AMERICAN UNIVERSITY OF BEIRUT

MEDICAL FUTILITY IN LEBANON

by
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Next to excellence is the appreciation of it.

AN ABSTRACT OF THE PROJECT OF

Dima Haidar Ahmad for Master of Science in Nursing
Major: Nursing Administration

Title: Medical Futility in Lebanon

Background: Medical futility is a controversial issue and has been defined by many scholars; medical futility means that the proposed therapy should not be performed because available data show that it will not improve the patient's medical condition.

Purpose: The main purpose of this project is to highlight the concept of medical futility, define what it is, and investigate why it lacks clarity in Lebanon. A second purpose is to provide guidelines for nurses and physicians involved in medical futility discussions.

Data Collection: This report expands on the literature review undertaken in a recent international report on medical futility in thirteen developed and developing countries. Since, Lebanon was not included in the report; this project provides the missing data and discusses its implications for policy makers and managers of healthcare facilities. A comparative analysis of the status of medical futility in the United States, Australia, Iran and the United Arab Emirates provides the background for clarifying the situation in Lebanon.

Results: There are no published reports on medical futility in Lebanon. However, health care providers in the country, including doctors and nurses need clarity about what medical futility is and how to discuss it with patients and families. This project report call for dialogue about medial futility in Lebanon and more transparency in end-of-life care decisions.

Recommendations: Legislative changes and guidelines for health care organizations are recommended. Scholars are encouraged to conduct further studies and case reports to promote further discussion of medical futility in Lebanon. Open engagement with the challenges of end-of-life care, particularly medical futility will assist policy and guideline development for use in Lebanon.

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CHAPTER I

INTRODUCTION

Health is a major concern, and the health sector has evolved with many advances and improvements. Advances in medicine have served to prolong life and improve quality of life for patients with life-limiting illness. Such advances have encouraged more attention to patient autonomy and raised expectations about access to health care of the highest quality. As longevity has improved and acknowledgment of patient's rights has become more widespread, treatment preferences and choices in end-of-life have become an important component of health care delivery. At the same time, access to better healthcare and increased life expectancy has increased the burden on the health sectors of developed countries. As higher proportions of populations are living longer, and as the burden of chronic disease continues to increase, health policy makers have become increasingly concerned about the rising cost of healthcare delivery and resources wasted on patients whose co-morbidities make it highly unlikely that they can stave off becoming overwhelmed by their disease. Consequently, ethical debates among health care givers and patients are becoming more common and dealing with complex diseases and critical decisions about stopping; withholding or not initiating a treatment has become a daily challenge for many physicians and nurses.

A. Background of the project

Literature shows that discussions about end-of life care issues and related ethical dilemmas a have been discussed throughout history. Medical futility is the most recent concept to be used to describe situations in which further medical intervention will not affect the patient's survival or their quality of life. In Lebanon, as in more developed countries, the advance of medical technology has increased demand for more aggressive interventions despite the hopelessness of the patient's condition. As medical interventions have become more complex, more sophisticated, and more dependent on expensive technology, there is a general expectation that successful treatment is always possible no matter the hopelessness of the patient's condition. As a result, an increased responsibility is placed on health professionals to provide the all possible treatments within available resources and in accordance with national and organizational policies in the relevant country. However, healthcare resources are finite in any country and decisions have to be made about when further intervention is pointless. Such decisions create ethical dilemmas for physicians in particular, but for all healthcare workers involved in end-of-life care, emergency care, neonatal units, intensive care units, and in all those settings in which decisions have to be made about whether to administer or withhold further active treatment.

Faced with such decisions, physicians have to balance their allegiance to the Hippocratic School in medicine that guides them to cure, relieve suffering and refuse to treat those who are over mastered by their diseases with the demands of patients and families for unlimited active treatment however futile. Such wishes in Lebanon are often based on culture and religion. The personal beliefs and values of physicians can add yet another layer of complexity to an already seemingly intractable problem. The

multiple complexities and inherent ethical dilemmas require clarification. A possible starting point is to understand the concept of medical futility in practice. However, in Lebanon, many relevant to decision making during end-of -life care are highly sensitive, which discourages open discussion of the limits to curative care, the need for palliative care, and what it is to have a good death. The purpose of this project is to encourage open discussion of ethical dilemmas in end-of-life care by examining the concept of medical futility, how it is defined, why it lacks clarity in Lebanon, its significance and impact on health care decisions, and the need for policies and guidelines. The project will have been worthwhile if it encourages more transparency in end-of-life decisions to the benefit of patients, families, physicians, nurses and other healthcare workers. Furthermore, this project report calls for dialogue about medical futility in Lebanon and more transparency in end-of-life care decisions.

