedical ethics based on common norms or natural law that is shared by all humanity. As Joseph Boyle (2006) argues, natural law theory allows for general and universal consensus on global ethical principles, which includes bioethical standards.<sup>27</sup>

Lisa Cahill (2005) asserts that religion provides contributions to biomedical ethical literature; she mentions prominent theologians who contribute greatly to contemporary bioethical work by promoting its evolvement as a distinctive branch of philosophy with practical solicitations. Theologians such as Paul Ramsey<sup>28</sup>, Richard McCormick, and James Gustafson based in Christianity, as well Fred Rosner, Elliott Dorff and David Bleich based in Judaism provide insight related to issues concerning biomedical ethics by articulating theological positions that provide a potent and rational solution for biomedical ethics inquiries.<sup>29</sup> David Smith (1996) asserts that since the beginning of biomedical ethics, religion has been present and a significant contributor to its development, therefore playing an important role in justice and societal equity.

The Roman Catholic tradition is an excellent example of how religion has evolved in relation to the rationalization of bioethics and the imposition of religious teachings on bioethics in general.

As do other religions, Roman Catholic teachings have a similarly structured moral system which adopts the common norms of human nature, emphasizing reasoning and human experience as key to articulate upon moral issues.<sup>30</sup> On the other hand, Roman Catholicism has minimal reliance on the interpretation of biblical scriptures<sup>31</sup> when determining moral issues, which is accounted for by adapting other sources to obtain moral judgments;<sup>32</sup> this is demonstrated through the magisterium teachings<sup>33</sup> as a contemporary manifestation of Christ continuing teachings.

According to Kelly, the current Catholic prospective toward bioethics has developed through three stages<sup>34</sup>: first is the traditional period, second is the transitional period, and third is the current period; the year 1960 became a milestone between stages when the Vatican II was held.<sup>35</sup> This development of viewpoint on ethical issues has shifted the Roman Catholic position from centralization on physicalism, which focuses on the physical nature of the act regardless of other examinations, to an approach called personalism which considers the situation and consequences of the act when determining morality of actions. Kelly claims that in Catholicism, humans are responsible for their actions and they have free will to choose them<sup>36</sup>; however, humans maintain free will while submitting to God's commands and obeying magisterium teachings<sup>37</sup>.

The issue of contraception clearly represents the transitional process in Catholic bioethics. Kelly demonstrates that the ancient Roman Catholic perspective towards contraception methods is based on Augustine view and teachings.<sup>38</sup> Augustine prohibits all forms of

contraceptive methods including rhythm and coitus interrupts in addition to prohibiting married couples from having sex during pregnancy. Augustine views sexuality as an extension of the original sin, which therefore will only be permitted for reproduction purposes between married couples. This Catholic teaching prohibiting all contraceptive methods changed in 1930<sup>39</sup> when Pope Pius XI initiated new thought in family planning which considers the human physical need for reproduction and the emotional, psychological aspects as well.

The application of Catholic-framed bioethical principles provides a practical framework to solve various biomedical ethics dilemmas through the principle of double effect. Introduced first by St. Thomas Aquinas, the doctrine of double effect was originally enacted to justify killing as an act of self-defense.<sup>40</sup> David Kelly (2004) claims that the principle of double effect is a proper method to examine biomedical ethical inquires with minimal limitations and flaws.<sup>41</sup> The principle of double effect determines the rightness or the wrongness of the act by fulfilling four basic conditions: first, the act in its intrinsic nature is not wrong, the second condition states that the good thing should not come from the bad effect, the third condition is that the causative agent should not intended to do wrong, the final condition is that the bad effect consequently should not overwhelm the good effect.<sup>42</sup>

In practical situations, the principle of double effect should give a clear ethical answer of whether an act is wrong or right<sup>43</sup>. The complexity of abortion, as it is deemed prohibited by Catholic traditions, ought to be solved in today's context through the application of the principle of double effect. In reference to abortion and the principle of double effect, Kelly writes, "...enabled them to make clear and precise judgments in each kind of abortion situation."<sup>44</sup>

For example, to save a pregnant woman from death due to a pathological pregnancy, a biomedical ethicist should apply the principle of double effect to the woman's case. In other



words, the ethicist will contemplate tiring choices; the ethicist will either permit abortion which is forbidden in the Roman Catholicism, or allow the woman's life to be disposed for the sake of obeying religious teachings. When the principle of double effect is applied to the situation at hand, the double effect condition number four will be fulfilled to resolve the issue. In this example, the nature of the act is good because of saving the woman. In consideration of the third condition, when the intention is good not to kill the baby but to save the woman's life, the fourth condition is also met in which the good effect of saving a woman's life outweighs the bad outcome of killing the unborn fetus. The concept of double effect also is applicable in other biomedical settings such as end of life issues and artificial conception.

An additional religion-based example that represents the role of religion in biomedicine ethics is the Jewish contribution to bioethics. According to Aaron Mackler (2003), the difference between Catholicism and Judaism is that the Catholic perception of reasoning and human experience is considered key when justifying the Roman Catholic position towards medical issues,<sup>45</sup> whereas Jewish ethicists adopt religious tradition as the main force governing health related ethical inquires.

The Torah of Moses is the main contributing source to Jewish moral life by shaping the relationship between Jewish people and God; the Torah is believed to have been received by Moses, containing the Ten Commandments and other spiritual teachings. Another divine source for moral teaching is the Babylonian Torah or the Talmud; in addition, other important sources of *Halakhah* and *Aggadah* stem from interpretations of the Torah and the Talmud. Jewish ethicists including rabbis rely on these sources to obtain spiritual and moral teachings; therefore, when ethical concerns arise related to medical care, especially in near death situations, Jewish bioethicists will review and adhere to the holy scripts of Talmud and Torah teachings to find a

precedent example to articulate upon.<sup>46</sup> Jewish bioethicists consider the precedent traditions of *Halakhah* and *Aggadah*<sup>47</sup> to interpret the Torah and the Talmud when the issue at hand is too difficult to resolve. As mentioned previously, Mackler states that the traditional Jewish moral teachings are based upon those ancient scripts and the rules of precedent traditions and scripts overrule the principles of reasoning and human experience.<sup>48</sup> Mackler also declares that the principle of reasoning and human experiences are not ignored, but are considered only when adherent to the Jewish scripts and tradition.<sup>49</sup>

This description of the Jewish moral system is adopted by Orthodox Jewish ethicists; other Jewish moral schools adopt new methodologies to examine contemporary medical care ethical dilemmas to which vast attention to reasoning and human experience is adopted. To demonstrate an example of the Jewish approach to health care ethics, the issue of abortion will serve as an example. Jewish ethicists use the Torah teaching which states that people should not kill, therefore abortion is considered killing according to Jewish methodology. This teaching is consistent with the common norm shared by all human beings, but in other respects, removal of a fetus is not considered as killing because the fetus is not considered *nefesh*, or a human being. Contemporary Jewish ethicists conclude that abortion is not equal to killing; therefore, abortion may be permitted under certain circumstances. In addition to Jewish religious understanding of abortion and reliance on scripts, Jewish ethicists look to reasoning and human experience to justify the act of abortion from economical, physiological, and psychological perspectives. This perspective of permissibility of abortion is similar to reductionist view towards abortion: “The reductionist argument that the morality of abortion depends on the woman’s choice.”<sup>50</sup>

Within an Islamic context, Mohammed Ali Albar and Hassan Chamsi-Pasha (2015) establish a connection between Islamic biomedical ethics and the principles of biomedical ethics;

the authors provide an Islamic rationalization and justification of the of principlism and highlight the similarity of moral values embedded within principles of biomedical ethics similar to Islamic moral values.<sup>51</sup>

Abdul-Aziz Sachedina (2004) asserts a fundamental relationship between biomedical ethics and Islam; the author claims that Islam do not separate religious and secular affairs, as Islam provides a comprehensive moral system that engages aspects of Muslim life in all affairs, specifically in the medical domain.<sup>52</sup> The majority of Muslims believe that they are accountable for every word and deed they commit and that they must be observant of virtuous conduct to live a moral life.

Secular philosophers reject the inclusion of religion in the determination of bioethical standards; individuals from secular schools of thought contest the influence of religion on bioethical standards, as they deter discussions away from theologically grounded rationality. For example, Stephen Lammers (1996) and Daniel Callahan (1990) concur that the role of religion in bioethics has been marginalized and overlooked in pluralistic societies such as in the United States.<sup>53</sup> Callahan also recalls the time period in 1960 when he became interested in bioethics; the author claims that there were no founding source for bioethics other than theological reflection.<sup>54</sup> Callahan states that there has been a continuous decline of the effect of religion on bioethical discourse since this time, as new schools of thought enter the field of bioethics with new ideologies and convictions. Philosophers, lawyers, and medically trained personnel present new thought to the field and therefore reduce the role of religion in bioethics to a marginal influence.<sup>55</sup>

In accordance to the previous statement, bioethics no longer derives its normative values from religious narrated integrities, instate legal codes, and organizational standards; in today's secular communities, secular thoughts are the new determinants of bioethics norms.<sup>56</sup>

Ashcroft (1996) claims that the subordinate role of religion in social and political life became prominent practice in contemporary social sciences, as John Locke states in his philosophy of political power.<sup>57</sup>

Despite the marginalization of religion in bioethics, Smith (1996) argues that many bioethicists with no prior training in theology demonstrate keen interest in theological reflection as they recognize the perspective religion offers for particular issues. Unlike Lammers and Callahan, Smith does not believe that the role of religion is diminished by the work of biomedical ethicists in pluralistic societies; he argues that theology provides insights that greatly add to the knowledge of bioethics. For instance, the application of religious outlooks while providing pragmatic solutions in practical settings is demonstrated by David Kelly (2006). In reference to the financial burdens of death and dying Kelly writes, "The Catholic tradition is clear about this. The sick need not sacrifice the financial survival of their families to prolong life,"<sup>58</sup> This statement represents the role of religion in determining ethical norms that can be utilized to lower the operational costs in healthcare settings.

Based on previous scholarly opinions, it can be inferred that the problematic nature of the current state of bioethical affairs due to the conceptual origin of bioethics normative principles. The question of the universality of bioethical standards is increasingly complex, as scholars demonstrate religious origins to bioethics, which are trusted to encourage the discussion and consideration of bioethical matters. In contrast, many Western secular communities find this link to be controversial when initiating common bioethical standards to be generalized in all settings.

To represent the problem of incorporating univocal religious outlooks into bioethics, the following questions are legitimate. If Christian bioethics affirm certain Christian values to be incorporated into biomedical ethics, will these principles be approved by Muslims for their communities? What if religious beliefs conflict with land laws and policies?

To elaborate more on this issue, Raymond De Vries (2015) in *Good Without God: Bioethics and the Sacred*, brings attention to the conflict that arises between religion and bioethics; the author suggests that the current secular approach to morality in bioethics is unfamiliar with religious and other nonwestern ideologies. De Vries claims that current biomedical ethics fail to appreciate certain aspects of human endeavors; for example, bioethics do not recognize the meaning, purpose, and implications of suffering as it demonstrates the purpose of medicine, examines relationships between people, and reveals the nature of the individuals that suffer.<sup>59</sup> De Vries also stresses the pluralistic nature of bioethics, which limits new ideas that may come from religious origins.

As De Vries and various scholarly quarrels mention, <sup>60</sup> current secularized bioethical discourse often contrasts societal religious belief in its current terminology and lacks true reflection of the beliefs of its followers.

However, many scholars believe that pluralistic, secularized societies such as the United States require the incorporation of secularly based bioethical standards to align varying community beliefs in one single creed. Therefore, the secularization of biomedical ethics in pluralistic societies has set a unified framework capable of filling gaps; it has also produced a unified set of bioethical principles that reduces the majorities' beliefs to a simple consensus.

To conclude upon the current relationship and interaction between religion and bioethics, lapses occur in the determination of the origin and scope of bioethics in many healthcare systems

around the world. These lapses happen when bioethical standards that are assumed to be universal, pluralistic, and multicultural are imposed on patients established in and loyal to a specific religious tradition.

A common example is the moral and legal dilemma that arises when determining the appropriateness of transfusing blood for an uncooperative patient who is a Jehovah witness. The problem arises when principles of religion that its followers (patients) obey conflict with the procedures and legal statutes that constitutes the healthcare facilities.

Another example is when a devoted Catholic obstetrician refuses to provide a lifesaving abortion to a mother to spare the fetus due to belief in Catholic values concerning gestation termination. An additional situation represents the clash between the religious old and the secular new, or as H. Tristram Engelhardt Jr. (2006) refers to it as the traditional vs. post traditional morality in bioethics;<sup>61</sup> this example is the restrictions placed on certain in vitro fertilizations (IVF) procedures conducted by Muslim and traditional Christian theologians who demand that the ovum and the gamete be extracted from married parents. No external sperm (other than the husband's) is allowed to be implanted in the woman's womb. This procedure may appear less controversial, as parents can choose to not undergo IVF and remain childless, but this also ties in the secular principle of respecting patients' right to conceive (autonomy) which challenges religious teachings that perceive the implantation of exterior seeds as an act of illicit fornication. From an Islamic perspective, such restriction on IVF procedures is due to the principle authority, as blood lineage, inheritance, and marriage are all dependent on it.

Concerns related to compliance with religious teachings in biomedical endeavors is regarded as peculiar acceptance or denial, as in post-modern multicultural societies there are few opportunities for devoted worshippers to receive religiously-based treatments based on their

inclinations. This occurs due to the firm separation of civil values and religious beliefs that is enforced in postmodern secular societies. The pluralistic foundation and democratic environment of these societies bypass the religious beliefs of patients and providers to promote values and safeguard the rights of individuals in pluralistic societies. People living in a multicultural, secular society in the industrialized West cannot request for women to be circumcised yet in the same country, Catholic healthcare clinics can refuse to provide abortion services based on religious reasoning. Such denial to acknowledge certain cultural specifications when refusing to cut females genitals is typically perceived as disregarding peoples' right to cultural standards respected; yet, such an act can permit people to obtain safe and standardized treatments without opening questions of religious relativism. Balancing the sacred and the standard in bioethics is relevant in communities with contrasting cultures with accompanying religious components. In Saudi Arabia, the social and religious fabrics of communities are interconnected, which allows for a more secure relationship between religious and bioethical standards.

Aasim Padela (2013) explains this point clearly: "Religion, therefore, significantly shapes both patients and provider's health related behaviors. Yet when it comes to bioethics the physician obligations toward patients are more commonly framed within a secular professional framework."<sup>62</sup> Padela affirms the role that religion plays in shaping the inner convictions of the two components of the equation of healthcare service, the patients and providers; these individuals are subject to personal religious beliefs, but must submit to pluralistic state norms manifested in bioethical standards.

As previously stated, the role religion plays in shaping biomedical ethical norms is marginalized in respect to modern philosophy in postmodern secular societies; this is also relevant to certain Muslim countries. Soroush, Sadri and Sadri (2000) write, "Religion, in other

words, has clearly lost its monopoly on public perception, morality, and conscience.

Modernization and secularization have made religious exclusion or absorption of competing ways of life and belief nearly impossible.”<sup>63</sup>

Despite assurances made in pluralistic proposals, there are aspects of society that are not in favor of secularly based medical services; as mentioned previously, many people in these societies strive to live in accordance to religious moral standards. This point is presented by Austriaco who reveals the moral struggle of Catholic devotees struggling to live in secular societies, as he suggests that such secular societies do not support the message of Christ (religion).<sup>64</sup> De Vries and Rott (2011) contend that the current biomedical ethical movement reflects the mission of an evangelist, in which a unilateral perspective of biomedical ethical issue is imposed upon dissimilar communities. These perspectives represent marginalization of sources of bioethical standards that vary from mainstream secularly based bioethics through the imposition of universal bioethical standards on all communities.

Despite the attempts to secularize and forego traditional sources of bioethical principles, diverse religious creeds still influence decisions regarding everyday concerns specific to biomedical settings. In addition, religions around the world refuse under appreciation of their role in bioethical matters and express this dissatisfaction clearly. As described, Catholic sponsored hospitals refuse certain abortion procedures, while the procedures are lawful and practiced in nearby healthcare facilities.

Islamic teachings provide an example of how religions resist secularizing and generalizing language of certain aspects of social, moral, and political endeavors including principles enacted by international organizations. Observing the work of many can manifest this resistance; for instance, some Muslim countries receive the universalization of international



principles with doubt and reservations.<sup>65</sup> Iran, Sudan, Pakistan and Saudi Arabia have objections to a few international acted articles,<sup>66</sup> as they are deemed unacceptable and unattainable in Muslim communities.

Abdul-Aziz Sachedina (2009)<sup>67</sup> and Cooke and Lawrence (1996)<sup>68</sup> claim that the universal principles of human rights and its origins are Western concepts, which are formulated based on secular ideologies; consequentially these principles are suitable for Western pluralistic societies. Sachedina also claims that since these principles of human rights are not based on theological reasoning, they lack vital societal consensus for broader recognition and international support. In a similar way, Jack Harford (2002) reiterate this specific argument to biomedicine by emphasizing the role of religion in defining medical ethics norms.<sup>69</sup>

These scholarly opinions infer the unsuitable nature of certain principles of *Human Rights Universal Declaration* (Article 18 for example)<sup>70</sup> when applied in Muslim countries, which can be reflected in bioethical discourse. The UNESCO *Universal Declaration on Bioethics and Human Rights* deduces similar principles while enacting its articles.

Oversimplification of the idea that biomedical principles are suitable to be implemented in various communities across the globe, UNESCO declaration is a part of this generalization attempts, is received with hesitation by some scholars. For instance Catharine Myser (2011) calls to reexamine exported ideas concerning bioethics, which may not suite other communities needs and values.<sup>71</sup> To represent the alternative method to bioethics and to weigh the validity of these scholarly voices which reject widely recognized international enacted principles, Islamic sources of biomedical ethics will be discussed further in the next section.

## 4.2 Sources of Islamic Biomedical Ethics

The cores of human rights principles are fundamental to Islamic religious teachings as Nader Hashemi and Emran Qureshi describe, “Concepts analogous to human rights have certain precursors in Islamic philosophy and theology;”<sup>72</sup> despite this, many Muslim scholars and states reject the internationalization of the principles of the universal declaration that are founded on secular Western values<sup>73</sup> and Judeo-Christian heritages,<sup>74</sup> which do not reflect the peoples’ native religion and cultures. Abdullahi An-Na’im (2012) argues that all humans are entitled to human rights due to their nature as humans; however, current human rights discourse refutes this argument due to its vague scope and the due consequences that arise from applying these principles at a global level. An-Na’im suggests that human rights discourse must adapt an inclusive, interdisciplinary approach in order to prevent its dismissal.<sup>75</sup>

In addition, concerns and objections arise due to the varying nature of identifying values and interpretation of international principles from one country or culture to another;<sup>76</sup> this demonstrates the troubling nature of imposed, generalized norms as it overlooks individual cultural specifications. The idea of occidental roots to the principles of human rights is a common perspective among scholars including Westerner intellectuals. For example, Heiner Bielefeldt relates current human rights principles to Western roots.<sup>77</sup>

In the same respect, David Little, Sachedina, and Kelsay (1996) write, “While descriptions of human rights documents as culturally biased and ethnocentric need to be taken seriously.”<sup>78</sup> Little, Sachedina, and Kelsay demonstrate that defenses for current principles of human rights ought to be addressed, as opposing perspectives believe that these principles do not represent all cultures; this would therefore make human rights principles culture specific which decreases its validity as an inclusive and internationally feasible document.

Due to these perspectives, scholars determine that international principles, which include articles of the UNESCO Universal Declaration on Bioethics and Human Rights, are controversial principles and incompatible with the norms of civilizations that incorporate the Islamic civilization. John Andrews and W. Hines (1987) argue that Anglo-Saxon perspectives of human rights emphasizes civil and political liberties common to the nineteenth century, meanwhile Islamic perspectives places the community as superior over individuals in terms of rights and duties. This represents aspects of conflict between the secular West and Islam when observing the principles of human rights and its due implications.<sup>79</sup>

The scholarly perspectives that infer the principles embedded in the Universal Declaration are incompatible with Muslim societies,<sup>80</sup> demonstrates the perception that Islam has unique biomedical principles that vary from the international principles. On the other hand, many Muslim scholars believe that international declarations such as the Universal Declaration on Human Rights and the UNESCO Universal Declaration on Bioethics and Human Right are protected by Islamic law and embedded in traditional Islamic teachings.<sup>81</sup>

These principles are addressed and approached in different manners to enforce Islamic stipulations in bioethical discourse.<sup>82</sup> Within Islamic practice, Muslims observe Sharia law in all aspects of life, including matters of bioethical concerns. This Muslim observation of Sharia law is fundamental to Islam and cannot be overridden or overlooked in any circumstance; therefore as demonstrated in the Qur'an the following passage represents this point, "Obey God and His Prophet and obey those who hold authority among you' (4:59)."<sup>83</sup>

Manfred Sing (2008) claims that there are no major differences concerning Islamic and Western bioethics, as both ascribe to similar concepts of common morality and prescribe bioethical norms accordingly. Furthermore, Sing argues that some Muslim and non-Muslim

intellectuals overstress Islamic ethics in the form of applied ethics concerning biomedicine due to the desire to provide Islamic legal opinion *fatwa*, or supremacy over other statutory frames.<sup>84</sup>

In consideration to sources of Islamic biomedical ethics, Dariusch Atighetchi (2009), Abdallah Daar and Binsumeit Alkhitamy (2001), and Aasim Padela (2013) cite sources that constitute current Islamic bioethics discourse. These sources are as follows: Islamic divine scripts,<sup>85</sup> Hippocratic ethics,<sup>86</sup> international treaties, and contemporary medical ethics methodologies including the principles of biomedical ethics.<sup>87</sup> According to these perspectives, Islamic bioethics share common themes with other bioethical methods such as Beauchamp and Childress' principlism;<sup>88</sup> this also supports Sing's claim related to the intimate relationship between Islamic and Western bioethics.

When discussing the current state of affairs concerning Islamic bioethics, it is crucial to elaborate on traditional, Islamic sources which establish Islamic moral and judicial norms as well as bioethical norms and ruling. This discussion will begin by representing the importance of Islamic bioethics to Muslim laymen and the significance of Islamic bioethics according to scholarly perspectives.

Daar and Alkhitamy stress that in Islam, Muslims are obliged to observe religious duties in every aspect of life, including health and treatment. This demonstrates the importance of Islamic-based biomedical ethics. Meanwhile, Abdul-Aziz Sachedina (2009) writes that Islam is a comprehensive system that constitutes legal and moral incentives of its followers, without separation from spiritual and practical life.<sup>89</sup>

The duty to observe God's revelations and Prophet Mohammed's teachings in biomedical settings is natural to Islam; these practices are not isolated to Islam alone as many major religions such as Catholicism and Judaism expect followers to live according to religious

teachings and law while searching for remedies. Due to centrality of Islamic teachings in Muslim life, Islamic-based biomedical ethics strive to provide Muslims with religiously compatible standards and rules that provide answers to dilemmas in healthcare settings. Sachedina (2009) states, “Epistemically, inquiry about the new issues connected with modern biomedical advancements is situated in Islamic legal- ethical studies.”<sup>90</sup>

Abdulrahman, C. Amine, and Elkadi (2000)<sup>91</sup> contend that Islamic bioethics yield the perfect set of moral principles, capable of solving ethical dilemmas in contemporary times.<sup>92</sup> This outlook is common among Muslims despite varying schools of thought. John Kelsay (1994) agrees that there is a unique Islamic approach to biomedical ethics which is embedded in its religious teachings.<sup>93</sup> Islamic countries produce different products to allow *sharia* to reflect on biomedicine and its ethical topics. For instance, the Islamic Organization of Medical Science IOMS,<sup>94</sup> the Organization of Islamic Conference OIC,<sup>95</sup> the Islamic Fiqh Academy, the Islamic Juridical Council,<sup>96</sup> and additional specialized and semi-specialized organization meet periodically to discuss current topics of biomedical ethics and provide recommendations that reflect the concepts of *sharia*.<sup>97</sup>

A brief sketch on Islamic medical ethics will begin the discussion of a further elaboration of the new discipline of Islamic biomedical ethics.<sup>98</sup> According to Samar Farage (2008), Islamic medical ethics originated fourteen hundred years ago, correlating with the Galeno-Islamic tradition of medical knowledge marked by the translation of medical science from Greek to Arabic and other Islam indigenous languages.<sup>99</sup> As a natural extension of Greek medical ethical knowledge, Islamic medical ethics is concerned with the personal characteristics and care conducts of the physician;<sup>100</sup> in addition, it elaborates on the promotion of Islamic etiquettes in the work of physicians such as *Adab al –Tabib*.<sup>101</sup> Many Muslim physicians have contributed to

medical ethics throughout the decades; Al-Ruhawy and Al Razi, two famous physicians and philosophers, produced literatures concerning medical ethics ten centuries ago.<sup>102</sup>

Due to contemporary advancements in the biomedical arena and accompanying ethical dilemmas, it has become crucial to incorporate the Islamic perspective towards biomedical ethical issues; the twenty first century has marked major advancements in Islamic bioethics, which has been accompanied by mass production of medical ethical literature.<sup>103</sup> The elaboration upon areas of Islamic bioethics brings scholars from all disciplines to contribute to the Islamic perspective of bioethics issues. Imams, Muftis, Fuqaha, Ulama<sup>104</sup> among other religious clerks with various titles and descriptions in addition to scholars in law, social studies, history, and most prominently physicians present academic and religious backgrounds to influence the discussion on Islamic biomedical ethics. However, the extent of the Islamic biomedical ethical impact upon issues of biomedicine is limited, given the novelty of Islamic perspectives related to current biomedical topics and limited, associated literatures.<sup>105</sup> Mohammed Ghaly (2013) mentions that Vardit Rispler-Chaim wonders if there is anything previously existed that could be considered Islamic bioethics, which can represent Islamic standpoints related to medical disputes.<sup>106</sup> Some Muslim scholars such as Aasim Padela, Shanawani, and Arozullah (2011) find the discipline, methodologies, and the scope of Islamic bioethics debatable, and lacking in the delivery of theological based verdicts that meet current challenges in ever-changing biomedical settings.<sup>107</sup> This is supported by Aasim Padela (2013), who claims that Islamic law does not properly introduce the Islamic teachings in ethical formulation.<sup>108</sup>

However, Islamic biomedical ethics is still considered a branch of Islamic law<sup>109</sup> with specific concentration on biomedical issues. Muslims all over the world, despite classification

and sub-divisions, classify Islamic law (*Shari'a*) as a set of binding laws with divine origin that embeds canonical principles with aid by holy locus. Richard Bulliet (1996) notes that Muslims respect *Shari'a* law, honoring its principles as divine revelations may not be overruled by earthly laws,<sup>110</sup> ideologies, and regulations. Muslims believe that the *Shari'a* constitutes the individual's relationship with God and provides the person means to sponsor rightness and live a pious life.

Mohamed Rady and Joseph Verheijde (2014)<sup>111</sup> as well as Jonathan Brockopp and Thomas Eich (2008)<sup>112</sup> mention that *Shari'a* deduces its commands from the *Qur'an*, *Sunna*, and the precedent work of companions of the Prophet<sup>113</sup> in addition to earlier religious clerks *Salaf*, which demonstrates its validity over other legislative figures.

Though these sacred sources are deemed capable of delivering potent and moral judgment in every aspect of human life including bioethics, Islam promotes critical thinking and the practice of rational judgment when discussing bioethics issues in correlation with the fundamentals of Islamic *Sharia*. This is mentioned by Abdul-Aziz Sachedina (2005) who states, "...it is noteworthy that even when the source of normative life was revealed by God in the *Shari'a*, the procurement of a judgment (*hukm*) and its application were dependent on reasons used in moral deliberation."<sup>114</sup>

When Islamic judgments are not presented in ethical dilemmas, Islam allows the following of moral decrees based on common norms and shared values through justified rationalization; this is especially relevant in countries where Islamic teachings are not as accessible. For example, Muslims residing in non-Muslim countries such as the West and secular states are obliged to observe the rules of the host counties as well as encouraged to practice rightness and observe norms of common morality in accordance to Islamic teachings and rulings.

The benefits of reason and rationality in the discussion of bioethical topics as relevant to contemporary bioethics include the employment of rationality and practicality to bioethical norms. Therefore, the theory of utilitarianism, principlism, and other relevant viewpoints resemble the essences of Islamic biomedical ethical standards to a certain extent. For example, many Western countries and secular societies maintain a utilitarianism scheme in determining public policies especially in regard to public health topics<sup>115</sup> such as the allocation of scarce healthcare resources to ensure rational distribution. Similar to this methodological approach, Islam supports rational judgment in the allocation of fair treatment in societies, even if such methods are not attained from religious directives and lack the divine enforcement.<sup>116</sup>

The *Qur'an*, *Sunna*, and other original sources of Islamic legal and moral legislation will be presented in brief. The *Qur'an* is an ancient text that is regarded as the most sacred book in Islam; it is believed to be God's (*Allah's*) divine revelations to the Prophet *Mohammed* revealed to him throughout his lifetime (23 years)<sup>117</sup> fourteen centuries ago. The *Qur'an* is described by Mashood Baderin (2009), "It contains more than 6000 verses of varied lengths covering spiritual, moral and secular matters of life. Some of the verses cover matters of life. Some of the verses cover issues of ethics and morality such as respect for parents, while some are legal- specific regulating temporal matters such as trade and crimes."<sup>118</sup>

Therefore, in Islamic legislative system and canonical ranking the revelation *Tanzil*<sup>119</sup> (*Qur'an*) is ranked first and considered superior in Islamic jurisdictional sources. *Sunna*, which dictates the Prophet *Mohammed's* dictum<sup>120</sup> and practical undertakings until his passing on 632 AD<sup>121</sup> is considered second in the hierarchy of Islamic legislative sources. Muslims believe that *Sunna* is second most important Islamic source in the determination of moral and legal affairs due to the belief that the life of the Prophet demonstrates the manifestation of God's revelations



which is binding and sacred, as reflected in the Prophet's teachings. The interpretations of the Prophet's teachings that are conducted by succeeding generations of Muslim clerks *Salaf*, follow the *Sunna* in the Islamic jurisdictional hierarchy.

According to Jan Michiel Otto (2010), *fiqh* or the Islamic jurisprudence was introduced in the eighth century<sup>122</sup> by Muslim clerics to interpret the *Qur'an* and to narrate the Prophet *Sunna* in order to develop moral and legal verdicts that are applicable to contemporary eras. *Fiqh* is a progressive discipline that continues to evolve in order to deliver Islamic perspectives related to every aspect of Muslim affairs, while reflecting upon contemporary legal and moral inquiry.

Otto (2010) and Hamid Mavani (2014) cite *Ijihad* as a determinant of Islamic legislation. Though Otto and Baderin claim that the *Ijihad* was discounted in the thirteenth century, *Ijihad* remains a controversial discussion among different Islamic schools of thought.<sup>123</sup> According to *Sunni* Islam, there are four prominent schools of *Fiqh* that practice *Ijihad* after the Prophet's death: Al-Hanafi, Al-Maliki, Al-Shafi'i and Al-Hanbali.<sup>124</sup> These schools or *Math'hib* are named after the founding *Ulama*, who practices *Ijihad* according to independent reasoning and religious comprehension through the narration of *Qur'an* and *Sunna* rulings.

*Ijihad* is described by Mavani: "Historically, *Ijihad* accommodated a plurality of views on the basis that each qualified jurist exerts himself to the maximum by using different sources to derive a legal ruling that would remain a considered opinion subject to error and revision."<sup>125</sup> However, the contemporary application of *Ijihad* when determining the laws of *Shari'a* varies between *Sunni* and *Shii* (*Shi'ite*) schools; the *Sunni* branch of Islam employs *ijmaa* (consensus) and *Qiyas* (analogy)<sup>126</sup> as foundations for obtaining *Shari'a* based rulings concerning contemporary topics,<sup>127</sup> meanwhile the *Shii* branch of Islam considers *Ijihad* as the second source in Islamic legal theory.<sup>128</sup>

The *Sunni* branch of Islam believes the *Ijithad* is no longer relevant to *Sharia* due to the conclusion of *Ijithad* around the thirteenth century because the four schools of Sunni Islam (Al-Hanafi, Al-Maliki, Al-Shafi'I, and Al-Hanbali) had already produced possible answers for religiously-based inquires; according to Baderin, this concludes Islamic law as complete and capable of answering any questions.<sup>129</sup> This is supported by Robert Gleave (2001), who elaborates upon the *Shi'i* and *Sunni* argument over *Ijithad*.<sup>130</sup>

An example will be provided to demonstrate how the Islamic system of edict infers upon the upcoming topics that require Islamic ruling. If a Muslim clerk encounters a contemporary ethical dilemma that requires an Islamic-based verdict with no precedent example and no ruling *Hukm* from *Quran* and *Sunna*, he will apply *Qiyas* to obtain a verdict through modeling similar cases or precedent *Hukm*. The application of *Qiyas* is only permissible within the boundaries of original sources of Islamic teachings, by which any produced verdict must not conflict with fundamentals of *Fiqh* and *Sharia* which are founded upon *Quran* and *Sunna*. In addition, *Qiyas* based verdicts must be consistent with common norms and promote the essences of rightness and goodness *Masl'aha*. *Masl'aha*, or common good, is a crucial pillar of Islamic jurisprudence which provides contemporary insight in Islamic current laws and legitimizes modern legal and ethical inquiries that are compatible with *Sharia* law.<sup>131</sup> An important source of ruling in the Islamic legal system is referred to as the principle of *Urf*.<sup>132</sup> This principle determines Islamic-based verdicts by incorporating elements such as social and cultural norms, professional codes, and international treaties. The principles of *Urf* are applied when determining Islamic legal and moral verdicts when all other religious sources relevant to finding an answer or ruling are exhausted. However, the applications of this principle in contemporary times and professional settings are practical and multiple. In relation to patient's rights, the principle of *Urf* corresponds

to several international ethics as it is considered a normative principle in many communities. The term *Urf* means norms, and every community has its shared or distinctive norms that originate from cultural, political, or economical characteristics which are not merely associated with the religion. For example, in Saudi Arabia communities across the nation maintain cultural customs related to marriage arrangements. Though these arrangements share common fundamentals based in Islam, individual communities have cultural specifications regarding the amount of money that should be given to the bride as a gift *M'a'har*. Here, the principle of *Urf* recognizes and promotes cultural differences, and therefore acknowledges that each community has the right to constitute affairs based on specific cultural and financial situations. The principle of *Urf* in relation to the rights of medical patients will be discussed in a later section of this chapter.

