THE CONTRIBUTION OF BIOETHICS TO HOME HEALTHCARE (HHC) IN SAUDI ARABIA

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

Duquesne University

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

By
Saeed Alghamdi

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ABSTRACT

THE CONTRIBUTION OF BIOETHICS TO HOME HEALTHCARE (HHC) IN SAUDI ARABIA

By
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December 2021

Dissertation supervised by Gerard Magill, PhD

This dissertation examines the contribution of bioethics to Home Healthcare (HHC) in Saudi Arabia (SA). Through exploring the critical bioethical issues that have influenced the implementation of home health care, the dissertation highlights the significance of incorporating bioethics in home health care. Organizational ethics has led to the regulation of healthcare professionals, patients, and the stakeholders within clinical care settings. Healthcare organizations and other stakeholders, such as global health bodies, should formulate laws and policies that promote bioethics in contemporary healthcare. The Kingdom of Saudi Arabia, through the Ministry of Health, should promote the adoption of home health care services across the country.

Understanding and respecting the cultural context of Saudi Arabia (SA) is crucial for understanding the contribution of bioethics to HHC. Hence, after the introduction to the dissertation in Chapter 1, the analysis in Chapter 2 examines the context of HHC in SA by focusing on culture and diversity. The next three chapters discuss clinical ethical issues from
the start to the end of life. Chapter 3 explores HHC at the beginning of life, examining the role of consent in decision-making, especially related to prenatal and neonatal care. Chapter 4 considers issues in HHC across the span of life, such as regarding mental health and breakthroughs in genetics and cancer care. Chapter 5 deals with ethical issues at the end of life in HHC, including the role of ethics consultations and concerns related to palliative care and assisted death. Chapter 6 shifts the analysis from clinical to professional and organizational ethics in HHC to discuss ethical issues related to moral distress among professionals and the connection between integrated care and quality improvement. The dissertation concludes with a brief conclusion in Chapter 7.
DEDICATION

To my family
ACKNOWLEDGMENT

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CHAPTER 1: INTRODUCTION

Over the years, health care organizations have adopted measures aimed at expanding health care services to the health consumers located in different parts of the globe. The Kingdom of Saudi Arabia (SA), through the Ministry of Health has spearheaded health programs aimed at establishing home health care in the country. Home health care (HHC) increases the access and quality of care since it provides home-based and patient-centered care. The formulation of health care laws that promote the adoption of home health care services has created an enabling environment for effective interaction between health care professionals and patients. The increase in the population of older people who are suffering from chronic and terminal illnesses has led to high demand for home health care. However, there are emerging critical issues that have influenced the implementation of home health care in the Kingdom. Home health care helps to shape caregiving in modern society. In contrast to hospital-based care, home health care provides a patient-centered focus that occurs within the home setting of health care consumers, especially for those who have difficulties in leaving home to seek hospital care. This turn to HHC is developing significantly in SA, where health care providers visit the patients both in the urban and in the rural areas and provide high-quality care. This demand for home health care can be attributed to chronic illness and terminal diseases that require the attention of both health care professionals and family members. The continuing development of HHC in Saudi Arabia has led to the emergence of bioethical issues that need to be addressed by health professionals and families. To engage these concerns, this dissertation discusses the contribution of bioethics to Home Health Care in Saudi Arabia.

The main argument behind the adoption of the HHC program in SA is that the provision of healthcare services in the natural environment improved access to health care as well as healthcare outcomes. This is because both the patients and the family members
receive medical support and nursing care provided by the healthcare professionals. Moreover, patients who stay for a long time in the hospital care setting experience depression due to their negative attitude towards the hospitals. Therefore, home healthcare is seen as an essential alternative that resulted in reducing the cost associated with hospital admissions. The need for home-based is also necessitated by the effect of clinical care setting on the patient as well as the prevalence of diseases associated with old age. A larger percentage of patients who are admitted for longer periods in hospitals develop a negative attitude towards the hospital environment. The Saudi Ministry of Health, therefore, saw the need to initiate a comprehensive implementation of the home healthcare program to address the issue of home health care. The home health care program, therefore, is centered on how to improve the quality of care by changing the environment and setting of caregiving. By exploring how bioethics has been incorporated within home health care, the dissertation provides an evidence-based argument on the significance of bioethics in different life stages, such as the beginning of life, during the lifespan, and at the end of life.

1.1 The Context of HHC

This chapter presents a comprehensive analysis of home health care in Saudi Arabia. The section focuses on the adoption and implementation of home-based care in Saudi Arabia. The Ministry of Health has adopted policies and programs that have led to increased access and quality of health care services in both rural and urban areas.

1.1. a. Home Health Care in Saudi Arabia

Since the adoption of home health care in the 1980s, the Saudi Arabian Ministry of Health has been advocating for the implementation of home healthcare programs across the Kingdom. The primary factor that has boosted the adoption of home healthcare in the Kingdom is the introduction of bioethics as well as the coordination of operations from various stakeholders such as the government, healthcare organizations, physicians, nursing
teams, community-based health organizations, family members as well as the patients. The trend of health care in Saudi Arabia shows that the demand for home healthcare will continue to grow in the near future hence the need to embrace a collective action towards boosting the quality and accessibility of care both in the urban and in the rural areas.\textsuperscript{3} The Saudi government has recognized the devastating impact of hospital-based care on patient health hence leading to the incorporation of strategies that are aimed towards promoting home healthcare across the nation.

1.1.a. i. Background

Since the adoption and implementation of the health program requires collective action of various stakeholders, healthcare organizations such as King Fahad Hospital has ensured the coordination of operations between healthcare professionals and home-based caregivers.\textsuperscript{4} The Ministry of Health has ensured that professional and highly skilled nursing teams are sent to provide care in home-based care settings. Diverse communication channels have also been adopted to enhance the relationship between the patients, physicians, as well as the families of the health consumers. Community health organizations and various civil society groups have also recognized the role of home healthcare within the Kingdom.\textsuperscript{5} Such groups support the health programs by creating awareness through the mobilization of the members of the local community to support the home-based healthcare program. Although there has been a steady increase in population growth, the Kingdom has adopted strategies aimed at enhancing home-based care programs. Moreover, there has been a rise in the population of older people in recent years, increasing the number of people who require home healthcare across the nation.

Home healthcare in Saudi Arabia has brought a great impact on the health sector. The home-based care enables the primary caregiver to provide care in a sustainable and patient-centered environment characterized by the presence of close family members.\textsuperscript{6} Home
healthcare is multi-faceted care since it incorporates both the role of the primary caregiver as well as the family members. Through the collaboration between the primary caregiver and the close relatives of the patient, home-based care provides care that satisfies the needs and preferences of a patient. HHC has been critical in the treatment and management of chronic illness and mental disorders among the aged in Saudi Arabia. The help from the Saudi government has improved the implementation of home healthcare through the provision of financial resources as well as training of the primary caregivers. The health program has shown the role of the home setting in the health of patients.

Although the hospital care setting is critical in the provision of care, home healthcare presents a more comfortable and encouraging environment that results in high quality and patient-oriented caregiving. The government, therefore, should create awareness to ensure that every area within the Kingdom adopts the concepts of home healthcare. Through coordination of action, primary caregivers, relatives, the government, and the local community can promote patient-centered care in Saudi Arabia. The major stakeholders who have promoted the implementation of home health care in Saudi Arabia include the Ministry of Health and Non-governmental organizations and civil societies.

1.1.a.ii. Significance and Challenges

**Significance of Home Healthcare** - The primary aim of Home Health Care is to provide an enabling environment for the provision of healthcare services in the home environment. As opposed to the traditional healthcare setting that was primarily in the hospital, HHC focused on providing healthcare to the patients at their homes. Home-based care avails a suitable opportunity for the primary caregiver to interact with both the patients and the next of kin. The advantage of associating with the family members is that the relatives can effortlessly provide any information relating to the progress of the patient with a particular intervention method.
The home healthcare program also increases access to healthcare services. Since healthcare services are costly, health consumers from low socio-economic backgrounds usually cannot afford such health services. Access to healthcare is one of the most crucial issues in modern healthcare.\textsuperscript{10} The Saudi Ministry of Health, therefore, adopted Home Healthcare programs as one of the measures of reducing the gap of healthcare access between the wealthy and the working-class members of the society.

Home healthcare is also focused on achieving preventive care. Prevention of diseases, as well as disorders such as depression and schizophrenia, is one way of combating diseases. Among the old population, preventive care has enhanced the prevention of health conditions that are associated with old age.

**Challenges facing Home Healthcare in Saudi Arabia**- The major barrier to the implementation of patient-centered home healthcare program is the occurrence of diseases with different patterns and rates of prevalence. Patients suffer from different diseases such as respiratory diseases as well as mental disorders.\textsuperscript{11} However, the pattern and distribution of these diseases differ from region to region hence presenting a challenge towards the implementation of the home-based programs.

HHC program in Saudi Arabia is also influenced by the shortage of funds that are needed to implement the health projects. Since HHC provides patient-centered and customized health care services to the patients, there is a need to incorporate high-quality care that is provided by the presence of qualified and experienced healthcare professionals such as Home-Health Nurses. Over the years, there has been a significant rise in the demand for home health care programs. The popularity of home-based care services has caused a high demand for services from all parts of the Kingdom.\textsuperscript{12}

**Addressing the Challenges Facing HHC**- The Kingdom of Saudi Arabia, through the Ministry of Health, has developed training programs aimed at enhancing the skills of the
primary caregivers. Since the shortage of qualified medical personnel has hindered effective home healthcare in the country, the strategy is expected to boost the quality of healthcare in the long term.\textsuperscript{13} The Saudi government has also increased the budget for home healthcare programs across the country. The kingdom has provided over SAR 30 million in the health budget to increase access to healthcare by promoting home healthcare programs. The Ministry of Health has also spearheaded the mass production of drugs in pharmaceutical companies. The pharmaceutical companies have led to an increase in the accessibility of both efficient drugs that are used in the treatment of various diseases and chronic mental disorders.

1.1.b. Culture and Diversity in Health Care

1.1.b.i. Challenges in Cross-Cultural Health Setting

The adoption and implementation of healthcare ethics in a cross-cultural health setting have become a challenge in modern society. Primary caregivers have faced diverse challenges due to the presence of patients from different cultural backgrounds, gender, socio-economic status, and religious beliefs.\textsuperscript{14} Such differences influence the way patients respond to new disease intervention methods. For example, modern techniques such as gene editing have been adopted by healthcare organizations to create treatment for diseases such as cancer and other life-threatening diseases. To address the challenges of cross-cultural background on healthcare delivery, health care organizations can encourage tolerance to diversity, training on cross-cultural competence, adoption of diversity-centered leadership as well as the formulation of policies such as common morality that promote the adoption of bioethics in healthcare.\textsuperscript{15}

The incorporation and implementation of effective bioethics policies within a multicultural society can play an essential role in responding to the challenges of a cross-cultural society regarding the adoption of a bioethics in a specific setting. The challenges presented by multicultural healthcare settings, such as differences in religion, gender,
language, education status, and social status, hinders the implementation of normative ethics in a multi-ethnic society. However, the implementation of ethical policies has faced challenges due to different beliefs of the various healthcare practices. There are different methods in which healthcare organizations can facilitate the implementation of normative ethical care in a multi-ethnic society. Adopting strategies such as; cultural competence and tolerance to diversity can play an instrumental role in enhancing the adoption of normative ethics in healthcare. Stakeholders in healthcare, such as the Saudi Ministry of Health, patients, and the local community, should embrace a coordinated action aimed at responding to the challenges of diverse cultural and ethnic backgrounds on the provision of home health care.

1.1.b.ii. Addressing the Challenges

Promoting Tolerance to Diversity- The contemporary health setting has been characterized by the presence of patients from different cultural backgrounds. Developed Western nations such as the UK, United States, as well as Middle East countries consist of people from different cultural and religious backgrounds. Another important way that can be used to address the challenges of various cultural backgrounds on the implementation of healthcare bio-ethics is to launch on comprehensive awareness creation on the need to recognize the significance of tolerance to diversity. Healthcare stakeholders such as the government, World Health Organizations, and the Saudi Arabian Ministry of Health should undertake an extensive awareness creation among the healthcare professionals, patients as well as the members of the society. The United States culture has adopted more progressive views on healthcare delivery as well as emerging disease-intervention techniques such as gene therapy. On the other hand, Saudi Arabia, being an Islamic nation, adheres strictly to the religious doctrines that have become a stumbling block to the implementation of new medical practices such as surrogacy in prenatal care.
Training on Trans-cultural competence- Healthcare stakeholders should also embrace strategies aimed at initiating a comprehensive training on cross-cultural competence. Training ensures that health professionals, health consumers and family members of the patient acquire comprehensive knowledge about the cultural and religious beliefs of different cultures and how they affect the response to healthcare practices in the modern society. Therefore, responding to the challenges of diverse cultural background on healthcare ethics should be marked by the adoption of training and skill development on multi-ethnic competence. Healthcare organizations, as well as other stakeholders such as CDC, should embark on initiating skill and knowledge acquisition programs concerning multicultural healthcare practices. Since different cultures have different beliefs and ideologies on healthcare, both healthcare professionals and healthcare consumers should learn more about the behavior, doctrines, and beliefs of other cultures as far as health is concerned.

Acquiring religious knowledge also affects the adoption of healthcare ethics in a multi-cultural society. The learning programs should also ensure that healthcare professionals, health consumers, government agencies, and the local community acquires knowledge about the religious beliefs of diverse cultures and how they affect the perception of medical practices. For example, the Middle East and American culture have displayed different religious ideologies regarding the adoption of healthcare practices. According to the Islamic religion, the occurrence of illness, pain, or death is a result of Allah’s plans on humankind. Allah is the provider of life and good health. Physicians are only supposed to support God’s work. Islam, which is practiced in Middle East countries, has stringent religious doctrines that have enormously affected the provision of healthcare services. For example, during the annual Islamic holidays, the faithful embrace fasting, and hence religious beliefs affect their perceptions of various activities and events in the society.
Cross-cultural competence enhances the process of solving ethical problems that arise from the interaction of individuals of different cultures. There is a need to create an enabling environment for the patients, family members, physicians, and nurse practitioners.\textsuperscript{24} Attaining inter-cultural knowledge allows health professionals to adopt effective solutions to ethical dilemmas and conflicts in home healthcare.

**Adoption of diversity-centered leadership**- Just like in other organizations, leadership can also enhance the adoption of bioethical behavior in home healthcare. The presence of a cross-cultural healthcare setting has a critical impact on the adoption of normative ethics.\textsuperscript{25} This is because every culture has its own ethnic beliefs, customs, and practices that affect how it views modern healthcare practices. However, healthcare organizations, as well as relevant stakeholders such as government agencies and global health organizations, should embrace diversity-oriented leadership that can boost the adoption of home health care.

**Implementation of favorable healthcare ethical policies**- Another important technique that can be used to eliminate the ethical challenges of a multi-ethnic society in contemporary clinical settings is to formulate laws and policies that prohibit various forms of prejudice and stigmatization.\textsuperscript{26} Laws and policies that promote tolerance to diversity can help in enhancing the implementation of home-based care in the Saudi Arabian society. One of the major barriers that hinder the application of bioethics in a cross-culture is the presence of diverse religious and cultural ideologies on emerging healthcare practices such as gene editing and withholding of tubal feeding and ventilation on patients with a terminal illness.

### 1.2. HHC at the Start of Life

This chapter focuses on how the incorporation of bioethics affects decision making at the beginning of life care in HHC. Decision making plays an instrumental role in promoting the adoption of patient-centered care. Informed consent ensures patient involvement. The
principles of informed consent, such as beneficence, justice, and patient autonomy, shape prenatal and neonatal care.

1.2. a. Critical Role of Consent in Decision-making

Ethics consultation plays an instrumental role in developing a sustainable health care setting for making informed consent during clinical decision making. The ethics consultation process ensures the observation of essential elements that mark the decision-making process. In general, ethics consultation examines the underlying factors that lead to the provision of informed consent hence improving the decision-making process. Informed consent is characterized by three vital processes that help in influencing the final decision of the patient. The initial step is information disclosure in which health care experts are supposed to disclose comprehensive information concerning the diagnosis and possible methods of intervention. The physicians and nurses and the ethics consultation team should practice cultural and religious tolerance while providing medical information to the patient. The primary aim of health care professionals should be to provide detailed and correct information to all patients. The subsequent stage is the assessment of the competency or capacity of the patient to understand and comprehend the information. The health care professional must inquire and assess if the patient or next of kin has understood the information provided during the information disclosure stage.

1.2.a.i. The Process of Giving Informed Consent

Ethics consultation allows the process of identifying, analyzing, and solving ethical conflicts. Therefore, the ethics consultation process allows health professionals to provide informed consent that leads to effective decision making within the clinical care setting. Informed consent occurs in three critical processes:

The first stage of seeking informed consent is information disclosure. The health professional must avail of all essential information depending on the patient’s medical
history, diagnosis, and treatment strategy. Both the advanced practice nurses and attending physicians are expected to avail information regarding the available healthcare interventions that can be undertaken to improve the health of the patient. For example, if the patient has a chronic and terminal illness that will eventually result in death, the physician is expected to disclose such information as well as the available healthcare methods that can be used to enhance the life of the patient. After the information disclosure stage, the next step that is essential in the provision of informed consent is the assessment of the competency of the patient. The physicians and the ethics consultation team should ensure that the patient or family representative understands the healthcare information regarding a particular case. The final element of informed consent is to provide free and voluntary informed consent. The patient should give free consent without any form of persuasion or threats from the attending physicians.

1.2.a.ii. Principles of Informed Consent and the Impact of Decision Making in Clinical Ethics

The first principle is beneficence. The ethical principle of beneficence posits that physicians and nurses should adopt health interventions that bring maximum health benefit to the patient. Particularly, health professionals should strive to focus on improving the welfare of patients. The main aim of treatment should be for the patient to get cured. The second principle is patient autonomy. According to the principle of patient autonomy, healthcare professionals should undertake activities that show respect to the healthcare rights of patients. This includes ethical rights such as the provision of high-quality care, privacy, non-discrimination, and disclosure of information. The third principle that controls the implementation of informed consent in clinical ethics is justice. The clinical ethics model focuses on access to patient-centered clinical care. One of the issues in modern healthcare is inequality in accessing high-quality clinical care. Healthcare consumers encounter barriers
when seeking high-quality healthcare. The existence of racial, ethnic, and gender-based discrimination in clinical care has led to a rise in the health inequality gap. The fourth principle in clinical ethics is non-maleficence. According to this clinical care model, primary caregivers are expected to focus on preventing any health-related harm before adopting a particular intervention method. The goal of non-maleficence is to ensure the safety of the patient during caregiving. Health professionals, such as physicians and nurses, are thus expected to adopt health interventions that cannot pose a health risk to the patient.

Decision making plays a vital role in improving the quality and access to patient-centered clinical care. Collective decision making is an important element in clinical ethics that results in the adoption of bioethical behavior as well as the adherence to the ethical principles that guide the provision of care in healthcare settings. The decision-making process needs the coordination of activities between the primary caregivers, ethicists, as well as the patients. One of the duties of health care decision-making is that it focuses on involving the patient in caregiving. The decision-making process aims at introducing a patient-participation or family-engagement approach. The adoption of informed consent is a crucial phase in decision making. The provision of informed consent proves that a particular patient has either accepted or opposed to undergoing a medical procedure. Moreover, informed consent shows that the patient or family member can understand all the information provided during the information disclosure stage. Informed consent is, therefore, the last stage of the home-based care decision-making process. The decision-making process also promotes the adoption of an informed and inclusive decision making into the clinical care setting. Ethical decision making in healthcare requires that health care professionals adopt the views, opinions, and needs of the patient in decision making. Various individuals have different beliefs, needs, and opinions concerning health care intervention methods.
The role of informed consent in the decision-making process is crucial. It results in a sustainable environment for undertaking an inclusive process of making clinical decisions. This is because the process of seeking informed consent initiates patient participation in clinical care. The inclusion of healthcare consumers in caregiving has become a major issue in contemporary healthcare. Another role of informed consent in the decision-making process is that it results in the incorporation of high quality and patient-oriented clinical care. As an element of clinical ethics, informed consent results in the implementation of a patient-centered decision that eventually results in the adoption of an inclusive intervention method. Informed consent also enables the primary stakeholders such as the patients, physicians, counselors, and the ethics consultation team to make collective deliberations before reaching a final decision. Collective decision making has become critical in contemporary healthcare.

Unlike in the past, where the health care professionals made all the clinical decisions, modern society has embraced the role of an active patient.

1.2. HHC, Prenatal Care & Neonatal Care

In prenatal care & neonatal care in a HHC setting, healthcare stakeholders play a tremendous role in the provision of high-quality care. Healthcare stakeholders include physicians, nursing practitioners, government health agencies, counselors as well as parents, or the local community. Through collaboration, the stakeholders can create an enabling environment for the provision of prenatal and neonatal care. This is because each stakeholder has a role to play during prenatal and neonatal care.

1.2.b.i. Importance of Healthcare stakeholders

The Saudi government, through the Ministry of Health, for instance, provides healthcare funding through subsidies to reduce the cost of healthcare. Moreover, government health agencies also act as regulatory agencies that ensure that health professionals provide patient-oriented care during both hospital and home-based healthcare. Parents, especially
mothers, can enhance the quality of prenatal and neonatal care by registering in home-healthcare programs and avoiding a sedentary lifestyle that may endanger the life of infants. Professional counselors, on the other hand, provide guidance and moral support that ensures that patients cope with the health condition during the treatment process. Nurses and physicians undertake in-depth and evidence-based tests and diagnoses to determine the health conditions that may affect neonates and infants. Hence, each health stakeholder has to perform in the process of providing care during prenatal and neonatal caregiving. Home healthcare, as opposed to clinical care settings, require commitment from the health stakeholders. This is because the home-based care setting does not have essential medical equipment as well as health professionals that can be found in a hospital setting. Modern healthcare organizations have recognized the need for a coordination of effort in the provision of prenatal and neonatal care.

Prenatal and neonatal care requires coordination of health care activities among the stakeholders to achieve health goals and objectives. Prenatal care ensures that the fetus undertakes normal growth and development. Moreover, during prenatal care, health professionals undertake disease prevention measures that may endanger the life of the fetus. The adoption of prenatal care can prevent high-risk conditions such as preterm birth and low birth weight. Neonatal care, on the other hand, also ensures that neonates are given customized care that can help in the prevention of health risks such as mental disorders and other diseases such as neonatal jaundice. During the provision of neonatal care, pediatric nurses play a vital role in ensuring that the infants acquire acute care that can prevent or treat the diseases that are usually prevalent at the beginning of life stages.

1.2.b.ii. Ethical Roles of Healthcare stakeholders

The health professionals, in coordination with other stakeholders, promote the adoption of effective home-based prenatal and neonatal care. For instance, government
agencies are tasked with providing funds that improve access to prenatal and neonatal care. Moreover, government health agencies help in regulation and policymaking that enable health professionals to boost the provision of neonatal and prenatal care. Through collaborative efforts, stakeholders in healthcare provide high-quality care that has led to a reduction in infant deaths as well as the occurrence of diseases that are common during the early stage of development. Healthcare stakeholders such as attending physicians, nurses, counselors, parents, and government health agencies have to apply bioethics, including the provision of informed consent, information disclosure, and policy formulation, as well as preventing racial and religious discrimination in prenatal and neonatal care settings.

Stakeholders in healthcare have bioethical and moral duties to observe during prenatal and neonatal care. Various health stakeholders such as physicians, registered nurses, midwives, counselors, governmental health agencies, and parents play a crucial role in the provision of high-quality prenatal and neonatal care. Midwives have also brought life-changing reforms in home healthcare by initiating prenatal care in rural areas. Healthcare organizations have realized the need to train midwives to enable them to acquire skills that can enhance the quality of home-based prenatal care. The ethical roles of midwives include ensuring that the pregnancy undergoes the normal developmental stages. Although the midwives are not as skilled as registered nurses, they have improved the provision of prenatal and neonatal care in home healthcare.

Both prenatal and neonatal intensive care has brought a great impact on the health of preterm infants. Ethical and moral issues affect the quality, access, and cost of neonatal care. Various bioethical elements such as information disclosure, infant and maternal rights, quality, and access to neonatal intensive care have enhanced the provision of care in various parts of the globe. There is a need for the adoption of diverse programs aimed at promoting the provision of neonatal intensive care. Essential programs such as ethics consultation,
parental involvement, pain management, and the adoption of advanced technology can help in solving the ethical issues that affect prenatal and neonatal care. Moreover, physicians and advanced practice nurses should address issues such as cultural backgrounds, discrimination, and socio-economic backgrounds and how they affect the perception of prenatal and neonatal care. Healthcare professionals should also adopt laws and policies that enhance access to high quality neonatal and prenatal care in both developed and developing countries.\textsuperscript{51}

Counselors, on the other hand, provide professional guidance and motivation to mothers who have experienced preterm births as well as the ones who have given birth to infants with adverse developmental disorders. Counseling has enhanced home-based prenatal and neonatal care since the parents acquire counseling services that enable them to cope with preterm infants.\textsuperscript{52} The parents also have an ethical role in seeking prenatal and neonatal care, ensuring that health professionals observe maternal and fetal rights and providing information about the history of any underlying disease or disorder. Women and mothers who have given birth to premature infants should undertake their ethical duties by participating in a coordinated aimed at enhancing the quality of prenatal and neonatal care. Among the stakeholders in healthcare, physicians play a crucial role during the provision of prenatal and neonatal care. Specifically, health caregivers, including pediatricians and obstetricians, provide high-quality care during the early stage of development.\textsuperscript{53}

Advanced practice nurses, as well as registered nurses, have spearheaded the implementation of high quality prenatal and neonatal care. Just like physicians, nursing practitioners have a great impact on the quality of neonatal and prenatal care. Among healthcare stakeholders, counselors play an instrumental role in the provision of prenatal and neonatal care. The government healthcare bodies also form one of the most beneficial health stakeholders in regards to the provision of prenatal and neonatal care.\textsuperscript{54} Healthcare services
can only occur in a sustainable political environment. Just like other healthcare stakeholders, parents have an important ethical role to play during prenatal and neonatal care.

1.3. HHC in the Lifespan

1.3.a. Mental Health

1.3.a.i. Bioethics Issues in Mental Health

The Kingdom of Saudi Arabia has recognized the need to address the mental health of the citizens. The high prevalence of mental health disorders such as Post-traumatic disorder and anxiety disorders has brought a devastating impact on the health and wellbeing of the people. The incorporation of bioethics has brought a tremendous impact on mental health care. In 2014, the Ministry of Health adopted the Mental Health Act, which was aimed at spearheading the implementation of mental health care programs across the nation. Moreover, the Patient’s Bill of Rights and Responsibilities have been at the forefront of promoting the adoption of patient-centered mental health care programs. According to the bill of rights, individuals with mental disorders have the right to access mental health care. Health professionals, therefore, should not practice discrimination during caregiving. The Ministry of Health has established several psychiatric specialty centers across the Kingdom.

The adoption of moral and ethical behavior can create a sustainable environment for the adoption of mental health care. Several elements in bioethics play a crucial role in the implementation of psychiatric health care in society. One of the most important ethical elements is respect for patient autonomy. Health professionals should observe patient autonomy by ensuring that the patient is involved during clinical decision making. Patients who are unable to provide informed consent due to severe mental illness should be assisted by surrogate decision-makers such as close family members. Psychiatric should assess the cognitive capability of the patient before making crucial health care decisions. Another vital ethical element is justice. Health care providers should ensure that they practice equality.
during the provision of mental care services. Discrimination and stigmatization have hindered access to better mental health care. Psychiatric nurses should ensure that they provide mental health care without any form of discrimination in clinical care. Another element in bioethics is beneficence. Health care professionals should focus on providing care that improves health outcomes. In essence, the goal of mental health care is to ensure maximum health benefits to the patient.

Informed consent also plays an instrumental role in the provision of mental health care. The health care providers should seek the opinion of the patient before undertaking a particular health intervention. A collective decision is important since it improves the relationship between the patient and the physicians. Moreover, the patient acquires the opportunity to reject or accept a particular intervention strategy. Moreover, patient confidentiality is also another issue in bioethics that affects the implementation of mental health care. Since people with mental illness face discrimination and stigmatization from the members of society, health care professionals should ensure that they observe privacy in regards to mental health information. The general public should not have access to confidential patient information, such as the diagnosis of a particular patient since it can lead to prejudice.

Individuals suffering from diverse mental disorders are usually vulnerable to exploitation from mental health professionals as well as the members of the society. Exploitation hinders the acquisition of high-quality care. This is because unethical health providers can exploit patients to serve their selfish interests. Since mentally incapacitated patients cannot provide efficient, informed consent or decision during clinical care, the stakeholders in health care can easily misuse the health care resources leading to low-quality care. Exploitation has been the major challenge that has prevented access to patient-oriented mental health care. The vulnerability of mentally ill patients has led to the adoption of laws
and policies that promote the adoption of bioethics in mental health care. The National Institute of Mental Health, for instance, creates awareness on the importance of practicing tolerance towards individuals with mental disorders.

1.3.a.ii. Social Workers and Incorporation of Bioethics in Mental Health Care

Among health care stakeholders, social workers play an instrumental role in mental health care. Social workers provide diverse mental support services, such as case management. By assessing different mental health care cases, social workers improve the quality of psychiatric care. This is because health care professionals gain in-depth information about mental disorders and their devastating impact on patients. Social workers also undertake the ethical duty of psycho-education. The health care providers educate the patients concerning the etiology of the mental diseases, the prevalence, the symptoms, health effect as well as the treatment and management strategies.

Psycho-education enables the patients to acquire sufficient information about a particular mental problem, thus allowing them to seek mental health care. It creates awareness on the prevalence and risks of mental diseases, thus ensuring that the members of the society adopt measures that can prevent the occurrence of mental disorders. Another role of social workers within the context of bioethics is psycho-therapy and counseling. Psycho-therapy is a strategy in which health care professionals provide care to mental health patients using talk therapy. Strategies such as cognitive behavioral therapy are used to ensure that the patients cope up with the mental problems as they receive high-quality care. Psycho-therapy has led to improved health outcomes regarding mental health care.

1.3.b. Genetics & Cancer Care

Healthcare stakeholders, such as health organizations, regulatory bodies, and health consumers, have focused on measures that aim at the realization of precision medicine. Precision medicine is patient-centered care that explores critical medical interventions such
as cancer genetic screening and stem cell biology. Understanding the genetics of cancer has been characterized by the need to observe ethical challenges that are faced during the implementation process among healthcare professionals in HHC.\textsuperscript{62} There are ethical considerations that should be examined to ensure that precision medicine methodologies such as cancer genetic screening process achieve its intended goals and objectives in HHC.

1.3.b.i. Genetic Screening & Stem Cell Biology

The changes in the genetic make-up of body cells contribute to the stimulation and eventual production of tumor cells that finally results in the development of cancer. Stakeholders in the field of healthcare have embraced different techniques aimed at identifying the genetic changes that result in the formation of cancerous cells in the human body. Genetic changes in cancer occur in two ways: acquired and gene mutations.\textsuperscript{63} Acquired mutations occur when the genetic composition of the cells in the human body undergoes destruction. Gene mutation occurs when inherited genes already exist within cancer cells. Genetic mutation can occur within one person in a family. During reproduction, the mutant gene is moved to the offspring leading to the infection of the genes of the children.

Healthcare stakeholders such as health professionals, regulatory bodies, and health consumers have focused on strategies that aim at the adoption of precision medicine. Acquiring sufficient information on the genetics of cancer has been marked by the need to observe ethical challenges that are faced during the implementation stage among healthcare professionals in HHC. The goals of cancer genetic screening, for example, are to acquire more data about the genetic factors that trigger the growth of cancer cells in the human body. The process, however, should observe bioethics at HHC level.\textsuperscript{64} Vital issues such as patient’s consent should be considered to ensure that the cancer genetic screening process observes the rights of the patient. There are genetic changes in cancer that result in the development of cancer. Hence there is a need to initiate in-depth cancer genomics research to investigate the
changes in cancer and how they present a chance for understanding the genetics of cancer. The cancer stem cell is another crucial part of the genetics of cancer. The cancer stem cell theory presents a hypothesis on how the development of cancer cells finally triggers the development of cancer.\textsuperscript{65}

1.3.b.ii. A Balance between Implementation of Precision Medicine and Ethical Principles

Modern healthcare organizations have realized the need to incorporate bioethics into the genetic screening of cancer cells. In recent years, ethical issues surrounding the adoption of genetic screening of cancer cells as well as stem cell biology has brought mixed reactions among HHC stakeholders.\textsuperscript{66} International healthcare regulatory bodies such as the CDC and WHO have been promoting the adoption of modern medical practices such as genetic testing and gene editing. Regulations of genetic testing processes are important since it controls the experiments and tests that are undertaken to provide more information on the genetics of cancer and how it should be applied in the interventions aimed at treating cancer.\textsuperscript{67} Patients can also show signs of progress in cancer genetic screening through participating in an inclusive decision making. The cancer genomics research has played a great role in the collection and sharing of comprehensive information in regards to the genetics of cancer.

The process of regulating genetic screening has brought a significant impact on cancer genomics research and disease intervention. By initiating step by step regulatory measures, key stakeholders such as the International Cancer Genome Consortium have managed to develop laws and policies that ensure the incorporation of bioethics during the cancer genetics screening and cancer genome research, that which extends to HHC. The understanding of the genetics of cancer has influenced the implementation of various interventions against cancer since it allows health professionals and researchers to adopt
patient-oriented interventions while observing the underlying ethical and moral factors in precision medicine.\textsuperscript{68}

The adoption and implementation of precision medicine have, therefore, brought a great change in modern healthcare. Through the adoption of patient-centered care, precision medicine allows health professionals to undertake individualized interventions in HHC. Precision medicine also enables health professionals to apply bioethics of behavior during caregiving in HHC. For example, intervention techniques such as cancer genetic screening, testing, molecular diagnosis, and gene therapy are conducted depending on the genetic composition of a particular patient. However, the adoption of precision medicine should be characterized by the observation of ethical and moral rights.\textsuperscript{69} Health professionals should ensure that they adopt the ethical considerations that can result in the adoption of intervention methods that satisfy the needs of the patients.

For instance, during the process of genetic screening and testing, health providers should ensure that patients provide information disclosure and also seek informed consent before any medical procedure is undertaken. Informed consent and information disclosure create an enabling environment for the participation of health consumers in the treatment process. Precision medicine also explores the genetic changes that occur in cancer as well as stem cell biology and how they lead to the development and growth of tumors that cause cancer.

Another benefit of precision medicine is that it has led to an enhanced understanding of the operations of cancer stem cells and how they cause the growth of cancer.\textsuperscript{70} Healthcare professionals have managed to study the cancer stem cells of patients leading to the collection of sufficient information in regards to the development of cancer. Regulation of genetic testing is also a vital aspect of regulation in precision medicine. Regulation of new health intervention strategies improves the quality of healthcare at HHC level. Healthcare
professionals, such as physicians and nurses, have also recognized the existing opportunities for advancement in precision medicine.

The opportunities for progress include improving the patient understanding of precision medicine, supporting decision making, as well as coordinating family communication and outreach.\textsuperscript{71} Stakeholders in the field of health care such as the WHO, CDC, and the International Cancer Genome Consortium have promoted the adoption of precision medicine, specifically in eradicating global diseases such as cancer.

Focusing on cancer genomics research has influenced the understanding of cancer stem cell biology and how they can shape the adoption of various therapeutic interventions.\textsuperscript{72} World health organizations such as CDC and cancer genomics research organizations have promoted advanced cancer stem cell research focused on developing strategies for preventing and treating cancer. According to the stem cell theory, the beginning of the growth of cancerous cells is undertaken by a specific subgroup of tumor cells. The regulation of cancer screening and testing is aimed at improving the collection, use, and interpretation of scientific data at both the national and HHC level. Lack of effective regulation of the process can result in misuse and misinterpretation of the data related to the cancer stem cell biology.\textsuperscript{73} The regulation process is spearheaded by various government health bodies as well as other healthcare stakeholders. In the US, for instance, the control and regulation of genetic testing are undertaken by the Centers for Medicare and Medicaid Services and Food and Drug Administration.

1.4. HHC at the End of Life

This chapter explores the role of ethics consultation in home health care at the end-of-life stage.
1.4.a. Ethics Consultation in Home Health Care

The incorporation of bioethics in health care also plays a critical impact during ethics consultation. Ethics consultation is an important practice in end-of-life care since it creates an essential framework for solving ethical and moral dilemmas that physicians face during caregiving. Ethics consultation explores the conflict that arises during clinical decision making regarding the various intervention methods that should be undertaken in clinical care. Ethics consultation plays a critical role in solving ethical issues that arise during the provision of healthcare services. Modern medical practices such as gene editing, withdrawal, and withholding of life support during the end-of-life care have brought the need to seek the help of professional bioethicists to provide ethics consultation. Ethics Consultation committee provides ethical guidance through conducting a professional assessment of the ethical dilemma or conflicts. The health consumers, health care professionals, and family members of the patient, however, still have the right to either support or oppose the professional advice given by the ethics consultants. Ethics consultation adopts diverse approaches that involve skilled bioethicists, healthcare professionals, and experts from legal organizations. The process is characterized by an ethical assessment of the problem as well as the rights of the patients and the primary caregivers and physicians. Ethics consultation in Saudi Arabia has improved considerably since the implementation of home health care. Home healthcare offers home-based care, unlike the hospital care setting. The Kingdom of Saudi Arabia has initiated various measures aimed at ensuring the adoption of ethics consultation in the home healthcare programs.

Ethics consultation has faced significant changes such as changes in the consulting model, consult process and the role of ethics. Moreover, ethical qualities in ethics consultation, such as process standards, core competencies, and standards of quality, have shaped the adoption of ethics consultation in home healthcare. Another critical measure that
has marked ethics consultation is the adoption of efficient strategies aimed at ensuring amicable credentialing, accreditation, and certification. These crucial issues have created an enabling environment for the implementation of ethics consultation in the home healthcare programs in Saudi Arabia.

The ethics consultation process facilitates the provision of measures that can be used to solve ethical dilemmas between patients and healthcare professions and finding an amicable solution to culturally-based healthcare ideologies. The changes that ethics consultation has undergone have influenced the whole process of consultation. For instance, the changes in the consult and process model have created an opportunity for home-based healthcare delivery. Moreover, the quality in ethics consultation, such as process standards, core competencies, and standards of quality, creates the framework that health professionals, patients, and the ethics consultation committee are expected to follow during the ethics consultation process. The adoption of other crucial issues, such as credentialing, accreditation, and certification, also improves the process of ethics consultation. This is because the process of accreditation and certification ensures that the ethics committee acquires vital skills and knowledge concerning ethics consultation. Ethics consultants should exhibit moral reasoning, the capability to assess the ethical dilemma, and also the legal impact of adopting a specific medical procedure or practice.

The adoption of ethics consultation within healthcare programs requires a detailed approach that will ensure that all the stakeholders benefit from the consultation process. For example, the bioethicists should be able to assess the request that has been made by the patient or family members. The decision of the ethics consultation committee should consider the health and rights of all the stakeholders such as government health agencies, patients, physicians, primary caregivers, as well as the family members of the patient. The ethics consultation team should also collaborate with relevant government agencies such as
the Ministry of Health, law enforcement agencies as well as global healthcare bodies such as the American Society for Bioethics & Humanities (ASBH). The adoption of collaborative efforts can boost the implementation of ethics consultation in home healthcare programs. The process of initiating ethics consultation has evolved over the years. The Saudi Ministry of Health has adopted methods aimed at implementing individualized and patient-centered ethics consultation in health. The changes have also been adopted in the consult process and consult model.

1.4.a.i. Role of Ethics Consultation in Home Healthcare

The primary role of ethics consultation is to find solutions to the diverse health concerns that arise during caregiving either in the hospital and home-based health care settings. Another major role of ethics consultantation is that it promotes critical and shared decision making among the members of the ethics consultant committee. Decision making is one of the most controversial issues in home healthcare. The adoption and implementation of an ethics consultant have also played a crucial role in improving the quality of home-based care in Saudi Arabia as well as across the globe. Ethical behavior is one of the primary values of contemporary home healthcare. Ethical behavior allows health professionals to adhere to the rights of the patients.

1.4.a.ii. Quality in Ethics Consultation

One of the main issues that have played a tremendous role in the implementation of ethics consultation in home healthcare programs is the quality of the ethics consultation process. Quality is a critical factor that determines the importance and impact of the ethics consultation process on the patients as well as next of kin. Healthcare organizations in Saudi Arabia and across the globe have appreciated the role that quality plays in the ethics consultation process. The vital aspect of quality that has been adopted includes; process standards, core competencies, and standards of quality. The relationship between the health
consumer, their families, and health professionals has a direct impact on the overall quality of healthcare services. This is because there the adoption of coordinated efforts between the different stakeholders influences the quality of health outcomes. Moreover, ethics consultation helps in solving ethical dilemmas that occur between the patients and the physicians.\textsuperscript{83} Resolving the conflict hence is critical in the home healthcare programs. One of the methods of conflict resolution that the ethics consultation committee has adopted is mediation. Since the health issues involve various stakeholders such as the patients, families, and physicians, mediation is used to arrive at a mutually beneficial solution that can benefit all the parties involved.

1.4.b. Dignity, Palliative Sedation & Assisted Death

The incorporation of bioethics has also enhanced end of life care in clinical care settings. Health professionals usually encounter diverse ethical challenges such as withdrawal and withholding of life support machines, mercy killing, and the issue of pain and suffering. Conventional health policies dictate that aged individuals with chronic and terminal illnesses are given clinical care that is aimed at eliminating pain and suffering.\textsuperscript{84} However, the issue of assisted death has elicited mixed reactions from individuals from different cultures and religions across the globe.

1.4.b.i. The Sanctity of Human Life

The adoption of mercy killing as a means of ending the physical pain and mental torture of terminally ill patients has redefined how people perceive the right to life. Religious doctrines and beliefs have shaped the opinions and ideologies of the members of the society. All medical services are discharged based on clinical judgment, ethics, and available evidence. According to the Islamic Law (Sharia law), the sanctity of life should be valued and respected; hence health professionals should not participate in actions that trigger the death of terminally ill patients. In essence, Sharia law prohibits euthanasia or mercy killing.
Based on the doctrines and beliefs advanced by Prophet Muhammad and the doctrines outlined in the Qur’an, human beings should value the life of other people since only Allah is the provider of life. According to Muslim scholars such as Māliki and Hanafi, Islamic doctrines allow medication only if it will benefit the patient.\(^8^5\) However, the issue of euthanasia has continued to elicit divergent opinions among scholars and different cultures across the globe.

Healthcare organizations have implemented alternative health practices such as palliative care to improve patients’ lives. The concept of palliative sedation is more morally acceptable than euthanasia. Euthanasia opposes the advancement of palliative care, even though palliative care is considered the morally accepted principle among Muslims.\(^8^6\) Palliative sedation is different from euthanasia since it ensures proper disease and pain management among patients suffering from terminal illnesses. The belief that sedation is a type of pain management strategy as opposed to euthanasia gives palliative care more moral support than a mercy killing.

1.4.b.ii. Pain and Suffering, Death, and Euthanasia - An Islamic Perspective

The main role of medicine is to prolong life and to eradicate the pain brought about by a disease or a mental condition. Islamic religion and culture recognize the existence of pain and suffering.\(^8^7\) However, euthanasia ends the life of individuals in society. Hence, Islam, as a religious opposes assisted death since it does not prolong the life of the sick individual in the long term. Death and dying is an ethical issue because the termination of human life violates religious beliefs and doctrines. Religion has inadvertently stepped up and given an inconclusive yet unquestionable response to the question of life after death. According to Islam, life is perceived as a gift from Allah, and it is only the Supreme Being that can take it away. Moreover, Islamic teachings were critical in the adoption and implementation of
medicine as a profession. Therefore, the science of medicine was based on morality and ethical backgrounds that valued the sanctity of human life.  

Death also triggers ethical issues because it is religiously perceived as the beginning of a new life. According to Islamic religious doctrines, death marks the transition from one life to another. Moreover, these religions teach that natural death is more acceptable than assisted suicide. Dying is a slow transitional process that should not be hastened by health professionals. Euthanasia, according to Islam, is morally unacceptable. Therefore, while death may be perceived as a process, it is also celebrated, as long as it is not hastened. In essence, religious doctrines and beliefs are against all forms of assisted deaths. Euthanasia and all other methods of assisted deaths are contrary to the beliefs of various religions such as Islam.

According to Islam, euthanasia does not respect the value of the sanctity of human life. The two primary roles of modern medicine are to reduce one’s pain and the suffering caused by diseases and also to extend the life of a patient. Therefore, apart from eradicating pain and suffering, medical care should extend the life of a particular patient. This element of medical care is the foundation of palliative care. Through palliative sedation, terminally ill patients can prolong their lives before the eventual death. The Islamic principle of hardship, qa'idat al mashaqqah plays an instrumental role in understanding pain and suffering. Even though health consumers experience both emotional and psychological distress due to their medical conditions, Islamic teachings have opposed the incorporation of assisted suicide.

Euthanasia, instead of preserving, terminates life and violates the religious doctrines; hence it cannot be classified as a morality. Pain and suffering, therefore, is not a sufficient reason that can result in the act of euthanasia among the members of the Islamic religion. There is a need to focus on other existing issues that might contribute to euthanasia instead of adopting assisted death. The Islamic religious beliefs on euthanasia are different from the
beliefs of the Western countries. According to non-Islamic states such as the United States, mercy killing is ethical since it ensures that the patient no longer experiences pain and mental torture.\textsuperscript{91} Moreover, it is needless for a patient to continue suffering when he or she has been diagnosed with a terminal illness that will eventually result in a painful death. Therefore, there has been a tremendous increase in the adoption of assisted death in these regions. In contrast, the Islamic religious doctrines oppose euthanasia since it leads to the death of the patient hence violates the religious doctrines. Through the withdrawing of tubal feeding, the patient is left to die without looking for the existing issues that contributed to the health condition.

Euthanasia is unethical since it does not respect religious ideas and doctrines. This is because euthanasia enables health professionals to determine who should die at their own volition.\textsuperscript{92} According to the Islamic religion, Allah is the only one who gives life and hence should be the one to end life. This statement thus justifies the Muslim position against euthanasia.

\textbf{1.5. Professional & Organizational Challenges in HHC}

This chapter examines the professional and organizational challenges that are faced during the implementation of home healthcare programs.

\textbf{1.5.a. Professional Moral Distress}

Organizational bio-ethics creates an enabling, ethical environment within a healthcare organization by ensuring health care regulation and control. Moreover, organizational ethics promotes the adoption and implementation of bioethics which creates an enabling environment for health professionals in healthcare institutions.\textsuperscript{93} The prevalence of moral distress has acted as a barrier to the provision of healthcare services in modern healthcare organizations. The changes in healthcare management styles marked by a low population of
professional nurses have contributed to moral distress. This is because the nurses experience a heavy workload that results in nurse burnout and patient avoidance.94

However, organizational and professional ethics can be used to prevent and manage moral distress in healthcare settings, such as mental healthcare organizations. Through controlling and regulating the issue of informed consent, marketing of medical products, diagnosis, as well as the relationship between a health organization and other stakeholders, organizational ethics have boosted healthcare outcomes in modern health organizations.95 Both organizational and professional ethics improves the management of moral distress in mental disorders through the adoption of crucial coping strategies as well as the eradication of moral distress.

1.5.a.i. Current State of Moral distress in Mental Healthcare

Developing effective therapeutic relationships when working with patients in mental healthcare institutions enhances the provision of effective intervention methods. Studies of the expected patient health goals in the field of mental health argue that therapeutic relationships improve patient health. Also, researchers researching therapeutic relationships with mental health nurses identify important topics critical to developing therapeutic relationships, such as trust, power, reciprocity, self-revelation, congruence, and credibility, all in the context of maintaining professional boundaries.96 The existence of various types of discrimination plays a pivotal role in preventing an effective relationship between the patients and the healthcare practitioners.

Various external structures influence the health system, for example, allocation of resources, power and gender inequality, and organizational policies. Issues that have existed in health care and led to ethical dilemmas in the ability of health professionals to express their opinions and ideologies continue to exist today.

1.5.a.ii. Organizational and Professional Ethics in Combating Moral Distress
Organizational ethics refers to the ethical practice that controls the operations of various activities in the healthcare setting. Ethics is used to examine critical issues such as confidentiality, integrity, respect, as well as nurse-patient relationships. The occurrence of diseases such as cancer, cardiovascular diseases as well as mental disorders in the society has increased the need to observe organizational ethics. This is because the availability of such health information to other parties can result in discrimination and prejudice from the members of the society.

Professional ethics, on the other hand, refers to the ethical conduct that is adopted by healthcare professionals to promote precision medicine in home healthcare. Professional ethics has created an opportunity for the adoption of favorable ethical behavior among healthcare professionals, such as physicians. Healthcare professionals’ behaviors influence the relationship between them and the patients. Professional ethics can, therefore, address the issue of moral distress among health providers who work with patients with psychiatric conditions.

