Biomedical Ethics in Cultural Diversity:

The Principle of Autonomy in Islamic Culture

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Abstract

This study examines how the concepts of biomedical ethics are considered in Islam and how historical Islamic medical scholars treated the concept of ethics in their practice of medicine. Moreover, this research explores the principle of autonomy in biomedical ethics as a factor in Islamic practice of medicine. The issue of autonomy in medical practice is an important topic of discussion requiring examination of the methods of its adaptation and application in Muslim-majority countries. The value and significance of this topic continues at a global level, involving Muslim communities in Non-Muslim countries experiencing religious and social diversity.

Deeper understanding of the concepts and roots contributes to the practical value and efficacy of biomedical ethics in general and the principle of autonomy in particular in diverse contemporary societies.

Historical records in Arabic in addition to the field's literature in English are utilized for the research. It is found that biomedical ethics hold significant and unique characteristics deeply connected to Sharia.

The more we understand Islamic perspectives of biomedical ethics and autonomy the more diverse communities in global societies will achieve understanding of each other. Moreover, this understanding facilitates and improves relations among medical practitioners and Muslim patients.

The fieldwork of this study was conducted in Turkey, Jordan and Gaza Strip, Palestine, investigating the subject matter with practitioners in health care sectors as

well as with leading academics, researchers, non-government organizations and policymakers.

The results indicate that the principle of autonomy is not fully implemented in the three countries from an Islamic perspective. The respective medical communities are still exploring ideas and methods of applying biomedical ethics and especially the principle of autonomy. The result of this study will be recommendations to medical practitioners in governmental and private sectors in addition to related civil societies organizations that are active in health and medical issues in Turkey, Jordan, and Gaza

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Acronyms

BETIM	Beşikçizade Center for Medical Humanities
CIOMS	Council for International Organizations of Medical Sciences
CSOs	Civil Society organizations
EDEP	Center for Excellence in Education
EMRO	Eastern Mediterranean Regional Office of the World Health Organization
EU	European Union
HCAC	Health Care Accreditation Council, Jordan
IBC	International Bioethics Committee
IC	Informed Consent
IMANA	Islamic Medical Association of North America
IOMS	Islamic Organization of Medical Science
ISAM	Center for Islamic Studies
IVF	In-Vitro-Fertilization treatment
KER	Knowledge Ethics and Research KER, part of WHO
MOH	Ministry of Health of the Palestinian National Authority
MWL	Muslim World League
NGOs	Non-Governmental Organizations
OECD	Organization for Economic Co-operation and Development
OIC-IFA	Organization of Islamic Conferences' Islamic Fiqh Academy
REC	Research Ethics Committee in Turkey
UN	United Nation
UNESCO	United Nations Educational, Scientific and Cultural Organization
WHO	World Health Organization

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Chapter 1

Biomedical Ethics in Cultural Diversity: The Principle of Autonomy in Islamic Culture

Introduction

The rapid development of science in the field of modern medicine raises many ethical questions and challenges in relation to social, religious and cultural backgrounds and conditions. Biomedical ethics studies aim to get maximum benefit from the advance of science while minimizing risks for human beings. The biomedical ethics field addresses moral and legal questions in connection with sensitive health related issues such as abortion, euthanasia, cloning, In-Vitro-Fertilization treatment (IVF), brain death, and organ transplantation. The principle of autonomy is the cornerstone of biomedical ethics in medical practice and biomedical research. It involves a decision-making collaboration between health care practitioners and patients which enables patients to exercise their right to make decisions about their lives. The quality of these decisions depends on adequate information related to diagnosis and potential side effects, as disclosed by a doctor. The information provides the opportunity for effective evaluation of a given medical case and thus supports a patient's rational choice to accept or refuse a treatment. The proper use of this principle prevents the likelihood of mistakes, neglect, and coercion.

Diversity and multiculturalism have become salient characteristics of many societies. Muslim population has reached almost one-fourth of the world’s population in an increasingly globalized world. Islamic perspectives on biomedical ethics are becoming more relevant and significant in the medical field and general health care in globally diverse and pluralistic societies as well

as in the Muslim world.

Universal terms such as death, life, suicide, and personal freedom are common, however there are certain differences in how they are understood and interpreted on religious and cultural backgrounds. Life from an Islamic point of view is a divine gift from God to human beings. In Islam, God created humans as superior to all other living creatures and thus honored the human being by mandating His successors (*caliphs*) on Earth. The Quranic verse says, "And We have certainly honored the children of Adam and carried them on the land and sea and provided for them of the good things and preferred them over much of what We have created, with [definite] preference"[1]. In another verse, "And [mention, O Muhammad], when your Lord said to the angels, "Indeed, I will make upon the earth a successive authority."[2] That mandate has been associated with a great responsibility to learn and make use of knowledge in order to implement God's rules and laws on earth.

The concept of life and death from the Islamic perspective is seen as a journey that Allah prescribes to all his creatures. Life is a transient stage and the worldly life is a station for good deeds and obedience to Allah in preparation for immortal life in the hereafter. "Every soul will taste death. Then to Us will you be returned."[3] Another verse says, "… the home of the Hereafter is best for those who fear Allah, so will you not reason?"[4] The permanent life is in the hereafter, in which God rewards people for their patience and good deeds in their mortal life. Death in Islam is considered the beginning of eternal life. Thus, the destiny after death is decided by our performance in this life and in the belief of a place for us in Paradise, or in Hell for penalty. The soul is one of the secrets of God in his creations. "And they ask you, [O Muhammad], about the soul. Say, "The soul is of the affair of my Lord. And mankind have not been given of knowledge except a little."[5] Death is considered an integrated aspect of the natural life cycle which begins with a fetus in the womb of the mother and ends with death as the transition to eternal life. Talk of death is about a crossroads be-

tween two paths; one is immortal and the other interim.

The concept of death in Islamic belief invokes meanings of faith, life, values and behavioral motives which may influence and change the nature of a human life from one which is trivial and unworthy to a life imbued with value and meaning. The purpose of such a life is to support and enable the common good. The belief in the existence of another permanent life, the hereafter, makes a believer to see death as part of the whole existence. A believer seeks reward from God for good deeds and actions in life and thus earning a future in paradise. A Muslim can look through the idea of death with greater patience; he/she has another life waiting in paradise. With death, all worldly actions stop except for three things according to the prophetic traditions. "When a man dies, his deeds come to an end except for three things: *sadaqah jariyah* (continuous charity); a knowledge which is beneficial, or a virtuous descendant who prays for him (for the deceased)."[6] The best kind of charity on behalf of a deceased person is the continuous charity, meaning the charity whose reward continues for its donor and it is recorded in his good deeds even after his death. [7] The charity of the deceased and the *Dua,* (prayer), are one of the things to which his reward is reached without controversy among all jurists.[8]

The continuous charity of organ donation is considered one of the greatest and most beneficial. Muslim jurists agree that organ donation is a form of ongoing charity because it can save the lives of people who are suffering from incurable diseases. "And whoever saves one - it is as if he had saved mankind entirely,"[9] the Quran says. The sources of organs for transplantation may be a living person, dead person, or brain-dead person. There are legal controls and conditions set by Muslim jurists for the permissibility of transfer and implanting organs. The author will discuss these conditions extensively in chapter four by providing perspectives of Muslim scholars. Today there is an awareness within the global Muslim community of the importance of organ donation and the

great spiritual reward attached to it. Certainly, death itself is not emotionally easy for the deceased's family. On personal and family levels death brings a range of emotions including pain, anxiety, and helplessness. From a human perspective, saving another life by donating an organ assumes a great sense of ethical and moral position. Religiously, organ donation also brings a sense of a reward granted by God in the hope benefitting the donor in this life and hereafter.

Suicide is considered a great sin in Islam. From an Islamic perspective, a believer in God must not get desperate, no matter what he/she suffers in life. Suicide is forbidden because it means one has despaired of God's mercy. It is considered *qatl-al-nafs* (self-murder). Muslims see suicide as a flight from reality. Death is not salvation. Moreover, Muslims believe that life does not end by death because there is a hereafter. It is not permissible for anyone to kill oneself, to trespass or destroy any part of his body because the body is an *amana* (trust) from God and each one has the responsibility to preserve it and protect it. Islamic Shariah obligates a human being to protect and preserve the five purposes of Shariah; life, religion, mind, progeny, and property. Protecting life is a major aim of Shariah and suicide means going against Shariah. Since suicide is a violation of one of the five objectives of Islamic Shariah, Islam prohibits it and made it a great sin which leads a person to God's punishment. Personal freedom means a person can choose and decide without causing harm to themselves or others. In other words, there is a limit to freedom. A human being does not have command or power over life and death, body and soul belong to God, who created humans in the best possible form. The act of killing one's self exceeds the limits of choice that God gave to a human. What is important is to find the balance between demands of the soul and needs of the body. Such balance is also about reconciling work in this life and preparing for the life of hereafter. Faith raises the soul to high levels by connecting with God through worship. The human soul is to be maintained and nourished and killing it means denying the soul the right to continue living. The

Quran clearly opposes taking away or killing the soul of a human being, "And do not kill the soul which Allah has forbidden, except by right."[10]

Autonomy in bioethics is highly influenced by cultural and social context in its applicability. Certainly, the issue of autonomy is considered more a matter of individualism as liberalism has spread in the modern Western societies. On the other hand, religious conservative societies primarily take into consideration religion and family. This impacts the ability of an individual to make his/her own decisions. It is the right of the patient to be fully informed to make an autonomous decision. This highlights the ability and capacity of the patient to make a reasonable judgment based on full information.

In the field of medical practice, the concept of autonomy has received significant attention, emerging as the most important principle in biomedical ethics. This view was adopted by the Belmont Report in 1978. The practice of autonomy in decision-making in medical practice depends on many factors influencing the relationship between the doctor and the patient. The purpose is to protect the rights of patient. The patient is considered the weaker party in such a relationship. Moreover, the decision-making process in "Autonomy" is context-related. It is significantly influenced by social, cultural, paternalism factors, and religion.

In terms of human rights in general and the patient's rights specifically, the concept of autonomy enables the patient to take any decision related to his/ her life after exercising due diligence in considering the advantages and disadvantages of a proposed medical treatment. The fundamental rights of any individual are based on the recognition of one's own humanity and the sanctity of life. The basic fact is that humans are born free. Taking account of this basic tenet of individual freedom and the rights of a patient, it is essential for the health care sector to endeavor towards the basic objectives of providing health care for the patient. Such rights are guaranteed by interna-

tional standards and norms and have precedent in cultural traditions. In other words, decision-making in medical practice supports the basic purpose of autonomy, which is to confirm and promote the right to self-determination.

This research aims to evaluate the understanding of the concept of biomedical ethics in general and autonomy specifically from an Islamic cultural perspective, at the levels of medical practitioners and patients alike. In other words, the research shall explore how doctors practice and apply the principle of autonomy in the medical field in different Muslim societies. The author will show how Islam deals with respecting the individuality of each person by protecting the rights and duties of each member of the community. It is highly significant to investigate this approach to the crucial issue of autonomy in the field of medicine and health practice in general in contemporary Muslim societies as well as Muslim communities living in diverse and multicultural global societies. The research will introduce recommendations aimed to help in understanding the concept of autonomy for Muslims patients. The aim is to facilitate communication between the doctor and the patient, which is a process that should be built on trust.

Contemporary Muslim scholars have produced studies on the principle of autonomy in biomedical ethics in recent times.[11] However, there remains much need for research to fully grasp and understand the Islamic perspective on the principle of autonomy. The Muslim Conference on Medical Ethics emphasized the crucial issue of autonomy but has not reached the common Muslim to become part of day-to-day culture. There remains a significant absence of understanding in Islamic societies of the concept of biomedical ethics in general and autonomy in particular at the levels of both medical practitioners and patients.

This thesis shall argue that for the principle of autonomy, in particular, and biomedical ethics, in general, to be applied in accordance with Islam, it is essential to rely foremost on the Is-

lamic frame of reference of *maqasid* (the higher objective of Shariah) in which Muslim scholars and jurists consult closely with medical professionals and scientists to seek the necessary knowledge in a certain biomedical issue for the purpose of producing an ethical ruling or opinion, formulated according to an "Islamic code of ethics."

Fieldwork has been conducted in Turkey, Jordan and Gaza-Strip, Palestine, investigating the subject matter with practitioners in the health and medical sector as well as leading academics, hospitals, researchers and policy makers in Turkey, Jordan and Gaza Strip, Palestine. The three selected cases are Muslim-Majority societies, but each society experiences a different legal and social context. Turkey is a Muslim-majority with a secular constitution. Jordanian society applies an Islam-based constitution. The Gaza-Strip is a Muslim-Majority civil society operating without a state structure for a long time. The principle of autonomy shall be tested in its applicability and practice within the three contexts. The expected result is likely to point out that the medical communities in Turkey and Jordan are seeking new approaches, ideas and methods in order to accommodate and apply the principle of autonomy in the medical practice from an Islamic perspective. In the Gaza-Strip, cultural, social, and institutional factors do influence the applicability of the principle of autonomy in informed consent in the field of medical practice and health provision. Muslim scholarship is aiming at facilitating rules concerned with biomedical ethics, particularly the principle of autonomy. The principle of autonomy in Islam aims at protecting the dignity and the right of a patient to make informed decisions. Everyone has the right to life and self-determination. This is evident in the conditions set by Islam in obtaining approval for the protection of this right through consultation. The doctor has the duty to inform and consult with the patient. Islamic values are increasingly relevant and crucial on a global scale in the medical field, biomedical research, and health provision throughout many culturally diverse societies.

Background of the study

The fundamental rights of any individual are based on the recognition of humanity and the sanctity of life. The basic fact is that humans are born free and shall always remain free. National and international laws recognize and respect values and the wishes of individuals. Such rights become even more important when the individual is at risk. It is essential for the health care sector to endeavor to achieve the basic objectives of providing health care while respecting the rights and duties guaranteed by all related international standards norms and legal frameworks.

In recent years, as a result of the globalization, the world has virtually become a small village. The exchange and handling of science and knowledge among countries has become easier, contributing to establish a standard for universal principles of Biomedical Ethics. These principles are applied worldwide taking into account the diversity of different cultures and religions in each country. In other words, science is similar worldwide, however the differences lay in how it is applied in different cultures.

Two American philosophers introduced the well-known Four-Principle Theory: Tom Beauchamp and James Childers in the 1970s. The theory outlined its main ethical principles when dealing with biomedical ethics; autonomy, beneficence, non-maleficence and justice. The authors claim that the Four-Principle theory has a universal character and thus it is in harmony with different traditions, philosophies of life and cultures.[12] The two authors are secular scholars who considered a new ethical dilemma in the practice of medicine and biomedical ethics. The dilemma lies in the fact that the theory was built on secular and philosophical principles and did not pay attention to the moral values that are based on religion.[13] The issue here is separating moral values from religion. The theory has become one of the most widely debated theories in the biomedical field.

Islam respects and protects the human being. This is obviously stated in Islamic legislation based on the Quran, Sunna and the work of Muslim scholars. Islamic religion attempts to facilitate rules concerned with all aspects of human life. The rules started from the nucleus of the society that represented the individual, and then extends to family, society and community. Islam honors the human being; it calls and strives for the dignity of man and woman. Moreover, the principle of autonomy in Islam aims at protecting the dignity and the right of a patient to make a decision. This is indicated in the Quran: "We have honored the sons of Adam, provided them with transport on land and sea; given them for sustenance of things good and pure; and conferred on them special favors; above a great part of our creation."[14] Everyone has the right to life and to determine his/her fate. That is evident in the conditions set by Islam in obtaining approval for the protection of this right through consultation. The doctor has the duty to inform and consult with the patient.

From this perspective, this paper explores how Islamic societies are dealing with biomedical ethics principles in general, and the principle of autonomy specifically, from an Islamic religious and cultural point of view. In addition, the research studies and evaluates the extent of application of the principle of autonomy in the health care sector in Muslim societies within an Islamic context and how such societies follow the International standards of biomedical ethics. It is important for the health care sector to endeavor to achieve the basic objectives of providing health care to the patient, while respecting the rights and duties guaranteed by all related international standards norms, and laws. In addition, the study looks into the main challenges that hinder the application of the principle of Informed Consent at the national level. The author examines the three cases of Turkey, Jordan and Palestine as Muslim societies. In the case of Turkey, it is a majority Muslim society under a secular state and constitution. Jordan and Palestine are both a Muslim-majority society, but Islam is an important source of legislation. This is significant in examining whether the state has the power

to oblige society to support the state's agenda or not.

1.1 Theoretical Debate

The Principle of Autonomy according to Muslim Scholars

Muslim scholars refer biomedical issues, generally, to Islamic Shariah. The main sources of Islamic Shariah come from the Quran, Sunna, Ijmaa and Qiyas. Scholars in Islam consider theological issues and moral questions which are raised by the application of contemporary science and technology. New advances and progress are integrated as part of the Islamic Shariah. For example, the abortion issue is one in which Muslim scholars have prohibited the practice because Islam considers abortion to be the crime of murder except in some cases, such as where pregnancy poses a threat to a mother's life or the baby is diagnosed with brain damage that will cause death after birth. In such cases the mother is legally and religiously permitted to abort her baby without blame. Such cases highlight the intersection between legal and theological concepts, which is the nature of Islamic Shariah.

Before addressing the matter of how Muslim scholars define the concept of autonomy, it is necessary to return to the meaning of the word autonomy in the Arabic language. The word "autonomy" comes from the verb "*istqal*" which means, "to became independent". Autonomy means any person governing oneself; it also means liberty to choose laws.[15] A majority of Muslim scholars classified the concept of autonomy under the heading of personal freedom, which is one of the necessities. It is not a type of complementary or luxury matter. Being independent or the idea of autonomy must be provided for and be available in people's lives. Islamic law must protect it[16].

Al Rahawi wrote a book entitled "Adab Al-Tabib" which means good manners of the doctor, where he relied on the work of Hippocrates and Galen.[17] The book is considered one of the oldest works written in Arabic in the field of medical ethics. [18]Likewise, Al-Razi was an influential

scholar of medicine and ethics. He wrote an important book entitled “Doctor's Ethics” (*Akhlaq Al-Tabib*). The book was divided into three concepts: the doctor's responsibility for his patients, the doctor responsibility for himself, and the responsibility of the patient towards the doctor.[19]

The contemporary prominent Islamic scholar, Mohammed Al-Ghazali[20], argues in his book “Human Rights between Islamic Teaching and UN Declaration”, published in 2005, that Islam preceded the known International convention on human rights 1400 years ago. He writes that human freedom is a sacred thing- like life; that it is born with the human being. This is also expressed in a statement of the prophet Mohammed, "Every child is born on instinct." Freedom is associated with the human being and no one has the right to abuse it. Moreover, government must provide adequate safeguards to protect the freedom of individuals. It may not restrict or reduce freedoms except when they are in contradiction with Islamic “Shariah”.[21]

In the same context, Mohamed Amara [22] agreed with al-Gazali in his view of the concept of freedom, which he equates with human life. Mohamed Amara mentioned in his book " Islam and Human rights,” that individual freedom in Islam is one of the most important “Purposes” needed to achieve true humanity in order to become a human being. In other words, Islam sees “freedom” as achieving the meaning of “life” for a human being. If one loses freedom, it is as if losing life. A person without liberty is not alive even if he/she still drinks and eats.[23]

In a similar school of thought, the scholar Muhammad Salem Al-Awa agreed with Al-Gazali and Amara that, “freedom of human beings is as sacred as his life"; whether in making decisions related to their own life or in exercising their freedom. In both cases Islam guarantees these rights. Freedom is the first character that is born with a human being. It is believed that liberty exists in the formative nature in man and woman. Moreover, related legislation, whether Abrahamic religions or others, are meant to prevent confiscation of freedom or tampering with it.

However, these freedoms are to be practiced only after a person reaches an age when they are responsible for their actions and decisions.[24]

The scholar Yusuf Al-Qaradawi was a student of Ghazali and shared the same idea about the concept of individual freedom. Qaradawi added more explanation on the nature of a decision-making process. He considered autonomy as a necessity rather than a kind of integration or well-being. Qaradawi elaborated that the state must provide this kind of freedom and make it available for all people. He went further by advocating that it should be protected Islamic law.[25] Some Muslim scholars criticized Qaradawi when he prioritized autonomy over the application of Islamic Shariah. He believes this kind of freedom is a prerequisite for the realization of Shariah, that it is a necessity that cannot be waived.[26]

From the perspective of other school of thoughts such as Al-Gazali, Emara, Al-Awa, all kinds of freedoms, whether religious, intellectual, civil or political, are inherent and born with human beings. The implication of this is that no one has sovereignty over another unless the objective person allows it. Since all people are created equal and free, an individual is the only one who can decide what he/she wants in matters pertaining to life choices. It is not possible to separate freedom and choice. A person cannot be described as a free person if he cannot take his own decision. This applies to decisions that concern all aspects of life. In the medical field, a person cannot be free and independent unless he is unable to take any decision regarding his/her health or life. For example, any person has the right to accept or reject the method of treatment or any medical procedure. In the event that someone is forced to do something contrary to his/her will, this constitutes a direct assault on personal freedom and it should obligate a punishment on anyone who carries out such an assault.

Dr. Mohammed Anani holds an interesting perspective on the concept of Autonomy. He sees autonomy as “a whole liberation from subservience and keep away from the external influences." [27] He believes that it is the most important aspects of the Sunna in confirming the freedom of Muslims in decision-making processes, away from any external stimulation, whether historical, economic, racial, social or family pressures. In addition, “the personal independence to carry the responsibility" contributes to support the freedom that is the foundation of the pillars of responsibility in self-development and society. If a community's members have autonomy, then this would translate into a positive impact on the community. Here, we find that the basic rule for the Muslim in bearing responsibility in a decision-making process is that this is a personal and direct responsibility that resides with the individual and no others.

Contemporary thinker Tariq Ramadan believes that autonomy in Islam is aimed at reaching a person's personal growth. Man becomes independent in all matters of life through decisions and choices and has the ability to exercise freedoms.[28]

Islam does not marginalize or suppress the value of personal autonomy. On the contrary, there exists Islamic traditions which promote the inculcation of normal autonomy within communities. However, the extent to which Muslims are encouraged to exercise their autonomy would depend on context. For example, how people interpret the concept of autonomy within the culture of their own community. Overall, the disagreements among Muslims on the definitions and application of autonomy illustrate why autonomy is not always applied in the right way.

Very often there is a perception that Islam does recognize individual freedom. Two factors contribute to the existence of this perception. The first factor is an assumption that Islam and human rights are irreconcilable. The concept of human rights is not Islamic but rather Western

and thus, has no place in Islamic thought. The second factor is related to orientalism. Orientalists do attack Islam as being a mode of thought, a civilization, and a religion. The impact has been immense in the ensuing confusion about Islam. A big gap of misunderstanding has resulted in a discourse of misinformation and confusion concerning the crucial concept of freedom within Islam. The emerging phenomenon of confusion and reality confronted the Muslims and they found themselves attempting to provide evidence from the Quran and Sunna without any real intellectual effort or scientific discussions. These unprepared mechanisms of self-defense lead to more confusion.[29]

Islam is a way of life aiming at the well-being of all humanity; building on the value system for the benefit of Muslim society and others. Islam is considered a moderate religion that rejects the extreme way of life and fosters a balance between the materialistic and the spiritual aspects of life. Thus, autonomy holds an important place in Islam.

The author faced a challenge to find a specific definition of the concept of autonomy, as explained above through the works of various Muslim scholars. This is perhaps the result of the scarcity of available Islamic sources that deal with the subject of medical ethics exclusively.[30]

From the author's point of view, Muslim scholars try to find a connection between the concept of autonomy in general and Islamic Shariah through the examination and study of Quranic verses and Hadith. Muslim scholars work to prove this principle exists in Islamic law, embedded in the Quran, which was revealed more than fourteen centuries ago. Contemporary Muslim scholars have not paid enough attention to the concept of autonomy in the medical field. Autonomy in the biomedical ethics arena will face limitations in its application in medical practice. The challenge will be in applying it. Yet the point that is not disputed by all Muslim scholars is the importance of this principle in Islamic law, whether it is sacred like human life or re-

lated to human dignity. All of them agree that it is a basic right for everyone whether they are Muslim or non-Muslim, and the state must protect this right.[31]

In the realm of medicine, the primary principle of the application of medicine in Islam is the emphasis on the sanctity of human life, as derived from the Quran[32] "We have honored Adam's children".[33] This verse states that the first principle of Islam is to honor the life of all mankind regardless of race, color and religion. The second key principle in medical practice in Islam is the emphasis on seeking a cure. This is clear in the statement of the Prophet Mohammed, "Seek treatment, for God the Exalted did not create a disease for which He did not create a treatment, except senility". A third principle informing medical practice within Islam is the aim of Shariah to provide protection and preservation of life, intellect, progeny, property and religion.[34]

Respect for autonomy by applying informed consent in the right way in Islam protects the dignity and the right of a patient to make decisions. Islam stresses this basic right of human beings, which is indicated clearly again in the Quran, "We have honored the sons of Adam, provided them with transport on land and sea; given them for sustenance of things good and pure; and conferred on them special favors; above a great part of our creation"[35.] In another verse, "Indeed, Allah commands you to render trusts to whom they are due and when you judge between people to judge with justice. Excellent is that which Allah instructs you. Indeed, Allah is ever Hearing and seeing."[36]

Everyone has the right to life and to determine his/her fate. That is evident in the conditions set by Islam in obtaining approval for the protection of this right through consultation. Doctors have a duty to inform and consult with the patient as the Holy Quran stipulates. Any adult person has the right to accept or reject the treatment. In addition, any consent achieved un-

der pressure or coercion will not be accepted by Islamic law even if it was influenced by parents or other relatives of a patient.

The conscience of the doctor needs to be clear and considered an *Amanah* (trust) from God, which means a patient is entrusted into the hands of the doctor. This requires that the doctor be honest and sincere with the patient.

Islam honors the human being and bestows them with powers over other non-human creatures. Such privilege requires that fundamental freedoms and rights are protected. That people must strive to protect their own rights, including the right to make decisions and live a decent life. Since the Palestinian society is a Muslim majority, ethical and moral references are highly influenced by Islam. It is therefore rather easy for the Palestinian community to accept related principles that are found in international law, especially in relation to the aims to protect and respect freedoms and human rights, as well as seeking to apply laws in order to achieve maximum benefit.

Finally, the concept of individual autonomy according to Muslim scholars is not as clear as it is in the opinions of western scholars, who often connect the principle with human rights or dignity. This connection is indeed stipulated by Shariah, yet it is rare to find Muslim scholars addressing the concept of autonomy independently.