As mentioned previously, the ranking in value of Islamic judicial sources is demonstrated in the story that occurred during the time of the Prophet. The Prophet and one of his companions that he was about to send to a distant city to maintain a judicial position had a conversation. The Prophet questioned the candidate's (his companion) reasoning and methodology to obtain a fair and appropriate judgment concerning a given event. The companion explained that to pass a verdict, he would first seek out guidance from *Qur'an*, then *Sunna*, and lastly if no resolution is determined from these references then he would pass the verdict through *Ijithad*.<sup>133</sup> The companion's response satisfied the Prophet and he granted him approval to hold the position as judge. This story is an important directive to follow when ranking the Islamic verdict producing methodology.

Again, the Islamic hierarchy of divine sources when determining Shari'a ruling is the following: Qur'an text, *Sunna* of the Prophet, *Salaf* sentiments, consensus *ijmaa*, *Qiyas* in respective order<sup>134</sup> and the principle of *Urf*. Therefore, all matters requiring Islamic involvement

must follow this ranking to obtain judgments, including matters of biomedical ethics. This discussion is crucial to understand the centrality of these sources in the determination of moral and legal norms in Muslims spiritual and practical endeavors. Therefore, Islamic religious teachings will be important for the upcoming section of the discussion of patients' rights in Islam and specifically Saudi Arabia, as Islamic teachings are important in shaping Saudi healthcare ethics normative standards.

#### **4.3 Patient Rights in Islam and in Saudi Arabia**

In a comparison to secularly-based values and religious philosophies concerning patients' rights, Hatami, Hatami, and Hatami (2012) claim that the current Patients' Bill of Rights is a descriptive briefing of patients' needs, not patients' rights. Hatami et al. discuss the limitations of this document, a famous piece of work concerning the rights of patients, which provide precise articles that address patients' rights in healthcare settings and targets general populations in vibrant and precise dialect. Hatami et al. claim that in the three major Monolithic religions including Islam, a comprehensive discussion related to patients' rights provides an all-encompassing option compared to a secularly written document. Therefore, Islam strives to provide a comprehensive framework for patients' rights and maintains clear direction to the manner in which patients' rights ought to be to secure the best services.<sup>135</sup> Hatami et al. cites the works of Muslim philosophers including Avicenna and Rhazes (865-925 AC) who wrote about physician ethics, *Akhlaaq- Altabib*,<sup>136</sup> Zakhireye, Khawrazmshahi, <sup>137</sup>and others who discuss the characteristics of Muslim physician and elaborate on patients' rights and the duties of physicians; these citations support the authors' argument of the value of religious scripts over earthly codes as well as highlight the Islamic role of advocating for patients' rights and protecting against

medical error. An example that represents the old and precedent interest of Muslim scholars in the discussion of patients' rights is the work of *AlRuhawi*, the first Muslim philosopher that wrote a book on medical ethics, *Adab Al Tabib*.<sup>138</sup>

Due to an argument concerning the limitations of the patients' bill of rights, the current patients' bill of rights was adapted and approved by the US advisory commission on consumer protection and quality in the healthcare industry in 1998. Hatami et al. fail to mention that the Patients' Bill of Rights is a mere illustration of the duties of patients; in fact, the Patients' Bill of Rights of 1998 provides general guidelines regarding the care patients ought to receive and things to expect from attending healthcare staffs. The Patients' Bill of Rights provides an ideal model of treatment for healthcare providers grounded by ethics and fairness. Due to the importance of advocating for patients' rights, numerous hospitals have developed Bills of Rights that mimic the original bill and utilize it for patients; an example of this is Johns Hopkins patients' Bill of Rights and Responsibilities.<sup>139</sup>

A religious perspective on patient health and care demonstrates deep religious appreciation of God's most precious creation, the human being. In Qur'an, the significance of human beings are mentioned frequently throughout the manuscript; for example, *Allah* said, "Behold thy Lord said to the Angels: I will create a vicegerent (*khalifa*) on earth (Q. 2:30)."<sup>140</sup> Due to the importance of the human beings, religions believe in sustaining health and promoting healthy living to empower humans with the capacity to live a meaningful life and attend to earthly work or religious duties.

In Islam, good physical and mental health is regarded as a fundamental obligation for Muslims to uphold prior to any other due religious obligations and duties;<sup>141</sup> many Qur'anic verses, *Hadiths*,<sup>142</sup> and other religiously-based, scholarly dictations confirm the responsibility to

maintain good health, abstain from harm to the body, and seek remedies when sick.<sup>143</sup> The Prophet Mohammed states, “Every illness has a cure, and when the proper cure is applied, it ends Allah's willing.”<sup>144</sup>

There are five cardinal fundamentals of Islamic teachings that must be observed and maintained under all circumstances. One of these cardinal obligations is the preservation of life, *Alnafs*;<sup>145</sup> in Islamic teachings, this obligation is rated high, as preservation of human life takes precedent over other considerations. For example, if a person is coerced to commit blasphemy under the threat of torture, then this person must not choose to endure physical pain.

The Islamic perspective related to the importance of preserving life is also demonstrated through the avoidance of inflicting harm on one's self by avoiding the search for remedies when sick. Muslims must search and obtain treatment to physical illnesses as they would seek spiritual treatment for the afflictions they may withstand. Therefore, Islam considers health and the preservation of life by seeking health and abstains from harm to the body from illness as a cardinal obligation.

To represent classical Islamic teachings that require Muslims to observe health such as in the *Qur'an*, many guiding verses obligate Muslims to observe cleanness and freshness which are considered crucial in preventive medicine; “The Qur'an states: O you who believe, when you prepare for prayer wash your faces, hands, heads, feet up to the ankles. If you are defiled purify yourselves. Allah does not wish to place you in a difficulty but to make you clean and to complete His favor to you ... (Q 5:6).”<sup>146</sup> *Hadith*, a reference to moderating eating habits is cited by the Prophet Mohammed, “The children of Adam fill no container worse than the way in which they fill their own stomachs. So let the children of Adam just have a few mouthfuls to strengthen their loins. If possible, one third of the stomach is for food, one third for drink and

one third for air.”<sup>147</sup>

Therefore, Islamic teachings consider the right to health and patients’ specific rights as religious duties inherent to all human beings.<sup>148</sup> Patients’ rights according to Islamic traditional teachings require Muslims to seek applied knowledge and useful sciences,<sup>149</sup> which includes the art of medicine; the Prophet Mohammed said, “Seeking for knowledge is compulsory upon every Muslim.”<sup>150</sup> The Islamic canonical doctrine holds the entire community accountable if the people abstain from acquiring relevant knowledge related to healing and educating members of the society on medicine to provide self-sufficient treatments and medical care.

As Islam requires Muslims to seek remedies when they are sick,<sup>151</sup> it also requires Muslims to provide medical care to the sick. Therefore, patient rights according to Islam require a few members of the society to learn proper and sufficient medical knowledge to provide healthcare to the sick. In Islam, there are rituals and obligations which do not require the attendance of the entire community if some members take on the burden and attend to it. In the case that the entire community fails to attend to the ritual obligations, the whole community bares the sin. For example, a Friday prayer occurring weekly is not assigned to all members of society, as few people are sufficient to perform this task. If no person performed the Friday prayer, then the whole community has committed a sinful act of neglecting a designated Islamic ritual. This example of shared religious duties among the entire Muslim community is related to the necessity of the Muslim community to designate a few of its members to learn medicine for its patients.

In order to protect patients’ rights and promote safe practices, Islam has produced a judicial system capable of producing moral and legally-binding verdicts. Imam Muhammad Al-Akili (1993) lists situations that illustrate scenarios in which physicians are held liable under

Islamic penal codes. This includes practicing medicine without the qualifications needed to meet safe practice standards; Al-Akili cites the Prophet proverb, “Whosoever claims to be a physician, though unknown to such profession, is subject to personal liability.”<sup>152</sup> Another code holds physicians liable for legal actions related to medical error; in this case, the physician that unintentionally inflicts damage upon a patient is liable to compensate for the medical costs or loss in functionality. In the case of providing inadequate or wrongdoing in medicine, such as treatment without consent, the physician will be held accountable for the harm that results from such actions.<sup>153</sup> Islamic schools of jurisprudence recognize the difference between medical errors committed by physicians acting on good intentions and medical errors committed by an unqualified person, even with patient consent. The motivations driving Islam are an important deterrent of the morality of consequential outcomes,<sup>154</sup> by which good intentions surpass wrongful outcomes, and the bad intentions justify consequential punishment.

However, the responsibilities of Islamic judicial ruling vary in order to address differential specifications and circumstances. The attention to varying Islamic schools of thought when passing judgments as well as designating specific verdicts upon medical situations will lead to the promotion of patients’ rights; these factors will provide patients assurance that only qualified physicians are permitted to provide care.

Patients’ rights are unique in Islam due to the Islamic texts that impose sacred obligations upon doctors to provide services to whomever it, regardless of the patients’ religion, gender, race, and background.<sup>155</sup> As a result of this compulsion to treat equally, patients’ rights are preserved and maintained. In the contemporary healthcare settings, many aspects of this Islamic concept of patients’ rights standards are resembled. For example, the WHO and other international treaties require healthcare systems around the world to provide medical services to



those in need of such services despite religious, racial, and social backgrounds.

An examination of patients' rights within contemporary biomedical ethical venture demonstrates that patients' rights can be met with collective moral acceptance and the highest standards of care; this is due to current biomedical ethical standards being focused primarily on promoting patients' rights in biomedical settings which is incorporated within all internationally enacted principles and articles. Atighetchi (2009) asserts that Islamic biomedical ethics correspond to modern principles of biomedical ethics; this means that the rights of patients in Islam ranks highly in comparison to current biomedical practices. This establishes that Islamic standards for patients' rights are compatible with internationally-based biomedical ethics standards, which are mainly founded upon Western ethics. Atighetchi mentions that the four principles of biomedical ethics Beauchamp and Childress present in their text, *The Principles of Biomedical Ethics*, are deeply rooted in and emphasized by monolithic religions.<sup>156</sup> However, Atighetchi affirms that even when these religions recognize these biomedical ethical principles, every religion imposes its own interpretation and application to these biomedical ethical and human rights principles, which can trigger controversy.<sup>157</sup>

The universal biomedical ethical standards and Islamic standards for patients' rights share a common moral theme, which is the respect for human dignity as a fundamental principle that is valued and promoted in all situations and circumstances. Therefore, the Islamic position on patients' rights originate from a deep appreciation for the nature of humans being *Khalifa* (deputy) of God on the earth, which entitles humans in comparison to God's other creations. Respect for human dignity represents understanding and exhibits this attitude towards humans. As stated previously, human dignity as a basic value in human rights discourse and when modeling norms of bioethics has been established, therefore laws related to patients' rights

influenced by internationally enacted biomedical standards correspond with Islamic teachings.

In consideration of current Islamic bioethical efforts, various Islamic organizations concerned with medical ethics and care have enacted laws and codes to promote the rights of patients in biomedical settings as well as manuals with patients' rights that are compatible with Muslim populations. Examples of this include the International Organization of Islamic Medicine of the Kuwait Document of 1981 which dictates the Islamic Code of Medical Ethics;<sup>158</sup> this document establishes patients' rights from an Islamic perspective represent evolving perspectives related to contemporary medical ethics issues.

Patients' rights in Islam reflect primarily common human rights practiced all over the world; therefore, Islamic biomedical ethics are compatible with other policies that aim to promote patients' rights. With an emphasis on Beauchamp and Childress' principles of biomedical ethics, current practices in Islamic countries and represent Islamic perspectives which incorporate various ethical principles, international codes, and regulations which aim to promote biomedical ethics standards and patients' rights.

In the Saudi healthcare system and other governmental and non-governmental agencies operating in Saudi Arabia, the Islamic Law *Shari'a* is the governing guidelines to observe when adapting, interpreting, and conducting various situations. For example, in financial sectors all banks and money exchange companies have Islamic counsels directed by clerks who stipulate financial discussion based on religious guidance. Similarly, in healthcare policies and procedures applied within the Saudi Arabian healthcare systems adhere to *Sharia* laws and the dominant Arabian culture.

As mentioned previously, Islam is significant to living traditions by providing moral and legal insights to everyday situations; patients' rights and bioethics are also governed by Islamic

laws, as Padela and Rasheed (2013) demonstrate that Islam provides guidelines concerning biomedical matters despite geographical and racial differences. Saudis in particular are strictly adherent to the observation of Islamic laws and Sharia ruling. This is due to the core constitution of Saudi Arabia which stresses relationship between the Saudi Kingdom and the religion of Islam.

According to the Basic Law of Governance of the Kingdom of Saudi Arabia, issued by Royal Order Number (A/90) in 1992, the first article of the constitution of Saudi Arabia is based on the *Qur'an* and *Sunna*,<sup>159</sup> which is comprised of Shari'a law.<sup>160</sup> Article twenty-six of the document states that the government must guard the rights of its citizens in accordance with *Shari'a*. Therefore, legislation must incorporate the Shari'a law and design its articles based on *Quran* and *Sunna*. Policies and laws including regulations in healthcare are not all based in religious, Islamic origins such as international trading treaties and declarations including the *Universal Declaration on Human Rights*, *UNESCO Universal Declaration on Biomedical Ethics and Human Rights*, and other documents the Kingdom of Saudi Arabia consider in these matters.

These secular laws, policies, and procedural guidelines must not conflict with Islamic laws and Arabian culture to gain the approval of the official agencies, secure community consensus, and prove its practicality in real-world settings.

In consideration of the medical care sector, basic laws of governance maintain Article twenty seven and Article thirty one which imply that the state must provide healthcare and public health protection to all citizens.<sup>161</sup> Therefore, healthcare and the consideration of patients' rights are influenced by Islamic Law in Saudi Arabia; this means that patients' rights in Saudi Arabia are included in the Islamic perspective toward biomedical ethics issues. Patients' rights in Saudi Arabia are linked to a larger ethical frame of the Islamic religion due to Saudi basic law and the

significance of Islam to this religious community. A separation between Islamic religious teachings and other determinants of Saudi biomedical ethical standards including Arabic culture and international influences will not succeed. For instance, the World Trade Press claims in a report issued in January 2010 that, “Saudi Arabia is a highly religious and deeply devout society. The population assiduously adheres to Islamic beliefs, customs, and practices. Islamic religious rites are considered vitally important, and a very high percentage of the population participates in them.”<sup>162</sup>

This example demonstrates that Saudi patients’ rights are fundamental to the core of Islam; therefore, a discussion of patients’ rights in the Saudi system will require a discussion of how patients’ rights are handled in Islam. Traditional texts concerning Islamic bioethics and patients’ rights are embedded in ethical codes which address characteristics of Muslim physicians, focusing on the moral obligations of physicians towards patients as well as ways to approach patients while maintaining dignity and respect for religious considerations. Modern Saudi Arabian patients’ rights and biomedical ethical policies reflect internationally-based procedural manuals which can be found in any hospital or medical care facility; this is due to the implementation of policies which constitute the operational and procedural work within hospitals that are customary in medical settings in Saudi Arabia. In other words, fundamentals to Islamic traditions concerning health and health care such as patients’ rights are protected by the Saudi legal system and embraced by the community, as it constitutes both the Saudi religious faith and an Arabic cultural component.

Saudi biomedical ethics derive its norms and philosophies from Islamic tradition as well as from normative determinants such as International treaties, imported procedural manuals, and general guidelines for bioethical norms.

In conclusion, patients' rights in the Saudi healthcare can be understood, studied, and influenced through an examination of Islamic biomedical ethics, though the Kingdom of Saudi Arabia considers current breakthroughs in areas of medicine and medical research in biomedical ethics. The Kingdom of Saudi Arabia in respect to its Islamic heritage is a permanent and participating member in international communities and provisions which has resulted in the enactment of international treaties and declarations related to biomedical ethics principles. In the next section, cultural forces that effect patients' rights discourse in Saudi Arabia will be examined.

#### **4.4 Cultural Forces Affecting Patients' Rights in Saudi Arabia**

This section addresses certain aspects of patient's rights in Saudi Arabia, and discusses challenges effecting patient's rights that result from the cultural norms of Saudis. In addition, it will elaborate upon the role of culture in the determination of biomedical ethical convictions and the role of religion in shaping Saudi culture which consequently affects patients' rights. This section will demonstrate how culture as an intermediary perceives common standards of biomedical ethics in various communities, including the Saudi Arabian community.

As mentioned previously, norms of biomedical ethics in healthcare systems are not dependent on single philosophical ideology or religious creed. Rational moral ruling (or norms), which convey practical solutions in real life settings, rely on complex moral frameworks such as religious teachings, culture contributions, and applied philosophies.

Some scholars believe that moral systems that influence bioethics are not convincing and lack necessary experience; Shabana (2014) mentions the Sachedina perspective on Islamic bioethics: "This is manifested in the absence of comprehensive Islamic ethico-legal frameworks

within which bioethical questions should be examined.”<sup>163</sup> This is noted by Aasim Padela (2013) who writes, “Yet, while Islamic law has an undeniable ethical character, it does not represent the totality of what the Islamic tradition has to say about ethical formation.”<sup>164</sup>

Frameworks that produce ethical guidelines that can gain corresponding approval and produce rational ethical verdicts that are reliant upon variables that delineate its normative reasoning, determines possible practices, and concludes upon the establishment of its philosophical traditions; Islamic ethics is an example of this concept.

A few of these variables include religious beliefs, cultures and customs, social and political environments, and economical factors. There are two crucial determinants of biomedical ethical norms which contribute greatly to the shaping of these norms in the community as well as the determination of collective moral convictions shared amongst a group of people with similar cultural characteristics; these are religious beliefs and cultural specifications. In previous sections, religious teachings as a crucial component to the Muslim moral system were discussed; this section will elaborate upon the role of culture in the determination of the essence of patients’ rights in Saudi Arabian healthcare systems. Ayman Shabana (2013) writes, “Since morality is closely tied to both culture and religion, bio-ethics must have room for the role of the cultural and religious contexts within which bioethics is constructed and implemented.”<sup>165</sup>

The Islamic contribution to morality shapes the convictions and core of biomedical ethics of the Saudi Arabian community, which then produces patients’ rights in Saudi Arabia based in the religious standards from Islam, customs, and cultures. Religion takes precedence over culture and other variables when determining normative moral judgments of Muslim communities, including Saudi Arabia. Shabana writes, “Islamic religious norms are important for Islamic bioethical deliberations. In Muslim societies religious and cultural norms are sometimes

confused but only the former are considered inviolable. I argue that respect for Islamic religious norms is essential for the legitimacy of bioethical standards in the Muslim context.”<sup>166</sup> This is supported by Stef Van Den Branden and Bert Broeckaert (2011) who, in a study concerning organ donation and blood transfusion in *Sunni Fatwas*, determine that evaluations completed by Muslim religious clerks are central in the discussion of biomedical ethics;<sup>167</sup> this illustrates how Islam establishes and influences biomedical norm formation, and determines its consequent outcomes. Even when imported policies and procedures govern healthcare systems, these policies must correspond with Islamic teachings in order to be feasible in Muslim communities such as Saudi Arabia.

In order to connect religious teachings of Islam and culture which influence the composition of bioethics norms, Abdul-Aziz Sachedina (2009) asserts that Muslim jurists, or religiously appointed legislators, cannot infer on ethical, religious, or legal issues and produce Islamic verdicts independent of cultural background.<sup>168</sup> This demonstrates the indispensable value of cultural norms in the ratification of legal and moral judgments including biomedical verdicts. Therefore, the relationship between religion and culture is apparent, as both religion and culture contribute to and interchangeably affect one another.

A brief description of cultural background will be provided to elaborate on the matter of religion and culture. Saudi Arabia is a conservative Arabic, Islamic country<sup>169</sup> that strongly considers Sharia law in comparison to other Islamic States;<sup>170</sup> Saudi Arabians relate ethical and religious matters extensively, as these individuals are strictly observant of Islamic teachings<sup>171</sup> in their daily affairs. A study from 2001-2003 by Mansoor Moaddel (2007) and the Pan- Arab Research Center discusses the degree of religious association that different Arabic nations demonstrate; this study concludes that people of the Kingdom of Saudi Arabia rank highest in

regards to the centrality of religion to their identity, as these individuals associate themselves with religion prior to describing themselves as Saudi nationals.<sup>172</sup> Saudis give considerable weight to religion and its teachings more than to national identity which means that religion is far more important to Saudis than culture.<sup>173</sup> Atighetchi mentions that only a few Islamic countries observe the essences of *Sharia* while creating legislative codes; Saudi Arabia, Iran, and Pakistan are the countries that consider these factors in legal matters.<sup>174</sup>

Culture is not an independent value that should be discussed separate from other structural elements that shape the convictions of modern community. Culture develops its terms and customs from sources including religion, national, ethnic, and political factors. In reference to Islamic teachings, Sachedina (2009) writes that mystic beliefs and daily religious responsibilities shape customs and political attitudes of Muslims as it constitutes interpersonal relationships that occur between individuals of the society.<sup>175</sup>

In regards to the interchangeable relationship between culture and religion, culture develops terminology from religion and religion, specifically Islam, finds significance in the shaping of Islamic moral and legal rulings based in culture and customs. Although *Urf* (*Al-Urf*), or a custom ruling, is mentioned in *Qur'an*: “Keep to forgiveness and enjoin, *Urf* and turn away from the ignorant.”<sup>176</sup> Sachedina (2009) claims that *Urf* is not considered an original source of ruling in *Sharia*, as the *Qur'an* and *Sunna* are considered. According to Sachedina, *Urf* was introduced around the sixteenth century as a supplement to pass verdicts related to contemporary legal and ethical issues that face the Muslim community.<sup>177</sup> Hafiz Abdul-Ghani (2011) considers *Urf* as an original source of Islamic law, capable of producing Islamic-based verdicts with *Ummah* consensus; the Prophet *Hadith* stresses the role of *Urf*: “Whatever the Muslims regard as good, it is good in the sight of *Allah*.”<sup>178</sup>



*Urf*, or customs, provide community consensus in the form of shared customs or approved culture specifications in accordance with Sharia laws and other sources of Islamic laws, as well as promote goodness in the society; these factors are considered to fabricate Islamic legal and moral verdicts. In other words, culture in the form of *Urf* is a distinguished Islamic ruling that offers unprecedented perspectives to address contemporary, biomedical ethical dilemmas.

In order for conclusions to be drawn in the context of Saudi Arabia, the discussion of patients' rights and bioethics should incorporate the examination of Islamic biomedical ethics, as it is frequently referred to by scholars, and Saudi Arabian biomedical ethics dependence on Islamic teachings in legal and moral legislations. In addition, specific Islamic verdicts concerning morality and legal legislations are dependent on current perspectives of the Muslim community, including Saudi culture and customs.

Therefore, different policies and principles such as imported western policies aim to establish and organize biomedical work in healthcare settings to be approved by Muslim religious clerks through the employment of *Urf* to promote common good. The adoption of *Urf* in healthcare settings will allow its influence upon contemporary ethical issues through the employment of contemporary Islamic filters as compatible with Islamic laws and to benefit the community (common good). This will secure clerk approval and gain common consensus in Saudi Arabian communities, as it is required to have religious approval and moral reasoning allows for public acceptance. As mentioned, biomedical ethics in Saudi Arabia are dependent on culture and religion in designating its norms; additionally, common international policies and procedures contribute to Saudi healthcare bioethics, as Abdullah Adlan (2013) claims that western imported principles are indigenous to Saudi healthcare settings.<sup>179</sup> The author notes that

the increasingly similar practice of healthcare policies and codes on an international scale are apparent in most healthcare settings, including Saudi Arabian healthcare settings.<sup>180</sup>

The interconnected relationship of religion and culture in Saudi Arabian healthcare systems allows an expanded view related to biomedical ethics which allows for combined efforts in the promotion of quality practice in patients' rights; quality practice can be accomplished by embracing common good (*Urf*) and promoting the respected,<sup>181</sup> comprehensive Islamic moral viewpoint on biomedical ethics.

On the other hand, when cultural norms are mistaken for being religious customs and a combination of religious and irreverent principles occur in social or biomedical settings, poor management of patients' rights will occur. In other words, when widely practiced cultural norms in a community are misconstrued as being of divine religious origin, then misinformed judgment may occur, which can lead to serious social and medical consequences. For example, if uninformed people fail to distinguish between religious and cultural norms when conveying a practical decision in medical settings regarding the morality of certain medical procedures on the false assumption that this procedure is impermissible in Islamic Sharia, then grave consequences might occur.

In the Saudi healthcare system, on occasion female patients are required by misinformed healthcare providers to gain approval from male guardians prior to giving consent in order to undergo certain medical procedures. This requirement of approval from a male guardian is mistakenly perceived as an Islamic practice based on the principle of male guardianship. This practice is based on customs and the communitarian cultural approach to autonomy, rather than being based on Islamic teachings. As these constitute cultural impediments of appropriate patients' rights practices, there are no restrictions that can be considered an organizational

impediment to limit female patients' right to autonomy; there are no formal policies in the Saudi healthcare system that require approval from male guardians, except in the case of minors and incompetent patients.

Another example of the confusion between sacred and irreverent practices in healthcare is the practice of female circumcision, or the cutting of female genitalia. Though it is not performed in Saudi healthcare facilities, many Muslims believe that the religion of Islam requires this practice in order to promote chastity; this practice actually originates from cultural origins specific to some African countries which does not indicate legitimate rationalization or origination in Islam. Atighetchi refutes the idea of female genital cutting as he asserts that such practices were performed in some Arabian and non-Arabian regions prior to the Islamic era. He also argues that some sources that link female genital cutting to *Hadith* and Islamic traditions are not authentic; he states that even the concept itself is rejected by *Qur'an* and by the traditions of the Prophet.<sup>182</sup>

Similarly, Padela (2013) states that people often frame their beliefs within religious contexts, even if such beliefs are not actually related to religion.<sup>183</sup> This combining of concepts may lead to serious consequences related to social and ethical principles, especially in religious societies such as of Saudi Arabia. Such mixing of concepts in healthcare settings alters people's perception of bioethical principles and decreases the determination to embrace better ethical practices.

This point is addressed by Sachedina (2009), who demonstrates the importance of differentiating between Islamic and pre-Islamic tribal cultural norms.<sup>184</sup> These misconceptions can affect patients' health outcomes, risk patient rights, and effect the perception and execution of humans rights, especially concerning those of vulnerable groups including women as noted by

Beth Speake (2012).<sup>185</sup>

The example of disclosure of personal information in healthcare settings will be used to elaborate upon the effect culture has on the execution of biomedical ethics as related to the prioritization or neglect of specific principles. Abdullah Adlan and Henk ten Have (2012) mention a case that occurred in a Saudi Arabian healthcare facility; a child with genetic anomalies was conceived outside of wedlock and her legal, non-biological father was unaware of the situation. After deliberations, the cultural specification of the Saudi tribal community pressured the ethics committee and physicians to refrain from disclosing this information to the legal father. This rationalization was based on the zero tolerance policy enforced by the tribal cultural system for relations out of wedlock, which would lead to severe social and legal consequences; therefore, it was preferable to withhold the information to the father.<sup>186</sup> Adlan and Ten Have write, “Thus, it is strongly argued that in this case the virtue of telling the truth may have the lowest priority due to the nature of the information, which may not only impact on a large number of people outside the case but also pose a threat to life.”<sup>187</sup>

The governing culture plays a major role in altering a fundamental principle of information disclosure, whereas it is considered unethical in other healthcare systems, such as in western countries, to refrain from disclosing information to a competent patients. In addition, Adlan and ten Have find that though Islam is central to Muslims, in cases that are culturally sensitive, culture is a major consideration to the decision makers which results in its surpassing of religious consideration; for example, cultural considerations would have influenced the father’s actions if he learned of the child’s illegitimacy, potentially resulting in an honor killing, a customary practice which is forbidden by Islamic teachings.<sup>188</sup>

Ali Aljubran (2010) stresses the power of social and cultural norms as a factor when

disclosing information to cancer patients regarding their condition in Saudi Arabia.<sup>189</sup> Aljubran mentions that the typical manner in which this information is disclosed in western countries is not practical or relevant in Saudi communities, as the role of culture and customs constitutes the relationship between healthcare providers and patients in Saudi communities. Aljubran concludes that in Saudi Arabian healthcare systems, the disclosure of information to patients must incorporate the inclusion of patients' families to the conversation to uphold the cultural specifications of the region. The author recommends that there be open channels of communication between the physician and family in order to adhere to customs of informing the relatives of patient circumstances specific to Saudis; this practice is not practiced internationally but is perceived as adherent to principles of international bioethics practices concerning the confidentiality of medical records and information. In another study by Rami Abo Khalil (2013), variations in practices of information disclosure in several Middle Eastern countries, including Saudi Arabia, were based on cultural perceptions of truth telling and the existence of relevant policies. Abo Khalil writes, "In this Saudi Arabian conservative Islamic society where policies regarding truth disclosure lacked, a report published in 1997 stated that, the patient's treatment was given by the family in order to avoid disturbing the patient emotionally."<sup>190</sup> This represents how cultures interfere with the appropriate channels of information disclosure in Saudi Arabia.

To elaborate on how the impact of culture influences patients' rights and influences biomedical ethical principles generally, Atighetchi contends that doctrines of bioethics in communities are similar in principle, but have variations in the perceptions, practices, and prioritization of the application of these principles.<sup>191</sup>

For example, Henk ten Have (2013) claims that in many non-Western cultures, the rights of the community surpass individual autonomy; this acknowledgement of community differences

in regards to the acceptance and implementation of ethics principles in accordance to social, cultural, economic specifications has its implications as related to the globalization of human rights principles and biomedical ethics standards.

Atighetchi provides an example of local cultural stipulations that perceive principles of bioethics different than the manner these principles are perceived in modern literature of bioethics or as Western communities practice. For instance, Egyptian doctors impose a socially acceptable, paternalistic approach to patient affairs that is based on the norms customary in Egyptian culture,<sup>192</sup> which also could be applied in Saudi context as well.

In Saudi Arabia, the dominant culture is centered on community and prioritizes family decisions over individual rights; this can impede upon the patients' ability to acquire rights in accordance to international interpretations of ethical principles. An example of this is when doctors or family members impose certain decisions upon patients; in this case, the autonomy of patient is grossly neglected and compromised.<sup>193</sup>

Another culturally-based impediment to proper practice of patients' rights in Saudi healthcare system is the presence of varying cultural motivations, which often conflict with the culture of Saudi Arabian citizens, which contribute to bioethical discourse in Saudi healthcare hospitals. The presence of numerous multi-national healthcare workers can create conflicting cultural influences in healthcare settings; each of these individuals perceives medicine from their cultural influences and can impose their cultural convictions within Saudi hospitals. This is especially the case when clear codes of ethics that organize and constitute standards of care are absent and when patients' lack awareness and advocacy for the rights of patients' in general. In reference to patients' rights in Saudi hospitals, Ali Albishi notes that patients' rights are not observed which results in the imposition of paternalistic practices by healthcare providers when

treating patients.<sup>194</sup>

According to a study by Khalid Bin Saeed (1999), multinational healthcare forces among Saudi national physicians in varying hospitals lack the ability to distinguish ethical issues they encounter during their work in Saudi hospitals. Among these ethical issues include information disclosure, discrimination against patients based on social ranking, and receiving favors from patients. Bin Saeed relates such ignorance to multicultural differences and the absence of a clear code of conduct in these hospitals.<sup>195</sup>

#### **4.5 Conclusion**

In conclusion, this chapter elaborates upon the role of religion in establishing bioethics norms, as religion proves to play a major role in shaping people's convictions and spiritual responsibilities when ethical dilemmas arise. The second portion of this chapter discusses the sources of Islamic biomedical ethics, as it exposes the significance of Islamic traditional sources and their role when providing moral and legal verdicts to contemporary issues Muslim communities face around the globe.