The ethical behavior that a healthcare organization adopts has a direct impact on the prevalence and elimination of moral distress. This is since ethical behavior adopted by both the nurses and the health organization influences the occurrence and prevalence of moral distress within a mental healthcare setting. Organizational ethics in mental healthcare is characterized by the creation of trust between the health professionals and the patients as well as the health organization. Trust is a critical aspect of organizational ethics. This is because it creates a bond between nurses and health consumers. Moreover, it creates an enabling environment for the nurse-patient relationship in the health care organization. Healthcare settings that are characterized by the appreciation of the role of trust have experienced significant prevention of moral distress and the eventual generation of positive patient outcomes.
The adoption of professional ethics can assist in the management and prevention of moral distress in modern healthcare settings. Professional ethics focuses on elements of nursing professionalism that can create a personal relationship between the nursing profession and the patients. Moral distress is most prevalent in healthcare organizations, and it hinders the achievement of the goals and objectives of health care.\textsuperscript{101} Integrity is marked by the ability to provide care without selfish interest. The process of accepting ethical and moral responsibility in a clinical setting results in the adoption of professional integrity. Nursing professionals, therefore, know their expectations concerning the needs of professional care.

Organizational ethics, for instance, have led to the adoption of effective and ethical behavior such as privacy, honesty, respect, and integrity. The adoption of professional ethics has led to the recognition of the role of therapeutic and interpersonal relationships in mental healthcare.\textsuperscript{102} The therapeutic relationship is essential for creating a good relationship between the patients and the health professionals as well as acquiring more information about the existing ethical issues as is the pillar of coping with moral distress. As opposed to adopting unethical behaviors such as patient avoidance, advanced practice nurses and other health professionals should observe organizational and professional ethics in clinical care settings.\textsuperscript{103} This is because; both organizational and professional ethics can significantly manage or eliminate moral distress in modern healthcare organizations. Adopting the ideology of moral distress, the underlying factors, as well as its relationship with organizational ethics, is important in its prevention and management. Healthcare stakeholders hence should promote the observation of organizational and professional ethics to address the issue of moral distress.\textsuperscript{104}
1.5.b. Integrated Care and Quality Improvement

1.5.b.i. Bioethics Issues in Integrated Care and Quality Improvement

Health care organizations have been at the forefront of adopting and implementing integrated care in modern clinical care settings. Integrated care is characterized by the coordination of health care activities between different stakeholders such as the Ministry of Health, health care professionals, the local communities, and health insurance providers. Integrated care improves the quality of health care since the collaboration among the health care providers results in patient-centered care. However, bioethics has created an enabling environment for the adoption of integrated care. Critical elements in bioethics such as the provision of standardized care have led to quality improvement in health care. Health professionals should ensure that they provide standardized care in both the clinical care and home health care setting. Global health bodies such as the World Health Organization sets the standards of health care in which nations across the globe are supposed to follow in the process of providing high-quality care. Through adopting standardized care, health care organizations observe ethics in their professional conduct.

Another element in integrated care is the adoption of precision medicine. Health professionals have adopted strategies aimed at incorporating precision medicine. Patient-oriented care focuses on ensuring that a patient acquires high-quality care within a particular clinical care setting. Precision medicine has led to quality improvement since the health care professionals focus on providing care that ensures maximum health benefits to a specific patient concerning the underlying health condition. For instance, a patient suffering from a terminal can be given home-based care to ensure maximum health benefits. Moreover, an information management system is also a useful bioethical element that affects integrated care. Integrated care is achieved through the sharing of medical information among health care stakeholders. Therefore, health care organizations should develop comprehensive
information management. Information management helps in collecting, storing, and sharing health data within the health care center. For example, the laboratory test results should be communicated to the physicians via sophisticated information sharing technology. Such data should also be shared with social workers, such as counselors. Therefore, an effective information management system enhances the adoption of integrated care and contributes to quality improvement. The Kingdom of Saudi Arabia, for instance, has promoted the adoption of a complex medical information collection and sharing system such as Electronic Health Records.

To adopt integrated care, health care stakeholders should also regulate and control the operations of health organizations. Regulation of health care activities is essential in ensuring equitable distribution of health care resources as well as the provision of high-quality care. Global regulatory bodies such as the WHO and the CDC enact laws and policies that are aimed at ensuring health care centers observe the globally acceptable health standards. Although each country has its health care policies, there are global health care laws that facilitate the observation of the safety and quality of clinical care. The laws and policies have also promoted the adoption of home health care to increase access to high-quality health care by individuals living in rural areas.

Community integration is another element in bioethics that enhances the adoption of integrated care. The members of the local community form part of health care stakeholders. The adoption of home health care has led to the recognition of the role of local communities in health care. The members of society play a vital role in the provision of home-based care. Family-based caregivers, such as family members, help in providing care to patients with chronic diseases and terminal illnesses. The goals of integrated care can only be achieved if the health care stakeholders, such as health professionals, coordinate actions with other stakeholders such as the community members.
1.5.b.ii. Significance of Bioethics in the Adoption of Integrated Care

The incorporation of bioethics has brought a great impact on integrated care and quality management. For example, bioethics leads to improved access to high-quality clinical care. Access to patient-centered care is one of the goals of modern health care.\textsuperscript{110} Through increasing the access and affordability of health care services, health professionals have spearheaded the implementation of awareness creation programs. The implementation of the elements in bioethics such as community integration, leads to collaborative efforts that result in the adoption of different ideas into health care. Coordination of health care operations ensures that the different stakeholders, such as the Ministry of Health, private health providers, and health professionals, embrace effective health care decisions. Incorporation of bioethics in healthcare settings also leads to the achievement of the goals of integrated care in home health care. Integrated care aims at collective participation of different stakeholders to improve the access and quality of health.\textsuperscript{111} Through enhancing the quality of health care, health consumers can acquire health care that improves health care outcomes. Therefore, the incorporation of bioethics in integrated care has brought a great impact on the quality of both hospital-based and home-based care.
Endnotes


CHAPTER 2: THE CONTEXT OF HHC

2. a. HHC in Saudi Arabia

2.a. i Background

Home Healthcare has played a fundamental role in shaping modern healthcare in contemporary society. There has been an increase in the adoption and implementation of Home Healthcare programs across several countries. Home healthcare aims towards the provision of home-based care to the patients through the coordination of healthcare professionals such as nursing team and family members. The healthcare services are usually provided at the home of the patient hence acting as a continuity of the care that has been provided at the hospital. One of the nations that have recognized the significance of home healthcare is the Kingdom of Saudi Arabia.\(^1\) The increase in population in recent years has led to a high demand for healthcare services in the country. Since the provision of healthcare services is home-based, caregivers such as nurses are required to adopt ethical behavior to improve the patient-caregiver relationship.\(^2\) Healthcare organizations hence, have advocated ethical behavior while providing healthcare services to the patients at their homes. The adoption of home healthcare has led to improved healthcare in Saudi Arabia through the creation of a patient-centered healthcare setting that is characterized by the presence and assistance of skilled primary caregivers as well as the family members of the patient.

Home healthcare program can be traced back in 1980 when Green Crescent Hospital began to provide home-based care to patients.\(^3\) The principle behind the program was that the provision of healthcare services in the natural surrounding and private environment enhanced the healthcare outcome. This is because both the patients and the family members received both psychosocial support and nursing care provided by the healthcare professionals.\(^4\) Moreover, patients who stayed for long periods in the hospitals were found to undergo mental torture and suffering due to their negative perception towards the hospitals. Therefore, home
healthcare was seen as a suitable alternative that resulted in reducing the need for clinical visits as well as hospital admissions. The need for home healthcare was also necessitated by the effect of hospital admission among the patient as well as the prevalence of old age-related diseases. A higher percentage of the patients who had been admitted for longer periods in hospitals developed a negative attitude towards the hospital environment. The Saudi Ministry of Health, therefore, saw the need to undertake a comprehensive implementation of the home healthcare program to address the issue. The home health care program, therefore, was focused on how to improve patient outcome by changing the environment of caregiving.

The shift from caregiving in the hospital to the home-based care was, therefore, one of the major accomplishments that were aimed at changing the face of healthcare provision. Moreover, patients with chronic diseases, terminally ill patients, and generally, the aged patients responded more effectively to home-based care as opposed to hospital care. This is because home healthcare involved the creation of a sustainable environment for healthcare services. Through the interaction with the patients and family members at home, the caregivers had a valuable opportunity of providing high quality and patient-oriented healthcare. Home-based care was also targeted towards individuals from low socioeconomic backgrounds who could not afford expensive medical care in hospitals.

2.a. i. 1 Key Influencers of HHC in KSA

Key stakeholders have shaped the adoption and implementation of HHC in the Kingdom of Saudi Arabia. The players determine the laws and policies that regulate the provision of HHC and also provide the medical expertise required during primary caregiving. The major influencers of HHC in the country include:

1) The Ministry of Health (MOH) - The Ministry of Health in Saudi Arabia has spearheaded the adoption of home healthcare. Since the adoption of the program almost three decades ago, the government, through the Ministry of Health has been at the forefront of
promoting the adoption of the home-based care within the country. The Ministry of Health is tasked with regulating the healthcare program in Saudi Arabia. For example, the ministry ensures that only qualified primary caregivers provided high-quality care to the patients in the home setting. Moreover, the department ensures equitable distribution of healthcare professionals in the HHC programs and also the training of the primary caregivers. The government also provides funds for running the operations of the HHC programs such as the purchase of medications as well as the payment of healthcare professionals. The Ministry of Health also conducts extensive awareness creation on the need to embrace HHC as opposed to hospital care. Through awareness creation, a more significant percentage of Saudi citizens have embraced the healthcare program.

II) Non-governmental organizations/civil societies- Civil societies have also promoted the adoption of home healthcare. The non-governmental agencies have initiated home healthcare services, especially in the Western region of Saudi Arabia. The operations of the civil societies have increased home-based healthcare access in remote areas as well as the neighboring urban centers. The civil societies advocate for the provision of healthcare at a reliable setting that satisfies the needs, taste, and preferences of a particular patient. Moreover, civil societies also promote HHC among the senior citizens in KSA. The aging population is encouraged to embrace HHC, especially individuals suffering from chronic diseases and terminal illnesses.

2.a. i. 2 Overview of the Current Status of HHC in Saudi Arabia

In recent years, the Ministry of Health in Saudi Arabia has been at the forefront of advocating for the implementation of home healthcare programs across the country. The main factor that has boosted the adoption of home healthcare in the Kingdom is coordination of operations from various stakeholders such as the government, healthcare organizations, physicians, nursing teams, family members as well as the patients. Coordination of
activities has enhanced patient outcomes since each in the cycle has a role to play to facilitate the provision of patient-centered healthcare. The government has focused that the population of the aging individuals will grow from 6% in 2005 to 12% in 2030. The trend denotes that the demand for home healthcare will continue to grow in the coming years hence the need to prepare for the expected growth in population.

The Saudi government noticed the impact of long hospital admission on patient health and decided to embrace strategies that are aimed towards promoting home healthcare across the country. Since the implementation of the health program requires coordination of various stakeholders, healthcare organizations such as King Fahad National Guard Hospital has ensured the coordination of activities between healthcare professionals and home-based caregivers. The hospital ensures that only qualified and highly skilled nursing teams are dispatched to provide care at the homes of the patients.

Effective communication channels have also been adopted to boost the relationship between the patients, caregivers, as well as the families of the patients. In the western region of Jeddah, civil society groups have also recognized the importance of home healthcare. Such groups support the initiative by creating awareness through the mobilization of the members of the local community to embrace the valuable healthcare program. Although there has been tremendous population growth, the country has adopted strategies aimed at enhancing home healthcare programs. Moreover, there has been a growing population of the aged since the turn of the millennium, increasing the number of people who require home healthcare services.

One factor that has played a great role in shaping home healthcare in Saudi Arabia is the adoption of ethical behavior. Home healthcare focuses on the provision of healthcare services to a special group of patients at their homes. Therefore, the program revolves around two major aspects; location of the service delivery and the type of patients. The service
delivery is undertaken at home to the minority group such as the aged, people with chronic diseases or disabilities. The program is essentially a physician or nurse follow-up in which a patient who has been discharged from the hospital is recommended for the home healthcare program. The nurses and physicians, therefore, ensure that the patient continues to receive healthcare attention at home rather than in the hospital.

The annual population growth rate of 2.2%, as well as a reduction in mortality rate among the aging population, has contributed to an increase in the demand for home healthcare in the country. The Saudi government, through the ministry of health, has created awareness on the need for the citizens to embrace home healthcare programs in various regions within the country. For example, the Saudi government has passed laws that enforce the implementation of the HHC in both the urban centers as well as the rural regions. The government has encouraged the adoption of home-based care in all the provinces in the country. The coordination between healthcare organizations, primary caregivers, family members, as well as the patients boosts the implementation of the process of the HHC programs. This is because each party has a role to play during caregiving. The primary caregivers are expected to provide care according to the medical history of the patient. For instance, in case the patient has a terminal illness, the primary caregivers such as the nurses are expected to coordinate with the family members to provide medical care as well as psychosocial comfort for the patient. However, in the case that a patient is suffering from a chronic disease, the practicing nurse is expected to conduct periodic visits to check on the progress of the patient.

According to the Saudi Ministry of Health (2013), the country had experienced a tremendous improvement in healthcare services in the past 25 years due to the implementation of the home healthcare program. This data was supported by the findings of the research in which 60% of the respondents agreed that the adoption of HHC had enhanced
the quality and access to better healthcare in Saudi Arabia. The findings highlight the role that HHC has played in improving the health of Saudi citizens.\textsuperscript{26}

One of the perennial problems that have faced healthcare in Saudi Arabia is a high number of inpatients. The increase in the number of patients being admitted in the hospitals triggers a shortage of hospital beds or new admissions.\textsuperscript{27} However, the introduction of home healthcare has reduced the shortage of hospital beds since almost 50\% of the patients have embraced HHC programs throughout the country.\textsuperscript{28} Through support from the government, HHC has played a great role in boosting the quality of healthcare through the incorporation of a holistic healthcare environment.

The quality of the home environment influences the healthcare outcome.\textsuperscript{29} The home setting, unlike the hospital setting, can be tailored towards the needs, taste, and preferences of a patient. The home care setting hence, can be customized, thus resulting in patient-centered care. For instance, patients suffering from chronic mental illness who hate the presence of many people can benefit from the home setting.\textsuperscript{30} Moreover, patients above the age of 65 mostly prefer an environment where they can easily associate with family members to the hospital setting. According to the Ministry of Health, over 50\% of the Saudi population has developed trust and confidence in the HHC program since its adoption a few decades ago. Research studies have found out that 50.8\% of the citizens agreed that the HHC programs have improved healthcare in the country through the creation of a suitable healthcare environment.\textsuperscript{31} Although home care setting lacks proper medical equipment as well as a highly skilled health professional, the surroundings offer a comforting and soothing environment that is important during the patient recovery or disease management process.\textsuperscript{32} Both the research and the existing literature have highlighted several benefits of home healthcare on patients with diverse illness and disorders.
Home healthcare program is focused on providing convenient and patient-centered healthcare. Convenience is one of the most important aspects of modern healthcare. It can occur through the availability of a suitable environment, cost, quality, and access to healthcare services.\textsuperscript{33} Since the establishment of home-based care in Saudi Arabia, there has been an increase in the demand for the healthcare program primarily since it is more convenient than hospital healthcare. According to the findings, HHC has increased access and also improved the quality of healthcare.\textsuperscript{34} The most fundamental characteristic of home-based care is the setting of care. Through the provision of healthcare at the homes of the patients, the primary caregiver acquires the opportunity to interact with the patient effectively and hence understands the underlying issues on the disease as well as the recovery process.\textsuperscript{35} The hospital setting, on the other hand, provides an inconvenient environment for aging patients as well as individuals with chronic diseases. Home healthcare has also been instrumental in handling emergency cases.

Since most hospitals are located in urban centers, the HHC program helps in handling emergency cases that occur in the rural regions of Saudi Arabia. Primary caregivers have the opportunity to provide customized and high-quality care during emergency cases such as health deterioration after hospitalization. Both existing literature and current studies on the impact of HHC on healthcare point to the direction that home-based healthcare has led to an increase in hospital bed spaces due to reduced hospitalization.\textsuperscript{36} The shortage of hospital bed spaces that has been a perennial problem has been solved through the implementation of the HHC programs across different regions within Saudi Arabia.

2.a. i. 3. Types of Home Visits in HHC

Healthcare professionals visit patients who are already mapped for the HHC program. The visits can be scheduled weekly or biweekly depending on the progress of the patient and the number of patients served by a physician or home health nurses.\textsuperscript{37} The types of home
visits differ since due to the different patterns of diseases, rate of prevalence, location of patients as well as the response of the patient towards a particular disease intervention method. The types of home visits include:

\textbf{I) Illness home visit} - Healthcare professionals undertake illness home visit to provide healthcare services during emergency cases or to manage acute or chronic illnesses.\textsuperscript{38} The purpose of the illness home visit is to provide care as a result of the occurrence of a particular disease or a disorder. For example, in case a patient who has been discharged in the hospital is put under HHC program, home healthcare nurses, therapists as well as physicians, must visit the patient regularly to provide healthcare services.\textsuperscript{39} During the illness home visit, the healthcare professionals check the progress of the patient, administer new drugs, and also offer psychosocial support to the patient. This type of visit is critical in the HHC program since it builds a lasting relationship between the patient and the health professional. During the home visit, the interaction between the physician and the patient can result in the generation of vital information that helps in the treatment and disease management process.

\textbf{II) Dying patient home visit} - Another type of HHC visit is a terminally ill home visit. Primary caregivers and physicians schedule a periodic visit at the homes of patients suffering from a terminal illness.\textsuperscript{40} Dying patients under the HHC program form a substantial percentage of the overall patients who have embraced home healthcare program. Terminally illness requires patient-centered care that is characterized by the provision of psychosocial and medical care.\textsuperscript{41} The primary caregivers, therefore, must coordinate activities to create a holistic environment as the patient awaits death. Due to the beliefs that are associated with the death such as the fear of dying as well as the aspect of the afterlife, most patients with terminal illness constantly need the presence and care of both family members and primary caregivers.\textsuperscript{42} The physicians and nurses that undertake dying patient visit must possess diverse medical and communication skills to provide high-quality care to the patients.
Moreover, the Saudi government has promoted the adoption of HHC programs, especially among patients with a terminal illness. As opposed to hospice care that is usually very expensive hence unaffordable, the government has encouraged the implementation of the HHC programs among the aged population. Moreover, the primary caregiver not only provides care before the death of the patient but also offer counseling services to the family even after the death of a loved one. The adoption of comprehensive care among patients with a terminal illness has led to the rising popularity among the HHC programs in the rural regions of Saudi Arabia.

**III) Assessment home visit**- This type of home visit focuses on investigating a particular disease or disorder. The primary caregiver or the physician visits to examine how the patient is responding to a particular disease intervention method. Moreover, the physicians also investigate the underlying issues surrounding a disease as well as the impact of home healthcare on the patient. The assessment results in the collection of vital information that aids in the process of provision of care by the primary caregivers as well as the family members. The assessment visit is critical in the management of different types of illness, such as chronic diseases. During the assessment home visit, the primary caregiver investigates the underlying factors surrounding a particular disease before adopting a comprehensive intervention method. For example, an aged patient suffering from a mild mental disorder requires a peaceful environment where he can interact with the members of the family and the primary caregiver.

**IV) Hospital follow-up home visit**- The final type of home visit under the home healthcare program is the hospital home visit. During such a visit, the primary caregiver undertakes a follow-up visit after a patient has been discharged from the hospital and admitted to the HHC program. For example, a patient who has undergone surgery requires periodic hospital visits. The primary caregiver must check the progress of the patient based
on the nature of the surgery. Moreover, the visit serves as an opportunity for the nurse and the physician to interact with the patient and examine the impact of the home care setting on the patient. In case the patient is not responding well to the HHC program, the primary caregiver can recommend re-hospitalization. Hospital home visit, just like other types of home visits, has highlighted the significance of home healthcare in enhancing primary healthcare in Saudi Arabia.

2.a. i. 4. Factors that Trigger the Adoption of Home Healthcare

I) Demand by the patient- A request by a patient can trigger the onset of a home healthcare program. Health consumers who have stayed for a longer period in the hospital can request the health professionals to be discharged and put in the home-based care. In most cases, aging patients suffering from chronic illness are the ones who are likely to request for home healthcare patients. Staying in hospitals for longer periods can have a devastating effect on aged patients since they require around the clock care, which cannot be acquired in the hospital setting. In such cases, a patient is required to submit a request to the resident physician to be allowed to begin home healthcare program. The demand by the patients is usually considered since home-based healthcare has reported positive results in regards to patient recovery when compared to hospital admission, especially among the aging population.

II) Demand by the patient’s family members- Family members and relatives can also request for the patient to be transferred from the hospital setting to the home healthcare setting. This can occur if the patient suffers from a terminal illness or a chronic illness. Moreover, in the case that a patient has suffered memory loss or is experiencing any form of disability, the family can decide to request the hospital to discharge such a patient. In such a scenario, home healthcare is the best option for patients suffering from a chronic or terminal illness. The relatives, however, must work together with the primary caregiver after the
patient has been put in the home healthcare program. According to the Saudi culture, the aged population is treated with the utmost respect and therefore, family members have been instrumental in the provision of assistance to the patient. Coordination of services among the patients, family members, and the registered nurses affect the quality of care provided in the home healthcare programs.54

**III) Recommendation by a physician** - Health professionals can also make recommendations, which result in the patient's transfer from the hospital care to home-based care. After a comprehensive examination of the progress of a particular patient, the physician can recommend the patient to be put in the HHC program. Over 70% of the patients that are admitted in the HHC program are recommended by qualified medical personnel.55 A Recommendation by a physician is important since it occurs after the health professional has undertaken an extensive analysis and examination of the medical history as well as the effect of the hospital setting on the patient. For example, senior citizens with chronic illness are usually recommended for HHC. Elderly population suffering from chronic illness and terminal illness has been found to respond effectively to home-based care as opposed to hospital care.56 Such patients require a comforting environment that is characterized by the presence of close family members as well as respectful primary caregivers. The nurses, physicians, and the family members should also bond with the patient so as the patient can feel loved and appreciated.57 Aged patients admitted to the hospital can experience isolation since the caregivers in the hospital setting are usually exhausted due to the high number of patients.

2.a. i. 5. **Occupational Hazards Associated with HHC**

Although the adoption of home healthcare has enhanced the quality and access to primary healthcare, some occupational hazards are associated with the healthcare program. Various
occupational challenges have hindered the effective implementation of home healthcare in Saudi Arabia.

I) The limited authority of caregivers in the home setting- The primary caregiver lacks full control of the home care setting. Unlike the hospital setting, home healthcare nurses and physicians do not have full control over the patient while at their homes. The family members and the patients can, therefore, prevent the health care professional from conducting the required duties. This occurs because patients, while at their homes, believe that they have the caregivers should only provide care that conforms to the patient's beliefs, ideologies as well as preferences. However, in the hospital setting, the caregiver has full control and freedom to initiate the appropriate disease intervention method. For instance, a patient can refuse to have an injection at home due to the authority in the home setting. At home, other friends or relatives of the patient can also distract caregiving since they can choose to visit the patient at any time.

II) Aggression- Primary caregivers can also encounter aggressive patients or family members during their home visits. Patients suffering from chronic mental disorders such as schizophrenia can exhibit aggressive behavior characterized by assault and insults aimed at the primary caregiver. Moreover, some close relatives may argue that the caregiver is incompetent and thus develop aggressive behavior. Caregivers who interact with aggressive patients or family members cannot provide high quality and patient-oriented care since he or she will be fearful during home visits. Moreover, since over 50% of the primary caregivers are women, cases of sexual harassment have been reported during the home visits. The development of aggressive behavior in the home care setting is one of the factors that has prevented primary caregivers in initiating an effective home-based care program.

III) Unexpected dangers- The health professionals can also encounter other forms of hazards such as weapons around the house or attack by domestic and wild animals. Since the
primary caregivers are usually unfamiliar with the home environment, they can be harmed by weapons in the house. Alternatively, they can be attacked by fierce dogs or even dangerous wild animals while on their way to visit the patients in remote areas.

2.a. ii. Significance and Challenges

2.a.ii.1. Significance of Home Health Care

Healthcare organizations, over the years, examined the behavior of patients admitted in the hospitals. It became evident that the patients who stayed longer in hospitals changed their perception of healthcare services within the hospital setting. Through a comprehensive examination and analysis of the behavior of patients within the hospital setting, it became clear that there was a need for the adoption of a new strategy of providing care to the patients. The main short and long-term role of HHC include:

I. Creation of a Patient-Centered Healthcare Setting - The most important aim of home health care is to provide a sustainable environment for the provision of healthcare services. Unlike the traditional healthcare setting that was primarily in the hospital, HHC focused on providing healthcare to the patients at their homes. Home-based care provides a suitable avenue for the primary caregiver to interact with both the patients and their family members. The benefit of associating with the family members is that the close relatives could quickly provide any information relating to the progress of the patient with the medication. Moreover, family members can also provide immediate assistance in case the patient needs to take medicine.

Another major significance of HHC in creating patient-centered care is its ability to influence the cognitive ability of the patients. A larger percentage of patients have recognized the psychosocial aspect of HHC in their lives. HCC fosters a sustainable environment that provides comfort and also improves the mental wellbeing of the patients.
hospital setting. The hospital environment hinders the emotional healing and growth among patients since the patients believe that they may die in the hospital. Home healthcare setting, however, is composed of various individuals such as the nursing team and relatives that improves the morale of the health consumers.

**II. Enhances Access to Healthcare Services** - Home healthcare program also enhances access to healthcare services. Since a higher percentage of healthcare services are relatively expensive, individuals from low socioeconomic background usually cannot afford such services. Access to healthcare is one of the most critical issues in modern healthcare. The Ministry of Health in Saudi Arabia, therefore, adopted Home Healthcare programs as one of the measures of bridging the gap of healthcare access between the upper class and the working members of the society. HHC is cheaper than hospital care; hence, it has become popular among health consumers in various regions within Saudi Arabia. Patients with chronic illness, terminal diseases, or disability are the major target of HHC in the country.

Moreover, most patients with such types of illnesses are generally within the aging population bracket. The increase in the number of aging patients has been characterized by a reduction in the amount of income. This trend occurs since the aged are no longer able to work and earn income. Through the implementation of home-based care in Saudi Arabia, aged patients suffering from various diseases such as chronic illness and terminal diseases have received proper disease intervention methods. Since its establishment, HCC has been associated with enhancing healthcare access throughout the country. Unlike in the past, where patients were required to stay in hospitals for long periods, the emergence of home-based care has changed the nature of healthcare provision in Saudi Arabia.

**III. Reduction of Health Inconsistencies** - The prevalence of health inconsistencies in the field of healthcare has hindered the adoption of patient-centered primary care. The occurrence of health inconsistencies such as poor coordination of the treatment process
between the physician and the resident nurses affects the overall quality of patient outcome during caregiving. Within the hospital settings, the physicians face difficulties in providing adequate care to the high number of patients.\textsuperscript{74} Moreover, since patient-centered care requires the efforts of both physicians and registered nurses, the population of healthcare consumers causes a challenge among healthcare professionals. In most cases, healthcare professionals cannot provide efficient patient-specific primary care. For example, events such as misdiagnosis, mistaken identity among patients as well as wrong medical prescription can easily occur within the hospital setting.\textsuperscript{75} However, the adoption and implementation of home healthcare in different regions within Saudi Arabia have led to the reduction of the rate of medical inconsistencies. Home healthcare programs reduce health inconsistencies since the primary caregiver focuses on the provision of high-quality care on a particular patient.\textsuperscript{76} The provision of care is thus patient-specific, unlike the case in the hospital setting.

According to HHC, the physicians and registered make periodic appointments, for example, twice a week and visit the patients at their homes of the patients.\textsuperscript{77} The physicians hence acquire the opportunity to concentrate on one patient at a time, thus reducing medical inconsistencies. It is challenging to undertake a misdiagnosis on a single patient as compared to when there are several patients. Another major health inconsistency is the poor record keeping of the patient's personal information. In the hospitals, there can be a mixed up, resulting in the loss of vital information relating to the medical history of a patient. HHC however, has ensured efficient collection, storage as well as usage of patient’s data during primary caregiving.

\textit{IV. Enhancing the Adoption of Preventive Care} - Home healthcare is also focused on the provision of preventive care.\textsuperscript{78} Prevention of diseases, as well as disorders such as post-traumatic stress disorder, is one way of combating diseases. Among the aging population, preventive care has played a critical role in the prevention of diseases that are associated with
old age. Moreover, preventive care can reduce the risk of terminal illness among the aged in society. This is because preventive care focuses on the ways through which a disease or a disorder can be prevented rather than cured. HHC programs have promoted preventive care through increasing access to healthcare information as well as primary care. During the physicians and nursing team visits, the patients are informed about the need to prevent chronic illnesses as well as devastating diseases such as cancer, diabetes, and cardiovascular diseases. Home-based care enables the nurses and physicians to educate the aging population on how to prevent life-threatening diseases. Home healthcare enables patients and healthcare professionals to interact with one another freely. The interaction can enhance the patient-physician relation, thus fostering primary caregiving. Since the HHC programs mostly target the aged people in the society, the knowledge and expertise about disease prevention have increased among the patients.

V. Improving the Management of Chronic Illnesses - One of the factors that contributed to the adoption of home healthcare programs in Saudi Arabia was the need to embrace effective strategies of managing chronic diseases. The aging population has exhibited a larger percentage of chronic diseases as opposed to non-chronic diseases. Chronic illness such as cardiovascular diseases affect the cognitive perception of the patients resulting in the depression and post-traumatic stress disorder. Therefore, healthcare professionals have encouraged the adoption of a holistic approach that is characterized by the implementation of home-based care. HHC creates an important setting in which primary caregivers can use to provide care. During the chronic illness visits, the primary caregivers can monitor the progress of the patient relative to the disease intervention methods that have already been adopted. For example, in the case where a patient is suffering from a terminal chronic illness such as cancer, home healthcare can play an instrumental role in ensuring patient-centered management of the disease. This is because the hospital has a different
healthcare setting when compared to home-based care. Several challenges are experienced when managing chronic illness in the hospital setting. For instance, the patient may not acquire proper attention from the primary caregiver due to the high number of patients in the hospital. However, HHC programs allow the nurses and physicians to attend to the patients directly without any interference. Moreover, HHC enables both the primary and patient to bond at an individual level. Bonding results in the creation of a strong relationship that eventually affects the quality of the patient outcome. The implementation of the HHC has therefore triggered proper management of chronic illness among the aged population in Saudi Arabia.

2.a.ii.2. Challenges Facing Home Healthcare in Saudi Arabia

Some of the challenges include:

**I. Dissimilarity in sickness patterns** - The major hindrance to the implementation of patient-centered home healthcare programs is the inconsistencies in the disease and disorder patterns. Patients suffer from different illnesses such as chronic cardiovascular diseases as well as mental disorders. However, the distribution or pattern of these illnesses differs from region to region hence presenting a challenge towards the implementation of the HHC programs. For instance, scheduling of physician visits is hindered by the geographical locations of patients suffering from a particular chronic disease. This is because the patients suffering from a specific chronic disease do no reside in a specific place. Moreover, there are various types of diseases and illnesses that more prevalent in one region as compared to other regions. Moreover, it is difficult to undertake the mapping process of the number of patients that have been registered in the home health care programs. This is unlike the hospital setting, which presents a viable opportunity to examine disease patterns and distribution depending on the age of the patients.
II. Inadequate funds- HHC program in Saudi Arabia is also affected by the shortage of funds that are required to implement the projects. Since HHC provides customized health care services to the patients, there is a need to embrace high-quality care that is characterized by the presence of qualified and experienced healthcare professionals such as Home-Health Nurses, Nurse Practitioners, Physician Assistants, Physical Therapists, physicians, as well as Occupational Therapists.86 Although the Saudi government has promoted the adoption of HHC in the country, the program still lacks sufficient funds that can be used to improve the quality of care. Lack of adequate funds has also led to the shortage of medical professionals since the established healthcare organization employs most of the healthcare professionals.

III. High demand for HHC programs- In recent years, there has been a significant increase in the demand for home health care programs. The popularity of home-based care services has triggered massive demand for services from all parts of the country. Individuals have recognized the impact of home healthcare in providing an enabling healing environment for patients with chronic illnesses. The high number of senior citizens has increased over the years leading to an increase in the demand for the HHC programs. Despite the presence of 8090 HHC programs throughout the regions in Saudi Arabia, the demand for home-based care has skyrocketed, resulting in reduced quality of services.87 The underlying factors that have contributed to the high demand for HHC also include healthcare behavior change among the aging population. The aged have changed their perception of old age sickness leading to the adoption of healthcare programs that are aimed towards combating chronic old age diseases.

To address these challenges, the following strategies can be adopted:

I. Training primary caregivers- The Saudi government, through the Ministry of Health, has initiated training programs aimed at improving the skills of the primary caregivers. Since the shortage of qualified medical personnel has hindered effective home
healthcare in the country, the measure is expected to boost the quality of healthcare in the long run.\textsuperscript{88} The home healthcare nurses and physicians are trained on how to provide patient-oriented care at the home care setting. Moreover, the Saudi government has offered post-graduate students a scholarship to advance their knowledge and skills in the field of medicine.\textsuperscript{89} Training of primary caregivers has brought a great impact on the adoption of HHC in the country. Patients no longer depend on hospital admission to acquire healthcare services. The HHC program has benefited a majority of the patients, especially aged patients suffering from chronic and mental diseases and disorders. The government has also encouraged nursing education through the establishment of relevant nursing courses. For example, 67\% of the nurses have received training at Health Institute and 30\% at Junior colleges within the Kingdom. Training has played an integral part in the provision of HHC since the primary caregivers acquire relevant skills that enable them to provide both medical and psychosocial care to the patients.\textsuperscript{90}

\textbf{II. Increasing HHC funds} - The Saudi government has also increased the budget for home healthcare program across the country. The kingdom has allocated over SAR 30 million in the health sector to increase access to healthcare through initiating home healthcare programs.\textsuperscript{91} The increase in the amount allocated for HHC has addressed the problem of shortage of funds that has been derailing the implementation of the program. Non-governmental organizations such as civil societies have also allocated funds that are used to promote home healthcare in different regions within Saudi Arabia.

\textbf{III. Medical device production} - The Kingdom, through the Ministry of Health, has also recognized the role of advanced medical equipment in home healthcare. Technological advances have led to the usage of sophisticated medical equipment such as CT scans, Magnetic Resonance Imaging machines as well as other devices that assist in surgery.\textsuperscript{92} The production of the medical equipment is aimed towards ensuring that both hospital care and
home healthcare results in the adoption of efficient healthcare services. Although the medical equipment is associated with hospital care setting, primary caregivers have utilized the medical equipment in providing care at the home-based care settings.

**IV. Pharmaceutical production** - The Ministry of Health has also embarked on full production of medicine in the pharmaceutical companies. The establishment of pharmaceutical companies has led to an increase in the availability of both first-hand and generic drugs that are used in the treatment of various illness and chronic mental disorders. Saudi Arabia has managed to produce medicine used for purposes such as pain management as well as treatment of chronic diseases. Moreover, the production of medicine in the country reduces the cost of importing drugs from other countries. In regards to home healthcare, local pharmaceutical companies have enhanced the quality of healthcare due to the availability of high-quality drugs.

**2.b. Culture & Diversity in Healthcare**

**2.b.i. Challenges in Cross-Cultural Health Setting**

The adoption and implementation of healthcare ethics in a cross-cultural health setting have become a challenge in modern society. Primary caregivers have faced diverse challenges due to the presence of patients from different cultural backgrounds, gender, socio-economic status, and religious beliefs. Such differences influence the way patients respond to new disease intervention methods. For example, modern approaches such as stem cell research has been adopted by healthcare organizations to develop treatment for diseases such as cancer and cardiovascular diseases. However, health consumers have shown reluctancy in embracing these new intervention methods due to different religious ideologies and cultural backgrounds. In the quest to respond to the challenges of different ethnic background on healthcare delivery, health care organizations can promote tolerance to diversity, training on transcultural competence, adoption of diversity-centered leadership as well as the
implementation of policies such as common morality that enhance the adoption of normative ethics in healthcare.

2.b.ii Addressing these Challenges

2.b.ii.1. Promoting Tolerance to Diversity

The contemporary society has been characterized by the presence of individuals from different cultural backgrounds. Western nations such as the United States as well as Middle East countries consist of people from different cultural backgrounds. The presence of a multicultural society has played an instrumental role in influencing the adoption of healthcare ethics in healthcare organizations. Due to the difference in cultural backgrounds, people possess divergent views on various medical practices and disease intervention methods such as gene editing and stem cell research. However, there are various ways that can be used to respond to the challenges of diverse cultural backgrounds on healthcare ethics.

I. Appreciating the existence of different cultural beliefs on healthcare

Responding to the challenges of diverse cultural background requires that stakeholders such as healthcare professionals, health consumers as well as family members appreciate recognize and appreciate the existence of different cultural beliefs on healthcare practice. The failure to appreciate the existence of different opinions or religious beliefs on healthcare is one of the main challenges that usually cause conflict during care giving. For example, in the case that a primary care giver comes from a culture that accepts physician-assisted suicide meets a patient whose religious beliefs does not allow the medical practice, the health professional and the patient are likely to disagree on the intervention method to embrace. Therefore, the health professionals should understand and appreciate the existence of diversity and its resultant impact on the adoption of healthcare ethics. Since individuals usually believe that their cultural beliefs on medical care are superior to others, they adopt bigoted views that are characterized by discrimination and prejudice against people who are considered to possess
foreign ideologies on health care practices. For instance, Saudi Arabia is increasing becoming a multi-cultural society due to the influx of foreigners from global nations. The immigrants, who are from different cultures subscribe to diverse religion such as Christianity and Buddhism while Saudi Arabians are predominantly practice Islam. When the foreigners seek medical attention at the local healthcare centers, they face challenges due to the different beliefs on the healthcare practices. For example, in Saudi Arabian society, healthcare services should be provided by gender-concordant primary care givers. The strict cultural ties dictate that male patients should be treated with male physicians while female health consumers should be handled by female primary care givers. Only under emergency situations is the cultural norm ignored in the Islamic society. Therefore, other cultures such as the American society should understand and appreciate the Islamic belief on the gender of primary care giver during healthcare delivery. Appreciating the different cultural views enables foreign care givers to co-exist with the individuals of different cultural or religious backgrounds.

Healthcare providers should foster a culture that promotes tolerance to diversity. There is a need to develop an attitude change towards the differences in religious beliefs, racial composition, sexual orientation, and socio-economic class. Physicians should understand that patients have different beliefs and opinions concerning various disease intervention methods. For example, culture plays a critical role in the perception of emerging medical approaches such as withholding of life support during end-of-life care. Health professionals should thus provide quality healthcare for both majority and minority communities without prejudice. Patients from cultural and religious groups that value the sanctity of life cannot support the withdrawal of life support machine, unlike the patients from non-conservative cultures. For example, the Islamic religion is against the withdrawal of life support in end-of-life care; hence, patients from Saudi Arabia cannot allow the medical procedure to be used on their family
Therefore, the resident physician and nursing practitioners should practice tolerance to religious and cultural diversity when providing care to such a patient. Even when health professionals support withdrawal of life support machine in end-of-life care, they should not force the patient to undergo the procedure since it undermines the fundamental ethical conduct of medical care. Moreover, such an act constitutes murder and hence is subjected to punishment by the law. Practicing tolerance to diversity also helps in eliminating the normative ethical challenges in a multiethnic health setting since it fosters effective physician-patient relationships. When physicians understand that the patient has a different perception of a medical procedure due to his religion or ethnic group, they will adopt an intervention method that adhere to the beliefs of the patients.

Creating an effective relationship between the primary caregiver and the health consumers is significant since results in the achievement of both short- and long-term goals and objectives of the health organization. Therefore, the nurses and physicians should ensure that the primary caregivers encourage a culture of tolerance to diversity. Every stakeholder within the healthcare organization, such as health executives, advanced practice nurses, physicians, and the department of healthcare services should promote tolerance to diversity. For example, when a nursing team is attending to a patient from the heterosexual and homosexual community, the team should understand and tolerate the views of the sexual minority instead of showing discrimination or prejudice. Through adopting tolerance, health professionals can easily eradicate the ethical challenges that occur in a multicultural society.

II. Creating awareness on the need to value the cultural differences - Another critical way that can be used to address the challenges of different cultural background on the implementation of healthcare ethics is to embark on a comprehensive awareness creation on the need to embrace tolerance to diversity. Healthcare stakeholders such as the
government, World Health Organizations, the Saudi Arabian Ministry of Health should undertake an extensive awareness creation among the healthcare professionals, patients as well as the local communities.\textsuperscript{112} Awareness campaigns can play an instrumental role in ensuring that the stakeholders recognize the significance of tolerance to diversity. Moreover, creating awareness is likely to provide sufficient information about the cultural and religious beliefs of a specific culture in regard to healthcare practices.\textsuperscript{113} For example, Saudi Arabian physicians who emigrate to the United States and acquire citizenship may encounter challenges during care giving. This is because the American society has a different approach to medical practices as compared with Saudi Arabia. The United States culture adopts a more liberal and progressive views on healthcare delivery as well as emerging medical practices.\textsuperscript{114} On the other hand, Saudi Arabia, being an Islamic nation, adheres strictly to the religious doctrines that affect the perception of healthcare. The American society has embraced emerging medical practices such as withholding of life support as well as gene editing as a way of combating diseases. According to most Americans, physicians have the moral duty of withdrawing life support machine of patients with terminal illness.\textsuperscript{115} The measure is aimed at ending the pain and suffering. However, according to Islamic traditions, Allah is the provider of Life and no other person should end the life of a person. Therefore, the two cultures have a different stand in regard to withdrawal of end-of-life care for terminally ill patients.\textsuperscript{116}

Creation of awareness provides essential information about the cultural beliefs of both cultures. The Saudis acquire critical cultural knowledge about the United States. Another significance of adopting awareness programs is that it reminds the multi-cultural society of the need to co-exist and apply the healthcare-based ethical values during treatment. Healthcare stakeholders should therefore initiate awareness programs in healthcare organizations as well as in the media.\textsuperscript{117} The main message of the multicultural awareness program is to recognize the significance of possessing different cultural beliefs on healthcare.
The creation of awareness initiative should also encourage health professionals and patients to tolerate the various socio-cultural beliefs that are associated with healthcare.

2.b.ii.2. Training on Trans-Cultural Competence

Healthcare stakeholders should also adopt strategies aimed at initiating a comprehensive training on transcultural competence. Training ensures that health experts, health consumers and family members of the patient gain in-depth knowledge about the cultural and religious beliefs of different cultures and how they affect the response to healthcare practices in the contemporary society. Therefore, responding to the challenges of diverse cultural background on healthcare ethics should be characterized by the adoption of training and skill development on multi-cultural competence.

I. Creating Skill Development Programs- Healthcare organizations as well as other stakeholders such as Department of Health and Human Services and World Health Organization should embark on initiating skill and knowledge acquisition programs in regards to multicultural healthcare beliefs. Since diverse cultures possess different beliefs and ideologies on healthcare, both healthcare professionals and healthcare consumers should learn more about the behavior, perceptions and beliefs of other cultures as far as health is concerned. The adoption and implementation of healthcare ethics can only occur if the healthcare professionals understand how other ethnic groups perceive healthcare practices. The skill development and knowledge program should focus on pertinent issues such as. Healthcare professionals such as physicians and nursing practitioners should also undertake diversity training programs to enable them to promote a culture of tolerance to diversity. Diversity training and skills development enable caregivers to attain multicultural competence. Understanding the differences in ethnic groups, religious ideologies, sexual orientation, as well as economic class and their impact on the perception of conflicting medical practices is important in clinical care.
Therefore, healthcare organization should initiate educational programs in which primary caregivers are taught how to observe normative ethics in a pluralist society. For example, the programs should focus on eliminating ethnic-based and religious discrimination, xenophobic attacks as well as stigmatization based on the beliefs of a particular medical approach.\textsuperscript{121} For instance, physicians in the United States and European nations should be taught to understand that not all cultures use Western medicine for treating diseases and conditions. Moreover, health care professionals should also learn how other religions, such as Islam, Buddhist, and Taoism, perceive emerging medical practices like physician-assisted suicide and gene editing.\textsuperscript{122} Healthcare organizations should ensure that both physicians and nurses undergo periodic training and skill development process before they provide clinical care to patients from multi-ethnic backgrounds. Moreover, healthcare organizations should strive to employ health experts who have attained multicultural competence. The physician and nurses should be expected to display knowledge of multiple languages that are spoken in different parts of the world.\textsuperscript{123} Through making multilingualism a prerequisite for entry into the healthcare profession, primary caregivers will develop both intrinsic and extrinsic motivation to learn more about the cultures of the world and their perception of various medical approaches.

Language has brought a great impact on the access to healthcare services both in the hospital-based and home healthcare. The language that healthcare professionals use to interact with the patients has a direct relation to the development of an efficient relation between the patient.\textsuperscript{124} This is because, primary physicians who share similar mother tongue with the patient is likely to develop an intimate relation as opposed to the case where the care giver uses a foreign language. However, healthcare organizations should ensure that physicians and registered nurses acquire multilingualism through learning several languages. For example, if a specific health practitioner is working in a US-based hospital, he or she
should master standard English, and learn other languages such as Arabic, French, Thai, Mandarin, Indian and Korean languages.\textsuperscript{125} This is because the United States of America is multi-cultural societies with cultures from around the globe. Therefore, becoming multilingual can become an important tool for a primary care giver. In case the patient cannot speak a particular second language such as English, the healthcare professional should switch to the appropriate language such as German, French or Arabic.

Although several healthcare organizations have employed language interpreters, the use of multilingual care givers is more beneficial during care giving.\textsuperscript{126} For instance, when a Saudi Arabian health provider interacts with an American citizen, the physician should switch from Arabic to English language so as to boost the understanding between the two parties. The advancement in technology has enhanced the language learning process. Therefore, healthcare organizations can adopt various measures such as the use of online language learning tool. Physicians and nurses should also undertake short language courses that focus on global languages that are currently becoming popular across the globe.\textsuperscript{127} For instance, French, German, Chinese Mandarin, Arabic and East African Swahili languages have gained popularity in the recent years. There has been a tremendous surge in the population of people who speak these languages in the world population. Moreover, English language has become the Lingua Franca of the world. The standardization of English language across the globe therefore shows that every healthcare provider should gain competency in the language. Acquiring linguistic performance and competence in several languages can play an instrumental role in the application of healthcare ethics since the health providers will acquire a channel of communicating and socializing with the patients.\textsuperscript{128}

Acquiring religious competence also shapes the adoption of healthcare ethics in a multi-cultural society. The cultural knowledge programs should also ensure that healthcare professionals, health consumers, government agencies and the local community acquires
knowledge about the religious beliefs of different cultures and how they affect the perception of medical practices. For example, Middle East countries and the American culture have displayed divergent religious ideologies regarding the adoption of healthcare practices. According to the Islamic religion, the occurrence of illness, pain or death is a test from God. Allah is the provider of life and good health. Physicians are only supposed to support God’s work. Islam, which is practiced in Middle East countries, has strict religious doctrines that have tremendously affected the provision of healthcare services. For example, during the holy month of Ramadhan, the faithful embrace fasting and hence does not take oral and fluid medication since they are considered to represent eating food. These religious beliefs usually result in conflict when it comes to providing care in a multi-cultural society. The Islamic religion also requires Muslims to pray five times a day while facing Mecca. The prayer times or Ramadhan can coincide with the time that a primary caregiver is supposed to undertake a particular medical process such as surgery or provision of oral medication. Therefore, when Muslim patients encounter healthcare professionals from Western nations, they face ethical dilemma that triggers conflict. This is because the healthcare consumers will expect that the physicians and primary care givers should understand the religious beliefs and how they affect the provision of healthcare services. Their gaining competence in religious beliefs of different cultures plays an integral role in the implementation of normative ethical behavior in healthcare settings. Islamic healthcare experts should also learn more about the religious beliefs of Western nations as well as the Eastern world. For example, Western countries believe in modern medicine and does not adhere to strict religious doctrines as the Islamic cultures.

The United State, for instance, have embraced liberal views concerning modern healthcare practices such as abortion, gene editing, palliative care and patient-assisted suicide. According to the Islamic beliefs, contemporary healthcare practices such as
physician-assisted suicide is prohibited. The US has been at the forefront of advocating for
the adoption of these emerging medical practices since they symbolize advances in the field
of medicine and disease eradication.\textsuperscript{134} Both healthcare professionals, patients, government
agencies and the masses thus should strive to gain competency in the religious beliefs of
different ethnic groups in a multi-cultural society. Physician-assisted suicide or euthanasia are
strongly prohibited in the Islamic religion since they go against the teaching of Prophet
Mohammed and Allah.

\textit{II. Creating a favorable environment for trans-cultural competence}- Trans-cultural
competence shapes the process of solving ethical problems that arises from the interaction of
different cultures. There is a need to create an enabling environment for the patients, family
members, physicians and nurse practitioners.\textsuperscript{135} Cultural competence enables the effective
solution of ethical dilemmas and conflicts in healthcare. Health professionals in a multi-
cultural health setting should understand the socio-cultural lifestyle of one another and how
they affect the consumption of healthcare services. For example, Islamic cultures in the
Middle East countries, believe in a close-knit family where people are treated as a family and
not as an individual. Therefore, during care giving, family members must be consulted before
undertaking any medical procedure. Family members shape the health decisions that
physicians apply during care giving.\textsuperscript{136} This is in contrast to Western nations where an
individual can easily seek private care without the consent of the family. Therefore,
healthcare professionals should provide a sustainable environment by adhering to the social
norms and cultural practices of a particular ethnic group.