The Principle of Autonomy according to Western Scholars

For over two hundred years, Western scholars and philosophers tried to find a definition for the concept of autonomy from many aspects based on their own background. Likewise, Muslim scholars had interest for this subject as well. In this part of the research, the author will examine the Western theories put forth by the most important scholars who argued the concept of autonomy.

In the second part the author explains the concept of autonomy as discussed by Muslim scholars as well as the Islamic perspective. Scholars and scientists from numerous disciplines have written about the subject of medical ethics. These scholars came from different backgrounds such as history, law, psychology, literature, theology, social psychology and philosophy. All of these disciplines contributed significantly to the enrichment of this area of study. A researcher can thus study the topic from different perspectives in a multi-disciplinary fashion. Various theories shed light on the subject of biomedical ethics from psychological, moral, legal and religious aspects.

The subject of ethics is divided into three kinds of ethical inquiry. First, is the normative ethics, meaning the theological and philosophical aspects of the subject. In other words, it is the study of what ought to be done. The second form of inquiry is meta-ethics, which answers questions raised in normative ethics in an orderly manner. This approach is critical and logical, investigating the meaning of relevant terms. For example, what is the meaning of "right"? What is the meaning of "duty?" The last kind of inquiry is descriptive ethics, which asks experimental questions to evaluate the direction of people and how they think about certain moral issues. These three kinds of ethics inquiry are complementary and provide the main lines of the subject of ethics.

The principle of autonomy is the most important among the four biomedical ethics principles. This hypothesis has been the subject of great discussion between scholars for many years. Some scholars agreed with this perspective and argued that the patient has the right to accept or reject medical treatment. They considered this principle to be a cornerstone of biomedical ethics principles. Other scholars see this principle as being less important than the beneficence principle. They see beneficence as actions normally taken to prevent or remove harms or to improve the situation of others. It is a greater priority than autonomy in decision-making.

The concept of self-determination has existed since ancient times and is found in ancient

Greek philosophy. Both Aristotle and Plato stressed that the most important part of the human is the rational aspect.[37]. "Autonomy comes from the Greek word root "auto" meaning "self" and nomos meaning "custom" or "law." This reflects the political sense of the word as in a group's right to self-government or self-rule. When a person seeks autonomy, he or she would like to be able to make decisions independently from an authority figure"[38]. In the context of biomedical ethics, autonomy simply means the right of a patient to accept or refuse treatment.

In the ancient Greek era one of the most prominent physicians in the history of medicine was Hippocrates. He was referred to as "the father of early medicine." Hippocrates revolutionized medicine in Greece and freed the people at that time from many misguided beliefs and superstitions. He is attributed with the creation of a fundamental document on the ethics of medical practice, known as the Hippocratic Oath. This oath has been used until recent days in most medical school on a global level. The Greek Renaissance continued until the Roman Empire came and settled in the fifth century AD. The Roman Empire developed in the fifth century and continued until its collapse in the fifteenth century, when the Renaissance began.[39] This period in Western history witnessed a decline in all fields of science and became the so-called Dark Ages of the West.[40] In contrast, this era is considered the Golden Age for Muslims in the Abbasid state. This Golden Age witnessed great development in the life sciences, including medicine and medical ethics. It was in this time that some of the greatest doctors in history emerged, among them Al-Razi, Ibn Sina, and Al-Rahawi. [41]

The second half of the seventeenth century witnessed an emergence of a new philosophical discourse, led by Kant. Kant saw autonomy as fundamental to morality.[42] He is considered one of the first philosophers to refer to the term of autonomy in relation to the individual and not just to politics. Prior to Kant, especially in antiquity, the term of autonomy was used to refer not to individuals, but as a concept of politics and cities that made their own laws.[43]

The conception of individual autonomy is an individual's capability to act independently in a sensible way. [44] The concept of autonomy in Kant's theory has value in moral philosophy, and the concept of freedom is a basis in the practice of the principle of autonomy. Kant believed that human rationality will be independent by operating without any influence of external factors. To be free, a person must physically and psychologically possess the ability to work. That means decisions which are taken through turmoil or fear do not represent an act of free will. Some scholars supported Kant's theory of autonomy, considering his theory to be, at least, a primitive theory of personal autonomy.[45]

Years later, John Stuart Mill appeared as the first philosopher who tried to combine the independence of the individual autonomy with naturalistic action.[46] Yet Mill points out that individual autonomy is derived from a naturalistic account of action. In other words, autonomy is part of human nature and action.

However, Mill never used the specific term autonomy but instead referred to "Civil or Social liberty". [47] He argued that a civil or social liberty guaranties the development and progress of a "Person of individuality and character". [48] Moreover, Mill sees the only way to develop and support the concept of individual autonomy is via civil or social liberty. He sees that the individual must be protected not only from the tyranny of the state, but also from the tyranny of a society as well.[49]Mill's explains in his own words about the nature of autonomy, "A person whose desires and impulses are his own are the expression of his own nature, as it has been developed and modified by his own culture- is said to have a character. One whose desire and impulses are not his own, has no character, no more than a steam engine has a character".[50]

In the late twentieth century, scholars supported Mill's theory and adopted it as a basis for defining of Autonomy. Those who expressed their stance as pro-Mill, "thought a naturalistic account of human action can be given, and specifically that all action has beliefs and desires among its causes". [51]

The author pointing at that time was tending towards Mill's theory rather than Kant's Theory, which makes Mill's theory more suitable to the natural account of a human actions. The most significant difference between Mill and Kant regarding the concept of Autonomy is that Kant's theory has a central value of ethics philosophy, while Mill saw autonomy as a fundamental state. [52] In Kant's view autonomous people have the capacity to determine their own destiny, and for that must be respected. While for Mill, the concept of autonomy involves the capacity to think and decide freely and independently without causing any harm to others.

In the second half of the nineteenth century, several philosophers emerged and tried to reach a definition of the concept of autonomy. Some of them distinguished between a concept of autonomy and respect for autonomy, which means the respect of individual choices and actions. Consequently, philosophers became divided into two main groups. The first group believed that the "autonomous person" owns a fixed principle and is independent in his/her decisions originating from beliefs and orientations without any authority of anyone. Benn's theory strongly supports this idea. [53] On the other hand, the other group, presented by Steven Pinker and Ruth Macklin (who came recently) aimed at respecting human dignity, which means autonomy.[54] Ruth sees human dignity as worthy only for those who arranged and organized thoughts and act based on their own individual perspective.[55]

Moreover, autonomy has earned a more significant and important role as a result of the highly influential book "Principles of Biomedical Ethics" by Thomas and Childress. The book considers autonomy as having primacy over all other principles. [56]In 1979, the first edition of the book "Principles of Biomedical Ethics" by Thomas and Childress replaced the principle of respect for persons by the term "Respect for Autonomy" which is more limited. [57] Years later the book became a standard textbook for biomedical ethics. The work addressed four principles of biomedical ethics and argued for each of them.

Thomas and Childress believe that respect for autonomy does not mean exercising the absolute and undue individualism that affects freedoms of others, nor does it mean a focus on only legal matters without neglecting their social practices and the responsibilities it entails. Respect for autonomy, according to Thomas and Childress, is manifested by respect for others' freedom, and the practice of free choices and actions without causing any harm to others.[58]

Thomas and Childress limit the autonomous person to "an autonomous person who signs a consent form for a procedure without reading or understanding the form has the capacity to act autonomously but fails to so act in this circumstance. Depending on the context, we might be able to correctly describe the act as one of placing trust in one's physician and therefore as an act that autonomously authorizes the physician to proceed."[59] The idea of autonomy in this context depends on autonomous choices and not an autonomous person, because sometimes the autonomous person can encounter limited judgment in case of illness, depression, ignorance and coercion. [60]

In 1994, an updated edition of the book of Thomas and Childress modified the definition of the principle of autonomy, claiming it as the most important among the four principles. The newly modified version faced a considerable debate between supporters and opponents. Supporters saw a doctor's commitment to the patient in the disclosure of information in order to obtain approval in an atmosphere of trust and confidentiality. This was perceived as the correct definition of autonomy. An opposing opinion considered that the doctor's commitment to the explanation is not directly related to the concept of autonomy or to get patient approval. They see it as mandatory to obtain utility and to do what is in the patient's interest, not to stimulate adopting the individual decision. [61]

Here, the idea of autonomy by Thomas and Childress appears as the most important principle among of the four principles. It emphasizes the respect for human rights, which takes into account the making of their own decisions that shape the rest of their life. Autonomy in decision-making enhances

respect and dignity for the person. This means no one has the right to violate the human dignity of any person.

If an autonomous person signs a form of consent without understanding or reading the form, this procedure does not mean it is an autonomous authorization. The reason is that such a person lacks enough information to make an effective decision. Moreover, a person who is in general incapable of autonomous decision-making cannot make autonomous choices. For example, mentally ill patients who are considered legally incompetent to take care of themselves, they may be considered as making autonomous choices in instances of rejecting medication or preferring a choice of meals. [62]

One theory on autonomy called Split-Theory became controversial. The theory points to two-level desires when one is confronted with making a choice.[63] One desire is the basic level called first order. The second order is another desire. For example, if an alcoholic has a desire to drink but the higher order desire tells him to stop drinking. This theory is problematic because any proposed theory should be consistent with pre-theoretical assumptions clearly stated in the principle respect for autonomy.[64]

Critics expressed a rejection of the split-theory on the premise that a theory of autonomy is only acceptable if it is within the reach of ordinary choosers and complaint agents; not an ambiguous idea. The author here sees that the split-theory is rather a case where a patient, in the case of a medical situation, is challenged between two choices of medical interventions or treatments. It is rather difficult to qualify a person choosing a higher preference and that complicates the process of decision-making as far as autonomy is concerned. However, if our intention is to be consistent within the theory or respect of autonomy, then it would be easier to consider the two choices as two separate entities of decision-making. Each entity can be presented as an autonomous case that needs to be examined according to the theory of respect of autonomy. Medical practitioners can become aware of such an

approach as two separate initiates of choices and a patient makes autonomous action based on the information of each case. Thus, here we can claim the legitimacy in upholding the theory of autonomy without the confusion caused by the split-level theory. [65]

The discussions and debates about the concept of autonomy have continued in contemporary times. Researchers like Ruth Macklin, Steven Pinker, and Lysaught contributed recently to the debate. They added some details and interpretations for the concept of autonomy. For example, after the principle of autonomy was established as being of key importance among the four principles, it included individuals who possess the ability to make rational decisions. Researcher Ruth Macklin confirmed it when she equated autonomy with human dignity. She mentioned autonomy having the right of those who can choose their actions freely as a result of their point of views. [66]

Lysaught has the same perspective as Ruth Macklin, and supports the concept of "respect for autonomy." Yet he rejects the other opinion that describes autonomy as "an autonomous person". He sees autonomy alone as a wide subject that could support actions of violation such as destroying embryos, creating embryos for research and creating embryos through cloning as "moral licit". [67]

Steven Pinker rejected Ruth Macklin opinion, considering that human dignity is "stupid", "a mess", a "dangerous and should be abandoned in favor of a focus on respect for autonomy".[68]

Another scholar, Carl Schneider, studied autonomy from a different angle. He asked many questions about what the patient wants with respect to autonomy, informed consent, and medical decision-making.[69] He mentioned that a high number of patients have a desire to get all their own medical information but at the same time there is a big part of them that do not want to participate in their own medical decisions. They are either elderly patients or patients in critical condition. [70]

As for as the right of a patient to reject treatment, in reality patients, whether they are sick or injured, may not fully utilized their autonomy and are thus not reliable in making a good decision. In

such a case, a patient may prefer to avoid dealing with the burden of a crucial or life-threating decision, and they may prefer doctors or others to decide on their behalf.

In conclusion, in the context of biomedical ethics, autonomy simply means the right of a patient to accept or refuse treatment. [71] Autonomy is considered the most powerful principle in American bioethics. In other words, patient autonomy becomes, "the most powerful principle in ethical decision making in American medicine".[72] However, the concept of autonomy in decision-making remains a point of debate for many Western scientists and researchers despite years of studying the subject matter. This points out how important the issue is. Here we discussed the most important perspectives and definitions adopted by scientists and researchers. Moreover, there are other scholars and philosophers tried to define autonomy through other aspects such as legal and political processes. However, these approaches are not directly related to decision-making in medical practice which is the main point of this research. Although the concept of autonomy has become somewhat clearer than it has been in the past, it is still subjected to conditions that qualify for enabling the person to make decisions on his/her own, away from the influence of any authority.

1.2 Methodology

1.2.1 Objective of the study

This research will explore a new approach in dealing with bioethics, specifically the principles of autonomy and informed consent in medical practice in the context of Islamic culture. The study aims to understand how to exercise and apply the principle of autonomy in an Islamic cultural context. This question is significant in order to investigate the way religious and cultural diversity differ in morals, values and approaches when addressing the crucial issue of autonomy in the field of medicine and health care practice in general. Applying the principle of autonomy enhances and encourages patients and doctors to actively exchange ideas and share power.

Furthermore, Muslim societies are experiencing differences among themselves in terms of being more or less conservative. Turkish, Jordanian and Palestinian societies are known as culturally and religiously conservative Muslim societies. Meanwhile, non-Muslim societies aspire to adopt the principles of autonomy in informed consent in the field of medicine by following international biomedical ethics standards.

In this thesis, the author studies and analyzes how Muslim societies apply and practice the principle of autonomy which is represented by informed consent in cultural diversity at national and global levels.

By comparing how biomedical issues are understood and implemented in Turkey, Jordan and Palestine, this paper explores whether the nature of a society is affected by the state. However, the ideology is different in the case of Turkey. All three countries have Muslim-majority populations and are considered to be conservative societies. While the Jordanian Hashemite Kingdom is constitutionally defined as a Muslim state, Turkey is a secular state, although more than 98% of its population is Muslim. As for Palestine, there is no independent state, thus the ministry of health performance is very limited under Israeli occupation. In most cases, Palestinians conduct their affairs by civil society.

By examining the approach to biomedical ethics adopted in these significantly different Muslim-majority countries, the author evaluates differing state responses in terms of policy and application, providing insights into the role of civil society and its relationship with the state. The paper focuses on autonomy and informed consent and how these are addressed according to Islamic or Western perspective. At the global level, it is also important to understand how non-Muslim countries can understand Muslims, who are living there, in sharing issues related to biomedical ethics and from an Islamic perspective.

1.2.2 Fieldwork

The fieldwork in Turkey, Jordan and Palestine included site visits to government-related institutions such as ministries of health, major clinics and hospitals to meet the medical staff who are working there. Numerous interviews were conducted with doctors working in the health sectors and related scholars in several universities. In addition, some of the visits included related local civil-society institutions.

During the interviews, the author asked about the concept of biomedical ethics, patient autonomy in decision making for medical intervention, informed consent, and research involving a human being. The author also asked about the procedure to obtain the consent from the patient. Some of the questions asked about the legal age at which a patient can make independent decision. Other questions dealt with sharing the information about diagnosis and treatment with the patients and their families. The second part of the questionnaire was related to the role of administration of hospitals in providing regular courses for doctors and medical stuff to inform them about new studies and researches related to biomedical ethics. This part meant to evaluate the knowledge and applicability of the doctors in applying the Informed Consent in a satisfactorily way.

In this study, the researcher faced some challenges and obstacles in each country covered by the research. One of the problems in Turkey for example was the language. Turkish is the official language in the country; thus, very little people could speak English as a second language. For that reason, the researcher often asked for the help of a doctor who spoke English well in order to translate from Turkish to English during the interviews. In the case of Jordan and Pales-

tine, all interviews were conducted in Arabic, so the researcher did not encounter any problem in the language there.

In Palestine, the biggest problem was the inability of the researcher to reach areas that belong to the Palestinian Authority in the West Bank. This was due to the complications for Gazans to obtain entry permits to visit the West Bank. However, the researcher found that the health situation in Gaza and the West Bank were generally equal at all levels in regard to treatment and general services. Both sides continued cooperation between their ministries of health despite the long division between Gaza and West Bank governments.

1.2.3 Why Turkey, Jordan and Gaza-Strip, Palestine?

The Muslim-majority societies of Turkey, Jordan and Gaza-Strip, Palestine are selected for the research. The selected cases are Muslim-majority but each society lives and experiences a different legal and social context. Turkey is a Muslim-majority with a strict secular constitution. Jordanian society operates according to an Islamic- based constitution. The Gaza-Strip is a Muslim-majority with civil-society based society; meaning organization via a non-state structure which has been the case for a long time.

The fieldwork was conducted in Turkey, Jordan and Gaza-Strip, Palestine. For Turkey, the legislation derives from the Turkish Constitution, drafted after the military coup in 1982. The Turkish government introduced the most recent amendment to facilitate coordination with EU legislation, and to improve democracy and human rights in Turkey. The modifications were based on two main theories; republicanism and secularism. The first one focuses on the terms, ‘independence’ and ‘participation’, while the second is concerned with removing the government’s reliance on religion.[73]Indeed, Turkey’s attempts to establish a secular state were met by a general resistance in the Turkish community, which increased people's pride in their religion

whenever the state tried to escalate secularity. Turkish society is considered a conservative society, despite the government's efforts. It has steadily experienced an increase in religiosity. Simply put, Turkey is a majority Muslim society with a secular government and constitution.

In the cases of Jordan and Palestine, both constitutions classify the respective societies as Muslim ones, where Islam is significant in public life and legislation. Jordan has enjoyed relative stability for a long time. Compared to regional and neighboring countries, Jordan has been spared many of the tragic events that have plagued next-door countries like Palestine, Lebanon, Iraq and Syria. The author selected Jordan as one case study to explore the relationship between state and society as it applies to medical issues and its relationship to religion at a national level.

Conversely in the case of Palestine, it is certainly not a sovereign 'state'. It is known as the Palestinian Authority but functions under complete Israeli occupation. This reality renders the situation quite unstable and volatile. Choosing Palestine as a case sheds a light on unstable Muslim societies. To know whether the semi-state or in other words "Authority" has the ability to work and apply international laws when they are not independent and subject to the rule of the occupation. In addition, civil society in Palestine is considered very active. It manages many health centers that target a large segment of people. Another factor that influenced the researcher to select Palestine as a case study was the opportunity to evaluate the role of civil society and its performance in terms of applying biomedical ethics principles.

In conclusion, all the above-mentioned factors prompted the author of this thesis to work on this study in the hope of pointing out the shortcomings and weaknesses of the Turkish, Jordanian and Palestinian health sectors. This shall hopefully improve and develop the health care sectors in the future for the previously mentioned countries. Moreover, highlighting the similarities and differences points to the applicability and practice of autonomy.

1.2.4 Chapters

The first chapter explains how the Islamic perspective deals with the concept of autonomy. Thus, the chapter discusses theories and literature related to the concept of autonomy from both Islamic and Western perspectives. The second chapter examines how Muslims scholars deal with the subject of biomedical ethics in general. Here, it is of high relevance to discuss the five Purposes of Islamic Shari-ah, (Islamic law) in this context. Chapter three addresses organ donation and the question of brain death from an Islamic perspective and how the principle of autonomy mitigates this issue from the view of Islamic biomedical ethics.

The fourth chapter examines the principle of autonomy in biomedical ethics. This principle is considered one of the most crucial pillars in upholding the integrity of medical practice in general and informed consent specifically. It is crucial to study how an Islamic perspective deals with the principle of autonomy. To understand the Islamic perspective, field research was conducted in Turkey, Jordan and Gaza-Strip, Palestine. The fifth chapter evaluates implementation of the principle of autonomy by obtaining informed consent from patients in the three countries of Turkey, Jordan and Gaza, Palestine. This will help in understanding what factors, whether cultural, social, paternalistic, or religious, that influence its practice and applicability. In addition, this chapter examines the issues affecting the lack of application of the principles of autonomy in the right ways. What is the role of Ministries of health in Turkey, Jordan and Palestine that must be played to inform the medical staff about the importance of this principle for both doctor and patient as well? It is crucial to increase awareness among people about their rights. Moreover, it is necessary to examine if there is any role to be played by the Interna-tional and National NGOs to inform medical staff and Ministries of health in countries covered by the survey of the importance of applying this principle in the right way. In addition to this, if the interna-tional organizations conducted any program in order to increase the awareness of people towards their

rights. Finally, Chapter Six is the overall conclusion with a critical analysis of how Muslim and non-Muslim countries are dealing with autonomy and biomedical issues.

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[3] Quran 29:57
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[5] Quran17:85
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[21] Mohammed Al-Gazali, "*Human Rights between Islamic teaching and UN declaration"*, P. 212
[22] Dr. Mohamed Emara born in 1931, he is an Islamic thinker and author and investigator and member of the Islamic Research Academy at Al-Azhar, Cairo.
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[33] Quran 17:70

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[60] Ibid., 102
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Chapter 2

Biomedical Ethics: An Islamic Perspective

Introduction

The ethical dilemmas that are raised by new advances in medicine and scientific technology have presented societies, religious and non-religious, with new challenges. A diverse array of societies across the globe face an increasingly urgent need to solve problems related to biomedical ethics at religious, medical tradition, philosophical and legal levels. The relationship between the medical practitioner or clinician and the patient is increasingly influenced by the cultural and religious background of either or both. In the absence of a universally accepted framework for the clinician and patient relationship, cultural and religious knowledge can be crucial in providing better and more effective medical care. Conversely, a lack of knowledge of cultural and religious matters could exacerbate conflict between clinician and patient. Such knowledge and competency do occupy a significant position in the biomedical ethics discourse. Thus, the focus of this paper is to explain and illustrate what is meant by Islamic biomedical ethics and its application in medical practice and biomedical science. The question is quite significant in order to understand the way Islamic biomedical ethics are being applied in every day's medical practice and bio research science. This is even more cogent considering our contemporary global age with its increasing social and cultural diversity. The understanding of Islamic biomedical ethics has repercussions for the harmony and coexistence of diverse communities in our modern, global age.

Currently, Muslims comprise almost one-fourth of the world's population. Diversity and multiculturalism have become a salient characteristic of many societies all over the world. The field of biomedicine and relevant ethical issues are becoming even more important in the daily lives. Biomedical ethicists worldwide are keenly aware of this contemporary development compelling them not only to understand their own traditions and cultural backgrounds but also those of communities around them. The urgency for understanding biomedical ethics from an Islamic perspective has been stressed as an important subject in the discourse of biomedical ethics deliberation.[1]

In Muslim societies, the values and teachings of Islam play a central role in shaping individual and social life as well as attitudes on health, illness, life and death. Religious values represent a major determining factor in the discussion concerning health care and the medical field. Also, Islamic Shariah extends the private lives of individual Muslims, therefore becoming a central frame of reference for public policies in Muslim societies or societies with significant Muslim populations. For years, Islamic legal and ethical traditions have dealt with inquiry and questions on emerging issues in the field of medicine.[2]Both scholars and jurists tried to respond to ethical questions according to the Islamic teachings. Yet, in the contemporary Muslim world, diversity is less tolerated when it comes to ideas and interpretations in some societies. Before examining the different points of view and challenges facing Muslims concerning the creation of a coherent Islamic Biomedical ethics, it is crucial to understand first the definitions and concept of Islamic Biomedical ethics.

2.1 Definitions and Terms

In this section, we are going to provide definitions for various terms that are related to the field of ethics in the medical and bioresearch fields. The various terms have contested definitions.[3] Contemporary ethicists in the field of medicine and biomedical research are still debating which terms need be used in order to reach an agreeable definition describing the phenomenon.[4]It is important also to point out a definition that Muslim scholars seem to agree upon. The terms which are most commonly used are "medical ethics," "bioethics," and "biomedical ethics."[5] Are there differences among them? And what term do Muslim scholars prefer to use?

The term "medical ethics" refers to rather a traditional field which focuses on the physician-patient relationship.[6] Thus, this term can be described as the more traditional one. Since it is confined to a direct relationship between physician and patient, the term in itself is rendered limited. In other words, the term medical ethics does not deal with stems cells or related technologies. Thus, it suggests an old definition that does not reflect the contemporary circumstances and diverse medical and related technology. One Muslim scholar of ethics described the term medical ethics as "Hippocratic thought,"[7] as the medical field has developed and progressed beyond such limitations. This, therefore, compels us to search for a more fitting term.

The Term "bioethics" appears to enjoy greater usage and breadth. As it implies, the word consists of "bio" and "ethics."[8] Bio comes from the Greek word meaning "living things."[9] Here the term's implications are broad, including agricultural products, food,

animals, etc. It can even go as far as covering public health and healthcare ethics. If, for example, animals are included under this broad terminology, "biomedical ethicists" do not take animals into consideration. Thus, the question begs; where does it end? It is a term that can be considered problematic. Even one of the contributors of the famous work, Principles of Biomedical Ethics, Mr. Beauchamp, does prefers not using the term despite that he did so in in his early writings.[10] Thus, the term "bioethics" does not fulfill the required definitions as it is too broad and open-ended. Finding a more appropriate terminology and definition is of high priority.

The term "biomedical ethics" is introduced to answer the rise not only of traditional medical field but also the biomedical technology and science.[11] The term means not only strictly medical, but includes topics such as cell research, genetics, reproductive health, research ethics, even human-experimentation. It is a broader term than medical ethics as it covers the medical field of human beings as well as related medical sciences and technological advances. This definition of biomedical ethics appears to be the most appropriate when refereeing to the relationship between ethics and "biomedical field." Muslim scholars have worked to find an equivalent meaning in Arabic to the term "biomedical ethics" in order to facilitate a better understanding of the general Islamic perspective on the ethics of biomedical field.

A debate has been ongoing among scholars, on the exact use of Arabic for the word "bio" in order to help define more correctly the term biomedical ethics. The word "bio" means "life" in Greek [12] which corresponds to the Arabic word *ahyaiyah* or *haywiyah*.[13] These two Arabic words are related to the Arabic world of life, Haya, The Moroccan scholar, Al Resouni, prefers the word *haywwiyah* as the term is not only much

more commonly used among ordinary people but also it simply means biology.[14] *Al-hayawiyah* implies in Arabic the meaning of "active" or "lively." This term gives a wider meaning than specifically medical. Medical in Arabic means *tibbiyah* and with that the intended meaning of the term "biomedical", the terms become in Arabic *hayawiyah tibbiyah*, in which *hayawiyah* refers to biology and *tibbiyah*, meaning medical. The combination becomes *hawayiah tibbiyah*.[15]

The word ethics itself had enjoyed a prominent attention in the wiring and Muslim scholars. The word ethics in Arabic can be translated into either *akhalaq* or *adab*. *Akhlaq* comes from the Arabic root verb *kh-la-qa*, meaning "to create" or "to form," pertaining to appropriate and done.[16] From this word, comes the Islamic discipline of knowledge known as *"ilm al-akhlaq,"* meaning the science of morality. The other well-known Arabic term and equivalent is the word *adab*. Literally, it means "literature". However, the meaning can be enlarged and extended to represent the connecting learning and knowledge to right and good conduct which is the foundation of human personality. One can say that *adab* is about improving the character and refine its conduct. It is about character ethics at personal and professional levels. As ethics mean *akhlaq* in Arabic but the word *adab* seems to aim at refining *akhalq*. One of the classic works in the field of medical ethics was the book *Adab* al-*Tabib*, Practical Ethics of the Physician. This significant book was the work of the physician Ishaq ibn Ali al-Ruhawi in the ninth century during the Abbasid era. *Al-Ruhawi* work is relevant to this day when it comes to the Islamic codes related to medical ethics.