This chapter also elaborates upon the roots of Saudi Arabian biomedical ethical standards; it has been determined that Saudi ethics are derivative of Islamic biomedical ethics, a comprehensive and established ethical system. This point is evident, as Islam is central to religious and practical life in Saudi Arabia, as well as in contemporary ethical discourse in Saudi Arabia including the establishment of biomedical ethical norms.

Patients' rights in Islam and Saudi Arabia are examined in another section, and conclusions are drawn which indicate that Saudi bioethical discourse is similar to Islamic biomedical discourse, as Saudi Arabian culture deduces its customs and norms from Islamic

traditions. Therefore, studies concerning patients' rights in Islam are relevant to the Saudi healthcare system. A separation should be made between religious and irreverent determinants of biomedical ethical norms as many people fail to distinguish the difference between the two.

It has been determined that Saudi biomedical ethics base its essences on Islamic teachings in addition to internationally-based biomedical ethical norms.

Finally, this chapter uses previous discussions as a basis for the identification of cultural obstacles which impact the implementation of universal principles of bioethics in the Saudi healthcare system. However, cultural obstacles to patients' rights in Saudi healthcare system are resolvable through the enforcement of respect for patients' rights in Saudi healthcare facilities. This introduces binding laws and feasible codes of patients' rights as Saudi biomedical ethics are framed in Islamic morality and correlate to fundamentals of international biomedical ethical norms; therefore, international biomedical ethics are feasible in the Saudi healthcare systems if cultural specification and religious requirements are considered and observed.

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<sup>1</sup> Bahaa Darwish, "Arab Perspectives," in *Handbook of Global Bioethics*, ed. Henk ten Have and Bert Gordijn (Dordrecht: Springer, 2014), 269.

<sup>2</sup> Harold Koenig, *Medicine, Religion, and Health: Where Science and Spirituality Meet* (Cincinnati, OH: Templeton Foundation Press, 2006), 9-20.

<sup>3</sup> Koenig, *Medicine, Religion, and Health: Where Science and Spirituality Meet*, 11.

<sup>4</sup> Candy Gunther Brown, "Integrative Medicine in the Hospital: Secular or Religious?" *Society* 52, no. 5 (2015): 462-468.

<sup>5</sup> Richard Bulliet, "The Individual in Islamic Society," in *Religious Diversity and Human Rights*, ed. Irene Bloom, Paul Martin and Wayne Proudfoot (New York: Columbia University Press, 1996), 186.

<sup>6</sup> Abdullah S. Daar and A. Khitam, "Bioethics for Clinicians: 21 Islamic Bioethics." *Canadian Medical Association Journal* 164, no. 1 (2001).

<sup>7</sup> Omar Kasule, "Holistic vs. Biomedical Medicine," *Islamic Medical Education Resources* (2002).



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- 8 Mansoor Moaddel, "The Saudi Public Speaks: Religion, Gender, and Politics," in *Values and Perceptions of the Islamic and Middle Eastern Publics*, ed. Mansoor Moaddel (New York: Palgrave Macmillan, 2007), 209-220.
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- 11 Sachedina, *Islamic Biomedical Ethics: Principles and application*, 8.
- 12 David F. Kelly, *Contemporary Catholic Healthcare Ethics* (Washington DC: Georgetown University Press, 2004), 88.
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- 17 Padela, "Islamic Bioethics: Between Sacred Law, Lived experiences, and State Authority," 66.
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## **Chapter Five: The Role of Healthcare Organizational Culture in the constitution of Patients' Rights and Organizational Impediments of Biomedical Ethics in the Saudi Healthcare System**

Following a discussion of the role of culture in biomedical ethics in Saudi Arabia, this chapter will elaborate on the role of the organizational culture in prioritizing patient's rights practices in the Saudi health care system. Abdul-Aziz Alkabba et al. (2012) suggest ten ethical problems that affect or are caused by the national healthcare system in Saudi Arabia; these ethical problems include, patients' rights, equality of resources and resource distribution, confidentiality, safety, conflicts of interest, ethics related to privacy, informed consent, gender, conception and end of life ethics, and the ethics of healthcare personnel. <sup>1</sup> However, ethical issues concerning patients' rights are the priority on this list; this demonstrates the importance of incorporating issues related to patients' rights in contemporary medical literatures in Saudi Arabia. These ethical concerns will be reviewed throughout this chapter and the following chapter, beginning with a discussion of the role of health care organizations in the promotion or hindrance of patients' rights.

Current healthcare systems in Saudi Arabia are not principally concerned with providing minimalist healthcare provisions to the community as they were some decades ago; rather, the contemporary reality of these healthcare systems is that they are more concerned with the improvement of quality healthcare services provided. Due to the benefits of booming oil revenues, the kingdom has improved in all areas of study in order to stay current with the modern world in all aspects, including the healthcare sector.

In order to improve healthcare performance and quality service provision to the community, the Saudi Arabian healthcare sector has identified its limitations to providing quality

healthcare services. A fine tuning of the Saudi Arabian healthcare organization is crucial to promote morality in healthcare and improve upon or protect patients' rights, beginning with the organization of the healthcare system itself.

Healthcare organizations maintain varying roles to promote the health status of the community. Zahra Mastaneh and Lotfollah Mouseli (2013) state that the roles of healthcare organizations are varied and numerous, including the deliverance of health care services, protection against preventable diseases, and provision of education to patients regarding health and their rights in healthcare settings.

Healthcare organizations create obstacles to the protection of patients' rights due to the failure to observe and adapt ethical principles, enforce relevant policies, maintain safety culture,<sup>2</sup> in addition to other logistic and managerial issues. Examples of this include lack of clarity in the adoption and enforcement of policies, vague strategies of implementation for regulatory standards and policies,<sup>3</sup> insufficient healthcare staff and deficient equipment,<sup>4</sup> inexperienced healthcare staff, language barriers, absence of binding policies, varying of cultural beliefs, toleration of paternalistic practices,<sup>5</sup> and the lack of effective reporting systems. These obstacles are all a direct result of the failure of the healthcare organization to protect patients' rights.

Therefore, the discussion of organizational ethics is crucial to better understand the impediments that affect bioethical standard implementation and the application of universal bioethical principles in the Saudi Arabian healthcare system.

This chapter will examine obstacles that are a result of the Saudi Arabian healthcare system organization affecting patients' rights, beyond the cultural contributions or prevention of patients' rights neglect. This discussion will also include the infringements upon patients' rights

due to the lack of binding laws and policies at both national and institutional levels. The concluding section will recommend methods to enhance organizational ethics by enforcing organizational cultural practices, as well as introducing culturally competent and patient centered care to the Saudi healthcare system.

The constant demand for healthcare services has created constraints within healthcare delivery systems around the globe. No matter the wealth and resources of a country, national healthcare services will face technical or financial restrictions that make it impossible for the healthcare system to deliver adequate medical services to all people, especially those belonging to vulnerable groups.<sup>7</sup>

Medical services in recent times are much more sophisticated, expensive, specialized, and highly technical than ever. These advancements result in costly moral and financial disadvantages. Even with the increases in governmental healthcare expenditure, many nations struggle to balance growing healthcare costs and increasing demand for medical services. For example, 14.9 %<sup>8</sup> of the Gross Domestic Product (GDP) in the United States is dedicated to health and healthcare services.<sup>9</sup> This represents huge financial expenditure and governmental commitment to financing the healthcare sector.

In addition to the scarcity and lack of accessibility of healthcare services faced by the growing populations, the healthcare industry suffers from problems within its facilities and related organizations regarding the morality of its operational conducts. Concern for patients' rights within healthcare organizations is significant to determine the quality of healthcare provided and work morality of healthcare providers. Patients' rights in biomedical settings, including healthcare facilities or research settings, demonstrate the scale by which organizations are judged related to the morality of their work.

Failure to observe patients' rights demonstrate the failure of healthcare organizations to deliver safe, adequate, and moral medical services to the public. Neglect of patients' rights contribute to an increase in morbidity and mortality rates, financial losses to compensate for legal lawsuits as a result of neglect or inadequate resource utilization, which thereby exacerbates the problems of exhausted healthcare industries. Zahra Mastaneh and Lotfollah Mouseli (2013) write,

Awareness of patients from their rights can bring about a lot of advantages such as increased quality of health care services, decreased costs, more prompt recovery, decreased length of stay in hospitals, lower risk of irreversible physical and spiritual damages, and more importantly, increased dignity of patients through informing them about their rights to participate in decision making. On the other hand, lack of respect to patients' rights may lead to hazards to security and health situation of patients. Besides, it may ruin the relationship between the staff and patients that consequently decreases efficiency, effectiveness, and suitable care of patients.<sup>10</sup>

Patient's rights abandonment and negligence in healthcare ventures takes many forms and shapes, and not associated only with observing patient's autonomy. For example, medical errors occurring in healthcare settings due to failure to respect patient's rights through abstaining from harm (non-maleficence) is a byproduct of overlooking appropriate patients' rights practices.

Desertion of patients' rights can lead to moral damage, rejection of patients' fundamental rights, in addition to grave physical, psychological and financial indemnities. A study concludes that the iatrogenic harm, which is defined as, "Avoidable harm caused by the process of healthcare itself, rather than by underlying injury or disease"<sup>11</sup> costs the United States of America an estimated 20 billion dollars per year; this cost is equal to 15% of the GDP, whereas in the United Kingdom, the cost is approximately 2 billion pounds per year.<sup>12</sup> This differs from many European countries where 9% of the national GDP is devoted to medical error compensation.<sup>13</sup> In 1999, the Institute of Medicine (IOM)<sup>14</sup> issued a report related to medical error called, *To Err is Human: Building a Safer Health System*, which estimates that medical errors kill 44,000 to

98,000 Americans per year.<sup>15</sup> These figures represent a minute portion of the adverse effects of medical errors, given that it is difficult to estimate numbers of lives lost and resources wasted. A study claims that the loss of human life is actually double that which is represented by the IOM figures<sup>16</sup> because numerous cases are unnoticed, undocumented, and unreported. Fears of litigation and disciplinary action are the main reasons for the under-reporting of medical errors in health care settings.

Though medical errors and adverse events as a result of ignoring patients' rights are theoretically preventable, many factors within the healthcare organization make it challenging to ensure patients' rights and safety. This occurs because patients' rights are not produced from a single creed or achieved by a singular effort; rather, patients' rights are established based on multiple factors and principles.

Patients' rights are established and maintained through various national and international regulations in addition to accreditation laws. Governmental agencies, civil rights movements, and general or private healthcare organizations participate in the advancement, establishment, and enforcement of patients' rights standards in healthcare facilities according to best practices and general biomedical moral principles. For example, the following regulatory agencies and enacted bills aim to regulate and enhance the explicit requirements to improve patients' rights in the United States: the patients' Bill of Rights of 2011, the Patient Care Partnership,<sup>17</sup> the Healthcare Insurance Portability and Accountability Act (HIPAA)<sup>18</sup>, the Joint Commission for Accreditation of Healthcare Organizations (JCAHO)<sup>19</sup>, and the Accreditation Council for Graduate Medical Education (ACGME). At the international level, the *UNESCO Universal Declaration on Bioethics and Human Rights*, the *Belmont Report*, and other international articles aim to promote patients' rights in healthcare settings and research.

Regulations and laws which promote efforts related to patients' rights, eliminate medical errors, and enhance the overall healthcare ventures are enacted at international and national levels. Despite this, the primary efforts to maintain bioethical venture and protect patients' rights is embedded within managerial and operational functions of the healthcare organization to maintain effective regulations and standards. This demonstrates that healthcare organizations are a factor in biomedical outcomes, as imported or imposed internationally-based regulatory laws are inadequate in promoting patients' rights without the participation of the healthcare organization itself. Steven Pearson, Sabin, and Emanuel (2003)<sup>20</sup> note that in relation to the role of the health care organization and policies or regulations, there is a need to improve the healthcare organization in order to anticipate errors and develop safe, quality practices. However, the authors claim that current regulatory standards and accreditation by governmental agencies are not effective in producing desired outcomes.<sup>21</sup>

In order to promote patients' rights in health care settings, health care organizations must undergo moral and structural assessments to determine areas of strength and weakness. Evan Winkler and Russell Gruen (2011) suggest four guiding principles to enhance moral agency of healthcare organizations: to provide care with compassion, to treat staff with dignity, to act in accordance to essences of teamwork, and to spend resources in reasonable ways.

While this chapter supports the preceding chapter and its discussion of cultural obstacles to adapting proper patients' rights in Saudi Healthcare systems, this chapter supports the discussion of the obstacles arising from organizational issues in the Saudi Healthcare system.

This discussion represents the significance of the role of health care organizations in the determination of biomedical ethics including the enforcement of patients' rights principles. This chapter will discuss the role of the organization of health care and resulting obstacles that occur

in the Saudi Healthcare settings. The chapter will open with an elaboration upon healthcare organization and the significance of organizational culture. A succeeding section will demonstrate the role of organization in healthcare and the role of biomedical ethics in promoting the understanding of patients' rights related to health care organization. The third section will discuss managerial, regulatory, and logistical issues that demonstrate organizational obstacles that decrease the ability of healthcare organizations to embrace biomedical ethics standards which promote patients' rights. The chapter will conclude with recommendations and remarks related to patients' rights and methods to implement biomedical ethics in the Saudi health care system.

### **5.1 Healthcare Organizations and the Significance of Organization Culture**

The year 1925 marks the birth of the Health Department and Bureau of Health and Aid, the oldest official office with concerns regarding healthcare in the kingdom of Saudi Arabia. This department worked to promote the health status of citizens, the *Hajj* and *Umra* pilgrimages, and visitors to the region.<sup>22</sup> Well-funded and organized healthcare efforts began with the foundation of the Health Ministry in 1951.<sup>23</sup> From that time forward, the health sector in the kingdom of Saudi Arabia has evolved to reflect the advancements in healthcare services occurring worldwide, and to meet the expectations of the growing population in Saudi Arabia.

As a result of the government expenditures in healthcare venture, countless modern hospitals, research centers, primary care facilities, geriatric hospice care facilities, and other specialized centers have been formed and spread throughout the Kingdom to provide citizens with free healthcare services.<sup>24</sup>

However, not all hospitals and healthcare facilities in Saudi Arabia operate under the supervision of the Ministry of Health. Various hospitals and healthcare clinics operate under governmental agencies and ministries.<sup>25</sup> This includes the ministry of national guards, ministry of defense, ministry of interior, oil company Aramco, Royal Commission for *Jubail* and *Yanbu*, and the ministry of education; each of these entities maintain privately operated hospitals, clinics, and other health services centers throughout the Kingdom to provide services to employees and their families.<sup>26</sup> An example of this is Riyadh Military Hospital (RMH), which is one of the hospitals supervised by the ministry of defense to provide services to military personnel and their families in Riyadh area with 1000 bed hospitals and 13 primary care centers.<sup>27</sup>

There are countless privately owned entities that provide healthcare services to Saudis through basic and advanced medical services. Despite this, the ministry of health is considered the largest healthcare provider in the country, providing 60 percent of all primary, secondary and tertiary healthcare services to the population of Saudi Arabia.<sup>28</sup>

In relation to the discussion of the healthcare system in Saudi Arabia, the consequence of various healthcare service providers is variation and inconsistent health care provision, dependent on individual ability to meet healthcare demands. Different providers have specific abilities to provide healthcare services, due to the inconsistency of governmental reimbursement to cover the operation expenses and healthcare costs.

As management of healthcare service provision varies, healthcare centers and hospitals have specific missions and policies to meet their needs and correlate with their duties related to scope of practice and goals. For instance, the Ministry of Health<sup>29</sup> has a general mission to serve the general public, whereas the Ministry of National Guards has a mission directed toward healthcare services for the ministry employees.



There are also variations in the application and promotion of patients' rights and professional standards such as protocol manuals in different healthcare facilities within Saudi Arabia. This is demonstrated through the existence of distinctive policies and procedures manuals that describe the internal operational policies for a healthcare organization dependent upon the organization type.<sup>30</sup> For example, a nursing manual titled, *Manual of Nursing policies and procedures*<sup>31</sup>, is provided by the Ministry of Health; therefore, this manual is available to workers and healthcare facilities that operate primarily under the Ministry of Health. This manual cannot be found in hospitals that follow different management. The *Saudi Commission for Health* provides a booklet titled, *Code of Ethics for Healthcare Practitioners*, to provide general biomedical ethical guidelines for unclassified healthcare providers within the Saudi healthcare system.

There is deficient communication between healthcare providers within Saudi Arabia; this potentially can be an area for growth to join efforts to foster healthcare provider collaboration. This key point is noted by Almalki, Fitzgerald, and Clark (2011) who write, "...it has been noted, however, that despite the multiplicity of health services providers there is no coordination or clear communication channels among them."<sup>32</sup>

Almalki, Fitzgerald, and Clark describe that due to deficient communication between healthcare providers and lack of collaborative work, the government introduced the Council of Health Services in 2002, with a goal to establish communication between healthcare providers in Saudi Arabia. Almalki, Fitzgerald, and Clark argue that the council fails to reach its goals and communication between healthcare providers continues to be deficient.<sup>33</sup>

Organization disadvantages are numerous and important, effecting the organization itself and the entire healthcare system. Many resources are wasted due to poor management and

countless opportunities are lost due to miscommunication between different entities; these internal and external organizational discrepancies contribute to the chronic financial drain occurring in the Saudi healthcare system.

In addition, the complications related to deciding, planning and enforcing healthcare ethical standards and operational manuals is a result of the lack of intercommunication between healthcare providers in Saudi Arabia. Each healthcare entity adapts and enforces the standards that are approved and by its own management; these standards can be developed internally to the healthcare organization or imported from national or international sources. For example, the Ministry of Health enforces policies and procedures that are consistent with the National Guard Healthcare Services manuals. Attempts to create unified national manuals establishing patients' rights have been considered; for example, Abdul-Aziz Alkabba et al (2012) reports that in the Saudi national healthcare system, there is only one incomplete, national guideline regarding patient's rights, therefore leaving every hospital to formulate their own manuals.<sup>34</sup>

It is apparent that there are many organizational barriers to the enforcement of appropriate biomedical ethics in the Saudi Arabian healthcare system. This lack of enforcement indicates the improper enforcement of patients' rights standards.

A discussion of the structural composition of the healthcare organization will demonstrate its significance in the determination healthcare patient outcomes and represent the impact organizational culture has on health status and healthcare ethics. In reference to the organization and ethics of healthcare, Azeem and Akhtar (2014) write, "If organization gives high value to ethical practices they becomes an active part of an employee's working knowledge, which affect the ethical decision making."<sup>35</sup>

Janie Butts (2008) defines the organization as the number of people working together to accomplish common goals<sup>36</sup>; meanwhile, Edward Spencer et al. (2000) writes, “Organizations are made up of a complex of changing, dynamic interrelationships through which the organization defines and regenerates itself and even metamorphoses as it interacts with changing surroundings.”<sup>37</sup> This definition frames organization as a functional unit capable of interacting with the surrounding environment and demonstrates that it has an inner constitution defining its missions, controlling its internal and external operative activities, and defining its relationships with surrounding environments. Therefore, the structure and inner culture of an organization will identify its moral status when dealing with its employees, clientele, and the greater community.

Spencer et al. also write, “Although organizations are not individuals, and therefore are not moral persons, they can be meaningfully said to be moral agents in several senses.”<sup>38</sup> If an organization follows its mission and vision statements established by its management, the organization becomes an extension of the beliefs and convictions of the management.<sup>39</sup>

Butts describes healthcare organization as an open system focusing primarily on dealing with external environments<sup>40</sup>; this makes the structural functions of healthcare organizations important to the organization and to the external stake holders such as patients, families, and the community.

When adverse events jeopardize the rights and safety of patients or neglect healthcare ethics, such as abandonment of safety protocols or failure to adopt ethical practices, medical errors and disregard for patients’ rights become habitual; therefore, the dominant culture of the organization requires reform to embrace a safety-based culture to promote patients’ rights.

A single medical error or instance of neglecting ethical practice is not necessarily the product of a singular wrong action. It can be the product of numerous events which can be linked to the dominant culture of the organization.

Though the culture of the healthcare has been deemed crucial in the practice of patients' rights, many scholars argue that the organization should be judged and dealt with as a moral agent to promote moral practices. Spencer et al. (2000) introduces four points, demonstrating the similarities of organizations and individual people; this argument illustrates that organizations can be regarded as people subject to moral judgments and found liable for actions and choices. First, organizations have goals similar to individuals. These goals are represented in the organization mission and vision statements. Second, organizations produce actions which can be either harmful or beneficial. Third, organizations undergo evaluation processes which mimic individual judgments. Finally, since organizations are capable of actions which can therefore be evaluated, the organizations can also be held responsible or accountable for actions.<sup>41</sup>

This demonstration of the individual and organizational moral liabilities promotes the understanding of how healthcare organizations are responsible for bioethical standard violations. Such recognition of the moral agency of health care organizations will lead to the creation of ethical operational frameworks, a tool to also assess the organization's ethical performance. In other words, organizational morality is similar to individual morality<sup>42</sup> which provides normative ethical standards that determine, constitute, and evaluate the morality of motives, actions, and consequences.<sup>43</sup> Spencer et al. supports this paradigm as they claim that, "Insofar as organizations also are ethical agents, and instruments of the society for health care, they are subject to many of the ethical expectations that the society has of individual providers."<sup>44</sup>

The determination of an organization's internal or external operational morality will promote the work of the healthcare organization beyond basic requirements, mandated by regulations and accreditation codes called, "moral minimums."<sup>45</sup>

There are two types of moral standards by which healthcare organizations are judged, including clinical and organizational ethics. Clinical ethics work to solve ethical dilemmas that occur in clinical settings involving individual patients<sup>46</sup> (e.g. end-of-life and abortion issues). Organizational ethics work to investigate the compliance of non-medical organizations since the Watergate scandal.<sup>47</sup> This ethical judgment is devoted to evaluating issues of an organizational nature; "Organizational ethics consists of a process to address ethical issues associated with business, financial, and management areas of health care organizations, as well as with professional, educational, and contractual relationships affecting the operation of the health care organization."<sup>48</sup>

Issues of patient confidentiality, conflicts of interest, and information disclosure or security are of interest to those committed to organizational ethics.<sup>49</sup> The philosophical focus of organizational ethics is also concerned with issues of employment and interpersonal relationships between employees as well as subordinates and their supervisors.<sup>50</sup> Many functional and structural layers are considered, but a crucial aspect of organizational ethics is the evaluation and shifting of corporate culture to foster better work environments which promote quality of goods and services and the safety of the patients (or the customers).

To elaborate on the culture of health care organization, Jacques (1951) defines organization culture as, "the customary or traditional ways of thinking and doing things, which are shared to greater or lesser extent by all members of the organization and which new members

of the organization must learn and at least partially accept in order to be accepted into the service of the firm”<sup>51</sup>

According to Mary Jo Hatch (1993), studies of organizational culture have been discussed since 1970.<sup>52</sup> The importance of culture to organizations is stressed by Frank Guldenmund, as he mentions that organizational culture can facilitate work, fluency and eliminate uncertainty. Guldenmund cites Van Hoewijk (1988) and Schein (2004), who elaborate upon and describe the function of organizational culture.<sup>53</sup>

Therefore, the dominant culture of the organization is established by its common practices and determines the moral norms to be followed and observed by its personnel. This demonstrates that organizational culture plays a major role in the establishment of patients’ rights and its related practices, as improper health care organizational culture sacrifices safety and therefore neglects the rights of patients.

The no blame culture is an example of effective handling of medical errors which therefore promotes organizational moral agency; this will promote patients’ rights and safety. This concept supports the importance of the organizational culture in promoting patients’ rights and safety within health care organizations. When an unintentional medical error occurs in health care organization, the typical organizational progression of reporting of the incident is initiated by self-report or by reporting another error of a team member. Systematic action will aim to minimize the impact of the potential harm. At the same time, managerial evaluation tools will analyze the sources and outcomes of the medical error and recommendations will be enacted to ensure that similar incidents do not occur in the future. Moeidh, Shah, and Almatari (2015)<sup>54</sup> argue that healthcare workers enhance the organization through discussions and reporting; this

makes employees accountable as their managers in the shaping of healthcare organizational culture, therefore impacting patients' rights in the healthcare.

This process represents the ideal culture of safety in healthcare organizations, but not all healthcare organizational cultures are so effective.

In contrast, some healthcare organizations adopt a culture of shame and blame, which humiliate the individual for causing such incidents. This culture is widely embraced in various healthcare organizations and holds the person at fault as worthy of punishment, regardless of other causative factors. These convictions are widely shared by segments of society and the culture of blame can restore order by providing justice to victims. If this principle is embraced by healthcare organizations when dealing with medical errors and protecting patients' rights, the outcomes can be disastrous.

The principle of justice necessitates the determination of responsibilities and enforces punishment; this does not easily reveal the medical errors that occur in health care. Self-report in an unsupportive healthcare organization is not likely to be achievable.

An example of how the system should function is when a doctor who prescribes the wrong dosage of medication or a nurse who gives the wrong medication, these individuals should voluntarily report the mistakes to directly address the error and provide the patient proper aftercare. However, this makes the individual vulnerable to accusation, discipline, and even legal prosecution; all of which may or may not be justified in this case. In organizations with a dominant culture of blame and shame, those at fault for medical errors will likely hesitate before reporting their mistakes. As a result, the blame culture is also a culture of denial due to hesitations to admit the employees are at fault. Therefore, this culture indirectly supports the

culture of errors by failing to tolerate, accept, and effectively deal with medical errors as a common reality.

Contrary to the concept of blame culture, Marx<sup>55</sup> suggests a proper ethical alternative referred to as “just culture”, to deliver effective evaluation methods; this alternative directs blame solely in cases that involve acts of gross negligence that result in avoidable medical errors. This culture identifies and distinguishes the errors that occur as a part of medical reality. It is a goal to avoid future incidents by handling such errors through proper, systematic organizational methods.

In conclusion, efforts to promote patient safety and rights in healthcare require consideration of the organizational culture as it plays a major role in patients’ rights. Therefore, the moral healthcare organization is crucial to promote patients’ rights within the healthcare organization. By embracing the aforementioned ethical principles, this will promote the prevention of medical errors and a high-quality organizational culture capable of dealing with ethical dilemmas at clinical and managerial levels.

## **5.2 The Role of Health Care Organization in Promoting Patients’ Rights**

This section will elaborate upon the role of the inner culture of healthcare organization when protecting and promoting patients’ rights and ethical agency of healthcare providers. In addition, moral values and principles will be discussed to advance the moral agency of healthcare organizations which will lead to the promotion of patients’ rights culture within the organization.

The role of health care organization in patients’ rights begins with adherence to regulatory policies and laws which govern the healthcare industry. The internally-based policies



of the organization establish daily operational tasks as well as the moral agency of healthcare providers, therefore defining the stance of healthcare organizations towards patients' rights and the organizational moral status.

An adoption of governmental and non-governmental standardizations and quality assessment procedures will allow healthcare organization adherence to required laws which establish the minimum, standardized principles that allow for safe practices. Laws and standardizations concerning healthcare produce favorable environments for the growth and protection of patients' rights; but, laws and compliance with healthcare regulations are not sufficiently effective to produce distinguished healthcare services that achieve best practices related to patients' rights. Eileen Morrison (2016) claims that commitment to quality beyond the standards and minimal requirements are not trivial, but it is a moral duty of the organization that needs to be attained and protected; the author writes, "Quality is important for reasons beyond meeting the standards of government and funding agencies and having a profitable business: it is also a Kantian duty. Providing safer, effective, and quality healthcare that benefit the patient would certainly pass the categorical imperative."<sup>56</sup>

In the United States there are numerous regulatory agencies that adhere to governmental and non-governmental entities concerned with healthcare services and patients' rights in healthcare settings. An example of this is *The Joint Commission*, an accreditation agency for healthcare entities focused on promoting quality of healthcare since 1965.<sup>57</sup> Other examples from the United States are the *Institute of Medicine*, Medicaid and Medicare services,<sup>58</sup> and the *Agency for Healthcare Research and Quality (AHRQ)*.<sup>59</sup> An example of a private regulatory organization is Leapfrog<sup>60</sup>, an entity that mandates adherence to specific standards to allow companies associated with Leapfrog to send employees to those health care providers.

In Saudi Arabia, the Saudi *Central Board for Accreditation of Healthcare Institutions* (CBAHI) is a governmental agency similar to the *Joint Commission*, working to provide standardization and accreditation services to healthcare organizations. Since 2001, CBAHI has developed a national standardization programs that were made effective in 2006, accredited its first hospital in 2010,<sup>61</sup> introduced the second edition of hospital accreditation standard compliance programs in 2012,<sup>62</sup> which was then followed by the third edition in 2016.<sup>63</sup> Despite these efforts, the accreditation and evaluation process as well as the normative standards established by CBAHI are limited and flawed. There are many scholarly critiques of CBAHI due to compounding reasons and given the sheer novelty of the organization. These critiques are typically directed toward the accreditation principles and the normative standardizations by which CBAHI frames its policies. When comparing CBAHI to the *International Society for Quality in Healthcare* (ISQua), Abdullah Alkhenizan and Charles Shaw (2010) note,

The CBAHI standards did not describe the process of development, evaluation or revision of the standards. Several standards are repetitive and ambiguous. CBAHI standards lack measurable elements for each standard. CBAHI standards met only one criterion (11.1%) of the Quality Improvement principle, two criteria (22.2%) of Patient/Service User Focus principle, four criteria (40%) of the Organizational Planning and Performance principle, the majority (70%) of the criteria for the safety principle, only one criterion (7.1%) for the Standards Development principle, and two criteria (50%) of the Standards Measurement principle.<sup>64</sup>

Mohammed Almasabi and Shane Thomas (2016) argue that in addition to ignorance related to the continuity of health care provision, the CBAHI is merely effective in producing quality outcomes.<sup>65</sup>

According to its mission and policy statements, CBAHI as an accreditation agency is working to revise and improve its policies and regulations to meet the advancements in healthcare accreditation in accordance with best practice, therefore assuring that accredited hospitals are taught best standards principles .

Healthcare organizational compliance with accreditation requirements will promote patients' rights by facilitating morality of the inner culture of the organization. This will lead to the enhancement of healthcare organization ethics culture which will enable ethical healthcare practices, therefore promoting patients' rights as a result.

In addition to the legal requirements and accreditation principles related to standards of care, Eva Winkler and Russell Gruen (2011) suggest four roles to be followed by the healthcare organization. The first is focused on promoting interpersonal communication between caregivers and receivers of healthcare services. Winkler and Gruen refer to this as "the role of care with compassion"; the authors suggest that all individuals involved with the organization incorporate these following values: "competence, compassion, shared decision-making and trust"<sup>66</sup>. The authors note that moral principles including respect for autonomy, value of confidentiality, and beneficence should be enforced to establish the relationship between care providers and patients. These principles all endorse "the role of care with compassion" in an organization and aim to promote the rights of patients.

The second role of healthcare organizations is to treat employees with respect.<sup>67</sup> Under this role, Winkler and Gruen incorporate ethical values from clinical, corporate, and political morality. This role allows caregivers to receive better, moral, and fair treatment, which enables these individuals to provide quality care through free expression within the organization. The third role is concerned with "settings limits fairly". According to this role, the healthcare organization is required to anticipate the outcomes of providing healthcare services to the community and evaluate the existing resources to allocate these resources equally. Winkler and Gruen argue that this balance of resources, expenditures, and other clinical and ethical concerns is difficult but necessary to address.

The fourth and final role is to “act in a public spirit”. Winkler and Gruen state that healthcare organizations are a public entity, therefore this entity should act in a publicly motivated spirit through accountability to public accreditation and regulatory laws; in addition, these entities must promote public interest and well-being by providing programs aiming to promote public goodness.<sup>68</sup>

These four roles required of healthcare organization, maintain countless ethical principles that aim to better overall healthcare settings, therefore promoting patients’ rights. These roles constitute the broad framework by which healthcare organizations committed to promoting patients’ rights follow in its inner organizational culture.

Similar to the four roles by Winkler and Gruen, the principles of biomedical ethics, introduced by Beauchamp and Childress, will identify and support patients’ rights in healthcare organizations through the promotion of moral agency, organizational sensitivity, and aptitude for patients’ rights. Principles such as respect for patient autonomy,<sup>69</sup> non-maleficence,<sup>70</sup> beneficence,<sup>71</sup> and justice<sup>72</sup> are deeply rooted in common morality<sup>73</sup>; therefore principlism is a widely accepted moral theory in healthcare settings, aiming to promote understanding and application of patients’ rights in healthcare organizations.

Principlism is effective in addressing ethical inquiries based on clinical experiences; in addition, it provides an ethical framework for inquiries from the organizational realm. Ruth Purtilo in, *Ethical Dimensions in Health Professions*, stresses the “principles” as elements that can be applied in an abstract form or in combination with ethical theories to form moral frameworks to solve ethical inquiries in any setting. The authors state, “... they are called principles, but I also think of them as elements because they do for ethical theory what the basic chemical elements do for chemistry theory...”<sup>74</sup> By applying these principles to healthcare

organizations as an ethical framework that evaluates and enacts internal regulation, the moral agency of these organizations will be enhanced.<sup>75</sup> When the morality of a healthcare organization is strengthened, the improvements will impact areas such as patient safety, confidentiality, medical error reporting, and the evaluation methodology of adverse incidences; these areas are all directly related to the four principles.