The issue of privacy and modesty is one critical area that has brought conflicts and
ethical dilemmas in a multi-cultural healthcare setting.\textsuperscript{137} Different cultures perceive privacy
and modesty issues differently in regards to healthcare. For example, Middle East countries
adhere to stringent privacy policy due to religious beliefs. Healthcare professionals are
expected to maintain privacy of the patients by ensuring that healthcare services are provided by gender-concordant health professionals. In most cases, female patients are treated by female healthcare professionals. This is beneficial especially when there is a need for a physical examination of a patient of a different gender.\textsuperscript{138} In case there is no gender-concordant healthcare provider, a family member must be present during the performance of a particular medical procedure. Therefore, healthcare providers from non-Islamic nations should understand the issue of privacy when it comes to providing care in a multi-ethnic healthcare setting. Another critical issue that physicians and registered nurses should learn is how different cultures perceive modesty. Although all cultures require healthcare professionals to observe modesty during care giving, other cultures such as the Islamic society adhere to strict dressing conduct.\textsuperscript{139} Female healthcare providers and nurses are expected to dress modestly especially in the presence of a male patient. Religious doctrines require that females wear long dresses as well as head scarfs. Therefore, foreign health professionals who are working in the Middle East countries should ensure that they observe modesty while providing care in a multi-ethnic care setting.

Healthcare organizations facing ethical challenges in a multi-ethnic society should also incorporate open communication within the organization.\textsuperscript{140} Communication plays an instrumental role in building relationships between groups of patients as well as the health professionals and the patients. Physicians and nurse practitioners thus should embrace open communication while interacting with both the patients as well as other stakeholders in the organization. Embracing open communication should be characterized by the elimination of hierarchical barriers between senior and junior health professionals. The patients should be in a position to readily interact with the nurse leaders as well as senior management of the organization. For example, in the case where there is a conflict of interest about differences
in ethnic beliefs, the incident should be swiftly communicated to the healthcare leaders following the available protocol.\textsuperscript{141}

Failure to disseminate the information can have a devastating impact on the health of the patient. For instance, if a patient has requested the hospital to conduct a physician-assisted suicide, physicians should communicate the information to all the relevant stakeholders such as the hospital management, nurse leaders and even the family of the patient.\textsuperscript{142} Therefore, the clinical team will thus decide to either conduct the medical procedure depending on the hospital’s policies on patient-assisted suicide. The law can also play an instrumental role in ensuring the provision of patient-centered care. Healthcare professionals hence should ensure that they incorporate reliable communication channels such as face to face, internal memos, charts, telephone calls, as well as computer-mediated platforms such as emails and teleconferencing. The aim of the communication channel should be to initiate a fast and reliable communication system that boosts the dissemination of information from one party to another.\textsuperscript{143}

Multicultural clinical settings also face the challenge of the language barrier. The presence of patients from different ethnic backgrounds can hinder effective communication due to the lack of a common language to use. Healthcare organizations, when operating in a multicultural society, should also use standardized languages such as English that have become a Lingua Franca in the world.\textsuperscript{144} The use of standardized language can play a critical role in enhancing the interaction between individuals of diverse cultures. In most cases, even non-English speaking countries have recognized the significance of the English language in socialization. Therefore, there has been an increase in the population of English speakers. In the case that a patient only understands the native language, healthcare professionals should employ interpreters who can assist in explaining the clinical care policies to the patients.\textsuperscript{145} For example, contemporary healthcare organizations should hire interpreters who are
eloquent in various languages such as Portuguese, Arabic, French, Germany, English, Thai, as well as even Mandarin. Such measures can create an enabling environment for embracing effective communication hence help in addressing the ethical challenges of a multicultural society in clinical care settings.

2.b.ii. 3. Adoption of Diversity-Centered Leadership

Just like in other organizations, leadership can also enhance the adoption of ethical behavior in healthcare. The presence of a multi-cultural healthcare setting has a critical impact on the adoption of normative ethics. This is due to the fact that every culture has its own cultural beliefs, customs and practices that affect how it perceives modern healthcare practices. However, healthcare organizations as well as relevant stakeholders such as government agencies and global health organizations should embrace diversity-centered leadership. The leadership style should be focused towards dealing with cultural diversity and how it can affect implementation of ethical behavior. Healthcare stakeholders should embrace transformative healthcare leadership that is aimed at fostering health ethics in a multicultural health setting.

I. Embrace transformational leadership - Transformative leadership is the hallmark for success in an organization. Healthcare organizations should therefore recognize the significance of adopting a transformative leadership to facilitate the adoption of ethical behavior in a multicultural society. Another important way of eradicating the ethical challenges in a multicultural clinical setting is to adopt and implement diversity-oriented leadership. Healthcare organizations should encourage a patient-centered form of leadership that is aimed towards fostering the adoption of normative ethics in a multi-ethnic society.

Since leaders are the role models of employees, physician and nurse leaders should spearhead the adoption policies that ensure the observation of normative ethics. Nurse leaders, for instance, should undertake diversity-centered leadership by ensuring that each team member
understands the significance of diversity in the quality of healthcare. Leaders in the field of healthcare should lead by example by incorporating diversity-centered leadership. This form of leadership can be achieved through embracing transformative leadership style. In addition to focusing on adopting healthcare ethics in a multi-ethnic clinical setting, leaders should spearhead the adoption of normative ethics regarding the culture of a particular health consumer. Hence the physician and nurse leaders should ensure that they acquire comprehensive information about the background of each patient within the healthcare setting. The contemporary healthcare setting is characterized by patients from diverse cultures, religious beliefs, gender, and level of education. For example, collectivist cultures such as Middle East countries have different approaches to crucial medical practices as opposed to individualist cultures such as Western civilization.

II. Make diversity-centered leadership decisions- Healthcare organizations have, over the years, embraced strategies aimed at addressing the ethical challenges that occur in multicultural healthcare settings. The presence of multicultural societies in modern society has influenced the implementation of ethical behavior as well as the provision of healthcare services. This is because, in a multi-ethnic society, various challenges such as differences in religious beliefs, racial composition, sexual orientation, and gender shape the implementation of normative ethics. Since the ethical behavior plays an instrumental role in ensuring patient-centered care, there has been an increasing need to develop ways of eradicating the ethical challenges of multi-ethnic society within clinical settings. Adopting ethical behavior creates an enabling environment for building an effective relationship between health professionals, family members and the patient. Implementing tolerance to diversity, common morality, and training health professionals on multicultural competence can help in responding to the ethical challenges of a multicultural society in contemporary clinical setting. Global countries such as the United States has in recent years, embraced
liberal views in regards to controversial medical practices ranging from abortion, euthanasia as well as stem cell research. The healthcare leaders should, therefore, handle a patient depending on his or her cultural background. The beliefs of the patient must not conform to the beliefs of the healthcare organization for the patient to receive high-quality care. For instance, in the case that a US national has visited Saudi Arabia to seek advanced medical care, nurse leaders should ensure that the attending nurses show respect to the views of the foreigner in regards to divisive medical practices such as gene editing. The leader should ensure that the nursing team understands the culture of the foreign patient. Therefore, adopting a diversity-oriented leadership that is characterized by transformative leadership can eradicate the ethical challenges that have been experienced in a multicultural society.

2.b. ii. 4. Implementation of Favorable Healthcare Ethical Policies

Another way that can be used to eradicate the ethical challenges of a multicultural society in contemporary clinical settings is to pass laws and policies that prohibit various forms of discrimination and stigmatization. Policies that promote tolerance to diversity can help in enhancing the implementation of bioethics in the society. One of the major challenges that hinder the application of normative ethics in a pluralist culture is the presence of diverse religious and socio-political views on controversial healthcare practices such as abortion and withdrawal of life support in end-of-life care. Moreover, in a multi-ethnic society, differences in the level of education, income as well as gender can cause conflicts of interest during the provision of healthcare services.

1. Adoption of common morality- Healthcare organizations should adopt a policy of common morality in their operations. The healthcare service providers should develop provisions that ensures that every health stakeholder such as primary care givers, physicians, health consumers and health agencies embrace the ideology of common morality. The adoption of common morality as a part of universal morality has played a significant role in
the implementation of normative ethics across the world. Common morality plays an instrumental role in highlighting the globally acceptable standards of normative ethical behavior. Healthcare organizations have recognized the desire to implement the various elements of common morality. Universal morality has affected the provision of healthcare services across the globe. According to common morality, people should not commit murder, cause harm or suffering or participate in violence. Moreover, the masses in the society are expected to obey laws and also help people who are in danger. Common morality also involves the observation of ethical standards such as integrity, justice, kindness and non-maleficence. Moreover, the implementation of the classical societal norms has also been used by some cultures to ensure the implementation of normative behavior. The religious rites involve taking oath to adhere to the ethical standards required by the healthcare practice. Therefore, healthcare stakeholders such as health organizations, patients, health professionals and the public should ensure that they implement common morality during the provision of healthcare services both in the hospital-based and home healthcare settings. Global healthcare organizations should adopt health policies that require the adoption of common morality as a culture in the healthcare centers. The adoption of common morality creates a sustainable environment for the application of effective ethical behavior and policies.

Healthcare organizations should also adopt policies that ensure the creation of a viable communication environment within a particular healthcare setting. The policies should highlight the provisions of language assistance to patients with language barriers. In a multicultural society, language barrier becomes one of the most important hindrances to effective communication. Therefore, health organizations should develop language assistance programs that can help health consumers from foreign nations. For example, hospitals should hire language interpreters who are fluent in various languages such as Arabic, English,
German, French, and Mandarin among others.\textsuperscript{163} The policies should state clearly how the health professionals should interact with patients from diverse language speaking cultures.

\textit{II. Adoption of diversity-centered laws and policies} - Healthcare stakeholders such as United States Department of Health and Human Services, American Nurse Association, patients, and the masses should spearhead the adoption of stringent laws and policies that prohibit health professionals from practicing discrimination or prejudice.\textsuperscript{164} The laws should highlight the measures to be taken in case the patient has a divergent opinion in regards to a particular disease intervention method. Moreover, the policies should enforce the observation of the fundamental elements of normative ethics such as consent, beneficence, respect for autonomy, and non-maleficence.\textsuperscript{165} The implementation of the laws and policies that regulate the observation of normative ethics in a multi-ethnic society is instrumental in the process of providing quality care. This is because the presence of laws will enable health practitioners to commit to incorporating ethical behavior in patient care. Moreover, the laws and policies should highlight the specific disciplinary measures that can be undertaken against primary caregivers who participate in any racial or religious-based discrimination in the clinical care setting.\textsuperscript{166}

The ethical challenges of multicultural society in clinical settings have played a significant role in modern healthcare. The emergence of radical and controversial medical practices such as physician-assisted suicide, abortion, gene editing, stem cell research as well as withholding of life support in end-of-life care has brought a tremendous effect among health consumers.\textsuperscript{167} Since there are different views and perceptions of the healthcare practices in a culturally diverse society, there is a need for collective action to ensure the elimination of ethical challenges in clinical settings. Healthcare experts should also avoid ethnic-based discrimination or stigmatization when providing care in a multicultural clinical setting.\textsuperscript{168} Physicians and advanced nurse practitioners should focus on understanding how
other cultures perceive medical approaches that elicit conflict of interest. Stakeholders should develop a multi-dimensional approach characterized by the adoption of a culture that promotes tolerance to diversity, transformational and diversity-centered leadership, open communication, and laws in clinical care settings.

Healthcare organizations and its stakeholders as federal health agencies should develop policies and principles that seek to respond to the ethical challenges of diverse cultural background on healthcare delivery. Another vital way of facilitating the observation of normative ethics in a multicultural healthcare setting is to adopt the ethical principles into the multicultural healthcare environment. Healthcare professionals should understand the relationship between ethical principles and the adoption of normative healthcare ethics. Initiating the ethical principles within the different aspects of a multicultural society assist in the implementation of normative ethics.

Stakeholders in the field of healthcare such as federal agencies and healthcare organizations should adopt and implement policies that seek to promote continuous engagement, improvement and accountability within a healthcare setting. All these measures are aimed at creating an enabling environment for the promotion of ethical behavior and how they can be used to respond to the challenges of diverse-cultures on healthcare delivery. According to the principles of normative ethics, healthcare professionals should ensure that they provide care at the best interest of the patient. The main focus of healthcare organizations should be to provide patient-centered care that results in improve the health of the patient. Therefore, to ensure the promotion of ethical behavior in a multicultural culture, health professionals should ensure every patient acquires globally acceptable care irrespective of the cultural or cultural background. Multi-ethnic health setting is usually characterized by variations in races, cultures, level of education, socio-economic status, religious ideologies, gender as well as sexual orientation. These differences present a lasting challenge to the
health professionals and registered nurses, resulting in ineffective care. For instance, religious beliefs of Islam and Christianity has led to strong opposition of modern medical practices such as withholding of life support in end-of-life care as well as physician-assisted suicide.

Hence, in the case that a healthcare professional interacts with a patient whose cultural beliefs does not support withdrawal of life support during the end of life care, the patient should still strive to give the best medical care that involves the adoption of the normative ethical standards such as beneficence and non-maleficence.\textsuperscript{174} Moreover, healthcare organizations should also aim to provide care that serves the interest of the patient even if the patient is from a minority racial group or social class. Underprivileged people from minority cultures have faced discrimination and prejudice during the provision of healthcare services. Healthcare professionals, in their desire for the adoption of normative ethics, should apply the principle of beneficence when caring for patients from diverse cultures.\textsuperscript{175} The physicians and nursing should focus on the goal of providing healthcare that works at the best interest of the patients within a multicultural healthcare setting. Through providing patient-centered care to individuals from different cultural, religious, and socio-economic backgrounds, healthcare professionals can find a chance to adopt normative ethics in a multicultural society. This is because patient-centered care creates an effective relationship between the patient and the primary care provider.\textsuperscript{176}

This is another important ethical principle in the field of healthcare. Healthcare professionals and nurse practitioners are required to give the patients the right to accept or refuse a particular disease intervention method. Healthcare professionals should provide care after acquiring the consent of the patient. The principle of autonomy has become a great issue due to the adoption of controversial medical practices that have elicited mixed reactions from the patients, governments, as well as the general public. For instance, the issue of withholding or withdrawing life support in end-of-life care has become a crucial issue in modern
healthcare. Normative healthcare ethics can exist in a multicultural health setting when the health professional knows and respects how different patients perceive medical practice. For example, the physician should inquire from the patient and the family, whether to withhold or withdraw life support in case the patient was suffering from a terminal illness. When healthcare organizations provide a sustainable environment through respect to autonomy, they will be applying normative ethics in a multicultural society.\textsuperscript{177}

Although various ethnic groups may value the family values as opposed to the respect for autonomy, the healthcare professionals should ensure provide care in respect to the normative ethical standards which outlines the acceptable measures of providing care in a culturally diverse healthcare setting. Another way that healthcare ethics can occur in a multicultural society is when physicians respect the decision of patients with a low level of education and low socioeconomic status. For example, patients with little education may not understand the need for Western medicine as well as complex medical practices.\textsuperscript{178} Healthcare professionals hence, should not force such individuals with medical practices that the patients do not understand since it is unethical.

Healthcare organizations should also adopt policies that focus on ensuring that healthcare consumers acquire justice in healthcare. Justice in healthcare is characterized by equitable distribution of healthcare resources that increases the access to high quality healthcare.\textsuperscript{179} According to the principles of normative ethics, healthcare professions should create a setting that is focused on enhancing access and affordability of healthcare. The ethical value posits that patient-centered care should be available to all people irrespective of their cultural and religious beliefs, socio-economic status, gender, and sexual orientation. Health organizations hence can adopt healthcare ethical values through ensuring equal distribution of health services. Diversity should not prevent the provision of high-quality care. Physicians and advanced practice nurses should focus on providing just and ethical
responsibility in the presence of heterogeneity. For example, when a Middle East-based physician is providing care to both local and foreigners, the health professional should ensure that there is equal distribution of health services. The health professionals should not practice either cultural, religious, or gender-based discrimination during the process of caregiving.

Equal provision of healthcare services shows that the healthcare organization observes normative healthcare ethics. This is because the provision of healthcare services should be focused on ensuring positive health outcomes among the health consumers despite of their cultures. Hence gaining knowledge of the different cultural aspects such as language, social status, level of education, and religious beliefs can affect the adoption of normative healthcare ethics. Healthcare ethics can exist in a multi-ethnic society if there is a collaborative action between healthcare organizations and health consumers. Healthcare organizations should therefore adopt policies that ensure that health consumers get justice during care giving.

Healthcare stakeholders should also embrace policies that prohibit non-maleficence in order to protect safeguard the life and health of the patient. The normative ethics gives priority to the safety of the patient. According to the principle of non-maleficence, healthcare professionals should first focus on preventing any harm that may come to the patient during caregiving. This is because the occurrence of injury or error during treatment can cause a terrible impact hence worsen the condition of the health consumer. Healthcare professionals can, therefore, adopt the normative ethical care through preventing any harm that can occur to the patient within the multi-ethnic care setting. One of the factors that affect the occurrence of healthcare-based harm on the patient is biasness, discrimination or negative attitude towards the culture, sexual orientation, personality, gender, and religious belief of the patient. For example, the sexual minority communities have experienced discrimination due to their sexual orientation. Hence a healthcare professional tasked with
providing care to both heterosexual and the LGBT group should focus on preventing any harm on the patients.\textsuperscript{186} Health professionals should not attend to the sexual minority community with hatred and prejudice since it can result in low-quality care.\textsuperscript{187} Health organizations should also avoid non-maleficence when giving care to health consumers from different religions, such as Islam, Christianity, and Buddhism. Therefore, physicians and nurse practitioners should adopt strategies aimed at preventing harm to patients from different cultures.\textsuperscript{188} Healthcare professionals should adopt the policy of non-maleficence to address the challenges that result due to the presence of a multicultural healthcare setting.

2.c. Conclusion

Home healthcare in Saudi Arabia has brought a tremendous impact on the health sector. The home-based care enables the primary caregiver to provide care in a holistic and patient-centered environment characterized by the presence of a health professional and the family members. The home healthcare is multi-dimensional care since it incorporates both the role of the primary caregiver as well as the family members. Through the coordination of care between the primary caregiver and the close relatives of the patient, HHC delivers care that satisfies the needs and preferences of a patient. HHC has been critical in the management of chronic illness and mental disorders among the aged in Saudi Arabia. The assistance of the Saudi government has improved the implementation of home healthcare through the provision of funds as well as training of the primary caregivers. The health program has highlighted the role of the home setting on the health of patients. Although the hospital care setting is essential in the provision of care, home healthcare presents a more sustainable environment that results in high quality and customized caregiving. The government, therefore, should create awareness to ensure that every region within the Kingdom embraces the ideology of home healthcare. Through collective action, primary caregivers, relatives, the government, and the local community can foster patient-centered care in Saudi Arabia.
The adoption and implementation of favorable bioethical policies within a multicultural society can play an integral role in responding to the challenges of a multi-ethnic society in regards to the adoption of ethical behavior. The challenges presented by multicultural healthcare setting such as variations in religion, gender, language, level of education, and socio-economic status hinders the implementation of normative ethics in a multicultural society. However, the application of ethical has faced challenges due to different beliefs of the various healthcare practices. There are different methods in which healthcare organizations can ensure the implementation of normative ethical care in a multi-ethnic society. Initiating strategies such as; common morality, cultural competence and tolerance to diversity can play a critical role in enhancing the adoption of normative ethics in healthcare. Stakeholders in healthcare such as the Department of Health and Human Services, healthcare organizations, patients and the general public should embrace a collective action aimed at responding to the challenges of diverse cultural background on healthcare delivery.
Endnotes


CHAPTER 3: HHC AT THE START OF LIFE

Home Healthcare is also prevalent at the start of life as the number of women who prefer to give birth at home have increased. As such, understanding the application of bioethics to the start of life is crucial.

3.a. Critical Role of Consent in Decision-Making

The modern healthcare setting is characterized by the need to observe patient autonomy. This has promoted the incorporation of informed consent during the decision-making process.\(^1\) Clinical ethics involves the adoption of ethics case consultation programs that are aimed at solving the ethical and moral dilemmas that health professionals face during caregiving. In most cases, clinical ethical conflicts occur during the critical care stages, such as the start or end-of-life care.\(^2\) Health care challenges that occur during prenatal and neonatal care as well as the aspect of withholding and withdrawing life support during the end-of-life care necessitates the adoption of ethics consultation.

Through undertaking case ethics consultation, ethics committee, health professionals, and patients can find the most appropriate solution to a particular health care ethical issue. Ethics consultation enhances decision making in providing an avenue for solving ethical dilemmas that are encountered in clinical care settings.\(^3\) As an essential element of clinical ethics, ethics consultation has brought a significant impact in the process of making collective clinical decisions since it allows for the patients, physicians, and the ethical team to find an inclusive solution to the ethical issues that arise during caregiving. Ethics consultation embraces multi-dimensional ways of handling various cases.\(^4\) The major ways of conducting case consultation include; the Four topics method, the CASES approach, and the Process and Format method. All these techniques are aimed at finding an effective solution that can shape the decision-making process. The role of the patient in caregiving has evolved from a passive to an active player. As opposed to the past in which the attending physician made all vital
decisions, there has been an increasing need to foster patient participation in clinical decision making.\footnote{5}

Patient participation is undertaken through information disclosure, followed by informed consent. In such a situation, the patient can choose to accept or decline a specific intervention method after deliberating with the health professionals and the ethics consultation committee. Once the patient and primary caregiver encounter an ethical dilemma, ethics consultation occurs that provides valuable information that will guide the patient or next of kin to make provide informed consent and hence make effective clinical decisions. The ethics consultation process enables the ethical committee and primary caregivers to embrace patient engagement.\footnote{6} In case the patient is suffering from mental or communication problems, the family members are engaged in the consultation process to find an ethical solution that will trigger the provision of voluntary consent. Ethics consultation allows for the integration of ethical principles and behavior that enhances informed consent. The main aim of an ethics case consultation is to find out the most suitable solution to an ethical problem and also to improve the patient-physician relationship. Informed consent enables health professionals and the ethical team to adopt a more inclusive healthcare intervention. The ethical consultation team should ensure that the patient or family representative understands the medical information that is related to a particular health care condition. Healthcare professionals and global healthcare bodies, such as the Center for Clinical Bioethics, have adopted diverse strategies focused on creating an enabling environment for inclusive decision making.\footnote{7} Patient participation in clinical care has, therefore, changed the perception of informed consent.

Unlike in the traditional health care setting in which informed consent was associated with signing a form, informed consent is now perceived to be a process in which health care consumers undergo deliberation with a health professional to adopt an effective intervention
method. In essence, the healthcare consumer and the physicians undertake a collective decision-making process where the physician discloses all relevant information and guides the patient in making a patient-centered clinical decision. One critical element of informed consent is patient competency in regards to the available intervention techniques. Before providing free consent, the patient should be able to comprehend all the underlying factors that affect a particular treatment option. Ethics consultation, therefore, can nurture informed consent during the decision making by ensuring that the patient understands the significance of a specific intervention technique before making a formal agreement or disagreement in the clinical care setting.

The need for informed consent in modern clinical care arises due to the changes in healthcare delivery. The role of the patient has changed over the years as healthcare consumers strive to fight for patient autonomy. Healthcare stakeholders, such as primary caregivers and ethicists, have adopted measures aimed at solving ethical problems. Informed consent allows the patient to willingly accept or decline a particular medical procedure after acquiring sufficient information regarding that intervention method. The ethics consultation process boosts the capacity of patients to provide informed consent during clinical decision making. For example, when the patient has shown displeasure with a particular treatment method, the primary caregiver and ethics consultation committee can call for an ethics consultation meeting to analyze the case. By presenting a viable solution to the ethical problem, the patient will be able to participate in the final decision-making process that will shape the specific intervention method that should be implemented in caregiving. The need for informed consent, therefore, arises from the desire to involve the patient in health care decision making. In other words, informed consent shows that the patient has comprehended the medical information that was provided during the information disclosure stage. There are different steps that a patient undergoes before signing the consent form. The
physicians, nurses, and the ethical team should ensure that the patient has shown competency in regards to the provided health care information. Moreover, the patient should understand the benefits and limitations of each intervention method before making a voluntary consent. Giving informed consent thus means that the health care team has fully engaged the patient in clinical care.

3.a.i. The Process of Giving Informed Consent

Ethics consultation facilitates the process of identifying, analyzing, and solving ethical conflicts. Therefore, the ethics consultation process allows patients to provide informed consent that contributes to effective decision making within the clinical care setting. Informed consent occurs in three critical processes:

3.a.i. 1. Information Disclosure

This is the initial stage of seeking informed consent. The health professional must provide all essential information depending on the patient’s medical history, diagnosis, and prognosis. Both the registered nurses and attending physicians are expected to avail of information regarding the existing healthcare interventions that can be undertaken to improve the health of the patient. For example, if the patient has a chronic and terminal illness that will eventually result in death, the physician is expected to disclose such information as well as the available healthcare techniques that can be used to enhance the life of the patient. For example, the patient can be admitted to hospice or home-based care. Moreover, the physician should provide information on the benefits and limitations of both withholding and withdrawing life support. In this stage, the healthcare professional must ensure that the patient acquires valuable information regarding the healthcare condition, diagnosis, and patient-centered intervention techniques that can be adopted during caregiving. Information disclosure plays a pivotal role in enhancing decision making in clinical ethics. The provision of informed consent has a direct impact on the decisions that the health care professional and
the patient adopt in clinical care. Through disclosing crucial medical information such as prognosis, diagnosis, and possible intervention methods, physicians allow the health care consumers to gather vital information that shapes the final decision. Information disclosure enables the patient and the attending physician to deliberate on controversial medical procedures. If the patient does not know the underlying factors that affect the prevalence of a particular health condition, the physicians have the chance to provide an in-depth explanation. This is because healthcare consumers, in most cases, do not possess comprehensive knowledge about the diseases as well as their respective intervention methods.\textsuperscript{15}

By undertaking information disclosure, health professionals also acquire the opportunity to discuss the various intervention techniques together with the patient. The patient also provides his or her opinion in regards to a critical intervention such as gene therapy. Informed consent promotes shared decision making that enhances the quality of care. Therefore, by undertaking ethics consultation and collective decision making, physicians can achieve the goals of clinical ethics. Hence, it is upon the physicians and advances practice nurses to disclose all the vital information that surrounds a particular health care condition. By undertaking information disclosure, the patients learn more about the disease, the causes, prevalence, and treatment regimen. Information disclosure further creates a bond between the physicians and the patient. The process act as a prerequisite to generating informed consent in clinical care settings.\textsuperscript{16} During the information disclosure process, the healthcare professional should ensure that the patient is emotionally prepared to receive the information. In other words, the physician should be focused on ensuring that the patient gains knowledge about a particular healthcare condition or mental disorder.

In most cases, information disclosure should be undertaken during a face-to-face meeting with the patient or a group of patients suffering from a similar disease. Another
factor that physicians should consider is the setting of information disclosure. Physicians should meet with the health consumers in a unique healthcare setting that can improve the emotional wellbeing of the patient. The resident physician must ensure that the patient acquires concise and detailed information regarding the prognosis, diagnosis as well as the various intervention strategies that can be implemented during caregiving. For example, in the case *When Physicians and Surrogates Disagree about Futility*, the attending physicians should disclose medical information to Mrs. Smith’s daughter since Mrs. Smith has been admitted to the critical care unit and hence cannot be involved in the process of generating informed consent. The physicians disclose information regarding prognosis and diagnosis, such as the presence of long QT syndrome, severe brain damage, kidney failure as well as several infections. Moreover, the physicians should inform Mrs. Smith’s daughter that continuing aggressive medication is likely to become futile since the patient has been diagnosed with a terminal illness that can easily result in death.

During the information disclosure stage, healthcare professionals should also provide information regarding the possible intervention methods that can be adopted during clinical care. For instance, in Mrs. Smith’s case, the physicians can provide information on the benefits and limitations of conducting the withdrawal of life support care. Since Mrs. Smith is likely to die from severe brain damage and long QT syndrome, the health experts can recommend withdrawal of life support since it is medically futile to continue with aggressive and invasive care that causes more harm than good to the patient.

3.a.i. 2. Assessment of Competency of the Patient/Surrogate Decision Maker

After the information disclosure stage, the next step that is critical in the provision of informed consent is the assessment of the competency of the patient. The physicians and the ethics consultation team should ensure that the patient or family representative comprehends the healthcare information regarding a particular case. For instance, in Mrs. Smith’s case,
her 20-year-old daughter should act as the surrogate decision-maker since Mrs. Smith is unable to comprehend the medical information; therefore, cannot provide informed consent. Competency of the patient or next of kin is critical since it will shape the decision-making process. Assessment of whether the patient has comprehended the information plays a crucial role since it helps in identifying patients who are not competent. Health consumers with severe health conditions such as terminal illness may not be able to understand the information provided by the health care team. In such cases, a surrogate decision-maker like a family member can be used to provide informed consent. A patient who understands the information that has been disclosed is likely to make critical decisions that will guide the treatment process. Since Mrs. Smith’s daughter is an adult that can make a sound decision about the health of her mother, she is competent enough to participate in the decision-making process. In case that the patient is unable to give informed consent due to underlying mental disorder or a communication problem, the physicians should use surrogate decision-makers such as close relatives as well as the ethical consultation team. Healthcare professionals, such as physicians and patients, encounter ethical challenges while adopting different intervention methods. Differences in cultural, religious, and social status affect the perception of health intervention methods. For example, physicians have faced a challenge during the provision of end-of-life care to health care consumers with terminal or chronic illness. Ethical consultation, therefore, uses a multidimensional approach that is aimed at ensuring that each participant fully engages in the consultation meeting.

The competency of the patient is a critical element in the provision of informed consent. The patient must be in a position to understand all the essential information regarding the nature of the intervention method as well as the impact of the caregiving process on the health and welfare of the patient. Competency moreover allows the patient to provide voluntary consent without any form of persuasion. Generally, parents are perceived
to be able to provide free consent since they can comprehend all the underlying factors that affect a particular medical procedure. For example, if the resident physician and advance practice nurses want to conduct surgery, an adult patient can provide voluntary consent before the procedure is undertaken.

However, some factors can hinder competency during the provision of informed consent. The presence of mental disorders and communication problems can prevent adults from providing free consent. In such cases, the patient is assisted by a surrogate decision-maker such as a family member or home caregiver. Children, on the other hand, cannot effectively exhibit competency during collective decision making. The parents, therefore, are expected to give consent on behalf of their children. However, some children can be allowed to give consent depending on their age and communication ability. Comprehension, therefore, plays a central role in the process of decision making in clinical care. It enables patients to understand the significance of a particular medical procedure before choosing to either accept or decline the intervention method. Competency hence perceives informed consent as a process and not just the act of signing a health agreement form.

3.a.i. 3. Free and Voluntary Consent

The final element of informed consent is to provide free and voluntary informed consent. The patient should give free consent without any form of coercion. After understanding the relevant information about the prognosis, diagnosis, and intervention technique in regards to a particular case, the physician should then allow the patient or family representative to make a final decision. The final stage involves either declining or accepting a suggested healthcare intervention. The patient or family representative should be allowed to decide after deliberating with the physicians or the ethics consultation team. In regards to Mrs. Smith’s case, Mrs. Smith’s daughter should be allowed to either accept or decline withdrawal of life support at the end-of-life care. According to the physicians
attending to Mrs. Smith, it is medically futile to continue withholding of life of the patient using advanced technological equipment such as mechanical ventilators. However, the patient’s daughter believes that healthcare professionals should not withdraw the life support machine to extend the life of her mother. The presence of divergent views on withholding and withdrawing of life support in Mrs. Smith’s case warrant the involvement of the ethics consultation committee. However, Mrs. Smith’s daughter should be allowed to make the final decision on the best intervention technique that healthcare professionals should adopt in the process of providing end of life care to the patient. After selecting the ideal healthcare intervention procedure, the patient or the family representative should then proceed to sign a consent form before the physicians embark on the caregiving process.

3.a.ii Principles of Informed Consent and Impact on Clinical Ethics

There are fundamental principles that guide the implementation of informed consent. The principles of seeking the patient’s consent play a vital role in the incorporation of ethics consultation and informed consent in clinical decision making. The main models of informed consent include justice, beneficence, and patient autonomy.

3.a.ii 1. Beneficence

The ethical principle of beneficence argues that physicians and nurses should adopt health interventions that bring maximum benefit to the patient. In essence, physicians and registered nurses should strive to focus on improving the welfare of the patients. The main purpose of treatment should be for the patient to get healed. Hence physicians should focus on healing the patient rather than undertaking aggressive and invasive treatments such as surgery and the use of mechanical ventilators. Therefore, healthcare professionals should ensure that they divulge medical information that can enable the patient to choose the intervention method that can promote the quality of healthcare services. Healthcare
professionals should be at the forefront of promoting the adoption of intervention or medical procedures that satisfies the goals of beneficence.

Since the ethical principles believe in the provision of healthcare with maximum benefits and minimum risks to the patient, it has elicited mixed reactions on the role of life support machines in beginning and end of life care. The advancement of biomedical technology has led to the incorporation of high quality and sophisticated medical equipment that can be used to support the end-of-life care. Patients admitted to an intensive care unit can stay alive for several months and years due to sophisticated clinical equipment such as mechanical ventilators and incubators.

One of the ethical conflicts that have arisen is whether to use advanced biomedical technology to extend the life of terminally ill patients. Although the relatives of patients in critical care units prefer withholding of life support during the provision of health care services to patients with a terminal illness, some physicians have supported the withdrawal of life support machines due to the ideology of medical futility. According to the proponents of withdrawal of life support in end-of-life care, it is needless to continue with invasive and complex treatment if the patient will not recover from the terminal illness. Moreover, the use of aggressive treatment techniques such as aortic valve replacement is likely to cause infections that may result in the death of the patient within the critical care units. Beneficence seeks to

It is, therefore, imperative to seek the informed consent of the patient or family representative. Seeking consent enables the patient to acquire the intervention method that can bring maximum benefit in regards to the existing healthcare condition. The principle of beneficence enhances the decision-making process by creating an enabling environment for the provision of informed consent. During the deliberation with the healthcare professionals and the ethics consultation team, the patient acquires the opportunity to select the best
healthcare intervention technique that can improve his or her health and welfare. During decision making, healthcare professionals have to balance the benefits and risks of a particular intervention method before its adoption in clinical care.³⁵

3.a.ii 2. Patient Autonomy

According to patient autonomy, healthcare professionals should observe the healthcare rights of patients. Fundamental ethical rights such as the acquisition of high-quality care, non-discrimination, and disclosure of information.³⁶ Patient autonomy shows that healthcare professionals respect the needs and rights of healthcare consumers. Moreover, patient autonomy also dictates that health professionals obey the rights of the vulnerable such as the mentally ill and individuals with communication problems. Unlike in the past, the modern healthcare system has promoted the participation of patients in clinical care. One of the ways in which physicians and other caregivers can undertake inclusive care is to observe patient autonomy. Patient participation during caregiving is achieved by building a formidable relationship between the patient and the healthcare professionals.³⁷ Various global healthcare bodies such as the World Health Organization and Centers for Disease Control and Prevention have been at the forefront of fighting for the observation of clinical ethics in healthcare settings. Healthcare professionals must observe human dignity that involves embracing the healthcare intervention method that can provide maximum benefit to the healthcare consumer. Stakeholders in the field of healthcare have recognized the importance of patient autonomy.

Healthcare professionals such as physicians, advanced practice nurses, and ethics consultation committees have, therefore, adopted a multi-dimensional strategy that is aimed at ensuring the implementation of patient autonomy.³⁸ The stakeholders are responsible for developing the framework for implementing patient autonomy. For example, the guidelines expect physicians and registered nurses to observe patient autonomy in clinical care settings.
It is the ethical obligation of physicians to ensure that patients participate in the clinical decision-making process. Inclusive decision making enables the patient to give his or her opinions in regards to a particular healthcare procedure. In the case that the patient is competent and has understood the information provided by the healthcare provider, he can quickly offer a concise and beneficial consent to a specific intervention method.

3.a. ii. 3. Justice

The third principle that guides the implementation of informed consent in clinical ethics is justice. The clinical ethics model focuses on access to patient-centered clinical care. One of the issues in contemporary healthcare is inequality in accessing high-quality clinical care. Healthcare consumers have faced barriers when seeking high-quality healthcare. The presence of racial, ethnic, and gender-based discrimination in clinical care has widened the health inequality gap. For instance, patients from dominant cultural groups can easily access patient-centered care as opposed to healthcare consumers from minority cultures such as African Americans and immigrants. The element of informed consent, therefore, plays an integral role in eliminating the barriers that are associated with access to clinical care.

Informed consent allows the patient only to accept the medical procedure that will ensure high-quality clinical care. Irrespective of gender and cultural background, patients provide informed consent that ensures they achieve the best possible care. Healthcare professionals are, therefore, expected to observe justice so that every patient acquires adequate care. Justice is an element of clinical ethics; hence it has a direct relationship with informed consent. During the process of seeking informed consent, the healthcare process should divulge important information to the patient irrespective of the cultural background, socioeconomic status, or gender. This is because, when patients acquire unbiased information, they will be capable of making efficient healthcare decisions that will enhance their health. Patient participation in clinical decision making depends on the information that
healthcare professionals provide in regards to the patient’s medical history, diagnosis, and possible intervention methods.\textsuperscript{43}

3.a. ii. 4. Non-Maleficence

Another fundamental principle in clinical ethics is non-maleficence. According to this clinical care model, health care professionals are expected to focus on preventing any health risk or harm before initiating a particular intervention method.\textsuperscript{44} The goal of non-maleficence is to ensure that the safety of the patient is guaranteed during clinical care. Primary caregivers, such as physicians and nurses, are thus expected to adopt health interventions that cannot pose a health risk to the patient. The model of non-maleficence is vital during the provision of informed consent since it enables the patients and healthcare experts to know the medical procedures that can cause more harm than good to the patient’s welfare.\textsuperscript{45}

In other words, non-maleficence supports the ideology of terminating care in case of medical futility. For instance, in Mrs. Smith’s case, continuing with surgeries and withholding of life support machines goes against the ethical principle of non-maleficence since such processes cause more harm than good. According to the primary caregivers, Mrs. Smith has suffered from different health complications involving congenital heart failure and brain damage. She is likely to die in the intensive care unit. However, the patient’s daughter believes that the physicians should apply any medical procedure that can extend the life of her mother. The case, therefore, represents a classic ethical dilemma scenario in which one party believes in medical futility while the patient’s family is interested in continued aggressive care.\textsuperscript{46} The principle of non-maleficence can be used to find a balance between the need to provide treatment and the need to prevent health risks that are associated with complex medical procedures in clinical care settings.
3.b. HHC, Prenatal Care & Neonatal Care

3.b.i Importance of Healthcare Stakeholders

In modern healthcare settings, health professionals have recognized the need to create a sustainable health environment. Healthcare stakeholders, including registered nurses, obstetricians, counsellors, federal government agencies and family members have different ethical and moral duties that they should undertake to ensure the provision of efficient prenatal and neonatal care. Prenatal and neonatal care requires collective action among the stakeholders to achieve the health goals and objectives. Prenatal care ensures that the fetus undertakes normal growth and development. Moreover, during prenatal care, health professionals prevent any disease or genetic conditions that may endanger the life of the fetus. High-risk issues such as preterm birth and low birth can be prevented by the adoption of prenatal care. Neonatal care, on the other hand, also ensures that neonates acquire individualized care that can help in the prevention of health risks such as congenital disabilities and other diseases such as neonatal jaundice. During the provision of neonatal care, pediatric nurses play an essential role in ensuring that the infants acquire acute care that can prevent or treat the beginning of life diseases.

The health professionals, in collaboration with other stakeholders, thus facilitate effective prenatal and neonatal care. For instance, government agencies are responsible for providing funds that improve access to prenatal and neonatal care. Moreover, government health agencies help in regulation and policy formulation that enable the streamline the provision of neonatal and prenatal care. Through coordination of efforts, stakeholders in healthcare provide high quality care that has led to a reduction in infant deaths as well as the prevalence of diseases that are common during the early stage of development. Healthcare stakeholders such as physicians, nurses, counsellors, parents and government health agencies have to observe ethical behavior including the provision of informed consent, information
disclosure, assistance in policy formulation as well as discouraging racial and religious discrimination in prenatal and neonatal care settings.

3.b.ii Ethical Roles of Healthcare Stakeholders

3. b.ii. 1 Ethical Roles of Physicians

Among the stakeholders in healthcare, physicians play a tremendous role during the provision of prenatal and neonatal care. Specifically, pediatricians and obstetricians provide high quality care during the early stage of development. However, physicians have to observe ethical roles during the provision of prenatal and neonatal care. Abiding by bioethics enables health professionals enhance the quality of care that is provided during the gestational period as well as the early stage of human development. Pediatric and obstetricians have the following ethical duties during the provision of prenatal and neonatal care.

I. Provision of Informed Consent on Maternal and Fetal Rights-
Informed consent is a crucial ethical and moral element that guides the provision of prenatal and neonatal care. Through seeking the opinion of the patient by providing the consent forms, health professionals facilitate the inclusion of the patients in the caregiving process. Informed consent is a type of information disclosure since it highlights the intervention methods that the physician is going to adopt. Therefore, the parents of an infant acquire the right of either accepting or declining a particular prenatal or neonatal medical procedure. Physicians, especially pediatric specialists, are entitled to ensure that the mother signs the consent form before any intervention procedure is undertaken. Seeking the consent of the pregnant woman or both parents shows that the physician observes ethical behavior. In essence, healthcare professionals have an obligation to provide informed consent on the maternal and fetal rights. Fetal rights play a crucial role during the provision of prenatal care. The fetus has the right to undergo normal growth and development until the time of birth. Therefore, the physicians should ensure that pregnant women understand the fetal rights and the
importance of observing the rights. One scenario that has elicited mixed reactions in regards to the rights of the fetus is the issue of abortion. Abortion creates controversy since physicians are forced to either obey the fetal or maternal rights. In case the fetus has developed a severe congenital disease that may endanger the life of the mother, the physician should seek informed consent from the pregnant woman before undertaking abortion. Moreover, if the mother is seeking abortion when there is no danger posed by the fetus, the physician should provide comprehensive information to the mother to observe the rights of the fetus. The provision of informed consent is, therefore, an ethical role that can improve the quality of prenatal care.

Moreover, physicians such as pediatricians can also undertake ethical duties by ensuring the provision of informed consent during neonatal care. Newborn infants can develop stunted growth, diseases or genetic conditions that may warrant specialized care. Early-stage health problems such as low birth weight, premature birth, neonatal jaundice as well as respiratory distress syndrome can endanger the life of an infant. Such newborn babies require individualized and high-quality care that is undertaken in incubators under the intensive care settings. There are instances that infants born with congenital diseases may need to undergo surgery. The pediatric surgeon hence should seek informed consent from the parents. In case that the infant is undergoing end of life care treatment due to severe health condition, the physicians are ethically mandated to provide informed consent on the need to either withhold or withdraw life support during neonatal care.

Physicians are expected to disclose information to the parents and seek their consent in regards to withholding and withdrawal of life support. By providing informed consent and information disclosure, physicians have been in a position to improve the quality of prenatal and neonatal care in a clinical health setting. Decision making has improved the provision of prenatal and neonatal care in modern healthcare. Healthcare organizations have
adopted multi-faceted ways of promoting inclusive decision making in health care settings. One of the causative factors of ethical conflicts that occur within clinical settings is lack of collective decision making among the patients, family members and healthcare experts. The issue of informed consent has led to mixed reactions from different healthcare stakeholders. Patients have the right to informed consent concerning a specific intervention method. Informed consent allows the patient to participate in the treatment process by giving his or her opinion in regards to the existing intervention methods. This is because health consumers with severe mental and communication disorders cannot seek an extensive consent to a particular disease intervention method. Collaborative participation in decision making plays a critical role in the provision of prenatal and neonatal care. This is because it enables inclusive decision making that finally adheres the patient’s rights and autonomy. Patients have the fundamental right to participate in the decision-making process that guides the prenatal care and treatment process.

Health providers hence should provide informed consent to the health professionals or the family members before undertaking a medical procedure such as withdrawal or withholding of life support in end-of-life care. Even patients with genetic disorders as well as the ones with communication problems have the right to give consent before vital intervention methods are undertaken by the health providers. By seeking the permission of the patient, the health professionals uphold the rights of the health professionals. The quest for patients’ consent has enhanced decision making in healthcare since it enables the health professionals to seek the decision of the patient concerning a specific intervention method.

II. Guiding patients on the available intervention methods - Physicians also play another ethical role in guiding patients concerning the available healthcare intervention methods in clinical care settings. During the provision of neonatal and prenatal care, healthcare professionals are supposed to guide the pregnant mother or the parents in general
during the regular check-ups. Guidance is a tremendous factor in choosing the best and high quality prenatal and neonatal care. In most cases, mothers lack sufficient information relating to prenatal and neonatal care. Therefore, when the fetus has developed severe congenital or genetic condition, the physicians are expected to guide the parents on the available intervention methods that can be adopted to improve the quality of life of the fetus or the infant. In modern healthcare settings, physicians have been at the forefront of guiding the best medical procedure or intervention approach that can reduce infant deaths, premature births and low birth weight, among other health risks. During prenatal care, physicians are expected to guide the mother to prevent the transmission of diseases from the mother to the child. For instance, guidance has been used by health professionals to prevent the transfer of the HIV virus from the mother to the child. Through the Prevention of Mother to Child Transmission (PMTCT) initiative, physicians such as obstetricians and pediatricians have managed to combat the global pandemic by ensuring that the fetus and the infants are not affected by the disease. In such a case, physicians are obliged to perform their ethical role of guiding the parents on the best intervention to use to ensure that the infant is born free of the deadly virus.

Moreover, during neonatal care, the infant may be suffering from genetic disorders or other conditions such as premature birth. The attending healthcare specialist, therefore, should help the mother in selecting the various medical intervention techniques such as surgery, hormonal therapy and gene therapy. During the process of providing guidance and assistance, the health professionals highlight the benefits and limitations of each intervention method hence allowing the mother to select the most effective intervention strategy for the prenatal or neonatal care.

III. Provision of equal access to prenatal and neonatal care without discrimination-
Physicians also expected to perform the ethical duty of providing equal access to both
prenatal and neonatal care. Access to high-quality beginning of life care has been a significant issue that has shaped the way healthcare services are provided in clinical care settings. There is an unequal distribution of prenatal and neonatal care services. Discrimination based on racial groups, religion, level of education and social class has become hindered the acquisition of patient-centered healthcare services. Physicians therefore have the moral duty of ensuring that pregnant mothers who attend prenatal check-ups acquire high quality care. Healthcare specialists such as obstetricians should ensure that all pregnant women have access to individualized and high-quality care that can enhance the quality of life of the fetus. In the United States, for instance, racial discrimination has affected access to prenatal and neonatal care.

Pregnant women from minority ethnic groups such as African Americans and Asian Americans face discrimination when they visit healthcare settings. The white majority community is given priority during prenatal and neonatal caregiving, thus leading to constant conflict between the dominant and the minority racial groups. In such settings, physicians should perform the ethical role of ensuring that they provide adequate prenatal and neonatal care without any form of racial and religious discrimination. For instance, pediatric surgeons should ensure that infants from minority communities have access to high quality surgeries as well as other advanced medical interventions to treat infant health conditions such as neonatal jaundice. During the prenatal and neonatal visits, the physicians moreover, should ensure that mothers are exposed to a favorable clinical care setting that can facilitate maximum care to the fetus and the infant.

3. b.ii. 2 Ethical roles of Nursing Practitioners and Midwives

Registered nurses have been at the forefront of providing efficient prenatal and neonatal care. Just like physicians, nursing practitioners have a direct impact on the quality of neonatal and prenatal care. While most nursing practitioners provide care in clinical health settings,
midwives have played an essential role in the provision of home-based beginning of life care. Both pediatric nurses and midwives have an ethical role that they should perform during the prenatal and neonatal care.

**I. Information disclosure on the existing maternal and fetal Rights** - Clinical nurses have a significant impact on the dissemination of crucial health information that enhances prenatal and neonatal care. Information disclosure is an essential measure during the beginning of life care since a larger percentage of pregnant women, and young mothers do not have access to useful information about prenatal and neonatal care. Therefore, nurses and midwives have the role of educating the mothers on the critical elements of care during the beginning of life stage. In most cases, pediatric nurses spend more time with pregnant women and young mothers more than physicians. Hence the nurses have ample time to undertake the ethical role of educating the mothers on the measures that they should take to improve the infant’s quality of life. There are different areas that nurses and midwives should ensure that mothers know concerning prenatal and neonatal care. For instance, neonate pain management. Premature infants born with health defects such as low birth weight and respiratory distress syndrome needs a comprehensive pain management strategy.