Moreover, ethics is referred to as "a sub-branch of applied philosophy" [17]that is inherently connected to morality, aiming at distinguishing between "right and wrong" and

the "good and the bad" of a conduct in a certain situation.[118] Ethics in the medical field and bio-research is considered as a subdivision of ethics which deals with moral principles in those fields. In the West, ethics emerged into the philosophical realm as it gradually broke away from the Christian definition of morality or the "good and bad" as shown throughout the writings of Western figures such as Augustine and Kant. The process of secularization that influenced Western discourse in contemporary time experienced a shift in the discourse of ethics in the West; one from religious ethics to philosophical, based on human experience, judging "right and wrong" and applying it in daily life. Such discourse is non-existent in Islamic intellectual perspective. Certainly, philosophical traditions have been studied and included whenever suitable in Islamic discourse; however, religion and religious text have always maintained a central role in shaping ethics in the Islamic discourse.[19]

2. 2 Islamic biomedical ethics: A Conception

Islamic sources, the Qur'an or Hadith (Sayings of Prophet Mohammad), are abundant with references to the human body, hygiene and health in general. Ritual purification *(al-tahara)* is explained at length throughout chapters written by jurists (*fuqha*). These *fuqha* wrote about maintaining the cleanliness of the human body, during both daily care and times of illness. Some of those *fuqha* were medical specialists themselves.[20] Such references in Islamic tradition to ritualistic hygiene and health by the jurists form the basis of the Islamic understanding of "medical ethics."[21] The goal "has always been to protect the life, dignity and the welfare of humankind by protecting their conscience, stability, integrity, and health."[22] The integrity of a person is connected to that

person's health because of the larger Islamic concept of life and death, and people's common good and interest. The main Islamic sources of the Quran and Hadith are filled with verses and the Prophet's sayings referring to health in many instances. Here, we are going to highlight some of the most important Quranic verses and Hadith sayings on health and medicine.

At the heart of the subject, the Quran correlates belief itself with health, as it says, "a guide and a remedy (a cure that restores health), for those who believe." [23] The implication is that the health of heart (mind/spirit) is essential to leading a healthy life.[24] In other words, living a healthy life is also about the heart being cured from vises such as lying, arrogance, ego, etc. Essentially, a person returns to God after death with "a healthy heart;" it is important to protect one's heart in life so that you return to God with *qalbin salim* (a healthy heart). As the Quran says, "a day when neither wealth nor children will be of any use, but for those who return to God with a sound (healthy, balanced, peaceful) *salim* heart."[25] The root verb of the word *salim* is *'sa-la-ma,* ' which refers to health and welfare, in addition to tranquility and spiritual peace.[26]

The revelation of God's word to the Prophet Mohammed is "a remedy,"[27] as it calls and encourages believing consciences to strive with all one's power for the inner health/peace, and ultimately an elevated state of wellbeing. Such a quest is embodied in the word *jihad* al *nafs*, meaning to exert one's utmost power to reach the highest form of a well-being and health.[28] According to this interpretation, the aim of human existence should be to fulfill the role given to us by God, and that role is to be stewards of life here on earth.[29]This implies that everyone bears a responsibility as guardians on this earth. The Quran says, "Then, we made you vicegerents on Earth."[30]This sense of responsibility is

extended, not only to one's own well-being, but to all fellow human beings. The Quran shows what an essential duty it is to save one human life, even going as far as to say that if you save one life, it is "as if they had saved all mankind."[31]The human body is given by God, so that we must care for our bodies, ensuring its healthiness and keeping it fit. During his lifetime, the Prophet Mohammad emphasized the necessity of keeping one's body healthy, clean and fit. He said, "Your body has rights over you."[32] What is meant by "rights' includes protecting life, which is one of the five goals of Islamic Shariah.[33] Protection of life implies hygiene, health care, well-being, and leads to the understanding that health is essential. Such emphasis on sound health is illustrated when the Prophet told his companions, "Ask God for health, for no body receives anything better than good health."[34]

For a Muslim, a person is the guardian of his/her own body. The body needs to be taken care of, nourished and respected. This is because God entrusted us with our bodies, and therefore we owe a *dayn* (debt) to Him, and one day the body returns to Him.[35] It becomes incumbent upon every person to implement practical ways of curing the body in a time of illness. The Hadith says, "There is no disease for which God has not provided a cure."[36] The quest for seeking new ways of curing illnesses and diseases is the way forward towards preserving health conditions of the body and the well-being of the heart. New medicine and scientific research discoveries can lead to the persevering and protection of life through the preservation of sound health of body and heart. What is explained here is not the definition of Islamic medicine or how it is different from Western medicine per se, but, how it relates to the question of medical ethics.

Explaining the importance of respecting the health of the body and heart according to the Islamic perspective is to highlight its link to ethics. What is important here is "establishing the objectives of Islamic ethics relative to the health of the heart and body." [37] Every day, we are faced with challenges concerning health and medical technology, including diseases, epidemics, and research on humans. Medical knowledge and related scientific discoveries do not exist in a vacuum, however. The tasks of medicine and research are performed within human and social environment, forcing us to consider new and efficient Islamic ethics to deal with them. [38] Therefore, it is necessary to understand what the term 'Islamic medical ethics' means.

From the outset, there is no distinct branch of knowledge or a known discipline that can be referred to as Islamic biomedical ethics. The term ethics itself certainly can be found in Islamic sciences and material, such as *fiqh* (Jurisprudence) or the science of *kalam* (scholastic theology) and *tafsir* (Qur'anic exogenesis).[39] In Islamic societies, the term 'ethics' has its roots in historical and religious texts, yet over time the interpretation has changed, even being used in recent times to describe "biomedical ethics as a separate discipline."[40]

2.3 Islamic Biomedical Ethics in light of Shariah and its Higher Objectives

The difference between Islamic biomedical ethics and the secular principles-based medical ethics is that the Islamic perspective gives ethics a religious basis.[41] The secular discourse of biomedical ethics, like the famous work of Beauchamp and Childress, deal with man as a social being.[42] However, in Islamic ethics, the basic tenet for both the

individual and the society is to have faith in, and get close to, Allah. The approach to Allah can be done through Shariah. Yet, almost no Muslim country applies Shariah as a legal framework. Shariah is applied at an individual level and remains a significant aspect of life for Muslims, no matter where they reside.[43]Shariah is defined as "the collective ethical subconscious of the Muslim community."[44] In practical terms, when a Muslim patient is facing a certain medical dilemma and has an ethical question concerning a certain medical issue, they may seek the opinion of an expert in Islamic law or a scholar of *faqih* (jurisprudence). The goal is to find the most appropriate divine law to protect the five necessities of a person; religion, life, intellect, lineage and property. To make the case for Islamic perspective of medical ethics clearer, it is important to observe that God alone defines what is right and what is wrong. In other words, good deeds are good because God commands them, and evil deeds are evil because God forbids them.[45] This means an entire dependence on revelation. However, God's command carries purpose and it is purposefulness of God's will in which human reason, in relying on revelation, can distinguish and design rules in order to apply them. From those two assumptions, a rich culture of legal thought, ethical traditions and material flourished throughout Islamic History. This materialized into the vast discipline of *usul ul-fiqh* (principles of jurisprudence) which is the science examining the sources of *fiqh*-law and brings about rules. *Usul* is the Arabic word for "root" and when is related to biomedical ethics; the attempt is to trace back the bases or the root of revelation to determine the specific reference which constitutes the actual law on a specific case. Thus, understanding what does Shariah as well as its objectives is of high significance in understanding the Islamic ethical dimension.

It is highly important to define the word Shariah to understand its relation to the larger context of Islamic biomedical ethics. The word Shariah come from the Arabic root verb, "*sha ra aa*," meaning to command, to designate, to make lawful, or to prevent. Also, it means the water spring (the source of water), and it can also mean "a straight road." Other meanings of Shariah include "flat and clear landscape."[46] Thus, the word indicates what is designated, clearly defined and free from ambiguity and vagueness. It is also defined as the complete guide of al din (religion), meaning it applies to the rules, commands and prohibitions that Allah ordained upon the believers. Moreover, the great Andalusian scholar *Ibn Hazm* defines Shariah as what Allah ordained through the message of Prophet Mohammad, and the messages of all prophets. He adds that Islamic belief brings Muslims together where Shariah organizes their lives to bring people from darkness into light.[47] In other words, Shariah, as principles and rules that Allah ordained to his servants, is to organize both religious and earthly lives, be it acts of devotion, *ibadat*, or transactions and dealings, *muamalat*; for the realization of happiness, stability and justice.[48]

The principles of Shariah are derived from the Quran, the Sunna and Ijmaa. All principals depend on two pillars; complete faith in Allah and it is he who created Shariah. Shariah is not subject to change and at the same time it is realistic and moderate, taking account of the conditions of people and giving everyone his/her right. It is applicable to every time and place for all people for the realization of an individual's happiness in this life and hereafter. Thus, it protects the rights of people and the well-known five necessities; the protection of religion, life, intellect, lineage and property. Recently, some scholars have added the protection of environment as it affects all of humanity in many

ways.[49] But, most importantly, modern Muslim scholars have worked to take the study of Shariah into a higher realm of scholarship for renewal and innovation.

The Tunisian scholar Ibn Ashur is one of the most renowned and great Islamic scholars of the 20th century. His book *Maqasid* Al Shariah (The Higher Objectives of Shariah) is a breakthrough in the studies of Shariah. He put forward the founding basis of *ilm al maqasid* (the science of higher objectives) and showed how it is important for the study of *fiqh* (jurisprudence). *Ilm al maqasid* is proposed as a methodology for the renewal of Islamic law, which has not undergone any serious development since the times of the great imams; Al Shafii, Malek, Ibn Hanbal and Hanafi between the 7th and 9th centuries.[50]Ibn Ashur argued that the text of Shariah is infinite, but events, incidents and issues are not infinite. His idea is to limit the disputes of differing opinions and fatwas (scholarly opinions) that may confuse contemporary Muslims. So, the door of *ijtihad* (free independent thinking based on reason)[51] and *tajdid* (renewal) becomes wide open and not bound by restrictions put forward by *ulama* (scholars; plural for *alim*, the learned one)[52] of the past and their biases for a certain madhhab (school of thought). The aim or objective is to address current and real challenges facing Muslim societies. This renewal in the methodology of Shariah is the first since the 9th century. The scholar pointed that the Quran requests us to seek the goal or objective of our existence, "We did not create the heavens and the earth and what is between them to play. We created them only for a specific purpose (intention)."[53] Thus, the concept and meaning of *maqasid* (ultimate objective or intention) has been consolidated in our contemporary time. And the driving intellectual force was Ibn Ashur.

Mohammad Al Taher Ibn Ashur was born in the city of Tunis in September 1879, two years before the start of the French colonization of Tunisia. He hails from a prominent family with roots in Andalusia (Muslim Spain) and a long tradition of scholars, *qadis* (judges), educators and political involvement. Ibn Ashur memorized the Quran at the early age of six. In 1893, he joined the well-known Zaitouna College in Tunis where he received education from Zaitouna's scholars in subjects such as Qur'anic studies, Hadith, *maliki fiqh* (jurisprudence of Maliki school), history, Arabic literature and Logic. Ibn Ashur, became head of the Science Council of Zaitouna College in 1907. By the year 1924, Ibn Ashur attained the position of chief *mufti* (jurist who gives nonbinding opinion on a point of Islamic law).[54] After the Independence of Tunisia in 1956, he was appointed as the dean of Zaitouna College. However, two years later, Ibn Ashur was forced to retire from the position of dean after objecting to the then President Bourqeiba's decision against fasting Ramadan. Ibn Ashur lived to the age of ninety-four years old.[55]

Throughout his long life and career, he authored many important books on the renewal of Islamic studies and *ijtihad* (exerting utmost physical and mental efforts).[56] For Ibn Ashur, *ijtihad* is thought of as an important approach for the jurist to rely on the mental faculty in solving legal issues and questions. For the study of the Quranic exegesis (*tafsir*), Ibn Ashur produced the important work, Al Tahrir wa Al Tanwir (Liberation and Enlighten). Educational and social reforms were crucially important to the intellectual discourse of Ibn Ashur. He produced highly acclaimed books on the "project" of reforming education for Tunisia and the Arab and Muslim World, titled, Alaisa as Subhi Bi Qarib? (Is not Dawn Near?) and *usul al ilm al ijtimai fi al Islam* (The Principles of Social Science in Islam).[57] His book, Madasid Al Shariah Al Islamiya, (The Higher

Objectives of Islamic Shariah), remains a milestone in the reforming of Islamic Shariah studies and renewal as a whole.

Perhaps one of the most comprehensive and concise definition of *maqasid* is produced by the contemporary scholar Al-Najjar.[58] He tried to introduce an accessible and easy way to understand what is meant by the ultimate or higher objective of Shariah. He says, "The ultimate objective of Shariah is to empower the human being to realize what is good for him and his wellbeing through realizing the reason for his/her existence in which a human being is the *khilafa*, vicegerent, on this earth by developing the individual self and social organization, community, for the purpose of facilitating happiness in this life and hereafter."[59]That's being illustrated but how *maqasid* is related to biomedical ethics?

Scholars in contemporary times have opted to apply the principle of *maqasid* on biomedical ethics as an approach in dealing with the many medical ethical issues and emerging biomedical research. *Maqasid* requires a holistic approach as it deals with the preservation of *nafs* (personal integrity). One's health and life become priorities based on the higher objective. The health of a human being cannot be reduced to mere chemicals and biological functions. A more comprehensive approach is necessary as to link the body or health to the wider context of spiritual state of a person. It is necessary to include that emotional well-being of a patient as well as the soundness of spirituality.[60]The approach refers to both structure and methodology and is deemed essential in handling such contemporary issues. But there is much needed work to refine and clarify the approach.[61] So, the *maqasid* approach, or "objective" approach, is a more holistic one that incorporates the patients spirit as well as the mind and body. Such a fundamental task is directly related

to the definition and the methodology of applying Islamic ethics in the biomedical field.[62] The result-based effort is the aim itself in applying bioethics. Thus, definitions and methodology are part of the effort to bring about an output which is directly related to *maqasid*; no matter how small or big the issue at stake is.[63] In other words, the approach to applying ethics from the Islamic point of view needs to be connected as much as possible to the biomedical field of knowledge. In all, three important steps are significant to realize a clear Islamic application of ethics in medical and biomedical field. First, one must defend the fundamental conception. The second is to determine the higher objective specific to the field of biomedical ethics. Lastly, we must formulate a terminology suitable to both the conception and ultimate goal.[64] As one Muslim scholar put it, "*maqasid* is to be used as a pragmatic checklist that can be utilized in tackling bioethical issues and dilemmas.[65] I think that the approach of *maqasid* is to put into question the entire issue of contemporary biomedical ethics in attempting to reform the approach. That is not for Islamic biomedical ethics to just adapt and limit the damage and risk which is applied, but rather reinvigorate an approach in its entirety. For this, Muslims approach Shariah and its higher goals to effectively mitigate and solve issues and problems related to ethics in the medical and biomedical research.

Thus, one can say that Shariah is seen as a living approach to daily life for both a Muslim individual and community. It is "both an individual and collective duty in Islam."[66] *Fatwa* (scholarly opinion) of a learned scholar provides guidance to those who seek answers on ethical questions, such as medical and biomedical areas. The *mufti* is the one who gives a *fatwa* but *fatwa* is not legally binding. The legal opinion of a *mufti* is different from a *qadi* (judge) where the decision of a judge is legally binding. In our present time,

one can notice numerous publication outlets which publish *fatwas* on many different matters of life; from finances, marriage and divorce, transactions, biomedical field, etc.[67]The *mufti* examines a case or question against juridical sources and principles of Shariah in addition to taking into consideration current context and reality. Thus, a collection of *fatwas* means a clear indication of the moral and ethical standing of a Muslim community on certain issues and questions. The scholarly opinion could arrive from any learned scholar regardless of origin of country or even institution.[68]

There is no 'church' in Islam, and thus no system of hierarchal clergy. Different learned scholars provide a questioner with different legal opinions. The collection of *fatwas* or legal opinions allows the seeker to choose from among the various opinions. It is up to the individual to choose which fatwa is most convincing and augmented. If an individual feels most at ease in his/her heart, then, they can make the choice. In other words, the seeker tries to find "an Islamic position" on a certain question. Ethical issues of the biomedical field are no different. Yet, to make his case more convincing and accepted by the general public, a *mufti* (a learned scholar) must seek the cooperation of a specialized medical professional. This is an essential aspect of Islamic biomedical ethics, as the Muslim legal scholar must consult with medical professionals. This constitutes the so called Islamic Code of Medical Ethics.[69] In other words, it is the duty of medical practitioners and researchers to collaborate and be consulted when needed by a *mufti*, as biological sciences undergo progress and advance constantly. It is generally pointed out that such cooperation between the legal scholars and medical professionals is witnessed throughout the numerous annual conferences worldwide. However, there is still much room for improvement.[70]

2. 4 Reconciliation of Science and Ethics: Islamic critique of the Four-Principle Theory

The well-known Four-Principle Theory was introduced by two American philosophers, Tom Beauchamp and James Childers in the 1970s. The theory outlined its main ethical principles when dealing with biomedical ethics: autonomy, beneficence, non-maleficence and justice. The authors claim that the Four-Principle theory has a universal character and thus it is in harmony with different traditions, philosophies of life and cultures.[71] The two authors are secular scholars who consider new ethical dilemmas in the practice of medicine and biomedical ethics. The dilemma lies in the fact that the theory was built on secular and philosophical principles but does not pay attention to the moral values that are based in religion.[72] The issue here is about separating moral values from religion. And the theory has become one of the most widely debated theories of biomedical field. The principle of autonomy has been considered by many ethicists to be the most important ethical principle which supersedes all others of the Four-Principled Theory. Thus, Islamic critique of the theory has ensued.

The western-based autonomy places considerable emphasis on individualism, self-actualization and personal gratification, however, it denies the role of faith in the supernatural being as well as the wider public interest over the rights of the individual. Autonomy of liberal individualism can be at odds with belief systems of some faith-based communities in which many still keep paternalistic attitudes on medical care provision. For a Muslim to exercise autonomy, privacy is requested especially for a female patient to be seen by same-gender physician if available; this needs to be respected. If not available,

it is Islamically allowed to be seen by a physician of opposite gender. Traditional Muslim physicians practiced with the guidance of God present in their minds. A Muslim doctor used to be called *'hakim'*, which in Arabic translates as 'wise'.

Muslim scholars point to the strictly secularist nature of the Four-Principle Theory. Secularization brought about "a fracture, giving ethics an independent status from knowledge."[73] It implies that the very subject of ethics and its role in society must be reconsidered. The Western discourse presupposes a secularist and rational nature. However, in reality it is a "reductionist, utilitarian compatibility and ethical measurability that tends to align with the dominant economic order."[74] Yet, the debate on biomedical ethics cannot be reduced to the point of simply rejecting the West and its science or even to providing evidence that biomedical ethics are compatible with Islam. [75]On the contrary, it is crucial to study the overall intention of the theory; that is putting to question the fundamental philosophical frame of reference and the method of implementing its ways, as devised by the two authors of the theory. Thus, a holistic approach is necessary to take into consideration the principles and yet again never lose sight of the ultimate goals.[76] We can say that biomedical ethics is, in a way, a field that aims at finding a common ground or reconciliation between biomedical ethics and the medical science on one hand and ethical imperative on the other.[77] It is this fundamental premise of reconciliation that is the more significant and certainly enduring for any foreseeable related intellectual discourse. Reconciliation with science lies at the root of the matter. We must question the role of science, its methods, its application and its utility. Islamic philosophical thought has always placed an emphasis on the inseparable relationship and the natural link between professional ethics and the goals of sciences. Certainly, the four-principle approach may

help examining ethical issues in a seemingly "universal and neutral" frame of ethics, but in reality, at individual and community levels, when treating patients, an alternative approach becomes imperative with due attention to different cultural backgrounds.[78]

2.5 Conclusion

At present, societies are becoming increasingly multicultural and diverse under the impact of globalization and modern technology, creating a plurality of value systems that may come into conflict. In the biomedical ethical field, cultural and religious differences can lead to ethical issues and dispute in the clinical realm. Yet, such cultural and religious diversity can open up new opportunities for understanding a different culture's values and ethics.

It is the hope here to facilitate an initial understanding by ethicists to analyze and discuss at a deeper level the Islamic perspective on biomedical ethics in comparison with the secular related ethics. The idea is not to reduce or reject the secular approach. The discourse on biomedical ethics from an Islamic perspective relies on morals derived from the Quran and Hadith (the sayings of the prophet). Unlike the secular discourse on biomedical ethics, where it deals with man as a social being, Islamic biomedical ethics relates to Islamic Shariah which functions as the collective ethical subconscious of the Muslim community, as well as a legal framework. It is a function of moral values and actions in Islam. In the practical field of biomedical ethics, the goal is to find the most appropriate divine law along with the professional expertise in biomedical practices and science. The goal is to bring about reconciliation between science and morality; considering the two as inseparable. Empirical and experimental efforts can be detached

from one's heart, conscience and intuition. Revelation and reason exit in harmony. In Islam, knowledge is ranked highly but it is subservient to the values of the Quran and ethics. That is why the Quran often points out the promise of good rewards for those who possess both knowledge and faith with good deeds. Thus, science from an Islamic view is a practical knowledge imbedded with virtue. For example, Islamic society aims at increasing spiritual awakening and builds a strong community as well as reduce dependence on consumption. For Muslims, the practice of religion is not the goal, but good deeds and actions are encouraged in all aspects and realms of life. The 9th century Muslim Physician, Ishaq bin Ali Rahwi described medical doctors as guardians of souls and bodies. Al-Razi, a well-known Muslim physician of the same era of 9th century stressed that the task of a doctor is to humanize medicine and to take care of patient's attitudes and problems. Nature and environment, for example, are pursued by science through Western consumer behavior that is threatening survival on this planet for future generations. Islamic ethics do not separate from science, including biomedical ethics.

Can religion play the role of producing a universal biomedical ethics? In other word, can we address the need for a universal biomedical ethics which emanates from an Islamic perspective? For the moment, challenges remain ahead for such an endeavor. Despite the rich discussion and debate within traditional Islamic references to health and medicine, the field of biomedical ethics from an Islamic perspective remains a challenge. Implementing the methodology of the ultimate objectives of Shariah (*maqasid*) seems to be the way forward to answer these challenges. *Maqasid* is proposed to be used as a practical checklist, which can be utilized in mitigating biomedical ethical issues and questions from an Islamic view. In all, an awareness of cultural and religious differences is

crucial in being sensitive to different value systems and hence a wider opportunity for better medical care in diverse and pluralistic societies.

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[69] Aasif I. Padela, op.cit., 178.

[70] Ibid

[71] Ghaly, op.cit., 4.

[72] Ibid.

[73] Ibid., 415.

[74] Ibid.

[75] Ibid.

[76] Ibid.

[77] Ibid., 416.

[78] Westra, A. E., Willems, D. L., & Smit, B. J. (Smit) Communicating with Muslim parents: " the four principles" are not as culturally neutral as suggested. European Journal of Pediatrics, 168 (November 2009), 1383-1387, 1383. Retrieved November 15, 2017, from https://link.springer.com/article/10.1007/s00431-009-0970-8

Chapter 3

Organ Donation for Transplantation and Brain Death: An Islamic Biomedical Perspective

3.0 Introduction

Since the advent of Islam 14 centuries ago, Muslim surgeons performed the medical practice of auto graft transplantation. It was originally developed and applied by the Indians.[1] Muslims surgeons learnt the method of medical grafting teeth and bones, utilizing human and animal sources about 1000 years ago. Muslim surgeons sought approval from the jurists.[2] Organ transplantation is not a 20th century phenomenon. It existed for a long time with certain types and shapes like grafting of teeth and bones. In Islam, three kinds of people are considered of paramount importance, "a knowledgeable and ascetic jurist, a good and component ruler and a discerning and trustworthy physician."[3] There are many examples of famous physicians in Islam who produced substantial work in philosophy relevant to medical practice. To name well-known name jurists/physicians who left an impact of historical proportions are Ibn Sina (Avicenna), Ibn Rushd (Averroes) and Ibn Zakariya al-Razi (Rhazes).[4] But, for those jurist-physicians, Ibn al Nafis is well established in this field. Over the centuries, rich literature on philosophy and theology developed and dealt with essential concerns of what we know now bioethical issues. Such literature examined important relevant matter such as remuneration, patient confidentiality, liability, identification and informed consent.[5]

For example, Muslim jurists allowed the practice of tooth and bone transplantation by Muslim surgeons as far back as 1000 years ago. The well-known jurist and scholar, Imam Nawawi (AD 1233-1272) produced what is considered a landmark extensive reference book called , *Al Majmu* (The Amalgamated). Later, he authored a more concise text book titled, *Minhaj al Thabitin* (The Procedure of the Enduring Ones.)[6] Another known scholar and jurist, Asshirbini, produced commentary in his groundbreaking book *Muqhani al Muhtaj* (Enricher of the Needy). In this book, Asshirbini explained in detail about the source of implanted bone. He elaborated that sources of bone could vary, be it from the same person (autograft) or from the body of a different person (allograft) or from an animal (xenograft). He went further, explaining the permissibility of grafting a bone from a slaughtered "*halal*" animal. In case of a bone grafted from a *najas,* a dead animal corpse or of porcine origin, those two particular sources were basically not allowed. However, if there is no other alternative, the practice is deemed necessary. A grand judge, *qadi*, in Iraq (AD 1203-1283) concluded that porcine bone graft worked more efficiently than other xenograft. His book, "Wonders of Creatures," illustrated this technique. Ibn Sina (Avicenna), 1210-1288, considered bone transplantation as a risky enterprise of a medical operation. In his voluminous book *Al Kanoon* (The Law) he stated he would not perform such an operation.[7]

Islamic principles respect the needs of the living over the dead. Life and its protection constitutes one of the main principles of Islamic teachings and Shariah. Thus, organ donation is encouraged under certain circumstances. Donating an organ means the possibility of saving a life. According to Islamic religious teachings, the saving of a human life is granted a reward in this life and the hereafter.