A brief introduction of the four principles of biomedical ethics will demonstrate the relationship of these principles to clinical ethics prior to a discussion of the role of principlism in promoting patients' rights and safe practices in healthcare organizations. Principlism is typically involved in the solving of ethical inquiries in clinical settings.

The principle of respect for patient autonomy<sup>76</sup> or self-determination<sup>77</sup> is focused on respect for individual choice based on the person's own reasoning and self-determination. Autonomy in the Greek language means self-rule or self-governance<sup>78</sup>; this has been interpreted as a manifestation of the idea of human dignity and a practical application of freedom. The practical application of autonomy in healthcare settings is based on the belief that every patient deserves respect in mind and body. The decision the patient makes regarding their condition and treatment ought to be respected, regardless what that choice may be. Confidentiality is an important component of the principle of respect for patient autonomy.

The second principle is the principle of non-maleficence<sup>79</sup> which is associated with the idea of "do no harm." This principle represents the core obligation of medical care providers to avoid harm to patients, a fundamental aspect of the doctor-patient relationship. Some refer to this relationship as a sacred covenant.

The third principle of biomedical ethics is called the principle of beneficence.<sup>80</sup> This principle represents the moral obligation of healthcare providers to promote the wellbeing of

patients beyond the minimum standards of care, as embodied by the principle of “non-maleficence.” Practical applications of this principle are quality of care as a concept and quality in providing best evidence-based practices.

The fourth principle of biomedical ethics is the principle of justice.<sup>81</sup> It is concerned with macro-level medical services and the distribution of scarce resources. Though many individual, clinical cases may apply justice in a more abstract manner, the typical applications of justice are devoted to the examination of important, practical issues. The application of this principle to promote organizational ethics and moral agency of healthcare organizations has the potential to positively impact organizational structures on multiple levels.

To promote patient safety and decrease errors in healthcare settings, many organizations use tools to evaluate and prevent these incidents. Examples of these organizational tools include risk assessment tools, quadruple-loop learning,<sup>82</sup> root cause analysis, RCA studies,<sup>83</sup> incident monitoring, and error reporting systems. These tools are all developed in correlation with quality assurance departments that are committed to patient wellbeing. Therefore, these quality-based tools are also deeply rooted in the theory of principlism because the values of principlism are moral guidelines that support patients' rights in clinical settings.

The principle of autonomy supports patient safety by emphasizing respect for the patient's body and mind. This means protecting, preserving, and promoting the soundness these patient factors to the greatest degree possible because patient autonomy depends on physical abilities and mental faculties. It is common for healthcare workers to become desensitized in healthcare settings after working there for some time. While this is a reasonable coping mechanism for healthcare workers who witness suffering and mortality, it comes with risks. This desensitizing process can manifest as insensitivity towards patients' needs and feelings. A

healthcare provider may begin to regard patients as “merely patients” or as human bodies, rather than viewing them as human beings with distinctive emotions, feelings, and expectations.

The principle of non-maleficence means to avoid intentional or unintentional harm. Healthcare regulations need to be established, interpreted, and enforced in a manner that correlates with this principle. Additionally, the principle of non-maleficence holds healthcare workers liable for their actions or medical errors. This means that if a health care worker is negligent, the person is morally responsible for the harm inflicted upon the patient even if there are no legal consequences. By promoting moral agency regarding the principle of non-maleficence, healthcare workers will understand and act upon the importance of avoiding harm to patients and due to the internal moral guidance that is founded upon the organization. For example, if an attending physician feels personally responsible for the safety of his patient based on the principle of non-maleficence, he may practice extra precautions to ensure that the correct drug is administered appropriately to the patient, rather than merely ordering the nurse to administer the medication based on hastily prescribed dosages and directions.

While the principle of non-maleficence protects patients' safety by setting standards of care and creating safe working environments in healthcare organizations, the principle of beneficence ensures patient safety and rights; this is done through the establishment of quality safety measurements beyond standard protection. By practicing the moral requirements of beneficence, healthcare organizations must seek out best practices to ensure that patients are safe and protected against medical errors in addition to the initiation of organization-wide, quality-driven safety practices. For example, the engineering of human factors is a science devoted to anticipating human error prior to its occurrence. This is a quality-based practice aiming to promote patient safety and rights.

Healthcare organizations must also commit to the principle of justice. Due to organizations being made up of individuals and the parallel nature of organizational morality to individual morality, each individual in the organization must be capable and committed to the empathetic nature of healthcare service delivery; this practice is in accordance with the principle of justice and the ethical principles in principlism. To achieve such high ethical standards, an organization must employ staff members with the moral responsibility to prioritize patients' rights, including cases that require the self-reporting of errors.

The promotion of healthcare moral agency beyond the legal and accreditation requirements is important to facilitate practices focused on patients' rights beyond the anticipated outcomes. For example, Almasabi and Thomas' accusations of CBAHI being ineffective in producing tangible, quality outcomes represents how accreditation agencies may bypass aspects of relevant principles; these principles may be enforced through the enhancement of the organization's moral agency to develop healthcare that identifies, corrects, and betters its basic moral and outcomes with or without the influence of accrediting agencies.

The promotion of patients' rights and avoidance of medical errors in healthcare facilities is not merely an ideal or regulation, but an achievable goal. By embracing the four roles of healthcare organization as mentioned by Winkler and Gruen as well as incorporating the principles of biomedical ethics, both individual, clinical ethics and healthcare organizations will offer the best, quality-based practices. This goal is achievable due to the organization's adoption of the foundational concept of principlism to its culture as a moral theory and practice; the practice will foster moral agency of healthcare organizations based on moral virtues extending beyond standard practices.



While government regulations and non-governmental accreditation standards have contributed to ensuring patient safety and quality of care, it is crucial to encompass systemic practices of principlism into organizational culture to achieve the highest levels of quality of care and enhance patient rights internally. In addition, this culture shift will foresee, prevent or reduce the risk of medical errors, therefore minimizing harmful effects.

Principlism incorporates four major principles of biomedical ethics that are crucial to developing moral agency within each individual healthcare professional; therefore these principles are equally necessary to promote organizational moral agency as an aspect of the healthcare facility. These principles include respect for patient autonomy, non-maleficence, beneficence, and justice. Each of the four principles provides moral guidance for healthcare workers to best uphold their duties. These principles contribute to patient safety in varying manners, but correlate in formulating a potent and applicable ethical framework to guide healthcare organizations through corporate cultural shifts from shame and blame to a culture of safety. All parties involved will benefit from this shift due to improved outcomes that positively impact the provider organization, the families of consumers, and ultimately the society at large. These outcomes will reduce the occurrence of medical errors and costs but will enhance medical safety; this will contribute to greater patient safety, improved quality of medical care, and enhancement of patients' rights in medical settings.

In next section, obstacles to proper healthcare practices related to patients' rights in Saudi Arabia due to organizational factors will be discussed.

### **5.3 Organizational Obstacles in Saudi Healthcare that Affect Patients' Rights**

Determining the susceptibility of the health care organization is an essential component

of the evaluation of patients' rights to detect risks, prevent medical mistakes, and to improve the overall quality and outcomes of the operation. Consequently, data collection and information management are crucial tools to effectively manage healthcare organizations; Philip Boyle et al., (2001) writes, "Information gathering is at the center of organizational ethics."<sup>84</sup>

The failure to anticipate incidences of iatrogenic harm<sup>85</sup> or to develop an effective system to address the barriers to the delivery of appropriate patient care is regarded as an organizational failure; failure at the organizational level will adversely affect patients' rights, health, and safety. Therefore, the management of healthcare organizations plays a crucial role in determining the incentives of patients' rights and constitutes health care outcomes. Clear and well-established organizational regulations will allow improved ethical practices among health care workers in the establishment. In other words, improved organizational ethics leads to improved personal ethics among health care providers, which eventually improves clinical ethics.<sup>86</sup>

However, organizational ethics in health care is tightly related to the innate religious teachings or philosophical obligations that constitute the ethics of the society.<sup>87</sup> This means that the health care organization ethics and the inner culture inside the organization are an extension to the dominant cultural of the community, and are conspicuously influenced by its customs. For instance, health care organizations in Saudi Arabia are influenced by the Arabic and Islamic refinements and in order to provide ethics oriented services to Saudis, health care organizations must prove adjacent to the dominant norms followed in the community.

Consequently, organizational ethics manifested by institutionalized policies and practices influence individuals manners and constitute their conducts in medical settings as well, Robert Hall (2000) states, "Organizations generally have a code of conduct, often called codes of ethics,

for their employees. These are guidelines for expected behavior that are more like rules and regulations prohibiting specific behaviors.”<sup>88</sup>

The introduction will infer on the influence of the societal culture on health care organization ethics; the culture of health care organizations impact individual ethics. Inferring on these relations give a conclusion which state that glitches to proper conducts of patients’ rights in health care organizations are byproducts of several factors and not merely induced by single agent or solitary event.

In Saudi health care systems, impediments to proper patients’ rights practices are not a derivative of single failure of clinical ethics judgments caused by solo individuals, but indeed the health care organization and the overall dominant culture and customs contribute to such drawbacks with variant degrees of involvements.

However, in this section, health care organizations in Saudi Arabia are under focus to point out several issues induced by the health care organization and effect clinical ethics and patients as terminal recipients of clinical ethics outcomes.

Therefore, every health care organization has limitations and shortfalls that need to be addressed in order to deliver effective and cohesive services to their patients and customers. Similarly, health care organizations in Saudi Arabia have limitations that need to be addressed to enhance the functionality of the health care organizational, thereby promoting the health status of the community.

In regards to the overall health care system in Saudi Arabia, Kwong and Levitt (2009) note that the organizational structure and operational functionality of the Saudi health care system is feeble compared to its Western counterparts.<sup>89</sup> Kwong and Levitt assign this weakness to the dominating environment, lax nature of related laws, and the vagueness and fluctuations in

adapting and enforcing health care ethical regulations of the health care organization.<sup>90</sup>

Indeed, such contributing factors originating from the overall Saudi health system, would directly affect the health care organization operating within such system. As discussed earlier, dominated surroundings, and practiced customs of the society would affect health care organization which eventually effect clinical ethics. Therefore, not all impediments to patients' rights in Saudi health care organizations are initiated on health care organizations level, as the proximate socio-political milieus unswervingly affect health care polices. For example, Eiman Alsafi et al. (2011) write, "Al-Iman General Hospital has not, so far, developed clear policies for error disclosure as is the case with most Ministry of Health Hospitals in Saudi Arabia." This statement shows that the absence of an effective mechanism to deal with error disclosure is inherent to the Ministry of Health hospitals, and not only effect a single health care organization operates within; and such practices result in failure to develop national methods to protect patients' rights through reducing medical errors.<sup>91</sup>

This section will focus primary on barriers of patients' rights as a result of health care organizations, and not on culturally induced impediments as discussed in the previous chapter.

It is worth mentioning that the availability of literature inferring on Saudi health care systems is generally limited; as a result, literature related to the barriers to patients' rights in Saudi Arabia due to the organizational impact are scarce.<sup>92</sup> Alkabba et al, (2012) writes, "However the ethical issues that conferment the Saudi health care system and public were not adequately studied, nor was there any attempt to collate and prioritize them."<sup>93</sup> This also shared by Sa'ad Alghanim (2011),<sup>94</sup> and by Omar AlSharqi and Mohammed Abdullah (2013).<sup>95</sup>

To begin discussing Saudi health care organization ethics, an example is given by Alkrajji, Jackson, and Murray (2016)<sup>96</sup> who identify organizational factors stirring in the Saudi

Arabian health care systems that reduce the ability of the Saudi health care system to adopt unified medical data standards which is regarded as component of proper patients right practices. As unified national data standardization would enable for unified data entry, storage, easy retrieval, and insure that all health care systems would follow similar qualitative data processing measurements. This study demonstrates the barriers to appropriate health care services as resulted from the organizational structure. Whether these barriers occur within the health care organization or impact the entire health care system, patients' rights will be affected as they are influenced by the managerial decisions and operational culture of the organization. Alkrajji et al. lists the variations in the quality of healthcare services as embedment to proper quality of care; as well authors mention some managerial challenges which negatively impact organizations outcomes,<sup>97</sup> these are multicultural environments, high turnover rates among health care personnel,<sup>98</sup> a dominant culture of resistance to change,<sup>99</sup> an absence of national plan and accreditation bodies, and lack of effective means to effectively enforce regulations.<sup>100</sup>

In addition, AlMutairi and Rondney (2013) stress lack of cultural competence<sup>101</sup> as organizational provoked barrier to the proper delivery of healthcare services. The authors report that the cultural difference between healthcare providers and patients is considered a logistical hurdle to patients' rights and is considered a prominent issue in Saudi healthcare systems. This will affect the established dialogue between health care providers, patients, and families in addition to other cultural competence issues.

Cultural incompetency occur when language barriers and cultural differences impact the relationship between healthcare providers and patients, as incentives of patients' rights and the overall performance of healthcare professionals in the organization will be tremendously affected by such disparities. In a study by Adel Almutairi (2012), the inadequate handling of patients'

affairs and patient endangerment in Saudi healthcare systems is related to the organizational failure to handle problems arising from cultural diversity within the organization.<sup>102</sup>

Also, in a study by Elgilany, Elwehady, and Amr (2010) regarding the violence committed against healthcare providers in a region of Saudi Arabia, the authors report that habitual victims of violence within the targeted healthcare organization are non-Saudi nationalities.<sup>103</sup> The authors also note that the absence of organizational policies to handle such events aggravates the problem.<sup>104</sup> This signifies the failure of the healthcare organization in Saudi healthcare system to provide effective structure to prevent undesirable experiences for patients and healthcare providers. In addition it shows the failure of the organization to implement regulations to prevent similar barriers.

Finally, Alkabba et al. (2012) reveal ten organizationally based ethical issues faced by the Saudi healthcare system:

The major 10 ethical issues, as perceived by the participants in order of their importance, were: (1) Patients' Rights, (2) Equity of resources, (3) Confidentiality of the patients, (4) Patient Safety, (5) Conflict of Interests, (6) Ethics of privatization, (7) Informed Consent, (8) Dealing with the opposite sex, (9) Beginning and end of life, and (10) Healthcare team ethics.<sup>105</sup>

Additional failures of the healthcare organization include understaffing of clinical departments and surgical units,<sup>106</sup> long working hours, and extended on-call hours, all of which impact and contribute to problems in Saudi healthcare systems.

However, barriers caused by the healthcare organizations that adversely affect the theories<sup>107</sup> and practice of patients' rights in Saudi healthcare can be also considered as hurdles to implement universal bioethics standards in Saudi hospitals. These organizational induced problems are summed up and categorized under three main themes: managerial and logistics issues, healthcare professionals induced problems, and regulations, policies and accreditation

contributions. These groupings distinguish these three concepts. Each of these categories will be elaborated upon separately to better allow improved understanding of the topic. These categories have an inseparable and interconnected relationship on numerous levels, as they heavily impact each other.

For example, the entire healthcare organization, including management and stakeholders such as doctors and nurses, must collaborate with each other to implement appropriate regulatory policies and comply with internal and external ethical standards to deliver best services for patients. Daniel Fox writes, “For instance, regulators could collaborate with associations of medical specialists to devise and routinely update criteria for evaluating evidence in medical records in the context of the best available scientific evidence about the effectiveness of alternative interventions.”<sup>108</sup>

The categorized concerns of healthcare organization in the Saudi healthcare systems will be discussed. This discussion will begin with managerial and logistical issues, followed by the role of healthcare professionals. Then the current reality of regulations and accreditations in the Saudi healthcare systems will be discussed, in addition to the role of regulations in promoting practices concerning patients’ rights.

### **5.3.1 Managerial and Logistics Issues**

In reference to organizational ethics, Spencer et al. (2000) write, “In its simplest terms, organization ethics is the articulation, application, and evaluation of the consistent values and moral positions of an organization by which it is defined, both internally and externally.”<sup>109</sup> This definition of organization ethics is not simple or an easy subject to understand; the complexity of current healthcare organizations make the structure and function more than primitive or

minimalistic. As Runciman et al. states, healthcare systems are similar to technological and hazardous, complex systems.<sup>110</sup> There are many barriers to best patient care in the Saudi healthcare organization. Among these barriers are managerial issues that require thorough examination and due reformatations.

Obstacles to proper adoption of patients' rights within the organization due to failures of the management are multiple and complex. Many of the organizational pitfalls and neglect for patients' rights can be related to the failure of the management to deliver appropriate practices.

Logistical services related to healthcare contribute to the negligence of certain patients' rights within the healthcare organization. These logistical issues include limited financial resources, lack of unified national policies concerning healthcare ethics, understated operational regulations, absence of interrelation between various providers, and the centralized healthcare system of Saudi Arabia all contribute to the implementation of patients' rights, directly impacting its related outcomes.

Logistical issues in the healthcare sector have externally causative factors including social, economic, and political drawbacks. The focus of this section is to examine the structural components of the healthcare organization.

As various healthcare providers have different standards for quality adeptness; therefore, there are vast variations in the services provided to the targeted populations. The massive and fragmented nature of healthcare services within Saudi healthcare systems present a challenge when implementing positive changes, and when promoting related plans. This would result in decreasing affinity to adopt better patients' rights practices within the Saudi Arabian healthcare system.



In regards to barriers to patients' rights caused by management, a study published in the *Journal of Medical Ethics* in 1999 by Khalid bin Saeed concludes that physicians who assign managerial positions fail to distinguish seven of the eight ethical problems occurring within the organizations.<sup>111</sup> Among these ethical issues are the following: providing favorable treatment to patients based on social pressures, disclosing medical information, discontinuing treatment, and issuing false reports. bin Saeed mentions that despite the failure of the executive physicians to identify similar ethics issues, other clinicians are better able to identify these issues as being unethical. The author relates the inconsistency between clinicians and executives to the relative impartiality of clinicians that are not assigned managerial and community-focused obligations; in comparison, executives are obligated to balance managerial duties in addition to clinical ethics, or utilitarian versus deontological obligations.<sup>112</sup>

Indeed, such failures to identify ethical problems by managers are crucial to understand why healthcare organizations fail to promote incentives of good patients' rights practices. That because when managers of hospitals who plan, guide, and execute quality programs fail to appreciate ethical challenges, then the organization at lower levels would clearly fail to observe ethics of care.

In reference to the vague ethical standards and job description policies in specific hospitals in Saudi Arabia, Mohammed Mahrous (2013) writes, "The group discussed the need for an approved, efficient organizational chart and job description manuals that organize and define every single job and process clearly."<sup>113</sup>

Bin Saeed relates this to the multinational variation of healthcare personnel who lack common perceptions related to ethical issues; "While the Kingdom of Saudi Arabia employs a significant number of foreign physicians of various nationalities, there is no specific code of

ethics for doctors working in its vast healthcare sector.”<sup>114</sup> This point is stressed by Almutairi (2012), who relates ethical problems that arise from multinational, diverse interactions with patients to the inability of organizations to enforce regulatory policies that protect patients’ rights practices.<sup>115</sup> The human factors that undermine the delivery of proper patients’ rights will be discussed in the next section.

Bin Saeed suggests that a unified set of codes of ethics be sanctioned to minimize the variations in approach to various ethical issues within Saudi healthcare systems. This is also recommended by Omar Alsharqi and Mohammed Abdullah (2013), who claim that standardizing healthcare in Saudi healthcare systems is fundamental to promoting patients’ rights.<sup>116</sup>

Bin Saeed’s study is relevant to another study by Alkabba et al. (2012), who identify ten obstacles to proper implementation of ethical work in Saudi healthcare systems. These ten ethical problems include patients’ rights, confidentiality of information, issues of equity, patients’ safety, and healthcare team ethics, which correlates with bin Saeed’s findings. For example, the failure of executive managers to formulate and enforce regulations that deal with routine ethical issues such as information disclosure, equal treatment of patients, and unethical favors due to social pressures, all are considered barriers to appropriate implementation of patients’ rights.

In other words, the inability of the management to detect ethical problems leads to organizational failure to deliver optimal and quality services. This failure is manifested through the lack of regulatory policies and an increase in ethical concerns within the organization.

One of major contributors to medical errors is the failure of management to anticipate the occurrence of errors and produce preventive measurements. When managers of healthcare organizations use inefficient tools to collect and analyze incoming data, this results in increased medical errors and a lack of a culture of safety. As mentioned by Alkabba et al., a common

ethical issue in Saudi healthcare systems is concerned with patients' safety; according to the author, the problem in Saudi healthcare is the lack of managerial awareness these unethical practices related to patients' safety.<sup>117</sup> In deed awareness of these ethical issues casts a shadow on workers within the organization, as the culture of negligence involves numerous aspects of healthcare organizational operations.

In relation to Karen Pellegrin and Hal Currey's (2011) claim that interpersonal communication within the organization is crucial to best practice,<sup>118</sup> Wahabi and Alziedan (2012) find that the lack of endorsements and understated protocols of asthma treatment in Saudi hospitals leads to the lack of awareness of the existence of such protocols;<sup>119</sup> this can cause grave complications including frequent medical error.

In a study carried by Yahiya Alkhalidi (2013) that involves 228 physicians working in primary care centers, the researcher finds that only 52 percent of the physicians could accurately define medical error; therefore, the researcher suggests that doctors and healthcare providers be enrolled in trainings that enhance their ability to identify and handle errors in medical settings.<sup>120</sup>

Though every healthcare organization is prone to error, the Institute of Medicine presents a solution. An effective way to handle and prevent future incidences is to develop and adopt mechanisms to address errors occurring in the organization and to promote culture of safety. According to Gerard Magill (2006) the IOM lists four recommendations for health care organizations to follow to best promote a culture of safety: to start leadership training, recognize human natural ability, enhance teamwork, and develop self-correction methodology through observation.<sup>121</sup>

In contrast, Alsafi et al. (2011) reports that it is more common for healthcare professionals to fail to report errors within Saudi healthcare systems. Alsafi et al. attributes this

finding to the absence of clear policies and effective regulations to report errors in Saudi hospitals. Evidently, the management of healthcare organizations is responsible for the implementation of appropriate regulations to ensure that errors are reported in order to avoid future error incidents.

### **5.3.2 Healthcare Professionals Contributions to the Problem**

According to Haya Alfozan (2013) 70 percent of nurses working in Saudi Arabian hospitals are expatriates<sup>122</sup>. In another survey, the researcher found that a wide range of multinational health care workers emerge from twenty-five countries that provide nursing services to Saudi patients.<sup>123</sup> Sidumo, Ehlers, and Hattingh (2010) identify fifty non-Muslim expatriates working in Saudi hospitals that lack knowledge of the Saudi or Muslim culture in a manner that directly affects interactions with patients. In most recent census produced by the Ministry of Health,<sup>124</sup> the numbers of expatriate healthcare workers in Saudi healthcare system are reflected in the following figures. The total number of physicians working in Saudi hospitals is 86,756 and only 26 percent of these physicians are Saudi nationals. The total number of nursing staff is 172,483 with only 38.3 percent being Saudis and Saudi pharmacists only make up 21 percent of the total 23,624 working pharmacists.

The statistics show a shortage in working Saudi nationals in medical field. The presence of such significant cultural diversity within the workforce leads to tangible consequences related to the quality of services to the patient population, enforcement of ethical care, and social and economic implications.

In addition, the imbalance in numbers of citizen and foreign, or temporary, healthcare providers impacts the planning and management of the healthcare sector in Saudi Arabia.

In contrast, the large numbers of foreign nationals providing medical services to the Saudi population allows the healthcare organizations to meet the growing demands of obtaining healthcare services.<sup>125</sup> Currently, the graduation rates of Saudi national, medical professionals are inconsistent with the increasing demands for skilled healthcare workers. In addition, the majorities of expatriate workers in the medical field are highly skilled and trained, which makes substitution plans with national workers challenging.

Alfozan categorizes problems that arise from dependence on large numbers of non-Saudi healthcare forces to three main points. Alfozan proclaims that such dependency produces issues such as language and communication barriers, provision of culturally insensitive services, and lack of sustainable nursing forces and its future implications on health care ventures.

In a study about the medical expertise working in Saudi Arabia by Sammy Showail, Judi Parks and Faye Smith (2013), the authors relate the challenges in Saudi healthcare settings to cultural shock, language barrier difficulties, and the extent of adjustable, professional interactions with local populations.<sup>126</sup>

In addition to the concerns of large numbers of expatriate workers as care providers in Saudi Arabia, other multidimensional concerns that impact social, political, and cultural parameters can occur accordingly. The study discusses the concerns related to ethical care from expatriate workers and corresponds to patients' rights within the health care organization.

Language barriers impact the ability to effectively communicate with patients in clinical settings, which can lead to healthcare provider and patient frustration; this is especially the case in homogenous communities such as Saudi communities that have individual languages with adjacent cultures and customs.<sup>127</sup>

Medical personnel with Arab backgrounds can effectively communicate and interact with

Saudi patients. On the other hand, foreign healthcare personnel that do not communicate in Arabic can face various scenarios; for example, patients can communicate in the native language of the healthcare provider or they can communicate through a translator. In the absence of these options, the interaction between the healthcare provider and patient can potentially be negatively impacted as a consequence of limited dialectal interactions.

This minimal or severed form of communication between healthcare providers and patients leads to many drawbacks and catastrophic incidences will occur. For example, language barriers can lead to miscommunication when providing instructions of how and when to take medications or result in a medical misdiagnosis.

Language barriers can lead to the neglect of patients' rights in medical settings and expose patients to unpleasant situations or vulnerable to medical errors. Many ethical issues occur due to circumstances such as these, as patients' rights and ethical care require an optimal provider-patient relationship to prevent ethical pitfalls.

For example, conversations in clinical settings and the process of informing patients of their rights require effective delivery of information to patients. Zahra Mataneh and Lotfollah Mouseli (2013) write, "Health care organizations are to deliver PRC to patients and make sure they have proper information about their rights. Assuring observance of patients' rights requires not only informing healthcare policy makers and providers, but also educating citizens about what they must expect from their governments and health care providers".<sup>128</sup>

This delicate task cannot be achieved by a limited ability to communicate; in a study concerning health education by Alkhashan et al. (2012) states, "The most frequently mentioned barriers and obstacles that study participants face with regard to health education, were the use of medical and technical terms, the little time the provider had to answer questions, and the problem

of a different language.” This is supported by Samar Altamimi et al. (2016), who identifies language barriers and cultural differences as a major impediment in the delivery of effective patient education in healthcare settings.<sup>129</sup>

In these studies, language barriers are considered obstacles to patients’ rights as it is the patients’ right to obtain information related to their condition. Alkhashan et al. mentions that there is limited time for healthcare workers to answer educator’s questions, who use medical terminology to explain medical conditions to patients. Such results are due to the limitation of communication skills from language barriers. For instance, if healthcare providers are limited in their ability to communicate in Arabic, then the provider will leave no time for further discussions or be obligated to use medical terminology with the patient which is difficult to comprehend by common people.

An example of the importance of language proficiency in medical settings is described by Ali Albishi (2004), who writes about his experience with a non-Arabic doctor in a Saudi hospital. Limited Arabic communication skills resulted in the disclosure of inaccurate information to the patients’ caregiver. However, when the caregiver managed to communicate to the same doctor in English, he revealed different and sufficient information regarding the patients’ medical status.<sup>130</sup> This situation is brought up during ethical inquiries regarding the ethics of care. It also represents how language barriers affect patients’ rights in medical settings and the experiences of patients and caregivers. Such practices contradict with patient-centered care, as coined by Edith Balint (1969), which provides social, psychological and physical considerations when treating and caring for patients.<sup>131</sup>

To address such organizationally-produced problems, in a study concerning language barriers in Saudi healthcare systems Khalid Almutairi (2015) concludes,

The available information provided by this review study shows that there is a communication barrier between patients and health care workers such as healthcare workers demonstrate low cultural competency. Despite the fact that the government provides programs for expatriate healthcare workers, there is a need to further improve educational and orientation programs regarding the culture and language in Saudi Arabia.<sup>132</sup>

In addition to barriers in communication, highly diverse staff in a health care system can lead to distinctive and multiple ethnic, cultural, social, and ethical perspectives that may influence preferences, behaviors, daily routines, and ethical decisions within the healthcare organization. In reference to the importation of Western technology in medicine, Adel Almutairi and Patricia Rondney (2013) mention that this results in the importation of Western views concerning healthcare implementation.<sup>133</sup>

It is crucial to provide culturally sensitive services to patients; Michelle Mclean and Roos Bernsen (2012) argue that when healthcare providers fail to provide services that are compatible with the patients' culture and religion, then the health care provider risks and compromises the patients' health status and outcomes.<sup>134</sup> This is mentioned by Khalid Almutairi (2015), who writes that cultural misunderstanding between patients and healthcare providers will result in dissatisfaction of providing services and result in a decrease in quality of care.<sup>135</sup> In studies concerning cultural diversity and its role in quality of healthcare, Almutairi mentions that much of the nursing staff lack the knowledge to effectively provide patients care.<sup>136</sup> Almutairi lists issues that are a result of cultural insensitivity from the nurses such as a lack of awareness for religious specifications such as dietary restrictions and certain rituals such as prayers and fasting.<sup>137</sup>

When discussing the issue of cultural diversity in Saudi healthcare, Adel AlMutairi and Patricia Rondney (2013) write,



While we see cultural diversity as a precious resource, culturally diverse encounters can have significant and profound consequences for providers, patients, and their families. Indeed, the consequences can jeopardize peace and health. Cultural diversity can produce a highly charged context for addressing human needs due to the different cultural norms, beliefs, and practices that cause conflicts and tension and that also provide a platform for discrimination and racism.<sup>138</sup>

This section lists language barriers and cultural incompetency as barriers to patients' rights caused by health care professions; this does not implicate that these are the only obstacles to patients' rights. There other examples of how healthcare providers contribute improper implementation of patients' rights and safety. For instance, incomplete documentation of medical data is a problem the Saudi healthcare sector faces which endangers patients' safety and wellbeing. In a randomized study concerning the quality of data documentation in primary healthcare centers, Amal Alghamdi et al. (2014) demonstrates that medical personnel are responsible for the gross negligence of documenting medical data into official patient files. Alghamdi et al. write, "The reviewed medical records enclosed within the family files used in the primary health care centers are lacking essential data about the patients and the health care providers, in addition, in most instances, are not meeting the standards and criteria for adequate quality of recording."<sup>139</sup>

The problems created by healthcare personnel are multiple and closely related to other components of healthcare organizations. The example of deficient documentation is as a result from personal factors such as lack of interest and sluggishness during daily tasks in clinical settings. This also occurs due to the failure of the healthcare organization management to adopt and enforce standards that promote appropriate processing of data documentation. Ali Abishi (2004) refers to nurses who do not feel personal urgency to adopt better data documentations, as they relate to the lack of obligation and enforcement mechanism called, "Lack of Legal Accountability".<sup>140</sup>

To avoid ethical issues, cultural conflicts between patients and healthcare workers, and to deliver quality services, all employees must be educated about cultural competency and learn the value of culture in shaping health care outcomes within the healthcare organization.

To fulfill the managerial obligations to the employees of the healthcare organization, the management should increase awareness of, adopt, and apply cohesive guidelines and ethical policies that reflect the culture and customs of Saudi Arabia.

Any idea that conflicts with the habitual beliefs and convictions of the people will be disregarded, especially in conservative, Saudi Arabian communities. Regulations and policies that provide executive enforcement of ideal and accepted standards crucial to healthcare ventures.

In the next section, specific regulations, policies and accreditations will be discussed in comparison to the healthcare regulations practiced in the United States. This will demonstrate how policies and regulations constitute healthcare organizations; this will help eliminate the pitfalls occurring in Saudi medical settings, as lack of proper enforcement is regarded as an organizational impediment to patients' rights.

### **5.3.3 Regulations, Policies, and Accreditations**

According to Runciman et al. (2007) relying on healthcare organizations or individuals to regulate themselves is at best unpredictable.<sup>141</sup> As any socially-based activity, healthcare venture is in need for regulations, policies, and rules that constitute the relationships between stakeholders of the organization. For example, medical professionals require parameters through official and qualification agencies to regulate their work and the integrity of medical professions. Medical professionals, namely physicians, are morally obligated by a code of conduct and professional principles to adhere to ethical standards and provide best services to their patients.

Medical organizations require regulations in order to organize internal and external operations to best promote a culture of safety and increase the quality of the organization. If internal or external regulations are not followed due to the absence of regulations, the negligence of healthcare personnel to adhere to regulations, or the vagueness of existing policies, this will lead to jeopardized patients' rights and safety.