Registered nurses, therefore, should inform the mothers on effective strategies that they can use to reduce pain during neonatal care. Some of the measures that can be undertaken during pain management include breastfeeding and incubation. The nurses also help the mothers to understand the significance of fetal and maternal rights during caregiving process. The fetal rights dictate that the mothers and healthcare professionals should observe the fundamental tenets of prenatal and neonatal care that involves periodic checkups and the provision of care that is aimed at improving the quality of life of the fetus or the infant.

Another vital role of information disclosure and informed consent is the collaborative participation. The process allows the patients or their family representatives to provide their
perception or view of the medical procedure. The involvement of the patient’s decisions can be used to improve healthcare. This is because health consumers can decide to oppose a treatment that can have a devastating impact on the patient. The first step in the process of adopting informed consent to mentally incapacitated patients is to undertake a capacity assessment. The process of evaluation enables health professionals to know if the patient can give consent to the intervention method.

The assessment should be guided by the global policy formulation accord of ethics such as The Mental Health Act Code of Practice. If the patient has an existing genetic disorder, he or she has the right to oppose the specific intervention methods that can endanger the normal growth and development. Information disclosure enables the patient to provide his or her opinion in regards to a particular medical treatment. Healthcare ethical issues such as maternal versus fetal rights and abortion can be solved by including the patients in decision making.

Information disclosure enables the patients to know the various risks and side effects of the available intervention methods. The patients need to understand the different risks that the various intervention methods possess to his or her health. For instance, withdrawal of life support during the end-of-life care automatically leads to death. In contrast, continuing withholding of life support enables the patient to stay alive but faces distress due to sophisticated medical interventions. Hence the patients should know that the intervention can also result in a negative health impact. Patients can only learn more about existing risks that may arise as a result of the adoption of various disease intervention method. Therefore, healthcare providers should spearhead information disclosure to enable the patients to acquire comprehensive information about their health risks associated with different interventions. Under such instances, the role of informed consent is to allow the patient to make effective decisions concerning his or her health. The health consumers will automatically oppose any
intervention that can cause devastating side effects such as chronic and debilitating diseases. However, collaborating in decision making also enables the health professionals to empower the health consumers on how to manage some critical medical conditions such as living with prenatal diseases as well as neonatal health conditions such as neonatal jaundice and preterm births. This is because some intervention strategies can be perceived to harm the health of the patient. Inclusive decision making therefore provides an important platform where the patient can acquire vital information about the various disease intervention techniques. Thus, healthcare stakeholders, such as counsellors can promote collaborative decision making that can enhance prenatal and neonatal care.

II. Guidance to the patients on the available intervention methods- Just like physicians, nurses and midwives also have the ethical duty of guiding the pregnant women and mothers on the existing intervention methods that can improve the quality of life of the fetus as well as the infants. The process of offering guidance helps in improving the quality of both prenatal and neonatal care. Since various processes are involved during the prenatal and neonatal care, there is a need to offer clinical guidance on the best medical procedures that health consumers should undertake. For instance, pregnant women should attend the monthly prenatal checkups during the first trimester. The nurses should ensure that pregnant women are aware of the visitation time frame and its importance in prenatal care. Moreover, the nurses should guide the expectant mothers on the significance of individual vs group care as well as the adoption of centering pregnancy.

The guidance also act as a vital intervention tool in the case where a pregnant woman has problems in communication or mental disorders. This is because collaboration and coordinated action ensure that healthcare organizations are well equipped with skills, knowledge, disease intervention techniques, financial resources, as well as guidance. Such crucial resources help health professionals to enhance the quality of care given to neonates
and infants. The relations between the stakeholders affect the quality of care since each stakeholder has to undertake in the cycle of prenatal and neonatal caregiving. Maternal nutrition and health in general, for instance, is critical since it shapes the quality of life of the neonate and the infant. However, health professionals must ensure that parents acquire essential information regarding prenatal and neonatal care. This is because some parents may lack vital information that can help in improving the lives of the infants.

**III. Assisting patients in interpreting complex medical procedures/terms**- Another ethical role of nurses and midwives is to undertake a comprehensive interpretation of complex medical procedures as well as medical jargon. Different medical procedures occur during the prenatal and neonatal care. In most cases, pregnant women, as well as mothers who have given birth, lack essential knowledge about the vital procedures such as incubation, oxygenation, pediatric surgeries, mechanical intervention and obstetric ultrasounds. All these crucial processes play a significant impact in both prenatal and neonatal care. The modern nurses and midwives, therefore, ensure that the mothers understand the meaning of the prenatal and neonatal medical procedures as well as their role in improving the quality of life of the fetus or the infant.

Another area that the nurses and midwives have shaped at the beginning of life care is to the adoption of centering pregnancy. Since its adoption in modern clinical care, nurses have played a crucial role in enabling healthcare consumers, especially pregnant women, understand the concept of centering pregnancy. Since it is a new concept in the medical world, pregnant women who undergo prenatal care have not understood its significance in preventing diseases and genetic conditions associated with the period of gestation. Centering pregnancy is an emerging medical technique that involves the incorporation of three important medical practices into one unit. The technique involves the adoption of risk assessment, education and support during prenatal care. By incorporating the vital aspects in
the gestational period, centering pregnancy allows pregnant women to effectively handle the health risks that occur during gestation leading to increased live births. Nurses have been at the forefront of advocating for the use of centering pregnancy. In the conventional prenatal care, pregnant women attend the prenatal checkups in which registered nurses, physicians as well as midwives attend to them individually. However, the new method of prenatal care involves putting the pregnant women in groups before undertaking a collective risk assessment, education and support. During the checkups, nursing practitioners ensure that pregnant women interact and discuss the problems that they are facing. Moreover, the nurses provide crucial information about the new techniques for improving the fetus’ quality of life. The nurses, as well as the midwives, helps in creating awareness on the importance of embracing emerging medical techniques such as centering pregnancy.

3. b. ii. 3. Ethical Roles of the Counsellors

Among healthcare stakeholders, counsellors play an instrumental role in the provision of prenatal and neonatal care. The gestational period is usually characterized by the occurrence of health problems such as obstetric malfunctions, high blood pressure, pelvic diseases, as well as uterine-based infections. Therefore, pregnant women encounter healthcare problems that can result in distress and emotional trauma. Moreover, most pregnant women fear other health risks such as preterm births as well as giving birth to a dead infant. Clinical counsellors, therefore, have an ethical duty of ensuring that women undergoing prenatal care are counselled and motivated to undergo the gestational period. Some of the techniques that counsellors use is to encourage the adoption of centering pregnancy that incorporates collective risk assessment, education and support.

1. Counselling parents on their ethical and fetal rights- The first ethical role of counsellors is to ensure that the parents understand the fetal and infant rights. Since most pregnant women and young mothers do not know the fetal and infant rights, they may
participate in actions that may jeopardize the life of the fetus and the neonate. Moreover, the stress that is associated with gestation as well as premature birth can cause trauma and stress. The counsellors, therefore, must ensure that the parents are motivated concerning providing high quality prenatal and neonatal care. Some of the issues that cause stress during prenatal care is the process of undertaking abortion. Some pregnant women may consider undertaking abortion to terminate a pregnancy. In such situations, the counsellors should provide an alternative step that involves encouraging the pregnant woman to carry the pregnancy to full term. This is because the fatal rights require that the fetus undergoes normal growth and development until birth. The counsellors also help in motivating mothers who are undergoing depression and trauma due to premature births and other congenital disabilities. Counselors should ensure that they balance between the need to observe the maternal and the fetal right.

This can be achieved by highlighting the benefits of observing the maternal rights at the expense of the fetal rights depending on the existing medical case. For example, the fetus can only be terminated if it poses a risk to the life of the mother. Moreover, if a preterm neonate has severe congenital disorders and hence may not survive in the intensive care nursery, the counselor may advise the mother on the need to withdraw life support. The withdrawal or withholding of life support, however, should be undertaken after involving the parents in a collective decision-making process. The counselor should also provide motivation and hope to a mother who has lost an infant due to severe developmental diseases.

**II. Counselling parents on information disclosure** - Another ethical role of counsellors is to ensure that pregnant women and mothers acquire comprehensive information regarding the essential elements of prenatal and neonatal care. Information disclosure is a critical tool that health professionals use to ensure the adoption of an inclusive beginning of life care. Pregnant women who attend prenatal care need to acquire comprehensive health information
that includes the prenatal nutrition, the use of folic acid, the role of physical exercise, biological changes that occur during gestation as well as how to prevent prenatal health risks such as preterm birth. The strategy and channel of dissemination health information also play an important role in prenatal healthcare. The counsellors should ensure that they create an enabling environment for disclosing vital information regarding the health status of the fetus or the infant. For instance, if a mother has experienced a preterm birth, she should undergo extensive counselling on how to cope up with the situation as the infant undergoes care in the incubator. Moreover, if the growth of the fetus has developed developmental disabilities, the mother should be counselled before the information is passed.

Counselling is also critical in helping mothers who have given birth to infants with severe congenital disorders to cope up with the condition before undertaking the process of pediatric surgery. Information disclosure goes hand in hand with the provision of informed consent. Due to the complexities that occur during prenatal and neonatal care, mothers can be overwhelmed with the information that they receive from the health professionals. For example, obstetric ultrasound can reveal that the fetus has severe disabilities and growth disorders. Such information can trigger mental trauma and depression. Therefore, it is the duty of the counselors to ensure that pregnant women and young mothers cope with the information regarding the condition of the fetus or the infant.

III. Provide guidance on maternal alcohol and drug use - Another critical factor in prenatal care is alcohol and drug use among pregnant women. Both smoking and alcohol use among pregnant women pose a danger to the health of the fetus. The drugs can hinder the normal development of the fetus, thus causing preterm births as well as low birth weight. Counsellors hence have the ethical and moral obligation of enlightening the pregnant women on the dangers of smoking and alcohol abuse. During the prenatal clinical care visits, the counsellors are expected to provide counselling services to women who smoke as well as the
ones who consume alcohol. The counsellors are tasked with convincing the pregnant women to change their lifestyle behavior in regards to alcohol consumption and cigarette smoking. Pregnant women who are addicted to smoking and alcohol use are encouraged to form a support group that is headed by the counselor. Another moral and ethical conflict in prenatal care is the use of alcohol and other drugs during pregnancy.

Drug usage during pregnancy has elicited mixed reactions among members of the society. While some pregnant mothers use alcohol and cigarettes, health professionals argue that the use of alcohol and drugs have an adverse impact on the unborn baby. Therefore, healthcare bodies such as the Center for Disease Control and Prevention have discouraged maternal drug use in the quest to improve the development of the fetus. Alcohol use during pregnancy affects the development of the brain. This is because the alcohol passes through the mother and enters the unborn baby’s blood hence destroying important growth organs. A significant percentage of women who consume drugs during pregnancy have a higher risk of giving birth to a newborn with adverse genetic disorders and developmental disabilities.

During prenatal care, the mothers are usually advised on the role of maternal alcohol and drug use on fetal and infant development. During the counselling sessions, the counselors provide information about the different techniques that gestating women can use to reduce alcohol and cigarette usage. For instance, pregnant women are encouraged to stop taking alcohol and smoking of cigarettes to prevent any diseases or conditions that may hinder the normal growth of the fetus or the infant.

3. b.ii. 4 Ethical roles of the Government and Healthcare bodies

The government healthcare agencies also form one of the most important health stakeholders in regards to the provision of prenatal and neonatal care. Healthcare services can only occur in a favorable political environment. The ethical roles of the government health agencies include the formulation of policies, enhancing access to prenatal and neonatal care as well as
creating awareness on the need to eradicate racial and religious discrimination in healthcare. The major governmental health organizations include Centers for Disease Control and Prevention, World Health Organization, Centers for Medicaid and Medicare Services as well as the United States Department of Health and Human Services.\textsuperscript{102}

I. Policy formulation - Global governments have been at the forefront of formulating healthcare policies that promote the provision of high quality prenatal and neonatal care. Policy formulation plays an integral role in boosting the provision of healthcare services during the beginning of life care.\textsuperscript{103} Various policies have been adopted by global healthcare organizations and the United States government. For instance, laws and policies promote equal access to prenatal and neonatal care. Every pregnant woman is required to seek prenatal care in clinical care settings to prevent health risks such as premature births and low birth weight.\textsuperscript{104} Attending prenatal care is mandatory, and the health professionals are expected to provide patient-centered care to increase the quality of life of the fetus and the infant. The Centers for Medicare and Medicaid Services have adopted programs that provide insurance to pregnant women who attend prenatal care. Moreover, infants who are born prematurely or the ones with developmental disabilities are expected to undergo neonatal care. During the neonatal care, the neonates are put in the incubators where life-saving measures such as oxygenation and mechanical ventilation are applied to boost the health of the infant. Policy formulation has also been characterized by the adoption of programs that bring pregnant mothers together through support groups.\textsuperscript{105}

II. Improving access to healthcare/ funding - Governmental health agencies also play an instrumental role in enhancing access to prenatal and neonatal care mainly through funding.\textsuperscript{106} One of the challenges that hinder access to effective healthcare is high costs of prenatal and neonatal care. A larger percentage of health consumers cannot afford advanced medical care due to its cost. Therefore, health organizations such as WHO and the United
States Department of Health and Human Services have increased healthcare budgetary allocation. The funds are meant to reduce the cost of accessing prenatal and neonatal care in different healthcare centers across the nation. Moreover, the United States government adopted the Affordable Care Act in 2010 to ensure that health consumers access various clinical care services. The Patient Protection and Affordable Care Act has brought a great impact in improving access to prenatal and neonatal care. The government hence has managed to undertake the ethical and moral duty of ensuring that health consumers have access to efficient healthcare. Increasing the funding of prenatal and neonatal care also helps in improving the quality of care since health organizations can employ highly skilled health professionals such as clinical obstetricians and pediatric surgeons. Moreover, both prenatal and neonatal care requires the adoption of effective health intervention that can only be provided by skilled and experienced healthcare specialists. Access and funding are the most important elements in prenatal and neonatal care.

Healthcare organizations have initiated the process of enacting policies that promote equal access to neonatal and prenatal care. One of the techniques that have been adopted is increased budgetary allocation for healthcare. Since prenatal and neonatal care requires specialized care to the mother, the issue of access has become a significant challenge in the provision of high-quality care. World healthcare bodies have recognized the role of equal access to prenatal care. All pregnant women are entitled to prenatal care, while infants have the right to high quality neonatal care. This is because prenatal care plays an essential role in the growth and development of the fetus. Global healthcare bodies have, therefore passed laws and policies that ensure that healthcare organizations have a functional prenatal care unit that provides around the clock care to pregnant women. The regulation also requires all pregnant mothers to seek prenatal care to increase the fetal quality of life. For instances, there are critical processes such as obstetric ultrasounds, pelvic examination, pediatric
surgery, treatment of congenital diseases, incubation, oxygenation and mechanical ventilation.\textsuperscript{110} All these medical procedures should be undertaken by experienced and skilled beginning of life medical practitioners.

\section*{III. Discourage racial and religious discrimination in healthcare settings} The governmental health agencies also have the ethical obligation of promoting inclusivity during prenatal and neonatal care. One of the significant challenges that have been facing the beginning of life care is the high prevalence of racial and religious discrimination that hinder access to prenatal and neonatal care.\textsuperscript{111} For instance, in the United States, racial discrimination has influenced access to healthcare. Health consumers from minority ethnic groups such as Black Americans as well as immigrants, are not given priority during prenatal and neonatal care. However, the white majority community have full access to efficient healthcare. The federal government has, however, adopted strategies aimed at creating awareness on the need to eradicate racial discrimination.\textsuperscript{112} African American community have been encouraged to seek prenatal and neonatal care without fear of discrimination. Religious discrimination also affects access to healthcare. Religions such as Islam is considered a foreign religion in the US and hence the pregnant Muslim women have faced discrimination while seeking prenatal and neonatal care. The government therefore have the moral obligation to ensure that the public is aware of the role of racial inclusivity in healthcare. The government undertakes awareness creation programs meant to empower the different racial groups on racial tolerance.\textsuperscript{113}

\section*{3. b. ii. 5. Ethical Roles of Parents} Just like other healthcare stakeholders, parents, especially the mothers, have an important ethical role to play during prenatal and neonatal care. Both pregnant women and mothers of infants have the duty to ensure that they collaborate in the provision of prenatal and neonatal care.\textsuperscript{114} Gestating women should seek prenatal care to ensure that the fetus does not acquire
developmental diseases or other growth defects such as preterm births and low birth weight. Health professionals such as pediatric nurses and physicians cannot undertake effective prenatal and neonatal care without the assistance of the parents. This is because, the pregnant women and the mothers must provide essential information such as the medical background and the biological changes that has been happening due to the pregnancy.**115**

1. **Seek prenatal and neonatal care program at healthcare facilities** - The first ethical role of a pregnant woman or a mother who has experienced a preterm birth is to seek prenatal and neonatal care. Parents should ensure that they seek high-quality care at the nearest healthcare facility. Although midwives can provide healthcare assistance during gestation, it is more beneficial to seek prenatal care in an established clinical care facility.**116** Seeking healthcare enables the pregnant woman to access health professionals such as obstetricians and pediatric nurses who possess the skills necessary for the beginning of life care. Moreover, healthcare professionals can only provide prenatal and neonatal care if pregnant women attend the monthly neonatal checkups that begin between the 1st and 28th week of pregnancy. Therefore, parents should ensure that they attend the prenatal checkups to initiate collaborative healthcare aimed at improving the health of the fetus or the infant. A larger percentage of developed nations such as the United States, Russia and Saudi Arabia have developed policies that ensure that pregnant women attend the prenatal and neonatal services.**117** Parents are encouraged to seek specialized beginning of life care in order to ensure that the growth of the fetus is not affected by gestational health conditions. Moreover, through attending neonatal care, preterm infants acquire an opportunity to life-saving medical care that is characterized by incubation, oxygenation and mechanical ventilation.

Moreover, in the case that the premature neonate needs urgent surgery or medical intervention, the pediatric surgeons can easily access the infant and thus provide specialized care.**118** Another benefit of seeking prenatal and neonatal care is that it enables pregnant
women as well as the infants to receive care in an effective clinical care setting. Healthcare settings present an efficient environment that is characterized by the presence of advanced medical equipment such as obstetric ultrasound detectors, imaging and scanning machines as well as modern incubators. Incubators allow preterm infants to undergo normal growth and development. Moreover, the clinical care setting possesses highly skilled medical specialists, unlike home-based care.\textsuperscript{119}

\textit{II. Fight for maternal, fetal and infant autonomy/rights}- Parents should ensure that they undertake the ethical role of fighting for maternal and fetal rights. During prenatal care, existing maternal and fetal rights should be observed. Healthcare professionals should ensure that they adopt intervention methods that adhere to the maternal autonomy and rights.\textsuperscript{120} For instance, advanced practice nurses and physicians should undertake information disclosure as well as informed consent. The healthcare providers should ensure that pregnant mothers acquire crucial information regarding the medical interventions that are adopted during prenatal care. Hence parents should fight for the maternal and fetal rights by ensuring that health professionals undertake vital processes such as general education on prenatal care, pelvic examination and obstetric ultrasounds to check the growth of the embryo. The primary ethical dilemma that affects the provision of prenatal care is the need to observe maternal autonomy as well as the existing fetal rights.\textsuperscript{121} The mothers have the right to acquire vital information about the intervention methods that health professionals have initiated during prenatal care. The provision of informed consent is significant in areas such as the need to undertake abortion. Moreover, in case the fetus has a developmental disorder, the mother should be informed before any health intervention is undertaken. In case the life of the mother is at risk due to the fetal growth disability, maternal autonomy is given priority resulting in saving the life of the mother by procuring abortion to end terminate the
pregnancy. However, the fetus also possesses vital rights just like the mother. Since life begins at conception, the fetus is considered to be a human being with the right to life. Therefore, prenatal care is supposed to ensure the fetus gets sufficient growth and development. Therefore, the mother should not engage in activities that may prevent the development of the fetus in the womb. Moreover, health professionals are required to observe the fetal rights by undertaking the act of beneficence. The termination of the fetus should only be undertaken when the life of the mother is in danger. Maternal and fetal rights have continued to improve prenatal and neonatal care in recent years due to different perceptions of the rights of the fetus and the mother. There are health stakeholders who believe that maternal rights are more important than the fetal rights while other people believe that the fetus should be given first priority.

There is a need to observe the rights of both the mother and the fetus during neonatal and prenatal care. Neonatal physicians such as obstetricians, for instance, have the ethical duty of information disclosure, informed consent, guiding mothers on the best intervention methods as well as providing patient-centered prenatal care. Registered nurses, on the other hand, provide guidance on the available intervention methods, educating pregnant women on emerging techniques of neonatal care as well as assisting the patients in understanding complex medical procedures and terms. During neonatal care, mothers should ensure that premature infants undergo neonatal intensive care through the use of incubators, oxygenation and mechanical ventilation. The mothers should ensure that the infant acquires high quality neonatal care irrespective of her racial or religious background. In the case that pediatric nurse and physician has decided to incorporate a particular intervention, they must first seek the consent of the mother before beginning the procedure. The mother must ensure that health professionals undertake an inclusive decision-making process before embarking on patient-centered beginning of life care.
Parents also have the ethical and moral duty of providing vital information about pregnancy as well as other existing health complications. During the regular prenatal checkup, the mother must divulge information about the medical background to the attending nurse and physician.\textsuperscript{127} This is because health professionals usually do not know about the lifestyle or health of the mother. Since lifestyle behavior such as alcohol and cigarette smoking has a great impact on pregnancy, the mother must provide accurate and truthful information about the social lifestyle so that the health professionals can undertake effective measures during prenatal care. The process of divulging information can also improve the quality of care since health professionals can adopt interventions to tackle underlying health conditions.\textsuperscript{128} For instance, if a pregnant woman underwent a c-section birth during the first pregnancy, she should inform the attending nurses since the information can help in enhancing the subsequent prenatal care.

Parents should also provide information on nutrition and diet to help health professionals to make effective decisions.\textsuperscript{129} For example, in the case that a pregnant woman has not been taking folic acid in her diet, the nurses can recommend the inclusion of folic acid in the diet to boost the health of the fetus. Apart from the information that the physicians acquire from undertaking physical examination and diagnosis, a larger percentage of medical information is given by the parents.\textsuperscript{130} Some infants may be born with severe genetic disorders that may hinder normal growth and development. In such cases, the mother can assist by providing crucial information on how the infant has been progressing with the developmental disability. Through giving information about the prevalence of a specific genetic condition in a family lineage, the health professionals can adopt an appropriate intervention method for treating the health condition.\textsuperscript{131} Therefore, parents should ensure that
they undertake the ethical role of providing medical information during prenatal and neonatal care.  

3.c. Conclusion

Ethics consultation plays a significant role in nurturing informed consent during clinical decision making. The ethics consultation process ensures the observation of critical elements that characterize the decision-making process. In general, ethics consultation explores the underlying factors that lead to the provision of informed consent hence enhancing the decision-making process. Informed consent is characterized by three critical processes that help in shaping the final decision of the patient. The first step is information disclosure in which health care experts are supposed to disclose comprehensive information regarding the prognosis, diagnosis, and possible methods of intervention. The physicians and nurses or the ethics consultation team should practice cultural and religious tolerance while disclosing medical information. The aim of the health care professionals should be to provide essential information to all patients. The next stage is the assessment of the competency or capacity of the patient. The health care professional must test and assess if the patient or next of kin has understood the information provided during the information disclosure stage.

Assessment of the patient’s competency enables physicians and the ethics consultation team to judge the patient on his or her capability of making an informed decision. Moreover, an assessment will enable health care professionals to know if the information disclosed has changed the perceptions and views of the patient. The final stage of the informed consent process is the provision of voluntary and free consent. After attaining evaluating the capacity of the patients to comprehend the provided information, the health care consumer is, therefore, expected to provide voluntary consent to a particular intervention method. Depending on the results of the diagnosis, the health professionals can suggest the
adoption of various interventions such as undertaking surgeries, pain management, critical
care management, withdrawal of life support or withholding of life support during the end-of-
life care. The patient, therefore, accepts or declines the proposed intervention and signs the
consent form before the physicians initiate the treatment process. Ethics consultation,
therefore, helps in nurturing informed consent that enhances shared decision-making in
modern health care settings.

Stakeholders in healthcare have ethical and moral duties to observe during prenatal
and neonatal care. Different health stakeholders such as physicians, registered
nurses/midwives, counselors, governmental health agencies and parents play a critical role in
the provision of high quality prenatal and neonatal care. Midwives have also
revolutionized home healthcare by initiating prenatal care in the rural areas. Healthcare
organizations have recognized the need to train midwives to enable them to acquire skills that
can improve the quality of home-based prenatal care. Ethical roles of midwives include
examining the pregnancy at different trimesters. Although the midwives are not as skilled as
registered nurses, they have enhanced the provision of prenatal and neonatal care in home
healthcare. Both prenatal and neonatal intensive care has brought a significant impact on the
health of preterm infants. Ethical and moral issues influence the quality, access and cost of
neonatal care. Various ethical elements such as information disclosure, infant and maternal
rights, quality and access of neonatal intensive care have enhanced the provision of care in
various parts of the globe. There is a need for the adoption of various programs aimed at
promoting the provision of neonatal intensive care. Critical programs such as ethics
consultation, parental involvement, pain management, and incorporation of advanced
technology can help in solving the ethical issues that affect prenatal and neonatal care.
Moreover, physicians and advanced practice nurses should recognize other issues such as
cultural backgrounds, discrimination and socio-economic backgrounds and how they affect
the perception of prenatal and neonatal care.\textsuperscript{144} Healthcare professionals should also implement laws and policies that promote access to high quality neonatal and prenatal care in both developed and developing countries.\textsuperscript{145}

Counselors, on the other hand, provide guidance and motivation to mothers who have experienced preterm births as well as the ones who have given birth to infants with developmental disorders.\textsuperscript{146} Counseling has shaped home-based prenatal and neonatal care since the parents undergo counseling sessions that enable them to cope with preterm infants.\textsuperscript{147} Finally, the parents also have an ethical role in seeking prenatal and neonatal care, ensuring that health professionals observe maternal and fetal rights and providing information about the history of any existing disease or disorder.\textsuperscript{148} Pregnant women and mothers who have given birth to premature infants must undertake their ethical duties by participating in a collective action aimed at improving the quality of prenatal and neonatal care.\textsuperscript{149}
Endnotes


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CHAPTER 4: HHC IN THE LIFESPAN

This chapter examines the incorporation bioethics in home health care and how it can be used to address lifespan-based diseases and conditions such as cancer. Precision medicine promotes the study of cancer genetics, genomics, and cancer stem cells. The incorporations of bioethics enable health professionals to improve home health care.

4.a. Mental Health

The increase in the prevalence of mental health conditions and disorders has brought a significant impact on human health across the global nations. Both developing and developed nations, such as Middle East countries, have experienced the devastating impact of mental disorders. Hence, stakeholders in the field of health care have adopted a multidimensional strategy aimed at addressing mental health in society.¹ The principle of ‘principlism’ examines the ethical dilemmas that health professionals face during the provision of psychiatrist care. The principles focus on objective and real-life ethical dilemmas such as the role of the patient in decision making and the patient-physician relationship. The primary elements of the principle of principlism include respect for autonomy, justice beneficence, and non-maleficence. Individuals with psychiatric disorders are incapable of making efficient health care decisions in regards to informed consent, autonomy, and co-existence with other members of society.² The implementation of bioethics has created an enabling environment for improving mental health since it provides an ethical framework that enhances the process of making effective mental health reforms.

Mental health has become a critical health concern in contemporary society. This is because the psychiatric health of individuals has a direct impact on a person’s socialization, personality, and product. For instance, individuals with mental health disorders such as compulsive disorders are likely to develop aggressive behavior that hinders interaction with other members of society.³ An issue such as patient autonomy, influences the adoption of
decision making in health care. This is because patients with mental disorders usually face a challenge in participating in collective decision making. Hence health professionals should adopt a strategy that can ensure the observation of patient autonomy during both hospital-based care and home health care. Health professionals should also recognize the role of social workers. In the presence of mental disorders affects almost all facets of life, such as participation in income-generating activities, religious activities as well as love relations. Therefore, it is essential to adopt measures aimed at boosting the mental health of the people through adopting a bioethics practice in the context of home health care. The adoption of the bioethics practice, such as ensuring patient autonomy, justice, and informed consent, enhances the mental health of the people and contributes to the prevention and treatment of mental health disorders. Essential bioethics elements such as justice, patient autonomy, non-maleficence, and beneficence play a crucial role in solving ethical dilemmas during the provision of mental health care. The principle of ‘principlism’ therefore plays a great impact in enhancing the quality of mental health care among primary care patients. The ideology of ‘principlism’ creates an enabling environment for undertaking case management by ensuring the observation of ethical conduct during the provision of mental health care services to the patients.

The Kingdom of Saudi Arabia has, over the years, recognized the need to enhance the mental health of its citizens. The adoption of the mental health act of 2014 played an instrumental role in boosting the psychiatric health of Saudi Arabians. The prevalence of mental disorders such as bipolar disorders and dementia brought a negative impact on the health and labor productivity of the people. Since the adoption of the mental health care act, various measures have been adopted to enhance psychiatric health in various parts of the Kingdom. The Ministry of Health has developed several specialty programs aimed at addressing mental health through the incorporation of bioethics. The Patient’s Bill of Rights
has created an enabling environment for enhancing mental health care services in the Kingdom. This is because Bill has increased access to mental health care in home health care.\textsuperscript{8} The Kingdom of Saudi Arabia has attributed the high prevalence of psychiatric conditions to dysfunctional family relationships, unemployment as well as chronic diseases. These factors have a devastating impact on the cognitive development of the victims hence increasing the chances of being a victim of adverse mental conditions.\textsuperscript{9}

4.a.i Bioethics Issues in Mental Health

4.a.i.1. The Bioethics Relevance of Principilism Regarding Mental Healthcare

Several principles guide the implementation of the bioethics practice. Principilism shape the adoption of bioethics behavior during the provision of care to patients with mental health conditions. The bioethics elements enable health care professionals and other health stakeholders to adopt diverse ethical and moral initiatives that control the prevention as well as treatment of mental health conditions.\textsuperscript{10} According to principlism, the major ethical and moral elements that shape ethical behavior in health care include, beneficence, patient autonomy, justice and non-maleficence. Mental health care requires collaboration and coordination of efforts among different health care professionals. For example, psychiatrists, advanced practice nurses, ethics consultation committees and counselors. For these health care professionals to effectively work together, they should embrace ethical and moral behavior. Bioethics practice improves the relationship between health care experts and patients with mental health conditions. There are crucial bioethics issues that affect the implementation of mental health services and the eradication of psychiatric disorders.\textsuperscript{11}

\textit{I. Respect for patient autonomy} - Patient autonomy is one of the essential moral philosophies that can be applied to addressing mental health conditions in society.\textsuperscript{12} The moral and ethical philosophies have a direct effect on the level of psychiatric care within a clinical care setting. Health professionals should ensure that they respect patient autonomy.
During the provision of care to patients with mental disorders, respect for patient autonomy plays an essential role in the provision of mental health care. This is because the ethical element gives the mentally ill individual a chance to make a critical decision that will shape the treatment process. Although mentally incapacitated patients are perceived to lack judgment capability, a non-severe form of mental disability can still make medical decisions. Therefore, health care professionals should assess the patient’s ability to make sound judgment to information disclosure. In case the patients can make collective decisions, they should be allowed to participate in the decision-making process. For instance, if an individual is suffering from moderate depression or is experiencing mild post-traumatic stress disorder, the health care professional should seek their opinion on the available intervention methods. Observing patient autonomy in mental health care should be characterized by the practice of ethical behavior. This is because the patient is allowed to determine or change the direction of the treatment process. Since there are different treatment options for mental disabilities, the patient can reject or accept a particular intervention based on his or her ideologies, cultural, and religious beliefs.

Patient autonomy also improves the patient-physician relationship since the patients will develop a productive relationship with the caregivers due to patient participation in the treatment process. Unlike in the traditional health care setting in which the patient was not involved in clinical decision making, modern health care recognized the importance of involving the patient in caregiving. Incorporating patient autonomy in mental health care has become a critical issue since patients with severe mental disabilities cannot acquire an opportunity to provide sound judgment during the decision-making process. However, health care professionals have recognized the significance of undertaking patient participation in mental health care in contemporary health settings. The observation of patient autonomy is a controversial issue in mental health care. This is because mentally incapacitated individuals
are not in a position to participate in collective decision making with health care professionals. However, global mental care regulatory bodies require that psychiatrists observe patient autonomy by ensuring that the patient is aware of a particular intervention method that has been adopted at a particular time.\textsuperscript{16} Since there are patients with severe mental illness as well as the ones with moderate mental disorders, health care providers should first assess the level or magnitude of mental disorders.

The severity of the psychiatric disorder enables the health care professional to decide whether to include a surrogate decision-maker or include the patient in decision making. In case the patient has a severe mental disorder and is not in a position to participate in collective decision-making during caregiving, the attending patient is required to seek the decision of the surrogate decision-maker such as a close family member. The presence of next of kin, such as children or parents, therefore, provides consent before a particular health intervention is adopted both in the clinical and home-based care settings.\textsuperscript{17} However, in the case in which a particular patient has a mild mental condition, the patient can be allowed to participate in collective decision making in regards to the health care intervention method. However, the patient should be in a position to understand the nature of the intervention method as well as the resultant effects on the wellbeing of the patient. For instance, patients suffering from moderate mental disorders such as anxiety disorders, depression, and aggressive behavior should be handled with a different approach as compared to individuals suffering from diverse mental disorders such as bipolar disorder.\textsuperscript{18} This is because these mental illnesses display a different level of severity and behavioral changes on the patient. Patient autonomy among mental health patients should depend on whether the patient is capable of making decisions during caregiving. However, health professionals, such as psychiatrists, should focus on ensuring that they respect patient autonomy during caregiving. Respect for patient autonomy shows that health care experts have observed fundamental
bioethics. Moreover, by recognizing the role of ethical and moral behavior in regards to patient autonomy, health care professionals can effectively achieve the goals of mental health care.\(^{19}\)

**II. Justice** - The observation of justice in mental health care settings deals with access to patient-centered mental health care. Equal distribution of mental health services is the key to improving the availability of standardized care in regards to mental health. This particular bioethics practice ensures equal access to mental health care.\(^{20}\) In society, access to psychiatric care has become a significant challenge among individuals suffering from mental disorders. Some factors have contributed to the unequal distribution of mental health care. For instance, cultural and religious perception of mental disorders has led to discrimination in accessing patient-centered mental health care. Health care stakeholders should ensure that several specialty programs are established to address mental health to reduce the prevalence of mental health disorders. Mental health care has become a critical facet of modern care since it affects the socio-economic, political, and religious development of the people.\(^{21}\) By ensuring justice, mental health organizations such as the Ministry of Health can create a binding relationship between psychiatric patients and the health professionals as well as the general members of the society. Through ensuring that mentally disabled individuals in society access mental health care, the health care stakeholders can achieve their long terms goals related to mental health in society. The bioethics philosophy, therefore, plays an instrumental role in boosting the access and quality of psychiatric care in the modern health care society. Another bioethics element in mental health care is justice.

This particular ethical issue focuses on how mental health patients acquire the opportunity to seek high-quality mental health care. In other words, people with mental disorders have the right to access patient-centered mental health care, just like patients without mental diseases.\(^{22}\) One of the factors that have contributed to unequal access to
mental health care services is the presence of discrimination and prejudice among the members of society. Since mental disorders are perceived to be signs of madness, patients suffering from different kinds of mental disorders such as severe depression have faced stigmatization and discrimination from the members of the society. Health professionals should, therefore, implement ways that can help in reducing and eliminating discrimination that targets patients suffering from mental problems. For example, physicians and nurses should ensure equality when providing health care services to the mentally disabled. Combating inequality in the distribution of health care resources requires collective action among the stakeholders in the field of health care.

In most cases, health care experts fear to provide health care services to patients with mental problems, unlike patients suffering from other diseases such as hypertension and cancer. Another strategy that can be used to increase the level of access to patient-centered mental health care is to provide truthful information regarding mental health care. The members of the public have developed a negative perception of individuals with mental health care problems due to a lack of truthful information regarding mental illness. Individuals with psychiatric diseases require care and love from the members of the community as opposed to isolation, hatred, and prejudice. Therefore, health care organizations should develop programs that aim at creating awareness on the need to practice tolerance towards individuals with different mental problems such as post-traumatic stress disorder. Through creating awareness on the need for collective action towards adopting effective health care, health care professionals can spearhead the fight against mental health disorders. Moreover, ethical and moral behavior plays an instrumental role in creating an enabling environment for initiating mental health care efforts within the Kingdom of Saudi Arabia.
III. Beneficence- According to the bioethics principle of beneficence, the primary goal of health professionals is to ensure that patients acquire beneficial and high-quality care. Patients with mental disorders should be able to achieve their health care goals characterized by patient-centered care. Beneficence is, therefore, a critical ethical and moral behavior that health care stakeholders should adopt in contemporary psychiatric care. Health care stakeholders, including nursing practitioners, physicians, and mental health regulatory agencies, should, therefore, create an enabling environment for the implementation of beneficial mental care. Just like other ethical issues in mental health care, beneficence posits that the main role of psychiatrists should be to improve the health of individuals with mental health disorders. Therefore, mental health experts should incorporate strategies that serve the interest of the patients. Psychiatric experts are obligated to maximize the health benefits when providing care to the mentally incapacitated patients.

The principle of beneficence therefore plays a significant impact in solving ethical problems and dilemma that health care professionals encounter during care giving. One of the most important ethical dilemmas that health care professionals face is the need to generate profits for the health care organization versus the need to provide a high-quality care. However, the principle of beneficence can effectively guide ethical decision making during the provision of mental health care. Health care professionals should balance the efforts required to provide patient-centered care as well as generating profits for the health organization. The mentally incapacitated acquire standardized care that can treat and manage diverse mental problems. Beneficence is one of the goals of health care professionals since it allows physicians and nurses to work towards achieving health care goals. Beneficence is a crucial ethical behavior that has played a great role in mental health care in Saudi Arabia and different nations across the globe. During caregiving, psychiatrists should ensure that they only incorporate medical interventions that can treat mental health disorders. Moreover,
health experts should ensure that they adopt other critical issues such as pain management through therapy and counseling. Patients with mental health disorders can benefit from therapy and counseling sessions in clinical and home-based settings. This is because counseling enables the mentally disabled patients to cope up with their health conditions even as they receive health care services. Therapy, on the other hand, helps in eliminating the pain and aggressiveness that is associated with different forms of mental illness such as anxiety disorders. The observation of ethical behavior ensures that mental health patients achieve their health goals by ensuring that health professionals provide high-quality care.

**IV. Non-Maleficence** - The principle of non-maleficence argues that health care professionals should focus on preventing any form of harm during care giving. Psychiatrists should first ensure patient safety before initiating the medical intervention methods. Patients suffering from diverse mental illnesses such as schizophrenia, anxiety disorders and bipolar disorder can easily harm themselves since they experience episodes associated with a particular mental disorder. Therefore, the health care professionals should ensure that the patients are safe from any form of harm. Moreover, during care giving, the psychiatrists should avoid any medical procedure that may harm the patient. The stakeholders in the field of mental care should adopt strategies aimed at avoiding deliberate harm that may befall the patient. For example, patients with anxiety disorders usually are not comfortable in a place with many people. Such patients should be isolated in a setting where they constantly interact with only health care professionals such as psychiatric nurses, counselors and family members. Mental health professionals should also ensure that the patients do not escape the mental health care centers or asylum since they can receive a hostile reception from the members of the public. Since the members of the society cannot easily identify an individual with a mental disorder, they can cause harm to the mental health patients when they interact with the people.
Moreover, the perception of patients with mental illness in the society had hindered effective relationship between the people and the mental health patients. In most cases, mental disorders are perceived to be a form of curses or madness hence the masses practice open discrimination and hatred against the mentally incapacitated individuals in the society. Therefore, the safety of the patients takes a center stage during the provision of mental health care. Although the health professional should aim at providing high quality and standardized care, they should also focus on preventing any form of harm that may occur during care giving. The mental health patients for instance should acquire correct diagnosis, intervention as well as disorder management strategy.

Therefore, the bioethics elements of principlism plays an essential role in the provision of mental health care services in the modern society. Respect for patient autonomy enables the psychiatrists to ensure that they seek the opinion of the patient before undertaking a particular health care procedure. Respect for patient autonomy thus improves the relationship between the patient and the health care expert such as psychiatrist and social workers. Moreover, the ethical perspective also symbolizes the observation of bioethics in mental health care. The incorporation of beneficence on the other hand has led to improved health care outcomes since the care givers focus only on the mental care interventions that seek to bring maximum health benefit to the patient. For example, an old patient with chronic schizophrenia and depression who receives mental health care in the home-based care setting can achieve the best health care outcomes as opposed to hospital health care. The principle of non-maleficence has led to the prevention of harm to the mentally incapacitated patients. Through focusing on the safety of the patients, health care professionals choose the ideal clinical care setting that can improve the health outcome. The ethical perspective of justice on the other hand has resulted in the elimination of discrimination in regards to access to mental health care. Stakeholders in the field of health care have focused on ensuring that all
individuals suffering from diverse psychiatric conditions access high quality and patient-oriented mental care. Equality in health care access is instrumental in the provision of mental health care. Both global and local health care organizations have spearheaded the observation of bioethics during the provision of psychiatric health care.36

4.a.i.2 The Application of Principlism to Bioethics in Mental Healthcare

The incorporation of principlism in mental health care has brought a tremendous revolution in the field of mental health care. There are diverse bioethics issues that affect the implementation of patient-centered mental health care.37 Since health care organizations have recognized the need to address the increasing cases of mental health disorders, there are critical bioethics issues that should be observed to enhance psychiatric health. There are crucial underlying factors that shape the adoption of ethical and moral behavior in clinical care settings. Principlism leads to the adoption of bioethics elements such as:

1. Informed Consent- Informed consent is an essential element of bioethics practice in mental health care. This is because individuals having diverse mental health conditions such as bipolar and compulsive obsessive disorders face a challenge in providing informed consent.38 The presence of psychiatric disorders acts as a barrier that prevents patients from giving informed consent. As opposed to individuals without mental health conditions, people who have various mental states have a higher chance of failing to provide a viable informed consent. This is because mental disorders have a devastating impact on memory and cognitive perception among the victims hence hindering the patients from participating in collective decision making.39 However, there are various measures that health care professionals and other health stakeholders can adopt to ensure that patients suffering from mental disorders provide informed consent. Since informed consent allows the patient to practice autonomy during caregiving, it is imperative for physicians and advances practice nurses to incorporate strategies of ensuring that the patients understand the various
interventions and provide informed consent. The measures that can be used to ensure that patients with mental disorders provide informed consent include:

Multi-dimensional Information Disclosure-Health professionals should ensure that they embrace a multi-faceted communication approach that can ensure that individuals with mental disorders understand information regarding the intervention method that the physicians have incorporated during caregiving. Information disclosure is the first step of informed consent since it allows the patient to acquire essential information concerning the available treatment methods. Patients with mental illnesses encounter difficulties in communication; hence physicians should adopt different strategies of ensuring that the patients understand the existing health information. Since patients with mental disorders cannot easily comprehend medical information during information disclosure, physicians and nurses should employ varied communication channels such as the use of charts, loudspeakers, symbols, and emblems to relay the vital health information. Moreover, during information disclosure, health care professionals should create an enabling environment that can ensure that patients with mental conditions are comfortable and not agitated. For instance, the patients should be moved to a place that is not crowded since individuals with mental disorders feel uncomfortable in crowded places such as general wards. By using communication aids such as large charts and symbols, the patients with mental conditions can easily acquire information during the disclosure stage, allowing the effective and reliable provision of informed consent. When health care professionals assist the patients in understanding the health information regarding the existing intervention measures, the patients acquire an opportunity to provide informed consent during caregiving.

Use of surrogate decision-makers/Family Members-Another measure that health care stakeholders can utilize to ensure the provision of informed consent among patients with mental disorders is the use of family representatives. Family members, friends, or relatives
can give consent on behalf of the mentally disabled patient. Since the goals of family members such as parents or siblings are to ensure that the patients access patient-centered care, they can easily make an informed decision on behalf of the patient. The use of surrogate decision-makers in providing informed consent has played a significant impact in ensuring the provision of effective informed consent among patients with mental health conditions. The bioethics issue of informed consent has brought a great impact on mental health care. This is because patients with mental health disorders face a challenge in providing informed consent during caregiving. Informed consent shows that a particular patient has been involved in collective decision making before the adoption of a particular intervention method. Modern health has recognized the significance of incorporating the views and opinions of the patients. This is because the opinions of the patient in regards to caregiving can help in improving the quality of care, thus resulting in patient-centered care. Moreover, informed consent depicts that health care professionals are focused on adopting integrated care, especially in mental health care.

Collective action towards achieving the goals of mental health care is one of the strategies that has been used to advance efficient mental health care across the Kingdom of Saudi Arabia. Through collaboration, health care professionals can share resources, expertise, and knowledge in regards to mental health with other health care organizations across the country. Informed consent also depends on the ability of the patient to understand the intervention methods and the nature of mental health diseases. During the provision of mental health care, health care professionals adopt a multi-faceted strategy that involves information disclosure and collective decision. The first step is to disclose relevant mental health care information. After assessing the severity of mental health disease, psychiatrists should divulge health information about a particular mental problem.
II. Confidentiality- Another important bioethics element is mental health care. Since psychiatric health is a controversial health issue that is surrounded by discrimination, prejudice, and underlying cultural and religious beliefs, physicians should ensure that they observe confidentiality in handling mentally ill patients. Health professionals should ensure the privacy and confidentiality of patients with mental disorders. Specifically, psychiatrists, counselors, psychologists, and nurses should not disclose patient health information to the general members of the public. This is because mental conditions face discrimination in society; the patients should be protected from ridicule and prejudice from the members of the society. Patient confidentiality is, therefore, an essential ethical issue in mental health care. Global health care stakeholders, such as the National Institute of Mental Health, WHO, and CDC, have promoted patient confidentiality in mental health care. Through comprehensive awareness creation, the organizations have created a viable environment for ensuring the observation of patient confidentiality in handling medical information such as diagnosis, prevention, and intervention methods concerning psychiatric disorders. Confidentiality focuses on the privacy of the patient’s medical information. Confidentiality is vital since it prevents unauthorized individuals from accessing the medical information of a particular patient. Mentally incapacitated patients value privacy due to the perception of mental illness in society.

Since mentally challenged individuals are discriminated in the local communities, health care professionals should ensure that the medical information is confidential. Private medical data about the diagnosis of a mental disorder should not be divulged to the public to avoid stigmatization and prejudice. In the case that health professionals need to share mental health data for research purposes, the identity of the patients should not be provided to avoid any negative consequence. Through observing confidentiality, patients with mental illness have been able to seek mental health care without the fear of facing stigmatization in society.
The Ministry of Health has also promoted tolerance towards people suffering from mental disorders. The members of the society are discouraged from believing in stereotypes that are associated with mental illness. For example, some people believe that Allah curses individuals suffering from mental illness. Confidentially, however, enables the patients to seek high-quality mental health care in clinical care settings.

**III. Conflict of Interest**- Another crucial bioethics issue in mental health care is the conflict of interest. Medical professionals encounter conflicting interests during the provision of psychiatric health services. The societal stereotypes and prejudices linked to mental illnesses, there are health professionals who may face challenges in providing standardized care to mentally disabled patients. Health providers, moreover, encounter a dilemma between achieving their goal of gaining profits versus ensuring that mentally incapacitated patients acquire patient-centered care. The presence of a conflict of interest reduces the quality of health care that is given to patients with diverse mental health conditions such as depression and schizophrenia. Although health professionals may develop an immense interest in ensuring that patients acquire high mental health, they are still obligated to ensure that they generate profits for the health care organization.

**IV. Therapeutic misconception**- Individuals who have mental conditions are likely to conflate the imperatives of research with diverse treatment aims. There is a need to ensure the observation of patient autonomy as well as cooperation among the patients suffering from different cognitive disabilities. Therapeutic misconception plays a crucial role in research that focuses on mental health. There is a need to understand the various dimensions of therapeutic misconception, such as treatment imperatives. Mentally incapacitated patients can participate in mental health research, thus help in promoting psychiatric literature. The main dimensions of therapeutic misconception include failure to understand the research goals, and benefits as well as a false expectation of individualized care.
V. Vulnerability/exploitation of mentally incapacitated patients - Another significant bioethics issue in mental health care is the exploitation of individuals with psychiatric conditions such as obsessive-compulsive disorder. Mentally incapacitated patients are vulnerable to exploitation since they are incapable of making beneficial health care decisions. Vulnerability is one of the significant issues that have hindered the achievement of health goals of mental health care. Unethical health care professionals and other health care stakeholders can easily exploit the mentally incapacitated individuals since they lack cognitive intelligence that can help them in identifying the best possible health intervention. However, health care stakeholders, such as the WHO, have been at the forefront of fighting for the rights of mentally incapacitated individuals in society. To achieve the goals of mental health care, the global health regulatory body has been encouraging developing and developed nations such as Saudi Arabia to create an enabling environment for initiating patient-centered mental health care in the society. Exploitation has been experienced in the process of adopting mental health care across Saudi Arabia. Patients with mental disorders are vulnerable to exploitation by unethical health care organizations as well as health care professionals.