In modern times, organ transplantation, no doubt, occupies an important area in the field of organ donation, organ transplantation and the accompanied ethical discourse. Important body of prominent Islamic *ulamaa* (scholars) for example, made significant progress on ethically related issues of organ donation and transplantation. The Islamic Council of Saudi Arabia explicitly allowed organ donation by permitting the removal of organs from a dead body. As for a living donor, the council permitted the removal of an organ from a living body but as long as no harm is done to the donor and as long as it is beneficial to the recipient.[8] Announcements by more than 18 religious opinions and conferences between 1959 and 1998 allowed and permitted donation and transplantation from cadaveric organ.[9] This shall be explained more in details later in this chapter. As organ transplantation evolved from the experimental to become more of a common procedure, particularly in the West, Muslim scholars began to consider and think about contemporary ethical issues relevant to organ donation.

Ethical issues shall continue to hold a significant meanings and challenges in the area of organ donation and transplantation.[10] Moral ambiguities are certain to arise in numerous treatments and therapeutic modalities when applied on medical treatment and saving life.[11] For example, for the "life prolonging" treatment, the human source poses a major concern. The questions peg what types of humans are used for organ donation. The question points towards various types of humans that potentially become organ donations; be it, live humans, brain dead, cadaveric, children and adults. In addition, procedures of obtaining organs and distribution pose serious concerns when facing issues of willing or not willing donors such as prisoners, needs-based distribution or purchasing organs.[12] These issues force upon scholars and society serious ethical dilemmas in terms of legal, psychological, social at individual and society levels.[13] Seeking answers for the above ethical questions require intellectual and serious efforts because it

affects the individual and society. That is why the pursuit of combining science and philosophy of ethics in Islam has always been looked upon of paramount importance, spanning all Islamic school of thoughts and jurisprudence. Ethics hold a central pillar in the life of Muslims. Prophet Mohammad described his whole mission as a prophet of Islam in an ethical context and light. He said, "I was commissioned to ennoble(man's) ethics."[14] This chapter is going to examine the Islamic approach to the ethical issues associated with donor donation and transplantation.

3.1 Contemporary Islamic Rulings on Organ Donation and Transplantation

Islamic thinkers and scholars began addressing organ donation and translation in the 1960s. As new medical treatments involving organ transplantation experienced technical advances in organ donation in the second half of twentieth century, Muslim scholars had to provide answers to ethical questions involving organ transplantation. By the 1980s, the subject of organ donation and transplantation experienced serious debate, discussions and policy making in the Islamic World.[15] The overriding theme that prevailed in the Muslim World pointed towards the Islamic ethical principle that "the needs of the living outweighs those of the dead."[16] It is of paramount importance to save a life in Islam as the verse of the Quran illustrates, 'And if any one sustains life, it would be as if he sustains the life of all mankind."[17]

Taking organs from any source, alive or dead, human or animal, mutilation is not allowed.[18] When a specialist performs post-mortems from a cadaver for organ donation, that is not an instance mutilation of the corpse or disrespect. If there is any harm in this case by removing the organ from a dead body, it must be measured against the necessity of saving a life of a recipient. Thus, saving a life is considered to take a precedence over whatever harm may be incurred upon the corpse.

According to Islam, the human body, living or dead, should be venerated.[19] And the dignity of a human being is to be enhanced and protected even when a person is ill or suffers from misfortune. Thus, donating an organ is considered an act of benevolence and a charity, which Allah loves and encourages.[20] To donate an organ does not mean an act of transgression. The idea of donating an organ for benevolence or a charity carries a significant religious and spiritual meaning to a donor. And it should be noted organs are not commodities or be traded. Motivation for donating an organ stems from a genuine feeling of caring for other fellow human beings and universal brotherhood. In contemporary times, Muslim scholars and jurists of various school of thoughts recommend the positive and legitimate use of donated organs from either the living or dead body. This approach was manifested in the Islamic Jurisprudence Assembly Council in Saudi Arabia in 1088 where resolution number 26.1.41 permitted the use of organs donated either from a living or dead body. The outcome of this important conference clearly pointed out that the idea of saving a life to take precedence over any other consideration. New treatments meant scholar must come with answers. For example, blood is considered *najas* (unclean) in Islam. Despite that, Muslim jurists permitted blood transfusion. It was the Grand Mufti of Egypt, back in 1959, who issued *fatwa* number 1055 that allowed blood transfusion. It shows the attitude of Muslim jurists in thinking and adapting to new and contemporary methods of treatment. The *fatwa* by Grand Mufti or as a result of a conference of jurists, it is considered a decree and not only a juridical opinion. Legislative parliaments by participating countries should endorse it to become a law.[21]

The second half of the twentieth century has seen numerous resolutions issued on organ donation and transplantation by number of councils and scholarly *fatwas*. The supreme Islamic Council in Algeria sanctioned organ transplantation in 1972.[22] In Malaysia, organ transplantation

was sanctioned in April 1969. The Saudi Department of *Fatwa* Research took into consideration the issue of corneal transplantation in the year 1977. The following year, 1978, the Saudi Grand Ualam issued decree No.66/1978 in which corneal transplantation was sanctioned.[23] The medical procedure of auto graft was sanctioned by the Saudi Grant Ulama with *fatwa* No. 99/1988. The *fatwa* went on to illustrate further that organ donation can be done from living person or dead body. Organ donation from a dead source is subject to availability of a will or testament through a family consent as recognized by the Islamic definition of next of kin.[24] In Kuwait, the ministry of Charitable Endowment produced *fatwa* No. 132/1980 which sanctioned organ donation from a living human and a cadaveric. Following up on this *fatwa*, the Kuwaiti Law No. 7 1983 stated that living donors must be over 21 years in order to be able to give own consent.[25] Scholars of Islamic jurisprudence continued to examine the subject of organ donation in the years to come to facilitate ethical answers to the widening field of medical treatment involving organ transplantation.

Moreover, at the Fourth International Conference of Islamic Jurists in Jeddah, Saudi Arabia, jurists, from different parts of the Muslim World, convened in February 1988 and introduced the most detailed *fatwa* on organ transplantation.[26] The conference concluded on endorsing all previous *fatwas* on organ transplantation with a new and clear emphasis on rejecting the trafficking or trading of organs. They upheld the principle of altruism in organ donation.[27] The conference was quite significant in opening new avenues of considering various types and organ donations for discussion and debate among scholars, jurists and medical professionals in later years. For example, some of the new subjects involving transplanting organs are the nerve tissue for the treatment of Parkinsonism from anencephalic, and tissues

taken from "embryos aborted spontaneously, medically or electively, and leftover pre-embryos in vitro fertilization."[28]

The Sixth International Conference of Islamic Jurists was held in March 1990 in Jeddah. The conference discussed in details the above-mentioned new subjects of organ transplantation. The scholars in the conference concluded by sanctioning the transplantation of nerve tissue to treat "ailments such as parkinsonism."[29] However, the jurists put forward one condition; this method of transplanting the nerve issue is confirmed superior to other established methods of treatment. The *fatwa* also outlined the sources of the nerve tissue. For example, auto graft method is approved by taking the suprarenal medulla of the patient. The xenograft method is confirmed when taking the nerve tissues from an animal embryo. The jurist confirmed a third source is approved the cultured human nerve cells brought from "spontaneous abortion or medically indicated abortions."[30]

Islamic perspective has a clear position on the issue of abortion and any related matters of organ donation connected to abortion. The above-mentioned conference, held in the city of Jeddah in 1990, disapproved of the practice of abortion for the purpose of procuring organs. The jurists reemphasized the Islamic view against abortion except on certain conditions such as "saving the life or health of the expectant mother."[31] An organ from aborted fetus can be procured if the parents decide to donate and only in the case of a fetus declared dead. The emphasis is that the aborted fetus cannot be viewed as a commodity for trading which is not permitted.[32] Scholars, *ulama,* extended opinions on matters related to embryo and the issue of organ donation. The example of anencephalic is not considered as viable for use unless it is declared cardiac dead or brain dead. In IVF projects, the jurists recommended the use of the leftover pre-embryo from IVF, only for the needed ova should be fertilized by the husband's

sperms. And if the fertilized ova exceeded necessity, they should be permitted to die spontaneously. The donation of fertilized ova or cryopreservation is permitted. The conference debated the transplantation of genitals and concluded not to permit the transplantation of gonads because those organ possess the genetic inheritance from the donor.[33] In the meanwhile, the scholars permitted the transplantation of other internal sex organs.[34] In its seventeenth session in the year 2003, the Islamic Jurisprudence Council of Islamic World League, in Mecca, ended in a consensus with *fatwa* No. 3, permitting the use of "leftover pre-embryos for stem cell research and treatment of serious ailments."[35]

New advances in the medical field are opening new opportunities in treatment of patients and scientific research. Yet, those same opportunities still represent challenges in the ethical level. Islamic jurists appear to have covered a considerable distance in keeping the pace of medical and scientific advances. The pace is to live up to the demand of answering crucial questions on formulating ethical positions and decisions relevant to the many aspects of medical and research progress. The above illustration of serious efforts by jurists in collaboration with scientist and medical practitioners show the pragmatism characterizing interpreting Islamic heritage being applied and becoming relevant to contemporary science. Such approach has proven its viability and relevance in the daily life of Muslims by bridging the ethical values based on the religion of Islam with current discoveries in science and medical treatments as in the case of organ transplantation. The applicability, with its challenges and possibilities, of Islamic ethics can be applied further into the other vast realms of human progress in the political, comical, social, financial, economic, cultural diversity, coexistence, etc.

The collaboration between the Islamic scholars and medical specialists/experts represents a necessity in the formation of an Islamic ethical position in the medical field. The purpose is to

establish an educated and detailed medical informative opinion, combined with the most ethical position possible. The jurist alone would be indeed incapable of formulating an ethical opinion based on Islamic ethics and legislation if it was not for the collaboration of specialists in organ donation and organ transplantation. Such practice in medicine can be looked upon as micro model of other fields for the Islamic discourse in contemporary issues and challenges facing the global Muslim community and humanity at large. It is the significance of the premise of this thesis on Islamic ethics as rooted in the spirit of Islam but can be formulated in the context of highly informed and updated know-how. This is highly indicative and telling not only in medicine or public health, but seamlessly into the fields of contemporary economics, finances, peace and war, social justice and government, societal organizations and state-craft. Islam or Islamic scholarship does not attempt to reinvent economy or government or state-craft or governance, but rather how the economy or government run on ethical frame of reference. A central pillar to ethics in Islam is the value of justice where every human being is included in such ethical pursuit of being treated fairly and justly whether it affects a patient, a bank customer, a prisoner, marginalized group, minority, a citizen, etc. Organ donation and organ transplantation can be indeed a revealing aspect of applied Islamic ethics as seen clearly in the continuous efforts, *ijtihad*, pursuing an application to contemporary science and medicine.

Indeed, organ donation remains subject to further medical scrutinizing in order to formulate a more nuance and informative opinion on relevant ethical opinions. The following sections shall examine in details three main sources of organ donations. Namely, they are organs donated from living donors, dead body or cadaveric and from brain-death donors. The third type, dealing with brain-death donor, requires further thorough examination in looking at various definitions of brain death as well as the related ethics. Islamic jurists carefully examined the

controversial issue of brain-death. We shall start first examining the case of organ donation from the living donors.

3.1.1 Living Donors

For the practice of taking an organ from a living donor, the most important Islamic position is the principle of doing no harm (permits non nocere). This principle cannot be more highly emphasized. The donor's life is sacred, and in no way should there be allowed a risk to one's life when donating an organ. According to Islamic ethical standing, if death results from donating an organ, it is considered an act of crime or homicide. Islam condemns such acts as serious crimes.[36] Moreover, donating an organ from a living donor invokes the principle of "accepting the lesser harm when faced with two evils."[37] In other words, when an organ is donated, the loss of a donated organ should cause no harm or at least a minimum risk to the overall health of the donor. The Islamic view is to accept the benefit to the recipient which should be greater than the harm. In other words, the organ donation is recognized as an important treatment. Organ transplantation can save lives and impact the quality of life of recipients. It is important to point out that the harm results by a donor is not to be compared with the harm resulting from a disease which in certain situations can kill. According to Islamic teaching and traditions, there is a cure to every disease and people are encouraged to seek every possible cure and remain steadfast and optimistic in finding a treatment and a cure. "For every disease, there is a cure," as prophetic hadith state. And if there is no treatment for a certain ailment at current time, there is a possibility of finding a cure in the future. We may not know of a treatment at present, but we must continue hope and efforts as believers in the blessings and bounty of God`s mercy and generosity. Donating an organ, thus, is an act and an expression of a love of fellow human being, unselfish attitude, altruism and a charity. If a recipient receives a donated organ, the fact

that his/her health improves and continue to live for years to come, the donor`s action is considered in Islam *sadaqa jairiah*, a continuous act of charity, leading to spiritual reward in this life and the life after, according to Islamic teachings.[38] At a practical level, what is the criteria for donating an organ from a living donor?

There are two types of organ donations as far as the living donors are concerned. First, living donors who are alive and leading a healthy life. They have the chance for an extended life with a healthy way and manner. For someone who is already ill may pose a risk to life and health in general. It is not permitted to risk the life of those people through the process of organ harvesting, as example. For this reason, donating a heart is not permitted in Islam. The second criteria in the case of living donor is the decision solely based on the free will of the person who gives the organ. In Islam there is no compulsion against the free will of a person, particularly in "non-obligatory acts in Islam."[39]

Organ donation from a living donor carries both benefits and disadvantages. One major benefit is time, especially in non-urgent cases. If time allows, the process of finding a donor who shares certain similarities with a recipient can be of a significant advantage. For example, finding compatible blood type and size such as in the case of pediatric recipient are vital for the treatment of organ transplantation and long-term recovery. Both the recipient and donor possess more time to psychologically rehabilitate themselves after a surgery. For the disadvantage, we may expect a physical harm is caused to one person to the benefit of another.[40] But, putting this outcome in the Islamic perspective, this specific scenario is considered an "acceptable side effect"[41] Because of the fact of choosing between the "lesser of two maladies."[42] In other words, which is better, "one person dies and one person lives, or, two people live but with certain physical deformities."[43] In the meanwhile, the issue of informed consent and autonomy must be

respected and thus to be taken into consideration in this vital and sensitive field of organ donation.

3.1.2 Cadaveric Donors

Islamic jurisprudence adheres clearly to the basic concept of the needs of the living outweigh those of the dead when dealing with organ donation and transplantation.[44] This conforms the Islamic concept that saving a life or extending it is like saving or extending the life of all mankind.[45] Doubtless today, the dead body bears its right to sanctity and wholeness. A medical team or doctors must discuss in advance with the family or relatives of the deceased in order to obtain the consent. There should be no pressure applied or any form of coercion on the family in taking organ donation of a deceased member of the family. This principle must be upheld according to Islamic ethics even if it means posing a risk to the life of a living person who happens to be gravely ill. The human body, even when dead, must be venerated and respected.

The soul departs the body, but it does not mean the value of the human body is lessened or undermined, according to the teachings of Islam.[46] A human body is venerated whether it is living or dead. A story is narrated about prophet Mohammad when he heard about a man who broke the bone of a dead man in a cemetery. The Prophet rebuked the man and said, "The sin of breaking the bones of a dead man is equal to the sin of breaking the bones of a living man."[47] Body mutilation is strictly forbidden in Islam. That is why some jurisprudents in the past objected to organ donation by cutting up an organ from a dead body or for organ harvesting. Such practice counted as body mutilation, the jurists believed. However, new discourse emerged. Scholars and jurisprudents justified organ donation from a dead corpse on the Islamic premise of

prolonging a life or saving it. This does not pertain merely to body mutilation. It is about the principle of saving a life which justifies taking an organ from a dead corpse. In many Muslim-Majority countries, medical knowledge and expertise have contributed to such outlook. Islamic view considers God is the ultimate "owner" of the organs as God is the creator of the universe and human body is a creation of God; an organ is like a property. Thus, for a Muslim to donate an organ is a justified and permissible act as God places a high value on saving or extending a life.[48]

Organ donation from a cadaveric donor carries positive and negative aspects. The method means avoiding a potential harm to the living by donating an organ. Also, multiple organs can be harvested from a cadaveric donor in one operation for an ultimate benefit for numerous people. The drawback concerning donating an organ from a cadaveric donor is the issue of the "quality" of an organ which could be compromised by ischemia or infection. Time factor is highly crucial in the immediate period for transplantation, depending on the overall state of the specific organ. In Islamic tradition, the dead body must be prepared for burial as soon as possible. A Dead body is subject to putrefaction which could be more so in a hot climate. Islam forbids cremation. The funeral of a dead person must be given full veneration. There is a story when Prophet Mohammad stood in veneration during the passing of a funeral of a dead Jew during a time when the Jews waged a war against him. One of the companions of the prophet said, "It is the funeral of a Jew." The prophet replied, "Is it not a human soul."[49]

Muslims across the world found themselves seeking *fatwas* and informed opinions on the question of organ donation from a dead body. Jurists produced many *fatwas* during the second half of the 20th century throughout the Islamic World. Jurists in Egypt and Tunisia permitted corneal transplants from dead cadaveric bodies under certain specific conditions. The Grand

Mufti of Egypt, Sheikh Hassan Mamoon allowed corneal transplants from a dead body of an unidentified person or from persons who agreed in advance to donate upon their death. This *fatwa* was dated to 14 April 1959 with number 1084. Al bar 820. Another *fatwa* by his successor Sheikh Hureidi, allowed organ donation to extend to other organs in 1966, known as *Fatwa* number 993.[50] In 1973, the Grant Mufti of Egypt, Sheikh Khater, permitted the harvesting of a skin from an unidentified dead corpse. Also, another Grand Mufti, Gad Al Haq, sanctioned organ donation from cadaveric donors under the condition there was a prior testament or a will. The consent by relatives is highly relevant and important as this *fatwa* indicates. In 1979, Fatwa number 1323 stated that an order from a magistrate must be obtained in advance of harvesting organs from an unidentified corpse.[51] Sheikh Gad Al Haq also pointed out that organ donation from living donors should be considered as a free act for good faith, love for God and human fraternity.[52] The International Islamic Jurists Council, in Amman, in 1986, acknowledged and recognized brain-death as a sign of death.[53] This decision took organ donation to another level where organs can be obtained from brain-dead persons. Saudi Arabia was one of the first countries in the Muslim World to implement the new direction of obtaining organ donation from brain-dead persons. Following to that decision, the International Islamic *Fiqh* Academy (IIFA) and the Islamic *Fiqh* Academy (IFA) came up with further important *fatwas* on the subject of donor donation. In Saudi Arabia alone, more than 3600 organs were transplanted from brain-death persons by the end of 2008.[54]

3.1.3 Brain Death and Organ Donation

The conception of brain death presents a real challenge to clinicians and medical experts when required to account for cultural and religious dimensions. Islamic scholars have been tackling the sensitive issue of brain death in the last few decades from the ethic-legal opinions. The issue at stake is whether brain death is accepted as true death according to Islamic law. Both the medical experts and Islamic scholars have been exerting efforts in using the tools of jurisprudence in order to formulate an ethic-legal opinion on brain death. The Organization of Islamic Conferences' Islamic *Fiqh* Academy, OIC-IFA, considers brain death similar to cardiopulmonary death. In the meanwhile, the Islamic Organization of Medical Science, IOMS, takes brain death as an intermediate state between life and death. The assessment is not entirely uniform. So far, the issue has not received enough attention or inefficiently dealt within the medical and *fiqh* literature. Thus, this study proposes to find out how Islamic perspective understand brain death as a clinical phenomenon? Or, how Islamic ethics treat such medical uncertainty? In other words, what are the Islamic ethics that should apply to the field of biomedical issues about life and death. Such questions are vital as certain ethical principles become ever more important for clinicians when treating patients with a different religious belief, thus, influencing the course of medical care and practice as well as the interface with local laws governing the determination of death.

The definition of death itself proves to be as complex as life itself according to varying cultural perspectives. Death is a mysterious moment of all human transitions. Individuals and communities view death in different ways whether looking at spiritually, ethically, legally, medically, etc. One can imagine the kind of challenge facing medical doctors or clinicians on closing the gap between medicine and related ethical, cultural, religious and legal aspects. And in

the case of "brain death," it poses even greater challenge to all stakeholders, be it patients, clinicians, family members, because of its seriousness and emotional potential. In non-Muslim societies, death is governed by state law. In global society, the interface of secular laws and definitions have been witnessing more attention and scrutiny as to adapt to the needs of religious and cultural sensitivities of people with different religions and cultures. What is being witnessed, though, is an evolutionary process of the means of determining brain death and how such concepts and notions are being interacted and debated within Islamic societies and communities. In other words, how Islamic jurists and medical professional try to answer the ethical question on brain death from an Islamic perspective. This paper is going to show that two scholarly schools of thoughts have shaped the debate within the Islamic biomedical ethics discourse to treat complex questions of brain death. Contemporary Muslim scholars have devised a renewed methodology within Islamic jurisprudence, known as *ilm al-maqasid*, the higher objectives of Islamic Shariah, which aims at renewing Islamic law and rulings. This methodology examines the entire field of biomedical ethics, including brain death, from a holistic approach. Utilized as a check list, the methodology of higher objectives requires the collaboration between Muslim scholars and biomedical professional so that scholars become well informed of the necessary medical and scientific knowledge of brain death. Such collaboration is deemed highly crucial for contemporary scholars in order to come up with the appropriate ethical rulings and scholarly opinions from and Islamic perspective.

In investigating the interface between brain death and related Islamic ethical principles, we can show further understanding of Islamic ethical perspective in dealing with commonly shared issues like wellbeing and health, caring of old-aged people, dementia, smoking, etc.

3.2 Informed Consent, Autonomy and Organ Donation in Islam

Islamic law affirms the intellectual autonomy of an individual adult, be man or woman. A human being is responsible for his/her own acts and that every individual possesses the free will as rationale being.[55] The essential point manifests itself on how Islam views man. The Qur'an points towards this vital view, "The truth is from your Lord, so let him who please believe and let him who please disbelieve."[56] Thus, when the subject of informed consent is raised, a sane and rational patient has the full right to decide with a free will on an operation procedure or a treatment, provided that he/she receives sufficient and accurate information. Under Islamic law, the patient consent is required when a living donor wishes to donate an organ; applied to man and woman. As long as the patient is sane and competent, he/she has possessed the right to decide alone. Even close relatives cannot decide for him/her. "Freedom, in truth, is to be free in all affairs," as the prophetic traditions points out.[57]

In the case of a dead corpse donor or brain-death donor, informed consent becomes subject to certain procedure according to Islamic law. It is required upon every adult individual in Islam to have a will. The will is entrusted to another person in order to carry out and facilitate applying the terms of the will. This includes the physical remains of a dead person. The decision belongs to an entrusted relative or close family member on what to do with the remains of the body. If the will explicitly mentions donating organs, thus, organs can be taken away from the deceased. If the will is clear on prohibiting taking away any organ, the decision by the living relative must adhere to the wish expressed in the will of the deceased. In 1988, the Islamic Jurisprudence Assembly Council of Saudi Arabia, issued a *fatwa* on allowing a proxy consent. The fatwa stated, "Transplantation of an organ of the dead to a living human being whose life or sectional function of the body would reply to the donated organ is allowed, provided that the

dead (before his death) or his heirs permit it. And the permission of the Islamic authority is needed."[58] However, informed consent and autonomy for brain death is more controversial. Definition of brain death plays an important factor on the decision-making process of organ donation. For those scholars who think brain death is not death, they do not permit organ harvesting. On the other hand, those how believe brain death is death, they do permit organ donation, however the issue of consent remains to be addressed.

3.3 Islamic Perspective on Brain Death: The Evolving Definition of Death

In medical practice, death has been defined traditionally as "the irreversible cessation of cardiac and respiratory activity."[59] This definition is mostly used in emergency medicine settings. Yet, technically speaking, how would it be possible to know the duration of cessation of the cardiopulmonary system? This point is further complicated by the newly introduced advanced technologies such as extracorporeal membrane oxygenation, mechanical ventilation as well as cardiac bypass. In such instances, cardiopulmonary function may temporarily cease, however the period of the function of the brain may become extended in time. Clinicians and medical institutions may differ in deciding the actual time point where the cessation of cardiopulmonary of a patient occurs. Also, the patient's health condition does represent a concern because of possibilities of comorbidities where a patient may suffer additional illnesses throughout such a process.

3.3.1 Definition of Brain Death

In 1959, the concept of "brain death" was introduced through studies conducted by Mollaret and Gluon[60] when they referred to patients with irreversible coma. By the mid-1960s, additional medical terms surfaced, namely "cerebral death syndrome" and "electro cerebral

silence," designated to describe patients with brain death.[61] A well-known report, The Ad Hoc Committee of the Harvard Medical School to Examine the Definition of Brain Death, was published in 1968. The report described irreversible coma as brain death. It stated, "an organ, brain, or other, that no longer functions and has no possibility of functioning again is for all practical purposes dead."[62] Moreover, the report based the diagnosis of brain death on the total unawareness of externally applied stimuli with no evidence of spontaneous breathing, no brainstem reflexes and a flat EEG."[63] Many counties, during the time of publishing the report, passed a law recognizing brain death.[64] Perhaps in one of the first conferences to be held, representatives of the three Abrahamic religions met to discuss ethical issues, focusing mainly on defining death. The outcome of the conference described cerebral death as "a reasonable concept fully within the province of the physician to identify.[65] By 1980, the Uniform Determination of Death Act produced a definition of brain death. It was sanctioned by the National Conference of Commissioners on uniform State Laws.[66] The act says, "An individual who has sustained either: 1. irreversible cessation of circulatory and respiratory functions, or 2. irreversible cessation of all functions of the entire brain, including brain stem, is dead. A determination of death must be made in accordance with accepted medical standards."[67]

Yet, the methodology and guideline used at the present time to identity the case of presence of brain death may differ according to a definition, legal precedent, compliance based on law or the policy of an individual policy.[68] Confusion is likely to occur among observers even after determination of brain death particularly with non-brain mediated spontaneous movements as they falsely tell of retaining brain function. For example, ventilator auto cycling could be falsely understood as breathing initiated by the patient. Another contentious difference is the period acceptable as a determination of irreversible cessation of neurologic functions. In order to

assess this condition sufficiently, there is no proof to determine the "optimal time period" for such an extremely delicate condition.[69] The limit of available data to know if the ancillary test is enough to determine irreversible cessation of brain function is a problematic factor.[70]

The Western definition of brain death was borrowed by Muslim scholars about 25 years ago along with the complicated attempts of defining brain death. This created a challenge to Islamic bioethics. The traditional Western definitions of brain death have been transplanted in the Islamic discourse and related biomedical ethics. Complexity of the issue is manifested by the traditional definition of brain death as cardiopulmonary. Or, brain death is a state between life and death. Also, the debate on the formulation of brain death is whether it is whole-brain death or brain-stem death. Clinicians do face a challenging task when considering the above-mentioned issues.