Standardized regulations must be applied to healthcare organizations and formally enforced to be effective and adoptable. In relation to this statement, Paul Schyve (1996) writes,

The organization could rely on the personal ethics of each practitioner in health care system to withstand all temptation and to do the right thing. This, however, does not account for the fact that some individuals do not live by high ethical principles, that most of us have occasional ethical lapses, and that knowing the right thing can be difficult when ethical principles conflict.<sup>142</sup>

Given that patients' rights and safety are moral obligations for the community, regulations that guarantee these rights are morally and legally binding in healthcare settings. Consequently, public and private agencies in addition to national and international organizations have established regulatory policies for healthcare facilities.

Government regulations and laws play a crucial role in preventing medical errors, promoting patients' rights, and increasing the quality of medical services provided to public. It is difficult to control a highly complex industry like the healthcare industry, especially when the organizations of the industry embrace a capital-driven culture and favor market-based activities. An ethical basis within an organization, manifested by policies and laws, can balance the rights of healthcare organizations and patients. Therefore, laws can substitute for organizational ethics to provide a safe environment for patients. The enforcement of laws that prosecute individuals or entire healthcare organizations that compromise the rights of patients will improve overall healthcare services, therefore setting an example for other healthcare workers.<sup>143</sup>

In the United States as in many countries, civil and criminal codes are used to discipline organizations and practitioners that commit medical errors due to ignorance of safety measurements or reckless deeds.<sup>144</sup> For example, a judge can verbally reprimand those who commit medical errors that jeopardize patients' health and rights. A court might require the culpable parties to monetarily compensate the victims monetarily, and criminal penal codes are used to prosecute gross acts of medical negligence and intentionally harmful acts.<sup>145</sup>

Nonetheless, many religious and philosophical perceptions that influence biomedical ethics believe that patients' rights in health care settings are moral obligations that the community must grant to all citizens. To fulfill such moral obligations and civic duties in the United States, public and private agencies establish codes that set standards for healthcare facilities and organize the healthcare sector.<sup>146</sup>

Governmental agencies formulate guidelines that regulate healthcare services and public safety; these standards are imposed by committees and enforced by the law. Such regulations are mandatory<sup>147</sup> and it is the responsibility of the healthcare organization to ensure these regulations are standardized and adopted in various departments.<sup>148</sup> Noncompliance, especially when it impacts patient safety, can subject an organization to legal action. To prevent medical errors that result from inadequate medical training, the Accreditation Council for Graduate Medical Education (ACGME) has the authority to eliminate any medical graduate program in healthcare organizations that do not adhere to ACGME regulatory requirements.<sup>149</sup>

The *Joint Commission for Accreditation of Healthcare Organizations (JCAHO)*<sup>150</sup> protocol, the *Universal Protocol to Prevent Wrong Side and Wrong Patient Surgery*,<sup>151</sup> is another example of government-specific guidelines aimed to promote patient safety and the prevention of medical errors. This protocol standardizes regulations that prevent medical errors

that can occur in the operation room. In 2006, the Joint Commission mandated the adoption of coded regulations in the healthcare settings that aim to prevent medical errors by improving standards of communication within the healthcare organization. These regulations are known as, *Joint Commission National Patient Safety Goal*.<sup>152</sup> Though they are highly recommended, regulatory bodies and governmental agencies do not enforce some of the regulations; these organizations leave the task of regulation enforcement to the healthcare organizations.

Another example is of governmental guidelines is *The Healthcare Insurance Portability and Accountability Act (HIPAA)*.<sup>153</sup> These guidelines have developed measures to uphold patient safety and privacy by protecting medical information and unifying the international disease code used in correspondence with other healthcare organizations, decreasing the chance of medical error and misinterpreting clinical data.

An example of a private regulatory organization is Leapfrog,<sup>154</sup> which mandates certain standards be followed to allow companies associated with Leapfrog to send their employees to healthcare organizations.

Another way to promote patients' rights in health care settings is the accreditation by specialized agencies concerned with the promotion of healthcare services; the accreditation requirements aim to enhance the quality of patient safety practices by encouraging the application of measurements derived from evidence-based medicine.<sup>155</sup>

An example of the role of accreditation in the promotion of patient rights is the Joint Commission<sup>156</sup> *Code of Organizational Ethics*, which promotes ethical practices within healthcare organizations.<sup>157</sup> The Joint Commission is an accreditation agency known to promote policies of patient safety; this agency encourages healthcare organizations to embrace ethical values as a basis for standard, patient safety practices. By encouraging healthcare organizations

to adopt ethical practices as a standard practice, the Joint Commission has determined principles of quality healthcare services far beyond minimal governmental standards.

Patients' rights can be promoted through non-legally binding affiliations such as prestigious medical centers including the Mayo Clinic and the Harvard Medical Center. Medical and social journals provide information related to issues concerning healthcare venture, bringing attention to matters of patients' rights and safety, and therefore producing indirect pressure on healthcare organizations to adopt better standards and practices. For example, the *New England Journal of Medicine* has issued studies related to medical errors and then analyzes the problems and suggests solutions.<sup>158</sup>

The markets competition and the influence of other healthcare facilities pressure healthcare organizations, especially those for profit, to provide excellent healthcare services. It also motivates various health care organizations to adopt and apply improved patients' rights practices, relevant guidelines, and quality assurance codes.

Despite efforts to protect patients' rights and promote safety in medical settings, medical violations continue that occur worldwide, especially in developing countries that lack regulatory laws or relevant agencies. Nevertheless, regulations and accreditation initiatives to promote patients' rights are being established in developing countries, including Saudi Arabia.<sup>159</sup> Due to underdevelopment of unified regulations that constitute the internal operation and ethics in the health care organization and because Saudi healthcare providers follow several state departments, numerous policies are followed in hospitals and medical centers. Alkabba (2012) writes,

The only known national document is the '*Manual Guide for Medical Practitioners*' issued to provide guidance to practitioners in Saudi Arabia. This clearly states the right of patients to: the access of 'good' treatment; give consent for any medical intervention; confidentiality of his / her medical information; and the right to refuse treatment against

medical advice. Since it is only a document that ‘guides’, the onus has been on the main hospitals to develop their Patients' Bill of Rights. Unfortunately, this is still in the process of being formulated, finalized, and endorsed.<sup>160</sup>

Al-Sharqi & Abdullah (2013) asserts that the Saudi healthcare system lacks a standardization of quality care due to the health care organizations inconsistent capabilities, making accreditation and the enforcement of quality standards difficult. Therefore, hospitals of Ministry of Health have distinctly different procedural policies when compared to the Armed Forces and National Guard hospitals.

Albishi (2004) proclaims that there are no unified set of ethical codes related to patients’ rights in Saudi hospitals. In fact, each hospital has its own regulations and policies to deal with issues of patients’ rights.<sup>161</sup>

Even in presence of isolated codes of ethics in different hospitals, the lack of standardized codes and other measures of quality assurance will jeopardize patients’ rights. According to Albishi (2004), the lack of standardized codes of patients’ rights results in the neglect of these ethical measures in hospitals as demonstrated by poor patient experiences, especially in rural areas.<sup>162</sup>

As mentioned previously, CBAHI or the Saudi Board for Accreditation of Healthcare Institutions has instituted standard policies to be followed in all hospitals under the Ministry of Health in Saudi Arabia. Though not every Saudi healthcare system is included under its accreditation power, such a process will lead to improved practices of patients’ rights due to unified standards of care.

The final section will discuss how to enhance the ethical practices of a healthcare organization through improvements in cultural competency.

## **5.4 Enhancing Ethics of Healthcare Organizations and Cultural Competency**

The obstacles to proper patients' rights practices and the underdevelopment of unified, nationalized standards have been identified to enable the Saudi healthcare system to adopt better patients' right practices. Issues faced by Saudi healthcare organizations will be addressed to better enable Saudi healthcare systems to provide up-to-date healthcare services and correlate with international ethics standards.

Mohammed Mahrous (2013) writes in relation to hospital affiliations with international standards in Saudi health care systems, "International standards and guidelines should be consulted when establishing new health facilities to assure that they comply with modern standards and satisfy the needs of the community."<sup>163</sup> Though this statement addresses issues of new health establishments, each hospital needs to update policies and procedures manuals to ensure best practices and outcomes. To ensure the best available model for health care organizations to follow, the standardization of policies must involve the adoption of international standards.

To enhance the ethics in healthcare organizations and adopt better practices of patients' rights in Saudi Arabia, several points must be discussed. Included in this discussion will be the importance of educating health professionals and patients of their rights in medical settings, the incorporation of cultural competency in medical licensing processes, the enhancement of policies and standardization of medical ventures, and improving the organizational culture of healthcare settings.

As stated previously, there are three themes that categorize the challenges arising from healthcare organizations: managerial, health professionals, and policies and accreditations. This section will suggest three points to overcome such impediments; an example will be provided in



regards to healthcare professional cultural and language incompatibility. Cultural competence among medical professionals can be taught and augmented, allowing for an improved patient-provider relationship and increased cultural sensitivity in medical settings.

In regards to healthcare management, the improvement of organizational and safety culture will promote patients' rights as a result. An attempt to unify policies and procedures of varying healthcare providers in Saudi Arabia will result in transitional advancements in patient care, increase organizational productivity, decrease undesired incidences, and promote the moral agency of healthcare personnel; as Joachim Sturmberg and Holly Lanham state, "Health policy and health care delivery are interconnected parts of the same health system"<sup>164</sup>.

International organizational accreditation and affiliation, in addition to acceptance of international ethical standards will enhance patients' rights in Saudi healthcare systems; this also will promote the national standardization of healthcare.

However, this section will discuss following topics: embracing cultural competence and teaching of medical ethics, developing national policies and adapting international ethics, as well as enhancing a culture of safety inside health care organization.

When discussing educating medical professionals about the importance of medical ethics, Bajammal et al. (2008) suggests that those applying for medical jobs in Saudi Arabia be examined to check their ethical proficiency. Bajammal et al. writes, "The second part of the licensing examination would focus on... communication skills, critical thinking, decision-making, breaking bad news, ethics, counseling skills, etc."<sup>165</sup>

By incorporating relevant knowledge regarding bioethics into undergraduate courses, future medical professionals will pass medical licensing examinations understanding how to identify and interpret the significance of ethics and its implications in healthcare settings. Due to

the influx of expatriate healthcare graduates and to enhance Saudi Arabian medical services, Bajammal et al. suggests the development of medical licensing requirements to meet international standards. Educating future healthcare workers about ethics and patients' rights will allow for improved healthcare outcomes, while protecting patients' rights.

This is supported in an article concerning patients' awareness in developing countries by Kuzu, Ergin, and Zencir (2006), who write, "Young professionals should learn the importance of patients' rights,"<sup>166</sup> Though this study was conducted in Turkey and addresses specific healthcare systems, Kuzu et al. provide a testimony that is applicable in all settings including Saudi Arabia.

Similarly, Frank Milligan (2007) stresses the importance of educating healthcare professionals to promote patient safety in medical settings; he argues that the culture of safety should be included in the curriculum which will improve the attitude and practices of health care professionals in clinical settings.<sup>167</sup>

In regards to expatriate workers in Saudi healthcare facilities, medical licenses should include education regarding the Saudi culture to promote culturally oriented and competent medical practice. Sherwood Thompson (2015) writes "Cultural education is a tool that can help promote respect and understanding for different cultures, practices, values, and perspectives."<sup>168</sup>

During the educational sessions that are completed prior to working in Saudi healthcare facilities, there is insufficient information regarding cultural specifications that may be encountered in medical settings that would improve a healthcare provider's competence. For example, Almutair (2012) writes in reference to a participant in a research study: "For Participant 8, orientation primarily focused on an introduction to the hospital, which she deemed essential, but with what appeared to be limited coverage of cultural requirements."<sup>169</sup> In addition,

Sammy Showail, Judi Parks, and Faye Smith (2013) claim that non-Saudi health care workers receive little support while coming to work in Saudi Arabia.<sup>170</sup>

Cultural competence in the medical setting is crucial when treating patients and effects healthcare outcomes; the failure to recognize and appreciate cultural differences leads to disregard for patients' rights and results in distrust between patients and care providers.

Almutairi (2012) lists several examples of how cultural incompetence occurs in healthcare settings. The author cites the participants who were expatriate workers that unintentionally demonstrate cultural incompetence by imposing their own cultural norms upon their patients.<sup>171</sup>

Other participants manifest cultural incompetency by judging Saudi patients and their cultural norms according to the participants' own perceptions;<sup>172</sup> Almutairi describes this as ethnocentrism.<sup>173</sup>

Cultural competence will be defined and its significance to Saudi healthcare systems will be discussed. According to Josepha Campinha-Bacote (2002), "cultural competence is an essential component in rendering effective and culturally responsive services to culturally and ethnically diverse clients."<sup>174</sup> Joseph Betancourt et al. has identified specific goals related to cultural competence which aim to provide healthcare settings the ability to provide best treatment to diverse patients and increase healthcare outcomes.<sup>175</sup> J. Owiti et al. describes cultural competence as, "a set of skills, attitudes and practices that enable the healthcare professionals to deliver high quality interventions to patients from diverse cultural backgrounds."<sup>176</sup>

Therefore, cultural competence from expatriate healthcare workers will enable them to better understand Saudi culture; this improved understanding will allow for culturally sensitive practices that will foster improved relationships between patients and healthcare workers.

Increased cultural competence will benefit patients, promote patients' rights, and increase job satisfaction among the expatriate healthcare workers;<sup>177</sup> the improvement of work life quality will decrease job turnover and the related costs as well as decrease the need to continually train new workers.

To address the issue of language barriers, language classes offered by the hospitals in Saudi Arabia would not only promote language proficiency, also increase overall cultural competence in the healthcare setting.

In order to adapt international ethical standards to enhance the operational and management performance of the organization, the Saudi healthcare system should adopt standardization requirement that soar beyond government minimal requirements. For example, the Joint Commission in the United States has set standards for quality healthcare that surpass the minimal governmental standards required by law. Attention must be brought to basic healthcare governance and management prior to the implementation of quality assurance programs to fine-tune the work of healthcare systems.

The obstacles to the function of Saudi healthcare organizations are a result of general healthcare problems. These problems include the absence of national health information systems,<sup>178</sup> underdevelopment of national health care systems,<sup>179</sup> lack of national crises management,<sup>180</sup> absence of clear and effective communication channels between healthcare providers,<sup>181</sup> lack of national regulations concerning data exchange,<sup>182</sup> absence of electronic health records,<sup>183</sup> lack of clear implementation of clinical protocols,<sup>184</sup> and absence of referral systems.<sup>185</sup>

For these reasons, Alkabba (2012) recommends that the decision makers within Saudi healthcare systems develop policies regarding the implementation of ethical care:

The higher authorities in the health delivery system hierarchy have to initiate more in-depth discussions on the ethical issues, in order to ultimately bring about changes in policies, particularly on resource allocation. Although a code of ethics need not lay down rules that are set in stone, it can provide guidance to deal with ethical issues as they arise.<sup>186</sup>

The unification of nationwide policies and procedures will decrease financial losses, promote national healthcare systems, and provide standardized policies in healthcare organizations in Saudi Arabia. Almalki, Fitzgerald, and Clark (2011) stress this point, saying, “It has noted however, that despite the multiplicity of health service providers there is no coordination or clear communication channels among them,”<sup>187</sup> Also, Mahrous (2013) referred to a sanction produced by a recommendation committee to provide manuals and polices for quality assurance in hospitals.<sup>188</sup>

Decision makers within Saudi national healthcare systems should address previously mentioned organizationally-based issues to increase the performance of there health care organizations. However, the affiliation with prestigious medical centers such as Mayo Clinic and Harvard Medical Center and accreditation from associations such as the Joint Commission, can increase practices that adhere to patients’ rights in Saudi healthcare facilities.

The incorporation of internationally enacted ethical principles and regulations, such as the UNESCO Universal Declaration of Bioethics and Human Rights, will allow for improved practices within healthcare organizations, an increase in ethical practices, and the promotion to patients’ rights in healthcare settings.

As mentioned previously, Islamic biomedical ethics, which is followed by Saudi healthcare systems, is compatible with international biomedical ethical standards; therefore, this makes international biomedical ethics applicable in Saudi healthcare systems. Therefore, the adoption of international treaty principles and application of international biomedical ethical

standards in Saudi Arabian healthcare systems will result in the advancement of healthcare provider and organizational ethics.

If international biomedical standards are adopted in conjunction with the resolution of current, national healthcare problems, the healthcare services in Saudi Arabia will be ideal as patients' rights will be observed.

The culture of safety in an organization will be discussed to suggest various promoters of patients' rights which enable the adoption of patient-centered care within Saudi healthcare systems.

Patient-centered care is not a binding approach in healthcare settings; however, according to Christine Williams (2007), if this approach is embraced in healthcare organizations, it will result in the promotion patients' rights, safety, and ethics.<sup>189</sup> Despite the complexity of patient-centered care and its various models, it is simply described as meeting the needs of patients and providing effective healthcare. Mickey Persons and Carolyn Murdaugh (1994) write, "Patient-Centered Care: A model for reconstructing deals with key success factor for all health providers – how to deliver high quality patient care while minimizing expense and maximizing patients' satisfaction."<sup>190</sup>

As related to patient-centered care, healthcare organizations must promote the culture of safety within the organization to meet such highly qualitative achievements.

Though regulations and laws that aim to promote patient safety and eliminate medical errors are enacted at national and international levels, protection from the occurrence of medical errors is best done within the healthcare organizations own system. This is due to the role the culture of safety, as embraced by the healthcare organization, has in ensuring the safety of its operations and patients. The core functional unit of the healthcare industry is the organization, so

it is crucial to enhance its performance by improving managerial tools, the detection and prevention of medical errors, and ability to manage risks.

As mentioned previously, Gerard Magill (2006) lists four IOM recommendations related to the promotion of the culture of safety in healthcare organizations, which can improve patient's safety and rights drastically. These four points include leadership training, distinguishing human natural ability, enhancing teamwork, and development of self-correction approach.<sup>191</sup>

Similarly, Frank Milliagan (2007) lists seven steps by the National Patients Safety Agency that aim to promote safety culture: building a safety culture, leading and supporting staff members, integrating risk management activities, reporting, involving patients, and implementing preventive solutions.

These steps provide practical tools for healthcare managers and healthcare professionals to promote the safety culture within the organization; this culture of safety cannot be achieved without prerequisite conditions. Fadi Eljardali et al. (2014) identifies factors that should provide a foundation for healthcare organizations for a culture of safety to flourish; these factors include communication, unified vision, leadership, commitment, and non-blaming error reporting.<sup>192</sup>

Educating patients of their rights and promoting such initiatives can maximize efforts to sustain the culture of safety within an organization. Runciman et al. (2007) refers to this as, “The patients as a force for safety.” Mastaneh and Mouseli (2013) write, “Awareness of patients of their rights can bring about a lot of advantages such as increased quality of health care services, decreased costs, more prompt recovery, decreased length of stay in hospitals, lower risk of irreversible physical and spiritual damages,”<sup>193</sup> Informed patients lead to safe patients; however, this is dependent on the willingness of healthcare providers to adopt a culture of safety and respect for patients' rights. This is stressed by Robert Hill Jr. et al., (2015) who related the

continuity of safety culture to the attitudes of healthcare personnel in the healthcare organization.<sup>194</sup>

Recommendations have been made to solve some of the interrelated barriers to appropriate medical practice that upholds patients' rights in Saudi healthcare systems. It has been suggested that cultural competence educational courses be taught to expatriate workers in Saudi Arabia. To best foster cooperative efforts between various healthcare providers, the enhancement of policies and unified guidelines in Saudi Arabia have been discussed. This was followed up with a discussion of the culture of safety. Though the discussion of challenges faced by Saudi healthcare systems does not provide an all-encompassing picture of the issue, it does provide examples of the existing reality.

## **5.5 Conclusion**

This chapter discusses barriers to proper patients' rights in Saudi medical settings. The culturally-induced impediments to patients' rights practice and organizational barriers to biomedical ethics in Saudi health care systems have been elaborated upon. In addition, the role of the healthcare organizational culture in establishing patients' rights has been presented.

This discussion began with discourse related to the significance of organizational culture in determining ethics of the health care organization. This was followed by an elaboration upon the role of health care organization in promoting patients' rights. These discussions introduced the specifics of Saudi Arabian healthcare organizations and the organizational barriers to proper and desired patients' rights.

Next, this chapter discussed managerial, regulatory, and logistical issues that represent the organizational obstacles that decrease the ability of Saudi healthcare organizations to



embrace optimal patients' rights. This chapter concluded with recommendations and practical remarks in regards to patients' rights, and suggested implementation methods for biomedical ethics in the Saudi healthcare system.

Finally, different approaches to solve organizationally-based problems including culture competency, improvements to accreditations and quality assurance, development of policies, application of standards, and promotion of the culture of safety were suggested for Saudi Arabian healthcare settings. The next chapter will discuss issues related to clinical bioethics in the Saudi Arabian healthcare system.

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## **Chapter Six: Concerns Related to Bioethics and Patients' Rights in Saudi Arabia**

Previously, the organizational challenges to patients' rights in Saudi Arabian healthcare systems were discussed. This chapter is dedicated to examining the issues that result in barriers to bioethical discourse in Saudi Arabian healthcare.

As in many health care systems around the world, the Saudi Arabian health care system has challenges that comprehend the ability of the national health care venture to provide distinguished health care services to their communities as anticipated and desired by the Saudi health care planners.

Challenges within the healthcare system that prevent the provision of acceptable services occur for many reasons; this may include and is not limited to constraints with financial resources, lack of suitable management, underdeveloped policies, deprived professional ethics, and lack of proper implementation of biomedical ethics in healthcare settings. The Saudi Arabian healthcare systems face similar challenges to biomedical ethics, as demonstrated by poor adoption of patients' rights and feeble enforcement of bioethics standards.

The organizationally-induced factors contributing to these challenges were discussed previously, including managerial contributions to underdevelopment and negligence of policies or standards that aim to promote bioethics and patients' rights. These problems are ethical concerns that patients, families, and healthcare providers frequently face in clinical settings.

Due to multiplicity and importance of biomedical ethical issues in the Saudi healthcare system, four biomedical ethical challenges have been selected to symbolize the current situations facing the Saudi healthcare systems. These include issues include vulnerability in health care, informed consent, paternalism, and confidentiality of medical information.

To represent the significance of these challenges in Saudi health care systems, a research study will be presented. R. Fayeze et al., (2013) reports the frequency of ethical problems in four tertiary care Saudi hospitals. The authors find that the most frequently occurring challenges to biomedical ethics are confidentiality and privacy related issues (36.3%), concerns over informed consent (60.2%), and infringement of patient autonomy (42.5%).

Using philosophical and practical perspectives, this chapter will evaluate these barriers to appropriate implementation of patients' rights and universal bioethical standards in the Saudi healthcare system.

This chapter will also discuss the relationship between the UNESCO Universal Declaration on Bioethics and Human Rights and Saudi healthcare systems by accepting patients' rights as an intrinsic value. This discussion will also lead into the following section by comparing the Saudi healthcare to other countries, primarily the United States healthcare system.

To elaborate on issues such as vulnerability in health care, informed consent, paternalism and confidentiality in the Saudi health care system, the principle of autonomy will be introduced. The principle of autonomy is a common theme among these issues, which is intimately associated with moral principles and practical implications in health care settings.

Autonomy means self-ruling in Greek language;<sup>1</sup> as Beauchamp and Childress (2013) write, "The autonomous individual acts freely in accordance with a self-chosen plan."<sup>2</sup> The principle of autonomy in healthcare settings is considered a principle that protects and respects the fundamentals of human rights of morality and quality healthcare services.

Respect for patients' choices and protection from doing things against their own will is a fundamental principle with justifiable religious and ethical rationale. Autonomy is also valued by humans, irrespective of cultural orientations, because it authorizes the pursuit of things that make

them content and innately fulfilled; free expression and self-ruling fulfills the human desire for liberty and satisfies the need to be respected, which leads to individual “irreplaceable satisfaction.”<sup>3</sup>

Respect for autonomy is the hallmark of virtuous and civilized societies. This is expressed through the establishment of moral and socially acceptable boundaries between people to strive for moral values, despite differences or conflicting beliefs.

The philosophical justification for considering autonomy as a fundamental principle is due to the intrinsic value of liberty, as reflected by autonomy, to humans.<sup>4</sup> Therefore, the principle of autonomy is crucial, especially in the contemporary era of globalization, where appreciation for this principle outweighs many other societal values. This is especially the case in western societies where individualism outweighs communitarian-oriented philosophies.

As a philosophical rule, failure to practice autonomy in healthcare creates barriers to peoples’ rights and free will, but also is immoral, unjustifiable, and results in jeopardizing of human rights principles.

Respect for autonomy in social settings can be expressed through civil rights, freedom of expression and alike. In medical settings, respect for autonomy is fundamental to the protection of patients’ interests and preservation of their rights; this is especially the case when patients are vulnerable or influenced by forces such as paternalism, ignorant practices of obtaining consent, inadequate patients’ rights practices, medical error, and confidentiality concerns.

Respect for autonomy in healthcare and research settings is just as valuable as in political and social ventures. This is because respect for autonomy in healthcare and research settings is considered a first line of defense to protect patients’ rights from being victimized or prone to manipulative practices.

Such practices of exploitation represent the lack of respect for patient autonomy which can manifest itself in numerous ways. For instance, doctors strongly influence patients in medical and in research settings;<sup>5</sup> when doctors fail to allow patient autonomy, paternalism occurs which jeopardizes patient autonomy and patients' rights.

In comparison to developed countries, respect for patient autonomy in developing countries is less feasible and enforced less frequently in medical settings. The inconsistent enforcement of laws and regulations related to autonomy occurs for many reasons. For example, social and cultural norms determine social norms and cultural positions in addition to the due implications concerning the principle of autonomy.

Western tradition gives precedence to individual needs over those of the community; this means that individuals are valued over communitarian considerations, values, or religious teachings in biomedical ethics. Therefore, respect for individual autonomy is fundamental to Western bioethical discourse. In contrast, many Eastern philosophical perspectives do not value individualism over communitarianism and associated values.

Contrary to international standards concerning informed consent, many parts of the world provide informed consent to the relatives of patients who can select therapeutic courses for the patient to follow, even if it is against the patient's resolve.

The organizational culture plays a role in confirming or undermining the right of autonomy through regulations that control professional behaviors in healthcare ventures.

The healthcare organizations sole responsibility is to ensure patients' rights to autonomy which is defined by its overall commitment to embrace ethics of patients' rights. This is attained by organizational policies and ethical standards within the organization which healthcare workers are obligated to follow.

In other words, the principle of autonomy is defined in biomedical ethical literature as respect for patients' autonomous choices, as every patient has the right to be fully informed regarding their state of affairs. Patients must be provided all related information in order to make an autonomous decision regarding treatment without being intimidated, forced, or deceived by the physician. The principle of autonomy preserves the right of patients to be respected in their body, reputation and mind; in other words, the patient's dignity will be preserved

In addition, the principle of autonomy means that any individual has the right to obtain information that is related to his/her health, illness, medical information and future outcomes. The patient must be informed of medical services and information that allows him/her to make an autonomous decision, and no information can be held back from him/her.

The autonomy of an individual should be determined in respect to other people's autonomy. In addition, his/her autonomous choice should originate from thorough information from a reasonable mind, otherwise individuals are unable to make autonomous decisions in respect to their personality and dignity; as Naas et al. states, "The primary justification for protecting personal privacy is to protect the interests of individuals."<sup>6</sup>

According to HIPAA privacy regulations, a notice of privacy practices (NPP) must be disclosed to any patient prior to admission and provision of health care services; notice of privacy practices is, "A written document detailing a health care provider's privacy practices."<sup>7</sup> A notice of privacy practices must be read, understood, and signed by the patient or an authorized relative. This common practice, which is enforced by HIPAA regulations, elaborates upon the importance of protecting patients' autonomy by disclosing privacy information of the healthcare providers to the patient. When the notice of privacy practices is provided and

disclosed to the patient, it will establish an excellent doctor-patient relationship based on autonomy and transparent practices provided by the healthcare facility.

HIPAA standards demand that entities treat and protect any identifiable information in addition to keeping these records secure unless the law demands that this information be revealed. This protect health information (PHI), in addition to the notice of privacy practices, provides excellent regulations that protect patient autonomy and wellbeing.

Jacob Rendtorff (2008) writes, “The principle of autonomy is proposed as a very basic and universal principle in bioethics and Biolaw.” According to Rendtorff, autonomy must be combined with other values to be effectively implemented in bioethics.<sup>8</sup> For example, in order for autonomy to fulfill its philosophical scope, the individual must be of able reasoning, as contrary to being child, unconscious, or insane. Autonomy could be affected in rational people who are experiencing physiological illnesses that impairs their intellectual ability; “...there is no gold standard for measuring competence.”<sup>9</sup>

To practice autonomy, the individual must be fully informed of his/her options. An uninformed individual will not be able to produce autonomous choices. In the next sections topics such as vulnerability, informed consent, confidentiality, and paternalism will be discussed.

## **6.1 Vulnerability in Health Care**

The vagueness of the concept of vulnerability<sup>10</sup> in health care settings<sup>11</sup> and the lack of a unified definition<sup>12</sup> or categorization of vulnerable groups creates confusion; this results in debates as many people are considered vulnerable. Henk ten Have (2015) affirms that the concept of vulnerability has become a popular subject since 2000; the concept itself is a

fundamental principle of bioethics according to the UNESCO Universal Declaration on Bioethics and Human Rights.<sup>13</sup>

Henk ten Have lists three points that represent key aspects of vulnerability; this includes distinguishing between types of vulnerability, issues of categorization, and the practical uses of this categorization as a rhetorical concept.<sup>14</sup>

To elaborate on the categorization and protection of vulnerable human groups, the International Bioethics Committee reports that the very nature of being human is indicative of vulnerability: “The human condition implies vulnerability.”<sup>15</sup> This is also supported by Hanneke van der Meide et al, (2015)<sup>16</sup>, Maria Neves (2009)<sup>17</sup>, and Michael Kottow (2004) who proclaim that all humans share the characteristic of vulnerability.<sup>18</sup>

Scholars such as O’Neill view injured individuals and patients as being vulnerable, as they need others to attend to them.<sup>19</sup> “Vulnerability is understood as identifiable increased likelihood of incurring additional or greater wrong.”<sup>20</sup> Vulnerable groups include but are not limited to foreigners, pregnant women, women, minorities, children, terminally ill patients, mental ill patients, under privileged communities, and uneducated people. Jan Helge Solbakk (2011) asserts that according to the UNESCO Universal Declaration, individuals, families, communities, and groups can be labeled as vulnerable.<sup>21</sup>

Though the concept of vulnerability is vague, many scholars in medical settings stress the importance of labeling people as vulnerable to protect them from exploitation and harm. This is due to the fundamental, moral necessity of protecting the vulnerable;<sup>22</sup> in addition, it is common for individuals in societies with moral and religious rationalizing backgrounds to support those who are regarded weak and prone to harm.<sup>23</sup>



In the *Handbook of Global Bioethics*, Sheila McLean<sup>24</sup> elaborates upon the matter of vulnerability; she discusses how the concept of vulnerability can be classified as “mere vulnerability” or “special vulnerability.” Though these terms have distinct meanings, neither definition has been used in practical settings when labeling groups of people as vulnerable. The WHO in cooperation with the Council for International Organizations of Medical Sciences CIOMS (2002) defines vulnerability in the International Ethical Guidelines for Biomedical Research Involving Human Subjects as, “Vulnerable persons are those who are relatively or absolutely incapable of protecting their own interests. More formally, they may have insufficient power, intelligence, education, resources, strength, or other needed attributes to protect their own interests.”<sup>25</sup> The Declaration of Helsinki,<sup>26</sup> formulated in response to the Nuremberg trials, describe vulnerable individuals as, “those who cannot give or refuse consent for themselves and those who may be vulnerable to coercion or undue influence.”<sup>27</sup> Article Number 8 in the UNESCO Declaration on Biomedical Ethic’s stresses the protection of those deemed as vulnerable in medical research settings.<sup>28</sup>

Kenneth Kipnis (2001) classifies vulnerability into various types including: cognitive and communicative, institutional, deferential, medical, economic, and social.<sup>29</sup> This classification sorts vulnerable groups according to their abilities such as competence or level of education. Other bioethicists suggest similar classifications based on competency and exercising autonomy.

Volnei Garrafa (2011) writes, “Within the field of ethics in clinical research, the concept of vulnerability was at first understood to be the limit of the capacity to consent.”<sup>30</sup> This limited understanding of vulnerability is no longer accurate in today’s medical system, as many groups fall under the description of vulnerability. Scholars now include minorities, children, women, individuals with disabilities, poor, and illiterate to category of vulnerability.<sup>31</sup>

As a general approach, Ganguli- Mitra and Biller- Andorno (2011) describe the ability of patients to give informed consent and to logically comprehend the situation as a standard to measure of vulnerability in medical settings.<sup>32</sup>

Unfortunately, the inclusion of groups of people the category of vulnerability is not always beneficial, ethically acceptable, or feasible. When people are labeled as vulnerable, they may lose the ability to make decisions independently, as their capacity to make decisions is questioned. Therefore, these groups are treated or undertreated accordingly, which leads to the potential of paternalistic supervision that compromises patient autonomy and wellbeing. Paternalistic practices with vulnerable groups begin with the ambiguous inclusion of various groups under the category of vulnerability; Sheila Mclean (2014) notes, “At some time in life, everyone is vulnerable.”<sup>33</sup>

The overprotection of individuals by labeling these people as vulnerable can cause harm and demean their right to autonomy; to protect those who are in need of protective measures, there must be a balance between including and excluding groups from being considered vulnerable. In addition, it promotes research without hindering people’s ability to advance scientific learning in their participation. If the categorization of vulnerable groups is tailored to recognize the differences between communities at a local level, the argument regarding vulnerability better serves these groups. This is stressed by Carol Levine et al., (2010) who writes that the stereotypes that occur due to vulnerability labels will not distinguish these individuals on a basic level, which is considered stigmatizing and stereotyping bias.<sup>34</sup> Garrafa and Prado (2001) also write in reference to the disadvantages occurring from labeling people as vulnerable, that being called vulnerable might prevent certain group of people from

getting benefits and care,<sup>35</sup> which is completely true in underdeveloped communities where the only care that might a person get is through participating in research.