Exploitation hinders the provision of high-quality health care. Moreover, exploitation also affects the level of access to mental care both in clinical and home-based care. The exploitation can occur either by limiting crucial resources that can be used to advance high-quality mental health care. Alternatively, a health care organization can mismanage the funds that are meant for establishing mental health centers. Vulnerability among patients with mental diseases has led to the provision of poor mental health services. Since a larger percentage of mentally incapacitated patients lack cognitive competence, it becomes difficult to undertake a collective decision-making process. Health care professionals, therefore, can make decisions that are meant for selfish gains as opposed to boosting mental health care.
Global health care bodies such as the World Health Organization have developed laws and policies that prohibit the exploitation of mentally incapacitated patients.

The laws and policies promote strict adherence to the standards of ethical behavior, such as respect for autonomy and the provision of patient-oriented care. Another vital element that has been examined by health care stakeholders is the safety of female patients with mental diseases. Since the female gender is more vulnerable than male patients, health care professionals are expected to observe fundamental ethical behavior to avoid issues such as physical and sexual harassment of patients suffering from psychiatric disorders. Most of the patients with mental problems cannot easily understand what the physicians are doing during caregiving. Therefore the Saudi Ministry of Health has been at the forefront of advocating for the need to prevent the exploitation of patients suffering from mental disorders. The adoption of ethical and moral behavior plays an instrumental role in enhancing mental health care since the patients solely rely on the decisions and behavior of the psychiatrists. Therefore, unethical medical personnel can exploit the mentally incapacitated patients since they are more vulnerable as compared to patients with other forms of diseases. Exploitation can also occur in the form of mismanagement of funds and medical equipment that are meant for mental hospitals. Exploitation hinders access to improved mental health services since it denies mental health centers the needed medical resources that can help in the achievement of the objectives and goals of mental health care.

4. a. ii Social Workers and Bioethics Practice in Mental Healthcare

Psychiatrist social workers have brought a tremendous impact on mental health care. Over the role of psychiatrists, social workers have evolved and played a crucial impact on the achievement of the goals of mental health care. Social workers within mental health care strive to ensure that individuals with mental health disorders acquire effective treatment as well as methods that they can use to cope up with the mental illnesses within the society.
Psychiatrist social workers also help in the prevention of mental disorders as well as other beneficial measures such as the provision of psycho-education and psychotherapy.

4. a.ii.1 Case Management and Support Services

Psychiatrist social workers handle mental health case management in the clinical care setting. The social workers that include: psychologists, psychiatrists, and counselors examine mental health cases and initiate a comprehensive measure that is focused on analyzing the underlying factors that affect a particular patient. Case management enables social workers to provide patient-focused care that enhances the quality of life of the mentally incapacitated patient. For instance, the psychiatrist social workers provide consultation and counseling services to patients with mental disorders. The process of providing psychosocial assessment plays an essential in ensuring that patients with mental disorders cope up with their conditions. The psychiatrist social workers, therefore, motivate the patients and create an enabling environment that can ensure that they learn how to live with mental health disorders. For instance, in the case that a particular patient is suffering from depression or post-traumatic stress disorder, the social workers should provide psychosocial assessment services that ensure that the patients can live with his or her conditions. By providing more information about coping strategies, the mentally incapacitated patients can easily cope up with the diverse psychiatric disorders. Psychosocial assessment enables the psychiatrist social workers to know how the patients are responding to the various intervention methods such as therapy.

The Saudi Arabian Ministry of Health has adopted policies that incorporate social workers in mental health care. Social workers, just like psychiatric nurses, helps in providing mental health care. Since the provision of mental health requires coordination of activities between different health stakeholders, social workers provide support services that enhance the health of the mental health patients. Social workers assist with case management. Social
workers assess and analyze different mentally disabled patients depending on the nature of the mental illness that they exhibit. For instance, social workers can develop a proper way of handling patients suffering from schizophrenia or anxiety disorders. Case management enables social workers to identify and isolate the factors that affect the behavior of mental health patients and how they are responding to treatment. Case analysis also enables the social workers to report their findings to the physicians and psychiatric nurses on how to handle the patients. Case management, therefore, enhances the quality of mental health care since they establish an efficient environment for the treatment and management of mental disorders.\textsuperscript{64}

Case management in mental health care plays a fundamental role in enhancing the quality of care. This is due to the fact that case management enables the psychiatrists, counselors, social workers, and family members to identify and implement the most appropriate intervention method. Case management can be undertaken based on several factors, such as the type of mental disorders, setting of care, and the age of the patient. For example, depression and anxiety disorders have a different effect on the children and aged individuals. Moreover, older people suffering from diverse mental diseases such as chronic depression and bipolar disorder can respond effectively to the home health care program as opposed to the hospital care setting.\textsuperscript{65} However, young adults with mental disorders should be given care in mental care hospitals such as asylums. Therefore, case management will enable the psychiatric nurses to handle each mental disorder or patient differently to identify a holistic approach that can be used to provide patient-centered care. Social workers, therefore, adopt strategies aimed at ensuring efficient case management in regards to a particular patient. The social workers undertake a comprehensive analysis and assessment of a particular mental disorder and its effect on the patient.\textsuperscript{66} For instance, the social workers can assess patients suffering from Post-traumatic stress disorder to examine the effect of the
disorder on the patients, the possible intervention strategy, pain management as well as coping up with the mental disease.

One of the factors that hinder the management and treatment of psychiatric disorders is the lack of coping strategies. In most cases, individuals with mental illness such as depression and bipolar disorders resort to a state of despair instead of adapting to their conditions. Therefore, health care organizations have embraced diverse strategies aimed at ensuring that the mentally incapacitated people learn how to cope up with the mental conditions.\textsuperscript{67} One of the strategies for coping with mental disorders is acceptance. Social workers encourage mentally incapacitated patients to accept the fact that they are suffering from a particular mental illness. Acceptance goes hand in hand with tolerance from the members of the society. Other people who do not suffer from psychiatric diseases should practice tolerance regarding individuals with mental illness. After embracing acceptance, the patients should change their lifestyle. Such individuals should avoid leading a solitary lifestyle that can trigger depression. Social workers encourage the formation of social support groups within the community to provide an enabling environment for coping up with the mental conditions.\textsuperscript{68} Through effective case management, social workers such as counselors can adopt a coping strategy that enables the patients to accept their conditions and thus lead to a normal life. During case management, the social workers examine each patient individually and explore other underlying conditions such as the prognosis as well as the possible management strategies that psychiatrists should adopt during caregiving. Case management leads to the adoption of patient-centered care since the health professionals adopt an intervention strategy that best suits a particular patient or group of patients.\textsuperscript{69} For example, if a social worker has interacted with a group of patients who are suffering from post-traumatic disorder, the social worker can identify the ideal disorder management strategy that can bring maximum benefit to the patients.
After a comprehensive analysis, the social worker can recommend if the patients should receive either hospital-based care or home health care. Patients who require hospital-based care can, therefore, be admitted to mental care centers such as asylum. However, aged mentally incapacitated patients can receive home-based care since they can interact with the family members. Case management enables health professionals as well as social workers to provide high-quality care that results in improved health outcomes.  

Individuals with psychiatric disorders such as bipolar disorder face stigmatization and discrimination within society. This is because mental illness is perceived to be a form of a curse that arises from the failure to observe social and religious doctrines in society. Hence patients who are undergoing psychiatric intervention face a big challenge in re-integrating into society. Social workers, therefore, play a crucial role in ensuring patients with mental health disorders co-exist with the members of the society. The Saudi Arabian Ministry of Health has recognized the critical need to ensure proper societal re-integration. The government health agency has adopted a comprehensive and evidence-based approach aimed at ensuring effective re-integration of the individuals suffering from diverse psychiatric disorders. One of the strategies that the Ministry of Health has adopted is the creation of awareness on the need to practice tolerance. Tolerance enables the members of the society to accept the presence of individuals with mental illness in society. Through coordinating operations with community-based organizations, the Ministry of Health has spearheaded the campaigns aimed at enlightening the local communities regarding the need to appreciate and co-exist with individuals with mental disorders. Co-existence with people who are undergoing treatment for mental disorders is a challenge to the members of the society since individuals without psychiatric disorders.
4. a .ii. 2 Psycho-Education

Another critical role of a psychiatrist social worker is to provide psycho-education to the mentally disabled individuals within the society. Global health care stakeholders such as the Centers for Disease Control and Prevention (CDC) have promoted psycho-education as a way of boosting the mental health of the members of the society. Psycho-education is a strategy in which mentally incapacitated patients acquire health information regarding their mental health care. Since most people in society lack information about mental health, there is a need to educate people about mental health disorders such as bipolar disorder and severe depression. Psycho-education enables people to acquire in-depth information about mental health and the causative factors. Therefore, social workers should ensure that the mentally ill patients, as well as the general public, acquire relevant information about mental health. For example, social workers can educate the public about the need to undertake preventive measures against mental health care. Moreover, the psychiatrist social workers can provide information regarding the co-existence of mentally incapacitated individuals with other members of society. The reintegration of individuals with mental problems has become a challenge within society. This is because mentally challenged people face discrimination and prejudice since they are perceived to be a threat to society. In some cases, mental disability is associated with madness and curses. Hence there is a need to educate the people about practicing tolerance to people with mental challenges. Tolerance to diversity is a critical strategy that facilitates co-existence with people with mental disabilities. The health stakeholders should adopt a sophisticated communication channel in educating people with mental problems since such individuals face communication challenges. The psychiatrist social workers should adopt various communication channels such as the use of audio-visuals, symbols, and charts to communicate mental health information to the patients.
The incorporation of psycho-education in has created a sustainable environment in mental health care. Psycho-education enables health care professionals to provide sufficient and in-depth information about a particular mental health problem such as bipolar disorder. Through adopting psycho-education, health care professionals underrate a comprehensive medical disclosure regarding a particular mental disorder. The health professionals ensure that patients acquire in-depth information about the etiology, symptoms, prevalence, treatment, and management strategies of a particular psychiatric disorder. The individuals who have diverse mental conditions such as obsessive-compulsive disorder, therefore, gain critical information that helps in coping up with mental disorders. One of the major challenges that face individuals with mental problems is the lack of medical information related to the specific psychiatric disorder. A more significant percentage of the patients do not understand the nature of the mental diseases, the symptoms as well as the intervention methods that can be adopted to treat and manage the diseases. Therefore, providing accurate and sufficient information plays a great role in informing the patients as well as the general public about mental health disorders. Psycho-education has a lot of health care benefits among patients suffering from mental disorders. For example, the incorporation of psycho-education helps in improving health outcomes.

Mental health care professionals who have recognized the benefit of psycho-education can play a vital role in improving health outcomes. This is because, through acquiring vital information in regards to the mental diseases, the patients can embrace collective decision making. Collaborative decision making allows the patients to make informed decisions that ensure that they take part in caregiving. For instance, the patient can identify the symptoms and help psychiatric nurses in the process of diagnosing mental disorders. Various mental problems such as severe anxiety disorder and aggressive behavior almost similar symptoms; hence they require a comprehensive assessment before diagnosis.
Psycho-education has been associated with improved mental health care across global nations. The Saudi Arabian Ministry of Health has adopted policies aimed at incorporating psycho-education in mental health care. Since the bioethics element helps in awareness creation, it promotes the adoption of patient-centered mental health care. For instance, patients who have the obsessive-compulsive disorder have benefited from psycho-education since they have access to etiological information that is related to the mental disorder. Psycho-education also promotes the management and prevention of mental health conditions. Since the patients have access to information about mental illnesses, they can adopt management as well as preventive measures, thus contribute to a reduction in the prevalence of mental disorders.

According to global health organizations such as WHO, the creation of awareness in regards to diseases play an instrumental role in the prevention of the diseases in the society. This is because the members of the community have sufficient information that enables them to adopt preventive measures. Another critical aspect of psycho-education in mental health care is the management of psychiatric disorders. Since mental diseases are chronic, there is a need to embrace long term management strategies. To cope up with chronic mental disorders such as bipolar disorders, the patients should acquire vital information about the management measures that can be undertaken both in the hospital as well as in home health care. The management of mental disorders is characterized by compliance with the medical regimen that has been prescribed by psychiatric experts. Individuals with mental diseases are expected to follow the guidelines that have been advanced by medical professionals as well as family caregivers. This is because the management of the chronic mental diseases depend on the level of adherence to the medical regimen as well as other lifestyle changes that the patients are expected to observe in the clinical care settings.
Psycho-education can either be undertaken as individual or group intervention. A group of patients who have a mental disorder such as anxiety disorder can be admitted to a psycho-education program. Alternatively, the program can focus on the individual patient in the case that it can result in maximum health benefits. However, health care organizations have promoted the adoption of group intervention since the patients can interact with each other and adapt to their situations. The management of mental diseases can either take place in the mental health care centers such as asylum or the home environment. Home health care has a lot of benefits since the patients can easily access to close family members such as parents and siblings. The love and care provided by the family members can enhance the management of mental health disorders. Therefore, psycho-education has brought a great impact on the adoption and implementation of mental health care in home health care in Saudi Arabia. Health care organizations should ensure that they incorporate psycho-education in their operations to improve health outcomes in mental health care.

4. a .ii. 3 Counseling and Psychotherapy

Psychiatrist social workers are also tasked with providing counseling and psychotherapy services. Patients with mental illnesses require continuous counseling so that they can prevent the onset of depression that may lead to other devastating actions such as suicide. Mental disability has been attributed to increased cases of despair, depression, and suicide. Hence health professionals such as psychiatrist disorders should ensure that they counsel the patients to motivate them and give them hope and energy to cope with their situations. Another vital role of social workers is to provide psychotherapy to mentally incapacitated patients. Psychotherapy is a medical intervention method in which health professionals undertake therapeutic intervention on patients with mental disabilities. Therapy is essential in treating mental disorders such as depression and bipolar disorders since it improves the cognitive capability of the patients within the clinical care setting.
Psychiatric social workers also undertake home visits and provide patient-centered care to mentally ill individuals. During the physical visits, the social workers acquire the opportunity of conducting a psychosocial analysis as well as the provision of proper medical care to the patients. The home visit allows health professionals to observe the welfare of the patients and monitor how they are responding to the various therapeutic sessions. Social workers also shape social integration among mentally incapacitated patients. The social workers develop a viable framework of integrating people with mental disorders into society.

Psycho-therapy refers to a type of talk therapy in which mental health specialists provide care to patients with mental diseases by analyzing the behaviors, symptoms, and thoughts of the patients. Psycho-therapy, therefore, enables mental health experts to interact with patients with mental disorders to find amicable intervention and management strategies.

Both counseling and psychotherapy help the patients to cope with mental disorders while acquiring patient-oriented mental health care. For example, through counseling, the mentally incapacitated patients learn the need to adopt effective management strategies that can assist in combating mental disorders. Another benefit of counseling is that it can foster the co-existence of patients with mental disorders with the members of the society. In most cases, mentally disabled patients face discrimination and prejudice in society. Therefore, mental health experts such as counselors can provide counseling to both the patients as well as their family members for the two parties to learn how to co-exist with one another in society.

Families with mentally challenged individuals are usually prone to depression and post-traumatic disorder due to the difficulty in dealing with the mentally incapacitated patients. Counselors have, therefore, recognized the need to provide counseling to the family members and educate them on how to interact with the mentally challenged individual in the family.
There are different types of psychotherapy that psychiatric experts can adopt in mental health care. For example, cognitive behavioral therapy focuses on the behavior displayed by patients with mental diseases and the possible intervention methods that can treat the disease. Inter-personal psycho-therapy is applied by developing a mutually beneficial relationship between the mentally incapacitated patient and the health care professional. In essence, the health care expert forges a close relationship with the patients and provides guidance and counseling that contributes to the management of the disease. The patient, therefore, realizes that even the psychiatric experts have developed immense interest in the treatment and management of the mental disease. Another form of psychotherapy is family or couple therapy. In this case, health care experts provide therapy to the family of the patient with the mental health condition in the presence of the patient. In case a couple is facing a mental disorder, they receive therapy together to learn how to manage the mental health condition. Just like psycho-education, psycho-therapy also improves health outcomes. This is because it helps the patients to cope up with the mental diseases as they undergo treatment and the management of psychiatric disorders.

4.b. Genetics & Cancer Care

Healthcare stakeholders such as health organizations, regulatory bodies and health consumers have focused on measures that aim at the realization of precision medicine at the home health care level. Precision medicine is a patient-centered care that explores critical medical interventions such as cancer genetic screening and the stem cell biology. Understanding the genetics of cancer in home healthcare has been characterized by the need to understand and overcome ethical challenges that are faced during the implementation process among healthcare professionals. There are ethical considerations that should be examined in order to ensure that cancer genetic screening process achieves its intended goals and objectives. The goals of cancer genetic screening, for instance, are to acquire more
information about the genetic factors that stimulate the growth of cancer cells in the human body. The process however, should adhere to the ethical and moral conduct. Issues such as patient’s consent should be considered in order to ensure that the cancer genetic screening process is observes the rights of the patient. There are genetic changes in cancer that contributes to the development of cancer. Hence, there is a need to undertake a comprehensive cancer genomics research by home health care providers in order to investigate the changes in cancer and how they present an opportunity for understanding the genetics of cancer.

The cancer stem cell is another important part in genetics of cancer. The cancer stem cell theory provides a hypothesis on how the development of cancer cells eventually results in tumors. Regulation of the genetic screening has brought a significant impact in cancer genomics research and intervention. By adopting a step-by-step regulatory measure, key stakeholders such as the International Cancer Genome Consortium have managed to develop laws and policies that ensure the observation of bioethics during the cancer genetics screening and cancer genome research not only at the hospital level, but also at the home healthcare level. The understanding of genetics of cancer has shaped the implementation of various interventions against cancer in home healthcare since it allows health professionals and researchers to adopt patient-centered interventions while observing the underlying ethical and moral factors in precision medicine.

4.b.i Genetics Screening and Stem Cell Biology

The changes in the genetic composition of body cells contribute to the stimulation and eventual formation of tumor cells that finally results in the development of cancer. Stakeholders in the field of healthcare have therefore adopted different techniques aimed at identifying the genetic changes that contributes to the formation of cancerous cells in the human body. The development of cancer majorly depends on the genetic make-up of the
human DNA. The most important way of identifying the genetic changes that occur in a cancer cell is to undertake DNA sequencing tests.

4.b.i 1. Genetic Changes in Cancer

Genetic changes in cancer occur in two major ways: acquired and germ line mutations. Acquired Mutations - Occurs when the genetic composition of the cells in the human body is damaged and destroyed. Acquired mutation is primarily caused by lifestyle conditions such as extreme usage of drugs such as tobacco. Moreover, the environment can also facilitate the process of developing cancer cells. Exposure to chemicals such as carcinogenic compounds can initiate gene deletion hence resulting into the damage of normal body cells. Acquired mutation thus results in sporadic cancer such as cancer of the colon. Conducting a DNA sequencing tests therefore can help in identifying the predisposing factors as well as the various therapeutic interventions that can be used to treat and prevent such cancers. The prevalence of acquired mutations has increased in the modern society. This is because the changes in lifestyle as well as the activities that occur in the environment. Severe drug usage as well as exposure to chemicals are the main risk factors that can cause acquired mutations. Healthcare organizations have created awareness on the need to embrace lifestyle behavior that can prevent the occurrence of acquired mutations.

Germ line mutations - This second type of gene mutation occurs when inherited genes of already exists within cancer cells. Genetic mutation can occur within one individual in a family. During reproduction, the mutant gene is transferred to the offspring leading to the infection of the genes of the offspring. Genetic mutation that is transferred by reproduction can occur in many generations. Genetic sequencing can therefore be used to determine if the mutant gene was inherited from a family member or acquired as a result of lifestyle conditions. Germ line mutations, however results in a smaller percentage of the cancer diseases. Gene inheritance can occur in several generations resulting into the transfer of
mutant genes from the parent to the offspring. The prevalence of germ line mutations however is lower than acquired mutations in the society. This is because technological advances have led to early detection leading to the adoption of effective measures that prevent such form of cancers from developing into full-blown cancer.\textsuperscript{103}

**DNA sequencing**- The DNA sequencing is important in the identification of crucial genetic changes that occur within the cancer cells.\textsuperscript{104} The adoption of modern technology in the field of medicine has brought a tremendous impact in promoting DNA sequencing. Before the process of sequencing begins, the patient is usually undertaken through counseling sessions. Counseling helps the patient to mentally prepare for the results of the tests. In some cases, the results may reveal the existence of germ line mutations which causes the development of the cancerous cells.\textsuperscript{105} Counseling has brought a great impact in the provision of information and guidance about coping up with the disease and the underlying genetic factors that relates to the disease. The process is therefore undertaken using advanced DNA sequencing machine that allows the monitoring of gene multiplication and deletion. Genetic sequencing is undertaken to identify the factor that drives the mutation process in the cancer cells.\textsuperscript{106} A representation of the chromosomes being sequenced must be assembled during the genetic sequencing process.

The human reference genome is important during the DNA sequencing tests since allows scientists to align the necessary genetic elements in the cell. Another crucial step that is undertaken is to compare the cancerous cells with the normal cells to help in tracing the catalyst to genetic mutations.\textsuperscript{107} This process is important since even cells that do not undergo mutation also accumulate somatic mutations. Therefore, scientist must ensure that the test occurs both in the normal and cancerous cells. After the identification of the mutant genes in the chromosomes, the next critical stage is to classify and characterize genes depending on
their rate of mutation. The speed of mutation affects the rate of forming cancerous cells. The genetic mutations can occur in the following two ways; germ line and acquired mutation.

4.b.i 2. Opportunities in Cancer Genomics Research

In order to understand the genetics of cancer, it is important to conduct a comprehensive genomics research. Research helps in the collection, analysis and interpretation of significant information surrounding human genetics and the development of cancer. Since cancer genomics is a relatively new area of study in the field of medicine, the use of research has been the most suitable tool of collecting empirical data about cancer. The continuous research on cancer genomics has been supported by global healthcare cancer research bodies as well as governmental organizations. Cancer genomics research therefore has gained popularity in the contemporary society.

Utilization of large-scale research studies- The International Cancer Genome Consortium has played a crucial role in the global cancer genomics research. Since its establishment in 2007, the intergovernmental research organization has been at the forefront of promoting and undertaking evidence-based cancer research across the globe. The research body plays an essential role of collecting, integrating, analyzing, sharing and publishing information about genetics of cancer. In collaboration with other organizations such as National Cancer Institute has developed the Cancer Genome Project that seeks to advance the field of genetics of cancer by conducting research, genome sequencing tests and publication of research data for global use. The Cancer Genome Project is funded by several organizations including the National Human Genome Research Institute to help in conducting research and genetic sequencing. The project has helped in developing diverse intervention approaches that are aimed at managing and preventing the occurrence of cancer. Through undertaking genetic screening, testing and gene sequencing, scientists and physicians have managed to develop viable cancer intervention approaches such as gene
therapy. The coordinated action aimed at boosting genomic research has improved the understanding of genetics of cancer as well as the continued research on the prevention and treatment of cancer. Since the increase in the number of cancer patients across the globe, there has been an increasing need to adopt ways of managing the disease. Cancer prevention has also been a priority of global health organizations. However, the major focus has been on how to develop viable intervention strategies that can help to eradicate cancer in the world. According to the Cancer Genome Project, one of the ways that can be used to fight the genetic disorder is to improve research on the field. Genetics of cancer is characterized by the identification of genetic changes, cancer genomics research and the challenges that affect the understanding of the relations between cancer and genetics. The genetic sequencing process is critical in the process of investigating the underlying issues in relation to the genetic mutation of cancer cells. The International Cancer Genome Consortium has played an essential role in the acquisition of information and knowledge about the genetics of cancer and the adoption of effective intervention in the treatment and prevention of cancer.

Healthcare professionals encourage that people should seek earlier detection by going for screening in healthcare centers. Research has found out that genetic testing and screening helps in isolating the cancer cells hence helps in diagnosis. During the screening process, it can be detected if the existing cancer cells have been caused by either acquired or germ line mutations. However, late diagnosis may result in the death of patients since it becomes difficult to embrace effective intervention methods.

*Expand the current genomic methods to investigate molecular basis of clinical phenotypes of cancer*- Another important element in genetics of cancer if the role of technology and how it can assist in the research of molecular basis of clinical phenotypes of cancer. The advancement of technology in the field of biomedical sciences has boosted the knowledge of different phenotypes of cancer. Scientists and health professionals apply the
knowledge of the clinical phenotypes of cancer to understand the stimulation of the growth of cancer cells and how they finally result in tumors. Healthcare organizations therefore are expected to adopt advanced technology that can improve the screening, tests and cancer diagnosis.\textsuperscript{117} Modern technology is also crucial in the treatment process. Alongside basic treatment processes such as chemotherapy therapy, modern technology enables health professionals to adopt technologies such as targeted therapy. Targeted therapy utilizes advanced medical equipment to alter the behavior of the mutant genes. Moreover, the therapy focuses on reducing the abilities of mutant genes that cause cancerous cells within the human body.\textsuperscript{118}

The cancer genome project conducts research and publishes the cancer-based literature in the cancer data base. The database provides information that relates to the latest findings, historical background, technological advances in biomedical sciences and the role of a collective action towards the fight against cancer across the world. Another vital role that cancer research has highlighted is the handling of patient information in regards to cancer.\textsuperscript{119} Cancer patients are likely to face discrimination both at their workplace and in the society. The adoption of more advanced genomic methods has brought a great impact in the generation of crucial information about cancer genetics. Since there are several underlying factors that can contribute to gene mutations, research bodies have focused on collecting viable information that can help in understanding the dynamics of cancer genomics. Therefore, The International Cancer Genome Consortium together with other organizations has spearheaded the adoption of anti-discrimination laws and policies.\textsuperscript{120} The Genetic Information Non-discrimination Act of 2008 was adopted to help in eradicating discrimination targeting individuals diagnosed with cancer.

The provisions of the law argue that individuals or social groups should refrain from practicing discrimination among people with different types of cancer in the society. The
laws and policies hence have played a significant impact in reducing cancer discrimination in the United States and Middle East nations among other countries. Moreover, healthcare organizations and scientist who access the private patient information should not share to unauthorized individuals such as the general public.\textsuperscript{121} Global organizations such as Centers for Disease Control and Prevention have also highlighted the importance of continued cancer genomics research in order to enhance the understanding and therapeutic interventions. Since technology advances at a faster rate, there is a need to embrace comprehensive cancer research, screening and diagnosis techniques.

The understanding of cancer stem cell biology has played a fundamental role in the development of immunotherapy that has been used to treat cancer. Crucial elements in cancer stem cell biology such as the stem cell model, genetics, epigenetic, tumor, and microenvironment and cancer immunotherapy have created an enabling environment for the adoption of intervention therapy for cancer.\textsuperscript{122} The relationship between genetics and epigenetic for instance enhances the knowledge on the various cancer-causing agents in the immune system. Therefore, the advances in the knowledge and information on the relationship between epigenetic and genetics have helped in the process of developing cancer therapeutic intervention. Health stakeholders across the globe should conduct more research on the cancer stem cell biology and how it can help future generations in the fight against cancer.\textsuperscript{123} The process should be undertaken by the latest technology available to improve efficiency. This is because understanding the genetics of cancer is very difficult since it involves the study of complex DNA sequence. For instance, cancer screening machines used in the 20th century should not be used in the 21st century due to the rate of technological revolution across the globe.\textsuperscript{124} The research findings should also be published online to allow easy access by health professionals and medical researchers in different parts of the world.
4.b.i 3. Challenges in Cancer Genomics Research

Despite the collective action among different Cancer Genomics Organizations, several challenges still occur in the field. The challenges have hindered the desire to improve genetics of cancer and the adoption of better intervention methods.

*Acquiring high-quality biological samples*- Global research bodies have faced the challenge of finding high quality biological sample. High quality biological samples can enhance cancer genomics research since they are used in the genetic sequencing process.\(^{125}\) However, finding the ideal biological sample is very difficult. In most cases, researchers encounter a challenge in finding subjects with high quality biological samples. This is because the moral issues surrounding genetic testing using human subjects. Another reason that has caused limited number of top-quality biological samples is the fear of genetic discrimination.\(^{126}\) Health consumers fear becoming test subjects since they know that their medical information may be known by the public. The high prevalence of genetic discrimination in the society makes people to avoid participating in the cancer genetic screening and testing.

*Problem of identification of the genetic changes that initiate cancer development*- Another limitation occurs during the isolation of the genetic elements that cause cancer. Various cancer cells are not linked to a particular gene. The occurrence of multiple gene mutations makes it difficult to identify the genetic changes that cause cancer development.\(^{127}\) Moreover, the interaction between the human genes and the environment can also cause cancer. The researchers have thus faced difficulties in isolating the mutant gene that speeds up gene mutation by either multiplication or deletion. Most countries especially the third world nations have not embraced modern technology hence they cannot carry out effective DNA genome sequencing program.\(^{128}\) A country’s economic development therefore affects the level of scientific research that such a country embrace. Highly developed nations such as
the US, Middle East nations, Russia and the United Kingdom have embraced comprehensive cancer genome research.

4.b.i 4. Stem Cells and Cancer Stem Cells

The focus on cancer genomic research has shaped the understanding of cancer stem cells and how it can influence the adoption of various therapeutic interventions. Global health organizations such as CDC and cancer genomics research organizations have been at the forefront of promoting advanced cancer stem cell research aimed at developing strategies of preventing and treating cancer. The understanding of critical subfields such as tumor microenvironment is instrumental in investigating the factors and conditions that promote the development of cancerous cells in the immune system as well as the relation between genetics and epigenetic. The trends in precision medicine have been characterized by various progress in cancer stem cell biology such as cancer stem cell, clinical trial of cancer stem cells, cancer immunotherapy and tumor microenvironment. All these elements in cancer stem cell biology have played a vital role in the understanding of the cancer stem cell as well as the adoption of therapeutic interventions against cancer.

According to the stem cell theory, the initiation of the growth of cancerous cells is undertaken by a specific subgroup of tumor cells. The subset of cancer cells increases the growth of tumors since they have the ability to undergo self-renewal. Moreover, the cancerous cells undergo a steady but slow replication process hence acting as a barrier to the therapeutic techniques such as radiotherapy and chemotherapy. Through the process of differentiated progeny, the stem cell hypothesis has a great impact on therapy that healthcare professionals embrace. The stem cell model has shaped the understanding of the relations between normal stem cells and the cancerous stem cells. Moreover, the hypothesis helps in generating crucial information on how the cancer stem cells trigger the growth of tumors.
4.b.i 5. Clinical Trial of Cancer Stem Cells

*Genetics and epigenetic* - In the modern clinical settings, the study of genetics has focused on epigenetic and how it affects the prevalence of genetic disorders. However, there are other heritable factors that affect the immune system. The epigenetic refers to the factors that control the immune system beyond the genetic composition.\(^{133}\) Epigenetic are the changes that affect genetic activity and prevalence without changing the sequence of the DNA.

Epigenetic affects the cognitive development of an individual. The occurrence risk factors such as addiction, stress and depressions act enhance the development of cancer cells in the body.\(^{134}\) Health consumers with mental problems such as Post Traumatic Stress Disorder, severe depression and schizophrenia have a higher chance of facing a change in genetic expression and gene activity.\(^{135}\) Epigenetic is characterized by the analysis of the environmental elements, social issues such as stress as well as health issues such as nutrition. Although a larger percentage of health consumers believe that cancer is primarily caused by hereditary factors, there are other elements that cause cancer without interfering with the DNA sequence. The health issues such as nutrition can also result in the development of cancer cells. The presence of lifestyle issues such as obesity and consumption of junk food can enhances the risk of acquiring cancer. Therefore, issues such as stress and trauma can also increase the risk of developing cancerous cells.\(^{136}\) This is because such issues affect the mental ability of individuals hence making them prone to other diseases. However, the alteration of an individual’s DNA is also another cause of cancer. The traits can be inherited from one person to another. Inherited cancer cells can be identified during the screening process. Cellular differentiation is one example of epigenetic that occurs in the human body.\(^{137}\)
Damage that occurs in the composition of the DNA is also likely to cause epigenetic changes. Although DNA repairs occur, epigenetic occur at the site of the damage. Epigenetic also affects gene expression as well as the gene activities. Although epigenetic does not alter the DNA sequence, it affects the gene activities. This influences gene differentiation and progression. Therefore, continuous impact on the gene activities results in the growth of cancerous cells that eventually form tumors. Both genetic and epigenetic elements play an effective role in the development of cancers. The epigenetic changes that are caused by cell differentiation also occur during the cell division process. The process can also be inherited from one generation to the next.

_Tumor microenvironment_- The tumor microenvironment refers to the essential elements that surround tumor cells. The elements include blood vessels, molecules, cells and fibroblasts. Tumor microenvironment has brought a great impact in the understanding of the operations of cancer stem cell biology since it influences the operations of the body immune system. Tumor microenvironment affects the immune system by promoting tumor angiogenesis, releasing signals as well as initiating peripheral immune tolerance. Through releasing signals in the immune system, tumors are capable of influencing the growth rate of cancerous cells in different parts of the immune system. Both the immune system and tumor microenvironment has developed a relation in which each party affects the operations of the other. For example, the immune cells in the microenvironment trigger the growth of cancer cells. The immune cells also make the cancer cells to evolve since they undergo changes such as differentiation and multiplication. There are several important elements in the tumor microenvironment including vasculature, enhanced permeability, and hypoxia.

In vasculature, a higher percentage of the cancerous cells are formed at the epithelial tissue in human body. Vasculature prevents tumors from growing longer than 2mm in
diameter. The process also hinders the formation of new blood vessels as well as the production of the vasculature tissue.

In enhanced permeability, the cancerous cells develop molecules in the blood stream. However, non-cancerous cells do not have the ability to accrue molecules around the blood stream. Tumors have enhanced permeability hence result in inflammation.\textsuperscript{143} Scientists and researchers have therefore found out that tumors have an inflammation effect. Moreover, the interaction with other elements in the body’s immune system results in the development of a permeable vasculature.

The most essential feature of tumor microenvironment is hypoxia. Tumor microenvironment can therefore be said to be hypoxic.\textsuperscript{144} However, one effect of hypoxic environment is that it results in genetic imbalance in the immune system. The occurrence of genetic imbalance increases the rate of cancer progression, cell migration and the eventual development of cancer.

There are different clinical implications of tumor microenvironment. One of the most common areas in which the elements of tumor microenvironment have been applied is in the production of drugs. Information about tumor microenvironment and its relation to the immune system has been used to develop cancer therapies and other drugs that are used in the fight against cancer.\textsuperscript{145} The stroma cells influence the process of developing therapies of cancer. During the development of cancer therapies, the antibodies and kinase inhibitors are used to ensure the manufacture of effective cancer drugs. The development of cancer therapies has brought a great impact in the fight against the disease.\textsuperscript{146} Moreover, the increased understanding of the cancer stem cell biology has also played a crucial role in enabling the adoption of various cancer intervention techniques across the globe.

\textit{Cancer immunotherapy}- Cancer immunotherapy can be grouped into active, passive and hybrid immunotherapy. Cancer immunotherapy stimulates the immune system to treat
cancer. The major effect of cancer immunotherapy is to enable the body to fight cancer naturally. There has been a comprehensive research studies on cancer immunology and oncology has shaped the understanding of the various factors that affect the process of cancer immunotherapy. The cancer-causing cells contain tumor antigens which react and bind with the antibody that is found in the immune system. The reaction between the antigen and the antibodies results in the development of natural treatment of cancer.

**Cellular immunotherapy** - The major composition of cellular immunotherapy is dendritic cell therapy. The therapy is responsible for initiating an anti-tumor response that helps in targeting cancer antigens. The process occurs by incubating blood within the cancerous cells’ antigens before activation of the whole process. The subsequent step is to mix dendritic cells with the cancer-carrying donors in order to induce a comprehensive immune response. The antibody types are also another important factor that affects cellular immunotherapy. The process known as conjugation ensures that cellular immunotherapy occurs within the stipulated time frame and also within the target cancer cells. Another feature of conjugation is monoclonal antibodies that lack any elements.

The monoclonal antibodies initiate the reaction with the antigens that exist in the tumors. The cancer therapies and other critical process such as chemotherapy are influenced by cellular immunotherapy. Another important event that occurs in cellular immunotherapy is human and non-human balance. The balance facilitates the processes that occur between the antigens and the antibodies hence resulting into the creation of an environment that inhibits the growth of cancerous tumors.

**Cytokine therapy** - Cytokine modulates the existing immune responses. This process is thus used to produce cancer therapies by initiating an immune response. The immune system also produces interferon that fights the various forms of cancerous cells in the body. The interleukin on the other hand is responsible for treating malignant cancer especially
The periodic cytokine therapy inhibits the production of tumors hence leading to the eventual treatment of the cancer. Health professionals and other health stakeholders have recognized the significance of cytokine therapy in the fight against different types of tumors. Another strategy that has been adopted is through combining of several immunotherapies in order to boost anti-tumor response.151

The main role of combining diverse immunotherapy is to initiate a comprehensive and evidence-based treat of cancer. Since cancer treatment is a complex process, there is a need for an effective process that is backed up with empirical evidence. Therefore, the combination of various immunotherapies can result in the adoption of a more efficient cancer treatment therapy.152 Moreover, the process of combining diverse immunotherapy also helps in developing the preventive medicine for cancer. Cancer prevention has become an important issue in modern medicine. Therefore, health professionals have been seeking ways that can be used to effectively prevent the development and growth of cancerous cells.

Genetic pre-testing - Diverse health stakeholders such as health professionals, regulatory bodies, health consumers and the members of the society have called for the adoption of affordable cancer therapies.153 This is because cancer treatment is expensive hence unaffordable by a larger percentage of the health consumers. The processes of treatment are also characterized by mental distress and pain hence the need to adopt preventive measures. Pre-testing leads to earlier detection that also boost the quality of treatment. The main preventive measure that has been adopted is genetic pre-testing. Individuals are encouraged to undergo cancer genetic testing to identify the occurrence of cancer in its earlier stages.154 It is easier to treat cancer in its initial stages as compared to the final stages. Genetic pre-testing enables health consumers to adopt preventive mechanisms such as lifestyle change and nutrition. Moreover, the tumor mutational burden shows the general cost of various immunotherapy and cancer medications. Global healthcare bodies
such as the CDC and have approved the use of genetic test to prevent cancer through earlier diagnosis and prevention. Genetic testing enables health consumers to know the type of cancer-causing agent that has led to the disease.

4.b.ii Balancing Implementation of Precision Medicine and Ethical Principles

Implementation of health practices of genetics and cancer care in home healthcare are guided by set of regulations. The regulation of genetic testing and screening is a vital aspect in the implementation of cancer stem cell biology in the treatment of genetic conditions such as cancer.\textsuperscript{155} Regulation prevents the healthcare organizations from conducting genetic testing that can have an adverse health effects among the patients. Since genetic testing involves the examination of the genetic changes that contribute to cancer, there are ethical and moral issues that must be observed during the testing and screening process. The essential issues in the regulation process include:

4.b. ii. 1. Collection, Misuse, and Misinterpretation of Scientific Data

The regulation of the cancer screening and testing is aimed at streamlining the collection, use and interpretation of scientific data.\textsuperscript{156} Failure to regulate the process can result in misuse and misinterpretation of the data related to the cancer stem cell biology. The stakeholders such as healthcare professionals and medical researchers first embark on the collection of scientific data from health consumers. During the collection of data, the health professionals and researchers must seek informed consent from the volunteers as well as patients who have sought cancer genetics screening and testing. Individuals who seek cancer screening as well as research volunteers provide accurate data in regards to their medical history and the presence of cancer in their family genealogy.\textsuperscript{157} Through understanding the opportunities for cancer genome research as well as the existing challenges, healthcare stakeholders can adopt a long-term intervention of cancer treatment and prevention. There is a need to focus on the challenges such as difficulty in getting high quality biological samples.
For example, the research bodies should create awareness on the importance of a collective action in the fight against cancer as well as cancer genome research. Health consumers should be allowed to participate in the DNA sequencing tests to enable the scientists to develop evidence-based findings about the genetics of cancer.\textsuperscript{158} Moreover, in order to address the challenge of complexities of genetic mutation, the health stakeholders should adopt modern technology that can isolate the genes that cause cancer during the genetic sequencing process. The clinical professionals therefore conduct an in-depth cancer genetic testing before collecting and recording the findings. The interpretation of the findings is an important factor since it determines the best intervention method that can be adopted during the treatment of cancer.

\textbf{4.b. ii. 2. Regulation in Genetic Testing}

The regulation process is overseen by various government health agencies as well as other healthcare stakeholders. In America, for instance, the regulation of genetic testing is conducted by Centers for Medicare and Medicaid Services and Food and Drug Administration.\textsuperscript{159} These federal agencies have adopted a multi-faceted approach aimed at controlling the activities of healthcare organizations as they undertake genetic testing and screening process. Other stakeholders such as International Cancer Genome Consortium, WHO and CDC also play an integral role in regulating genetic testing and the research on cancer stem cell biology. There are three crucial elements that occur during the regulation of gene testing. The three elements, analytical validity, clinical validity and clinical utility all shape the regulation of cancer genomics as well as the screening and testing process.

\textit{Analytical validity}-the regulatory bodies are mandated to know how the genetic testing will predict the genetic variations that occur in a cell.\textsuperscript{160} The FDA therefore must regulate the genetic testing process to ascertain how the tests conducted by clinical professionals and scientists will provide more knowledge on the genetic changes that occur in a cell. Moreover, the analytical validity strives to collect information on the effect of the
changes in the composition of the DNA and how they can trigger the onset of the growth of tumors.

**Clinical validity** - The next regulatory procedure is to determine how the genetic tests conducted are related to the emergence of cancer. Since gene testing and screening is conducted to identify and isolate cancerous cells from normal cells, the regulatory bodies should ensure that the tests are focused towards achieving the goals and objectives of gene testing. The federal regulatory agencies hence should ensure that the genetic tests attain a clinical validity before the findings are implemented in the treatment of cancer.

**Clinical utility** - This section examines how the genetic tests and screening process can provide crucial data about the diagnostic tests, treatment and prevention of risk factors especially cancer. The gene testing should possess a clinical utility by providing important framework that can be used in the fight against cancer. Clinical utility is an essential regulatory role in gene testing and cancer stem cell biology since it highlights the role of doing the screening and the tests. Moreover, the regulatory bodies must enforce the bioethics during genetic testing and screening. Regulation has also promoted the adoption of precision medicine in the treatment and prevention of genetic diseases such as cancer. This is because stakeholders such as healthcare organizations as well as health consumers associate precision medicine with a high quality and patient-centered care that is aimed at achieving the individual’s health goals. Health consumers are aware that precision medicine is aimed at boosting the health consumer’s quality of life.

**4.b. ii. 3. Enhancing Patient Understanding of Precision Medicine**

The emergence of individualized medicine has brought a great revolution in modern healthcare. As opposed to conventional medicine that aimed at providing care to patients in a health care setting, precision medicine is a patient-centered care in which health professionals provide individualized healthcare depending on a patient’s genetic composition, lifestyle and
Precision medicine moreover is a medical technique that seeks the best and most inclusive intervention strategies by examining patient-specific factors such as the DNA, susceptibility to diseases and other underlying factors such as nutrition and lifestyle of the people in the society. Stakeholders in the field of healthcare such as healthcare professionals, and global health organizations such as WHO and the Centers for Disease Control and Prevention (CDC) have adopted various measures aimed at ensuring that health consumers understand the ideology of precision medicine.

*Creating extensive awareness of the role of precision medicine*—Since precision medicine is a novel medical strategy, there is a need to create awareness on its importance so that health consumers and other stakeholders can recognize the importance of precision medicine. Healthcare organizations should provide information to the health consumers about the significance of precision medicine. Through highlighting the importance of precision medicine on the health of the individuals in the society.

The awareness creation strategy should be characterized by providing precise, accurate and comprehensive information about the role of precision medicine and how it can improve the treatment and prevention of disease and mental disorders. Healthcare professionals should adopt various communication channels such as social media sites, face to face meetings, and emails communication. Some of the benefits of precision medicine that should be highlighted include:

*Prediction of a patient’s susceptibility to a disease*—Precision medicine allows healthcare providers such as physicians and advance practice nurses to predict how a patient is susceptible to a particular disease. Precision medicine provides a customized care that allows physicians to identify how a patient can respond to a particular disease or mental condition. Health consumers have different rates of susceptibility to a particular disease. For
instance, there are individuals who are more susceptible to a various disease such as cancer as compared to other individuals. This is because there are underlying factors such as the genetic composition as well as the lifestyle of a person that affects the occurrence of diseases. Therefore, customized care enables physicians to predict the susceptibility of a patient in regards to a particular health condition.

*Improved disease prevention, detection and treatment*-Another benefit of precision medicine is that it results in improved disease prevention, detection and treatment. Precision medicine provides an individualized care that focuses the provision of care by analyzing the genetic factors of a patient and how they relate to the disease. As opposed to normal healthcare services that are provided in clinical care settings, precision medicine enhances the detection and treatment of a particular disease. Alternatively, precision medicine has enhanced the prevention of diseases since it allows health providers to undertake an in-depth analysis of the medical history, and susceptibility to diseases. Through the ability to conduct a comprehensive analysis of a patient’s medical history and prevailing health conditions, precision medicine can result in improved cancer diagnosis, treatment as well as the adoption of preventive approaches.

*Improved quality and access of patient-centered healthcare*-Another benefit of precision medicine is that it enhances the general quality and access of healthcare across the population of health consumers. One of the reasons why developed nations such as the United States have adopted precision medicine is because it improves the quality and access of healthcare. Unlike the normal healthcare, precision medicine plays a vital role in the achievement of healthcare goals. This is because precision medicine provides an individualized care that enables the healthcare providers to realize the health goals of healthcare consumers. Therefore, health organizations have recognized the significance of
implementing precision medicine to treat genetic conditions such as the growth and
development of cancerous cells and tumors.

4.b. ii. 4. Supporting Clinical Decision Making

Precision medicine has played an essential role in enhancing the quality of healthcare through supporting decision making in clinical care setting. Inclusive decision-making process is one of the factors that have promoted the acquisition of individualized care that is aimed at identification of a disease, measure of susceptibility, treatment as well as prevention of diseases and disorders.\textsuperscript{171} Through undertaking collective decision making, healthcare professionals and patients can decide on the most effective intervention measure that can enhance the quality of life of the patient. Precision medicine largely depends on the decisions that health professionals make in conjunction with patients during the provision of individualized care. To ensure that the clinical care is customized according to the health needs of a specific patient or a group of patients suffering from a similar disease, there is need for agreement on the various interventions that will be used during treatment.

Healthcare professionals should support clinical decision-making during care giving by providing sufficient information to the patients. Information disclosure plays fundamental role in the implementation of precision medicine.\textsuperscript{172} Both information disclosure and seeking of informed consent of the patient have shaped the diagnosis, treatment and prevention of emerging diseases such as cancer. Through making decisions together, health professionals can improve their relations with the patients. This is because the patients feel that the physicians are focused towards ensuring that they achieve their healthcare goals. Moreover, information disclosure improves the adoption of precision medicine by enabling healthcare professionals and patients to understand vital processes such as cancer genetics and the stem cell biology.\textsuperscript{173} There is a need for a collective decision making on the strategies that should be adopted during depending on a patient’s germ line DNA as well as the susceptibility to
diseases and genetic conditions such as cancer. Collective decision making can also allow the health professionals, family members and the patient to reach an agreement on the need to adopt a particular disease intervention method. In case that the physician has recommended an intervention technique such as gene therapy or chemotherapy, collective decision making can ensure that the patient agrees on the most suitable treatment method.

To effectively implement precision medicine, healthcare stakeholders should embrace coordination of information between the attending physician, the resident nurse, the patient as well as the family members. For instance, if a patient has sought cancer genetic screening, the physicians and patient should make critical decisions in the presence of other health professionals such as ethical consultants, advanced practice nurses and counselors. Through supporting clinical decision making, health stakeholders can improve the relationship with the patients hence promoting an efficient precision medicine.

**4.b. ii. 5. Supporting Family Communication and Outreach**

Another essential element in the adoption of precision medicine is the need to support family communication and outreach. There are important ethical and moral issues that characterize the adoption of individualized care such as cancer genetic screening and the incorporation of stem cell biology in combating cancer. Therefore, there is a need to support family communication since family members of the patient plays a crucial role during decision making. Families of the health consumers need to make sound decisions in regards to the intervention methods that a patient should seek. Effective communication within a family makes the work of health professionals easier during the implementation of precision medicine. By including the family members or close relatives during healthcare decision making, health professionals can acquire information that improves the provision of customized care. For instance, the patient may not be in a position to provide comprehensive information about his or her medical history to the health providers.
The patient may be having communication difficulties due to the existing health conditions. In such a case, family members are consulted in order to provide information regarding the history of the disease, the measures that the patient has undertaken as well as the religious beliefs. Moreover, in case the patient cannot provide informed consent on vital medical interventions such as genetic screening and testing, the family members are allowed to give informed consent on behalf of the patient. Family members are in a position to provide important information that may help in the course of treatment and disease management. For example, the family can provide viable information on how the patient has been responding to earlier interventions in regards to a particular disease. Family members can also assist physicians to know the prevalence of genetic disorders such as cancer within the family lineage. Therefore, healthcare stakeholders should create an enabling environment that can boost communication between the health providers and the patients as well as their families. One way that can be used to support family communication and outreach is to involve the family during decision making and other vital processes such as ethics consultation. Health professionals should include the family members during key decision-making processes including ethics consultation. This will provide the patient’s family to present their views and opinions in relation to a particular intervention method such as cancer genetic screening, chemotherapy and gene therapy. Moreover, the family will develop a good relationship with the attending physicians and the advanced practice nurses.