In the Muslim World, the issue of brain death is still debated widely on whether it is true death.[71] Such debate is not only restricted to religious aspect but also to include different judgments, rulings, diverge opinions on ethical and legal issues. The same would apply to secular laws that may be deemed contradictory from one another. For example, in the United States laws are enacted at the federal and state levels, taking into consideration "the constitution, statutes, regulations, and common law or case law."[72] Thus, assessment of the ethic-legality of brain death from an Islamic perspective can be varied and controversial. This fact can add a considerable strain upon clinicians, hospitals and medical institution in taking the religious belief of a patient as well as the local governing laws enacted to determine brain death. The entire medical care can be influenced by the religious aspect and local rules within a given culturally-diverse society. Muslim scholars have been working in the issue of brain death for decades.

Since the 1980s, Islamic scholars have collaborated with medical professional in order to come up with ethical and legal opinions on brain death using the necessary tools of Islamic Shariah and laws. These opinions and assessments, however, maintained its controversy as determination of brain death varied from one another. The Qur'an and Islamic tradition do not contain a specific and direct reference to brain death. The notion of brain death was brought to the forefront of the medical and intellectual discourse in the Muslim world about 50 years ago, mainly because of organ transplantation and its link to brain death. This started debate and discussions between Islamic jurists and clinicians.[73] The Quran does emphasize the universality of death.[74] The Islamic view, according to the Qur'an, is the moment of death, *al-mawt*, is the time when the soul, *al-ruh*, leaves or separates the soulless body. There is not a precise description of how the soul departs the body. Before death, however, the Islamic principle of "no harm," *la darer wa la dirar fi il islam*, is clear and present in the mind of a Muslim doctor when facing a situation of determining death. In other words, "no harm shall be inflicted or reciprocated in Islam."[75] The Islamic principle of "no harm" can be described to resemble the Western principle of no maleficence.[76] Reflecting on this significant Islamic biomedical ethical position on death, some highly influential Islamic conferences further explained this crucial principle, pointing out a position on determining brain death. In his/her defense of life, however, the doctor is well advised to realize his limit and not transgress it. If it is scientifically certain that life cannot be restored, then it is futile to diligently keep the patient in a vegetative state by heroic means or to preserve the patient by deep freezing or other artificial methods. It is the process of life that the doctor aims to maintain and not the process of dying. In any case, "the doctor shall not take a positive measure to terminate the patient's life."[77] As a well-known contemporary Muslim scholar elaborated, "life is given by God and cannot be taken away except

by Him or with his permission and that preservation of life is one of the five fundamental objectives of Islamic Shariah."[78] Some Islamic juridical councils have attempted to come up with certain definitions and opinions.

Some scholar Islamic councils and conferences have attempted to settle the controversy. The Organization of Islamic Conferences' Islamic *Fiqh* Academy, OIC-IFA, put forward a clear assessment by equating brain death with cardiopulmonary death. However, the Islamic Organization of Medical Science, IOMS, placed brain death between life and death. Other councils have denied and dismissed the whole notion of brain death. The result there is no consistent position on the ethical and legal aspect which reflects the lack of consensus on the entire concept of brain death.

However, the Islamic institutions' role is crucial for the understanding of brain death and its relation to Islamic biomedical ethical stand. The Organization of the Islamic Conference-Islamic *Fiqh* Academy, OIC-IFA, in 1986, and the Muslim World League, MWL, in 1987, produced *qarart* (decisions) concerned with legitimizing a criterion of brain death. In 1986, at the third annual conference in Amman, Jordan, the OIC-IFA produced resolution number Five.[79] The decision declared that a person is considered legally dead and Shariah principles can be applied when one of the following signs is confirmed; "1. complete stoppage of the heart and breathing, and the doctors decide that it is irreversible, 2. complete stoppage of all vital functions of the brain, and the doctors decide that it is irreversible, and the brain has started to degenerate." Under these circumstances, it is justified to disconnect life supporting systems even though some organs continue to function automatically, e.g. the heart, under the effect of the supporting devices."[80] In 2003, the ethics committee of the Islamic Medical Association of North America, IMANA, introduced and developed a document titled, "Medical Ethics: the IMANA

Perspective."[81] The document agrees, in general, with the assessment of the diagnosis of death. However, it provides more details, demanding attention on the need of training of a physician in diagnosing brain death. Despite the fact that the medical community refer most often to the resolution of OIC-IFA and IMANA, as an accepted notion of brain death within the Islamic law and Muslim Community, there are still remaining clinical and conceptual ambiguities.[82] The debate continues, whether whole-brain death or brain stem or the higher brain functions are most likely and fitting for the purpose of conceptualizing and diagnosis of brain death.[83]

3.4 Conclusion

The definition of death varies. However, clinicians and the medical community recognize that the patient's cultural norms and religious teachings directly influence the medical care particularly when it encounters the question of brain death and its related interface with local laws governing the determination of death. Thus, the challenge becomes how to bridge the gap between the concept of brain death and cultural/religious norms. Through the science of Jurisprudence, Islamic scholars have been working on the issue of brain death and its link to the Islamic perspective of biomedical ethics for the past decades. And the issue of brain death poses a considerable challenge because the main Islamic sources, Quran and Sunnah, do not specifically address brain death.

This explains the current controversy among Muslim jurists on the Islamic discourse concerning brain death. Yet, brain death has been recognized by many Muslim scholars and related medical Islamic organization. The Organization for Islamic Conference-Islamic *Fiqh* Academies and the Muslim World League, the Islamic Medical Association of North America and other religious-based medical organizations have in principle agreed that brain death represents true death. Yet,

the Muslim world does not unanimously agree on the above definition. As shown throughout the paper, and despite the complexity of this subject, Islamic scholars have basically created two main interpretations. One considers brain death equal to cardiopulmonary death. The other considers it as an intermediate state between life and death as brain death does not prescribe to the standard of legal death. Thus, application of Islamic biomedical ethics on brain death varies.

This paper, then, examines how the two scholarly schools have shaped the debate within the Islamic biomedical ethics discourse to treat complex questions of brain death. As explained in the discussion above, a renewed methodology has been devised which basically aims at a renewal of Islamic law and rulings. Contemporary Muslim scholars have opted to apply the methodology of *ilm al maqasid*, the higher objectives of Islamic Shariah, in the field of biomedical ethics. It is a method aims at addressing current issues of science and technologies which are moving in a fast pace in an unprecedented level. The renewed methodology avoids the tedious entanglements of past disputes among various schools of thought within Islamic jurisprudence. It is a simplified version of Shariah to reinvigorate the understanding of what does Shariah want ultimately. This renewed methodology of *ilm al maqasid* functions as a checklist which to be utilized in tackling bioethical issues and dilemmas. It examines the entire field of biomedical ethics, including brain death, in a holistic manner. Islamically, practical application of ethics requires careful consideration holistically. The structure of such an approach needs to be clear for the both the scholar and the medical professional. The collaboration between the scholars and practitioners cannot be overemphasized. For scholars to apply ethics, knowledge of biomedical field is crucially necessary to be informed by the collaboration of professionals in order to formulate an educated opinion and thus an ethical ruling without losing sight of the higher objectives of Shariah. The introspection of the spiritual and intellectual is far more

demanding. Therefore, it is possible, then, to say that Islamic biomedical ethics are applied. Since the 1980s, there has been encouraging progress in the increasing collaboration between Islamic scholars and medical professionals in order to come up with ethical and legal opinions on various biomedical issues, including brain death, using the tools of Islamic Shariah and its higher objectives.

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Chapter 4

Autonomy and Informed Consent in Muslim Context

Introduction

Individual autonomy in medical intervention and human subject research is a fundamental human right. It is the freedom of choice that enables each person to take decisions related to their life, health and preferences. Rapid development of medical science, combined with the need to respect human rights, has prompted considerable research on the principle of autonomy. In this chapter the author will shed light on the concepts of autonomy and informed consent and examine how these ideas are understood in medical practices. The author will also illuminate how these principles are addressed in accordance with both Western and Islamic perspectives.

4.1 The Concept of Autonomy in Medical Practice

The term 'autonomy' comes from the Greek language. The word consists of two parts: 'auto', meaning self, and 'nomoy,' meaning custom or law. The implications of the term are broad, ranging from the individual to the political. In its political aspect, autonomy reflects a group's right to self-government or self-rule. On the scale of individuals, when a person seeks autonomy, he or she desires to make decisions independently from authority figure. [1] In medical practice, the concept of autonomy simply indicates the right of the person to accept or refuse medical intervention or participate in human subject research.[2]

The principle of autonomy is the cornerstone of biomedical ethics as applied in medical practice. The importance of the concept of autonomy manifests as a form of freedom. Each individual has the freedom to take decisions concerning his/her life

in relation to body and health, without coercion by outside forces. The individual bears the responsibility of the decisions taken by him/her.

The principle of autonomy deals with individuals as independent agents who have the freedom to take their own decisions. Consequently, a person who is autonomous is a person who can make own decisions and work toward their own self-selected goals. Respect for autonomy is made manifest through non-interference in decision processes and allowing the independence of a person to express views and take decisions without obstruction or coercion. This kind of liberty would be hindered only in cases where these decisions may result in harm to others or impede the freedom and interests of other individuals. Respect for people is a moral belief which includes the protection of people who do not possess full independence or autonomy for reasons that cannot be amended.

Decision-making in medical intervention relies on the principle of autonomy as an essential pillar of medical ethics. Medical treatment is a collaborative endeavor undertaken by doctors and patients. Such a relationship cannot succeed without confidence and cooperation between all parties. The details of a patient's medical conditions and history are entrusted to a doctor who does all they can to improve a patient's state of health. This includes providing guidance and advice that enables a patient to make sound and informed decisions. It is the responsibility of the doctor to provide an understandable explanation of a medical condition to the patient. A patient possesses the right to either accept or reject the proposed treatment by a doctor. In order to uphold medical ethical standards a doctor must respect a decision taken by a patient who has been provided all necessary and sufficient information.

4.2 The Principle of Autonomy and Islamic Legislation

Islamic scholars consider the moral and theological dimensions of issues that are raised as a result of contemporary science and technology. They work to integrate new developments into an Islamic context, specifically the moral and legal framework of Shariah. Biomedical issues are primarily understood according to Shariah which is based on the main two information sources of Islam, Qur'an and Sunna (Prophet's sayings and actions) as well as work done by past and present scholars

The first principle of Islamic medicine is the emphasis on the sanctity of human life. This is derived from the Qur'an: "We have honored Adam's children".[3] The concept of autonomy is mentioned in many verses of the Qur'an and the Hadith and most Muslim scholars classify it under the category of personal freedom, which is based on the sanctity and security of human life. It is considered one of the necessities of life, neither complementary to other qualities nor a luxury matter. Thus, autonomy – that is, the freedom to be independent – must be allowed, provided for, and protected within Shariah.[4]

In his book, *Human Rights between Islamic Teaching and UN Declaration*, the contemporary Islamic scholar, Mohammed Al-Gazali argues that Islam's understanding of human rights preceded the current International Convention on Human Rights by 1,400 years. He considers human freedom to be sacred, like life; an innate quality that is born with each human being. As stated by the Prophet Mohammed: "Every child is born on instinct."[5] Thus it is associated with every individual and no one has the right to abuse it. Moreover, a political authority must provide adequate safeguards to protect the freedom of individuals and it may not restrict or reduce freedoms except in cases that contradict Shariah.6

Yusuf al-Qaradawi shared al-Ghazali's point of view and further elaborated the concept of individual freedom in the decision-making process of 'autonomy' as a necessity rather than a kind of integration or condition of well-being. The state must provide this kind of freedom and ensure it is manifested in all people's lives. Furthermore, this should be done to the extent that it is protected by Islamic law.[7] Muslim scholars criticized Qaradawi for his preference of prioritizing autonomy over simply applying Islamic Shariah. He believes that this kind of freedom is a prerequisite for the realization of Shariah.[8]

Muslim scholar Rachid Ghannouchi, who is a Tunisian political activist and Islamic thinker[9], connected the concept of autonomy with that of human dignity.[10] Here, the notion of providing a livelihood means preserving human dignity, removing each person from want, and sparing them from the need to ask for necessities, which leads to a loss of dignity. As the Qur'an says, "We have honored the sons of Adam, and provided them with transport on land and sea and provided them with good things and preferred them over many of those who created preference".[11] The Islamic perspective on respect for autonomy, as applied through informed consent, seeks to protect the dignity of patients and their right to make their own decisions regarding medical treatment. A related verse says, "Indeed, Allah commands you to render trusts to whom they are due and when you judge between people to judge with justice. Excellent is that which Allah instructs you. Indeed, Allah is ever hearing and seeing."[12]

The scarcity of available Islamic sources that deal with the subject of medical ethics presents a significant challenge in seeking a specific definition of autonomy. Likewise, the issue of the lack of available Islamic sources has been noted by other

researchers, for example by Dr. Ghaly in his article “Islam Bioethics in the twenty-first century " that was published in 2013.[13]

From the author's point of view, Muslims scholars typically try to find a connection between the concept of autonomy in general and Islamic law (Shariah) through Qur'anic verses and Hadith. Muslims scholars tend to take a defensive role regarding autonomy in their efforts to prove this principle or term has existed in Islamic law since the descent of the Qur'an. There is a lack of attempts to reach a thorough definition of this term in Islam. Moreover, contemporary Muslim scholars have paid little attention to the concept of autonomy as it relates to medical practice in particular. In broader terms, however, there is agreement among Muslim scholars about the importance of this principle in Islamic law, whether it is framed as sacred like human life or if it is related to human dignity. All of them agree it is a basic right for all members of society whether Muslim or non-Muslim, and that the state must protect it.

4.3 Concept of Informed Consent

The practice of achieving informed consent is more than just obtaining a signature on a consent form. It is a complex convention that stands at the intersection of medicine and law.[14]

The concept of a patient's right to self-determination or 'informed consent' evolved gradually. The early twentieth century saw serious consideration given to the concepts of freedom and human rights, including the rights of a patient in decision-making and self-determination.[15] It was during the period of 1950s -1960s that a significant change began to emerge where it became a doctor's duty to tell a patient about the information concerning his/her health in order to obtain consent to

implement treatment. This development marked the establishment of a newly devised term known as “informed consent”. It refers to the duty of medical practitioners to reveal to a patient all relevant information about diagnosis, potential risks, and treatment.

The history of informed consent in the realms of medical research and clinical medicine has evolved separately in each area, though the two lines remained parallel. Before the Second World War, the application of medical ethics to research and experiments did not exist.[16] A turning point took place when actions were taken following the Nuremberg trials that were held after the end of the Second World War. [17] Among other offenses, the Nuremberg trials investigated doctors who conducted medical experimentations on human beings without any consideration of their consent. The trials resulted in a revolution to the concept of informed consent and its importance in research involving human subjects and medical intervention.[18]

4. 3. 1 Definition of Informed Consent

According to the current literature and social practices, the term 'informed consent' has two very different meanings:

> In the first meaning, informed consent is an autonomous authorization of a medical intervention or of involvement in research by individual patients or subjects.[19]
>
> In the second meaning, informed consent is analyzed in terms of institutional and policy rules of consent. This sense expresses the mainstream conception in the regulatory rules of federal agencies and in healthcare institutions. Here 'informed consent' refers only

> to a legally or institutionally effective approval by a patient or subject.[20]

As far as the first definition is concerned, the author thinks that independent authorization has the additional requirement that a patient must understand significantly every detail related to diagnosis, treatment and potential side effects. This is to be implemented without intervention by a physician or other person from the patient family. This definition leads to the philosophical concept that informed consent is essential to the protection and empowerment of independence. In other words, the protection of freedom of decision, of self-determination of the patient, leads and accumulates toward a final decision, whether for medical treatment or participation in research.

In the second definition, the author sees that conditions and requirements of informed consent for approval are a relative matter. In other words, it is related to social and institutional frameworks within the state, which do not necessarily protect individual independence. The motivation behind this definition is to respond to the demands of the law and the system of health institutions.

In addition, informed consent is a voluntary permission given by a person or their representative to allow a remedial action, conduct necessary tests, or for approval to conduct certain studies. Either could be considered as beneficial to the person concerned, or to others. For example, the permission is valid after a full explanation to a person about the purpose of a surgical intervention or a study and research. Detailed explanation should be carried out elaborating the methods and procedures as well as the potential benefit or risks.

According to well-known scholars in the field of bioethics, Jay Katz[21] and Alexander Capron, the aims of informed consent are to strengthen autonomy and support rational decisions by individuals. Further, it is about preventing the participation of the public as far as decisions by the individual person are concerned. In addition, obtaining informed consent encourages and supports the necessary security of the doctor. It is important to reduce physicians' risks of criminal responsibility in the event of complications arising from justified and reasonable medical interventions.

4.3.2 Islam and Informed Consent

Applying the practice of informed consent in the medical field in Islam protects the dignity and the right of a patient to make an autonomous decision. Islam stresses the basic right of human beings which is indicated clearly in the Quran, "We have honored the sons of Adam, provided them with transport on land and sea; given them for sustenance of things good and pure; and conferred on them special favors; above a great part of our creation"[22.] In another verse, "Indeed, Allah commands you to render trusts to whom they are due and when you judge between people to judge with justice. Excellent is that which Allah instructs you. Indeed, Allah is ever hearing and seeing."[23]

Everyone has the right to live and determine his/her fate. That is evident in the conditions set by Islam in obtaining the approval of a patient and protecting this right through consultation. The doctor must inform and consult with the patient as this is what is stipulated by the Quran. The concept of consultation is clearly shown in *Surat Al-Shura*', where the name *Al-Shura* means consultation, "…Those who conduct their affairs by mutual consultation". The concept of consultation is highly emphasized in Islam to arrive at a right decision in issues that are related to human life. Even the

Prophet Mohammed continuously showed by his actions the example of conducting consultation both in private and public life. Thus, in the relationship between doctor and patient, informing a patient of the merits and risk of treatment is a form of consultation. This consultation is also extended to the family of a patient. This is the basis of informed consent.

It is recommended after consultations are completed that a prayer for a successful result is made. The Quran says, "…Therefore forgive them, pray for their forgiveness, and consult them in the conduct of affairs; then you have decided to proceed, depend on God for support…"[24] The phrase "for their forgiveness" is an important psychological aspect where a prayer is made for the sick and conveys the message to the patient that his/her treatment is of paramount importance. For example, there is a common Islamic prayer for the sick; "O Lord of Men! Remove this trouble, O Thou Healer! There's no cure except thy cure, such a cure as will leave no disease"[25]

Islam requires doctors to provide truthful answers unless there is justification for doing otherwise. This is the meaning of *Ihsan*[26]. Doctors are required to maintain the best interests of the patient as a priority, while taking into consideration the limitations of the patient. This supports a relationship built on trust between patient and doctor. The Quran says; "And make not God's (name) an excuse in your oaths against doing good, or acting rightly, or making peace between persons; for God is One Who heareth and knoweth all things."[27] "Those who faithfully keep their trusts and their covenants."[28]. In another verse, "O ye who believe! Fear God and be with those who are true. (in word and deed)."[29]

In Islam, the adult is responsible for himself and has the right to approve or refuse treatment without the influence of force or other coercion. Accordingly, any

approval achieved by force or pressure from doctors is invalid and unacceptable under Islamic law. Moreover, any attempts by parents or relatives to influence or pressure an individual are also rejected. Islam emphasizes that a doctor must possess a conscience; the patient is the *Amanah*[30] from God which requires the doctor to be honest and sincere with him.

4.3.3 The Elements of Informed Consent

Informed consent is an educational process that takes place between health providers and patients. The essential elements of the consent process include:

(1) Disclosure

(2) Comprehension

(3) Voluntariness

(4) Competence

(5) Consent[31]

Scholarship in the field has further formulated and categorized the elements of informed consent with more details and explanations as given below;

1-Threshold elements (preconditions)

1. Competence (to understand and decide)
2. Voluntariness (in deciding)

2. Information elements

3. Disclosure (of material information)
4. Recommendation (of plan)
5. Understanding (of terms 3 and 4)

3. Consent elements

    6. Decision (in favor of plan)

    7. Authorization (of the chosen plan)[32]

There are basic standards that must be met in the construction of informed consent, as detailed in the following points:

- Consent is a continuous process and not just a one-time decision. It is important to give the patient sufficient opportunity to ask questions and achieve understanding. Personal point of view must be respected.

- Consent must be obtained before any examination, treatment, or care.

- Full knowledge based on detailed explanation of the situation ensures that the patient or the person concerned understands the situation.

- Consent must be voluntary and given freely without any pressure or coercion.

- The patient can change their mind and has the right to withdraw their consent at any time.

- Informed consent documents must be written in a language understood by the patient and be dated and signed by the patient or representative.

- It is required that prior to giving consent a person has the ability to assess and understand the facts and consequences of their condition and treatment options. Establishing a legal age of consent for patients supports their self-determination while taking their own opinion into account. This age varies from country to country. For example, in the United Kingdom the legal age is sixteen years old and above. Patients of this age are considered capable to

make own decisions unless they are impaired by their condition, such as a neurological or psychological disorder. In such instances a patient is considered unable to achieve or provide informed consent. [33]

- Allowing sufficient time for a patient to consider information before giving their consent is necessary. The same applies for those who participate in research.

4.4 Informed consent in research involving a human subject

Informed consent in research involving a human subject is considered significant. Protecting human participants in scientific research means invoking informed consent. The Council for International Organizations of Medical Sciences (CIOMS) defines informed consent as (1) receiving information necessary to make an informed choice about study participation, (2) understanding that information, and (3) making a voluntary decision on whether to participate.[34] Thus for a person involved in research a full explanation should be provided in language that is clear and easy to understand. The participant has the right to obtain a copy of an approval document for their protection. Such a document for individuals involved in scientific research provides protection in the case of complications that occur during the research. In addition, the participant must be given sufficient time to consider and decide whether to participate in the research. The individual's decision must be fully respected, without application of force or pressure. A participant in scientific research must have the right to withdraw at any point in time of research.[35]

Throughout Islamic history, the pursuit of research in various fields of science and knowledge has been encouraged. The pursuit of public interest is highly relevant in protecting people from risks that may result from the rapid development of

science and technology. Islam opens horizons for human beings in research in various fields of science, technology and others. As mentioned previously, Islamic Shariah aims to pursue the interest of individuals and the general public. It aims to protect people from risks that may occur as a result of the use of science and technology. Islam prohibits actions of medical intervention or research participation without getting consent from the person concerned. A Quranic verse says, "There is no compulsion in religion"[36] Thus, a human being is essentially a free-willed individual.

Islamic ethical guidelines for scientific research are derived from the five higher objectives of Shariah. If any of the intended five purposes are at risk, a permission is not granted for participation.[37]

On the other hand, Muslims are encouraged to research and seek the best knowledge to uphold the moral conscience of a Muslim community. The right of an individual choice and decision-making must be protected. This is especially important when treatment involves updated and new treatment. The idea of promoting research and solutions brings benefit to patients and to humanity at large. This comes from the well-known five purposes of Shariah, which are: preservation of religion, life, intellect, lineage, and property are. The priority of a participant`s interest comes first and before the interest of the public in the case of possible risk which could cause damage during a treatment or conducting research.

In Islam, strict protective conditions have been laid down for research carried out on a human subject research. If the research intention is incorrect or the method used is scientifically unacceptable, the research project is rejected in Islam, and it is not permissible to do it. Another condition is that there must be some positive evidence that experiments are likely to be beneficial to humans. In addition, there must be a balance between the risks of research and the risk of the disease itself.[38] For

example, the research cannot be harmful to the person or affect his social, mental or psychological life that is necessary to achieve the five goals of Shariah. In the event of any danger to the participant the researcher must immediately stop the work and inform the participant of the hazard in addition to providing treatment for any harm which has already occurred.[39] Moreover, the purpose of the research must be useful to others, for example to find a cure for a disease.[40]

The aim is to avoid causing any harm to a research subject or a patient. The Prophet Hadith says, "Do not cause harm or return harm."[41] Thus, the voluntary consent of a person is necessary to participate in research by giving enough information on health. A person who is involved in human subject research has the right to withdraw their consent. That is one of the personal freedoms that must be respected.

4.5 Informed consent and autonomy in international organizations (UNESCO and WHO)

The subject of informed consent is a topic that grew significantly in the contemporary era, especially during the 1980s. It has attracted the attention and interest of many international bodies, non-governmental organizations, NGOs, and governments. Informed consent is linked directly to fundamental freedoms and touches all human lives. It is the responsibility of governments as well as the international community to protect human rights.

The necessity of developing universal ethical guidelines is understood to cover all related issues resulting from the rapid development of various scientific research fields. Hence the need for global guidelines that include basic standards for the protection of human rights. To this end, in October 2005 the General Assembly Conference adopted the UNESCO Universal Declaration on Bioethics and Human

Rights. The declaration included pledges from the 193 UNESCO member states, to respect and apply the basic principles mentioned in the declaration. The Universal Declaration on Bioethics and Human Rights was a response to rapid development in medical science, life science and technology in direct association with human beings. The adopted principles in the declaration are intended to keep up with developments in science while maintaining respect for human rights and fundamental freedoms. [42]

The UNESCO declaration plays an important role in identifying and defining universal principles, based on shared moral values, to guide scientific development while meeting the responsibility of present generations for future generations. That is, recognizing that a human being is a part of the biosphere and directly or indirectly influences other life forms. Therefore, methods of management or control must be implemented in order to benefit from technology without compromising the environment.

This declaration reminds us that cultural diversity is a source of creativity. It is about an exchange that considers the common heritage of all mankind. The declaration contains twenty-eight articles with each one detailing a particular point. The first part of the articles deals with general provisions explaining the scope and purpose of the declaration itself. In the second part, the declaration deals with the basic principles that must be respected in decision-making related to protect human dignity and rights. In its third part, it deals with how to apply the previous principles in a professional manner and conduct follow-up by competent authorities to obtain maximum benefit.