B. Definitions

1. Medical Futility

Medical futility is a controversial issue that still does not have a formal definition in many countries. However, it can be taken to mean that a proposed therapy should not be performed because available data show that it will not improve the patient's medical condition (Bernat, 2005). More, succinctly, medical futility occurs when treatments cannot accomplish the patient's medical goals (White & Kellum, 2013). More comprehensively, medical futility is n defined as providing inappropriate treatments that will not improve disease prognosis, alleviate physiological symptoms, or prolong survival (Mohammed & Peter, 2009). In other words, a treatment is termed futile when it is ineffective or unlikely to achieve an effect that the patient could

appreciate as a benefit (Jox, Schaider, Marckmann & Borasio, 2012). The notion of futile treatment goes back to the time of Hippocrates, who allegedly advised physicians "to refuse to treat those who are overmastered by their diseases, realizing that in such cases medicine is powerless".

2. Euthanasia

As a noun, euthanasia is defined as "a good death" by some and as a "morally outrageous death" by others (Kaptan, Dedeli & Önen, 2011). As a verb, euthanasia is the act of taking the life of a person who is hopelessly ill for reasons of compassion. Euthanasia is of two kinds: active and passive. Active euthanasia is mercy killing which is taking direct action to end life by for example giving a lethal dose of medication to end a painful or prolonged period of dying. Passive euthanasia is allowing a patient to die by withholding an action that could have kept her alive by administering a medical procedure. Discontinuing or not starting a treatment at the request of a patient are also regarded as examples of passive euthanasia. Euthanasia can be voluntary, involuntary, or non-voluntary. Voluntary euthanasia occurs when a patient wants to end her life and readily and willingly consents to an intervention or inaction that will result in death. Involuntary euthanasia occurs when a decision to end her life taken against the patient's wishes. Non-voluntary euthanasia occurs when action is taken to end a patient's life when she is unable to express or make known her wishes, such when a decision is made to turn off the ventilator of a brain dead patient (Kaptan, Dedeli & Önen, 2011), which is contrary to Lebanese law.

3. Palliative care

Palliative care, also known as hospice care, now sometimes delivered in the home, is an interdisciplinary medical specialty that focuses on preventing and relieving suffering

and on supporting the best possible quality of life to patients and their families who are facing either a serious or a life-threatening illness (White & Kellum, 2013). The World Health Organization (2014) defines palliative care as a comprehensive approach that improves the quality of life of patients and their families to face problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care includes providing relief from pain and suffering from other distressing symptoms and integrating the psychological and spiritual aspects of patient care. Palliative care is applicable at all stages of illness, in conjunction with other therapies that are intended to prolong life such as curative or life prolonging treatments (White & Kellum, 2013). Palliative care is a way to ease pain and make life better for people who are dying and for their loved ones. It means taking care of the whole person body, mind, spirit, heart and soul. Palliative care looks at dying as something natural, personal and its goal is to provide people with the best quality of life they can have during that time. ("Means to a Better End," 2002)

4. End-of-life care

End of life care is the care provided to a person in their final stages of life. It applies to people approaching death. This care involves several basic elements, including understanding the physical, psychological, spiritual, and practical dimensions of care giving; identifying and communicating diagnosis and prognosis; establishing goals and plans and fitting palliative or other care to these goals(Marilyn & Christine, 1997). End of life care includes hospice care, comfort care, supportive care, palliative care or symptom management (NIH, 2004).