Therefore, the concept of vulnerability represents an ethical dilemma because of problematic terminology, lack of clear categorization, and ambiguity or inclusion of several groups as being vulnerable. For example, if a new drug with the potential to cure a paralyzed child needs to be tested on children with paralysis, this may be rejected by an ethics committee due to the vulnerable status of disabled children; this would leave the drug untested and children without treatment. This scenario can occur in less severe forms when potential drug research trials are delayed or rejected due to precautionary measurements. Precautionary measures in research and protection of vulnerable groups can be justified due to the exploitation of vulnerable individuals and unethical use of research subjects.

The stressing of the concept of vulnerability is due to exploitation in medical and research settings; therefore, exploitation of these groups will be discussed further.

Exploitation in medical research settings occurs when the interest of researchers and participants conflict; this can be due to researchers using participants against their will as exemplified in Nazi camps, or simply because researchers do not inform participants of the potential harm that might occur as a direct or indirect result of the research, resulting in “stigmatization.”<sup>36</sup> Other forms of exploitation occur when less attention is paid to participant wellbeing or when participant wishes and expectations of research outcomes are underestimated. If the scope and objectives or harm and benefits of the research are not fully disclosed, distrust and confusion occurs, in addition to a breach in informed consent which jeopardizes the objectivity of the research, causing the entire research to be deemed unethical.<sup>37</sup> Avoiding exploitation in research is formulated by Kantian theory, which states that it is morally wrong to

use people as a means, not as an end in themselves.<sup>38</sup> Another perspective by Alan Wertheimer explains that exploitation occurs when benefits and harm are distributed unevenly by researchers upon two or more groups of participants.<sup>39</sup>

Though exploitation can be defined and applied in different ways within various contexts, it is simply considered unethical practice in research settings due to its dangerous or fatal nature, especially when involving vulnerable individuals or groups. To avoid future exploitative practices, Emanuel, Wendler, and Grady suggest eight ethical principles that ensure research that is free of exploitation, including: collaborative partnership, social value, scientific validity, fair participant selection, favorable risk benefit ratio, independent review, informed consent, and respect for the participants.<sup>40</sup> Ndeble states, “Ethical requirements have therefore been developed to ensure the minimization of the possibility of exploitation and harm by ensuring that research participants are not merely used as a means to an end but are treated with respect while they contribute to the social good.”<sup>41</sup>

International communities are eager to aid local ethical committees in promoting ethical work, defining vulnerability from a local perspective, eradicating exploitation in research settings, gaining better healthcare, and utilizing the outcomes of medical research activities. In adherence to international treaties and global collaboration to promote ethical practices in biomedical research, several declarations have been adopted to elaborate upon the matter of protecting vulnerable groups in research settings. McLean states, “Broadly, we agree that the vulnerable should be afforded some kind of special attention, or protection.”<sup>42</sup> These internationally-formulated declarations may be overprotective and their terms and conditions might not serve the best interests of communities at the local level.

Issues of vulnerability occurring in research settings are less relevant to Saudi healthcare

system due to the countries minimal involvement in few research activities involving Saudi populations. The concept of vulnerability in Saudi Arabia is important in medical settings; this includes issues concerning clinical ethics such as the ability to give informed consent, confidentiality, and issues of paternalism.

The role of gender must be discussed to elaborate upon vulnerability in Saudi healthcare systems, as social and cultural influences include women as a vulnerable group due to unequal healthcare opportunity. In reference to gender inequality in Saudi Arabian healthcare, Walker writes, “in the context of the kingdom, these inequalities arise from traditional, cultural, and social practices that may affect the health of women and migrant workers.”<sup>43</sup>

In conjunction with Kipnis’ approach, vulnerability in Saudi healthcare settings can be addressed by social or medical approaches, on the premise that societal and cultural norms cause vulnerability in medical settings. Women, as a vulnerable group of Saudi society, will be discussed in association with healthcare.

When reflecting upon the ability of women to provide consent in medical settings, Lara Walker (2014) indicates that it is broadly accepted as a Saudi cultural norm that women ought to obtain approval from a male regarding her affairs.<sup>44</sup> Walker writes,

...officials both private and public actors working in an official capacity such as doctors or lawyers, regularly request permission from the legal guardian, even when this is not mandatory or stipulated under government guidelines. This is the case in hospitals, where some require a guardian’s permission before woman are admitted or allowed to consent to medical procedures for themselves or their children.<sup>45</sup>

According to Samia Alamoudi (2012), *The Convention on the Elimination of all Forms of Discrimination against Women (CEDAW) Committee Report* of April 2008 explicitly criticizes the existence of such practices in Saudi Arabia. However, Alamoudi determines that accusations falsely determining that women cannot provide autonomous consent without the permission from

a male guardian leads to health inequalities. These health inequalities are such because it is supported by cultural norms in Saudi Arabia culture permitting such practices.

According to Walker, women in Saudi Arabia are deemed vulnerable due to their lack of equal access to healthcare in comparison to men; this vulnerability is considered secondary to societal cultural norms which categorize women as unequal to men.<sup>46</sup> In addition, Walker explains that barriers such as requiring a male guardian's permission to allow women medical attention and banning women from driving result in the vulnerable position of women, directly affecting her wellbeing; the author suggests a change in Saudi Arabian official and cultural perspectives concerning the censorship of women's affairs.<sup>47</sup> In a study by Asmaa Alyaemni et al. (2013) concerning the effect of cultural and social influences on the health of women in Saudi Arabia, the researchers conclude that there are notable differences in women's overall health in comparison to men's health due to social and gender factors. Alyaemni et al. reduce these gender factors to the following: "...their reproductive roles and responsibilities, restricted mobility and social relations."<sup>48</sup> These findings are similar to John Stone's (2002) rulings on causative factors occurring in U.S. healthcare. The author writes, "...that well-known causes of worse health are so-called social determinants of health, especially socioeconomic status. No surprise it is bad to be poor. Not only income and wealth, but related factors like education and environment dramatically affect health."

Alamoudi suggests that it is a misconception and false concept that women require a male guardian's permission to obtain medical services. Alamoudi writes, "The misconception about women's right to consent comes from the ignorance among some women and some doctors and their resulting beliefs that women have no right to give consent for medical procedures necessary for the women."<sup>49</sup> In partial agreement with Lara Walker's recommendations, Alamoudi

proposes that women and healthcare workers should be educated about women's rights such as seeking healthcare attention for herself and her children without male permission. Alamoudi stresses that these false assumptions presumed by healthcare providers and even by women are not supported by Islamic rational or legal codes in Saudi Arabia; in fact, Alamoudi relates these presumptions to the dominating cultural influence, "...women in Saudi Arabia have the right by Sharia law i.e. values of Islamic Law and by rules of Ministry of Health to take decisions and sign for themselves."<sup>50</sup>

Issues of vulnerability are complicated but the protection of vulnerable groups in medical and research settings is vital to uphold ethical standards. Many internationally-sanctioned policies require measurements to protect vulnerable groups and apply strict standards to avoid exploitative undertakings. Due to less Saudi contribution in medical research for social and economic reasons, the issue of vulnerability in Saudi Arabia concerns the role of gender in healthcare, as many women are vulnerable to biased medical practices. It is recommended by Alamoudi and Walker that healthcare providers should educate women about how to exercise their rights in medical and social settings through autonomy and self-ruling, as permitted by Islam and Saudi laws. In the next session, issues related to informed consent in Saudi Arabia will be discussed.

## **6.2 Informed Consent**

John Kultgen (1995) writes, "If paternalism is coercive by nature, consent would seem to make an action non paternalistic. This disposes of justification by definition: only consent can justify intervention."<sup>51</sup> In conjunction with this statement, it is considered standard practice in biomedical ventures to obtain informed consent in order to protect patients' and subjects' dignity

and rights. Therefore, doctors and medical researchers are required by multiple national and international laws in addition to professional codes of ethics to disclose relevant information regarding the proposed undertakings to patients and research participants before they submit to procedures. This includes what a participant may experience and the anticipated outcomes from such procedures. According to Islam, policies regarding informed consent originate from religious narrations regarding the uniqueness of human beings and the right of humans to be autonomous. Mohammed Rathor et al. (2011) write, “Islamic jurisprudence acknowledges autonomy as stipulated by the assertion that no one is entitled to dispose of the right of a human being without his permission.”<sup>52</sup>

Full disclosure of information is required in order to obtain informed consent but also demonstrates the commitment of doctors and researchers to respecting the dignity and autonomy of patients and participants.<sup>53</sup>

According to article six of the UNESCO Universal Declaration on Bioethics and Human Rights, “Any preventive, diagnostic and therapeutic medical intervention is only to be carried out with the prior, free, and informed consent of the person concerned, based on adequate information. The consent should, where appropriate, be express and may be withdrawn by the person concerned at any time and for any reason without disadvantage or prejudice.”<sup>54</sup>

The reason behind such sound arguments for consent is related to the preceding events where patients’ rights were neglected resulting in disastrous outcomes due to unrestrained and unethical research studies.<sup>55</sup> These unethical biomedical occurrences were conducted upon helpless individuals without obtaining proper approval or consent.

For example, Nazis in Germany conducted unethical research trials that involved prisoners of war across Europe during World War II. Hundreds of thousands of people died or



were left with permanent physical or mental damage as a consequence of these biomedical experiments. These devastating events led to post-war investigations that made ethical determinations and resulted in the creation of the Nuremberg prosecutions; this led to the Declaration of the Nuremberg code which has been followed by the Helsinki Declarations.<sup>56</sup>

Decades after the Nuremberg trials, informed consent has evolved and become increasingly persuasive and strengthened to help in preserve patient and research participant dignity in biomedical settings. In 1970, informed consent as a binding legal document has become more exhaustive and comprehensive.<sup>57</sup>

In the contemporary healthcare and research facilities, obtaining informed consent is a strictly enforced routine. Detailed consent forms are required by healthcare workers to inform patients of their options, as well as to reflect upon patients' choices.

According to Beauchamp and Childress, in order to guarantee a patients' informed consent, the disclosed information ought to have specific, fundamental components. These components include the following: information that is considered vital to the patient, information that is vital to the healthcare provider, professional recommendations, the reasons behind requiring consent, in addition to the nature and limitations of consent.<sup>58</sup>

Beauchamp and Childress (2013) believe that informed consent has two meanings; the first is that informed consent is regarded as, "...an individual's autonomous authorization of a medical intervention or of participation in research". The second is considered as, "...analyzable in terms of the social rules of consent that maintain that one must obtain legally or institutionally valid consent from patients or subjects before proceeding with diagnostic, therapeutic, or research procedures."

The first definition of informed consent focuses on patient understanding of informed consent and the fulfillment of the human desire to be respected in medical choices and decisions; the second definition encompasses a general view of informed consent primarily concerned with the process of obtaining consent directed toward social echelons rather than individual interests, in addition to providing healthcare providers with legal documentation.<sup>59</sup>

There are ethical considerations that allude to potential barriers to the attainment of valid informed consent. An example of this is when patients consent to procedures under duress or assuming that they will benefit from a certain procedure.

The doctrine of informed consent is a biomedical ethical issue that directly affects patients, the morality of research and medical ventures, and determines the accountability of healthcare providers. Informed consent is considered a difficult ethical requirement to acquire in healthcare and research settings; this is because informed is a signed document that prevents legal persecutions, but does not discount the ethical responsibilities required by ethical doctrines.

As Beauchamp and Childress (2013) argue, the focus of the informed consent has shifted from the obligation of doctors to disclose information to patients to focusing on the extent of the patient's understanding of the information to ensure quality information.<sup>60</sup>

There are five components of informed consent are discussed by Beauchamp and Childress.<sup>61</sup> The first component is competency which means,<sup>62</sup> "...the ability to do what is needed to perform a task;" the definition of a competent person is, "If persons can understand and appreciate the information given by professionals then they are competent". The next component is information disclosure, as this information must be in a language understandable to the patient and in familiar terminology rather than detailed in medical and scientific terminology. The third component is ensuring patient understanding of the disclosed information. The fourth

component is the voluntary act of providing informed consent free from coercion, persuasion, and manipulation. The final, fifth component is the actual consent.

In order to ensure that informed consent is valid, consent should be given by a rational person that understands the nature of the procedures and consequences of his/her participation. While consent from a caregiver is sufficient in pediatric cases or when a participant is found incompetent, other situations require a concerned person explicit consent. Though information that is disclosed to patients should be fully understood to give informed decision, the details and nature of the information produces debates; “One of slightly complicated issues with informed consent is deciding the limit of the information to be passed on to potential respondents.”<sup>63</sup>

The complications of informed consent are multiple, as there are logistical, organizational, and cultural that influence and interfere with the process of informed consent. For example, the overwhelming use of scientific terms can limit the full comprehension of the nature and consequences of a procedure, which negatively affects the patient’s ability to provide informed consent. The fundamentals importance of informed consent is agreed upon on an international level, but there are variations and barriers that occur during the consent process, choices, and presentation to the patients.

In Saudi Arabia, legal documentation of consent is required for patients to undergo medical procedures or participate in research studies. Consent can be easily explained to patients and families, and they typically expect informed consent forms to sign before undergoing medical interventions.

The challenges to informed consent in Saudi medical settings are related to the process of obtaining consent, and most individuals are concerned with who has the right to sign the consent

forms. Other barriers to obtaining meaningful and ethical informed consent include language barriers, illiteracy, and paternalistic practices in medical settings.

Due to language barriers and cultural incompetence of expatriate workers, the relationship between healthcare providers and patients is affected; this results in paternalistic practices by health care providers which jeopardizes the validity of patient informed consent. Aboalfotouh and Adlan (2012) confirm these statements, as they write, “In the present study, a striking finding was that more than 50% of our study population believed that their decision was not important because the physician had already decided for them.”

The vulnerable groups found in medical settings such as women or elderly tend will tolerate paternalistic practices from family members; this in turn impacts the process and ethics of informed consent.

Informed consent as a philosophical requirement in biomedical settings remains consistent across the world in description and philosophical notion; these countries use unified standards from international declarations. Adlan (2013) claims that the Saudi National committee of medical and bioethics determines the country’s informed consent policies based on international practices.<sup>64</sup> In addition, he claims that prior to the National Medical and Bioethical Committees, each hospital maintained varying informed consent policies.<sup>65</sup>

Different communities, cultures, and healthcare systems perceive, interpret, and practice informed consent in various ways.

Cultural norms play a large role in the informed consent process as well as its norms and applications. For example, the difference between Saudi Arabia and the United States regarding informed consent is the attainment process; in the United States, informed consent is obtained

from a patient or a legal guardian, while in Saudi Arabia consent can be obtained from the patient, husband, or another family member.<sup>66</sup>

As is customary or normative practice in Saudi culture, many healthcare providers ask for a signature of consent from a male relative or acquaintance despite the consenting competence of a women.<sup>67</sup> This practice of informed consent would be deemed unethical when measured in comparison to Western bioethical standards, as it would be regarded as a violation of patient privacy and contradictory to autonomy and self-ruling.

Adlan (2013) counters this, claiming that informed consent has existed in Saudi Arabia for decades, but is regarded as an imported Western principle that fails to serve its purpose of recognizing differences in culture. This is also supported by Del Pozo & Fins (2008), who cite their observations regarding the informed consent and information disclosure in the state of Qatar; the authors note that the process of information disclosure as related to informed consent follows a specific pattern due to cultural factors, which varies from the process of Western information disclosure.<sup>68</sup>

To best examine these practices in accordance to cultural competency recommendations, the varying cultural specifications and customs between Saudi Arabia and the United States must be considered as a factor in the standards of acceptable norms in medical settings including consent and paternalism regarding healthcare decisions. Abdallah Adlan (2013) writes in relation to this; “The Saudi personality poses a challenge to the individualistic autonomous notion that induced the informed consent concept.”<sup>69</sup> In addition, Del Pozo & Fins (2008) write, “These cultural idiosyncrasies play a critical role in determining the standards of disclosure adopted by each society and can thus have a dramatic impact in the clinical sphere, influencing the contents and practice of informed consent.”<sup>70</sup>

For example, patients are typically admitted to hospital in Saudi Arabia accompanied by close relatives that ask questions concerning the situation and potential outcomes. These practices are customary to Saudi Arabian culture and are regarded as a caring and sympathetic gesture toward the patient, even if it interferes with decision making and medical planning. Due to the strong sense of community among Saudis, patient typically do not mind that relatives getting involved in medical matters. There are exceptions to this cultural matter, as some people do not approve consent or influence in medical matters from relatives.

According to the dominant culture in community-centered societies such as Saudi Arabia, it is assumed that elders, children, incompetent individuals, and sometimes women require the involvement of a relative to consent for major procedures in social and medical venues. Abdallah Adlan (2013) illustrates this concept in his story, *Informed Consent in Saudi Arabia*, Adlan has consented to medical procedures on behalf of his father without referring to his wishes; this is also supported by Chirk Jenn Ng et al. (2013) who mention the paternalistic practices of medical staff in another Islamic country similar to Saudi Arabia, Malaysia.<sup>71</sup>

This can be explained in the following scenarios from various communities. If an elder male has been admitted to a hospital for a complicated diabetic foot, the surgeons would recommend amputating his leg. The patient may disapprove of the suggested procedure and refuse to give consent. If the patient's son, a physician, disapproves of his father's decision, he may ask the surgeon to proceed with the amputation on the basis of saving his father's life.

In the context of Western cultural, the treating staff would honor the patient's decision no matter what that decision was; in cultural settings that base customs on communitarian philosophies such as Saudi Arabia, the patient's decision would be bypassed in cases when patients are elderly, vulnerable, or to observe the Islamic principle of preserving life and

avoiding harm. In the proposed scenario, the consent forms would be signed by the son in assumption that the elderly man is unaware of the consequences of his refusal. It can be assumed that the patient would likely concede with his son's wishes, especially when supported by medical recommendations and religious principles.

Some scholars reference the role of religion in informed consent, as autonomy may be viewed as incompatible with religious canonical laws;<sup>72</sup> in the case of a life-saving procedure such as an amputation, refusing this procedure contradicts with the religious law of self-maintenance and self-preservation. Therefore, these scholars argue for a restriction on autonomy as absolute autonomy secured by consent touches sensitive boundaries.

Most Saudi Arabian healthcare literatures reference males as the head of the family and responsible for the family; this role suggests that he maintains an important role in social and healthcare settings. These references interpret issues of informed consent in Saudi Arabian society in relation to paternalism and cultural specifications. Mohammad Alshahri (2002) writes, "In ordinary situations, a male member leads the Saudi family. The family leader is often the breadwinner, protector, disciplinarian, and spokesperson. He is usually the ultimate, but not absolute, decision maker."<sup>73</sup> Alshahri illustrates the role of the male in Saudi culture who is assigned paternal roles, which entitles him dominancy over members of his family, including the females, children, and elders.

In most healthcare systems around the world, children and elders that are deemed unable to provide informed consent require the assistance of caregivers to provide consent. In these contexts, females typically preserve their right to make autonomous decisions regarding their health and social determinations; in Saudi Arabian contexts, patient autonomy may be disregarded in order to give the male guardian a partial or a complete role in the decision-making

process. Alshahri explains this concept:

Generally speaking, the Saudi female enjoys familial social security because usually a male relative is legitimately and culturally responsible for meeting her basic needs (feeding, clothing, habitation, health needs, etc.) even if she was wealthier than him. The social warmth generated by this system helps to abolish the tendency for independency and autonomy among females. It is not surprising, therefore, that females tend to delegate the task of signing consents to close male relatives despite their legal right of making completely independent decisions.<sup>74</sup>

This depiction that demonstrates aspects of Saudi culture and relates to providing consent is also referenced by Adlan, who depicts the inseparable bond between patients and family members when determining courses of action for medical procedures.<sup>75</sup> Abbas Almutair et al. (2014) elaborates upon this matter, as the authors stress the role of family in the life of Muslims; as devoted followers of Islam, Saudis have special consideration for family members which makes social relationships binding, even in medical settings. Almutair et al. suggests a shift toward family-centered care in the Saudi medical system to allow the provision of culturally-sensitive and customs driven healthcare services.<sup>76</sup>

There are various challenges from within Saudi healthcare systems that adversely affect informed consent. This includes medical professionals, including medical graduates, working in Saudi hospitals that are not aware of the importance of informed consent; ElSobkey et al. (2014) recounts a similar observation of Saudi medical students that were entirely unaware of the bill of patients' rights.<sup>77</sup>

In addition to culturally-based barriers, other challenges to informed consent include organizational shortfalls related to educating patients about their medical rights and providing them the information that is required for informed consent. Adlan (2013) reports that almost 66.5% of consenting patients have been told that informed consent is merely paperwork; this indicates severe neglect of proper disclosure of information by healthcare personnel.



A study from King Abdul-Aziz Medical City in Riyadh concludes poor quality of informed consent obtained from patients that were to undergo invasive procedures. The study demonstrates that the patients were either not aware of their rights or experienced paternalistic treatment: “The percent mean score of quality of the informed consent was 50.97% 17.49%, denoting poor quality, with no significant sex difference.”<sup>78</sup>

The issues facing appropriate practice of informed consent in Saudi healthcare systems originate from cultural and organizational factors. Organizational factors originate from poor enforcement of regulatory policies, lax enforcement of informed consent, and operational negligence of informed consent. These influences upon informed consent can be eliminated by the enforcement of standard practices and the unification of related policies.

The primary challenge to the practice of informed consent in Saudi healthcare systems is the cultural predisposition regarding the theory and practice of informed consent. As discussed previously, Islam views women as equal in their right to provide consent and handle her affairs without the influence of a male relative; this supports Hunida Abdulhameed et al.’s (2011) notion that attitudes regarding medical issues are produced by non-religious deterrents such as the dominant culture, and play a major role in shaping related convictions and actions.<sup>79</sup>

Medical professionals must be educated about the philosophy and practical implications of informed consent to promote ethical practices in Saudi healthcare systems and to protect both patients and healthcare providers.<sup>80</sup> Healthcare providers, especially expatriate workers, must also be educated about other ethical issues such as paternalism, vulnerability, and the role of Islam in providing practices of culturally competent consent.

In regards to the cultural specifications of Saudi Arabia, the international biomedical ethical standards, namely the UNESCO Universal Declaration on Bioethics and Human Rights<sup>81</sup>

ought to be incorporated into Saudi healthcare systems; this will lead to the improvement of informed consent practices, especially due to the similarities between the moral principles of Islam and international bioethical standards. Paternalism in Saudi healthcare systems will be discussed further, as it is intimately related to the discussion of informed consent.

### **6.3 Paternalism at Bedside**

The majority of political regimes and governments formulate laws and regulations in order to protect the society and avoid exploitative behaviors. However, there are laws that are not agreed upon. Not all people are bound by an internal moral compass to respect laws, but these laws are expected to be obeyed and respected by the majority.

To ensure compliance and obedience of laws, policymakers use soft and hard paternalism to effectively endorse these laws.<sup>82</sup> Policymakers for healthcare ventures draw upon similar approaches to protect the interests and safety of people in biomedical settings. These enforce regulations include childhood immunization programs, regulations and laws for research activities, professional codes of conduct, and quarantine standards.

Despite the types and categorizations of paternalism as a philosophical theory, there is a heated debate regarding the basic, fundamental form of paternalism which challenges the concept of autonomy and liberty.

Unlike liberalism, which is considered an “anti-paternalistic political philosophy,”<sup>83</sup> paternalism is considered a philosophical theory, which is defined as, “Practices and actions are paternalistic when those in positions of authority refuse to act according to people’s wishes, or they restrict people’s freedom, or in other ways attempt to influence their behavior, allegedly in the recipient’s own best interests.”<sup>84</sup> Paternalism is the imposition of ideas or situations upon

people against their own free will; this jeopardizes individual autonomy and contradicts liberalism. Paternalism can be considered ethically justified; an example of this is when paternalism is utilized in the event of a pandemic due to the importance of isolation procedures to protect the community from infection, even when forced upon an individual.

Paternalism is typically perceived as a compulsory method that results in the deprivation of free expression of wishes and desires; this prevents the translation of these wishes into medical action, despite the rightness or wrongness of the action. This interference with autonomy and free action is considered an intrusion upon human nature and liberty. Therefore, many scholars perceive paternalism as an extreme philosophical theory which oppresses the actions of individuals with the goal of ensuring common goodness and mutual benefit.

These scholars base arguments in opposition to paternalism upon two basic fundamental claims. The first claim is that paternalism fails to respect people as human beings that are capable of making wise and rational decisions regarding their wellbeing.<sup>85</sup> The second claim is that paternalism leads to social inequality by assuming that there are people who are wiser and more rational than others, therefore giving these people the right to dictate the matters of fellow human beings.<sup>86</sup>

Even scholars that support paternalistic practices understand that these practices should be implemented in moderation and limited to few and specific occasions.<sup>87</sup> These scholars argue that paternalistic applications should be less intrusive especially when executed by the state or authoritative agencies; Conly states, “No reasonable paternalist (and this includes me) thinks that legislation should control every aspect of life.”<sup>88</sup>

There are many forms of state methods of paternalism that vary in scope, nature, and degree, which have been enforced and practiced by governments around the globe.<sup>89</sup>

Examples of paternalistic applications include laws, regulations, codes, and social norms, which aim to regulate, discipline, and tame the behaviors of people. These methods are developed to influence the behaviors and relationships of people in relation to the state and other members of the community. Those who reject these laws of social norms typically trespass against these laws and clash with societal norms.

The scholarly, philosophical justification for paternalistic practices in society influences moral and ethical norms that stress social applications, interpersonal relationships, supporting others, beneficence, and none-maleficence. Therefore, the ethical framework justifying paternalism is due to the intention to promote goodness, prevent wrongness, and solve social problems. When evaluating norms, “many moralists appeal to what they call “intuition”<sup>90</sup> or “considered judgment.”<sup>91</sup> Moralists use intuition to identify cases that are morally prohibited, permitted, or obligatory. The concept of using intuition to justify paternalistic practices allows vulnerability to coercive and overbearing paternalistic practices within social systems. According to Wertheimer (2011), reasoning can determine the goodness or badness of actions, and logic through the doctrine of common rule justifies paternalism that is aimed to protect vulnerable groups.<sup>92</sup> Conly states,

Others accept paternalism, whatever the state of the agent, if the harm that will come from his action is sufficiently great and sufficiently immediate – thus, we see widespread acceptance of seat belt laws, even for adults who are sober, rational, competent, and so on, because they so clearly prevent great harms in circumstances where there is no other way to stave off the damage that will otherwise ensue.<sup>93</sup>

The theory of paternalism is often associated with totalitarian or oppressive regimes; similarly, the definition of paternalism contradicts autonomy and freedom in literature. Paternalism is a popular concept that is supported by philosophical arguments and capable of providing practical solutions to public health issues. A range of public health issues, including

mass immunizations against endemic diseases, childhood immunization programs, fair distribution of medical care, equity, seat belt laws, biomedical research laws, quarantine procedures, and organ donation lists, utilize paternalistic methods to arrange scarce resources, protect the community, and achieve social justice through direct interventions.

John Kultgen supports the notion of serving the society based on the promotion of good in his statement, “Real societies are not composed of fully developed and completely caring people. People who do care must deal with many who do not.”<sup>94</sup> Therefore, it can be assumed that the primary motive behind the adoption of paternalistic methods is due to its effectiveness, practicality, and usefulness in justifying and enforcing public health policies.

Many public health agendas are not agreed upon and require the implementation of practical, radical and effective policies; these new policies would better serve the public in a feasible manner, thereby securing social justice. An example of this is public law that mandates the use of helmets on motorcycles. These laws were enacted to promote goodness and safety, and reduce fatal injuries<sup>95</sup> in addition to reducing medical expenses resulting from traffic accidents. The reduction of these medical expenses consequentially frees up scarce resources that can be used to serve other healthcare needs.

In addition, the fulfillment of the moral obligation of distributive justice has caused law makers to consider the benefits of protecting and promoting health rather than falter due to the objections from opponents. In addition, individuals who oppose laws of compulsion present ambiguous claims for autonomy which hinder the protection of public interest and formulation of feasible regulations; this is supported by Conly, who states, “Most people grant that paternalism is a good idea in at least some situations where people pick poor means to their ends.”<sup>96</sup>

Many philosophers reject paternalistic practices in order to respect the autonomy of people, even the choices that result in harmful outcomes. Paternalism may be partially or totally opposed, as rejection of these practices becomes more radical when carried out by the state. The classic argument against paternalism is that it fails to respect individual rationality and choice making. In addition, paternalism is perceived as a serious threat to personal liberty, human dignity, and human rights; therefore, it is perceived that the rejection of paternalistic practices is morally obligatory. John Stuart Mill is a philosopher that rejects paternalism.<sup>97</sup> Contrary to the theory of utilitarianism,<sup>98</sup> Mill's philosophy promotes the concept of liberty and the right to autonomy. In regards to social responsibility and the role of civilized communities, Mill approves the theory of paternalism to produce social goodness and prevent wrongful acts. Mill permits paternalistic methods to be used by policymakers in cases such as the development of laws regarding the education of children.<sup>99</sup> In addition, Mill permits these practices to be used as preventative action to decrease harm to others as embodied in the statement, "Your freedom to swing your arm ends where my nose begins;"<sup>100</sup> this includes situations such as self-infliction of harm. In *The Harm Principle*<sup>101</sup> Mill permits paternalistic methods aimed to prevent harmful action that cannot otherwise be prevented when relying on the person's own autonomous and rational judgment; paternalistic methods are especially supported when such actions cannot be overlooked or morally reduced. A category of accepted paternalism is described as, "the attempt to impose limitations on someone or to require actions by someone for his her own good."<sup>102</sup>

According to Mill, there are two situations that permit paternalistic action to protect the rights of the patient; these situations include, "(1) with children because it is assumed that they are incapable of deciding on their own behalf, and (2) with those who, because of cognitive limitations, cannot choose on their own behalf."<sup>103</sup>

Despite Mill's claim to individuality,<sup>104</sup> the idea of using paternalistic methods to limit self-harm and harm to others is a widely accepted argument. According to Sullum, "Most public health practitioners would presumably recoil at the full implications of the argument that government should override individual decisions affecting health because such decisions have an impact on society as a whole."<sup>105</sup> This perspective is shared by many writers, including Robert Goodin (2007), who provides an example of "favor[ing] a restriction on smoking;"<sup>106</sup> in this example, he demonstrates that such an intrusion upon the autonomy of people by restricting harm to one's self or others by smoking is permissible, and benefits the society at large "relying on utilitarian thinking."<sup>107</sup> Collectively, Beauchamp and Goodin support the imposition of coercive paternalistic practices upon those demonstrating self-harm behaviors or those ignorant of gross danger, with the condition that these practices must be limited to a certain period.<sup>108</sup>

Opposition to paternalistic practices is perceived by many as noble or admirable, especially when it challenges coercive measures or suppressive regimes. In reality, this opposition is impractical and obstructs the promotion of public health programming aimed to advance common social good. For example, the most widely used public health methods to promote health awareness and protect people are education, taxes, prohibition;<sup>109</sup> all of which are paternalistic practices. Nevertheless, there is reason for caution; "Educational efforts are the least intrusive on the claims of individual autonomy but can pose unique questions when they begin to employ manipulative strategies."<sup>110</sup>

The concept and applications of paternalistic practices in public health are common. Therefore, paternalistic methods that are aimed to promote public safety are permissible and employed by healthcare policymakers when developing and launching health programs.

In public health, the practical theory of paternalism is relatively acceptable and widely practiced. Paternalistic practices in healthcare settings and biomedical research are dissimilar, as paternalism is generally considered unethical and unacceptable in healthcare settings. This is especially the case when these methods are used by healthcare providers or patient families, which oppose a rational patient's choices and force treatments or procedures upon the patient.

With the exception of Mill's argument for the permissibility of paternalism, the justification for these practices is when it promotes goodness in the cases of children and incompetent patients, who will then be assigned a legal guardian to provide consent.<sup>111</sup> A legal guardian can represent the child's wishes according to the guardian's best judgment and the good of the patient.

Unfortunately, in situations where people represent the interests of others and make research-based and medical decisions, there is the potential for a caring gesture to turn into paternalistic and coercive practices. Therefore, there must be a distinction between enabling loved ones to treat incompetent patients according to their best judgment and rationalizing paternalistic practices in medical settings that does not serve the patient's interests.