Healthcare organizations and health stakeholders have recognized the increasing need to adopt ethics consultation programs during the implementation of precision medicine. Ethics consultation plays an instrumental role in solving ethical and moral dilemmas that occur during care giving. In modern society, healthcare professionals and patients have encountered conflicts concerning the adoption of various intervention methods. For example, ethical issues such as end of life care and advances in biomedical sciences such as gene
therapy have caused conflicts during care giving. Conducting a case consultation therefore plays a critical role in solving of ethical conflicts that arise in clinical care settings. Supporting family communications and outreach therefore plays a crucial role in the implementation of precision medicine. The emergence of precision medicine in the intervention of diseases and genetic disorders such as cancer has led to the adoption of ways of managing such diseases. For instance, cancer genetic screening, molecular diagnosis, gene therapy and prevention initiatives have shaped the adoption of precision medicine. Healthcare professionals should create an extensive awareness that target the patient’s family members as well as the members of the society. The awareness programs should highlight the role that family members can play in providing informed consent on behalf of the patient as well as in participating in vital decision-making process. Families should use both verbal and non-verbal communication cues to initiate communication that is targeted towards improving the quality of care. Healthcare organizations can support family communications by highlighting its benefits during the provision of precision medicine.

4.c. Conclusion

The adoption of bioethics has, therefore, enhanced mental health care in modern society. Developed nations such as Saudi Arabia have recognized the importance of incorporating bioethics practice to spearhead the provision of mental health care services in the nation. Ethical and moral behavior creates a sustainable environment for the provision of high quality and patient-centered health care. Moreover, bioethics practice results in the implementation of observation and addressing of critical elements such as patient autonomy, beneficence, informed consent, therapeutic misconception, exploitation, and confidentiality in mental health care. The incorporation of a bioethics has the capability of causing reforms in health care within the nation. This is because ethical and moral behavior enhances the relationship between health care providers and the patients as well as members of the
community. Patients with mental problems, for instance, can acquire patient-centered clinical care in case the health professionals apply the fundamental ethical behaviors such as beneficence, informed consent, and respect for autonomy.

The focus of the department of health is to spearhead the adoption of effective mental health care. Moreover, another area in mental health care that has been enhanced by bioethics behavior is the exploitation of mentally incapacitated patients. Due to the societal based prejudice that individuals with mental disorders face, they are usually vulnerable to exploitation. Unethical health professionals can easily ignore the standards of care to achieve selfish profits. For example, patients can receive low-quality care since they cannot comprehend the type of intervention method in clinical care settings. Moreover, such patients usually face the challenge of giving informed consent during caregiving. Critical bioethics elements such as patient autonomy and justice play a crucial role in improving the mental health of the people through the management of mental disorders. Global health care bodies such as the National Institute of Mental Health, the Saudi Arabian Ministry of Health, and the WHO should promote the efforts aimed at boosting mental health care in modern society.

The implementation of precision medicine has therefore revolutionized modern healthcare. Through the adoption of individualized care, precision medicine allows health professionals to undertake patient-centered interventions. Precision medicine also enables health professionals to apply the ethical and moral behavior during care giving. For instance, intervention techniques such as cancer genetic screening, testing, molecular diagnosis and gene therapy are conducted depending on the genetic composition of a particular patient. However, the adoption of individualized medicine should be characterized by the observation of ethical and moral rights. Health professionals should ensure that they apply the ethical considerations that can result in the adoption of interventions methods that satisfy the needs of the patients. For instance, during the process of genetic screening and testing, health
providers should ensure that patients provide informed consent before any medical procedure is undertaken. Informed consent and information disclosure foster the participation of health consumers in the treatment process. Precision medicine for instance explores the genetic changes that occur in cancer as well as the stem cell biology and how they contribute to the stimulation and growth of tumors.\textsuperscript{193}

Another significance of precision medicine is that it has led to an improved understanding of the operations of cancer stem cells and how they cause the growth of cancer. Healthcare experts have managed to study the cancer stem cells of patients leading to the generation of sufficient information in regards to the development of cancer.\textsuperscript{194} Regulation of genetic testing is also another important aspect of regulation in precision medicine. Regulation of emerging health conditions improves the quality of healthcare. Healthcare providers such as physicians and nursing practitioners have also recognized the available opportunities for advancement in precision medicine.\textsuperscript{195}

The possibilities of progress include enhancing the patient understanding of precision medicine, supporting decision making, as well as supporting family communication and outreach. Healthcare stakeholders such as the WHO, CDC and the International Cancer Genome Consortium have been in the forefront of promoting the adoption of precision medicine especially in combating global diseases such as cancer.
Endnotes


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"The Precision Medicine Initiative’s All of Us Research Program: A agenda for research on its ethical, legal, and social issues." Genetics in Medicine 19, no. 7 (2017): 743-750.


CHAPTER 5: HHC AT THE END OF LIFE

The adoption of ethics consultation has enhanced home healthcare since it creates an enabling environment for the adoption of inclusive decision making.

5.a. Ethics Consultations in HCC

Healthcare organizations across the globe have recognized the significance of ethics consultation. Ethics consultation plays an instrumental role in solving ethical issues that arise during the provision of healthcare services. Emerging medical practices such as withdrawal and withholding of life support during end-of-life care has brought the need to seek the help of professional bioethicists to provide ethics consultation. Ethics Consultation committee acts as an advisory team through providing professional assessment of the ethical dilemma or conflicts.\(^1\) The patients, health care professionals and family members of the patient however, still has the right to either apply or reject the professional advice given by the ethics consultants. Ethics consultation adopts a multi-dimensional approach that involves skilled bioethicists, healthcare professionals and experts from legal entities. The process involves the assessment of the problem based on the ethical conduct as well as the rights of the patients and the primary care givers and physicians.\(^2\) Ethics consultation in Saudi Arabia has undergone a tremendous revolution over the years with the adoption of home healthcare. Home healthcare provides home-based care unlike the hospital care setting. The Kingdom of Saudi Arabia has adopted various measures aimed at ensuring the implementation of ethics consultation in the home healthcare programs. Ethics consultation has undergone significant changes such as changes in the consult model, consult process and the role of ethics.\(^3\) Moreover, qualities in ethics consultation such as process standards, core competencies and standards of quality have shaped the adoption of ethics consultation in home healthcare. Another critical measure that has characterized ethics consultation is the adoption of effective strategies aimed at ensuring proper credentialing, accreditation and certification. These
fundamental issues have created an enabling environment for the implementation of ethics consultation in the home healthcare programs in Saudi Arabia.

5.a.i Evolution of Ethics Consultation

Ethics consultation has brought a tremendous impact on modern healthcare. The adoption of ethics consultation plays a vital role in facilitating an informed decision making and problem-solving thus resulting in an improved quality of healthcare service. Ethics consultants enhance the relationship among the patients, physicians, families of the patients as well as the healthcare organization through facilitating discussions, education, expertise as well as critical decision making. Therefore the main aim of ethics consultants is to ensure the creation of a sustainable environment for the adoption of patient-centered healthcare that is characterized by the observation of the fundamental ethical issues that surround patient care.

Over the years, ethical consultation has undergone a significant evolution resulting in the adoption of new approaches to the consultation model and process. Moreover, the evolution of ethics consultation has been characterized by the shift from the full-committee model to the adaptive small committee model.

5.a.i. 1. Changes to the Consult Model

The changes that have been experienced in the contemporary ethics consultation have significantly affected the consulting process. As the healthcare organizations began recognizing the role of ethics consultation, it became evident that there was a need to incorporate a consultation model that would ensure the provision of high-quality healthcare service delivery. Healthcare organizations experienced an ethical dilemma and challenges in regards to different issues such as patient-physician relations, emergency care, the value of care, as well as handling patients with mental conditions. Therefore, the traditional approach that was adopted was the full-committee model. The model consisted of members of the
consultation committee who were selected from different medical subfields such as psychiatry, pediatrics, pathology, general medicine as well as nursing.\textsuperscript{8}

Moreover, the members of the committee had representatives from the pastoral care, social work, risk management, and risk management department. The committee was expected to undertake periodic consults to the patients either in the presence or absence of family members.\textsuperscript{9} The consultation committee arbitrated on crucial issues such as clarifying on pertinent topics such as the rights of the patients and the physicians. The presence of professionals from diverse medical fields in the ethics consultation committee led to the pooling of critical ideas that helped in instilling accountability among the health care team and also improving the quality of care.\textsuperscript{10}

The full-committee model facilitated democracy in decision making. The members of the ethics consultation committee were tasked with developing ethical policies and regulations within a particular healthcare organization.\textsuperscript{11} Since the representatives were drawn from different departments within a health care organization, the members had the right to make decisions and agree on implementing the decisions within the healthcare organization. However, it reached a time that health professionals realized that the ethics consultation model was not effective in achieving medical accountability as well as the rights of the patients.\textsuperscript{12} Due to the presence of a large number of representatives in the committee, coordination of operations became a challenge. The presence of diverse views on the relationship between the physicians and the patients also created a rift between the members of the committee. Another factor that hastened the evolution of the ethics consultation was the negative perception of the full-committee model.\textsuperscript{13} The patients and some junior physicians perceived the committee as a tribunal or disciplinary committee rather than an inclusive ethics consultation committee. The patients felt that the ethics committee was formed to support the bureaucratic ideologies and policies of the healthcare systems.\textsuperscript{14} For
example, in most cases, the ethics consultation committee made decisions that favored the healthcare system as opposed to the patients and their families. This occurred since almost 80% of the committee members were physicians.

Healthcare organizations, therefore, decided to embrace two major models; individual and adaptive small team committee. The primary determinant that influenced the number of representatives in the ethics committee was the type and nature of a case. For example, in the fact that involved withholding or withdrawing life support in emergency care, the healthcare provider is supposed to use the small adaptive team committed to making the critical ethical decision. The patients and physicians developed an interest in the small team committee of ethical consultants. This is because the committee consisted of specialists from the field that is directly related to the case. The small team committee comprises of the ethicists, physician representative, nursing administrator, social worker, and a risk manager.

Ethics consultation also underwent crucial changes when healthcare organizations began undertaking periodic ethics education. Each stakeholder comprising of physicians, patients, social workers, and the local community are taught the tenets of ethics consultations. As opposed to the traditional ethics consultation that did not incorporate ethics education, the modern approach is characterized by the provision of ethical education. The ethics education is aimed at creating awareness among the stakeholders on the benefits of ethics consultation. Global healthcare organizations have adopted the small team committee that is characterized by the presence of emergency care, palliative care, child life, pastoral care, as well as legal services. The contemporary ethics consultation committee is, therefore, a flexible committee that aims at ensuring the clarification of patient’s rights and making important decisions regarding patient admission, home healthcare, and treatment methods. Through providing high-quality ethics consultation based on the specific needs of a case, a new ethics
consultation committee has created a sustainable healthcare environment in which the ethical needs of the patients and the physicians are observed.

5.a.i.2. Changes to the Consult Process

Several changes have occurred in the process of ethics consultation. The consult process is influenced by the access to ethics consultation, notification, documentation, and the case review. These four competencies have undergone evolution due to the changing healthcare environment, the need to provide patient-centered care as well as the need to observe the ethical elements that affect the relationship between the health professionals and the patients.

Changes in access to ethics consultation- Healthcare policies require in-patients, out-patients, and home-based care patients seek ethics consultation. Moreover, the family members of the patient are allowed to access the services of the ethics consultation committee. Traditionally, only patients were allowed to call for a consult. However, the stakeholders in healthcare soon realized that there was a need to diversify the ethics consultation process. The decision to embrace diversity in the access to ethics consultation is because collaborative action between the patients, healthcare professionals, and the family members can facilitate improved care both in the hospital care and home care setting. The individuals who need ethics consultation can request for consultation any time of the day through the ethics committee secretary. As opposed to the traditional consult process, the modern approach is aimed towards promoting collective action to facilitate improved healthcare services. Since there has been an increase in the number of people who can access a consult, the role of an ethics consultation committee has evolved to become more influential and crucial on home healthcare.

Changes in the notification process - The ethics committee is tasked with notifying the person who has requested the consult through issuing an informational brochure. The
secretary of the ethics consult committee collects relevant information and make records for the committee. The consult process has also embraced advanced technology through facilitating a web-based communication between the physicians, and the patients or family members who have requested for an ethics consultation. The notification can be made through various channels such as email, short-messages and even through social media sites. The adoption of a multi-dimensional notification approach ensures that the patients and their families acquire timely updates on the progress of the ethics notification from the beginning until the case review phase. The notification strategy has led to the adoption of an efficient ethics consultation process in the home healthcare programs.

Changes in the documentation approach - Documentation is an important aspect of ethical consultation. The proceedings of the ethical committee meetings must be documented for future analysis and reference. Before the evolution of the ethical consultation, the primary methods of documentation were patient charts and the committee’s records. However, the advent of modern technology has led to the incorporation of electronic health records keeping. The proceedings, findings and resolutions of the ethical committees are kept in a central database that can be accessed by an inter-agency medical team or different healthcare organizations. The adoption of electronic documentation has improved the safety of the records. Moreover, the aspect of patient confidentiality is also guaranteed by the new documentation approach. The ethics questions, background information, as well as future recommendations, should be properly documented by the ethics consult committee. Therefore the resolution that the committee adopts can be used to determine other related cases that occur during home-based healthcare. Contemporary healthcare organizations have recognized the need for proper documentation of the ethics consultation meeting. The committee members and the patients and the family must utilize the ethics consultation process to solve health concern, such as the issue of withholding or withdrawing life
support. After the consultation is completed, the committee is expected to record the recommendations as well as the short- and long-term objectives. The committee then is expected to utilize the recommendations to solve future conflicts in healthcare.

Changes in the case review - After the ethics consultation committee has undertaken a comprehensive discussion on the particular case at hand, the committee are expected to conduct a periodic case review. The case review help in assessing the outcomes of the meeting, the resolutions and the recommendations that should be undertaken. For instance, if a home-based care patient seeks an ethics consultation meeting with healthcare experts, the committee should undertake either a bi-monthly or a monthly case review. The review can be used to assess if the recommended measures were adopted within the stipulated time frame. Case reviews play a significant impact on ethics consultation since they provide an opportunity to gauge the effectiveness of the ethics consultation through analyzing its impact on the quality of patient care. A case review is also important in highlighting the regulations that should be used in determining major health concerns in home healthcare.

5.a.i. 3. Role of Ethics Consultation in Home Healthcare

The adoption of ethics consultation has revolutionized contemporary healthcare. Ethics consultation is a multi-dimensional approach that seeks to make critical clarification on conflicting health care services and also ensures the respects of the values and rights of the patients as well as the health care team. Home health is an important healthcare system since it is provided in a unique home healthcare setting. The home healthcare setting usually lacks vital medical equipment and professionals who can easily provide reliable medical care. Therefore, home-based care has failed to embrace an effective ethics consultation approach due to the nature of the health care setting. However, most healthcare organizations have recognized the need for home healthcare to incorporate ethics consultation for the patients who receive care at their homes. An increasing number of healthcare organizations across the
globe have initiated ethics consultations in home healthcare. For example, the Kingdom of Saudi Arabia has adopted strategies aimed at promoting the adoption of ethics consultation in the home healthcare programs across the Kingdom. The role of ethics consultation in home healthcare include:

**Facilitates the solving of health concerns, conflicts and ethical dilemmas** - The main role of ethics consultation is to solve diverse health concerns that arise during caregiving either in the hospital and home-based health care setting. The adoption of ethical consultation has shaped the process of handling conflicts and ethical dilemma that health professionals face while providing care in the home healthcare programs. In the home healthcare setting, the ethics consultation committee has adopted an effective strategy aimed at solving diverse problems that affect the relationship between the patients and the caregivers. For example, some of the problems that have been faced in the home healthcare programs include the frequency of physician and nurse visits, the quality of health care and the role of home-based caregivers. In most cases, the limited number of doctor visits affects the quality of care given in the home healthcare programs. The physicians do not provide around the clock care to the patients. Therefore, the patients may feel neglected by primary caregivers. The ethics consultation committee, therefore, is expected to develop a strategy for solving such conflicts that arise in the home healthcare setting.

**Promotes shared decision making** - Another significant role of ethics consultant is that it promotes critical and shared decision making among the ethics consultant committee. Decision making is one of the most challenging issues in home healthcare. This is because the setting does not provide an enabling environment for collective decision making. For instance, in most cases, the absence of nurse managers and physicians who are readily available usually complicate the decision-making process in the home-based care setting. Therefore, the adoption of ethics consultation has helped in ensuring effective decision
Physicians participating in home healthcare programs usually undertake different home visits such as illness, dying patient and assessment home visits. Therefore making decisions on the type of home visit that should be adopted in a particular case can become a challenge in the absence of an ethics consultation committee. The formation of the ethics committee hence facilitates the adoption of a strategy that guides the nature and frequency of visits that the nurses or physicians undertake.

The implementation of ethics consultation in home healthcare is characterized by the presence of the primary caregiver, physician, and other experts in the medical field, such as social workers. Home healthcare setting presents a challenge in decision making due to its setting. Home-based care, unlike the hospital setting, lacks a comprehensive strategy for making decisions regarding the ethical standards in healthcare. However, the presence of an ethics consultation committee has adopted measures aimed at initiating critical decision making within home healthcare programs.

Improves the quality of home healthcare services - The implementation of an ethics consultant has also played a crucial role in enhancing the quality of home-based care in Saudi Arabia as well as across the globe. Through clarifying on vital issues such as patient-physician relations, treatment options and handling of different opinions among physicians, ethics consultations have contributed to high-quality home healthcare services. The relationship between the patients, their families and the health professionals have a direct impact on the overall quality of healthcare services. This is because there the adoption of collaborative efforts between the different stakeholders influences the quality of health outcomes. Moreover, ethics consultation helps in solving conflicts that occur between the patients and the physicians. Conflict resolution hence is critical in the home healthcare programs. One of the strategies of conflict resolution that ethics consultation committee has adopted is mediation. Since the health issues involve different parties such as the patients,
families and physicians, mediation is used to arrive at an amicable solution that can benefit all the parties involved.

Results in the observation of the rights and values of the patients and health professionals. Ethical behavior is one of the fundamental tenets of contemporary home healthcare. Ethical behavior enables health professionals to observe the rights of the patients. The observation of ethical behavior among the health professionals as well as the patients results in the creation of a sustainable environment for both the patients and the health professionals. Home healthcare, just like the hospital care setting, requires the observation of fundamental ethics. When home-based care setting embraces ethical behavior, the stakeholders, especially the patients, will attain a suitable environment that is critical in the disease-recovery process. Ethics consultation also ensures that healthcare professionals show respect to patients during home visits.

For example, when handling cases in which the patients suffer from mental disorders, the primary caregivers are expected to exercise tolerance. The health professionals should not show discrimination based on the nature of the illness. Moreover, ethics consultation also results in the adoption of regulations on how to handle aged or terminally ill patients under the home healthcare programs. Therefore, the adoption of ethics consultation has created a viable platform for the observation of the rights and values of patients, families as well as healthcare professionals.

5.a.ii. Quality in Ethics Consultation

One of the major issues that have played a significant role in the implementation of ethics consultation in home healthcare programs is the quality of the ethics consultation process. Quality is a significant determinant of the overall importance and impact of the ethics consultation process on the patients as well as their families. Healthcare organizations in Saudi Arabia and across the globe have recognized the role that quality plays
on the ethics consultation process. The crucial aspect of quality that has been incorporated includes; process standards, core competencies, and standards of quality.

5.a.ii.1. Process Standards

There are different measures that the ethics consultation committee must undertake to ensure that the consultation process achieves its mission. The process standards are the ideal practices that shape the ethics consultation process and results in the realization of the goals and objectives.55 The methods that are adopted include:

Initiating and maintaining an efficient relationship with the patients/requestor- The first crucial step that the ethics consultation team must undertake is to make contact with the requestor of the ethics consultation.56 The requestor can be the patient or family members. After making contact, the ethicists should develop and maintain a binding relationship through clarifying the ethics questions, and listening to the opinions of the patients in regarding the case.57 The committee should commit to gathering information about the situation, the ethical dilemma, and any conflict that can arise from the fact. For example, if the case was about ideal home-based care for aged patients with a terminal illness, the ethics consultation committee should ensure that it makes positive contact with the patient and the family members.58 The committee should also include the stakeholders that can help in the process of deliberations. The ethicists should develop an evidence-based strategy for clarifying ethics questions surrounding the case in question. Making effective clarification helps the consultation requestor to fully understand the underlying ethical issues regarding the case. Moreover, the ethics committee should also address misconceptions that surround the role of bioethics.

Since most patients and their family members tend to perceive the ethic consultation committee as a team that only promotes the policies of the healthcare organization, process standards require the ethics consultation committee to address the misconceptions and
highlight the truth about the significance of ethics consultation.\textsuperscript{59} The committee should show the patients that the team is meant to safeguard the fundamental ethical values and also to ensure that the patients receive high-quality care both in the hospital and home-based care.\textsuperscript{60}

The process of building and maintaining a relationship with the requestor should also involve responding to the clinical team. In most cases, conflicts and ethical dilemma that occur in healthcare involves between the patients and the clinical team.\textsuperscript{61} The consultation team, therefore, should seek and address the issues that the healthcare team has raised in regards to the particular case. In case that the clinical team has differences with the patient over disease-intervention methods, the ethics consultation committee should embrace an effective strategy to solve the conflict before meeting with the patients.\textsuperscript{62}

**Framing ethics questions**- The process standard also dictates that the framing of the specific ethics question must be aimed towards achieving the goals of ethics consultation. Framing the ethical consultation question plays a critical role in the overall consultation process.\textsuperscript{63} This is because how the committee frames the ethics questions will enable the requestor to change his or her opinion of the role of the consultation process. The consultation team hence, should ensure that the questions are clear, coherent, and ethics-oriented. Moreover, the ethics consultation committee should ask questions that show that it respects the ethical values of the patients and family.\textsuperscript{64}

**Selecting an inclusive intervention method**- The next stage is to select an ideal intervention method or recommendations that should be undertaken by patients, family, clinical team, and the ethics consultation committee. The consultation team should select an intervention that considers the welfare of all the stakeholders, especially the patients.\textsuperscript{65} The committee should choose an inclusive intervention method that results in a win-win situation for both patients and the healthcare team. For example, there are three major approaches that
are considered suitable for the ethics consultation process. The intervention strategies include mediation, clarifying of the ethical policies, and communication coaching.

Mediation is one of the most important conflicts resolution methods both in hospital care as well as home healthcare setting. The process allows the ethics consultation committee to arrive at a consensus that benefits both the patients and the clinical team. For example, if the case brought to the consultation team was about withdrawing or withholding life support for a terminally ill patient, the committee should mediate and recommend the most appropriate method to be undertaken. For instance, if the terminal disease was causing debilitating pain to the patient, the committee and the family members can agree on withdrawing the life support machine so that the patient can die instead of continued suffering. Mediation is beneficial since it enables all the parties concerned to agree on the most important strategy that should be embraced to ensure that the ethical values of the patient are observed.

Another vital process standard is to ensure efficient clarification of the available ethical policies. The ethics consultation team should make coherent clarification of the ethical values, expectations, and healthcare rights of the patients. Moreover, the committee should spearhead the understanding of the pertinent issues that surround the consultation process. The process standards expect the consultation team to ensure that the requestor understands all the issues on the ethics consultation process. Understanding all the policies and regulations in home healthcare can help the patients and their families to know when to request an ethics consultation meeting.

Communication plays a vital role in the ethics consultation process. The communication strategies that the committee adopts have a direct impact on the outcome of the consultation process. The consultation team should coach the clinical team on how to build and maintain a lasting relationship with the patients and their family members. The
communication strategies should be characterized by the adoption of skills such as listening and speaking skills. Moreover, the ethics consultation committee should observe respect, honesty, integrity, as well as tolerance to diversity. For example, in the case of home healthcare programs, diversity usually occurs in regards to culture, religion, gender, and personality. Therefore, the ethics consultation team should coach the clinical team on how to develop and maintain a relationship with the requestor by employing effective communication skills.

**Recommendations to the patient**- The second last process standard examines the quality of recommendations that should be made to the patients and their family. The ethics consultation committee should make recommendations to solve the ethical concern or conflict. The recommendations, moreover, should not favor the clinical team or the healthcare organization. All the parties present should be satisfied with the recommendations that the consultation team has arrived at during the consultation.

**Documentation**- The final process standard is to facilitate effective documentation of the whole ethics consultation process. The ethicists should document the patient information gathering process, analysis, mediation, as well as the recommendations. The documentation can be made on the patient’s medical file or stored in the electronic database for future reference. The adoption of electronic documentation is efficient since it enables inter-organizational sharing of patient’s data hence improving the level of healthcare.

**5.a.ii.2. Core Competencies**

The core competencies are the fundamental tenets that show the role of ethics consultation. The acquisition of the knowledge of the core competencies is important for the ethicists that take parts in ethical consultation. The core competencies include:

**Knowledge**-The ethical consultation team is expected to possess knowledge of the role of ethics consultation in modern healthcare. Knowing all factors, elements, policies, and
regulations that surround ethical consultation is critical in the process of ethical consultation. The ethicists should be in a position to generate evidence-based ethical arguments during the consultation. Moreover, knowledge of decision making is key during the consultation process. The ethical consultation team should initiate effective decision-making skills aimed at solving an ethical dilemma.

The decision-making process should be done after considering the critical underlying factors such as the nature of the conflict, type of healthcare setting, and available intervention methods. Moreover, both the clinical team and the ethical consultation committee should acquire knowledge about emerging issues such as LGBTQ and lifestyle diseases. Moreover, having background knowledge of healthcare issues such as hospital-based and home-based care can help in solving the conflicts that arise between the patient and the healthcare professionals. The knowledge of various conflict resolution methods such as mediation, negotiation, and arbitration is also important among ethics consultation teams. This is since the ethicists are expected to adopt conflict resolution skills to solve the ethical dilemma and health concerns that arise during caregiving. For example, nursing practitioners may encounter a challenge while providing palliative care to aged persons with chronic illness. Such nurses may encounter moral distress and thus should work in collaboration with the family members of the patient. Moral distress affects the performance of healthcare professionals, especially in the hospital setting. However, the intervention of the ethics consultation committee can result in ensuring that the patient is transferred to the home healthcare program. Therefore, the ethics consultation team should possess the knowledge of various disciplines within the medical field.

**Attributes/Behaviors** - The behavior or personality that the ethics consultation committee and medical team display during the ethics consultation team affects the outcome of the consultation process. There are personal attributes that will change the perception of
the patients on the role of the ethics consultation. There are diverse attributes that the committee is expected to exhibit to facilitate an enabling conflict resolution process. The behaviors include tolerance, patience, integrity, and leadership.

The ethics consultation team should practice tolerance to diversity. During the consultation process, the team can interact with patients from different cultural backgrounds such as the Arabs, Whites, and the African American community. Moreover, individuals can possess different religious and political views that may influence how they perceive healthcare services. Home healthcare, due to its nature of healthcare setting, enables the ethics team to meet individuals from different cultures or sub-cultures. Hence tolerance to diversity can help in achieving the goals of the ethics consultation.

Patience is another important issue in the ethics consultation process. This is because the committee should be able to exercise patience after initiating a reconciliation process between the healthcare team and the patients. The requestor usually takes a lot of time before agreeing to conform to the recommended policies and decisions. In most cases, the patients take a long time before changing their perception of the role of ethics consultation.

Both the health care team and the ethics committee should exercise honesty and integrity while handling ethical conflicts. During the process of clarifying the ethical questions, values, and policies, there is a need for an honest team to build trust with the patients and their families. For example, the ethics team should state clearly the healthcare organization’s policies concerning the specific case. For instance, if the case was about how to provide home-based care for an aged person with chronic migraines, the ethics team should highlight the organization’s policies as well as the available options for the patient.

The ethics consultation team is expected to display leadership skills while spearheading the consultation process. This is since the team is tasked with clarifying the ethical values and policies in the presence of a conflict. Displaying effective leadership
qualities is needed to ensure peace in the presence of the warring parties.\footnote{90} Good leadership is also needed during the mediation process. The ethicists, who are derived from different medical sub-fields such as clinical care emergency care, psychiatry, and home-based care, should thus possess effective leadership qualities during the consultation process.

**Skills**—Possessing skills is the third core competency that the ethics consultation committee is expected to display during the consultation process.\footnote{91} There are different skills that are required in each phase of ethics consultation. This includes assessment skills, analytical skills, process skills, and evaluation skills.

Assessing the case or health concern is the first important step in ethics consultation.\footnote{92} Therefore, the ethicists should possess assessment skills to effectively assess the initial causes and underlying issues that may have contributed to the ethical conflict. The ethics consultation team should also be in a position to analyze the patient data that has been collected concerning the case in question. Analysis skills enable the committee to develop a multi-dimensional strategy aimed at solving the health concern.\footnote{93} The analysis should be characterized by examination of the patient’s medical record, analysis of the impact of the conflict on the patient as well as the family members. The ethics consultation committee is also expected to gain an understanding of the process standards.\footnote{94} For example, the process standards such as building and maintain a relationship with the patient and framing the question must be understood by both the clinical team and the ethicists. Finally, the ethics committee should possess evaluation skills. Just like assessment, evaluation is also critical in the process of conflict resolution in healthcare. The ethicists should evaluate the case, findings, and recommendations before making a judgment on the case.

### 5.a.ii.3. Standards of Quality

Since the adoption and implementation of ethics consultation, healthcare organizations and home healthcare programs have recognized the significance of the
standards of quality. The ethics consultation process must adhere to the quality standards to ensure the achievement of the goals and objectives of the consultation process.

**Ethics integration** - The integration of ethical behavior and values within ethics consultation is one of the most important standards of quality in an ethics consultation process. The way bioethics is integrated into the consultation initiative indicates whether the process can achieve its goals and objectives. Therefore, ethics integration deals with the structural aspects of the ethics consultation process such as personnel, resources, documentation structures, as well as the environment. This is because all these factors play a major role in influencing how ethics are integrated into the consultation process. Hence, a high-quality ethics consultation should be characterized by efficient ethics integration procedure that examines other crucial aspects such as the availability of skilled ethicists, and a suitable healthcare environment such as home healthcare.

**System of accountability** - Another measure of standards of quality is the presence of a comprehensive system of accountability. Ethics consultation can only be successful if the parties involved; clinical team, ethics committee, and the patients exhibit accountability in behavior. The ethics committee, for instance, should follow the policies and rules that control ethics consultation. The team, moreover, should take a neutral stand through acting as the mediator between the health professionals and the patients. Adopting a system of accountability will enable the ethics consultation committee to commit to its work of ensuring that the ethical values of the patients or their family are observed within a particular healthcare setting. The clinical team, on the other hand, should observe ethical conduct while providing for primary care to avoid cases of conflicts. For instance, primary caregivers under home healthcare programs should conduct illness home visits and initiate a comprehensive treatment plan aimed at eradicating diseases. Such measures can result in
satisfaction among the patients as well as a change in perception on the home-based healthcare services.100

Leadership support- Another standard of quality in ethics consultation is leadership support.101 The ethics consultation team, that act as the leaders of the consultation process, should acquire support from various stakeholders such as the health organization, clinical team, patients, as well as the local community.102 Effective leadership requires collective action from different stakeholders. The ethicists should hence seek the assistance of the health experts as well as the managers of the health organization on how to effectively develop a comprehensive and patient-centered ethics consultation procedure. An ethics consultation committee that has recognized the role of leadership support will be in a position to achieve both short- and long-term goals.103 Leadership support, moreover, plays a fundamental role in creating a sustainable environment for the ethics consultation process.

5.a.ii.4. Quality Issues in Ethics Consultation

Credentialing, Accreditation, and Certification- The adoption of ethics consultation has been characterized by the need to ensure accountability and possession of skills and knowledge relevant for bioethics consultation. Accreditation and certification ensure that the ethics committee acquires the knowledge that is relevant to the contemporary ethics consultation.104 The process involved in credentialing, accreditation and certification aims at ensuring that ethical consultants attain competency in ethical issues and the intervention measures. Credentialing, accreditation and certification adopts a multi-dimensional approach that involves educational bodies, healthcare organizations, legal entities and government agencies. The learning centers provide the basic knowledge as well as advanced skills that help in enhancing the competency of the bioethicists.

Credentialing focuses on the level of healthcare that a particular healthcare professional can provide in a healthcare setting. The credentialing process highlights the
relevant core competencies, skills and knowledge that a bioethicist must acquire before being allowed to undertake professional ethics consultation. Before a professional ethics consultant is certified and given licensure to work as an ethics consultant, there are specific skills and knowledge that are required by the certifying body. They include knowledge area and skills area.

In the knowledge area, several elements such as moral reasoning and ethical theory, knowledge of bioethical issues and concepts, laws, policies, and basic and advanced knowledge in healthcare ethics. In the moral reasoning and ethical theory, the ethics consultant is expected to display moral reasoning and knowledge in fundamental ethical theories. Moral reasoning enables the bioethicists to understand the underlying factors in ethical consultation. For example, a bioethicist with moral reasoning will be in a position to undertake an effective moral assessment of a particular ethical issues in healthcare before applying relevant ethical theory to find a proper intervention method. In case the family of the patient has requested for an ethics consultation due to inability to either choose withholding or withdrawal of life support machine in end of life care, the members of the ethics committee should be in a position to apply moral reasoning in regards to the cultural background of the patient. For instance, if the patient is from the Western culture, he is likely to embrace withdrawal of life support. Moral reasoning and knowledge in ethical theory enables the ethics consultant to effectively solve the ethical dilemma concerning a particular conflict in healthcare.

In the knowledge of bioethical issues and concepts, the accreditation body also requires prospective ethical consultant to have a comprehensive knowledge on traditional and modern bioethical issues and concepts such as application of ethics consultation in home healthcare. Since ethics consultation has undergone revolution in the recent years, the bioethicists should be in a position to apply the changes in process and consult models. Moreover, the
bioethicists should possess knowledge of the elements of quality of ethics consultation such as process standards, core competencies and standards of quality. Knowledge of bioethical issues and concepts gives the ethics consultant a background knowledge about ethics consultation in the modern world. In the laws, policies and ethics conduct, the accreditation bodies also require professional ethics consultants to have immense knowledge on the laws, and policies that regulate healthcare activities within a particular area.\textsuperscript{110} Since local laws are different from laws of other jurisdictions, the bioethicists should be in a position to understand the laws that govern ethical consultation and emerging programs such as home healthcare. For example, the kingdom of Saudi Arabia has been at the forefront of creating an enabling environment for the application of ethics consultation in the home healthcare programs.

In the basic and advanced knowledge, healthcare ethics accreditation bodies require that ethics consultants attain diploma, degree, Masters and even PhD in healthcare and related courses. Health professionals such as physicians and registered nurses should possess relevant knowledge in educational centers.\textsuperscript{111} Moreover, before accreditation and certification, ethic consultants must undertake and pass a comprehensive examination that consist of an essay, multiple choice questions, case study and oral interview. Moreover, bioethicists are required to observe actual ethics consultation process or participate in a simulated ethic consultation process. Prospective ethics consultants who pass the multi-level accreditation exams are therefore certified to become members of an ethics committee.

In the skills area, several elements such as ethical assessment skills, process skills, ability to build a moral consensus/agreement, and interpersonal skills. In ethical assessment skills, the ethical consultants are required to acquire and display comprehensive ethical assessment skills. The ability to assess a particular ethical problem during ethics consultation plays a vital role in finding an amicable solution for the problem.\textsuperscript{112} Ethics consultants thus are required to exhibit top notch assessment skills regarding a particular ethical conflict. The
assessments involve examining the causative factors, impact, and possible intervention methods. Process skills are important during ethics consultation. The skills enable the bioethicists to make critical decisions during the consultation process. Process skills enable ethics consultants to develop different strategies of solving a particular issue. Decision making is important during ethics consultation since the ethics committee must present a final decision to the patient or family member that requested the ethics consultation session.

Ability to build a moral consensus/Agreement is all about the ethics consultants being required to possess skills that can enable them to build a moral consensus during ethics consultation. A moral consensus plays a critical role in ensuring that the ethical consultation committee adopts a solution that benefits all the parties involved in the conflict. For example, in case the primary caregiver and the patient do not agree on the intervention method that should be used to treat a chronic health condition, the ethics committee should adopt a solution that results in a win-win situation for both the patient and the health professional. Interpersonal Skills are critical. Just like in any profession, the possession of interpersonal skills is beneficial during ethics consultation. The accreditation bodies such as the American College of Healthcare Executives require that before a bioethicist is allowed to work in the ethics committee, he or she should display the right interpersonal skills. For example, listening and speaking skills, use of non-verbal cues as well as the understanding of the cultural aspects of different cultures and how they affect perception of medical practices and techniques. The main role of interpersonal skills is that it improves the relationship between the warring parties. For instance, in a case where the family members of the patient are accusing the health professional of failing to give informed consent on a critical medical procedure, the application of interpersonal skills can help in bringing together the parties in conflict.

Clinical Health Committees: Clinical health committees play an integral role in overseeing the ethics consultation process. The committee selects skilled and experienced
bioethicists to conduct the clinical ethics consultation process. The clinical ethics committee is headed by a chairperson who ensures that the team provides ethic-oriented advisory to the patient or family member. Once a request has been made, the ethics committee assembles and undertakes an in-depth assessment of the underlying factors and measures of solving the impasse. The chairperson of the committee ensures that all the relevant personnel such as health professional, legal practitioner, religious leader and social worker is represented in the ethics consultation committee. The American Society for Bioethics and Humanities have shaped the process of ethics consultation. The ethics committee ensures that the parties understand the relation between the conflict and ethics and legal impact and all parties involved in the conflict reaches a moral consensus. The ethics consultation team explains to the parties in the conflict the role of ethics consultation in relation to the bioethics conduct as well as the impact of on the health consumers. Through explaining the disagreement to the parties involved in the conflict, they can understand the source of the problem as well as the measures that can be taken to prevent further conflicts during patient care. The ethics committee undertakes strategic measures aimed at reaching a mutually beneficial solution to the problem. The suggestion should seek to solve the ethical dilemma and satisfies the needs and expectations of all the parties involved in the conflict.

Informing Ethics Education and Policy in HHC- The application of effective principles and policies of bioethics in home healthcare requires the coordination of efforts among healthcare stakeholders. Ethics education promotes the adoption and understanding of the ethical policies and how they can affect the application of ethics consultation in home-based care in Saudi Arabia. Informing ethics education and policy in home healthcare can occur through promoting ethics education in learning institutions and initiating proper accreditation and certification process. The stakeholders in healthcare such as the Ministry of Health, healthcare organizations and legal practitioners should ensure that educational centers
create an enabling environment for the acquisition of knowledge on bioethics. Healthcare ethics should be taught in learning institutions and healthcare practitioners should acquire relevant knowledge about healthcare ethics while still pursuing their degree and masters in various healthcare fields. For example, nursing practitioners and advanced nurse practitioners should enroll in courses that provide valuable knowledge on fundamental healthcare ethics as well as other aspects such as ethics consultation. Relevant stakeholders should also ensure that healthcare professionals undergo the procedures that are required before the accreditation and certification process. The health practitioners should possess both the skills and knowledge regarding healthcare ethics and ethics consultation in home healthcare. All bioethicists should be subjected to rigorous accreditation process that involves assessing their skills and experience in healthcare ethics. Moreover, healthcare professionals should understand the significance of getting accreditation and certification in relation to healthcare ethics.

5.b. Dignity, Palliative Sedation, Assisted Death

Even as the field of ethics aims at assessing what is right and wrong, there are many factors to consider before concluding that an act is right and wrong. Of interest to the field of healthcare, ethics is the issue of life and death, especially the process of dying. Perceptions of how one is expected to die, guided under the religious realm have been the topic of discussion by ethicists for decades. Still, the complexity of human life and the multifaceted nature of what guides one’s way of life have made it more complex to create a standard method that each person can follow as they live their life. Of great interest to the field of ethics are euthanasia and the question of its morality. The nature of euthanasia is based on the fields of medicine and has created a debate on what and when to consider the rights of patients versus the duties of the medical practitioners. As a result, euthanasia has become an interdisciplinary topic discussed by several professionals from philosophers, academicians,
physicians, and most importantly religious scholars. Researchers such as Brockop and Fletcher\textsuperscript{125} are in support of this act whereas other researchers such as al Qaradawi and Banner\textsuperscript{126} are against it. To Muslims, Allah creates humans, and it is only Him who can take a life.\textsuperscript{127} Some Islamic scholars argue that no matter the state of pain and suffering that a patient is in, there is still a chance for survival and hope for the betterment of life. As it is, Islam values the sanctity of human life and is against Euthanasia.

5.b.i Sanctity of Human Life

5.b.i.1.Medication According to Islamic Teachings

The discourse about medication in the Muslim perspective has been a subject of debate for years. Many scholars including Māliki and Hanafi argue that that medication is permitted (\textit{mubāh})\textsuperscript{128} whereas other Muslim Shāfi‘I jurist such as Ibn ‘Aqil and Ibn al-Jawzi, and al-Qadi argue that medication is recommended (\textit{mustahāb}).\textsuperscript{129} For the Shāfi‘I, the treatment is mustahāb meaning that it may not be beneficial in the end. However, when the treatment has certainty and will be beneficial to the receiver the medication, then it is obligatory (\textit{wājib}).\textsuperscript{130}

The Qur’an and the Sunnah are the foundations that guide medical treatments in Islam. Furthermore, other sources such as the Islamic jurisprudence commonly known as \textit{al-qawā'id al-fiqhīyyah}, which is also gotten from the Qur’an guides Islamic medical treatments.\textsuperscript{131} The \textit{al-qawā'id al-fiqhīyyah} known as the Islamic legal maxims can be applied widely when discussing the moral dilemma brought about by euthanasia. As the Qur’an provides clear guidelines, rules, and commandments against killing,\textsuperscript{132} the Sunnah, commonly associated as the tradition developed by Prophet Muhammad provides a comprehensive Islamic approach to medical treatment and medication.\textsuperscript{133} The traditions within the Sunnah help to formulate the approaches to medication as a whole and to describe how to receive medication in a specific way. Among the traditions in the Sunnah is that of
encouraging medical treatment. This is seen in the book of Hadith, *Musnad* written by Imam Ahmad, who stated that the companion of the Prophet Muhammed Usāmah bin Shurayk once said that he was with the mighty prophet when the Bedouins came to him to ask if they could seek medicine, and the mighty prophet responded that they should indeed seek treatment since Allah had not created disease but its cure, except for the illness of old age, which has no cure.  

Drawing from one of Prophet’s companion, Abu Khuzāmah question on whether the medicine Muslims take and the prevention from diseases that they seek change Allah’s appointed destiny, it is established that the Prophet affirmed that the medication was, in fact, Allah’s prescribed destiny to humankind. The prophet further reaffirms that Allah has created no disease, but the treatment for diseases have been provided. It, therefore, seems like the concept of losing hope as the argument for seeking euthanasia does not hold water concerning Islamic teachings on medication.

Ebrahim stated that Muslims view diseases as a test of their faith and that such challenges are punishment for their sins. When afflicted with diseases, Muslims pray that their sins are forgiven, for it is Allah who curses them with the diseases that can absolve them, or decide to take away their life using the disease. Allah can also show mercy upon them by facilitating the cure in several ways such as the use of medication. It is, therefore, unorthodox for a human being, a creation of Allah to determine when and how one should die since they have no power or authority bestowed upon them to do so, but are only agents of Allah to ensure that medications are dispensed in a bid to save a life and cure diseases.

Once a custom has been set and accepted, it becomes the norm. Customs follows the force of the set law, ala’adamuhakkamah. Physician have the duty to preserve life and not to take it away. It is this concept that it arguably explains the idea of the goals of medicine, especially the stand that it does not and is not aimed at intentionally or directly killing
patients. Since medical professions are bound to save and not to take life, they are, therefore, expected to follow the principle of not to kill.

5.b.i.2. Quality and Purpose Preserving Life in Q’uran

The Qur’an values human life and upholds the need to preserve it. According to the Qur’an, euthanasia is prohibited since it results in destroys life. Islamic teachings provide insightful arguments that show the need to uphold the sanctity of human life. Brown et al., argues that since the result of both passive and active mercy killing is death, the act becomes unethical or illegal from a religious perspective. The quality of life is the most important aspect of living. For example, critical elements such as hydration, nutrition, as well as effective treatment for diseases should be undertaken by both healthcare organizations as well as health consumers. According to Islam, every disease or disorder has a particular treatment method. Moreover, if the disease lacks a known treatment method, there is available technology that can be used to initiate patient-centered medical research to find the cure of that particular disease or the disorder. Hence, mercy killing should not be an option for people suffering from terminal illness. Euthanasia violates the fundamental religious doctrines that promote the value and sanctity of human life.

Euthanasia is unethical since it does not preserve religious ideas and doctrines. This is because euthanasia enables human beings to determine who should die at their own discretion. Allah is the only one who gives life and hence should be the one to take away life. This argument thus justifies the Muslim stand against euthanasia. The Qur’an, chapter 5:28, says, “If you do stretch your hand to slay me, it is not for me to stretch my hand to slay you for I do fear God the Cherisher of the worlds.” Muslim scholars such as Ibrahim, argues that the Qur’an’s view of life is what guides the behavior of the Muslim faiths towards embracing a behavior that promotes the preservation of human life. Mercy killing, however, do not
preserve human life since it results in the death of a person. The Qur’an also observes that “Do not take life which Allah made sacred, other than in the cause of justice.

“The enormity of the sin on a person who deliberately terminates a life other than in the course of justice such as murder or spreading mischief in the land is as if he has killed the whole people” (Qur’an 5:32). It is evident from the Muslims holy book that Allah prohibits people from taking part in activities that destroy both life and religion. The teachings of Prophet Muhammad also supported Islam’s view on euthanasia. Prophet Muhammad, in his teachings, encouraged Muslims to avoid participating in acts that led to the death of others.

5.b.i.3. Sharia (Islamic law) and Legal Maxims of Islamic Jurisprudence

Islamic Law has shaped the perception of the role of euthanasia among Muslims. The Sharia Law outlines several elements that provide a comprehensive asupporting the sanctity of life. The injury code, ‘qa’idat al dharar’ states that the members of the society should not undertake activities that may cause harm to another person. Injury goes against the Islamic values that are enshrined in the holy books such as the Sunny and the Qur’an. Mercy killing, therefore, brings injury to terminally ill patients. Moreover, the family of the patient with terminal illness experiences psychological injury when they lose their beloved relative through euthanasia. Although proponents of mercy killing can argue that the slow death of a terminally ill patient results in emotional injury, the religious doctrines of Islam prohibit mercy killing since it brings injury to both the patient as well as the family.

Singer observes that the Sharia Law, any injury caused by pain and suffering associated with a terminal illness should not be mitigated through initiating another major injury such as mercy killing. Other alternative measures such as palliative care should be undertaken to prevent euthanasia. Moreover, another element in the principle of injury is that the interest of the public is more important than the interest of an individual. Hence, granting mercy killing to a one patient will encourage the practice among the masses.
The intention principle, *Qa’idat Al Qassd* states that the intention of a particular medical practice such as euthanasia plays an integral role in judging the moral and ethical viability of such a practice. Hence, the legal aspect of active and passive euthanasia does not matter since the intention of mercy killing is to end the life of the patient. The conditions under which euthanasia is administered do not matter but the outcome of the act itself. Since Islam values the sanctity of human life, euthanasia is therefore unethical. Healthcare professionals should adopt measures aimed at preserving or prolonging life.

Some Muslim jurists have examined the significance of mercy killing and its role in the typical Muslim society. Al-Qaradawi, for example, recognized the relationship between euthanasia and murder. According to the jurist, the act of mercy killing is similar to the act of murder. This is because the intention in both cases is to terminate the life of the victims. The jurist further issued a jurisprudence degree, *fatwa* that ensured that any incidence of mercy killing is treated as murder in Saudi Arabia. According to the Islamic Code of Medical Ethics, euthanasia is similar to suicide, since mercy killing shows that people do not believe in the role of the present and the after-life. People who allow euthanasia are just like atheists who do not believe in Allah and his role as the provider of life. The Muslim world, however, respects the teaching of Allah and Prophet Muhammad that prohibits taking away the life of another person under whichever condition.

Other major areas that the legal maxim of Islam jurisprudence examines include human pain can be managed through medicine. The proponents of euthanasia argue that terminally ill patients experience severe pain and suffering hence should have the right to die to prevent suffering. However, Islam recognizes the immense contribution that medicine has brought in stopping and managing pain as well as suffering. Therefore, it is not logical for society to allow euthanasia based on the pain and suffering that the patients are undergoing. The adoption of proper disease intervention methods can assist in eliminating
pain among terminally ill patients. For example, patients who have cancer can undergo advanced chemotherapy and other resulted treatment options that can reduce the pain of and suffering.