All the above mentioned terms deal with patients approaching death process and patients suffering from a disease or serious illness that impairs quality of life and aggravate suffering. Medical futility, euthanasia, end-of-life care and palliative care intersect at the point where curative treatment is not sufficient to recommence the patient's previous medical condition before illness. Medical futility is applied when the recommended treatment will not achieve the required goals. At this point, the patients and their families need a comprehensive support that comprise all their needs including physical, psychological, social, cultural etc. Thus, palliative and end of life care takes the space as complementary to medical futility. In addition, Euthanasia is accepted in some countries and referred as the patients right to decide on their lives; medical futility is accepted in many countries in sake of saving resources and ethically accepted for alleviating suffering and protecting patients from unnecessary interventions that will not improve the patient's condition. Palliative and end of life care is widely accepted and is identified by the World health organization, as well as awareness for this concept is increasing and its application in practice is improving.

Dying is a fact of life, and death comes to all. Talking about death and the process of dying seem easier than its application. Feeling the power of life, instinct of living and connection to humanity makes the approach to death hard to humans. With the advance of medicine, limited resource availability and accessibility evolved ethical dilemmas and conflicts towards providing futile treatment to patients have evoked the discussion about end of life options and latitudes. Talking about medical futility, end of life care, hospice and palliative care, all discuss a phase of life that will approach us all. Those concepts intersect at some point as mentioned above. However, each one is distinctive and can be distinguished from the other. Euthanasia is illegal and

unacceptable in most of the countries, and discussion in this concept is prohibited, especially in the eastern countries. Medical futility is an evolving concept and its definition is still debatable and still needs a community policy and legal designation in most countries. Palliative care and end of life care are well defined by the world health organization, legalized and ethically accepted in most countries.

C. Good death

Death is a fearful event and a frightening happening that will occur to everyone at a lifetime, it is a major concern of people to meet with and the dying process worries people rather than dying itself (Kübler-Ross, 2009; Carr, 2003; Marilyn & Christine, 1997). The Institute of Medicine defines good death as a "one that is free from avoidable death and suffering for patients, families and caregivers in general accordance with the patients' and families' wishes."(Egnew, 2005). Good death is characterized by physical comfort, social support, medical treatment that control symptoms, and minimal suffering, pain, psychological distress and dignity preservation to the dying patients, including their families (Marilyn & Christine,1997).

Good death embraces preparation of patient and family for death and getting the opportunity for closure of the life (Dyer, 2006). Good death can be approached by understanding the meaning of suffering and healing. Suffering is personal, individual, and commonly expressed as a narrative, and healing is defined as "the process of bringing together aspects of one's self, body-mind-spirit, at deeper levels of inner knowledge, leading toward integration and balance with each aspect having equal importance and value". Nevertheless, healing is an intensely personal and subjective experience. It is associated with themes of wholeness, narrative and spirituality.

Medicine is traditionally considered a healing profession, and modern medicine claims legitimacy to heal through its scientific approach to medicine. Physicians are trained as biomedical scientists; they focus on the diagnosis, treatment, and prevention of disease. The focus of cure, not care, became the primary purpose of medicine, and the physician's role became "curer of disease" rather than "healer of the sick." (Egnew, 2005). Good death is a combination of the whole patient's condition, including the psychological, physical, and social part. It also includes the family and their role in making the dying process easier, acceptable and conserves the patient's wishes and dignity.

The focus of this study is on medical futility in Lebanon. The definitions that have been offered help to situate the contents of this report within the context of relevant concepts. The process in which medical futility has to be considered is that of end-of-life care, which should be managed by health professionals to ensure a good death as understood in the relevant culture within the reference society. In Lebanon, the idea of a good death rules out the possibility of euthanasia for deep seated cultural and religious reasons. Therefore, palliative care is the basis for culturally acceptable end-of-life care in the country, although this is not always acknowledged explicitly because relatives if not patients themselves demand aggressive medical intervention, however futile. Consequently, medical futility has to be considered from the perspective of how unnecessary and non-beneficial treatments can be withheld while avoiding euthanasia and providing the patient with the highest standard of end-of-life care possible.