The debate over the ethical legitimacy of paternalism focuses on the charge that it violates individual autonomy and choices. It is assumed that even with the best intentions, paternalistic methods limit the ability of individuals to express their wishes and translate those into actions, regardless of the wisdom or appropriateness behind it. Sarah Conly (2013) rejects paternalism because it fails to respect the ability of rational individuals to make decisions and due to its promotion of inequality by determining that some people are wiser than others, and therefore have the right to make decisions for them. In contrast, paternalism is defended by some scholars including John Kultgen (1995), who claim that it safeguards "real societies" by allowing



people to aid and protect those who cannot do so for themselves, while implementing Mill's restrictive interpretation of paternalism as a way to limit harm.

Paternalism in Saudi healthcare is widely practiced and considered culturally acceptable in many local communities. This is because paternalistic healthcare, in its most abstract form, is associated with the theory of communitarianism which gives family authority over individual needs and choices. Therefore, in Saudi Arabia and many Eastern cultures, the family frequently intervenes in the decision-making process for patients within medical settings. Alshahri (2002) recommends that healthcare workers seek out and consult an appropriate male presence when attending to female patients; this gesture is regarded as acknowledgement and respect for Saudi cultural specifications.

Mobeireek et al.'s (2008) study recommends the incorporation of the families of patients in the decision-making process, as the authors conclude that the majority of Saudi patients prefer a family-centered approach to healthcare. This demonstrates that the inclusion of family in medical decision-making on behalf of patients comes from culturally-based paternalistic practices from relatives of the patients.

Paternalistic practices from healthcare providers are a widely practiced norm in Saudi hospitals. Abolfotouh and Adlan (2012) write, "Aside from these limitations, the results of this study suggest either those patients are not aware of their rights or that physician paternalism is practiced in Saudi Arabia."<sup>112</sup>

Paternalism in Saudi medical settings is justified based on the following: cultural specifications, organizational causes, religious reasoning, and scholarly validations. Manne Sjostrand et al. (2013) argue that paternalism protects individual autonomy as it prevents harm to patients;<sup>113</sup> this is supported by John Kultgen's (1995) account, as mentioned previously.

According to these perspectives, the restriction of patients' choices through paternalistic practices is mandatory to protect patients in medical settings, in addition to social and political venues. For example, restricting patient autonomy to prevent practices such as euthanasia is widely practiced in healthcare systems around the globe with a few exceptions. The argument in support of restricting patient autonomy is justified based on religious and philosophical reasoning. However, the application of paternalistic practices in less serious situations such as undergoing beneficial treatments is justified differently. This support for paternalism is determined based on the patient's specific social and medical situations. For example, if the patient and family are illiterate and are limited in knowledge regarding the illness and the appropriate interventions, paternalistic practices are supported and it is appropriate if the healthcare professional suggests a specific course of action for the patient.

Paternalistic practices by healthcare providers in Saudi Arabia result from the cultural perceptions of high regard for physicians, assuming that physicians know better what ought to be done. Therefore, patients and families typically accept physician's decisions, typically without questioning their instructions or motives. This puts physicians in favored positions that sanction paternalistic practices. This is not a concept that is specific to only Saudi, Arab, or Islamic cultures, as many cultures permit these practices.

In addition, paternalistic practices by healthcare professionals relate to the absence of organizationally-based regulations that promote patients' rights by educating professionals and patients of their roles and rights. Among these rights is the right to be free from coercive and patronizing medical care.

As an organizationally-based barrier, paternalism in Saudi healthcare is aggravated by language barriers between healthcare professionals and patients; this can permit cultural

incompetency which puts healthcare providers in a position to exercise paternalism. As communication affects the patients' experience in healthcare settings, Rhea Racque and Yvan Leanzo (2015) write, "...adequate communication fosters the development of a satisfactory relationship, allows patient and physician to engage in proper information exchange, decide on a treatment plan, and ensure adherence to treatment."<sup>114</sup>

If healthcare organizations disregard the education of healthcare professionals regarding their roles and limitations in patient care, then paternalistic practices become habitual and normative.

Paternalism is typically practiced upon vulnerable groups in Saudi healthcare settings; this includes when families do not allow individuals to consent or choose the course of treatment. Religious teachings also justify the overprotection of female patients by male acquaintances based on the assumption that Islamic teachings mandate such practices; however, Islamic teachings do not support such paternalistic practices, it is the dominant culture that is responsible for such practices. People often mix religious canons and cultural customs, which make the separation between divine and culture norms difficult, especially in religious societies such as Saudi Arabia.

In regards to the dilemmas of paternalism and autonomy, and to compensate for the paternalistic healthcare practices aggravated by the passiveness of patients due to the lack of knowledge regarding their own rights, several scholars suggest approaches to address these issues in healthcare settings. In *Medical Paternalism Serves the Patient Best*, L.S. Lim (2002) suggests guided paternalism. Lim suggests a balance between absolute paternalism brought on by principles of harm, welfare, and legal moralism, and limited practices due to the fear of harmful paternalism, as demonstrate by failing to guide patients through the medical process by

withholding professional and expert recommendations.<sup>115</sup>

As related to Lim's suggestions, Chin (2002) mentions the following approach, "An approach that serves the patient best is probably one that promotes a harmonious marriage of beneficence and autonomy. By sharing the decision making, the meaning, richness and accuracy of patient's choices can be enhanced by the physician's recommendations and advice."

Finding a balance between professional paternalism and absolute, unrestricted self-ruling is the best approach for Saudi healthcare systems. With this approach, medical illiteracy and limited patient knowledge will be compensated by a process guided by professionals which allows patients to choose freely without imposing options upon them. However, such methods including "guided paternalism" require collective efforts to attain the desired outcomes.

As suggested previously, educating patients of their rights in medical settings includes special attention to the cultural specifications contributing to the problem; this will help to decrease the victimization of patients to paternalistic practices in healthcare settings. Setting limits, educating healthcare professionals regarding the ethics of care and communication, and enforcing policies and standards will help to eliminate paternalistic practices in Saudi healthcare. A discussion of confidentiality in Saudi healthcare will follow.

#### **6.4 Confidentiality in Health Care**

Nass et al. state, "Medical records can include some of the most intimate details about a person's life. They document a patient's physical and mental health, and can include information on social behaviors, personal relationships, and financial status."<sup>116</sup>

The increasing demand upon healthcare services by growing populations has resulted in discussions regarding the regulation and organization of the system. This includes medical care

ranging from basic general practices, to hospital services, to rehabilitation centers, and to extended hospice services. Each of these healthcare facets requires standard regulations and binding laws to ensure the functional and professional practice of healthcare providers.

Throughout the history of medicine, ethical care has been focused on physicians and their work, and physicians practiced medicine according to their knowledge and personal ethics. Due to current reality of medicine and the complexity of healthcare, systems around the world have been introduced to social and legislative entities to protect patients' rights in medical settings.

Nations around the world have introduced legislations and policies that govern healthcare services in regards to confidentiality, healthcare data privacy, and patient information.

These governmental policies ensure morality in healthcare by protecting the individual's rights and safety through autonomy and confidentiality. A primary issue concerning governmental agencies and individuals is confidentiality and infringement of privacy in healthcare. Sharyl Nass et al. (2009) writes, "Surveys show that medical privacy is a major concern for many Americans"<sup>117</sup>

There are numerous and variable issues of confidentiality; for example, people are concerned with the confidentiality of their medical information from the doctor's office to pharmacies or to other hospital departments. There is great concern for protecting information from unauthorized third parties, which affects individual safety and reputation.

The role of confidentiality in healthcare is crucial to protect and promote patients' rights and wellbeing, and any disclosure of patient information to a third party without consent is an invasion of patient privacy.

Many healthcare workers fail to protect patient information that has been entrusted to them. Chris Cox (2015) argues that many healthcare workers do not know how much and what

information is appropriate to disclose to third parties,<sup>118</sup> therefore violating the moral boundaries that dictate the relationships between healthcare providers and patients.

Confidentiality in medical ventures, the constitution of confidential information, and the importance of protecting confidential information in medical settings will be elaborated upon. After this discussion, a practical example of laws protecting confidentiality in medical settings such as HIPAA will be provided, and confidentiality in Saudi healthcare settings will be elaborated upon.

This discussion of confidentiality represents a crucial issue regarding bioethics in Saudi healthcare settings, which includes confidentiality of medical information and the role of third parties in collectivist culture. Barriers to confidentiality in Saudi medical settings have cultural roots that must be examined to implement improved biomedical ethical standards, thereby promoting patients' rights.

Tom Beauchamp and James Childress (2013) describe confidentiality as following, "Confidentiality is present when one person discloses information to another, whether through words or other means, and the person to whom the information is disclosed pledges, implicitly or explicitly, not to divulge that information to a third party without the confider's permission."<sup>119</sup>

When applied to healthcare settings, this general description of confidentiality means that any information the patient discloses to the caregiver is protected and regarded as confidential information. According to Tavaokkoli, Nejad sarvari, and Ebrahimi (2015), confidentiality in medical settings is regarded as an ancient concept, traced back to the Hippocratic Oath.<sup>120</sup>

Therefore, the relationship between physicians and patients is primarily based on principle of confidentiality. This is because the patient must trust the healthcare provider with private matters to better establish a diagnosis and treatment. If patients cannot trust the

healthcare provider, then the treatment will not reflect the true condition of the patient which can be deficient or harmful. Beauchamp and Childress consider this “consequences argument” as well as autonomy and the right to privacy arguments for confidentiality in healthcare settings.<sup>121</sup> Tavaokkoli et al. views this concept from a utilitarian perspective; by maintaining confidentiality in medical settings patients will be provided the assurance that disclosed information that is relevant and accurate will secure them the desired benefits.

According to this argument, patients will not trust healthcare providers that do not assure protection of confidential information. Therefore, confidentiality of patient information is necessary. In addition, confidentiality is based on the principles of respect for individual autonomy and rights to privacy. Accordingly, the justifications for confidentiality rely on the principle of respecting individual autonomy,<sup>122</sup> which is self-evident and have religious and rational validity and support.

The concept of confidentiality is not absolute,<sup>123</sup> as any information confessed by the patient that has the potential to harm themselves or others would void promise of confidentiality with the healthcare provider. Moral and legal statutes require healthcare providers to notify related authorities and people of the potential harm.<sup>124</sup>

Protection of confidentiality in medical settings is manifested through policies that ensure the privacy of healthcare data and the mechanism by which this data is protected. For example, the Health Insurance Portability and Accountability Act (HIPAA) in the United States is a lawfully binding act aimed to protect patient confidentiality; HIPAA as a practical method of protecting confidentiality in healthcare settings will be discussed further.

HIPAA organizes and facilitates medical correspondences to ensure the security of this information; this is known as “title 2 of HIPAA.”<sup>125</sup> Title one relates to insurance issues, title

three regards tax related health provisions, title four is concerned with the application and enforcement of group health insurance requirements, and title five relates to the revenue offsets.<sup>126</sup> HIPAA requires that healthcare providers comply with these standards to maintain operational certification for the business. HIPAA standards are important to promote healthcare business and to provide an ethical framework for facilities to operate within. Patient autonomy, none-maleficence, beneficence, and justice are justified and feasible within the standards of HIPAA title two; these standards adhere to the principles of biomedical ethics that are widely recognized in biomedical ethics as important moral tools, ensuring the morality of healthcare activities. HIPAA title two standards will be examined thoroughly to highlight its moral dimension, which proves that these regulations are crucial to conducting ethical healthcare services. Recommendations will be provided to minimize the limitations of HIPAA title two that may jeopardize the morality of HIPAA regulations.

The definition of HIPAA will be provided to increase understanding of its rules and regulations. According to Pabrai, “The Health Insurance Portability and Accountability Act (HIPAA) is about information efficiency, privacy, and security in the U.S. health care industry.”<sup>127</sup> Meanwhile, Sharyl J. Nass, Laura A. Levit, and Lawrence O. Gostin of the Institute of Medicine described HIPAA: “HIPAA was passed on August 21, 1996, with the dual goals of making health care delivery more efficient and increasing the number of Americans with health insurance coverage.”<sup>128</sup> Under HIPAA laws, title two requires healthcare entities to comply with rules and regulations related to electronic transmission of information and data.<sup>129</sup> Entities that must follow HIPAA regulations include hospitals, medical centers, pharmacies, private practices, and alike.<sup>130</sup>



Therefore, it can be concluded that HIPAA title two helps manage and improve the electronic healthcare system in addition to ensuring the maintenance of information privacy to promote individual autonomy;<sup>131</sup> however, other HIPAA titles help protect healthcare professionals from medical errors that may subject them to legal liability and professional misconduct, in addition to regulating general insurance and management issues.

Though HIPAA regulations are meant to enhance the performance of the healthcare sector, these rules affect all parties involved, including the care providers.

The benefits of HIPAA regulations will be illustrated to improve understanding of its moral value, and social and economic benefits. Benefits of HIPAA regulations fall into four main categories: medical, managerial, economic, and social benefits. Regulations related to medical benefits eliminate disease description and dosage errors. Managerial benefits result from proper filling, unified coding, and decreasing poor time management resulting from poor communication. HIPAA regulations unifying spoken language within the healthcare industry has resulted in increased understanding and confidentiality. The economic benefits of HIPAA regulations decrease claim time and dependency on paper correspondences in addition to its storage expenses. The social benefits of HIPAA regulations lead to an increase in privacy, encouraging individuals to make autonomous decisions regarding their health and the promotion of the moral dimension in healthcare services.

Protecting confidentiality in medical settings by using HIPAA or other governmental and private regulations set examples for other healthcare systems to better promote confidentiality and patients' rights.

Confidentiality in the Saudi medical setting has differing cultural specifications and organizational barriers. R. Fayed et al. (2013) identify unethical behaviors in Saudi Arabia

regarding the compromising of confidentiality at a rate of 36.3% of the surveyed healthcare professionals.<sup>132</sup>

For example, the mechanisms of obtaining medical attention and communication in Saudi society differ from the healthcare system in the United States. Del Pozo and Fins (2008) report that Middle Eastern patients often receive medical information through a proxy and make decisions regarding treatment with family participation. This reliance on family or a proxy infringes upon patient confidentiality, as the patient and healthcare provider no longer control the information and a third party is involved, which may result in the inaccurate disclosure of information or paternalistic practices.

These practices are native to Saudi culture, as in many community-centered societies, and do not provide a standard model of the confidentiality of healthcare data management. Almutair et al. (2014) notes that this process is not ethical or proper regarding the gaining and disclosing of confidential information according to Western ethical standards and practices.

From an Islamic and Saudi Arabian perspective, Ghiath Alahmad & Kris Dierickx (2014) find that confidentiality is necessary as a religious duty based on three principles. First, is that Islam forbids spitefulness, which is believed to occur during information disclosure to other parties. Second is the religious duty of preserving secrets of others and thirdly is the loyalty patients feel toward the treating healthcare provider;<sup>133</sup> the healthcare provider must meet such a gesture with trustworthiness and confidentiality.

According to Alahmad and Dierickx, the Islamic perspective towards confidentiality in healthcare produces fatwas regulating confidentiality issues in medical settings, “This lengthy fatwa ....addresses the obligation of maintaining medical confidentiality...”<sup>134</sup> Many fatwas produced by Islamic legislative centers inferring on confidentiality, are compatible with the

international principles and standardization concerning medical confidentiality.<sup>135</sup>

Islamic perspectives are related to official Saudi standpoints regarding confidentiality in medical settings; this “Saudi” perspective is not precisely followed by Saudis due to cultural specifications. According to Alshahri (2002), Islam is a main contributor to Saudi culture, “Saudis have a great deal of common cultural aspects with Arabs and Muslims worldwide. However, the Saudi culture, similar to every other culture, is still unique in many ways.”<sup>136</sup> Indeed every community has its cultural specifications, thus Saudi Arabia deduces its cultural specifications from Arabic heritage and Islamic traditions. However, Saudi Arabian cultures have different norms diverge from other adjacent bordering Islamic and Arabic cultures such as of Egypt or Syria.

As an example of the collectivist culture and Saudi perspective related to confidentiality, Saudis involve themselves with the affairs of their relatives and contribute to the discussion of the patient’s affairs. This is a typical process and custom of Saudi society, as they view patients as part of their family which require care while sick.

There are different degrees of involvement in the pursuing of medical information by relatives; it is more common if a patient is elderly or female but less intrusive and severe if the patient does not want to include family.

These practices relate to the process of obtaining informed consent in Saudi healthcare settings; as mentioned previously each of these matters are closely related to respecting patient autonomy and free will.

These practices concerning patient affairs and information confidentiality are not custom to non-collectivist cultures such as Western culture, as it is considered an act of infringement upon patient confidentiality and individualism.

Commitment to the confidentiality of healthcare data privacy in Saudi Arabian healthcare systems is subject to organizationally-based barriers. This is due to the varying policies, standardizations, and programs related to access and protection of confidentiality in healthcare facilities.<sup>137</sup> In addition, healthcare providers maintain differing views related to the disclosure of information to third parties; this can be related to the absence of protective and binding laws or personal preferences.

In conclusion, cultural collectiveness leads to the justification of family involvement in medical information and decision-making; this therefore displays confidential patient information to third parties. Islamic teachings in biomedical settings in Saudi healthcare, encourages the protection of confidential information. Therefore, by supporting Islamic teachings regarding confidentiality through the education and promotion of patients' rights, Saudi Arabians will prioritize the protection of personal and family's confidential information in healthcare settings. Practices that violate confidentiality based on cultural rationale will be disregarded, as Islamic teachings are prioritized in Saudi Arabia. The adoption of universal principles of biomedical ethics will enable the protection of patient confidentiality in Saudi healthcare settings because these practices are embedded in these standards.

In addition, individual consideration and solving of issues regarding informed consent, vulnerability, and paternalism in Saudi Arabia will preserve and protect confidentiality, as each of these matters are closely related to each other.

## **6.5 The UNESCO Universal Declaration on Bioethics and Human Rights and Saudi Health Care – Patients’ Rights as Inalienable Rights**

Prior to examining the UNESCO Universal Declaration on Biomedical Ethics and Human Rights from a Saudi perspective, a brief introduction to the UNESCO Declaration will be presented. This examination of the UNESCO Universal Declaration will demonstrate the feasibility of this document’s principles in local, Saudi settings.

According to Henk ten Have and Michele Jean (2009), the “UNESCO is directed by its constitution, adopted in November 1945, affirming that the purpose of the organization is ... ‘to contribute to peace and security by promoting collaboration among the nations through education, science, and culture in order to further universal respect for justice, for the rule of law and for the human rights and fundamental freedoms.’”<sup>138</sup>

Therefore, the principles of the UNESCO Universal Declaration are directly related to the fundamental principles governing UNESCO as an international organization.

The existence of this declaration regarding the ethics of biomedical activities requires the understanding of the need for fruitful collaboration between nations.

The UNESCO Universal Declaration on Bioethics and Human Rights ensures the focus and morality of biomedical work, a natural extension of previous efforts made by the international community to protect human rights. These previous efforts to protect human wellbeing include the Declaration of Human Rights, the Declaration of Helsinki, the Nuremberg Code, and the United Nations Declaration on Human Rights; each of these documents demonstrate the importance of the UNESCO Universal Declaration on Bioethics and Human Rights as a tool to ensure justice and equality in biomedical activities.<sup>139</sup>

The UNESCO Universal Declaration on Bioethics and Human Rights was presented and adopted by 192 member countries on October 19, 2005.<sup>140</sup> After six official preamble amendments<sup>141</sup> and many discussions, the UNESCO Universal Declaration on Bioethics and Human Rights came into existence to continue the legacy of bioethical standards.

Each of the principles from the UNESCO Declaration are derived from the common heritage of humankind therefore, these principles represent common norms and fundamental ethical virtues that human communities share.

This makes the principles of the UNESCO Universal Declaration easy to adopt and justifiable by any rationale in communities regardless of culture specifications, religions, traditions, and socio-economical differences.

The UNESCO Universal Declaration is significant due to its vast acceptance by nations, despite the non-binding nature of the declaration.<sup>142</sup> In addition, the principles of the UNESCO Universal Declaration on Bioethics and Human Rights aim to protect individuals from unethical biomedical activities and violations of human rights. The UNESCO Universal Declaration on Bioethics and Human Rights is crucial to professional education, as many member countries lack pertinent bioethical infrastructure and educational programs focused on these principles. The UNESCO Universal Declaration provides a bioethical framework to be followed in order to promote national bioethical standards and programs; ten Have and Jean state, “The standard setting activity of UNESCO in the area of ethics of science is important, since many Member States have only a limited infrastructure in bioethics. They lack expertise, educational programs, bioethics committees, legal frameworks and public debate<sup>143</sup>”

The universality of the principles from the UNESCO Declaration on Bioethics and Human Rights make it appealing and relevant to diverse communities; this is based on the

commonly shared understanding of human rights principles and the importance of protecting human dignity. In addition, the principles of the UNESCO Declaration are linked to biomedical ethical principles,<sup>144</sup> as many of the declaration articles are linked to principlism.

The concepts of autonomy, non-maleficence, beneficence, and justice are represented by the principles of the UNESCO Universal Declaration. This includes the principle of informed consent, as respect for patient privacy and autonomy as well as the protection of vulnerable groups are linked to the principle of autonomy. In addition, social responsibility, sharing of benefits and the principle of solidarity are relevant to beneficence.<sup>145</sup> Non-maleficence<sup>146</sup> is related to the protection of future generations, non-discrimination, and protection of the ecosystem. The principle of justice is represented by equity, distributive justice, and equality.

Therefore, the Declaration is accepted by the diverse members of the UNESCO due to the linking human rights and dignity and the principles of bioethics in the UNESCO declaration.

Ten Have and Jean state, “The aims of the Declaration are multiple. However, the most important aim is to provide ‘a universal framework of principles and procedures to guide States in the formulation of their legislation, policies or other instruments in the field of bioethics.’”<sup>147</sup> According to this statement, the purpose of the Universal Declaration is to guide the formulation of bioethical systems in different nations based on the principles of the declaration.

Despite the arguments for the importance of UNESCO Universal Declaration, there are scholarly reservations regarding the significance and feasibility of the Declaration in varying international venues. These reservations make some people entities hesitant to adopt the UNESCO Declaration. A brief discussion of the reservations regarding the UNESCO Universal Declaration will be reiterated.

David Benatar (2005) accuses international declarations, such as the Universal Declaration on Human Rights and the UNESCO Universal Declaration on Bioethics and Human Rights, of being minimal and vague, making it impossible for them to produce tangible guidance to the nations through enacted principles.<sup>148</sup>

This point is supported by Mary Rawlinson and Ann Donchin (2005),<sup>149</sup> and Cheryl Cox Macpherson (2006),<sup>150</sup> who claim that the Declaration is not universal due to its inability to account for cultural specifications, socio-economical inequalities, and gender realities; these considerations are crucial to provide true universality in its principles.

Michael Selgelid (2005) argues that the principles of the UNESCO Universal Declaration are written in absolute terms, thereby conflicting with each other; in addition, he states that the Declaration does not have a mechanism to determine the prioritization of these principles in order to avoid discrepancies.

It would be plausible to assume that the healthcare community in Saudi Arabia like any other intellectual community around the globe may have supporter and opponents of the incorporation of principles of the UNESCO Universal Declaration in local settings. However, there are no sufficient reports that discuss the UNESCO Universal Declaration on Bioethics and Human Rights and its feasibility in Saudi Arabia. Nonetheless, the Kingdom of Saudi Arabia has always been an active member of the UNESCO since 1946, taking part in bioethical commissions, boards, and committees, in addition to a number of conventions.<sup>151</sup>

The reservations Saudi Arabians may have regarding the feasibility of the UNESCO Universal Declaration in Saudi healthcare settings likely reflect those previously stated, including the vague, minimal, and culturally insensitive nature of the Declaration.



As a part of the modern, global healthcare system, the current Saudi healthcare system is subject to and governed by global standards and policies. These standards determine the work of modern healthcare organizations and influence the ethical issues within these settings. This includes quality assurance programs and hospital accreditation in the Saudi healthcare systems that determine its principles and standards from international programs such as the Joint Commission accreditation certificates, ISO rating programs, and many others.

The enforcement of various ethical codes, medical care standards, and accreditation principles in the healthcare sector<sup>152</sup> demonstrate the determination of the Saudi Arabian healthcare system to collaborate and cooperate internationally in medicine and allied sciences, including bioethics. It is a general rule in Saudi Arabian healthcare that these ethical codes, medical care standards, and accreditation principles must be compatible to local cultural norms and Sharia Law to secure the acceptance of these principles and guidelines.<sup>153</sup>

As demonstrated in previous chapters, UNESCO Universal Declaration determines its principles from the essences of human rights principles; this correlates with Islam, and therefore Saudi culture of practicing similar standards of human rights. Henk ten Have (2013) states that Islamic bioethics have been well represented by scholars during the formulation of the UNESCO Universal Declaration in 2004.<sup>154</sup>

Henk ten Have (2013) claims that Islamic bioethical standards should be treated as a part of global bioethics, rather than a distinctive bioethical form. This is supported by Manfred Sing (2008), who argues that the overemphasis of the distinct nature of Islamic biomedical ethics in regards to global bioethics by Muslim and Western scholars<sup>155</sup> is inaccurate.

It can be assumed that in general, Saudi Arabians accept the UNESCO Universal Declaration on Bioethics and Human Rights within their medical and local settings.

A discussion of patients' rights as inalienable rights will be discussed further to demonstrate the correlation of bioethical standards in Saudi medical settings with international healthcare systems; this will support the argument for the compatibility of the UNESCO Universal Declaration and Saudi healthcare settings.

Patients' rights in practical settings are enforced through codes and principles that take form in bulleted lists with concise wording which primarily address patients upon their arrival to medical settings. In healthcare systems around the world, patients' rights manifest through the patient's bill of rights (PBR). According to Salwa Elsobokey et al. (2014), PBR was first introduced by the World Health Organization (WHO) following the Declaration on Human Rights of 1948; since that time, PBR has played a crucial role in the determination of ethics in medical work as related to the patient and the promotion of patient rights in healthcare settings. Elsobokey et al. writes,

In 2006, the Saudi Ministry of Health defined the patient's rights as the policies and rules that must be preserved and protected by the health facility toward patients and their families and it declared the PBR. The Saudi PBR is composed of 12 items related to knowing patient and family rights and responsibilities, getting healthcare, privacy and confidentiality, safety and protection, respect and appreciation, participation in healthcare plan, treatment refusal, participation in research study, organ and tissue donation, health insurance and financial policies, clear and comprehensive declaration forms, and complains and suggestions policies and procedures.<sup>156</sup>

Despite the institution of the Saudi PBR in 2006, this bill is not well-represented throughout the Saudi medical communities and systems; this is due to the lack of patient, healthcare provider, and medical student<sup>157</sup> awareness of its existence. Saad Alghanim (2012) concludes this statement in his study involving patients and healthcare providers, demonstrating the lack of awareness of PBR in both of these groups.<sup>158</sup>

This lack of awareness is an issue within healthcare systems in Saudi Arabian and other countries; this is demonstrated in a study by Zahra Mastaneh and Lotfollah Mouseli (2013), who

came to similar conclusions regarding the republic of Iran.<sup>159</sup>

The purpose of this discussion regarding PBR in Saudi Arabia is to show the keen interest of these systems to introduce the culture of patients' rights and endorse it to patients, in addition to educating healthcare workers of the importance of PBR. The relationships between patients and healthcare workers as a result of PBR guidelines represent the commitment of Saudi policymakers to incorporate internationally endorsed principles to local Saudi settings.

Patients' rights are often determined to be inalienable rights; Terrance Mcconnell (2000) describes this concept: "...inalienable rights are ones that may never be taken from a person."<sup>160</sup> It can be concluded that such inalienable rights must be observed, respected, and promoted in all medical settings, including Saudi healthcare settings. In addition, regardless of the specific healthcare system a patient may be admitted to, in Western and Eastern countries, the inalienability of patients' rights warrants similar ethical treatments and due respect to all patients.

The inalienable nature of patients' rights exists in variable ways in healthcare systems due to the differing nature of patient's rights moral codes, or PBRs. The UNESCO Universal Declaration on Human Rights and Bioethics prevails as a universally acceptable, moral and ethical standard for patients' rights. The UNESCO Universal Declaration on Bioethics and Human Rights has great influence in biomedical ethics with potential universal applicability, given its special consideration for cultural competency, pluralism, and respect for diversity, as mentioned in article 12.

In addition, the generalized language and nonbinding implications of the UNESCO Universal Declaration contribute to its appeal; it provides a general framework that is acceptable to varying healthcare systems that promotes the development of their own standards.

## **6.6 Comparison between Bioethics in the Saudi Healthcare System, and Recent Practices of Biomedical Ethics in other Countries**

Many scholars including Tom Beauchamp and Amartya Sen, reject the idea of unique moral values that are solely associated with specific geographical region,<sup>161</sup> such as oriental values or western values. There are other scholars that believe the current international standards and laws regarding human rights and biomedical ethics are designed to address these issues based on Western ethical norms.

According to these perspectives, the prioritization of the principles of westernized international laws in biomedical ethical matters is due to the development of these principles within western countries. It is not surprising that international principles reflect western ideals and philosophies because of the pioneer work of contemporary western scientists and bioethicists, resulting in the enactment of these principles.

The influence of western moral philosophy, specifically European and American philosophy, and its applied ethics on universal biomedical ethics is profound.<sup>162</sup> Therefore, the rules and principles of biomedical ethics reflect the western focus on individualism, rather than collectivism, as a revered principle which emphasizes values such as autonomy and individualism in regards to biomedical ethics norms, social equity, and social justice.

Eastern biomedical norms focus on values of collectivism, giving precedence to community-oriented values rather than individual values.<sup>163</sup> Collectivism emphasizes the role of the community in the determination of individual medical decisions and healthcare ethical standards. Letty Kuan and Josephine Lumitao (2001) write, “In developing countries, the family assumes a moral importance it no longer has in the West.”<sup>164</sup>

Kuan and Lumitao regard Eastern families as a social unit, which shapes the relationships between its members, their environments, and other components of society; in addition, these relationships dictate the decisions made regarding education and healthcare decision-making.<sup>165</sup>

Western ethical theories, which constitute fundamental biomedical ethical standards such as informed consent and rights to privacy, are not simply accepted in many societies, especially less differentiated societies.

For example, respect for patient autonomy is perceived differently across cultures and its importance, scope and applicability are subject to cultural and religious interpretation. Kuan and Lumitao describe, “The closely knit structure of the Filipino family renders unacceptable Western principles such as autonomy, informed consent, and confidentiality.”<sup>166</sup>

Here, Kuan and Lumitao describe the principles of autonomy and confidentiality as Western values that are marginal to the Pilipino culture, and thereby in Philippines biomedical ethics.<sup>167</sup> This perspective represents local understanding and practices of biomedical ethics, in addition to the dominant culture, which contrasts with the fundamental basics of global biomedical ethics.

Biomedical research trials conducted around the world by multi-national entities frequently cross ethical boundaries; these ethical dilemmas occur due to the discrepancies between universal ethical standards and local cultural norms. For example, in many societies including developing countries, elder members of families have a strong influence in enrolling younger men and women to join biomedical trials, even against their own free will. In addition, local culture mandates that the researchers disclose a patient’s confidential information to the head of families, which can endanger the lives and reputations of the participants.

The universal form of respect for participant autonomy and right to confidentiality often conflicts with local customs; this is demonstrated in Philippine medical settings, as autonomy, informed consent, and confidentiality are viewed inversely from the local cultural perspective.

From the Saudi Arabian perspective, the maintenance of social norms in the collectivist approach to informed consent is detrimental to proper and culturally competent medical services. Patricia Marshall (2007) asserts the significance of the, “reality of cultural beliefs,”<sup>168</sup> and its unfavorable role in obtaining informed consent.

Bakur Jamjoom et al. (2010) present a comparative study concerning surgeons from the United Kingdom (UK) and Saudi Arabian and the practice of obtaining informed consent. The researchers find that Saudi surgeons impose paternalistic practices upon their patients, encouraging them to make decisions based on their opinions; it was found that this is not the case with the UK surgeons.

Fayez et al. (2013) proclaim that paternalistic practices of informed consent are decreasing in the Saudi healthcare setting in favor of proper, moral practices of informed consent due to global interaction with other healthcare systems through expatriate workers.<sup>169</sup>

Communities perceive and handle biomedical ethical issues and agendas based on the dominating culture, religious beliefs,<sup>170</sup> and socio-economic dynamics. In some underprivileged communities, certain biomedical ethical values are less influential than others; for example, access to medical services is more important than requesting healthcare services explicitly from a healthcare provider of the same gender. In many Islamic countries, basic healthcare services are congregated and are not of great concern; United Arab Emirates is an example of this concept.<sup>171</sup> This is noted by Mary Rider and Carole Makela (2003) in a comparison study regarding patients’ rights, as the researchers demonstrate that patients’ rights and consumer satisfaction vary from

one country to another.<sup>172</sup>

Contemporary bioethical discourse depends on international laws and regulations; this is due to the universality of biomedical work and parallel moral principles, which are believed to be shared by all humans as universal norms.<sup>173</sup> In addition, globalization requires the formulation of common moral standards and universal guidelines to solve the growing ethical challenges. Human communities are in need of the adoption of a unified set of guidelines to collectively solve biomedical challenges.