Part four of the declaration involves defining the state's role in the implementation and activation of these principles by means of education, training and

increase of awareness. Finally, part five covers the fundamental principle of maintaining and protecting public safety, human rights and freedoms.

Definition of Informed Consent in UNESCO

The concept of informed consent, as a fundamental principle of Bioethics, was not presented clearly until early 1970s. The American scientist Ruth Faden, who did her PhD thesis in the 1980s on this subject, defined informed consent as "patient's or research subject's statement that authorizes a physician to carry out specific measures, therapy or include a subject on research protocol".

In the declaration adopted by the 33rd General Conference of UNESCO in October 2005, the issue of informed consent was discussed in Articles 6 and 7 of the document, as follows:

> *Article 6 – Consent*
> 1. 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 expressed and may be withdrawn by the person concerned at any time and for any reason without disadvantage or prejudice.
>
> 2. Scientific research should only be carried out with the prior, free, and expressed and informed consent of the person concerned. The information should be adequate, provided in a comprehensible form and should include modalities for withdrawal of consent. Consent may be withdrawn by the person concerned at any time and for any reason without any disadvantage or prejudice. Exceptions to this principle should be made only in accordance with ethical and legal standards adopted by States, consistent with the principles and provisions set out in this Declaration, in particular in Article 27, and international human rights law.
>
> 3. In appropriate cases of research carried out on a group of persons or a community, additional agreement of the legal representatives of the group or community concerned may be sought. In no case should a collective community agreement or the consent of a community leader or other authority substitute for an individual's informed consent.

> *Article 7 – Persons without the capacity to consent*
> In accordance with domestic law, special protection is to be given to persons who do not have the capacity to consent: a) authorization for research and medical practice should be obtained in accordance with the best interest of the person concerned and in accordance with domestic law. However, the person concerned should be involved to the greatest extent possible in the decision-making process of consent, as well as that of withdrawing consent;
>
> b) Research should only be carried out for his or her direct health benefit, subject to the authorization and the protective conditions prescribed by law, and if there is no research alternative of comparable effectiveness with research participants able to consent. Research which does not have potential direct health benefit should only be undertaken by way of exception, with the utmost restraint, exposing the person only to a minimal risk and minimal burden and, if the research is expected to contribute to the health benefit of other persons in the same category, subject to the conditions prescribed by law and compatible with the protection of the individual's human rights. Refusal of such persons to take part in research should be respected.[43]

UNESCO for Humanities and Social Sciences Sector devised specific divisions of Ethics of Science and Technology. However, in 2008, Bioethics became a core curriculum, adopted and taught as a curriculum for medical students. This curriculum consists of two parts; the first is the syllabus and the second part is about study material. The curriculum consists of seventeen units, each unit explains one principle of Bioethics. Units six and seven deal with the principle of informed consent in detail.

The goal of the sixth unit is to introduce the concept of informed consent to students and explain how to apply it properly in medical intervention and research. The student should be able to explain to patients the necessary requirements of obtaining informed consent, taking into consideration that there are exceptional cases

preventing approval of the patient, such as in emergency situations, or in the case of minors, or mental incapacity. In addition, this unit explains the concept of informed consent and its relationship to human rights, autonomy, and individual responsibility. The seventh unit of the UNESCO curriculum of Bioethics defines the meaning of "capacity to consent" and the criteria to approve in different circumstances both for the treatment or to participate in research. Furthermore, this unit deals with the categories of persons lacking the capacity to give their consent and how to deal with those people to protect them from any exploitation. A published report in 2008 was devoted the issues in the sixth and seventh Articles of the UNESCO Declaration on Bioethics and Human Rights. After the publication of this report, the International Bioethics Committee (IBC) presented an analytical study at the UNESCO General Conference.

WHO and Informed Consent

The World Health Organization (WHO) is one of the agencies belonging to the United Nation (UN). It was established in April 1948 in Geneva, Switzerland. It is the directing and coordinating authority in the field of health in the United Nations. The central role of WHO is following up on global issues and setting standards and conditions for research programs to protect all human groups and minorities from exploitation and to provide easy access to health services for all human beings. Moreover, the WHO has a role in monitoring and evaluating health conditions in various countries of the world. [44]

Until 2002 there was no clear role for the World Health Organization in the area of informed consent. In October 2002 the WHO launched an initiative on Ethics and Health which aimed to provide consideration and specialization in ethical issues raised by the activities of the organization in all countries and regional offices.

Its activities are related to rapid development in medical science and technology, in areas such as organ and tissue transplantation, the evolution of genes and other subjects. The initiative also engages with the moral aspects of these subjects through the means of international laws and national norms.

Recently, the subject of health ethics is an integral part of the activities of the World Health Organization in all its departments and units. The department of Knowledge Ethics and Research KER has been established as a separate entity in WHO to follow-up on ethical aspects of research and technology development.[45] EMRO is one of six regional offices around the world. The mission of the EMRO office covers 21 countries and contributes to improving health in the Eastern Mediterranean region by promoting Bioethics and Informed Consent issues.[46]

The World Health Organization developed templates for informed consent as an important step in establishing fixed models and specific frameworks for what should be included in the informed consent document for research carried out on humans. These templates of informed consent must be composed of two parts. The first model addresses information and explanation. The second one is a certificate of approval. Examples of various templates with a specific focus include templates for clinical studies, a template of informed consent for qualitative studies, and a template of informed consent for research involving children.[47]

4.6 Conclusion

In conclusion, there are few sources dealing with a precise Islamic definition of informed consent in medical ethics. The concept of autonomy in general includes personal, social and philosophical aspects. In the medical realm, the patient`s autonomy has been described as the underlying principle in all human interactions, both legally and morally. Individuals understand autonomy from the perspectives of

religious values, morals, and cultural factors as well. All these factors affect either negatively or positively the decision-making process. Islamic Shariah aims to protect and respect individual freedom and human rights in applying its principles to achieve the maximum benefit for humanity. Islamic Shariah balances respect of individual and family privacy with the need for full disclosure of information that must be met to achieve full disclosure of information. However, the principle of informed consent is not applied in certain societies nor is it always applied properly. In almost all Muslim societies, the absolute autonomy of a patient is rare. Most patients belong to social communities where family, parents and relatives hold a significant role in decision-making.

Thus, in the context of the high likelihood of family domination over an individual decision, a physician or a health-service provider needs to be aware of the cultural and religious backgrounds. The likelihood of interventions by family is high. The respect for autonomy requires awareness on the part of a patient and the surrounding family and community. Knowledge of cultural and religious values is vital for medical practitioners and health providers.

[1] Ibid.

[2] Ethics in medicine University of Washington School of Medicine, *Research ethics*, Lizbeth A. Adams, 2013. Available at https://depts.washington.edu/bioethx/topics/resrch.html.

[3] Quran, 17: 70.

[4] Youssef Qaradawi, "The Freedom and Necessities in Islam," Al-Jazeera.net, September 22, (2011). http://www.aljazeera.net/programs/religionandlife/2011/9/22/%D8%A7%D9%84%D8%AD%D8%B1%D9%8A%D8%A9-%D9%88%D8%B6%D8%B1%D9%88%D8%B1%D8%A7%D8%AA%D9%87%D8%A7-%D9%81%D9%8A-%D8%A7%D9%84%D8%A5%D8%B3%D9%84%D8%A7%D9%85, February 10 ,2016.

[5] Sahih Muslim, *Hadith No. 2658.* Destiny Books. http://hadith.al-islam.com/Page.aspx?pageid=192&BookID=25&PID=4876 , August 15,2016.

[6] Mohammed Al-Gazali, *Human Rights between Islamic teaching and UN declaration*, General Administration for Publication: Egypt, (2005).

[7] Ibid.

[8] Ibid.

[9] Encyclopaedia Britannica, accessed 2018, https://www.britannica.com/biography/Rachid-al-Ghannouchi

[10] Rached Ghannouchi's , *The public freedom in Islamic state.*

[11] Qur'an 17: 70.

[12] Qur'an 4:58.

[13] Ghaly Mohammed, *Islam Bioethics in the twenty-first century*, 2013

[14] Jonathan F. Will, A Brief Historical and Theoretical Perspective on Patient Autonomy and Medical Decision Making: Part II: The Autonomy Model, 2011, P 1491.

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[18] Ibid.

19 Tom L. Beauchamp, R. R. Meaning and elements of informed consent. *In informed consent*. (p.1239).

20 Ibid.

[21]Hevesi, Deniss. "Jay Katz." *The New York Times*, 2008: 1.

[22] Quran 17: 17

[23] Quran 4: 58

[24] Quran 3:159

[25] Bukhari, hadith No. 5435, Available at http://hadithportal.com/index.php?show=hadith&h_id=5435&uid=0&sharh=31&book=33&bab_id=.

[26] Ihsan refers to the acts of worship by a believer with the belief that Allah is present and watching that act of worship. Islamic Ethics: *The Attributes of Al-Ihsan in the Qur'an and Its Effects on Muslim Morality*, International Journal of Business and Social Science, 2017

[27] Quran 2: 224
[28] Quran 23: 8
[29] Quran 9:119
[30] *Amanah* literally means trust, trustworthiness, loyalty and faithfulness, Concept of Amanah in Islam, June 2013.
[31]Tom L. Beauchamp, R. R. Meaning and Elements of Informed Consent. (P. 1239).

[32] Tom L. Beauchamp, R. R. Meaning and Elements of Informed Consent. (p.1239).

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36 Quran 2:256
37 Raafat Y. Afifi, *Biomedical research ethics: An Islamic view – part I*, , International Journal for Surgery, 2007, (p 292).
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[39] Mohammed Ali Al-Bar, *Contemporary Bioethics Islamic Perspective*. (p 94).
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Chapter 5
Applicability of Biomedical Ethics, Autonomy and Informed Consent;

Case Studies of Turkey, Jordan and Palestine

5.0 Introduction

Every person has the right to access to health care provision during one's lifetime. It is their right to take advantage of all necessary services provided by the health care system. It is also the right of patients to be treated with full respect for their wishes and opinions which are built on the explanations and recommendations of the treating physician. Ethical adherence to the principle of autonomy aims to protect individual choice, rights, and freedoms against the control of other people or the state. It allows each of us to be own our rulers.

Through comparison of how biomedical issues are understood and implemented in Turkey, Jordan and Gaza Strip, this paper explores whether the nature of a society is affected by the state having a different ideology from its populace. The three countries studied have Muslim-majority populations and are considered to be conservative societies. However, while the Jordanian Hashemite Kingdom is constitutionally defined as a Muslim state, Turkey is a secular state, although more than 98% of its population is Muslim. On the other hand the case of Gaza is highlighted because its society is a Muslim-majority that has no state of its own. In the absence of a sovereign state, and living under military occupation, Palestinians in Gaza-Strip especially have often relied on society's resilience through volunteerism and civil society organizations.

By examining the approach that has been adopted in these significantly different countries, to biomedical ethics in general, and autonomy and informed consent specifically, the author evaluates the states' responses regarding policy and application, providing insights into the role of civil society and its relationship with the state. Moreover, in this chapter, the author evaluates the status of the application of the principle of autonomy in the medical field in Turkey, Jordan, and Palestine. How these countries address this principle to get approval (informed consent) from a patient is also examined.

The international perspective of informed consent is a significant development manifested by the UNESCO Declaration of Medical Ethics and Human Rights. The author highlights the role of the World Health Organization in recommending procedures for obtaining and applying the principle of informed consent correctly.

5.1 Methodology

During the fieldwork, interviews were conducted with medical practitioners, academics, and decision-makers in the three countries. These discussions explored the role of biomedical ethics, informed consent, and patient autonomy in decision-making in medical intervention and research involving human beings. In addition to addressing the procedure for obtaining approval and the legal age when a patient can make independent decisions, the interview schedule included questions concerning sharing information about diagnosis and treatment with patients and their families. The interviews also focused on the role of hospital administration in providing regular courses for doctors and medical staff to inform them about new studies and research related to biomedical ethics.

In Turkey, the interviews were conducted with doctors/directors in hospitals, and doctors volunteering in non-governmental organizations (NGOs). Most of the interviewees were decision-makers in the Ministry of Health. Other interviews were conducted with professors of theology and the Law Faculty at Istanbul University, and academics from medical schools in Istanbul Medeniyet University, Bezim Alim University, Al-Fatih Sultan Mehmet Vakf University, and Medipol University, respectively.

In Jordan the author interviewed medical practitioners from public hospitals (two of whom were directors of hospitals); academics in universities; officials in the Ministry of Waqf and Religious Affairs and Ministry of Labor; the Chairman and four members of the Jordanian National Committee for Ethics in Science and Technology; and several members of NGOs concerned with ethics.

On the other hand in the Gaza Strip, the author conducted interviews that included site visits to government-related institutions such as the Palestinian Ministry of Health, primary clinics, and hospitals. The interviews were conducted with medical staff including surgeons working in hospitals of the Ministry of Health. The survey also included interviews with international stakeholders located in Gaza such as the UNESCO Office, the Eastern Mediterranean Regional Office of the World Health Organization (EMRO), WHO, and other UN organization, namely, United Nations Relief and Works Agency, UNRWA. Other related local civil-society institutions were included in the survey, such as the Medical College of Al-Azhar University of Gaza and the Islamic University. The study sought to discover if these institutions propose programs or training for the medical staff to increase awareness and knowledge about patient rights.

The table below shows the number of interviewees according to position. Note that all the doctors working in government also teach in medical schools.

	Doctors working in government	Medical practitioners and academics	Legal and theological academics	NGO medical representatives	Total
Turkey	4	8	5	10	27
Jordan	3	6	5	5	19
Gaza	15	15	4	7	41

Interviews in Turkey were conducted in the English language while in Jordan and Palestine the author used the Arabic language; all interviewees gave their informed consent to have their names, positions and interview data included in this paper.

5.2 Why the Principle of Autonomy

In Islam, no one has the right to interfere in another's life or in the decisions of others without being authorized in the first place. Evidence for this is found in this Quranic verse, "We have honored Adam's children."[1] The importance of the principle of autonomy derives from this statement. It is an issue tied closely to human rights and how a person can respect and apply this right in the medical field.

The ability of self-determination is crucially connected to the maturity and capacity of an individual. No one has the right to ban or restrict this right except in special situations where a person is unable to act in their own best interests, such as mental disability or unconsciousness. Other circumstances can also limit personal liberty

such as in a time of war or imprisonment or merely being a child. Such circumstances require that a person's well-being and rights are protected by the decisions of external agents such as family members.

From an Islamic perspective it is not permissible for a doctor to perform any medical procedure without obtaining permission or consent from those considered sane, adult and conscious. Individual autonomy in medical treatment means a patient has the right to decide what is good for his/her body. In religious terms, God will ask each human being about his/her body in the day of resurrection; how each man or woman 'wear' the body and take care of it. As the Prophet Mohammed said, "Man's feet will not move on the Day of Resurrection before he is asked about his life, how did he consume it, about his knowledge; what did he do with it, his wealth; how did he earn it and how did he dispose of it, and about his body, how did he wear it out."[2] That is based on what Imam Shafei said, “If a boy is brought to a doctor for circumcision or for incising a wound or cutting a sore, then the boy had a damage, in this case, the doctor must pay a compensation of the boy.” [3] The human body is considered a gift from God, thus no one has the right to interfere without permission from the owner of it.

5.3 Current State of Autonomy in medical treatment in Turkish, Jordanian and Palestinian societies

5.3.1 Case Study One: Turkey

Legislation in Turkey derives from the Turkish Constitution, drafted after the military coup in 1982 to replace the 1961 version, with amendments in 1995, 2001 and 2004. In 2010, the government introduced the most recent amendment to facilitate coordination with EU legislation and to improve democracy and human rights in Turkey. The modifications were based on two main theories of republicanism and secularism. The first focuses on the terms, ‘independence’ and ‘participation', while the second is concerned with removing the government’s reliance on religion.[4] Turkish political culture has experienced profound changes over the past century through attempts to separate religion from all areas of state and general life. However, despite efforts towards secularization and 'modernization', Islamic values have remained steadfast, and the process of secularization and Westernization has not succeeded in replacing the function of metaphysical religion.[5]

Despite the attempts of the Turkish government to establish a secular state, this was rejected and met by a general resistance from the Turkish community. Whenever the state tried to escalate secularity, that steadily experienced an increase in religiosity and increased peoples' pride in their religion. Moreover, some interviewed scholars saw when the state attempts to limit the influence of religion on individuals’ private lives the outcomes are negative for both the religion and community. Religion is generally viewed as protective and strengthening for individuals and community alike.[6]

The Health System in Turkey

In 2003, the new Ministry of Health team designed an urgent preliminary plan called the Health Transformation Program (2003-2011). This aimed to improve the performance of the health system, raise the level of primary healthcare services, and provide health insurance equally for all citizens. The new government started implementing the program immediately.

Several years later, the Ministry of Health introduced two new strategic plans. The Strategic Health Development Plan, implemented between 2010 until 2014, set out health-orientated objectives and goals according to certain priorities, including increasing health facilities in isolated areas by improving access to primary healthcare centers. Budget allocations were assessed and increased. The second plan, 2013-2017, was based on the results of the first plan and the earlier Health Transformation Program. In this, attention was paid to biomedical ethics throughout medical practice and research involving human subjects.

Consequently, patients' rights are now recognized, leading to improved services provided by the state. According to a 2015 WHO report, the overall improvement in health services resulted in a significant decrease in mortality rate, especially in rural areas. The infant mortality rate per 1000 live births dropped from 31.5 in 2002 to 7.4 in 2012.[7]

To evaluate the situation of biomedical ethics and explore the main factors affecting it is applicability in the health sector in Turkey, the author raised the following

questions for interviewees: What hinders the correct application of bioethical principles? Since the relationship between doctor and patient are reflected in the extent to which the patient accepts treatment, from your point of view, how do you evaluate the relationship between doctor and patient? All doctors had seen the unstable political situation in neighboring countries and the increasing influx of refugees and were aware that the government had to provide health services to many refugees as well as citizens, which had significant impact on the quality of health services.

Turkey receives patients from neighboring countries of Eastern Europe and some Arab countries as the Turkish health system is perceived as developed. Moreover, the presence of a large number of Syrian and Iraqi refugees put tremendous pressure on the Turkish government and hospitals to provide services for all. Turkish law allows anyone residing in Turkey to be treated in its hospitals and benefit from the health system. The health insurance does not cost much money. All these factors increased pressure on the hospitals belonging to the Ministry of Health and consequently affected the type and quality of services provided.

The OECD Health Statistics confirmed that there was a shortage of doctors, with only 1.8 doctors per 1,000 people, allowing each patient only six to eight minutes to explain their symptoms and receive diagnosis and treatment.[8] Since this is not enough time for a doctor to explain the diagnosis, the different kinds of treatment and the potential side effects of drugs, this undermines the patient's right to know everything related to his/her situation.

[9]The doctors interviewed had recently seen the relationship between doctors and patients deteriorate.[10] For instance, each year, at least two doctors are reported being killed by families of patients who had died during or after surgery. In other cases, the patient's family has taken the doctor to court. These reactions are associated with the lack of information given to patients and their families regarding operations and potential complications. In other words, several interviewees considered the main reason for such tragic conflict was that the doctor failed to apply the principle of informed consent correctly.

Government Policy regarding Biomedical Ethics

To avoid potential conflict with the secular state establishment, who attributes the success of the Turkish state to abandoning religion, the current Turkish government has followed the western model in various fields including economy, medicine, and human rights issues. These procedures were applied to fulfill the government aspirations to become a member of the European Union (EU). In addition, the western approach is more suitable for the secular state of Turkey. Accordingly, the government has taken several steps to develop the field of medical ethics along western lines.

The first regulatory system appeared in Turkey in 1993 when the government issued the "Regulations on Drug Research". The primary objective of this body was to establish central and local ethics committees to provide administrative control. At that time, there was no required curriculum on medical ethics, so the proposal recommended that the committees must play a central educational role by training research teams and physicians to become aware of ethical issues. In the same year, the Research Ethics Committee (REC) was established to provide management and oversight of research on

humans.[11] Some scholars have seen this step as the result of pressure from the western scientific community. The aim of this committee was also to aid recognition of research conducted in Turkey.[12]

When interviewing doctors working in the government (some of whom have decision-making power), the author asked them if there are any national commissions (governmental or otherwise) specifically concerned with biomedical ethics and patients' rights. Further questions were asked about how the government can improve services provided by the Ministry of Health regarding ethical issues arising as a result of rapid scientific development, and if there was any law to ensure the correct application of the principles of biomedical ethics in health practice. Their answers provided the following insights:

1. There is a general desire among doctors to establish an autonomous and interdisciplinary national biomedical ethics commission comprised of clerics, doctors, jurists, and scholars. The aim of this commission would be to oversee developing scientific research and to standardize a national curriculum and competence measures in all Turkish medical schools, as well as highlighting the importance of applying basic principles of biomedical ethics in Turkish hospitals.[13]

2. The Turkish government supports and encourages universities to hold conferences and workshops, where experts and academics can discuss contemporary biomedical ethics issues. These events provide a platform to discuss national priorities and address the need to find culturally appropriate solutions to biomedical ethics issues in the Turkish community.

3. Some medical schools in Turkish universities have adopted a new biomedical ethics curriculum, comprising two credit-hours teaching during the first year of medical school as a first step to increase the awareness toward biomedical ethics in general.

4. In reference to laws that ensure the correct application of the principles of biomedical ethics in health practice, several doctors explained that, as yet, there was no such law nor was there any provision to penalize those who fail to apply such principles.

These insights indicate an overall awareness of the issues and some progress in resolving them. However, the Ministry of Health does not provide training courses for doctors to refresh their knowledge or to inform them of new relevant studies. In other words, the Ministry of Health in Turkey still needs to improve the systematic application and teaching of biomedical ethics.

Biomedical Ethics and Turkish Law

When the author interviewed three professors who are working in the law faculty of Istanbul University, the following questions were raised: How does Turkish law ensure and protect patients' rights? Is there any Turkish law or statute law that protects patients' rights? Does Turkish law have a position on contemporary medical issues such as abortion, organ transplants, adoption, clinical death, euthanasia and other issues that concern the rights of the individual? And, at what age is a person considered legally capable of making decisions on matters related to his/her life.

All the professors agreed that, in principle, the Turkish government is responsible for the protection of the human rights of citizens according to international standards and

that one of the fundamental human rights is the right to live in dignity. Turkish criminal law strictly prohibits aiding suicide by euthanasia; offenders can be prosecuted for murder and are liable to life imprisonment. Islam categorically rejects euthanasia or suicide since Muslims consider it a sin to end one's own life; that only God grants and takes life.

Recently, 'edge of life' issues have become central to bioethics discussions in Turkey. In 1983, Turkish law introduced the population planning law. This grants a married woman the right to abort until the tenth week of pregnancy, taking into consideration the consent of the spouse. The abortion issue has been debated from two sides. One is religious, whereby traditional scholars look upon life as a holy matter and so consider the embryo to have the right to live, and that life begins from the first moment of fertilization. The other side believes that only the woman has the right to decide freely about anything related to her body.[14]

In Turkish law, patients do not have the right to make any decision relating to their life until they are 18 years old. Before this age, a person is considered a child and their family normally decides such issues on their behalf. However, there is no specific law to protect patients' rights. The court intervenes only in cases where a patient's family raises a lawsuit against a doctor or hospital regarding the patient's death. In this situation, only the court may carry out investigations and act upon these.[15]

Bioethics, Autonomy, Informed Consent Application and Ignoring in Turkey

In this section, the author explores doctors' perspective on the application of biomedical ethics in Turkish hospitals; in particular, whether this is carried out from an Islamic or a western perspective. All the doctors interviewed agreed that currently applied biomedical ethics from a purely western and secular perspective are related to the fact that Turkey is represented in its constitution as a secular state. According to the director of Istanbul Medeniyet University, seventy percent of the doctors who work in the Ministry of Health are secularist. Moreover, the administrations of hospitals do not allow doctors to use Islamic bioethics terms during practice and when on duty.

At the implementation level of applying informed consent, for many years, a fully trained nurse or a doctor obtained patient consent for medical intervention without explaining the operation or treatment and possible side effects. In the last eight years, the Turkish Ministry of Health developed and adopted a system requiring informed consent for each type of surgical intervention to protect doctors and avoid potential problems. The procedure involves clear explanation and details of the diagnosis, the proposed surgical methods and the potential impact of treatment. In Turkish hospitals, they use fifteen different forms for informed consent; for example, for colon tumors, stomach tumors, stomach ulcers, abdominal hernias, testicle hernias.[16]

The author asked the interviewed doctors their opinion about the form of informed consent that is used in the hospitals that belong to the Ministry of Health, in

addition to the procedures to obtain the approval from patients, to evaluate whether it is applied in the appropriate way or not.

All doctors who interviewed agreed that informed consent is a contract between two parties; the doctor and the patient (or whomever represents him/her) to enable a process of legality and shared responsibility. However, the *twelve* doctors interviewed had different perspectives on how to obtain the consent, particularly regarding its application. Two doctors believed that verbal consent is enough on its own, arguing that the informed consent form was dysfunctional and without benefits. Some doctors considered that applying for the relevant form caused additional work, especially as doctors have little enough time for each patient. Others said that both verbal and written consent is essential and complementary to each other. Some doctors thought applying informed consent is insufficient to protect doctors in case of any complications occurring during or after surgery or other treatment.

The author asked the doctors their opinions regarding sharing information with patients' families even in cases when the patient was capable of making independent decisions without family consent; in particular, regarding autonomy in matters of surgical intervention. All doctors asserted that all related surgery information, including potential complications after surgery, must be described and shared with patients' families, even if the patient is more than eighteen years old and is fully able to make decisions related to his/her life. This is so that in the event that a patient dies or something goes wrong, their family will need to confront the doctor. Regarding this, one professor explained that some hospitals, such as Bezmialem Hospital, have a center for receiving complaints from

patients about their treatment. The director of the hospital must see it, and it must be resolved within 15 days.[17]

Moreover, the author asked doctors about the informed consent form that is used in medical research. They explained that this is entirely different to that used for medical treatment and typically takes into account the company or research center involved, although the opinion of the participant's family is also considered essential to avoid later problems.