CHAPTER 2

LITERATURE REVIEW

A. Bagheri report

Discussions about medical futility started almost three decades ago in the United States, but few publications have discussed the importance of its context (Schneiderman, Jecker & Jonsen, 1990; Schneiderman, 2011; Winkler, Hiddemann & Marckmann, 2012). Nevertheless, literature from other countries is limited and to learn more about medical futility aspects all over the world, authors from thirteen different developed and developing countries contributed to a single unified book that explicates the concept of medical futility and its application to patient's health care decisions in different healthcare systems (Bagheri, 2013). Those countries include United States, Brazil, Belgium, Venezuela, Russia, Australia, China, Korea, Switzerland/Germany, Turkey, Iran and United Arab Emirates. In their book Medical Futility: A Cross-National Study, the authors inspect how financial resources including payment models and insurance plans shape the approach to medical futility. As well, they explain how social, cultural, ethical, moral and religious beliefs influence the discussion on medical futility and superimposed on financial considerations. Each chapter of (Bagheri, 2013) edited book was assembled to illustrate five themes on medical futility from each contributor's country:

- Country's health care system, its payment system and its impact on medical futility
- Ethics and moral values in dealing with end-of-life issues in their society
- Legislations, guidelines, and protocols that tackle medical futility
- Nature of decision making regarding futile care
- Euthanasia distinguishing from medical futility in their country

Lebanon was not included in Bagheri's review. However, the contributors to his book provide a useful background against which to consider the status of 'medical futility' in the country. For the purposes of this project report, the status of 'medical futility' in Lebanon was compared with that in four selected countries.

1. Comparative analysis

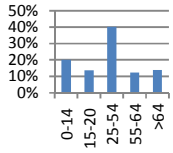
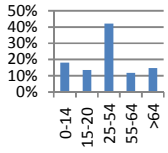
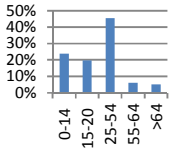
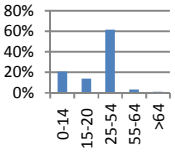
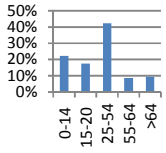
The comparison countries are United States, Australia, Iran, and the United Arab Emirates (UAE). A comparative analysis of Lebanon and the four countries is shown in the tables below.

Table 2.1: Comparative analysis of geographical characteristics in five countries

	United States	Australia	Iran	UAE	Lebanon
Location	North America, bordering both the North Atlantic Ocean and the North Pacific Ocean, between Canada and Mexico	located in Oceania, continent between the Indian Ocean and the South Pacific Ocean	Middle East, bordering the Gulf of Oman, the Persian Gulf, and the Caspian Sea, between Iraq and Pakistan	Middle East, bordering the Gulf of Oman and the Persian Gulf, between Oman and Saudi Arabia	Middle East, bordering Israel and Syria

Central Intelligence Agency,2013: World Health Fact Book 2013-2014

Table 2:2: Comparative analysis of population characteristics in five countries

Total area	9,826,675 sq/km	7,741,220 sq/km	1,648,195 sq/km	83,600 sq/km	10,400 sq/km
Population number	316,668,567	22,262,501	79,853,900	5,473,972	4,131,583
Age structure					
Life expectancy	78.62 –years	81.98 years	70.62 years	76.91 years	75.46 years

Central Intelligence Agency,2013: World Health Fact Book 2013-2014

Table 2.3: Comparative analysis of health care expenditures and healthcare resources in five countries

	United States	Australia	Iran	UAE	Lebanon
Health expenditure	17.9% of GDP	9% of GDP	6% of GDP	3.3% of GDP	6.3% of GDP
Physicians density per 1,000 population	2.42	3.85	0.89	1.93	3.54
Hospital bed density per 1,000 population	3	3.9	1.7	1.9	3.5
Health care system	Complex, multidimensional, non-socialized, free enterprise, individualistic health care	Consists of a national public healthcare program named Medicare	Government owns and runs the largest health care delivery network through Ministry of Health and Medical Education with referral system.	Universal healthcare system that provides access for healthcare to its citizens	Highly fragmented health care system, services are more oriented towards curative care with a rapid growth in the number of hospitals and centers for high technology services.