Muslims believe that there is not a single disease that cannot be treated. The process of treatment can help in reducing pain and suffering among patients with terminally ill patients. The perception of euthanasia among Muslims also symbolizes the people’s belief in Islamic religious doctrines as well as the holy books such as Qur’an and Sunnah. Through relating euthanasia with atheism, Muslim teachings show that religion is a more important part of human life. Therefore, people should not participate in activities that destroy life or demean religion. The legal maxims of Islam jurisprudence hence examine the laws that shape the people's belief in the critical issue of euthanasia. The jurisprudence presents an argument that supports Islam’s stand against mercy killing as well as the need to uphold healthcare practices that preserve human life. The legal maxim of Islamic jurisprudence hence has shaped the perception of Islamic believes in relation to the controversial issue of euthanasia. Despite the presence of diverse views on the issue, the Islamic culture and religion has a firm belief that it is better to adopt ways of managing pain instead of mercy killing.

5.b.ii Pain and Suffering, Death, and Euthanasia

5.b.ii.1. Definition and General Assessment of Euthanasia

Over the years, the concept of euthanasia has brought a significant impact on society. Euthanasia has elicited mixed reactions from different world religions as well as the members of the society. Euthanasia involves the dying patient, the health practitioner who is tasked with carrying out the process as well as the family of the terminally ill patient. Euthanasia refers to the initiation of a painless death that is aimed at ending suffering and pain on a terminally ill patient. The word euthanasia traces back to the Greek words, eu, meaning well
and thanatos meaning death. In essence, euthanasia represents a “good death”. However, the acceptable medical term that has been used to describe euthanasia in recent years is ‘Mercy Killing.’

Different scholars and medical organizations have various definitions of the term euthanasia. For example, according to the Euthanasia Society of America, “euthanasia is the termination of human life by a painless means to an end severe physical suffering.” The main reason why euthanasia has generated controversy is the subject of the sacredness of human existence. Each person has the right to live. However, euthanasia goes against this fundamental right. Mercy killing can either be performed on patients in two distinct situations. The first situation when a patient is in an eternal vegetative state and is only supported using advanced life support machines. Under such a situation, the patient lack awareness of the events that are taking place in the physical environment. The second situation is when a patient has a terminal disease that is characterized by severe pain and suffering. Euthanasia is, therefore, performed to end the pain, trauma, and suffering on the patient. Nikookar et al., observes that euthanasia has become ones of the most researched areas in the field of bioethics. This is because it draws controversy across the globe based on religious, ideological and personal beliefs. However, in most western countries such as the United States, active euthanasia is legal in some states within the country. The practice is however illegal in the Muslim world due to the religious beliefs that value the sanctity of human life.

Active euthanasia is the killing a patient intentionally. Therefore, active euthanasia is conducted by a physician, and it is done to end a patient’s life. There are different forms of euthanasia. Voluntary euthanasia happens when a patient who can make informed consent requests the process of mercy killing. The patient personally requests to be assisted to die to end any form of suffering. Non-voluntary euthanasia on the hand occurs when a patient
undergoes euthanasia since he is incapable of making tangible decisions or judgment on euthanasia. Non-voluntary euthanasia is illegal in several countries since it does not consider the presence of informed consent from the patient. For example, a patient who is in comatose can be subjected to euthanasia since he or she cannot make an informed decision due to the health condition. Involuntary euthanasia, however, happens when the patient declines to consent to the killing but is nevertheless killed. For example, prisoners who are sentenced to death by lethal injection are killed even though they do not want to die. Physicians should not promote euthanasia since it results in ending the life of a patient.

Passive euthanasia refers to mercy killing that occurs when a health professional withdraws the life support machine and other necessary medical services that were keeping the patient alive. Through withholding such important life supporting machines, the terminally ill patient dies. There are various instances under which the euthanasia is considered to be a passive mercy killing. For example, passive mercy killing occurs when: when physicians withdraw medical treatment of the patients with terminal illness, withdrawing the critical medical treatment of patients with terminal health conditions, refusing medication care as well as discounting life support for patients who are dying. One important aspect of passive euthanasia is the presence of a variety of options that are available for both the health practitioner and the patient. Unlike in active euthanasia, doctors have various options of ending life such as withholding critical medical treatment or withdrawing the patient from the life support machine. Islamic tradition, culture, and literature have examined the issue of Euthanasia. Hedayat & Roya posits that through fundamental literature such as the Sunnah, Qur’an, and fatwa, the Islamic perspective on the euthanasia can be analyzed on ethical grounds. The debate around the ethical viability of euthanasia depends on the following arguments. For example, according to the proponents of euthanasia, individuals have the right to determine what they want and hence should be
allowed to make any form of healthcare decision even if it touches on the issue of life and death. Moreover, assisting a terminally ill patient is better than the person to suffer until their death. Moreover, allowing euthanasia in society does not always result in dire consequences among people.\textsuperscript{168} However, scholars and people who oppose euthanasia have argued that there are other alternative healthcare measures such as palliative care that can be undertaken instead of mercy killing. Moreover, some types of deaths are not painful; hence does not require euthanasia. Moreover, the people who oppose mercy killing have argued that both active and passive euthanasia is unethical and immoral according to the religious and fundamental societal values about life.

\textbf{5.b.ii.2. Islamic Views Against Euthanasia}

The Question of Pain and Suffering - For several years, there have been two traditions of modern medicines, the relief of pain and to prolong life. The concept of suffering was coined several years ago by Eric Cassel, an American Physician in his paper titled, “The nature of Suffering and the Goals of Medicine.” Islamic scholars have over the years studied the concept of euthanasia and how Muslims perceive it. According to Islam, euthanasia ignores the value of the sanctity of human life.\textsuperscript{169} The two main roles of modern medicine are to reduce one’s pain and the suffering cause by diseases and also to prolong the life of a patient. Therefore, apart from eliminating pain and suffering, medical care should elongate the life of a particular patient. This facet of medical care is the basis of palliative care. Through palliative sedation, terminally ill patients can sustain their lives before the eventual death. The Islamic principle of hardship, \textit{qa’idat al mashaggah} plays a vital role in understanding pain and suffering.\textsuperscript{170} Classical jurist does not consider pain and suffering experienced by patients with a terminal illnesses hardships. Even though the patients experience both emotional and psychological distress due to their medical conditions, classical jurist does not see this as a strong reason to seek euthanasia.
In Western countries, such as the United States, terminally ill patients who experience extreme pain are allowed to give their consent for euthanasia. Islamic scholars have argued that the pain and suffering that terminally ill patients undergo cannot be legally classified as a hardship. Scholars such as Ogunsola have argued that necessity needs to be established in a particular form of hardship so that it can be recognized as a hardship.\textsuperscript{171} In cases where hardships are established, what is prohibited can be temporarily allowed up to a time when the hardship eased; commonly guided inal dharurat tubiihu al mahdhurat. However, the necessity must also not hinder the critical elements of the law such as life and religion. Mercy killing, instead of preserving, destroys both life and religion; hence it cannot be classified as a necessity. The question of pain and suffering, therefore, is not a sufficient reason that can warrant the act of euthanasia among the members of the Islamic religion. There is a need to focus on the underlying issues that might contribute to euthanasia instead of adopting the health procedure. The Islamic religious views on euthanasia are totally different from the beliefs of the Western countries. According to non-Islamic states, mercy killing is ethical since it ensures that the patient no longer experience pain and mental anguish. Moreover, there is no need for a patient to continue suffering when he or she has been diagnosed with a terminal illness. Therefore, there has been an increase in the adoption of mercy killing in these regions. In contrast, the Islamic religious doctrines detests euthanasia since it leads to the patient’s death. This belief shows that Muslims believe in consequentialism that argues that the consequences of an action are what matter and not the cause of an action. Although euthanasia is meant to eliminate pain, it causes the patient’s death. Since Allah is the provider of Life, no one is allowed to take the life of another. Thus, euthanasia is unethical in the Islamic religion purely based on the consequences and not the cause of action.

Refusal of Tubal Feeding - One important ethical aspect of euthanasia is the right to refuse tubal feeding. In most cases, patients in a vegetative state are put in a life support
machine. In case the life support machine is removed, the patient dies right away. The question of whether to withhold or withdraw life support or treatment has become a controversial issue among healthcare organizations.\textsuperscript{172} It has been found that it is easier to start tubal feeding than to discontinue it. Therefore, measures should be taken to prevent euthanasia. The Islamic perspective on refusal to tubal feeding is based on the belief that euthanasia should be avoided in the first place. To avoid the dilemma on whether to withhold or withdraw the forms of life support machines such as tubal feeding, healthcare organizations and patients should adopt strategies that are aimed towards preventing mercy killing. According to Audah, there are laws that provides guidelines on the ethical elements that surround the issue of euthanasia.\textsuperscript{173} Withholding tubal feeding can enhance the rate at which a terminally ill patient succumbs to the disorder or disease. On the other hand, when a health practitioner withdraws a tubal feeding machine and other life support equipment, the patients face imminent death due to the lack of crucial life support machines. Through withdrawing or withholding tubal feeding, the patient is left to die without looking for the underlying issues that caused the current state of the patient.

For example, several diseases or disorders can generate a terminal illness. Diseases such as Cancer and HIV and mental disorders are terminal diseases that can expose an individual to euthanasia. Moreover, diseases associated with old age can also make an individual request for mercy killing. However, according to the Islamic religious doctrines and cultural believes, healthcare professionals and patients should focus on preventing or managing the diseases that cause terminal illness.\textsuperscript{174} For instance, healthcare organizations should provide home-based care for terminally ill patients with mental disorders.

Health organizations should also provide patient-centered care to extend terminally ill patients’ lives instead of waiting for the patient to develop advanced stages of a disease or disorder to warrant mercy killing. Muslims advocate for the adoption of proper intervention
strategies that can prolong the life of terminally ill patients. Moreover, healthcare organizations can create awareness of the need to prevent terminal diseases. Through promoting behavior change in the society, the number of terminal illness can reduce hence reducing the need for euthanasia.

The Islamic perspective on tubal feeding, therefore, prohibits the discontinuation tubal feeding but advocates for the examination of underlying issues that can influence the prevalence of terminal diseases and disorders. Muslims advocate for the prevention of euthanasia instead of dealing with issues such as withholding and withdrawing of critical life support machines.

5.b.ii.3. The Ethical Code of Medical Ethics

The International Islamic Code for Medical and Ethics contains a comprehensive analysis of the Islamic perspective on the issue of Euthanasia. According to the code, a health professional is prohibited from terminating the life of an individual. This is because Allah is the provider of Life and He is the one who should take it away. The code hence prohibits any form of mercy killing whether the patient has made an informed consent or if the patient is forced due to extreme health conditions such as comatose. According to most Muslim scholars such as Laila, euthanasia is both ethically and legally wrong. The codes have provided guidelines that control how the Muslims perceive the issue of mercy killing. For example, according to the code of Medical Ethics, medical practitioners are not allowed to undertake mercy killing since it goes against the teachings of Allah and Prophet Muhammad. Three major areas are considered to be mercy killing.

The first area is patient-assisted suicide. Islamic literature such as the International Islamic Code for Medical and Ethics states that healthcare professionals should not participate in activities that help a terminally ill patient to end his life. Through assisting a patient to die, the physician takes part in the killing process. Islamic doctrines prohibit killing
another person. The health practitioners hence are not supposed to participate in patient-assisted suicide. The second area is the intentional killing of an individual who volunteers to be killed. Even if a patient with terminal illness volunteers to be killed, health care providers should not initiate mercy killing. This is because killing a person who has agreed to die is similar to killing any other person. The third areas are the intentional killing of infants with various forms of disabilities or mental disorders. Healthcare professionals should not take advantage of the presence of disabilities or deformities to kill infants. Allah is the only provider of life and is the one who is allowed to take the life of a person.

In a broader sense, euthanasia is ethically wrong since it fails to adhere to the doctrines enshrined in the holy texts such as Qur’an and Sunnah. Euthanasia both involves committing and collaborating in acts that result in the death of individuals who have the right to life. Another reason that has been advanced by Muslim scholars is the idea that it is not guaranteed that people who do not suffer from terminal illness will outlive the terminally ill patients. Therefore, dying patients should not be subjected to mercy killing as they are entitled to the right to life. Even though there are people who believe that patient-assisted suicide plays a role in eliminating pain and suffering among patients with terminal illness, it is still a way of ending life.

According to the Islamic teachings, the biggest pain is to end the life of an individual. Therefore, Muslims believe that it is not logical to embrace euthanasia as a means of ending pain and suffering. Moreover, there are other ways that can be used eliminate or manage pain. For example, the use of patient-centered care can be of great importance in combating pain associated with terminal illness. Instead of initiating patient-assisted suicide, patients with life threatening health conditions should seek specialized care in which proper medicine are used to manage the particular disease or mental condition.
Moreover, Islam religious ideologies and beliefs oppose the non-voluntary, voluntary and involuntary mercy killing.\textsuperscript{189} This is because the intention of each type of the above-mentioned types of euthanasia is to terminate the life of the patients with terminal illness. Islam, therefore, recognizes the fact that the intention of mercy killing is what makes the act to be unethical and not the prevailing conditions.\textsuperscript{190} Since all types of euthanasia such as voluntary euthanasia lead to death, it thereby shows that the act goes against the important religious doctrines that value the sanctity of human life.

5.b.ii.4. The Alternative: Palliative Care

Palliative care has brought a tremendous impact healthcare. Palliative care refers to the intervention methods adopted to improve human life through pain management, eradication of symptoms, physical and mental stress.\textsuperscript{191} The practice has shaped care-giving among patients with terminal illness. Palliative care should be embraced as an alternative to euthanasia.\textsuperscript{192} This is because euthanasia does not preserve life while palliative care involves the adoption of healthcare practices that are aimed towards improving the quality and also to prolong the life of the patients.\textsuperscript{193} The main difference between palliative care and mercy killing lies in their intentions. Sepúlveda observes that palliative care is undertaken to preserve life while euthanasia is undertaken to destroy life under the pretext of eradicating pain and suffering.\textsuperscript{194} Therefore, stakeholders in the field of healthcare organizations such as healthcare professionals, patients, and government agencies as well as the local community should implement palliative instead of euthanasia.\textsuperscript{195}

One critical component of palliative care is palliative sedation.\textsuperscript{196} The practice ensures that the patient undergoes pain management, symptom eradication as well as the management of emotional and physical stress.\textsuperscript{197} Palliative care is an ethical means of managing terminal illness since it adopts patient-centered strategies that are meant to improve the patient’s life. The complexities to understand palliative can be broken down to the simple phrase of “the
use of sedative medication to ease excruciating suffering by reducing the patient’s consciousness. Empirical studies reveal that the therapy of palliative care does to fasten death at all, thereby removing the “wrong effect.” Unlike euthanasia, palliative care is not a mechanism of resulting in death and death is not the goal of palliative care. Moreover, while euthanasia disrupts the link between the condition of the patient and the medical treatment available for symptom management, palliative care preserves this moral link, thereby enabling the patient to receive normal care through medically advanced techniques. Therefore, palliation is a process of symptom management, not a facilitator of death. As such, the method of achieving unconsciousness through sedation is justifiable even in circumstances that it may lead to death.

The first underlying concept under palliative care is managing total pain. The intervention methods that are used to manage pain play a crucial role in palliative care. Patients suffering from terminal illness usually experience physical, psychological and spiritual pain. Life threatening illness makes people redefine their spirituality. The thought of an imminent death changes the perception of an individual towards the socio-economic, political and religious ideologies. Palliative care is characterized by the presence of medical practitioners, clinical psychologists, registered nurses, and skilled counselors. These health professionals enable the terminally ill patients to acquire efficient care to improve their life at their final moments.

The second underlying concept under palliative care is managing physical pain. Patients are suffering from terminal illness such as cancer experience severe pain as a result of the health condition. The debilitating pain can trigger trauma and depression. Moreover, terminal illnesses are usually chronic that makes the patients feel the pain constantly. Physical pain is managed through the administration of strong pain management medications. The health practitioners first critically examine the patient about the
underlying disease or disorder. Stjernswärd posits that pain management is important since it helps in reducing the severity of the disease through providing temporary relief to the patients. As opposed to euthanasia that results a patient’s death, physical pain management in palliative care improves one’s life.

The third underlying concept under palliative care is managing psychological/emotional pain. Most health consumers with terminal illnesses experience emotional pain. Chronic diseases create a platform for depression and trauma. Moreover, terminal illness makes the patients develop anxiety and fear of death. In palliative care centers, counselors and clinical psychologists help the patients to manage emotional pain. Through building a lasting relationship with the patients, the medical practitioners can achieve positive health outcomes.

The fourth underlying concept under palliative care is managing spiritual pain. Another pain that terminally ill patients experience is spiritual pain. When a patient knows that death is near, he will develop a closer relationship with God (Allah). This is due to the fact the most people believe in life after death. Even individuals who were known to be pure atheists usually want to associate with some form of religion. The question of immortality makes people want to connect to Allah with the hope of enjoying life with Him after during Judgment Day. Therefore, most palliative care centers have ensured that religious leaders, depending on the religion of the patient, are present to connect the patient to Allah in case the patient is a Muslim. Therefore, palliative care is the most efficient alternative that can be used instead of euthanasia. Palliative care enhances life via the management of physical, emotional and spiritual pain. In comparison, Euthanasia does not respect the sacredness of life in society.

It is this concept that it arguably explains the idea of the goals of medicine, especially the stand that it does not and is not aimed at intentionally or directly killing patients. Since
medical professions are bound to save and not to take life, they are therefore expected to follow the principle of not to kill. Therefore, within the palliative care context, euthanasia and assisted suicide is not only wrong but represents a morally forbidden option to end of life. Palliative sedation represents the available life-sustaining and pain control treatment in place of the direct and intentional killing options. It is the anxiety that comes with the process of dying that may tempt patients to request for a quick method of ending their life even though options life palliative sedation is available.

The neuropsychological suffering can be managed through the pain management mechanism as well as with the compassion of family members, medical practitioners, and other involved parties. As such, palliative sedation takes a different stance and moves away to create a debatable aspect on the end-of-life ethics. Palliative care should be used especially among patients with life threatening health conditions. Individuals with extreme mental disorders, severe brain injury and chronic cardiovascular diseases should be put under palliative care as opposed to euthanasia. This is due to the fact that palliative care will result in the management of pain among the terminal patients.

5.c. Conclusion

Ethics consultation has brought a tremendous impact on home healthcare. The ethics consultation process ensures provision of measures that can be used to solve conflicts between patients and healthcare professions, ethical dilemmas and finding amicably solution to culturally-based healthcare beliefs. The changes that ethics consultation has undergone has shaped the whole process of consultation. For example, the changes in the consult and process model have created a platform for home-based healthcare delivery. Moreover, the quality in ethics consultation such as process standards, core competences and standards of quality provides the framework that health professionals, patients and the ethics consultation committee are expected to follow during ethics consultation process. The adoption of
underlying crucial issues such as credentialing, accreditation and certification also improves the process of ethics consultation. This is because the accreditation and certification process ensure that the members of the ethics committee acquire relevant skills and knowledge concerning ethics consultation. Ethics consultants should possess moral reasoning, the capability to assess the ethical conflict and also the legal impact of adopting a particular medical procedure or practice.

The adoption of ethics consultation within healthcare programs requires a comprehensive approach that will ensure that all the stakeholders benefit from the consultation process. For instance, the bioethicists should be able to assess the request that has been made by the patient or family members. The decision of the ethics consultation committee should consider the welfare and rights of all the stakeholders such as government health agencies, patients, physicians, primary care givers as well as the family members of the patient. The ethics consultation team should also coordinate activities with relevant government agencies such as the Ministry of Health, law enforcement agencies as well as healthcare learning institutions such as the American Society for Bioethics & Humanities (ASBH). The adoption of coordinated efforts can boost the implementation of ethics consultation in the home healthcare programs.

The adoption of euthanasia as a means of ending the pain and suffering of terminally ill patients has redefined how people perceive the right to life. Religious doctrines and beliefs have shaped the opinions and ideologies of the members of the society. All medical services are discharged based on clinical judgment, ethics, and available evidence. Death remains a painful experience, and no one is ever prepared enough to cope with the accompanying loss. Therefore, death and dying have ethical and moral implications, making it an ethical concern even today. Among the Muslims, euthanasia is unethical since it results in the termination of the life of an individual. According to the Islamic religious doctrines, any person who
participates in the act that leads to the death of another does not value the sanctity of life. People should strive to participate in activities that preserve human life. The Islamic religious views based on the question of pain and suffering, refusal of tubal feeding, quality and purpose of preserving life, the Sharia law, and legal maxims of Islam jurisprudence, depicts the religion’s firm stand against euthanasia as a way of ending pain and suffering among individuals with terminal illness.

Healthcare organizations should adopt alternative health practices such as palliative care to improve patients’ lives. Although the constructs of morality are currently debatable, the concept of palliative sedation is more morally acceptable than euthanasia. Euthanasia discourages the advancement of palliative care even though palliative care is considered the morally accepted principle in Islam. Palliative sedation is different from euthanasia by maintaining the moral link between patients’ conditions and medical treatment. The argument that sedation to unconsciousness is a symptoms management process as opposed to death-machine processes of euthanasia gives palliation more moral grounding than either of the two. Overall, the distinguishing moral arguments classify euthanasia and assisted suicide as opposed to common principles of morality while highlighting palliative sedation as the embodiment of morality.
Endnotes


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CHAPTER 6: PROFESSIONAL AND ORGANIZATIONAL CHALLENGES IN HHC

Professional moral distress hinders health care professionals from providing patient-centered care at the home health care level. Heavy workload leads to burnout, thereby reducing the productivity of the health care professionals as well as other stakeholders in the clinical care settings.

6.a Professional Moral Distress

Central to the definition of moral distress (MD) is the recognition that failure to accept the values underlying health practices can have serious consequences for HCPs. The identification of an MD was based on nursing care, and subsequently, most of the research to date has been conducted on nursing care.1 However, recent conceptual studies have been conducted through interdisciplinary teams across disciplines. Varcoe defines MD as a change in the socio-political and cultural context of the nurse working environment brought stressful organizational barriers such as heavy workload.2 However, this definition does not provide a dynamic decision-making process, given the relationship between moral authority and the context in which HCPs operate. For this reason, it is necessary to focus on the importance of understanding MD because of the reciprocity between structures and agents, intending to move towards interventions.

Over the years, the adoption of organizational ethics has brought a significant impact on the operations of healthcare organizations. Organizational ethics creates a sustainable, ethical environment within a healthcare organization by ensuring health care regulation. Moreover, organizational ethics promotes the implementation of a proper code of conduct that can be used to create an enabling environment for the nurse professionals in mental healthcare institutions. The prevalence of moral distress has hindered the provision of healthcare services in modern healthcare organizations. The changes in healthcare management styles characterized by low nurse-patient ratio have contributed to moral distress. This is because the
nurses experience a heavy workload that results in nurse burnout and patient avoidance. However, organizational and professional ethics can be used to alleviate moral distress in healthcare settings such as mental healthcare organizations. Through addressing and regulating the issue of informed consent, marketing of medical products, diagnosis, billing as well as the relationship between a health organization and the staff, organizational ethics have enhanced healthcare outcomes in modern health organizations. Both organizational and professional ethics enhance the management of moral distress in mental disorders through the adoption of effective coping strategies as well as the elimination of moral distress.

Healthcare organizations have also recognized the need to endorse moral agency in modern mental healthcare. Moral agency refers to the ability of a healthcare professional to make a moral judgment based on what is right and wrong. Moral agency makes the undertaker of the action be held accountable by a third party. Therefore, the moral agency has a significant impact on the operations of healthcare organizations. Nurse professionals and healthcare organizations must provide patient-centered healthcare service. However, self-centered gains such as compensated care can make a healthcare organization to ignore the role of moral agency. Healthcare organizations or registered nurses who ignore moral agency are likely to face moral distress. This is because they will realize that what they are doing is not morally right. Both organizational and professional ethics can be used to promote moral agency within a healthcare setting.

Speculation regarding the potential moral implications of healthcare are on the rise, backed up by a desire for efficiency, which has led to a constant and rapid restructuring of the health care system. Some of these consequences include moral disengagement and moral residue. Mental healthcare settings experience diverse moral and ethical dilemma. For example, the nurse professionals, who provide care to individuals with different mental disorders such as dementia and schizophrenia, can sometimes show prejudice and discrimination to the
Such unethical behaviors can hinder the development of therapeutic relationships between caregivers and patients. Therefore, endorsing moral agency can improve the relationship between healthcare professionals and patients. Endorsing moral agency contributes to the reduction in moral distress in healthcare settings.

One of the most important things that ethics addresses are the confidentiality of healthcare consumers. Among healthcare organizations, there are several channels that patients’ data must follow during the process of admission until discharge. For example, the areas that require patient’s personal information diagnosis, billing, electronic health records keeping as well as the department of research. Therefore, it becomes a challenge on how to deal with the privacy of a patient if all the areas have access to the patient’s personal information. Organizational ethics thus ensures that each department within the healthcare organizations adheres to the ethical conduct about preserving the confidentiality of the healthcare consumer. For example, the nurses, physicians, billing clerks, and the electronics healthcare records keeper should not divulge sensitive patient information to a third party. The prevalence of diseases such as cancer, dementia as well as mental disorders in the population has increased the need to observe organizational ethics. This is because the exposure of such health information to third parties can result in stigma from the members of the society. Ethics has therefore played a critical role in addressing patient confidentiality among healthcare organizations.

6.a.i Current State of Moral Distress in Mental Healthcare

6.a.i. 1. Patient care

The key to working with patients in mental healthcare institutions is the development of therapeutic relationships, as it is how all interventions are implemented. Studies of patient outcomes in the field of mental health confirm that therapeutic relationships improve patient health. Also, researchers researching therapeutic relationships with mental health nurses
identify key topics critical to building therapeutic relationships, such as trust, power, reciprocity, self-revelation, congruence and credibility, all in the context of maintaining professional boundaries. The occurrence of various types of discrimination plays a pivotal role in hindering an effective relationship between the patients and the healthcare practitioners.13

The topics identified by participants in these studies indicate that time is one of the elements that contribute to the development of therapeutic relationships. Interestingly, the key point for Jameton, which distinguishes the nurse's story from that of the doctor's dilemma, was that he acknowledged that the nurse had already made a moral judgment about what to do in such a situation, and was subsequently in distress.14 What makes this interesting is that the emotional component of history that hinted that something else other than something morally wrong was happening. However, Jameton did not link his definition or appropriate explanation of the emotional or psychological aspects of the experience.

Although the term MD is an important public health phenomenon, the definition proposed by Jameton was not adequate to explain the depth of indignation caused by this experience and did not reflect the complexity of the MD situation.15 The definition of MD seems linear and does not take into account contextual factors that allow and support institutional constraints. This is explained by the fact that an MD consists of complex and interrelated interactions between organizational and social structures and actors trying to act morally. For healthcare professionals (HCPs), they have to act morally to accomplish their ethical obligations to patients following the acceptable code of ethical behavior and professionalism.

Commentators note that the health care system should provide processes that demonstrate the importance of therapeutic relationships, and that HCPs should support the readiness to interact with the patient at the center of their care. For example, in a study by Austin et al., nurses identified situations of care that they considered morally distressing.
Lack of time has become one of the main causes of MD.\textsuperscript{16} Although these changes were not described in detail, the stories presented by the participants showed that these changes were the result of attempts to limit health care costs, which resulted in an increased workload and limited access to the basic resources needed to provide quality health care. Participants discussed how time pressures are hampering the development of therapeutic relationships and the ability to provide safe and ethical treatment. This resulted in nurses feeling disconnected from their patients and each other and not treating patients with dignity and respect. Participants described examples of emotional avoidance of situations that caused moral stress. Avoiding behavior due to MD was one of the conclusions made by Burston and Tucket in their review of the literature on MD and may have consequences for the patient's outcome, such as failure to rescue.\textsuperscript{17} In addition to staffing levels, avoiding the patient due to MD can also contribute to FTR. Avoiding patients and FTR is particularly important in psychiatric emergency settings, where it has been found that lack of time, which hinders the development of therapeutic relationships, contributes to the experience of MD.\textsuperscript{18} It is increasingly recognized that mentally ill patients have significant co-morbidities leading to reduced life expectancy.

In another study with the psychiatric nurses, Ohnishi et al. investigated the relationship between MD and burnout in the Japanese context; they also found that staff shortages correlate with MD and burnout.\textsuperscript{19} In particular, Ohnishi et al. also found that the frequency and intensity of MD were positively correlated with higher levels of cynicism and exhaustion. Interestingly, the authors noted that nurses caring for large numbers of patients reported that they felt less exhausted. This conclusion contradicts earlier conclusions linking MD to low staffing levels. A potential explanation for this finding is that participants working with large numbers of patients used psychological coping strategies, such as moral disengagement to protect themselves from any suffering they may have experienced. A
common feature of both studies was that the lack of external resources led to inadequate care or to patients being treated inappropriately, and thus both situations caused MD in many participants.

One of the gaps in the knowledge of MD in mental health care is the understanding of the impact of this experience on the quality of patient care. This includes understanding the influence of avoidant behavior\textsuperscript{20}, moral rejection\textsuperscript{21} and the influence of MD on the formation of therapeutic relationships in psychiatric institutions.\textsuperscript{22} Given that therapeutic relationships are fundamental to the implementation of mental health interventions, anything that impedes the development of such relationships may hinder positive outcomes for patients. Clarifying the relationship between MD, burnout and FTR in mental health care will help to identify ways to support HCPs.

6.a.i.2. External Structures that Shape Care

The external structures that shape the health system include; resource allocation, power and gender inequality, and organizational policies. Issues that have historically existed in health care and led to a crisis in the ability of health professionals to express their values continue to exist today. The global discourse on fiscal restraint and the application of business models to health systems has created an environment for action that may conflict with core values and codes of ethics for HCPs.\textsuperscript{23} One of the consequences of this conflict of values has been the experiences of MD. Nursing is a moral undertaking that is well argued in the literature; however, the impact of the Code of Ethics on MD is not clear. An example of reciprocity between structures and moral agents is the development of a nurse's moral identity. Peter and Lyashchenko reviewed MD using a feminist lens. In doing so, they emphasize the moral construction of a sisterly identity rooted in a historical and relational context.\textsuperscript{24} This shows that there is a reciprocity between social structures, such as public institutions and professional organizations, and those involved in the profession.\textsuperscript{25} The ethical
standards of practice are part of a narrative that shapes socialization into the profession and
defines relationships and responsibilities.

Austin with his psychologist colleagues found that experience of MD is based on a
sense of professional integrity. The authors identify the prerequisites for MD, including an
understanding of ethical issues and acceptance of moral responsibility. Austin et al. argue that
moral responsibility or duty is inherent in the role of a professional and that a threat to
professional integrity arises when psychologists, for example, consider themselves incapable
of fulfilling their moral obligations. Similarly, Peter and Lyashchenko argue that MD may
arise from limitations on moral freedom and the inability to perform socially constructed
professional responsibilities that individual agents also assume.

In most literary works, the definition of the structure was often simply implied,
leaving the reader with a context-specific explanation. When reviewing the literature on
nursing ethics, attachment theory, moral psychology, sociology and neuroscience regarding
MD, both external health care structures, such as resources and internal human structures,
have contributed to restrictive actions, but the components of internal and external structures
may differ. In other words, some structures are material or observable while others are
intangible and not directly observable, but both forms of structure affect the agent's ability to
act. Inadequate policies or policies that run counter to professional or personal values can
lead to the formation of material and observable structures that inhibit action and lead to MD,
e.g., hospital policies that result in an inadequate ratio of registered nurses (RMS) to acutely
ill patients.

Hierarchical power relations within medical teams are examples of structures that are
not only intangible but also inhibit the actions of others. Both of these examples reflect the
external constraints that constrain action. However, an understanding of the observed and
unobserved structures is necessary, but not sufficient; such an understanding does not shed
light on the relationship between the agency or on how the agency may influence change in these circumstances. Failure to rescue (FTR) technique is a sensitive nursing measure that can be used as part of a quality assessment of hospital care. As a result, sensitive to nurses' influence, FTR was tied to a staff ratio and was initially only studied in surgical departments, but since then studies have been extended to medical departments, intensive care units, and perinatal areas. Nursing care provides a link between staff levels and the FTR and includes an initial and ongoing assessment of a patient's health status to detect changes in his or her health status. Another element of FTR, after a potentially serious complication, has been observed, is that the nurse should quickly mobilize hospital resources.

In addition to staffing levels, avoiding the patient due to MD can also contribute to FTR. Avoiding patients and FTR is particularly important in psychiatric emergency settings, where it has been found that lack of time, which hinders the development of therapeutic relationships, contributes to the experience of MD. It is increasingly recognized that mentally ill patients have significant co-morbidities leading to reduced life expectancy. HCPs are legally obliged to carry out their activities following the standards established by their regulatory body; however, HCPs are also responsible to the public. For example, research conducted by Austin et al. showed that psychiatrists experienced MD in an attempt to balance responsibility to their patients in line with Hippocratic principles and the expectation that they would protect society from deviant behavior. The legal responsibility and public expectations can exacerbate the sense of moral duty on HCPs and can exacerbate MD when HCPs are unable to cope with these tensions.

6.a.ii. Organizational and Professional Ethics in Combating Moral Distress

6.a.ii.1. Organizational Ethics

Organizational ethics refers to the behavior that controls the operations of various activities in the healthcare setting. Ethics is used to address fundamental issues such as
confidentiality, integrity, respect as well as nurse-patient relationships. The prevalence of diseases such as cancer, dementia as well as mental disorders in the population has increased the need to observe organizational ethics. This is because the exposure of such health information to third parties can result in stigma from the members of the society. Organizational ethics has therefore played a critical role in addressing patient confidentiality among healthcare organizations. Another crucial area that has been addressed by organizational ethics is the conduct of uncompensated care. Several not-for-profit healthcare organizations participate in the provision of healthcare services.

However, most healthcare organizations operate as for-profit organizations since they aim towards generating profits in their operations. The main issue within these two arrangements is the ethical viability of each healthcare provider. Uncompensated care should ensure that it provides high-quality care to health consumers. Such organizations should focus on quality and patient outcomes. For-profit healthcare organizations, on the other hand, should focus on ensuring that healthcare is accessible to all people. Such organizations should not charge exorbitant prices that can prevent individuals from poor economic backgrounds from accessing healthcare services. Both compensated and uncompensated care should embrace organizational ethics to provide patient-centered health services.

Organizational ethics also addresses the issue of discrimination in healthcare organizations. The occurrence of various types of discrimination plays a pivotal role in hindering an effective relationship between the patients and the healthcare organizations. Discrimination based on gender, race, disability and professional hierarchy is some of the barriers that have elicited mixed ethical reactions. It is unethical for healthcare professionals such as nurses and physicians to practice any form of discrimination on a patient or fellow healthcare professional. Racial discrimination and discrimination based on the professional hierarchy are some of the most common types of discrimination in health organizations. For
example, in the United States, patients from the dominant white culture are likely to receive healthcare services faster than members of the minority African American community. Moreover, physicians have shown discrimination towards junior nurses thus hindering effective communication and teamwork. Since physicians usually work with the help of resident nurses, the occurrence of discrimination fuels hatred and therefore acting as a barrier to the adoption of patient-centered health intervention.

Organizational ethics, however, requires healthcare organizations to create an enabling environment that is devoid of any form of discrimination. The code of conduct promotes fair treatment and tolerance towards diversity in health care organizations. The implementation of organizational ethics has also helped in addressing fundamental environmental concerns. The advent of climate change and global warming has led to an increase in the need to embrace environmental conservation measures. Wastes from healthcare organizations such as medical wastes are harmful to both humans and the environment. Therefore, it is unethical to expose the medical wastes into the environment without proper treatment or management. Organizational ethics has led to the adoption of environmental policies that regulate the management of toxic medical wastes.

Among mental healthcare organizations, the issue of conflict of interest has shaped the provision of healthcare services. Under some situations, healthcare professionals undertake activities that are aimed at promoting self-interest rather than the interest of the patients. For example, when a physician is promised more money to treat a different patient at the expense of another who had been admitted earlier, the patient can decide to ignore the first patient thereby ignoring the ethical conduct. The adoption of organizational ethics, however, ensures that healthcare professionals focus on patient-centered care rather than their interest. Moreover, another organizational ethics perspective is a corporate culture perspective. Organizational ethics results in the adoption of a corporate culture that aims towards the implementation of
ethical conduct. The culture adopted by the healthcare organization should focus on ethical behavior among the various departments within the organization. Healthcare organizations have embraced a collective action towards promoting ethical conduct within the organization.\textsuperscript{43} Each healthcare stakeholder, such as the physicians, nurses, general staff, federal government healthcare agencies as well as the local community participate in advancing organization ethics. The collaborative efforts have led to an increase in the implementation of ethical behavior within the organization. Moreover, healthcare organizations have also adopted technology to monitor the ethical behavior of health professionals within health organizations.

\textbf{6.a.ii.2. Professional Ethics}

Professional ethics refers to the ethical behavior that is adopted by healthcare professionals to promote patient-centered healthcare.\textsuperscript{44} Professional ethics has created a platform for the adoption of favorable ethical behavior among healthcare professionals such as nurses. The ethical behavior that a healthcare professional displays have a direct impact on improving the nurse-patient relationship thereby enhancing health outcomes.\textsuperscript{45} Professional ethics can, therefore, prevent moral distress among health practitioners who work with patients with mental disorders. Several professional, ethical behaviors can shape the perception of a particular intervention method.

Health practitioners should focus on providing healthcare services that benefit the health consumer. The main emphasis should be on the welfare of the patient. Since healthcare consumers usually undergo pain, trauma, and depression due to health conditions, health professionals should provide care that can benefit the patients.\textsuperscript{46} Beneficence thus is one of the most important professional, ethical behaviors in healthcare. If the patients believe that a healthcare professional is focused on providing a health benefit, the patient will change his perception of professional healthcare. Beneficence promotes the provision of health service
that results in positive health outcomes among the patients. Healthcare professionals hence should ensure that they adopt a professional behavior that promotes beneficence.

Non-Maleficence ensures that healthcare professionals do not undertake activities that can harm health consumers.\(^{47}\) According to the principle, the most important element in the treatment process is to prevent any form of harm that a patient may be exposed to. The principle argues the first objective is to avoid harming the patient before adopting the required intervention method.\(^ {48}\) The prevalence of moral distress has brought a tremendous impact on the quality of patient outcome as well as the emotional development of nurses in different health care settings.\(^ {49}\) Moral distress hinders the nurses from effectively providing patient-centered care. The occurrence of moral distress in mental healthcare organizations has played a critical role in reducing the quality of healthcare services since in that particular healthcare setting; there is a dire need for the creation of a therapeutic relationship between the patients and the health professionals. Contemporary mental health organizations have however recognized the role that both organizational ethics and professional ethics can play in alleviating moral distress.

Organizational ethics and professional ethics help in eliminating or managing moral distress by creating a sustainable environment that is characterized by integrity, honesty, and professionalism.\(^ {50}\) Although the presence of health conditions such as dementia can make it difficult for patients to make rational decisions, the focus should be to initiate an intervention method that conforms with the patient's beliefs, ideologies, and personal taste. For example, a patient should not be forced to undergo surgery if he has refused the critical medical procedure. Medical professionals should adopt an ethical professional behavior that can allow them to grant patients the autonomy to make informed consent.

Professional ethics also advocates for health maximization among healthcare organizations. Health maximization facilitates the increase in health opportunities for the
particular target population. For example, health practitioners should provide various health services such as counseling, home-based care, community awareness creation, diagnosis of chronic ailments as well as the adoption of disease intervention methods. Health maximization enhances health outcomes since the patients acquire a variety of health services. Such measures can reduce moral distress and therefore enhance nurse-patient relations. Moreover, the concept aids in dealing with multiple health conditions such as terminal diseases, mental health conditions as well as general diseases. Through health maximization, patients with mental disorders can acquire counseling services, testing, diagnosis, treatment as well as home-based care.

Professional and organizational ethics have promoted the provision of high-quality healthcare in healthcare organizations. Organizational ethics has led to the implementation of the code of conducts that regulate the behavior of healthcare professionals, the patients and the stakeholders within a healthcare organization. Professional ethics, on the other hand, sets the values that promote the adoption of patient-centered healthcare by health practitioners. Healthcare organizations and other stakeholders such as global health bodies should adopt policies that promote both organizational and professional ethics in the field of healthcare.

Justice in healthcare also shapes the provision of high-quality health care. Healthcare professionals should ensure equal distribution of healthcare resources such as personnel, medical equipment, and medical practitioners. Much of the research on MD reflects the nursing profession from which it arose; as such, most of the early research is on nursing. However, recent research has been published, which includes interdisciplinary research designed to provide a better understanding of the phenomenon.

6.a.ii.3. Organizational Ethics and Moral Distress

The ethical code of conduct that a healthcare organization embraces has a direct impact on the occurrence and eradication of moral distress. This is since ethical behavior
adopted by both the nurses, and the health organization shapes the occurrence and prevalence of moral distress within a mental healthcare institution. Organizational ethics in mental healthcare is characterized by the development of trust between the nurses and the patients and the nurses and the health organization. Trust is a fundamental element of organizational ethics. This is because it initiates a therapeutic relationship between nurses and health consumers. Moreover, it improves the nurse-patient relationship in the health care organization. Healthcare settings that are characterized by the recognition of the role of trust have experienced a tremendous reduction of moral distress and the subsequent achievement of positive patient outcomes.

One of the crucial elements of the ethical code of conduct is integrity. The adoption of organizational ethics, therefore, enables the health professionals and nurses to practice integrity. In mental health care, integrity plays a pivotal role since it enhances patient outcomes by reducing moral distress. One of the factors that contribute to moral distress among the nurses is staffing shortages that result in heavy workload within a health care setting. The nurses, therefore, experience burn out since they provide care to several patients within a particular time. Heavy workload affects the emotional development of the nurses and makes them develop a negative attitude towards providing care in the health care settings. Integrity, however, can ensure that healthcare organizations respect the

Another critical element of organizational ethics that can be used to manage moral distress is respect. Organizational ethics enable the nurses and the healthcare organization to appreciate the value of respect. For example, respect ensures that the healthcare organization does not provide heavy workload that will cause nurse burnout. Through respecting the welfare of the nurses, the management of healthcare organization can appreciate the rights of the nurses and the need to create a sustainable environment that does not trigger moral distress. The health organization can, for instance, increase the number of
staff to reduce the workload for each nurse in various departments such as critical care nurses. Respect, as ethical behavior, enables the nursing professionals to show respect to the rights of the patient. For instance, the patients have a right to high-quality care even if they have different beliefs with professional nurses. The nurses, therefore, should ensure that they respect the rights of the nurses. There are different ways through which healthcare organizations can use to promote ethical behavior with the aim of copying and eradicating moral distress. The strategies include:

Healthcare organizations should initiate educational programs in nursing professionals to acquire crucial knowledge about proper ethical conduct. Ethical education results in ethical competence which is a vital aspect of managing moral distress. Nursing professional should be taught on how to handle different stressful situations and ethical dilemmas that they face in the line of duty. For example, heavy workload as a result of poor staffing hinders the provision of high-quality professional care. Moral distress affects the behavior of registered nurses resulting in poor patient outcomes. For example, nurses that experience moral distress usually display aggressive behavior as well as patient avoidance tendencies. In most cases, these patients are forced to provide care to hundreds of patients. Hence, they lack the opportunity to develop therapeutic relationships with the patients.

Another strategy that can be used to manage moral distress is to encourage nurse participation in the observation of ethical behavior. Just like in other aspects of healthcare, collective action or teamwork plays a critical role in copying up with moral distress. Mental healthcare organizations should organize meetings and discussion programs in which the nurses share their encounter with morally distressing situations and the effective ways that such situations can be avoided in the health care setting. Through a collective observation of ethical behavior such as honesty, respect, and trust, the nursing profession can acquire the capability of dealing with moral distress. Nurse participation is important in the adoption of
an ethical code of conduct that is instrumental in the eradication of moral distress in healthcare.

The nurse-patient and nurse-healthcare organization’s relationship is instrumental in managing and eliminating moral distress in a health care setting. Healthcare organizations, therefore, should adopt effective strategies that can ensure that both parties build interpersonal relationships. Through building interpersonal relationships, professional nurses acquire a chance to prevent conflicts that usually arise with the patients. This is because; the nurses will be in a position to clearly understand the beliefs, expectations, and opinions of the patients in regards to a particular healthcare intervention. For example, in case a nurse is providing care to an aged patient with schizophrenia, the nurse should create a relationship with the patient so that the patient can feel that the nurse understands his mental health condition. Building an effective relationship is an important aspect of ethical behavior that can be used to prevent or manage moral distress in a healthcare setting.

There are strategic tools that can be used to manage moral distress. Ethical tools such as ethical rounds, seminars and 4A tools play an instrumental role in the management of moral distress in the healthcare setting. Healthcare organizations should ensure that they embrace the tools and facilitate nurse-centered programs that aim towards reducing the severity of moral distress. For example, nurse professionals who are most affected by moral distress should attend ethical seminars in which ethical specialists discuss ways of dealing with moral distress especially in mental health care. Ethical specialists can also work together with nurse leaders to promote ethical behavior such as tolerance towards diverse opinions, respect of the patient’s rights as well as the development of the therapeutic relationship between the nurse professionals and the health consumers.

Another area in which nurses usually experience moral distress is how to handle the personal information of health consumers. The privacy of the patient’s data plays an integral
role in shaping the relationship between patients and healthcare organization.\textsuperscript{69} The handling of patient information from admission, diagnosis, treatment, billing, and discharge should be undertaken with confidentiality. Mental healthcare, for example, requires a high level of privacy due to the presence of stigmatization of the patients in the society.\textsuperscript{70} The health information of patients with mental disorders such as dementia and schizophrenia should not be divulged to a third party. Modern healthcare organizations have adopted electronic healthcare information management system to store patient data. However, ethical behavior is still needed to prevent moral distress.\textsuperscript{71} This is because sometimes, the nurse professionals face a situation in which they may be tempted to use patient information for selfish gain. Moral distress related to the privacy of patient information can be managed through the adoption of ethical behavior such as integrity or honesty.\textsuperscript{72} While handling patient information, nursing professionals should display integrity and honesty.

The freedom of making an informed decision is crucial in mental health care. The patients should be allowed to make informed consent before a particular intervention method is undertaken.\textsuperscript{73} Denying a patient the right to make informed consent can trigger moral distress. This is because conflict will arise between the nursing professional and the patient. However, the adoption of an ethical code of conduct can help in preventing any form of moral distress.\textsuperscript{74} Ethical behavior enables the nursing professionals to recognize the need to grant the patient autonomy that allows them to make informed consent on various intervention methods.\textsuperscript{75} Healthcare professionals who fail to provide informed consent can contribute to legal conflicts since the family of the patient can sue the hospital in case of death or an increase in the severity of the mental condition. Such conflicts thus result in moral distress within a health care setting.\textsuperscript{76} The ability to give health consumers the right to informed consent is an important aspect of organizational ethics. Therefore, organizational
ethics eradicate moral distress by ensuring that nursing professionals understand the importance of patient autonomy in healthcare.\textsuperscript{77}

6.a.ii.4. Professional Ethics and Moral Distress

The adoption of professional ethics can help in the management and prevention of moral distress in modern healthcare settings.\textsuperscript{78} Professional ethics focus on aspects of nursing professionalism that can create a therapeutic and personal relationship between the nursing profession and the patients.

Moral distress is most prevalent in healthcare organizations that have not recognized the role of professional integrity.\textsuperscript{79} Integrity is characterized by honesty or the ability to provide care without selfish interest. The process of accepting moral responsibility in a healthcare setting results in the adoption of professional integrity.\textsuperscript{80} Nursing professionals therefore clearly understand their expectations in regards to professional care. The adoption of professional integrity enables a nursing professional to participate in activities that are aimed towards ensuring high-quality care.\textsuperscript{81} Improving the patient outcome, therefore, becomes the sole purpose of a healthcare professional who understands professional integrity.

For instance, when a nursing professional ordered only to provide care to a section of the patients, the caregiver will ensure that he provides care to all the patients that have sought healthcare services.\textsuperscript{82} Through professional integrity, nursing professionals can prevent moral distress that is associated with organizational barriers or desire for profits rather than the health of the patients.\textsuperscript{83} Hence professional ethics can help in reducing moral distress through guiding the nursing professionals on the most effective professional behavior to adopt while providing care in mental health care settings.

The presence of poor nurse staffing strategies results in heavy workload for the nurses. Although healthcare organizations believe that limited nurses reduce the expenditure for the organization, it results in moral distress as well as nurse burn out.\textsuperscript{84} The nurses,
However, embrace coping strategies that further trigger moral distress. Some of the coping strategies are moral disengagement and patient avoidance. The nursing professionals, in this case, provide care without any form of emotional attachment on the profession. This act hinders the development of a therapeutic relationship between the nurses and the patients thus contributing to low-quality care. The healthcare professional detaches emotionally from the patients to avoid moral distress. However, the incorporation of professional ethics can play an integral role in eliminating moral disengagement among the registered. The aspects of professional ethics such as the creation of an effective interpersonal relationship will enable the nurses to interact and connect with the patients emotionally.