However, there is still a general lack of awareness about the importance of applying biomedical ethics. Due to the conservative nature of the Turkish society, its disposition regarding biomedical issues is significantly different from western societies; especially regarding the concept of autonomy. As a principle of practice it is not as clear as in western culture. Thus, while there is a good understanding of the importance of this fundamental principle at academic and administrative levels, difficulties remain in its application on a practical level. Moreover, in Turkey, since the family is considered the smallest unit and is expected to operate as an independent entity, it is responsible for decision-making regarding all familial issues. Thus the Turkish cultural understanding differs significantly from the western understanding of autonomy and, consequently, of informed consent as represented in the secular model.[18]

The Role of Civil Society

The history of civil society in Turkey began with the Ottoman Empire, which had a long history of associational activities. A second distinct period started in the 1980s when the relationship between the Turkish state and civil society became problematic due to the unprecedented influence of the military elite over the political process. Considering civil society organizations (CSOs) to be a potential threat, the militaristic state imposed restrictions on their activities and introduced new rules making them fully answerable to state authority. In the 1990s, when the Turkish government was seeking to join the EU, it introduced reforms supporting human rights and allowing civil society more autonomy. Currently, Turkish civil society is trying to build strong community relations to rely on the internal financial support to resolve their community issues. In order to avoid the problems associated with conditional foreign aid from the EU.[19]

During the fieldwork in Turkey, the author interviewed people from three NGOs whose work is relevant to bioethical issues and patients' rights. These were the Beşikçizade Center for Medical Humanities (BETIM), the Center for Excellence in Education (EDEP) and the Center for Islamic Studies (ISAM).

1. The Beşikçizade Center for Medical Humanities

The BETIM center specializes in research and advancing the field of biomedical ethics in Turkey from an explicitly Islamic viewpoint. It was founded in

2012 to enable scholars from various disciplines to discuss and develop related issues from an Islamic perspective and how to apply them in the Turkish local health sector.

The center works in parallel line with German doctors and universities, focusing primarily on ethical issues to improve the quality of health provision for the large Turkish community in Germany. They also invite Turkish doctors to learn from the success of the health system in Germany. As Dr. Bromer, one of the founders of BETIM, told the author: "One of the main goals of the BETIM center is to adopt the principles of biomedical ethics as guidelines in medical centers by creating a foundation of biomedical ethics to improve the health system in Turkey."[20] BETIM is supported by Dr. Sara Ogulo, the former prime minister's wife, who is a pediatric doctor and involved in many activities and projects related to biomedical ethics; aiming to eventually create a platform for discussion of biomedical ethics in Turkey.

2. The Center for Excellence in Education

Launched in 2014 to educate outstanding female scholars from diverse academic fields, EDEP provides an excellent scientific program for graduate and post-graduate students through seminars and workshops that include ancient and Islamic science.[21] The main goals of the EDEP center are to introduce women students, who will be future academics, to high standards of science, ethics, and protocols for doing good service (or Ehsan, which calls for the highest levels of good deeds and piety). The center teaches women how to lead a life with high moral standards, following the Prophet Mohamed. The center stresses this aspect, as well as freely sharing the knowledge gained with others as an act of charity.[22]

As stated by Dr. Rajab Shinturk, the center director, it is "a civilization project that aims at repairing the broken relationship between knowledge, thought, and art." Moreover, students of EDEP are encouraged to consider and think of problems as affecting all humanity, whether morally or tangibly, and to endeavor to find solutions based on Islamic perspectives. The author found the center is still new and had observed that its programs are still limited nor is there any clear plan regarding the possibilities of conducting training courses for workers in biomedical ethics from an Islamic perspective.

3. The Center for Islamic Studies

As a subsidiary of the Turkish Religious Foundation, the primary objective of ISAM is to contribute to trustworthy and scientific investigation, as well as the accurate presentation of Turkish/Islamic history, culture, and civilization.

It is one of the most important centers for Islamic Studies in Istanbul with an extensive library established in 1984, which is considered as one of the most important libraries for Islamic Studies, Ottoman Studies, and social sciences. It contains thousands of Islamic manuscripts and a vast number of essential books on Islamic medical science, including several on biomedical ethics, and can provide members of the center with any scholarly article or manuscript available, free of charge.

Overall, it became clear from the surveys that the number of CSOs concerned with biomedical ethics is limited in Turkey. Despite recent improvements allowing more space for civil society, there is still far to go. Also, the government only

allows CSOs with known affiliations to the current government to work and function because of its lack of trust in others.[23]

5.3.2 Case Study Two: The Kingdom of Jordan

The Hashemite Kingdom of Jordan is defined in its constitution as a Muslim country: "Islam is the religion of the State";[24] Muslims in Jordan represent more than 94% of the population. For this reason, the author chose Jordan as a model of Muslim society with a Muslim state.

Jordan is considered one of the most advanced Arab countries regarding medical science and the use of new medical technologies. Moreover, medical services are relatively low in cost compared with neighboring Arab countries. Consequently, Jordan attracts many patients from other Arab countries, including the Gulf States, Iraq, Libya, Yemen, Syria, Yemen, and Palestine. For medical tourism, Jordan ranked first among Arab countries and fifth globally. Therapeutic tourism is considered an essential contribution to the Jordanian gross domestic product, estimated at significantly over a billion US dollars in 2014[25]. Consequently, the state is concerned to maintain the private health sector and keep standards at international levels.[26] However, Jordan has borders with three Arab countries that are experiencing political crises. In addition, like Turkey, Jordan has experienced a heavy burden on health services because of the influx of refugees.

The Health System in Jordan

The Ministry of Health has played a significant role in the success of the health sector, specifically through protocols of international health cooperation with some Arab

and other countries. The Ministry acts as a partner and observer of the entire health sector, including government and private hospitals, and imposes standards and fundamental laws protecting patients and doctors; in particular, aiming to prevent transmission of infectious diseases. This has had a significant role in promoting health and safety as well as encouraging medical tourism.[27]

The health sector in Jordan is interested in developing the quality of the services that it provides to its civilians. The NGO, Health Care Accreditation Council (HCAC), was established in December of 2007, in collaboration with the Ministry of Health and the US Agency for International Development, to ensure continuous improvement of health services and patient safety.[28]

The instability of the political situation in neighboring countries of the Jordanian kingdom has a positive impact on the health system in Jordan in financial terms. In Jordan, for a patient to be able to access a public hospital and to get benefits from the health system, the patient must have insurance. The health insurance costs much money in comparison to Turkey where it is made available and for free for all civilians and refugees.

Government Policy regarding Biomedical Ethics

During the fieldwork in Jordan, the author raised questions to the scholars who are working in the Ministry of Health, (who also teach in medical schools attached to universities), about the role of both the government and the government's national commission on bioethics and patients' rights, regarding follow-up on ethical issues

arising from the rapid development of science. Other questions concerned the government's role in improving services provided by the Ministry of Health and whether there are hospitals in Jordan representing a bioethical model, or that can act as a reference for doctors.

The interviewees indicated that there had been some initiatives by the government to improve the performance of medical staff in hospitals and treatment centers. For instance, the University of Jordan, which is a government university and most prestigious higher education institution, adopted a curriculum containing biomedical ethics subjects for the first year of its nursing college and medical school. The Committee of the Jordanian National Ethics of Science and Technology established in 1998 as a response to the UNESCO resolution of 1997 urging its members to take appropriate action to promote the application of the principles of the Universal Declaration on the Human Genome and Human Rights. The committee consists of doctors, religious scholars, lawyers, and representatives of the union and aims to promote the implementation of the Declaration at the national level. The author had the opportunity to interview the Chairman and four members of this Committee, who explained the Committee's work and activities that included conferences, workshops, and training for medical staff.

In 2003, the committee was reformed under the name of Jordanian National Committee for Ethics in Science and Technology, with 17 members from public universities, Ministry of *Alwqaf* and Islamic Affairs, the Supreme Judge Department, the Secretary of the Jordanian National Committee for Education, Culture and Science, the Director of Curriculum and Textbooks, and members of the media and legal

establishments. This Committee aims to consider contemporary issues from moral and religious perspectives and to increase awareness (both of the population generally and of decision-makers in the field) regarding the importance of applying the principles of biomedical ethics. Although it has limited financial capacity, the Committee achieved many important objectives, including a symposium in 2010 to implement the three UNESCO declarations (1948, 1997 and 2003) that relate to the field of biomedical ethics. Moreover, the committee issued recommendations that included the need to emphasize the importance of educating citizens about their rights when participating in research. To meet the need to move from a theoretical approach to more practical issues to change the prevailing culture amongst the general population and make them aware of the new concepts and ideas.

In the following year, another national symposium was held that aimed to develop a law to oversee the use of stem cells. This symposium issued recommendations based on respect for human dignity and protection of human rights, as well as respect for the fundamental freedoms guaranteed by the Islamic religion and confirmed by the Constitution of the Jordanian Kingdom. The symposium established a national body to oversee research on stem cells, which is responsible for the enactment of legislation relating to stem cell research, and which relies on previous studies and experiments conducted in Arabic and Islamic countries. Moreover, it highlighted the need for promoting awareness of the importance of this subject concerning Islamic rulings and Jordanian laws.

The author conducted a significant interview with Dr. Salem, who is a Head of Division of Pharmaceutical Studies at the Jordan Food and Drug Administration.

This is an independent association but under the supervision of the government. He explained that Jordan was considered one of the leading Arab countries in the field of pharmaceutical studies. Dr. Salim mentioned that the Food and Drug Administration implements all kinds of regulations that contribute to ensuring the health and safety of all participants in pharmaceutical studies. It has also set up a committee to follow up research; this uses a database of names and information of all research participants to ensure their prior consent and the proper use of informed consent.

Moreover, the Jordanian government also conducts awareness campaigns through the media and TV to educate people about bioethical issues, linking them to Islamic values and morals and encouraging the population to be aware of new issues that affect individuals' lives.

Clearly, the survey results show that the Jordanian government has made progress regarding discussions, recommendations and training in the field of biomedical ethics. Moreover, it has a clear role in supporting centers and associations interested in improving the performance of health services. The author believes all these efforts and recommendations remain in the theoretical level and there is still a special need for practical steps such as enactment of laws in the Jordanian Constitution to protect the rights of patients and participants in research as a kind of transition to the stage of real implementation.

Biomedical Ethics and Jordanian Law

Jordanian legislation derives from its Constitution, which was ratified in 1952 and which safeguards public freedoms and human rights. The articles and provisions are

inspired by two sources: Shariah law and the Declaration of Human Rights of the United Nations (1948). In particular, Article 7 of the Constitution asserts that "personal freedom is inviolable".[29]

Despite occasional amendments to the Constitution, there is no specific law to protect patients' rights. To remedy this, early in 2014, Parliament discussed the creation of a medical accountability law. The demand for this law reflected an urgent need to reduce the number of medical errors that occur in Jordan. However, this law has not yet been passed.

Regarding biomedical ethics, the Jordanian National Committee for Ethics in Science and Technology is considered as a source of legislation for emerging issues raised by new technology. Regular workshops are held where scholars and clerics, specializing in the fields of medicine and bioethics, research and discuss emerging biomedical issues. They determine the Islamic ruling on each case, assessing whether it should be accepted or prohibited under Shariah law. They then make a declaration ensuring the verdict is a clear opinion applicable to those concerned.

Bioethics, autonomy, and Informed Consent between Application and Ignoring in Jordan

In Jordan, the application of biomedical ethics in its hospitals derives from its legislation based on western bioethics, which has been adapted to reflect Islamic values. This is significantly different to the situation in Turkey where, even though it is a Muslim-majority society, medical ethics are applied from the standpoint of a purely western and secular perspective. In Jordan, western biomedical ethics are adapted to fit

the Muslim community's values; for instance in cases of controversial issues, such as selecting a baby's gender and (IVF) In Vitro Fertilization, are presented in accessible terms explaining the Islamic view to be understandable to the general public

In Jordan, every hospital has a committee to oversee professional ethics in medical practice and to keep in touch with its administration. This committee plays an active role in initial monitoring and following up any irregularities occurring within the hospital, be they medical errors or any medical ethics transgressions, and carries out investigative procedures where necessary. Members of these committees come from various disciplines and include surgeons, nurses, laboratory technicians, administrators and specialists. Their role is to oversee and monitor the performance of medical staff.

In cases where the committee is unable to solve an issue, then as a second step, the patient or their family raise the problem to a national body which is the Syndicate of Doctors. In this step, the Syndicate will take any necessary action against the doctor or hospital to solve the issue. As a last step, if the problem remains unsolved or the patient or his family is dissatisfied with the actions (or lack of action) on the part of the Syndicate, they can take a claim to court. Thus, the initial responsibility lies on the Doctor's Syndicate, which has an important and useful role in resolving problems and complaints submitted to it. In some cases, it can assign severe penalties such as prohibiting a doctor from working if irregularities on his/her part have caused a patient`s death.

In Turkey, however, there is no body that plays the role of mediator as the Jordanian doctors' Syndicate does. Thus, people take their complaints directly to the courts. In terms of applying the principle of autonomy and informed consent, in the

present time, there is more awareness of the importance of the informed consent form for both doctor and patient.

For many years, obtaining patient consent for medical treatment or surgical intervention was done by a fully trained nurse or a doctor, without giving any explanation of the operation, treatment or the potential side effects. In the last ten years, the Ministry of Health has developed several models for each surgical intervention, containing a full explanation of surgery and the possible side effects after the operation. These models are written in both English and Arabic languages, using simple medical terms to make it easier for the patient to understand. The patient and two witnesses from his/her family must sign the form to confirm family participation in decision-making and sharing of responsibility (even in the case of an adult patient). These conditions are meant to avoid any conflicts with the patient's family in case of complications after surgery.

All the interviewed doctors agreed that prior approval is very important for patient and doctor, alike. This ensures the doctor obeys the laws of the Ministry of Health and does not contravene the regulations of the Syndicate of Doctors. In cases of absence of a written consent form for surgical intervention, the Syndicate has strict rules, and the doctor would become subject to a rigorous accountability process. However, two of the six doctors who have been interviewed had another opinion, where they did not consider the use of a detailed consent form necessary because that might make the patient doubtful about going ahead in operation or his decision in general.

The legal age in Jordan to consider a patient qualified to sign a consent form for medical intervention is 18 years old. If the patient is a woman, the consent of her father is essential, likewise her husband's approval is required if she is married.

In conclusion, the author found, in both Turkey and Jordan, there is still a lack of awareness of the importance of applying biomedical ethics in the correct way or even of applying them at all.

The Role of Civil Society in Jordan

The first NGO in Jordan was registered in 1912. The Non-Government Organizations in Jordan are working in many fields and disciplines to help and develop Jordanian society. With the transition to democracy in 1989, the Jordanian community witnessed a massive increase in the number of civil society institutions, estimated at nearly 2,000 organizations by 2011.

There was also a significant increase in their degree of independence, recognition of their role, and their effectiveness. As a part of their strong emphasis on democracy, civil society organizations played a key role in demanding amendments to the Constitution in 2011 to support the democratization process. These amendments enhanced the level of democracy and supported the original understanding that people are the source of authority, as well as promoting public freedoms.[30]

The author concludes that despite the flourishing of civil society in Jordan and its high degree of independence from the government, there is still no civil society association working in the field of medical ethics issues. There remains an enormous vacuum in civil society institutions. The author believes that although the government gave civil society organizations some freedom to do their work, there are still restrictions. This may be a reason for the lack of an association working in the medical ethics specialty.

5.3.3 Case Study Three: Palestine, Gaza Strip

Palestine has a strategic location between Lebanon, Syria, and Egypt. The Palestinian crisis started when the British Mandate permitted the Israeli people to make their state on Palestinian land in 1947. At that time more than three quarters of the Palestinian people became refugees in neighboring Arab countries. The second war was in 1967 when Israel occupied the rest of Palestine, which is the West Bank, East Jerusalem, and Gaza Strip. This land called the occupied Palestine territory is the term used by the UN for the region of land occupied in 1967. After the Oslo agreement in 1993, the Palestinian Authority was established in 1994 in the West Bank and Gaza Strip, and became the Palestinian National Authority. This Authority established the Palestinian government and Palestinian ministries in West Bank and Gaza Strip. [31]

The Ministry of Health of the Palestinian National Authority (MOH) was established in 1994 after the Oslo agreement. It was working in the West Bank and Gaza Strip under the management of one minister until 2006 when Hamas won the Palestinian legislative elections and became the majority in the Palestinian parliament. The international community and Israel decided to boycott the new government. After a few months of trying to overthrow the new government of Hamas leading from inside and outside, Hamas controlled the Gaza Strip and became a separate government and administration.

The Health System in Gaza Strip, Palestine

After Hamas won the election in 2006, the Israeli government and the international community decided to boycott the newly elected government. A severe political and economic blockade was imposed on the Gaza Strip and left more than two million Palestinian trapped and suffering a collective punishment.

In consequence, most of the budget of the Ministry of Health in both the West Bank and Gaza Strip is provided by local taxes and foreign aid. The last years the situation of the Ministry of Health in the Gaza Strip has become more embarrassing due to the cutting of funding from international donors and Palestinian tax revenues being withheld by Israel, an estimated 75% of the Palestinian budget.[32]

In recent years the Ministry of Health in Gaza suffered from a significant shortage of many kinds of treatments and drugs. Cancer treatment drugs, heart disease and kidney failure treatments, and many kinds of antibiotics are not available to Palestinians. A significant worsening of these shortages has been observed in recent years. Furthermore, the levels of supply in the repository of the Ministry reached zero. This issue has significantly limited the capability of the Ministry to provide health care.[33]

The situation became worse after Egyptian President Assisi closed the Rafah crossing and prevented the movement of many kinds of goods, medications, medical instruments, food, even the movement of people. This siege profoundly affects life inside Gaza by increasing poverty and unemployment. The performances of all sectors are reduced, especially in the health care sector.

Government Policy regarding Biomedical Ethics and Biomedical Ethics and Palestinian Law

The Palestinian Authority does not have a constitution as a basis for Palestinian legislation, as it does not have state sovereignty. In 1997, the Palestinian Legislative Council established a law called the Palestinian Basic Law as an interim constitution for the Palestinian Authority until the establishment of an independent state with a permanent constitution. In 2002, this law was approved by the former President Arafat and continues to be used as a primary reference, with some modifications made in 2003 and 2005, respectively.[34]

Article 16 in the Palestinian basic law states, "It is unlawful to conduct any medical or scientific experiment on any person without his prior legal consent. No person shall be subject to medical examination, treatment, or surgery, except in accordance with law. Transplantation of human organs, and new scientific developments shall be regulated to serve legitimate humanitarian purposes." [35] This addresses issues of biomedical ethics in a theoretical aspect, while at the practical level there is no action or ruling issued by the Ministry of Health to obligate workers in the Ministry to respect and implement the rights of patients.

The survey points out that the administration of Ministry of Health in Palestine has not played any active role in applying biomedical ethics principles. For instance, there has been no adoption of a new form for informed consent, instead there is just one used in all kind of surgeries in the hospitals that belong to the Ministry. Nor does the Ministry do regular training of doctors to inform them of what is new in the field of

biomedical ethics in general or in the application of the principle of autonomy and how it is practiced when obtaining consent from a patient. There have been no public awareness campaigns to inform them about their rights and duties in medical practices. Moreover, most doctors who were surveyed had no knowledge of the UNESCO Declaration. Only 21 percent of surgeons interviewed, and 17 percent of pediatric surgeons interviewed had previous knowledge of UNESCO's declaration.

Bioethics, Autonomy, and Informed Consent Applied and Ignored in Gaza Strip, Palestine

There are several factors that explain why the Ministry of Health does not have the ability to play an efficient role in administration of the health sector. Some factors are internal, and others are external. The physical, geographical separation between West Bank and Gaza Strip is a major factor. The Israel military occupation has imposed restriction of the free movement of Palestinian people between the West Bank and Gaza Strip since 1993. This has had a strong negative impact on the economy, society and the attempts to build effective national institutions by the Palestinian Authority.

The second factor is that the Palestinian National Authority lacks power in in controlling natural resources like water, land and the environment. The Palestinian authority has no control over the physical movement of people within the occupied Palestinian territory. The third factor is the complete dependence of the Palestinian National Authority on financial assistance from international donors. The majority of the large aid agencies follow political agendas, which could undermine the long-term benefit of the Palestinians, especially the establishment of a sovereign Palestinian state.[36]

Furthermore, the political divide between Fatah and Hamas that started in 2007, has adversely affected the performance of the Ministry of Health. After Hamas took control of the Gaza Strip in 2007, Israel blockaded the entire area of Gaza. This collective punishment has isolated Gaza from the rest of the world. Doctors and health care professionals in Gaza are cut off from the outside world. Few doctors, nurses, and health technicians have been able to leave the Gaza Strip for training to update their knowledge or learn new skills and technology since 2000. This has a huge impact on the ability to provide good quality health care. [37] This reality has prevented Palestinian doctors from traveling abroad for conferences, further studies and conducting international workshops outside Gaza. The international aid community has supported the authority in the West Bank and ignored the Gaza Strip. Consequently, various budgets of the Gaza administration became very limited, impacting training and upgrading multiple skills in general. Doctors and members of the medical staff are unable to join training courses outside of the Gaza Strip.

The author believes that medical practitioners and staff should view an alternative possibility to learn as a form of challenge against the siege. For instance, by using the Internet, downloading and applying recorded workshops and conferences. To follow and be informed of what is new in general in all fields of studies and biomedical ethics specifically. Anyone can download new studies, conference reports and published reports by research centers. For example, it is possible to download the report of Human Rights and Bioethics of 2005 from the website of UNESCO. In general, Palestinian are known for being highly educated, but unfortunately, there is a weak culture of "reading," be it reports, books or specialized studies. A majority of Palestinians are avid readers of a

daily newspaper and weekly magazines, however, beyond that, the reading horizon becomes limited.

In terms of applying informed consent, the Ministry of Health in Gaza does not play their expected role in applying it in the right way. Specifically the have done no work to improve the form that is used for all kind of surgeries in its hospitals.

The consent form that is used by the Ministry is a standard procedure that applies to all surgeries. That means there are no specific explanations for various kinds of surgery. Almost all the doctors interviewed said the official form implying informed consent in the Ministry of Health in Palestine is not insufficient because there is inadequate explanation on the form. Most doctors criticize the form because they consider it inadequate to protect them in case of complications. In addition, doctors feel threatened by both the hospital administration and the families of patients. In some cases when surgeries go bad, families harass or threaten the doctor physically. In cases when a patient dies, hospitals cannot protect the doctor from the family of the patient, even in front of the law. For this reason, many doctors write and use their own handwritten 'consent form'.

A few surgeons explain that not applying informed consent for prior approval in hospitals is due to the instability of the political situation in Palestine and the Gaza Strip in particular. If we look for the number of doctors who have considered political circumstances as the reason, the numbers are not high. The author of this paper believes that political instability does not prevent appropriate and correct application of informed consent. That is because in wartime and in emergency situations, the time for intervention is limited and saving a patient's life does not need an informed consent. It is impossible to

explain medical conditions or treatment fully to a patient's family during wartime. It is different from a normal situation during times of peace. The Palestinian Ministry of Health did not sufficiently play the necessary role towards developing the form that is used in its hospitals.

After the interviews were conducted with doctors the author could evaluate the situation in the Ministry of Health in the Gaza Strip regarding general knowledge of biomedical ethics and specifically informed consent. There remains a lack of a regular training for doctors and medical stuff to be informed and updated in the area of biomedical ethics and patients' rights in order to promote the application of informed consent.

That is why during the survey all doctors suggested strongly making a new informed consent document for each kind of specialized surgery, each containing full information and details of surgery, treatment, measures of risk, and potential side effects. The doctors want to protect themselves legally in case complications happened during or after surgery.

Palestinian Civil Society, Health Sector and Biomedical Ethics

In Palestinian civil society, Palestinian Human Rights Organizations do not possess a systematic framework to manage issues of medical ethics. Certainly, many Palestinian NGOs are working in the field of relief and other areas to deal with the effects of military occupation, and its subsequent economic, political and health-related impact on people. The author conducted interviews and visited related civil society (human rights) organizations. The NGOs deal with individual cases in the health sectors. NGOs

concerned with the field of health are more often absent. Human Rights NGOs deal mostly with political and security situation. Despite their active role in local society performing training sessions, workshops, and conferences, such activities almost always deal with political freedom, political prisoners, women's issues, gender questions, child rights and the impact of Israeli occupation. NGOs take on issues dealing with the rights of patients only when serious problems arise.

For example, NGOs take actions when a patient dies in surgery or a woman loses her life during birth labor or an infant loses life due to carelessness in a hospital or medical errors. Civil society in Gaza has not yet fully grasped the awareness and value of integrating medical ethics in the field of health provision in the Gaza Strip. Normal life in Gaza means dealing with the turbulent upheaval caused by the siege and occupation by the Israeli military. Civil society organizations more often deal with humanitarian and relief efforts as a priority. Human rights NGOs spend effort and time on issues related to prisoners' release and defending the rights of people and communities. Health-related civil society in Gaza believes in the importance of medical ethics and its potential to be applied. But at the moment concerned practitioners in civil society in Gaza think that there are more immediate and urgent issues to deal with such as the need for relief of people suffering the severe consequences of war. Biomedical ethics and the principle of autonomy appear to be items of luxury at the moment. In general, it can be said that Palestinian civil society needs to develop a vision of promoting biomedical ethics in the Gaza Strip and Palestine health sectors.

The issue of human rights has always been a core value of the Palestinian conscience because of its centrality in the national struggle. The issue of human rights of

the patient is not difficult to be recognized at deeper levels and in the conscience of both the doctor and the patient. Informed consent is an issue of the human rights of patients. The politically aware Palestinians are intellectually well equipped to fully understand the human rights dimension of informed consent.

5.4 Conclusion

Application of biomedical ethics in Muslim communities whether in Muslim or non-Muslim nations is strongly related to and dominated by the culture of the society, separate from the effects of the religion recognized as a feature of the state.

At the level of government, Turkish and Jordanian governments have the same desire to improve the performance of their ministries and provide the best services for their people. This is accomplished through support of related centers and associations interested in enhancing the understanding and application of biomedical ethics in the health care sector. In the case of Palestine, the government has no interest to improve their services provided by the Ministry of Health nor does it work to increase awareness of ethical issues encountered in the hospitals under its administration. The author has observed neglect of biomedical ethics by the government. The unstable political situation does negatively effect the performance of the Ministry, but in the case of Palestine there is total disregard for all patients' rights by the Ministry of Health.

Regarding the importance of applying the principles of medical ethics, in general, and autonomy (informed consent) in particular, the author found there was awareness among the staff in the Ministries of Health in both Turkey and Jordan and Gaza, Palestine. A majority of doctors interviewed in the three countries had previous

knowledge of bioethics as a subject during their study in medical school, while after that and during their career they did not receive any training to stay updated in the field of biomedical ethics and patient rights. The author concludes that the responsibility in this lies with the Ministries of Health in the three countries. It is assumed that it is part of their role and duty to strive for the development of medical staff and improve their performance.