This is because biomedical problems are no longer localized or confined to certain geographical regions, as research activities, medical tourism, and advancing medical outcomes occur around the globe in diverse culture settings.

The normative work of local ethical agencies fails to address biomedicine and biomedical ethical concerns due to the inability to cope and identify current moral problems from a perspective utilizing traditional cultural norms. This may also occur due to the lack of exposure to similar situations or the novelty of the bioethical questioning, especially in high-tech settings such as genetic counseling, nuclear therapy, or cloning.

Therefore, local biomedical standards based on individual ideology or isolated norms cannot provide ethical solutions to protect people in medical settings in the same manner as universal guidelines. This is due to the complexity of biomedical ethical dilemmas and interpreted solutions made by local, inexperienced ethics workers. Biomedical ethics and patients' rights cannot be completely trusted to local bioethical agencies; this is because under the justification of cultural specifications, consequences such as female genital cutting can occur. Tom Beauchamp warns people of these concerns, as he proclaims that the government ascribes to claims of cultural specification to surpass people's rights.<sup>174</sup>

## **6.7. Conclusion**

This chapter has examined prevalent problems regarding biomedical ethical concerns in Saudi healthcare systems; these are considered to be crucial barriers to the advancement of universally acceptable bioethical standards in Saudi Arabia. The concept of patient autonomy has been discussed in regards to the numerous biomedical ethical principles in Saudi Arabian healthcare settings. Informed consent, vulnerability, paternalism, privacy, and confidentiality in medical systems have been discussed to highlight the reality of biomedical ethics in Saudi healthcare systems.

Barriers to these biomedical topics have organizational and cultural causative factors; the dominant culture and healthcare organization of Saudi Arabia contribute to the issues of informed consent, vulnerability, confidentiality, and autonomy in medical settings.

This chapter has elaborated upon the UNESCO Universal Declaration on Bioethics and Human Rights and its feasibility in Saudi healthcare systems. It has been determined that the Universal Declaration is the most general, culturally competent and comprehensive form of international biomedical ethical regulations. Therefore, the incorporation of the Universal Declaration into the Saudi medical system will improve ethical ventures in healthcare systems; the Universal Declaration is feasible in Saudi healthcare settings due to its compatibility with the culture and Islamic religion.

Finally, this chapter has examined issues arising from the varying acceptance of biomedical standards in international healthcare settings. It has been concluded that cultural and socio-economic dynamics are fundamental to bioethical discourse, and therefore effects the prioritization of bioethical issues in international settings.



Notes:

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- 1 Tom Beauchamp and James Childress, *Principles of Biomedical Ethics*. 7<sup>th</sup> ed (New York: Oxford University Press, 2013), 101.
  - 2 Beauchamp and Childress, *Principles of Biomedical Ethics*. 7<sup>th</sup> ed, 101.
  - 3 John Kultgen, *Autonomy and intervention: Paternalism in the caring life* (New York: Oxford University Press, 1995), 113.
  - 4 Kultgen, *Autonomy and intervention: Paternalism in the caring life*, 113.
  - 5 Elmar Doppelfeld, “Appropriate Regulations for Different Types of Medical Research,” in *Human Rights and Biomedicine*, ed. André den Exter (Antwerpen: Maklu, 2010), 109.
  - 6 Sharyl Nass, Laura Levit, and Lawrence Gostin, eds., *Beyond the HIPAA Privacy Rule: Enhancing Privacy, Improving health through Research* (Washington DC: National Academies Press, 2009), 75.
  - 7 Karen Judson and Carlene Harrison, *Law and Ethics: For the Health Professions* (New York: McGraw Hill Higher Education, 2013).
  - 8 Jacob Rendtorff, “The limitations and accomplishments of autonomy as a basic principle in bioethics and biolaw,” in *Autonomy and Human Rights in Health Care*, ed. David Weisstub and Guillermo Pintos (Dordrecht: Springer, 2008), 75.
  - 9 Agomoni Ganguli-Mitra and Nikola Biller-Andorno, “Vulnerability in Healthcare and research Ethics” in *The SAGE Hand Book of Health Care Ethics: Core and Emerging Issues*, ed. Ruth Chadwick, Henk ten Have and Eric Meslin (Los Angeles: SAGE Publications, 2011), 241.
  - 10 Henk ten Have, “Respect for Human Vulnerability: The Emergence of a New Principle in Bioethics,” *Bioethical Inquiry* 12, no. 3 (2015): 395.
  - 11 Sheila McLean, “Respect for Human Vulnerability and Personal Integrity,” in *Handbook of Global Bioethics*, ed. Henk ten Have and Bert Gordijn (Dordrecht: Springer, 2014), 106.
  - 12 Samia A. Hurst, “Vulnerability in Research and Health Care, Describing the Elephant in the Room?” *Bioethics* 22, no. 4 (2008): 191-194.
  - 13 ten Have, “Respect for Human Vulnerability: The Emergence of a New Principle in Bioethics,” 395.
  - 14 ten Have, “Respect for Human Vulnerability: The Emergence of a New Principle in Bioethics,” 395.
  - 15 UNESCO, “The Principle of Respect for Human Vulnerability and Person Integrity: Report of the International Bioethics Committee of UNESCO (IBC),” in *United Nations Educational, Scientific and Cultural Organization* (Paris, France: UNESCO, 2013).
  - 16 Hanneke van der Meide, Gert Olthuis, and Carlo Leget, “Why frailty needs vulnerability: A care ethical perspective on hospital care for older patients,” *Nursing Ethics* 22, no. 8 (2015): 860-869.
  - 17 Maria Neves, “Respect for human vulnerability and personal integrity,” in *The UNESCO Universal Declaration on Bioethics and Human Rights: Background, principles, and application*, ed. Henk ten Have and Michele S. Jean (Paris: UNESCO Publishing, 2009), 155-164.
  - 18 Michael H. Kottow “Scientific Contribution Vulnerability: What kind of principle is it?” *Medicine Health Care and Philosophy* 7, no. 3 (2004): 281–287.
  - 19 Ganguli-Mitra and Biller-Andorno, “Vulnerability in Healthcare and research Ethics,” 242.
  - 20 Ganguli-Mitra and Biller-Andorno, “Vulnerability in Healthcare and research Ethics,” 239.

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- 21 Jan Helge Solbakk, "Vulnerability: A Futile or Useful Principle in Healthcare Ethics?" in *The SAGE Hand Book of Health Care Ethics: Core and Emerging Issues*, ed. Ruth Chadwick, Henk ten Have and Eric Meslin (Los Angeles: SAGE Publications, 2011), 228.
- 22 Hamza Hammad, "Persons with Special Needs, a Comparative Study of Islamic Jurisprudence vs. Arab Laws: UAE Law as Case Study," *Issues in Law & Medicine* 29, no. 2 (2014): 244.
- 23 Rendtorff, Jacob Dahl, "Basic ethical principles in European bioethics and biolaw: Autonomy, dignity, integrity and vulnerability—Towards a foundation of bioethics and biolaw," *Medicine, Health Care and Philosophy* 5, no. 3 (2002): 237.
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## **Chapter Seven: Recommendations, Clarification, and Summary**

This chapter consists of three interrelated sections; the first section provides recommendations to maximize patients' rights in Saudi healthcare systems by incorporating the Islamic notion of beneficence, *Masl'aha*. This is followed by recommendations for Saudi biomedical systems to promote patients' rights in accordance to international, bioethical standards and to adopt organizational and bedside changes for improved care.

The next section clarifies any outstanding debates regarding the importance of Islamic bioethics and Arabic culture in the determination of contemporary Saudi healthcare bioethical norms; this therefore, constitutes the biomedical activities in this country. The dominant culture and Islamic teachings will be assessed, deliberated upon, and considered when discussing collaborative work between Saudi healthcare systems and international bioethical efforts. This will include a discussion of the universal principles of bioethics within Saudi healthcare systems.

This section will also stress the applicability of the UNESCO Universal Declaration on Bioethics and Human Rights in Saudi healthcare settings, given the importance of Islam to Saudi culture and the related moral values and ethical principles of the declaration.

The third section of this chapter will summarize this dissertation. The key points will be discussed to provide a precise and comprehensive conclusion.

### **7.1 Recommendations**

This section is dedicated to providing practical recommendations that promote the concept and practices of patients' rights in Saudi healthcare settings. It is recommended that the Islamic notion of beneficence, *Masl'aha*, ought to be incorporated into Saudi biomedical settings; the integration of this concept will foster religious and cultural contributions to the

ethics of Saudi healthcare. This will be followed by practical recommendations aiming to promote patients' rights in Saudi healthcare systems. These recommendations involve changing perspectives and the incorporation of organizational and bedside techniques that support patients' rights activities.

### **7.1.1 Maximizing Patients' Rights through the Incorporation of an Islamic notion of Beneficence (*Masl'aha*)**

Ayman Shabana (2014) argues that many Muslim scholars are concerned with the representation of Islamic traditions based on "pure rational grounds;"<sup>1</sup> these scholars employ this concept when defending Islamic traditions against other religious and philosophical arguments. According to Abdul-Aziz Sachedina (2008), secular bioethicists have only recently begun to consider religious reflections in bioethical matters.<sup>2</sup>

The rational justification of religious perspectives makes these outlooks significant, resulting in the accommodation of numerous, distinctive views. This enables those in opposition to these perspectives the opportunity to work in harmony with religiously-based standpoints to accomplish related tasks. For example, Islamic variables are considered when passing Islamic laws, absent of precedent verdicts; Mohamed Rady and Joseph Verheijde (2014) write, "Social contexts may be considered in the interpretation of the Islamic moral code about human acts that are not mentioned in the Quran or Sunnah."<sup>3</sup>

In order to promote patients' rights and wellbeing in medical settings, bioethical matters require the aligning with various perspectives. Raymond De Vries (2014) reminisces the origins of bioethics, as this concept is the mixing of contrasting ethical perspectives; the author states, "Bioethics was born in a context characterized by moral pluralism and shifting ideas about the

nature of moral authority; it was, and is, an effort to develop a set of principles and a method for moral decision-making acceptable to all, regardless of one's religion or ideology.”<sup>4</sup>

The rationalization of religious perspectives is imperative and challenging when dealing with secular perspectives and nonreligious scholars. Therefore, the practical rationality of religion is crucial to the validity of religion in biomedical settings. The rationalization and justification of religious positions has practical implications; for example, the promotion of religious influences in Saudi Arabian healthcare settings will boost the physiological and psychological wellbeing of patients.

A contemporary example of Islamic concepts and practical models will be provided that compare to other philosophies; this enables mutual collaboration between international entities and Islamic philosophy in regards to bioethics. The concept of beneficence in Arabic and Islamic literature, known as *Masl'aha*, will be discussed further.

*Masl'aha* is a practical solution to promoting patients' rights in medical settings. This concept represents the practicality of Islamic religious teachings and pragmatism in regards to biomedical ethics.

According to Felicitas Opwis (2010), *Masl'aha* is an important judicial tool and theological mean capable of providing religious judgments on biomedical issues; the author states, “In its relationship to what is referred to as the purposes of the Sharī‘a (maqāṣ id al-sharī‘a) *Masl'aha* is one of the main procedural vehicles to address legal change.”<sup>5</sup>

Al-Ghazali<sup>6</sup> and Al-Shatibi<sup>7</sup> are among the Muslim theologians that develop and elaborate upon the concept of *Masl'aha*. *Masl'aha* contributes to sources of Islamic ruling in order to address biomedical issues; these issues require Islamic-based verdicts, especially when there are no previously passed verdicts or when there are contrasting rulings and perspectives.

*Masl'aha*, which corresponds to the maximization of utility, social benefit,<sup>8</sup> and common good, is an original, Islamic concept that favors actions based on the anticipated outcomes; therefore, *Masl'aha* is widely recognized and permitted by religious scholars of Islamic schools.<sup>9</sup>

The disregard for religious rulings and theological obligations can be permitted through maximizing *Masl'aha*, to attain personal and public goodness.<sup>10</sup> For example, according to Islam, the consumption of pork products and alcoholic beverages is prohibited; these prohibitions can be conditional in cases of *Darura*, or neediness and restrictions can be lifted.<sup>11</sup>

The utilization of *Masl'aha* in medical settings influences and justifies interventions as they become more prominent or necessary; Sherine Hamdy (2008)<sup>12</sup> supports this, arguing that when it is necessary, or *Darura*, the Islamic method of *Masl'aha* legally permits certain prohibited acts.<sup>13</sup> For example, Islam prohibits the practice of abortion; under the concept of *Darura*, this practice can be allowed in order to preserve the woman's health.<sup>14</sup>

The incorporation of *Masl'aha* to address biomedical ethics issues is appealing, especially in conservative communities such as of the Saudi Arabia; this is due to the ability for *Masl'aha* to reason and prioritize principles or resources in a practical manner without compromising religious validation. For example, organ transplantation is permitted and justified based on *Masl'aha*, as common good occurs as an outcome;<sup>15</sup> in addition, public or religious communities accept such rulings because of its religious rationalization.

In addition, *Masl'aha* has been implemented in healthcare systems for a long time. Examples of this are the required public health measurements such as immunization programs and health quarantines that aim to maximize benefits of the community (*Masl'aha*). Therefore, *Masl'aha* can be used to promote patients' rights in Saudi medical settings by justifying and advocating for programming based on the Islamic perspective regarding these issues.

The advancement of patients' rights occurs by advocating for the common good of Saudi populations; this is the case when the concept of *Masl'aha* is emphasized in healthcare settings to workers, patients, and families. For example, by stressing *Masl'aha* when advocating for organ donations, vaccination programs, or preserving resources, Saudi communities will approve of such initiatives. This concept draws upon the temperament of the Saudi religion, as it benefits the collective good and is compatible with the community's religious beliefs.

### **7.1.2 Promoting Patients' Rights through Changing Prospects, Enhancing Organizational and Bedside Approaches**

In order to promote patients' rights in Saudi healthcare settings, changes to perspectives regarding international bioethics must be incorporated. These changes will foster international collaboration in medical and bioethical care. For example, despite the disagreements over universal morals and the universality of biomedical ethical principles, as are rejected by Chattopadhyay and De Vries (2013)<sup>16</sup> yet supported by Ten Have and Gordijn (2011),<sup>17</sup> there are general agreements to provide feasible recommendations regarding patients' rights in Saudi healthcare settings based on universal bioethical principles.

This may require changes regarding the perceptions of universal values and preset, collective standpoints of international principles. This includes perceptions of the Declaration of Human Rights, which is perceived by communities and scholars as a western-designed initiative that ought to better incorporate occidental values and moral imperialism.

The claim of the westernization and inapplicability of international principles can be rejected based on rational and religious justification. For example, Saudi cultural norms that draw upon Islamic teachings and Arabic heritage correlate with fundamentals and applications of

international biomedical ethical principles. There are no fundamental discrepancies existing between the norms of the applications of international bioethical principles, including autonomy, confidentiality, and informed consent, and the ethical norms of Saudi Arabian in biomedicine as well as Islamic and Arabic culture.

The collaboration between internationally-enacted bioethical principles and Saudi Arabian healthcare agencies are theoretically and practically possible; this is demonstrated in the UNESCO Universal Declaration on Bioethics and Human Rights which is considered universally and culturally proficient. Therefore, the UNESCO Universal Declaration promotes and supports patients' rights in Saudi healthcare systems.

To overcome the barriers to proper implementation of programs advocating for patients' rights in the Saudi healthcare system, procedures to enhance organizational ethics and bioethical principles at bedside must to be integrated into the system.

Given that organizational culture is central to healthcare ethics,<sup>18</sup> the healthcare organization must address areas of weakness at an administrative and organization level before addressing ethical issues of patients' rights for the public and the internal stakeholders.<sup>19</sup>

The organizational structure and functionality as well as organizational ethics promote the proper infrastructure to implement desired policies of ideal practices of patients' rights.

National Saudi healthcare organizations such as National Guard hospitals, Armed Forces, and Ministry of Health must adopt standard patients' rights policies concerning to better implement ethical practice of patients' rights that correlate with international guidelines.

For example, the bill of patient's rights ought to be equally incorporated across all Saudi healthcare systems regardless of its specific agency; bin Saeed (1999)<sup>20</sup> states that codes of ethics for health professionals must also be unified and procedural manuals must be consistent

throughout healthcare settings to ensure standard practice. This involves the use of unified quality assessments and coalesced accreditation processing.

Saudi Arabian healthcare organizations must reevaluate methods of quality checking to become more efficient, well positioned, updated, internationally compatible, and centered on patient care. This is consistent with the desires of the Saudi healthcare system to advocate for a holistic approach to patient-centered care.

AlJarallah and AlRowaiss (2013)<sup>21</sup> and Alghamdi et al. (2014)<sup>22</sup> mention that medical information and data<sup>23</sup> must be reported properly; this is an example of the necessary organizational reformation and promotion of patients' rights in Saudi healthcare systems.

In addition, the handling of medical errors in a transparent manner can foster patients' safety and rights within the healthcare organization. Boyle et al. (2001)<sup>24</sup> suggests the implementation of an accreditation agency to correspond healthcare organizational ethics to those of JACHO, rather than using committees or "task forces" to resolve ethical issues. This will enable the identification of ethical dilemmas, in addition to the incorporation of these issues into education, consultation, and modification policies.

The recommendations made to promote patients' rights in Saudi healthcare are primarily concerned with issues of informed consent, confidentiality, paternalism, and labeling of vulnerable groups and their rights.

These areas must be reassessed via social and biomedical ethics to better incorporate proper practices of autonomy, confidentiality, and avoiding paternalism to improve quality of care. These goals can be achieved by directing energies and resources of care toward a patient-centered care model;<sup>25</sup> Rhea Rocque and Yvan Leanza (2015) refer to this as, "tailored intervention to patient preference,"<sup>26</sup> which devotes the best possible care that is aligned with

universal ethical values to the patient. Patient-centered care in Saudi Arabian healthcare settings allows for improved adoption of international ethical standards and practices, as required by the UNESCO Universal Declaration on Bioethics and Human Rights.

The education of patients regarding their medical rights is essential; these rights must be known to patients and respected by workers in healthcare settings. Patient education programs will fulfill the requirements of international patients' rights principles.<sup>27</sup> For example, when a patient is informed of their rights to autonomy and privacy, then the patient is likely to provide autonomous decisions and expect confidentiality. The patient's bill of rights, as enacted by the Ministry of Health, must be pursued and adopted throughout public or private healthcare entities. PBR requires this advocacy; ElSobkey et al (2014) and Saad Alghanim (2012) find that PBR is not popular or known by patients<sup>28</sup> or healthcare providers or medical students in Saudi Arabia.<sup>29</sup>

In order for PBR to be a success, there must be collective efforts to advocate and implement this practice, including those in management and patients themselves. Jean Clark (2011) mentions that patients are responsible to seek out appropriate patients' rights practices, which is related to the Joint Commission guidelines.<sup>30</sup>

Cultural competency must be addressed in Saudi healthcare to increase communication and proficiency between healthcare providers and patients;<sup>31</sup> in addition, the development of the culture of patient rights will be impacted. The concept of cultural competency can advance through programming, policies, and unified practices across different healthcare entities.

Increasing cultural competency among healthcare providers will allow increased understanding of the Saudi culture and Islamic religion; this will deter future conflicts occurring as a result of misunderstanding cultural customs or norms. Almutairi and Rodney (2013) find that cultural incompetence in Saudi medical settings jeopardizes the safety and wellbeing of



patients and healthcare providers.<sup>32</sup>

ALYateem et al. (2015) states the necessity of educating the healthcare workers.<sup>33</sup> Expatriate workers will benefit from attending a cultural competency program prior to treating Saudi populations; the knowledge of social and cultural customs will deter judgmental practices and promote neutral, patient-provider relationships. These relationships will lead to the promotion of patients' rights practices and improved overall experiences. Rocque and Leanza (2015) write, "For instance, adequate communication fosters the development of a satisfactory relationship, allows patient and physician to engage in proper information exchange, decide on a treatment plan, and ensure adherence to treatment."<sup>34</sup>

This section provides organizational and practical ethical suggestions to promote healthcare ethics in Saudi healthcare systems. The Islamic concept of *Masl'aha* is suggested to be incorporated into Saudi bioethical activities due to its rationalizing ability and its religious depth.

In addition, the unification of healthcare ethical principles, manuals, and codes across Saudi healthcare entities will allow for standardized quality checks and accreditation processes. This will permit the best practice of patients' rights, especially in healthcare entities that lack quality infrastructures and assessment programs.

The incorporation of universally-enacted biomedical ethical principles, such as the UNESCO Universal Declaration on Bioethics and Human Rights, and international accreditation agencies, such as the Joint Commission, will increase the ability of local entities to practice standard bioethical care and patients' rights. The following section will elaborate upon the relationship between Islamic biomedical ethics and patients' rights in Saudi Arabia.

## **7.2 Clarifying Reservations Regarding the Role of Religion and Culture in Saudi Healthcare Bioethics and the UNESCO Declaration on Bioethics**

As previously discussed, Islamic teachings have a prominent role in Saudi Arabian healthcare systems and bioethical matters. This section will focus on clarifying the relationship between Islamic teachings and bioethics in Saudi Arabia. In addition, the feasibility of the universal principles of bioethics in Saudi medical settings, such as the UNESCO Universal Declaration on Bioethics and Human Rights, will be discussed.

It is evident that religion and culture help to shape people's beliefs, especially in health care settings.<sup>35</sup> For example, there are many hospitals in the United States that are recipients of Catholic funds that refuse to provide abortion services to women based on religious reasons. According to Rachel Spector (2000)<sup>36</sup> and Stacey Langwick et al. (2012),<sup>37</sup> religion, culture, and ethnicity are the dominant forces that contribute to people's actions regarding situations of illness, birth, and death.

Therefore, religion and culture are persuasive social factors in healthcare settings; in conservative societies such as Saudi Arabia, these influences are prominent<sup>38</sup> and demand consideration for these social and practical influences.

Dariusch Atighetchi (2009) confirms the significance of Islamic teachings in the life of Muslims<sup>39</sup> and the Saudi cultural influence on bioethical practices; as mentioned by Asmaa Alyaemni et al. (2013),<sup>40</sup> this includes aspects of care such as informed consent<sup>41</sup>

In Saudi medical settings, ethical principles will be measured according to Islamic and cultural scales. Therefore, that which is considered compatible with Saudi culture and Islamic religion is considered feasible with Saudi healthcare settings. In regards to the Gulf Cooperative Council (GCC), Hamza Eskandarani (2008) writes, "The GCC states follow the *Sharia* (Islamic

Law) in all their ordinances.” This includes laws and standards regarding biomedical activities.<sup>42</sup>

In addition, Islamic teaching is rooted in Saudi culture in a manner that makes it difficult to distinguish between religious and cultural norms. Ayman Shabana (2013) writes, “In Muslim societies religious and cultural norms are sometimes confused but only the former are considered inviolable.”<sup>43</sup> Aasim Padela (2013) states that beliefs are often framed within religious contexts, even these beliefs are not actually religious.<sup>44</sup> Abdul-Aziz Sachedina (2009) recommends distinguishing Islamic and pre-Islamic norms, as both are considered interchangeable.<sup>45</sup>

Islamic laws constitute bioethical discourse in Saudi medical settings and shape related practices. Mohammed Albar and Hassan Chamsi-Pasha (2015) write, “As the growing literature shows Muslim jurists have been active in studying these contentious subjects and providing religious and ethical guidance in the form of fatwas (religious decisions) that are followed by healthcare providers in the Muslim world.”<sup>46</sup>

Many scholars claim that Islam constitutes a comprehensive set of moral codes and spiritual guidance for its followers, capable of protecting patients’ rights and moralities. In regards to bioethical norms, Islamic teachings promote ethical standards in healthcare settings according to international guidelines and recommendations. Daar and Alkhitamy (2001) write, “Because Islam shares many foundational values with Judaism and Christianity, the informed Canadian physician will find Islamic bioethics quite familiar.”<sup>47</sup>

Shanawani & Khalil (2008) argue that Islamic biomedical ethics benefit from ideals of Western bioethical standards, as the majority of medical breakthroughs and ethical discussions occur in Europe and North America.<sup>48</sup> Henk Ten Have (2013) claims that the Islamic position regarding bioethical principles correlate with principles of the UNESCO Declaration.<sup>49</sup> Tom Beauchamp (2010) demonstrates that Islamic teachings and Western bioethical philosophies

foster multicultural collaborations that minimize conflicts; rather, this collaboration stresses common virtues and universal norms, or the “common heritage.”<sup>50</sup>

According to scholarly opinions, Islam and contemporary biomedical ethical discourse are compatible, as both draw upon ethical and moral norms that are shared by all communities.

Whether the ethical principle has Western or Islamic origins, contemporary biomedical discourse aligns with Islamic bioethics; this can be considered reasonable to implement in Saudi healthcare settings. For ethical principles to be applied in Saudi healthcare settings, they must be compatible to Islamic laws and ethics; Shabana (2013) states, “I argue that respect for Islamic religious norms is essential for the legitimacy of bioethical standards in the Muslim context.”<sup>51</sup>

According to article twelve of the UNESCO Universal Declaration on Bioethics and Human Rights, cultural pluralism is crucial to determining bioethical principles; therefore, the UNESCO Universal Declaration on Bioethics and Human Rights is believed to be compatible with the Islamic and Saudi biomedical ethics.

Due to the compatibility of Islamic and international bioethical standards, the UNESCO Universal Declaration on Bioethics and Human Rights is applicable in Saudi healthcare settings.

In conclusion, this section addresses the applicability of Islamic and Saudi bioethics, as well as the universal principles of bioethics in Saudi healthcare systems. Due to the strong cultural influences of Islamic teachings in Saudi Arabia, which demonstrate respect for human rights in general and biomedical settings, these bioethical principles are deemed possible. The founding principles of bioethics are currently practiced in Saudi healthcare systems due to Saudi adherence to Islamic bioethics. This demonstrates that universal standards of bioethical practice are being practiced in Saudi healthcare systems.

There are special considerations for individual cultures when enforcing universal

bioethical principles, as different cultures have different ways to implement specific bioethical principles in communities; this is stressed by Shabana (2013), who recommends the fostering of international cooperation between cultures and UNESCO initiatives for bioethical activities.<sup>52</sup>

Biomedical ethical universality and international advocacy for universal adoption of applied biomedical ethical principles, namely the UNESCO Universal Declaration on Bioethics and Human Rights, enforces improved global ethics and enables the advancement of bioethical practices in local communities.

The UNESCO Universal Declaration on Bioethics and Human Rights results in the condemning of unethical biomedical practices in local communities. The UNESCO Declaration provides rational reasoning to provide judgement regarding harmful customs occurring in local communities, which may currently be justified by cultural specifications.

A comprehensive summary of the dissertation will follow in the next section.

### **7.3 Conclusion**

This study has discussed patients' rights in Saudi Arabia, opening with an overview to explain the subject at hand and followed by a discussion of the relevant social and cultural background of Saudi Arabia. The history, geography, socio-politics, and healthcare system of the country have been overviewed. This was followed by an elaboration upon the history of modern medicine and the developmental milestones of modern medicine. Finally, the history of biomedical ethics was discussed, in addition to contemporary declarations and ethical principles.

The following chapter mentions two interwoven relationships, involving the relationship between dignity and human rights and the relationship between human rights and the rights of patients. These relationships provide a foundation for the implementation of universal bioethical

principles in Saudi healthcare systems. In addition, issues of global bioethics, cosmopolitanism, and multiculturalism in regards to bioethics and international principles were discussed.

The role of Islam in the determination of normative principles of morality and the shaping of Muslim perceptions regarding biomedical ethics were highlighted. In addition, the sources of Islamic law and reasoning, as well as culturally-induced barriers to patients' rights in Saudi Arabia have been elaborated upon.

The role of the culture of healthcare organizations in the determination of patients' rights in Saudi Healthcare system has been mentioned. In addition, the influences of organizationally-induced barriers to proper biomedical ethical practice have been discussed, as related to Saudi healthcare systems.

There has been a discussion about the relationship between the UNESCO Universal Declaration on Bioethics and Human Rights and Saudi healthcare systems. The bioethical practices in Saudi healthcare have been compared to other healthcare systems, with a primary focus on the United States healthcare system. In addition, issues with biomedical ethical significance such as vulnerability, informed consent, paternalism, confidentiality, and autonomy in Saudi healthcare settings have been elaborated upon.

Finally this study concludes upon the recommendations necessary to promote patients' rights in Saudi healthcare systems, as well as the role of *Masl'aha*. This was followed by a discussion of how to promote patients' rights in accordance to international standards of bioethics by applying organizational and bedside changes. In addition, questions regarding the significance of Islam in shaping the Saudi healthcare bioethical norms were clarified.

This study is devoted to the discussion of aspects of and barriers to patients' rights in Saudi healthcare systems, as well as the relationship between Saudi bioethics and ethical

discourse at global level. The subject of patients' rights in Saudi Arabian healthcare is not novel, as many precedent studies and research trials have discussed the relevant themes; this study approaches patients' rights in Saudi healthcare systems from an alternative perspective. The role of culture and Islam in shaping people's convictions and actions in healthcare settings has been examined. In addition, this study has highlighted barriers that occur due to culture and the organization affecting patients' rights and bioethical discourse in Saudi healthcare systems.

The barriers to the practice of proper patients' rights in Saudi Arabia are not due to a lack of bioethical discourse or regulatory laws. Rather, issues related to patients' rights in Saudi Arabian healthcare systems are caused by cultural and organizational factors that negatively affect bioethical discourse.

The UNESCO Universal Declaration on Bioethics and Human Rights represents the most comprehensive, international principles of bioethics. The feasibility of this declaration in different localities, including Saudi Arabian healthcare settings, was discussed. In addition, the applicability of principles of human rights in non-western countries was elaborated upon, as many scholars claim that internationally-enacted treaties are not compatible with different local cultures and religions. It is important to discuss the importance of the UNESCO Universal Declaration while providing recommendations to adopt a unified set of biomedical principles in order to ensure moral, ethical care for every human in the world.

The previous sections provide the structure of this dissertation to highlight broad aspects of the study and to introduce its significance to the reader; the following paragraphs will conclude the dissertation.

The primary focus of this study is to discuss the feasibility of international, biomedical principles in Saudi healthcare systems, in the form of the UNESCO Universal Declaration on

Bioethics and Human Rights. The relatively new healthcare systems of Saudi Arabia face organizationally and culturally induced barriers that negatively impact patients' rights discourse.

To examine such an inquiry, a comprehensive analysis and in-depth examination of Saudi culture and its sources is provided to deliver an accurate answer. Therefore, Islamic and Saudi tradition and the role of religion in regards to bioethical matters were examined, and a history of medicine and bioethics were provided during the investigation.

This study examines the universality of human rights and its relationship to dignity and biomedical ethics. It has been concluded that since human rights is fundamentally related to human dignity and the basic principles of human rights discourse influence universal bioethics, then the principles of biomedical ethics are universally applicable in all settings.

In addition, Islam shares similar moral norms with other civilizations including western societies. Due to the conservative and religious nature of Saudis, then universally enacted principles, including those of biomedical ethics, are compatible with Saudi healthcare systems. Despite the arguments of the universality of biomedical standards, Saudi healthcare systems require similar principles to enhance bioethical discourse and provide patients with the current and evidence-based bioethical standards.

There are internal issues within Saudi healthcare systems that delay the incorporation of universal guidelines that advance patients' rights. These problems can be classified into two categories depending on the causative factor. This includes culturally-induced challenges, arising from different variables. Cultural challenges in the Saudi healthcare settings are discussed through the examination of the role religion in determining bioethical standards and the differentiation between religion and cultural customs. In addition, the impact of cultural variation through expatriate workers in biomedical settings and cultural specifications of local customs has



been discussed, adding to the challenges to patients' rights.

Organizationally-induced challenges are also barriers to proper patients' rights practices. Problems related to management and logistics, healthcare professionals, cultural incompetency, and ineffective regulations, policies, and accreditations are responsible for the advancement or crippling of patients' rights.

Patients' rights in Saudi Arabia must be addressed through an international lens to promote its applications and moral standings; however, the Saudi culture must be considered before blindly incorporating international bioethical standards in local settings. Though there are no fundamental differences between the UNESCO Universal Declaration and Saudi bioethical ventures, the culture of Saudi healthcare settings that impact bioethical matters must adopt mechanisms of international, bioethical standards and practices, and disregard improper practices common in local settings. For example, practices of informed consent must incorporate international standards and current practices of paternalism by healthcare providers and male relatives must be stopped to promote improved patients' rights practices.

Several recommendations have been discussed to eliminate the barriers to proper patients' rights practice and discourse within Saudi healthcare organizations.

The findings, conclusions, and recommendations of this study refer to the healthcare systems in Saudi Arabia. Due to the scarcity of research studies regarding the Saudi healthcare system, and specifically patients' rights within this system, this study will contribute significantly to the subject at hand.

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