Patient avoidance is also a coping strategy that registered nurses have embraced to manage moral distress. However, it hurts the quality of the patient outcome. Patient avoidance hinders the patient and the nurse professional from developing a patient-centered relationship. This is since the caregiver will always be trying to avoid mental health patients. However, in the long run, patient avoidance still contributes to moral distress since the caregiver will feel the guilt of avoiding the patients. Professional ethics, on the other hand, can be used to prevent patient avoidance. Professionalism in healthcare enables nurses to recognize the value of improving the quality of healthcare in a mental health care setting.

Studies have shown that nursing professionals in most healthcare settings lack the opportunity to develop therapeutic relationships with patients. This can be as a result of a high number of patients. The therapeutic relationship is the most important elements of professional ethics that can enhance the provision of care in mental health organizations. Professionalism results in the creation of a nurse-patient therapeutic relationship in a healthcare setting. Observation of ethics among healthcare professionals on the other hand, leads to the creation of a suitable environment for the development of therapeutic
relationships. Through ethical education, nurses can learn the strategies that can be used to cope with moral distress. For example, the practice of tolerance of the views and beliefs of the patient as well as the patient’s family can be critical in solving conflicts that arise during the treatment of patients with mental disorders. This is because the conflict between nurses and patients usually increases moral distress since the nurses face a dilemma between providing high-quality healthcare care versus the existing disagreement with the patient.

Ethical education has been instrumental in combating moral distress. This is because, during the ethical education programs, healthcare professionals are taught various evidence-based strategies that can be used to manage moral distress in demanding health care settings such as mental health institutions.

Healthcare inequality is one of the factors that has hindered the provision of patient-centered healthcare. This is because some regions possess high quality and abundant health resources as compared to other regions. Social justice, therefore, promotes health equity in society. Health professionals should ensure that each patient despite racial or socio-economic background is entitled to high-quality healthcare. This is professional ethics ensures that the nursing professional change attitude to ensure positive outcome among the patients. The perspective is important since there are instances in which health practitioners have initiated intervention methods that have resulted in the death of the patients. Such scenarios occur due to the extreme emphasis on treatment without first examining the risk that the patient may be exposed to by the particular intervention method. Professional ethics create a viable environment that boosts the development of therapeutic relationships within a mental healthcare setting. Both organizational and professional ethics can shape the implementation of effective strategies that can be used to control the effects of moral distress within a healthcare setting.
6.b Integrated Care and Quality Improvement

Integrated care has brought a significant impact on enhancing the quality of health care services in contemporary society. Integrated care results in a collective action aimed at creating an enabling environment for the provision of patient-centered health care. Through coordination of health care activities, healthcare stakeholders such as the Saudi Arabian Ministry of Health have adopted measures aimed at ensuring the adoption of the principles of bioethics. The observation of bioethical principles such as patient autonomy and justice improves the relationship between health consumers and health professionals as well as other health care stakeholders. This is because the application of bioethics is a critical aspect of integrated care. When healthcare professionals adopt fundamental principles such as patient autonomy and justice, the patients will be in a position to access high quality and patient-centered care that will result in the achievement of health care goals. Incorporating bioethics also triggers quality improvement within clinical care settings. The quality of health care in a particular clinical setting has a direct impact on the observation of the ethical code of conduct. This is because when a health care practitioner observes ethical behavior, the patient has a higher chance of acquiring high-quality care. The essay, therefore, undertakes a step-by-step analysis of the role of bioethics in the implementation of integrated care in modern health care settings. Through the incorporation of bioethics in integrated care, health consumers can easily and efficiently experience quality improvement in regards to standards of home health care.

Global health care organizations such as the WHO have implemented strategies aimed at promoting the adoption of integrated care in modern health care. Integrated care has enabled stakeholders to enhance the access and quality of health care by adopting patient-centered care. Boosting the quality in health care has been attributed to the adoption of integrated care in various clinical care settings. Integrated care is characterized by the
coordination of health care resources, such as skilled psychiatric experts, medical information, and management. A bioethical approach towards the implementation of integrated care ensures the observation and application of an ethical code of conduct, which eventually contributes to efficient integrated care and quality improvement. Bioethics forms the basis for moral behavior in health care. Stakeholders in health care can facilitate the adoption of integrated care by promoting the observation of moral and ethical practice during caregiving. Crucial elements of morality that can be applied include inclusive decision making, adoption of precision medicine, recognition of the role of the members of the society, and regulation of health care activities. Regulation and control of home health care activities, for instance, ensures that home health care follows the global health care standards that promote the wellbeing of health consumers.

Another critical aspect of bioethics in integrated care is its impact on health consumers. Through the collaboration and coordination of efforts, health care stakeholders are in a position to improve access to high quality and patient-oriented health care services in the society. However, health professionals have recognized the role of bioethics during the implementation of integrated care. Bioethical practice creates a moral and ethical framework for adopting integrated care. In essence, the incorporation of bioethics enhances the process of implementing integrated care hence leading to quality improvement in the field of health care as well as the achievement of the goals of home health care.

6.b.i. Bioethics Issues in Integrated Care and Quality Improvement

6.b.i.1. Provision of Standardized Care by Healthcare Professionals

One of the essential elements of integrated care is the provision of standardized care. Integrated care must focus on the provision of standardized care to health consumers. Standardized care is a type of care that has been approved by global health care regulatory organizations. The goal of health care professionals, as well as stakeholders, is to provide
standardized care that aims to improve the quality of life of the patient. The main goal of modern health professionals is to ensure that health consumers acquire standardized care. As opposed to hospital-based care, home health care has a different setting since most of the medical equipment, and health professionals are not easily available. The absence of these crucial health care resources can hinder the provision of standardized care.\footnote{112} Therefore health providers must ensure that the standard of home-based care is similar to hospital-based health care. Health care stakeholders such as physicians, nurses, health care regulators, and counselors must consistently undertake periodic home visits to provide clinical care services to the patients within the home environment.

**Collaboration between physicians, nurses, and counselors:** Integrated care is characterized by collaboration and coordinated efforts between health care professionals such as nursing practitioners, physicians, counselors, and social workers.\footnote{113} To achieve the goals and objectives of integrated care, health professionals must collaborate and share vital medical knowledge as well as resources that ensure increased access and quality of health care. Health care organizations, therefore, should create a sustainable clinical care environment to improve the relationship between health professionals. To collaborate, health providers must forge a productive relationship that is characterized by the desire to work together to achieve health care goals.\footnote{114} Health organizations have promoted collaborative efforts among physicians, nurses, and other stakeholders to incorporate integrated care.\footnote{115}

Integrated care cannot be achieved without the coordination of action among the health care stakeholders. The members of the community should provide medical data about the prevalence of a particular disease and the general health of a particular population.\footnote{116} After acquiring the information, health care professionals, including physicians and practicing nurses, should adopt a strategy of undertaking home visits to provide health care services to the sick in the home setting. Alternatively, patients who have sought hospital-
based care should be admitted to the home-based care system. For instance, the aged patients
with a chronic and terminal illness can easily benefit from the home health care system.
Patients suffering from chronic diseases that are associated with old age can acquire more
efficient health care in the home-based care setting as opposed to clinical care settings.¹¹⁷
This is because, in home health care, health professionals such as nurses and physicians can
coordinate health activities with the family members, next of kin, or the guardian. Moreover,
the home setting provides a comforting environment that allows the patients to recover in the
presence of the family members.

**Physician integration and disease management**- Physician integration in disease
management is another vital aspect of integrated care. Health professionals must adopt a
useful framework for ensuring that the patient acquires standardized care.¹¹⁸ Physician
integration into the adoption of various intervention methods plays a crucial role in ensuring
the prevention, management, and treatment of various diseases and mental conditions.
Disease management requires coordination of efforts since it may take a long time for a
particular disease to be eradicated from the body. For instance, chronic diseases that affect
aged individuals requires the collaboration between physicians, counselors, attending nurses
as well as social workers. Integrated care is beneficial in disease management since each
health care stakeholder undertakes a particular duty within the process of treatment and
management of chronic diseases.¹¹⁹ For instance, the management of diseases such as
diabetes, ulcers, and cardiovascular conditions requires the intervention of different health
specialists. Physician integration plays a vital in home health care. The application of a
bioethical practice in integrated care results in the realization of home health care goals, such
as the implementation of standardized care.

Health care professionals have been spearheading the adoption of precision medicine
since it results in high-quality care that focuses on the health of patients in different regions
within the Kingdom.\textsuperscript{120} The adoption of ethical behavior also leads to the coordination of health care activities and collective action towards achieving integrated care. One of the most vital elements of integrated care is the collective action and collaborative efforts among health care stakeholders. The stakeholders, such as the health consumer and health professionals, should collaborate to adopt integrated care. For instance, health professionals should collaborate with the members of the community to generate information about the existence of different ailments and mental health disorders within rural areas.\textsuperscript{121} Health care organizations such as the Ministry of Health and the WHO have embraced collective action towards adopting health care laws and policies that enhance the adoption of integrated care within home health care and clinical care settings. The incorporation of ethical behavior during the adoption of integrated care has brought a significant impact on enhancing the quality of home health care.\textsuperscript{122}

Moreover, the adoption of bioethical behavior during the implementation of integrated care leads to an improvement in the quality and access to patient-centered care. The bioethical practice also improves collaboration and coordination of operations among the diverse health care stakeholders within a specific health care setting.\textsuperscript{123} For instance, in the home-based care setting, there is a critical need for the coordination of health care operations among the health professionals and health agencies as well as family members. As opposed to hospital-based care, home health care allows health professionals to interact with the patient effectively. Critical issues such as physician burnout can be rarely experienced during home-based care. Hence the physician can provide health care attention to a particular patient. Moreover, the attending physician and the advanced practice nurses can coordinate activities with the family members to provide effective care and also monitor the recovery of the patient. Disease management is one of the major functions of integrated care.\textsuperscript{124} Health
Health consumers suffering from chronic illness and terminal diseases require effective disease management strategies. The process of undertaking disease management is also characterized by focusing on essential issues such as pain management and treatment of the specific disease. Some of the ailments that are usually managed through home health care include high blood pressure, cancer, migraines, and diabetes. To ensure effective pain management, attending physicians and nurses should coordinate operations with family members of the patient. The next of kin is mandated with ensuring that the patient lives in a comfortable environment characterized by love and appreciation. Moreover, the family members should ensure that they pray together with the sick to seek divine intervention.

6.b.i.2. Patient Focus/Precision Medicine

Incorporation of precision medicine- In contemporary society, health care professionals have recognized the significance of precision medicine. Unlike traditional health care practice, stakeholders in the field of health care have created an enabling environment for the adoption of precision medicine. The increasing need to provide patient-centered care has led to the adoption of precision medicine. Through undertaking precision medicine, health care providers can focus on the patient and conduct diagnosis, treatment, preventive measures as well as disease management within a particular context. Therefore, the adoption of precision medicine has become an ethical practice since it focuses on improving the quality of life of the patient through access to precision medicine that satisfies the needs of a specific patient or group of patients. For instance, a patient who is suffering from cancer is given specialized care that aims at managing the disease and eventual eradication. Bioethical behavior is essential in the provision of high-quality integrated care in different clinical care settings.
Another ethical perspective in integrated care is the incorporation of precision medicine. Health providers have adopted strategies aimed at adopting precision medicine. The patient-centered care aims at ensuring that a patient receives high-quality care within a specific clinical care setting. Precision medicine has contributed to quality improvement since the health care experts focus on providing care that ensures significant health benefits to a particular patient in regards to the existing health condition. Moreover, the information management system in clinical care is also a significant ethical element that influences integrated care. Integrated care is achieved by the dissemination and tracking of medical data among the different health care stakeholders. Therefore, health care providers should develop an in-depth information management system. Information management assists in the collection, storage, and sharing of health information within the health care center. For instance, the results of diagnostic tests should be communicated to the physicians through a correct and reliable information sharing platform. Such information should also be shared with other health care stakeholders, such as the ethical consultation committee and family members. Therefore, a quality-oriented information management system improves the adoption of integrated care and leads to quality improvement. The government health agencies such as the Ministry of Health, for instance, have promoted the implementation of a sophisticated medical information collection and dissemination system such as the online health database.

One of the revolutionary health care strategies that have been adopted in modern health care settings is precision medicine. This type of health care focuses on providing health care services that are tailored to the health needs of a specific patient. By focusing on the health needs of a patient concerning a particular health condition, health care professionals are position to embrace health interventions that can result in the achievement of home health care goals. Integrated care has promoted the adoption of precision medicine
since different health care stakeholders and divisions can work together towards delivering high-quality health care services. For example, health care professionals can share patient health care information with global health care organizations such as the WHO and CDC regarding a particular disease.\textsuperscript{133} Through the sharing of information, the different health organizations can develop an effective intervention that can have a positive long-term effect on the provision of home health care. Health care organizations usually strive to ensure quality improvement in clinical care settings. Home health care also focuses on ensuring the improvement of the quality of care in rural areas across Saudi Arabia. Through observing the bioethical code of conduct, health care professionals such as counselors, physicians, nurses, and ethical consultation committees can work together with the patient’s family members in ensuring improved health outcomes.

\textbf{Adoption of effective intervention method}- To effectively embrace integrated care and quality improvement, health care professionals should be in a position to select and implement efficient intervention methods. The intervention methods should be chosen depending on the existing disease or mental condition, as well as other underlying factors such as the availability of health care resources.\textsuperscript{134} According to the codes of ethics, health care professionals should adopt an efficient intervention method that will enable the patient to realize his or her health goals. The focus of a particular intervention is to treat the disease and boost the quality of life of health consumers. Health professionals should avoid practicing any form of gender, racial, and religious discrimination. This is because discrimination act as a barrier to the physician-patient relationship. However, the physicians and advanced practice nurses should ensure that they involve the patient during the decision making. Patient involvement in caregiving symbolizes that the caregivers observe the ethical code of conduct.\textsuperscript{135} The inclusion of ethical practice in integrated care results in the coordination of
health operations and the achievement of the goals of home-based care in both urban and rural areas in the Kingdom of Saudi Arabia.

One of the roles of integrated care is to foster the adoption and implementation of effective intervention methods in home health care. Coordination of health care activities is done to ensure that the patient who is receiving home-based care acquires the best possible health care attention. For instance, in the case in which patients are suffering from chronic illness and old-age related illness, the most suitable intervention method is to ensure that the patients acquire home-based care in which physicians and nurses conduct periodic home visits. During the home visits, the health care professionals acquire information on how the patient is faring from the family members who also play a critical role in home health care. Family members become beneficial since they can attend to any emergency by informing the physicians about the health status of the patient. Another critical element of integrated care in home health care is the ability to incorporate diverse strategies of ensuring treatment, disease, and pain management. For example, in case a patient who is suffering from chronic cardiovascular and respiratory disease is receiving home-based care, the health care professionals can initiate caregiving alongside counselors, religious leaders, and the close family members. All these parties have a role to play to ensure that the patient receives care in a sustainable environment. The religious leaders ensure that the patient receives divine intervention while the counselors provide counseling services during the whole process of home-based caregiving. Therefore, the adoption of an effective intervention method depends on the implementation of bioethical practice in home health care.

6.b.i.3. Information Management Systems

Incorporation of advanced technology in healthcare. The management of health information has evolved over the years due to the adoption of modern technology in home health care. Information management systems play a crucial role in the process of managing
health data as well as the process of sharing patient medical information across different health care organizations and research institutions. The adoption of advanced technology has led to the adoption of electronic health records (EHRS), which has, in turn, brought a tremendous impact on the collection, analysis, and sharing of health care data across different health care organizations.\textsuperscript{139} According to organizations such as the American Health Information Management Association, policies have been adopted that guide the process of handling medical information. For instance, the privacy of the patient’s information must be adhered to by the health professionals and other health care stakeholders. Some of the documents that are stored electronically include different patient records. Hence health organizations can share medical data and research findings. Health information professionals ensure the safety of patient data by using sophisticated medical technology. Health information management is also an essential element of integrated care that can be applied in home health care. Just like in hospital-based care in which electronic health records are used in storing and sharing of patient data, home health care can also benefit from efficient information management systems.\textsuperscript{140} Health professionals can adopt a multifaceted health information management system that involves the prevalence of diseases, patients, treatment options, and home-based caregivers such as family members. The integration of care in the home environment requires the adoption of a viable information-sharing platform that can enable the sharing of information between the home-based caregivers, including physicians, nurses, midwives, and close family members. Health information management has been associated with a reduction in medical errors such as loss of patients’ data, misdiagnosis, and acquisition of a patient’s medical data by unauthorized personnel.\textsuperscript{141} Health organizations that have embraced effective health information management are more likely to provide patient-centered care than clinical care centers without proper health information systems.
Adoption of communication support systems- Another element that enhances the health information management system is the communication support systems that health care organizations implement in their operations. Communication is the ideal tool that is used to make informed decisions as well as the sharing of vital patient information regarding patient history, diagnosis, treatment, and disease management. Health information management system cannot occur effectively if a proper communication framework is lacking within a particular health care setting. Health care professionals, therefore, ensure that they adopt a multi-dimensional communication strategy that involves the patients, physicians, nurses, health information managers, counselors as well as social workers. Both vertical and horizontal communication strategies can be employed to ensure a seamless flow of health information across different health care organizations.

Through the use of advanced communication technologies such as teleconferencing, use of emails, Skype, as well as social media, health providers have increased access to medical information and other health care resources. Significant advances, such as telemedicine, has revolutionized caregiving. However, the communication support system has been attributed to the adoption of an effective information management system. The adoption of advanced technology in the field of health care has enhanced the process of sharing of health information. Unlike in the past, the application of modern technology in the field of health care has enhanced the quality of health care services by ensuring that different health care stakeholders access patient information. For instance, physicians are in a position to share patient’s health data in regards to diagnosis and treatment with medical research organizations, global organizations, and other health care providers to adopt an effective health intervention strategy. Dealing with emerging global pandemics such as Covid-19 can easily be undertaken by sharing of health information with different health care stakeholders. Due to the WHO findings that Covid-19 has a devastating impact among aged
individuals with underlying health conditions such as cardiovascular diseases, such information can be shared across different health organizations to handle the pandemic effectively.\textsuperscript{145} Home-based care can only be efficient if proper medical information is exchanged between the various players within health care.

6.b.i.4. Regulation and Control

Formulation of laws and policies- The Kingdom of Saudi Arabia has adopted a multi-tier health care system that is focused on promoting the adoption of integrative medicine and integrated care. The Ministry of Health primarily passes the laws and policies. Other organizations that provide integrated care include teaching and university hospitals, armed forces health care services as well as the Saudi Aramco health care services.\textsuperscript{146} All these health care providers have embraced collaborative effort in the regulation and management of health care services across the Kingdom. Another vital bioethical element that affects the adoption of integrated health and quality improvement is the formulation of health laws and policies. Laws guide the operations that occur within health care organizations. For instance, laws govern the actions of the provision of standardized care, precision medicine, and the adoption of ethics. Regulation of health care operations is undertaken by different health stakeholders such as health organizations, regional regulatory bodies, as well as global health care organizations.\textsuperscript{147} For instance, health care organizations must establish its laws and regulations that aim at ensuring the adoption of integrated care and quality improvement.

The health policies should develop a framework on how the health care institution is going to implement integrated care to achieve quality improvement in the provision of health care services. To implement integrated care, health care stakeholders should also embrace regulation and control of the operations of health care centers.\textsuperscript{148} Regulation of health care operations is essential in ensuring the equal provision of health care resources and the provision of high-quality care. Although each nation has its health care laws and policies,
there are global health care laws that ensure the observation of the ethical code of health care conduct in health care centers. The laws and policies have also contributed to the adoption of home health care to improve access to high-quality health care by health care consumers in different parts of the KSA.

The Kingdom of Saudi Arabia has been at the front of adopting and formulating laws that control health care activities across the nation. The policies are focused on promoting the adoption of integrated care and how it can be effectively applied in home health care. Regional health care centers are required to establish a home health care program through integrated care. Integrated care allows health care organizations to deliver health care goals in coordination with the local community, the Ministry of Health, and health consumers. The process of formulating laws and policies should be undertaken after examining internal issues that affect a particular health care setting. For instance, the availability of skilled and experienced health professionals, the culture of the members of the society, the economy of the country, the prevalence of various diseases, and the global health care policies. For example, most health care centers have passed laws that ensure the provision of integrated care that involves the collaboration between the patients, health professionals, the federal government, investors, and the individuals in the community.

Regulation of health activities is another important aspect of integrated health care and quality improvement. This is because integrated care involves the coordination of activities among key players such as the Saudi Ministry of Health, WHO, health care organizations within Saudi Arabia, the local communities, and health consumers in the region. Regulation of home health care activities plays an instrumental role in fostering the implementation of high-quality health care activities. Home health care also should undergo regulation to ensure that health care professionals provide standardized care. Therefore, there is a need to address the prevailing challenges that may hinder the regulation of integrated care.
in home health care. For example, the funding for rolling out home health care should be regulated to ensure that it is used for its intended purpose. Moreover, health care professionals should observe health care equality by ensuring that home-based patients acquire health services of the same standard as the patients in the hospital setting.\textsuperscript{152}

\textbf{Control by global health care bodies-} Global health care bodies such as the FDA, CDC, and WHO have brought a tremendous impact on the regulation of health care across the globe. Through cooperation with the governments of various nations, health organizations such as the World Health Organization have developed global frameworks that control and regulate the implementation of integrated care and quality improvement. For instance, WHO collaborated with the US Department of Health to pass the Patient Protection and Affordable Care Act of 2010. The law aims at ensuring enhanced accessibility and affordability of care within the United States. The Kingdom of Saudi Arabia, through the Ministry of Health, has also established health care laws that promote integrated health.\textsuperscript{153} The laws and policies, however, must adhere to the health standards that have been advanced by global health organizations such as the WHO. For example, the emergence of the new pandemic, Covid-19, has led to the establishment of health regulations and guidelines such as the application of social distancing, sanitization, and wearing of face masks to prevent the spread of the novel disease. Global health care bodies and the Saudi Ministry of Health have managed to control and regulate health care in Saudi Arabia.

\textbf{6.b.i.5. Community Integration}

\textit{Community participation-} Community participation plays an instrumental role in the adoption of integrated health and quality improvement in the field of health care.\textsuperscript{154} Involving the members of the society has brought a significant impact in the quest to achieve the goals of integrated care. Health care organizations such as the World Health Organization and the CDC have been at the forefront of promoting community participation in integrated care. The
members of the community form a vital health care stakeholder alongside the health professionals, advanced practice nurses, counselors, and social workers. Through involving the local community, the stakeholders in the field of health care can acquire crucial information on the health issues that are affecting the people in the society. Moreover, people can participate in collective decision making, thus leading to the adoption of precision medicine or patient-centered care. It is, therefore, evident that integrated care cannot be fully and effectively implemented without the inclusion of the fundamental code of ethics.

**Community support groups**- Community participation can occur in different ways, such as the creation of community-based support groups. Health care professionals are capable of establishing community support groups that focus on identifying and assessing the prevalence of various diseases and mental health conditions within the community. Through a coordinated approach involving home-based caregivers, the sick in the community can easily acquire patient-centered care hence increasing the quality of life of the people in the society. Through liaising with the regional health care centers, community support centers can achieve quality improvement and integrated care. Community integration is another crucial ethical perspective that improves the adoption of integrated care.

The local community can play a critical role in the provision of home-based health care services. The incorporation of home health care programs has led to the recognition of the role of the members of the society in the provision of local health care. The local community plays a significant role in the provision of home-based care. Home-based care providers such as close family members assist in providing care to patients with diverse ailments such as cardiovascular and old-aged diseases and disorders. The goals and objectives of integrated care can only be achieved if the players in the field of health care, such as physicians embrace collaborative action with other stakeholders such as the patients. Another critical role that community support groups can initiate within the community is
awareness creation on the need to prevent diseases and also seek health care services in clinical care settings.\textsuperscript{159} Through creating awareness both in the rural and urban centers, community support groups help in achieving the goals of integrated care. In most cases, the members of the community lack vital information on how to prevent various diseases such as obesity, cancer, hypertension, HIV/AIDS, Covid-19, or cardiovascular diseases. Surprisingly, other people are just ignorant about the diseases; hence there is a need to undertake a comprehensive awareness creation in different parts of the country.

Moreover, another hindrance to access to health care is underlying religious doctrines. For instance, Islamic nations adhere to Sharia law that argues that people who believe in Allah can easily get cured even without seeking conventional medical care.\textsuperscript{160} Unlike in the past, where the community played a minimal role in health care, the modern health care system has adopted a multi-dimensional strategy aimed at incorporating the community in caregiving. Community integration forms one of the most vital aspects of integrated care. This is because home health care occurs within the community. Therefore, health care providers must work alongside the community leaders and the family members of the patients. Coordination of activities with the members of the community has been associated with increased access to high-quality care and improved wellbeing of the members of the society.\textsuperscript{161}

Several benefits can be acquired through community integration in home health care. For example, the members of the community can act as a link that connects the health professionals and the patients. The home-based caregivers can inform the health care professionals in case of a medical emergency. For example, if a patient who is under home-based care needs urgent medical attention, the members of the community are in a position to inform the medical personnel without waiting for the next physician home visit. Moreover, community integration also shows that health care stakeholders appreciate the role of the
community in achieving the goals of home health care. Just like physicians and advanced practice nurses, the local community also plays an instrumental role in implementing integrated care in society. The members of the community can also undertake awareness campaigns on the importance of seeking home health care as an effective alternative to hospital-based care. One of the challenges that face the implementation of integrated care is the lack of adequate information on the benefit of both hospital-based care and home health care. Due to underlying religious beliefs, some individuals do not believe in seeking health care services. Therefore, there is a need to ensure that the members of the community acquire in-depth information on the benefit of seeking either hospital-based or home health care services. Communication is the primary tool that can be used to ensure that the public acquires truthful and adequate health information.

Therefore, the members of the community can conduct door to door awareness creation programs to empower the members of the public on the benefit of home health care. The coordination of health activities among the different health providers enhances care giving. Integrated care hence results in the enhancement of the quality of the clinical care services within a specific health care setting. Important elements of integrated care, such as community integration and regulation, enhance the quality of care. The adoption of ethical practice, therefore, enables health professionals to adopt integrated care and experience improvement in the quality of home health care. Integrated care has played a tremendous role in enhancing the quality of health care in modern society. Moreover, integrated care leads to a collective action aimed at ensuring an enabling environment for the provision of high-quality health care. Through coordination of health care operations, healthcare stakeholders such as the health consumers and government health agencies have adopted measures aimed at ensuring the adoption of ethical and moral practice.
The application of bioethical practice, such as patient autonomy and non-maleficence, improves the relationship between patients and health professionals as well as other health care stakeholders such as members of the community. This is because the adoption of bioethics is a significant aspect of integrated care. When healthcare experts adopt essential principles such as patient autonomy and justice, the patients will be able to access high quality and precision medicine care that will result in the achievement of health care goals.\textsuperscript{166} Adopting bioethics also results in quality improvement within home health care as well as clinical care settings. The quality of health care in a specific health setting has a great impact on the application of the ethical code of behavior. This is due to the fact that when a health care expert adopts ethical behavior, the patient can easily acquire high-quality care. Through the incorporation of ethical behavior in integrated care, patients can easily and effectively achieve quality improvement during the provision of home health care. Health care providers have promoted the adoption and implementation of integrated care in contemporary clinical care settings.\textsuperscript{167}

Integrated care enhances the quality of health care since the collaboration among health care providers leads to patient-oriented care. However, the observation of the bioethical code of behavior has created a sustainable environment for the application of integrated care. Crucial ethical elements such as the provision of high-quality care have led to an improvement in access to health care services.\textsuperscript{168} Health providers should ensure that they provide globally acceptable care in both the clinical care and home health care environment. Global health agencies such as the Centers for Disease Control and Prevention adopts the standards of health care in which countries across the globe are required to follow in the process of providing standardized care. Through adopting high-quality care, health care organizations adopt the bioethical code of health care conduct.
6.b.i.6. Performance Management and Monitoring

Monitoring quality and access to health care- Integrated care also involves the management of health care performance. The overall performance of the health care operations is critical in achieving the goals of integrated care and quality improvement. Health care professionals should be in a position to establish a health care performance management team that is tasked with monitoring how health care professionals are working towards achieving health goals. Just like in any other field, the field of health care also requires performance management. The different health care services that health professionals undertake should undergo close monitoring to ensure that they focus on health care goals. For example, the resources that have been allocated for implementing integrated care should be monitored to ensure that they perform their intended duties.

Performance management has been attributed to improved access and quality of health care services across the globe. Developed nations such as Saudi Arabia have embraced a multi-dimensional strategy aimed at fostering effective performance management in clinical care. The Saudi Arabian Ministry of Health has recognized the significance of performance management and monitoring in health care. Health care performance management involves the process of monitoring how the health professionals provide health care services, examining the achievement of the goals of integrated care as well as other issues such as the welfare of the health professionals.

Provision of health resources- For health care stakeholders to achieve the goals of integrated care and quality improvement, essential healthcare-based resources such as health professionals, medical equipment, and funds must be present within a particular clinical care setting. Health resources must be present for health care professionals to effectively coordinate operations with other stakeholders in health care, such as the federal department of health as well as health consumers. One of the most significant health resources is the
availability of skilled health care professionals. Health care organizations should ensure that health care settings possess skilled and experienced physicians, advanced practice nurses, counselors, psychologists, and social workers. One way of ensuring the availability of skilled health professionals is through continuous training of medical specialists.\(^{173}\) For example, physicians and nursing practitioners should be trained to ensure that they provide high quality and patient-oriented health care services within the clinical care settings. Another vital health care resource is medical equipment.

The adoption of advanced medical technology has enhanced the provision of precision medicine. For example, advanced machines such as Computed Tomography scans, Magnetic Resonance Imaging has enhanced the screening of underlying diseases such as brain tumors and cancer. Moreover, advanced medical technology has been used in medical breakthroughs such as gene editing, gene therapy, 3D printing, and Telemedicine.\(^{174}\) Moreover, global health care stakeholders such as the World Health Organization, CDC, and the FDA have promoted global health through the provision of funds and medical equipment in various countries. Therefore, the presence of health care resources has promoted the adoption of integrated care and quality development among different health care organizations. Health resources enable health professionals to undertake health care activities in home care settings. The availability of crucial resources such as funds, skilled physicians, nurses, and counselors have boosted the process of adopting integrated care. This is because the availability of the essential resources has a direct impact on the quality of health care. However, bioethical behavior should be observed during the adoption of integrated care. Ethical and moral behavior creates a viable framework that allows health care stakeholders to implement the objectives of home health care.\(^{175}\) For instance, by appreciating the role of every health care stakeholder, in the integrated care system, the stakeholders such as the local community can continue to promote advanced care in the home care settings. The health care
resources, such as medical equipment that are used to undertake therapies, are usually found in established health care centers. However, through the adoption of integrated care, such essential medical technologies can be used by the patients in the home care setting.

6.b. ii. Significance of Bioethics in Adoption of Integrated Care

6.b.ii.1. Improved Access to Patient-Centered Care

The incorporation of bioethical practice in clinical care settings has brought a tremendous impact on access to affordable health care services. Access to patient-centered care, as well as precision medicine, has, over the years, become a significant challenge among health consumers. Moreover, the goals and objectives of health care organizations are always to ensure that health consumers and the local community, in general, have access to patient-oriented care within health care and clinical care settings. Since health care stakeholders have identified integrated care to be the solution to improved care, there has been an increasing need to incorporate bioethical practice during the implementation of integrated care. The application of bioethics in integrated care has, therefore, enhanced the access to health care services through the recognition of the role of each health care stakeholders and health care procedures. Integrated care involves collective action among health care specialists, stakeholders, and other support systems that increases access to improved care.

Bioethics introduces a moral and ethical perspective in integrated care that enhances the quality of health care operations. For instance, the coordination of activities between the health professionals, health information managers, patients, government health agencies, and the local community health care organization can identify the most suitable strategy that can be used to increase the access to patient-centered care. Patient-centered care enables health care providers to achieve the goals of home health care. The incorporation of ethical behavior in integrated care acts as the foundation for initiating patient-oriented care. This is because
health professionals, as well as other stakeholders, recognize and observe critical ethical and moral values such as the right to acquire efficient treatment, patient autonomy, and non-discrimination in health care. Moreover, the health professionals are in a position to coordinate actions with different health organizations such as the Ministry of Health, community health organizations, and the public in the quest for an effective home health care. The desire to ensure that health consumers both in the urban and rural areas, acquire health attention that boosts their wellbeing has led to the adoption of patient-focused health care decisions and programs.\(^\text{178}\)

The Kingdom of Saudi Arabia has undertaken measures aimed at reducing inequality in health care. Regions that experience slow economic growth and development have faced the challenge of accessing high quality and patient-centered medicine. Therefore, access to precision medicine has become a major issue in different parts of Saudi Arabia. The implementation of integrated care has, however, led to an improvement in access to better health care services.\(^\text{179}\) Moreover, bioethical practice in health care creates an enabling environment for the coordination of health care activities between the physicians, attending nurses, counselors, social workers, and religious leaders as well as the ethics consultation committee. When the stakeholders embrace bioethical behavior during caregiving, they can exercise collective decision making that eventually enhances the quality of health care. Collective decision making is one of the tenets of integrated care in both home-based and clinical care settings. This is because integrated care involves different stakeholders who must work together to achieve the goals of health care. Collective decision making, therefore, enables the health care stakeholders to adopt a uniform decision that can be used to spearhead the home health care programs.\(^\text{180}\) Decision making must involve government health agencies such as the Ministry of Health, global health organizations, patients, and local communities.
6.b.ii.2. Increased Quality of Health Care Services

The adoption of bioethical behavior during the implementation of integrated care also enhances the quality of health care services within a particular clinical care setting. The primary goal of integrated care is to undertake collective and coordinated health care efforts to improve the access and quality of health care services.\textsuperscript{181} Therefore, the incorporation of an ethical code of conduct creates a sustainable working environment that motivates the health professionals as well as other stakeholders, thus leading to quality improvement. Quality improvement has been attributed to the adoption of integrated care within health care organizations. However, bioethical practice, such as the observation of an ethical code of behavior, creates an efficient relationship between the health providers, patients, as well as other health care stakeholders.\textsuperscript{182} Health care professionals who observe bioethical behavior such as patient autonomy and justice have a higher chance of forging a beneficial relationship with the patients and other players in the field of health care such as health information managers. Good relations will stimulate collaborative efforts hence leading to collective decision making that eventually boosts the quality of health care services.

Since moral and ethical behavior promotes coordination of activities across different health departments, the health providers acquire an opportunity to share medical information regarding the diagnosis and intervention methods for a particular patient.\textsuperscript{183} Health care professionals, therefore, focus on measures aimed at improving the quality of health care services. Since the observation of ethical and moral behavior creates an enabling environment for the adoption of integrated care, health care professionals, and other health stakeholders have implemented strategies aimed at boosting health care in the country.\textsuperscript{184} Quality is one of the most important aspects of home health care. Just like hospital-based care, the implementation of integrated care in home-based care should also facilitate high-quality health care services. This is because both health care settings have similar goals of ensuring
that the patients acquire satisfactory and beneficial health care services. However, as opposed to clinical-based care, home health care is usually characterized by several challenges that affect the quality of health care services. These challenges include shortage of health care professionals, medical equipment, and lack of quick response in case of a medical emergency.¹⁸⁵

Home health care programs depend on health care experts from established health organizations such as King Fahad Hospital. Therefore, physicians and nurses have to make periodic home visits to treat the sick in rural areas. In essence, the physicians are not readily available as compared to the hospital setting.¹⁸⁶ However, the adoption of bioethical practice in integrated care can create an opportunity in which health care professionals from different health care centers coordinate activities to increase the number of home visits. Integrated care focuses on the co-ordination of health activities between different stakeholders to achieve the goals of home health care. The incorporation of various bioethical practices has brought a significant impact on integrated care and quality management. For instance, ethical and moral behavior leads to enhanced access to high-quality clinical care. The availability of patient-oriented care is one of the goals of contemporary health care.¹⁸⁷ Through boosting the access and quality of health care services, health professionals have enhanced the implementation of awareness creation campaigns. The incorporation of bioethical elements such as information management systems and community integration leads to collaborative action that results in the adoption of diverse decisions into health care.

Coordination of clinical care activities ensures that the various stakeholders, such as the health consumers and health providers, embrace high-quality health care decisions. Bioethical behavior also results in the realization of the goals of integrated care in home health care. Integrated care focuses on the coordination of activities and the sharing of health decisions among different stakeholders to enhance the access and affordability of health.
Through improving the quality of health care, patients can acquire clinical care services that enhance health outcomes.\textsuperscript{188} Therefore, the adoption of moral and ethical behavior in integrated care has brought a tremendous impact on the quality of both clinical care and home health care settings.

6.b.ii.3. Enhanced Collaboration and Participation

Another essential role of incorporating bioethics in integrated care is that it enhances collaboration and coordination of health care activities. Integrated care is a multi-faceted approach that involves different health care stakeholders, resources, and divisions.\textsuperscript{189} For instance, the health information manager must coordinate operations with the physicians, advanced practice nurses, counselors, and social workers as well as global health care bodies. Integrated care relies on collaborative efforts among health professionals, global regulatory bodies, the health consumer, members of the community as well as the government. However, integrated health and quality management cannot be achieved if ethical behavior is not observed. Ethical behavior such as the provision of informed consent, respect for diverse opinions, and patient autonomy improves the relationship between the health professionals and the patients as well as other health care stakeholders.\textsuperscript{190} Therefore, the adoption of bioethical behavior has a great impact on enhancing collaboration and coordination of health care operations. Enhanced collaboration and collective action, in turn, enables the patients to acquire high-quality health care services within the health care services.

Coordination of health care efforts is the primary element of integrated care and quality improvement since each stakeholder has a role to play in the process of providing patient-oriented health care services. Health care professionals have adopted various strategies that are focused on promoting collaboration and collective participation to adopt integrated health. Coordination of health care efforts plays a vital role in the process of implementing home health care programs.\textsuperscript{191} Different health stakeholders such as the
government, the Ministry of Health, health organizations, and the general public must work together to ensure that home-based care achieves its intended purpose of providing patient-centered care in the home environment. Through collaboration, the various stakeholders can easily combat challenges such as a shortage of financial resources and a lack of awareness on the need to seek home health care. The aging population with diverse health problems such as chronic heart diseases, cancer, and diabetes usually lack efficient information on the significance of seeking high-quality health care services. Old age-related ailments require coordinated care that is provided by health care experts as well as family members. Therefore, home health care has been recognized to provide an efficient clinical setting for handling chronic diseases that usually affect the aging population. Collaboration among the stakeholders, therefore, has brought a great impact on the adoption of integrated care.

The adoption and implementation of integrated care depend on the ability of different health stakeholders to embrace collective participation in the provision of patient-oriented care. Each stakeholder is expected to undertake its duty in the process of caregiving. For example, government health agencies such as the Ministry of Health should provide funds that are used to promote the implementation of integrated care. The Ministry of Health is also tasked with creating awareness on the significance of embracing integrated care both in clinical and home health care settings. Health care professionals, such as physicians, on the other hand, should provide high-quality care to the patients. By incorporating a bioethical code of conduct such as patient autonomy and beneficence, health professionals can initiate standardized care that contributes to the implementation of integrated care. Health consumers are expected to contribute to the adoption of integrated care by seeking clinical and home-based care and also through providing valuable health information that can help in improving the quality of health care. Other stakeholders, such as social workers, counselors,
and the ethical consultation committee, are also obligated to conduct their duty by ensuring the provision of patient-centered care.\textsuperscript{196}

6.b.ii.4. Achievement of Health Care Goals and Objectives

The implementation of bioethical behavior also leads to the achievement of goals and objectives of health care organizations as well as patients. Integrated health is aimed at ensuring that the patients acquire high-quality care that eventually results in the achievement of the health care goals.\textsuperscript{197} However, ethical and moral behavior must be incorporated into integrated health to ensure the creation of a sustainable clinical care setting. Bioethics triggers the achievement of health care goals since it promotes the collective action and coordination of health care activities among the different stakeholders. For instance, health professionals can easily work alongside health information managers, patients, federal government health agencies, and the local community to identify an ideal method of enhancing the health of the members of the community.\textsuperscript{198} The goal of integrated care is to boost the quality of health care services through collaboration among health stakeholders. To achieve the goals of integrated care, health care stakeholders must streamline the available health care resources and undertake a collective decision-making process.\textsuperscript{199}

Health care organizations that observe ethical behavior can easily achieve health care goals through acquiring a viable opportunity to adopt integrated care and quality improvement. Integrated care also focuses on realizing the long-term health goals of home health care. Since the launching of home health care programs within the Kingdom of Saudi Arabia, the level of health care services has increased tremendously since integrated care has enhanced access to health care services. Home-based care enables health consumers to access health care services within the home environment.\textsuperscript{200} Hence patients do not necessarily need to visit health care centers to get treatment. The Ministry of Health set goals that the country was supposed to achieve to improve the health of the citizens. One of the underlying elements
in the health goals was to improve the health and wellbeing of the citizens by increasing the access to health care services in different regions in the Kingdom. Another aspect that the health care stakeholders realized was the significance of adopting an integrated health care system.\textsuperscript{201} Through coordination of health activities, health professionals can easily acquire an opportunity to achieve both the short- and long-term goals. However, the incorporation of moral and ethical values in integrated care has created an enabling environment for implementing home health care across the Kingdom.

Bioethics results in the observation of fundamental human rights concerning health care. Issues such as equality, non-discrimination, and patient autonomy are observed during the process of implementing integrated care to achieve health care quality improvement.\textsuperscript{202} Unlike in the past, modern health care has redefined the concept of achieving the goals of health care. Although the main goal of health care is to improve the health outcome, ethical and moral code of conduct dictates that health care providers should undertake health care operations that prevent any harm that the experience during caregiving. The ethical element of non-maleficence has taken center stage in contemporary health care.\textsuperscript{203} This is because it has been found out that some patients develop health complications even after receiving care in clinical care settings. Therefore, health care professionals such as physicians and advanced practice nurses should ensure that they prevent any possible harm that may occur during caregiving before proceeding with caregiving. For instance, if undertaking a surgical procedure can lead to the development of more complications, it is better to adopt alternative intervention methods to save patients in High Dependency Units.\textsuperscript{204} Therefore, achieving the goals of health care should not only focus on improving the health outcomes but also preventing harm that the patient may face in home-based care and clinical care settings.
6.c. Conclusion

In summary, nursing is a moral undertaking that is well argued in the literature. Professional and organizational ethics have promoted the provision of high-quality healthcare in healthcare organizations. Organizational ethics has led to the implementation of the code of conducts that regulate the behavior of healthcare professionals, the patients and the stakeholders within a healthcare organization. Professional ethics, on the other hand, sets the values that promote the adoption of patient-centered healthcare by health practitioners. Healthcare organizations and other stakeholders such as global health bodies should adopt policies that promote both organizational and professional ethics in the field of healthcare.

Organizational ethics, therefore, can bring a tremendous impact in the management and eradication of moral distress in modern healthcare settings. Organizational ethics, for instance, have instilled effective, ethical behavior such as honesty, respect, and integrity. The adoption of professional ethics has led to the recognition of the role of therapeutic and interpersonal relationships in mental healthcare. The therapeutic relationship is critical for creating a bond between the patients and the nurse professionals. Understanding the underlying ethical issues as is the hallmarks of coping with moral distress. Instead of adopting unethical behaviors such as patient avoidance and moral disengagement, registered nurses should observe organizational and professional ethics in health care settings. This is because; both organizational and professional ethics can tremendously manage or eradicate moral distress in modern healthcare organizations. Implementing the concept of moral distress, the underlying factors, as well as its relationship with organizational ethics, is instrumental in its prevention and management. Healthcare organizations hence should encourage the observation of organizational and professional ethics to combat moral distress.

Bioethics has brought a critical impact on the adoption of integrated care. Health care stakeholders have advocated for the implementation of integrated care and quality
improvement. Across the globe, health care professionals have adopted diverse strategies aimed at incorporating bioethical practice during the adoption of integrated care. Since integrated care is characterized by the coordination of health care activities and collaboration between different health stakeholders, bioethical behavior has provided a useful framework for promoting integrated care and quality improvement. Home health care has led to improved health and wellbeing of Saudi citizens. This is because the adoption of integrated care has created an enabling environment for the provision of patient-centered care. However, integrated care and quality improvement can only be achieved if health care providers adopt ethical and moral behavior. The adoption of a bioethical perspective in integrated care results in the achievement of home health care goals, such as the implementation of precision medicine.

Health care professionals have been at the forefront of promoting precision medicine since it results in patient-centered care that focuses on the health of a particular patient. The adoption of bioethics also results in the coordination of health care activities and collaboration towards achieving integrated care. One of the most important elements of integrated care is the collaboration and coordination of efforts among health care stakeholders. The health care stakeholders, such as the Ministry of Health, health professionals, patients, and the local community, should collaborate to implement integrated care. For example, health professionals should liaise with the community leaders to generate information about the prevalence of various diseases and mental health conditions within the village. Health care organizations such as the Saudi Arabian Ministry of Health and the CDC have undertaken collective efforts towards adopting health policies that promote integrated care within clinical care settings. The recognition of the importance of bioethical practice during the adoption of integrated care has brought a great impact on improving the quality of home health care. Integrated care can only be adopted and implemented within the
Kingdom of Saudi Arabia if the health care stakeholders undertake their duties in collaboration with another. Integrated care is characterized by the coordination of health operations among different departments and stakeholders such as government health agencies, health insurance firms, patients, local communities, and health care professionals.
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CHAPTER 7: CONCLUSION

Home health care helps to shape caregiving in modern society. In contrast to hospital-based care, home health care provides a patient-centered focus that occurs within the home setting of health care consumers, especially for those who have difficulties in leaving home to seek hospital care. This turn to HHC is developing significantly in SA, where health care providers visit the patients both in the urban and in the rural areas and provide high-quality care. This demand for home health care can be attributed to chronic illness and terminal diseases that require the attention of both health care professionals and family members. The continuing development of HHC in Saudi Arabia has led to the emergence of bioethical issues that need to be addressed by health professionals and families. To engage these concerns, this dissertation discusses the contribution of bioethics to Home Health Care in Saudi Arabia.

Over the years, the Ministry of Health in Saudi Arabia has spearheaded the implementation of home healthcare programs across the country. The primary factor that has enhanced the adoption of home healthcare in the Kingdom is the coordination of operations from diverse stakeholders such as the health professionals, government, healthcare organizations, family members as well as the health consumers. Collaboration in undertaking health care activities has enhanced patient outcomes since each stakeholder has a role to play to facilitate the provision of precision medicine in the home environment. There is also a likelihood of an increase in the population of older adults in SA. The trend shows that the demand for home healthcare will continue to grow in the coming years hence the need to prepare for the forecasted growth in population.

The Saudi government, having recognized the impact of long hospital admission on patient health, has decided to embrace strategies that are aimed towards promoting home healthcare across the Kingdom. Since the adoption of the health program needs the
coordination of different stakeholders, healthcare providers have ensured the coordination of health operations between healthcare professionals and home-based caregivers. The clinical care setting ensures that only experienced and highly skilled nursing teams are sent to provide care at the homes of the health consumers.

Multi-dimensional communication strategy has also been adopted to ensure the coordination of operations between the patients, caregivers, as well as the families of the patients. In several regions such as Jeddah, civil society groups have also realized the importance of home healthcare. Such community-based health organizations groups create awareness through the mobilization of the members of the local community to join the beneficial home health care program. Since there has been significant population growth, the country has adopted strategies aimed at implementing home healthcare programs. The Kingdom of Saudi Arabia, through the Ministry of Health, has created a sustainable environment for the adoption of home health care programs across the Kingdom.

Since health professionals face several ethical challenges during caregiving, the adoption of bioethical behavior has been used to solve ethical issues. For example, decision making and the provision of informed consent plays a tremendous role during the implementation of home health care. During home-based caregiving, there is a need for an inclusive decision making that involves physicians, attending nurses, counselors, and family members. Collective decision-making shows that the health team observes patient autonomy. This is because the patient has the right to support or oppose a particular health care intervention before the adoption of that specific method. For instance, during the end-of-life care, the health professionals and the family members can initiate an ethics consultation program to adopt the most effective intervention that should be selected during caregiving. The role of informed consent during decision making is also another essential ethical issue in home-based care. Patients with chronic diseases as well as patients with a terminal illness
should be allowed to provide informed consent during caregiving. The contribution of bioethics in home healthcare is to have increased access to healthcare services. The incorporation of bioethics in home health care creates a sustainable environment for the adoption of patient-centered care and also addressing ethical issues such as informed consent, euthanasia, palliative care, cultural diversity, and ethics consultation.

Also, the decision-making process shapes the beginning of life health issues such as prenatal and neonatal care. Emerging health care issues such as the genetics of cancer have enabled health care professionals to examine the factors that affect the prevalence of cancer as well as the measures that can be undertaken to manage the disease in the society. Another issue that has been addressed by home health care is palliative care and assisted death. The Islamic law values the sanctity of life and hence is against euthanasia or mercy killing. The Saudi Arabian Ministry of Health has thus recognized the need to adopt bioethical practice during the implementation of home health care in different parts of the kingdom.


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