In the last six years, informed consent has become a matter of great interest in the Ministries of Health in Turkey and Jordan alike. Both countries have produced specific models for each medical process, treatment or surgery. A range of informed consent forms have been developed and adopted to protect doctors and patients and their families. Each form has adequate information relating to the procedure and potential side effects of treatment. In the case of Gaza, Palestine, just one consent document is used for all surgeries.

There are significant similarities between Turkish, Jordanian and Palestinian communities regarding their commitment to public morality. Moreover, all three countries are considered conservative societies regardless of the orientation of their administration. The author's findings support the argument that, in the case of Turkey, the Constitution has not changed the nature of the conservative Muslim society; instead, the government and the community have different ideologies, and the secular nature of the state does not significantly affect how Turkish society, in general, understands medical ethics and informed consent. The central issue in applying the principle of autonomy in those countries is the structure of their communities, of which the family is the smallest unit, functioning as an autonomous entity with a high level of paternalism. Making

independent decisions away from the influence of close family members' pressure is virtually impossible

This study found the differences between Turkey and Jordan regarding the application of biomedical ethics stem from the perspective on which their systems are based, Islamic or western. Turkey applies biomedical ethics from a purely western perspective as set out in the United Nations Charter and does not permit the use of any religious terms or references to Islam, despite the majority of the population being Muslim. That is because the national constitution of Turkey is based on strict secularism. In Jordan, also, we find that the basic reference for the application of biomedical ethics derives from the UN Charter. However, here, this has been developed to suit the Muslim-majority society, and the government has referenced Islamic values, linking the underlying principles of both perspectives to relate more clearly to Islamic values and the culture of the Muslim community. Thus, while in Turkey, biomedical ethics are understood regarding 'right or wrong,' according to international standards, Jordan relies on more in-depth considerations that relate to the specifics of its population. While in Palestine, despite the Palestinian basic law addressing some points related to patient rights, at the practical level there is no any interest or attempt to adopt a western or Islamic perspective.

In Muslim-majority societies such as Turkey, Jordan, and Gaza-Strip, Palestine, the concept of autonomy is understood differently from that of western societies. The family is responsible for decision-making on all medical issues whether they involve an individual or a whole family. Family decisions normally function by consensus among members of the family. In other words, individual choices within the

family to a large extent do not exist in societies of Turkey, Jordan and Gaza-Strip, Palestine.

Overall, neither country applies the principle of autonomy in a way considered acceptable according to international human rights or the scholarly understanding of Islamic ethics discussed above. Although there is an understanding of the importance of this fundamental principle in biomedical ethics at academic and administrative levels, there remain some difficulties in its application. This is mainly due to the need to incorporate the difference in understanding of autonomy between that of the UN Charter and the Islamic concepts underlying the lived experience of Jordanian and Turkish and Palestinian societies.

Regarding civil society, the study indicated a further difference between Turkey and Jordan. In Turkey, the government allows only pro-government CSOs or those affiliated with the current government to work inside Turkey. They do not trust others and see them as a potential threat to the state. Nevertheless, this research found one CSO that is involved in biomedical ethics in Turkey (and this is overtly Islamic) while, in Jordan, although CSOs are allowed more space to work, they do not play an active role in this field. For the Gaza Strip, Palestinians remain living under military occupation. In the absence of the state, society mitigates its needs and aims through civil society in different fields and sectors of living and services. Despite the fact that there is interim Palestinian self-rule in the West Bank, and to a lesser extent in Gaza Strip, the so-called Palestinian Authority does not possess sovereign control over the West Bank and Gaza. Palestinians are thus inclined to meet their needs through civil society. The health

care sector is one major area of activities of civil society in the Gaza Strip but operates far away from the biomedical ethics issues.

Individual autonomy is intrinsic to the Islamic faith. It is in the practical outward manifestations with relation to public interest, and the ultimate view of the human being's subservience to God which contrast significantly with the western philosophical model. While individual autonomy in Islam and the pursuit of knowledge are promoted, so are the values of family, society and the consideration as mentioned earlier of public interest.

A western grounded philosophy of autonomy, which emphasizes individualism and self-actualization, denies the role of faith in a supernatural being, and often also the greater importance of societal benefit and public interest over the rights of the individual.

Functionally, the practice of autonomy does not only mean obtaining patient approval for medical intervention; it goes beyond that. For example, when a Muslim asks to be seen by a same-gender physician if available and possible, this should be respected as an exercise of her autonomy in ensuring privacy. However, in Islam even this can be overridden in cases where the principle of Darūra (necessity) is applicable. If a same-gender physician is not available, it becomes permissible for the Muslim patient to be treated by a physician of the opposite gender.

Moreover, the concept that both parties – the doctor and the patient – have rights and duties that should be considered by both parties is not widely respected. Clearly this reflects the similarities in the three societies in terms of family and tribal structures. Consequently, there is a need for the three Ministries of Health to work in parallel with civil society to educate the public and medical staff through workshops, training courses, and publication of relevant information.

The discussion here on the Islamic aspect of the principle of autonomy and informed consent application specifically in Turkey and Jordan is not deeply elaborated. This is because these two countries follow a secular model and still lack deep Islamic knowledge of the principle of autonomy. Turkey and Jordan have yet to establish consultation mechanisms with Islamic scholars. In the case of Gaza there is no constitution, but there is existing Islamic knowledge. Despite deep Islamic knowledge in Gaza the health sector and medical practice still need to utilize this knowledge to strengthen the application of the principle of autonomy and informed consent. In the case of Turkey, the author recommends establishing studies of the principle of autonomy from an Islamic perspective. Turkey is currently a destination for medical tourism geared towards western tourists. In the near future Turkey will experience greater diversity among medical tourists as the country continues to move in the direction of increasing globalization.

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Chapter Six

Conclusion

The significance of the role of religion in producing a universal biomedical ethics is becoming increasingly relevant. The pursuit of universal values is needed as the pace of globalization is accelerating towards new levels. Can we meet the need for a universal biomedical ethics emanating from an Islamic perspective? Scholars and specialists are seeking to meet this challenge. The realm of biomedical ethics is essentially about the application of ethics. The study of applied ethics points as well toward other fields of application, informing us about the relationships between ethics and various area of human conduct. For Muslims, the goal is not the practice of religion, but right actions and good deeds are highly emphasized and encouraged in all walks and realms of life. Historical Muslims figures in medicine, such as 19th century physicians Ishaq bin Ali Rahwi and Al-Razi described medical doctors as guardians of souls and bodies and explained that a doctor's duty was to humanize medicine, to take care of a patient's attitudes and problems. In present times, the planet's environment and nature are exploited by science and modern consumerism, threatening the survival of living species and the future well-being of the planet. Islamic ethics apply to science and it cannot be separated. This includes the practice of biomedical ethics.

Maintaining a biomedical ethics dialogue is vital for the global Muslim community as one fifth of the world population is Islamic, whether in Majority-Muslim countries or existing within multi-cultural societies. A new discourse with fresh guidelines has become necessary in bringing about harmony with the worldview of the Muslim global community on the applicability of biomedical issues and related research. Thus, the compelling task is to seek Islamic solutions for present biomedical challenges and issues. In such a pursuit, a larger task arises which is the manifestation of a dialogue not only between science and religion but also the pursuit of ethics itself

in areas such as political conduct, economic practice, social organization, civil society, philosophy of education, and international relations. Ethics is central in Islamic teachings. God's main goal in sending Mohammad as a prophet was to ennoble Man's morals. Islamic writing and discussions on morality are found traditionally in categories of *akhlaq*, (morality), *suluk*, (right conduct), and *tasawwuf* (spiritual cleansing). According to these categories, a Muslim pursues such efforts to realize their best personality, self-improvement, ethics conduct and thus ultimately becomes closer to God. The discourse of biomedical ethics is deeply linked to the wider context of Islamic ethics, based on the teachings of the Quran and the tradition of the Prophet Mohammad and the interpretation of Islamic law. The specific area of biomedical ethics is relatively new in the Muslim world. However, medical ethics existed in Islam since the time of the Prophet Mohammad himself who addressed the physician's accountability, remuneration and communication with patients. Religious opinions and rulings do not emerge from vacuum. They are highly influenced by social norms, and legal and political systems. Bioethics, according to the Islamic perspective is not only about the rights of an individual but also about the responsibilities attached to those rights.

There is a wide misconception in understanding Islam as a monolithic and static dogma by non-Muslims and Muslim commentators alike. This misunderstanding projects Shariah law or *fiqh*, Islamic Jurisprudence, as unrelated to contemporary life or current issues and questions. Shariah law is often looked upon as frozen in a time in the past. However, reality projects a different panoramic view of Muslims living in diverse regional and cultural contexts. One essential premise of Islamic Shariah is to understand, discern, and analyze a situation or an issue of importance for an individual or a community. Muslims exist within a plurality of positions in which ethical and legal opinions are required to enable right action in these positions. Scholars deal with various situation and such intellectual and jurisprudence inquiry can produce differences in opinions and rulings. It is the well-known tradition of *ikhtilaf*, (differences, disagreements) in which is exemplified the juristic positions on issues such as organ donation, brain death, autonomy and informed consent.

The contemporary secular perspective of biomedical ethics is symbolized by the Four-Principle theory. The field of bioethics is recognized as multidisciplinary in nature and dependent on various sources of inputs. The theory claims a universal dimension which can be applied harmoniously in different cultures and societies. Islamic critics of the theory argue that the theory is based on secular and philosophical principles and stops short of taking into consideration moral and ethical values that are based on religion. The problems lie in separating morality from religion. As a result, the famous theory of the four-principles has become one of the most widely debated theories since it arose in the 1970s. The critical concern of Muslim scholars is the western discourse implying the reconsideration of the role of ethics in society at its core. The secularist approach separates ethics from knowledge as a different and independent subject. To Muslims, ethics are inseparable from science and knowledge. If separation is imposed, this creates a fracture by providing ethics an independent status which can be utilized and made compatible at some convenience. Ethics in this case, becomes reductionist and measurable according to a dominate economic order. Vulnerability of the weak, particularly the sick and injured, looms large as a problem in society due to corruption and mishandling of the relativity and questionability of ethical standards. The value of justice is at the heart of the notion of ethics in Islam. That is why ethical opinions and positions from an Islamic perspective refer to the Islamic frame reference, rooted in justice. Yet, this is not about rejecting a western discourse or the theory as a whole. It is certainly crucial to study the aim of the theory and the way the two authors implement the methodology of achieving results. The theory needs to be analyzed in a holistic manner with the frame of reference of the overall objectives of Shariah. Such an approach entails a wider and inclusive methodology which includes the ideas and technicalities the Four-Principle theory implies alongside the larger intention or a holistic approach taken into consideration. Such an outlook is not a replacement or a rejection of a methodology but rather the constructive pursuit of consistency of the ultimate goals. Bioethics field can facilitate and mediate discussion of what is wrong and what is right and how we

can examine such ethical and moral questions regarding a given medical practice as a scientific application or technology. In this day and age of globalization, different cultures and religions interact at higher rates than ever before. New scientific technology and medical discoveries add up to new challenges facing the individual and the community. Bioethics thus can be considered an important decision-making process where right or wrong have not been identified clearly. Biomedical efforts aim at preserving the values and sensibilities of both the individual and community. Understanding religion is necessary because religious values matter to individuals and communities who hold closely to spiritual and conservative values. In this context, the relationship between a medical doctor and a patient is essentially a relationship of mutual understanding, communication and trust. Deeply held values, no matter what they are, must be acknowledged. As individuals and communities reflect their values, physicians and scientist cannot afford to isolate a patient from these core beliefs. Biotechnological and biomedical applications test the discussion process of determining what is wrong and right and must meanwhile keep in mind cultural and religious values. For instance, the four ethical principles of autonomy, beneficence, non-malfeasance and justice find common ground between western and Islamic intellectual traditions, however difference are bound to arise. Islam emphasizes justice and beneficence over autonomy if there is a conflict with the public good.

The debate of biomedical ethics, Islam and the west cannot be confined or reduced to either reject the western philosophical approach or prove bioethical compatibility with Islam. Any ethical principle derived from a philosophical discipline or tradition ultimately must undergo questioning its fundamental philosophical reference and its method. Muslim scholars take such an account seriously through an elaborate method based on a holistic aim with respect to any emerging or philosophical principle and the ultimate goals of Islamic Shariah. Islamic intellectual history and thought has always considered professional ethics as a natural course. Science is inseparable from ethics as the tradition implies. Ultimately, the Islamic way is to reconcile science with ethics. It is

worth emphasizing that the idea is not to cancel out a secular approach. Ethicists need to analyze and understand at a deeper level the Islamic perspective of biomedical ethics. The approach can be compared to the secular one. Reductionism is not the way forward as it can impede understanding, becoming a hurdle in the way of advancing the necessary understanding. The Islamic perspective, unlike the secular one, relies on morals derived from the Quran and Sunna (sayings and actions by the Prophet.) That is why Islamic Shariah plays a significant role in the formulation of ethical positions covering the spectrum of biomedical fields and relevant scientific research and technology.

What does Shariah mean to Muslims and the global Muslim community? Shariah is considered a guide not only for religious duties and rituals like prayers, fasting, and performing pilgrimage (*haj*), but also dealings in worldly matters and the interpersonal, pertaining to the legal and ethical of all aspects of Muslim lives. This means ethics constitute an integral part of Shariah law. Jurists, *fuqhaa*, play a central role in the ethical discourse and exert every possible effort to decide what is right and what is wrong. In other words, Islamic law is highly vital not only in the realm of legality but also as an ethical and epistemological system. For a Muslim, Shariah is also part of the subconscious that influences the way an individual lives life and crucial to that is the ethical dimension. Formulating a ruling or a law, Muslims understand it as the work of a jurist, *faqih*. A Muslim theologian or a philosopher is not involved in formulating a law. Most Muslims understand the difference between a jurist, *faqih*, and a theologian or a philosopher since ethics and law are integral to each other, also, the roles of a jurist and a theologian are mutually relevant and beneficial for the purpose of formulating the best possible informed opinion or a ruling on issues. As Islamic law is divinely ordained, at the end, it is the kind of rigorous intellectual work that jurists, *fuqaha*, and theologians/philosophers, *ulama*, employ human reasoning and discernment.

Organ donation and transplantation opened a new frontier in the field of medical treatment. Organ transplantation saves and improves the quality of many people's lives. The Muslim faith

requires believers not to despair. There is a cure for every ailment and Muslims are encouraged to pursue science and research in order to find the necessary cure for a disease or illness. Scientists may not know of a cure in the present moment, but hope is not lost. A cure will arrive at a certain point in the future if the search for solutions and cures continue. Islam invokes a great respect for a human life. A human being is honored by God. Muslims' belief in God means preserving the dignity of what God has honored and bestowed upon human beings. Thus, Muslim scholars and jurists welcomed organ donation as a contemporary method for treatment. Organ donation saves life and prolongs it and Islamic scholars opted to seriously study and examine it for the benefit of people. Numerous jurisprudence conferences focused on the newly emerging organ donation since the second half of the 20th century. Various councils on jurisprudence continuously examine and study new challenges in the area of organ transplantation. Muslim jurists must keep pace with new procedures and therapeutic techniques in order to give a ruling of what is acceptable or not. As this thesis explained previously, scholars and jurists, along with medical experts and practitioners, work jointly in order to come up with the most informed and accepted ruling according to the Islamic perspective. Brain death is one major example where Islamic scholars debated thoroughly the definition of brain death. Consequently, the issue of organ donation from brain death must follow Islamically defined criteria of what defines brain death in the first place. Resultant definitions influence the issue and procedures of harvesting organs from brain-death cases. From a religious point of view, donating an organ is looked upon as an act of charity, love for mankind, benevolence and altruism. In the end, what does this inform us about Islamic perspective and organ donation? Islamic law and ethical systems keep pace with new scientific and medical frontiers. Tremendous advancements in medicine and biotechnology are taking place continuously. The above discussion illustrates the pragmatism that prevails in utilizing, interpreting Islamic traditions and heritage and applying it to current technical development and science.

The principle of autonomy is considered the pillar of biomedical ethics. Muslim scholars support the principle of autonomy, however special attention to the role played by parents and family is necessary. Certainly, Shariahh invokes free will of the individual as God divinely ordained the honoring of human beings. Islamically, an individual is free to exercise their free will. Autonomy is an expression of such a free will. However, a majority of Muslim families remain conservative in the area of decision making, generally influencing a family member. Here, a difference may arise when invoking the secular concept of autonomy. As the four-principle theory puts autonomy as the most important element of the theory, autonomy simply supersedes other principles of the theory. Muslim scholars criticize this specific position by saying that western-based autonomy is heavily emphasizing individualism, personal gratification and self-actualization. Accordingly, such inclination underlines the role of faith in the supernatural being in addition to the larger public interest over an individual's right. Some faith-based communities continue to hold paternalistic attitudes when medical care and treatments are involved. Such an outlook may not necessarily coincide harmoniously with the concept of autonomy of liberal individualism. It is worth pointing out a Muslim requests privacy when exercising autonomy, particularly when a female patient is involved. A Muslim female patient wishes to be seen by the same gender physician if available. Such a request needs to be respected. In the case of no availability of a same gender physician, Islamic law allows a doctor of an opposite gender to medically treat the patient. In Islamic tradition, the physician is known as *hakim* in Arabic which translates as the wise. Such social nuances and sensibilities can make a difference in medical practice from a Muslim point of view. Physicians practice medical profession with the guidance of God, according to Islamic traditions.

Application of informed consent remains quite limited in medical institutions in the cases examined by the field work in Gaza, Palestine, Jordan and Turkey. The lack of application of informed consent points to a lack of exercising rights and duties by both the medical practitioner

and the patient alike. For the patient, informed consent pertains to respecting and upholding the fundamental rights of the patient. At the same time, informed consent is viewed in Muslim-majority societies of Palestine's Gaza, Jordan and Turkey as a method of protecting a medical doctor in case something goes wrong during surgical intervention. In the three cases, rights and duties of both doctor and patient as a course of practice are not widely respected. The role of family and tribes are an influential factor in the process of interaction. In a society where tribes and family can wield power, medical practitioners may fear the outcome of a surgical intervention gone wrong, for example. That is why public awareness of the basic and essential understanding of informed consent is vital. Civil society and public education institutions possess the ability to intervene at a social level to educate the public about informed consent in the field of health provision and medical treatment. Medical practitioners in Gaza, Jordan and Turkey would encourage and welcome such a new public discourse for improving health provision.

The case of Gaza argues for a different perspective on the lack of applying informed consent. As field work shows, some Palestinian doctors talk about the vulnerable and risk-prone Gaza situation which contributes to the lack of applying informed consent. During times of war and aerial bombardment of Gaza, the number of casualties rise sharply in this densely populated narrow strip of land. The population density of Gaza stands at 4500 people per square kilometer, classifying the Gaza Strip as the second most densely populated area in the world. Dropping bombs from the air or shelling from land, it is inevitable that the number of killed and injured people is very high. This exerts tremendous pressure on the health provision system of Gaza, mainly hospitals. Emergency situations become the norm for days on end when sustained aerial bombing occurs over populated areas. Emergency doctors make interventions to save as many lives as possible in such critical circumstances. When it comes to saving a life in these circumstances, informed consent is not needed because there is not enough time to explain the details of medical intervention to an injured person or their family. Under such conditions, informed consent would appear to be a

luxury when hospitals in times of war could face a hundred serious injuries. The doctors' mission is to save as many as possible. Often Palestinian doctors in Gaza talk about the hard choices they have to make in prioritizing certain cases over others for medical surgical intervention during aerial bombardment. Many injured people wait in agony in hospital corridors waiting for their turn to be treated by surgeons. Lack of medicine and equipment at the hospitals due to a military siege imposed by Israel hinders even minimal surgery and treatment. However, the Palestinian Ministry of Health has not developed the necessary procedure or process for making informed consent institutionally available. Lack of capacity in resources and training may contribute to such consequences as the lack of informed consent. Threatened by continuous war and political uncertainties, leaders in the health sector place certain priorities over others. In the case of Gaza, the challenge of saving lives overwhelms the ideal practice of high biomedical ethical standards.

The Islamic Way?

Throughout this research, we argue for the centrality of *maqasid* as a frame of reference and methodology for the application of ethics in the field of biomedical ethics. In particular, the application of the principle of autonomy, ensuing and pursing a way forward for *ijtihad*, (rational intellectual pursuit), and *tajdid*, (renewal). This would open a new horizon of *maqasid* or the objectives of Islamic law by broadening the prospect and engagement in a process of review and reappraisal of the methodology of Islamic jurisprudence. This new discourse widens the scope from the current legislative leanings of Islamic jurisprudence toward a wider perspective of civil renewal, *tajdid*, and renaissance. The vital combination of *maqasid* and *ijtihad*, intellectual pursuit, needs to be supported with an effective methodology. *Maqasid* functions as a practical framework for the Islamic perspective of biomedical ethics. This framework, based on Islamic Shariah, is versatile and can be employed in delivering deliberations on any bioethical issues. With the clear understanding of the five objectives of Islamic Shariah: protection of life, religion (worship), intellect, property

and lineage, ethicists and those concerned can attempt to examine and ascertain any biomedical challenge or dilemma that is a consequence of advancement of medical science and biotechnology. This approach does not contradict the conventional biomedical approach. In fact, *maqasid* can be employed in resolving issues and challenges involving disputed moral and ethical obligations. As Shariah is considered a total way of life for Muslims, the five objectives can complement conventional biomedical ethics. Thus, *maqasid* is proposed to be utilized as a practical check list. This methodology appears to be the way forward and is suited to answer many of the moral challenges despite the rich discussion and debate within traditional Islamic references to medicine and health.

There are still challenges remaining in the pursuit of Islamic perspective on biomedical ethics. New advances in medical science and biomedical technology produce new ethical and moral challenges. Communication and joint efforts must be pursued and intensified among medical practitioners, jurists, philosophers and theologians. Such collective efforts must weigh in and examine the moral and ethical dimensions of new procedures. A lack of such collective efforts leads to confusion and inconsistent responses to new biomedical issues. The combined work of intellectual pursuit by experts, Muslim jurists and philosophers in the biomedical field informs health care decisions and also extends to the solution of similar problems in other areas of life.

The Muslim intellectual

The Muslim world is facing tremendous challenges. What is needed is a new discourse articulating Islamic philosophy and its larger objectives. Extremism and terrorism result from both extreme injustices and the wrong utilization of religion for violent and extreme aims. A new discourse can be imagined via what can be called the Muslim intellectual, separate from the jurist or preacher. This kind of intellectual does not dismiss religion because religion remains central to the values of millions of people. The intellectual can utilize religion to combat extremism and violence.

What is needed is the establishment of religious intellectual institutions that work to answer challenging questions facing the Muslim world. Such institutions are based on Islamic civilizational principles, referring to it and defending it. It must be relevant enough to address questions about values, identities, and intellectual pursuits that Muslim societies and communities are much in need of answering.

An intellectual relationship with religion is not limited to determination of rulings and opinions in the role of the jurist. The intellectual relationship with the religion of Islam is much wider, involving adopting visions and imaginings in various fields based on a wide religious frame of reference. What is needed is a genuine effort to understand the present complex systems, locally, nationally and globally to produce solutions to pressing issues such as extremism, terrorism, identities. If the jurist's task is to spread the knowledge of jurisprudence, the Muslim intellectual aims at envisioning an Islamic world placed at the heart of the contemporary world to take part in intellectual and epistemological discussions relevant to all people.

Muslims are encouraged to engage in a traditional method where Muslim scholars were able to adapt Islamic law to the changing contexts while keeping true to historical traditions. Muslims are encouraged to be more involved in Islamic law to realize its potential as a vibrant, forward looking source of good in the world. It is a combination of the knowledge of religion and its wider ethical and philosophical underpinnings and the awareness of the cultural and social at global level. This is central to the construction of intellectual discourse that is in harmony with the objectives of Islam and open to shared human values.

Islamic ethics cannot be monopolized by political movements or parties. Islamic movements in the Arab world or the larger Islamic world do pay attention to the area of ethics. They stress good ethics among adherents but most of these ethics such as patience, courage, charity and conflict resolution are universal values. However, another side of ethics processed by main

stream movements are reflected in the conservative nature of such societies. Some of these values are presented as if in collusion against global values or imported values from other cultures. This creates a gap between theory and practice among members and fosters ethical alienation. This alienation could potentially cast a shadow of enmity with the west and other cultures.

In Islam, faith, *iman*, essentially is the confirmation, *tasddiq*, of the heart, words and actions. It is not permitted to worship without a moral ethical standing because morals and ethics are the outcome and fruit of worship. It is the responsibility of Muslims to understand the characteristics of the Islamic religion, to prepare with knowledge and the required ethical standing at times of unfortunate media messages spreading negative images of Islam. The Islamic idea of worship is multifarious, practiced in the mind by invoking reasoning and reflection as well as in the heart through prayer.

One significant factor in building a good relationship between a doctor and patient is the understanding of a medical practitioner or a doctor in differentiation among people. A doctor needs to recognize the diversity of religious backgrounds of patients and avoid stereotyping. Non-Muslim physicians can make a big difference to their Muslim patients by being aware of Islamic biomedical ethics. This sensitivity can be very helpful in building a relationship of trust between a doctor and patient. The understanding of religion and culture would indeed generate practical considerations to apply in providing health care, understanding, mutual respect, inclusivity in a multicultural society.

Globalization is an increasing phenomenon at present and societies are becoming more diverse and multicultural under this influence. Consequently, the polarity of differing value systems may result in conflict. The field of biomedical ethics reflects the applied ethics of different cultures and religions which could lead to ethical disputes in the realm of medical care and health provision. Yet, such differences in cultural norms and religious diversity are also an opportunity to set in motion dialogue at a practical level. This creates new possibilities and paths for broader

understanding of cultural values and ethics. Diverse social situations and circumstances require flexibility and Islamic teachings are both flexible and adaptable. Islamic moral and legal principles are wide enough to include the needs of all times and places. A Muslim scholar is accountable for his opinion and responsible for the outcome of benefits or the sins of other Muslims who follow his opinion. For Muslims, God cannot be separated from daily life. That is why for a researcher on Muslim community, it is important to take into consideration the context of Shariah as a source of law and ethics in Islam.

Western and secular ethicists should consider the Islamic perspective of biomedical ethics as coming from a virtue-oriented and religious basis in contrast to the currently dominant secular and materialistic approach. At the same time, biomedical ethicists and medical practitioners from Islamic, Christian and Jewish traditions need to appreciate and understand the differences and similarities of perspectives and approaches to reach the goal of inclusive discussion and debate on biomedical ethics from religious perspectives. Further research in biomedical ethics from an Islamic perspective can contribute greatly to the debate and understanding of religion, science and ethics.

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