Central Intelligence Agency,2013: World Health Fact Book 2013-2014

Table 2.4: Comparative analysis religious affiliation and ethnicity in five countries

	United States	Australia	Iran	UAE	Lebanon
Religion	78.5% Christians predominant Protestant 51.3% others include Jewish, Buddhist Muslim, and unspecified	63.8 Christians predominant Anglican 18.7%, and Catholic 25.8% others include Buddhist, Muslim, unspecified and none	98% Muslim predominant Shiia 89% of the population	predominant Muslim Sunni 96% of the population	17 religious recognized Muslim 59.7% Christian 39% other 1.3%
Ethnic group	White 79.96%, Black 12.85%, Asian 4.43%, and others.	White 92%, Asian 7%, and other 1%	Persian 61%, Azeri 16%, Kurd 10%, Lur 6%, others include Baloch, Arab, Turkmen and Turkic tribes	Emirati 19%, other Arab and Iranian 23%, South Asian 50%, Less than 20% are UAE citizens	Arab 95%, Armenian 4%, other 1%

Central Intelligence Agency,2013: World Health Fact Book 2013-2014

Table 2.5: Comparative analysis of governmental structures in five countries

	United States	Australia	Iran	UAE	Lebanon
Government type	Constitution-Based Federal Republic; strong Democratic tradition	Federal Parliamentary Democracy and a Common Wealth Realm	Theocratic Republic	Federation with specified powers delegated to the UAE federal government and other powers reserved to member emirates	Republic

Central Intelligence Agency,2013: World Health Fact Book 2013-2014

Table 2.6: Comparative analysis of legal systems and status of euthanasia and medical futility in five countries

	United States	Australia	Iran	UAE	Lebanon
Legal system	Common Law System based on English Common Law at the Federal Level; state Legal Systems based on Common Law.	Common Law System based on the English Model	Religious Legal System based on Sharia Law	Mixed Legal System of Islamic Law and Civil Law	Mixed Legal System of Civil Law based on the French Civil Code, and Religious Laws (for personal status, and other family relations, etc.)
Medical futility policy	Texas and Virginia states adopted such policies.	No formal definition in Australian legislations	No legal definition	No legal definition	No legal definition
Euthanasia	Assisted suicide is legal in Oregon, Washington and Montana state.	Australia, Northern Territory in 1995 was the first in the world to legalize active voluntary euthanasia, but in 2005 the Federal Parliament illegalized this law.	Not acceptable	Not acceptable	Not Legal

Central Intelligence Agency,2013: World Health Fact Book 2013-2014

2. Analysis

With the exception of Australia, Tables 2.1 and 2.2 show that the larger the land area of a country, and the bigger the population, the larger the percentage of health expenditures as a proportion of gross domestic product (GDP). Table 2.4 show that in Iran and UAE, the dominant religion is Islam and their legal system is based on Sharia law, whereas in the US and Australia jurisprudence is based on common law.

In Lebanon, there are at least 18 confessional groups (Central Intelligence Agency, 2013) and the legal system is mixed based on civil law, including elements carried over from the Napoleonic Code, and religious law.

Table 2.6 shows that US and Australia both western countries are ahead in the explicit discussion of medical futility and euthanasia. Eastern countries, including Iran, UAE, and Lebanon have paid less attention to public debate about 'medical futility' perhaps because religious teaching in these countries inhibits discussions about futile medical interventions from secular perspectives such as those based on defensive medicine practiced to stave of prosecution of physicians and concerns about keeping the wishes of the patient paramount in accordance with common law principles and human rights concerns. Discussion of futile medical intervention in Lebanon is influenced by the religion, culture and political governance. Lebanon differs from other countries in that politics, religion and the health care system. Legislation in Lebanon is effectively paralysed due to reliance on caretaker government, pending Presidential and parliamentary elections. Hence, there is no governmental forum in which controversial health issues can be debated due to the partisan nature of politicians and more pressing concerns with the country's security, internal divisions, and economy. Religious and political considerations offer and constrain opportunities to debate medical futility, but they are not the only influences on the extent to which it is a topic that requires civil society and government attention.

Life expectancy peaks in the 25-54 years age group in all selected countries. However, the proportion of the population aged ≥64 years varies from 1% in UAE, through 5.1% in Iran, and 9.4% in Lebanon to 13.9% in the US and 14.7% in Australia. The age structure of the population is important when considering medical futility

because, other things being equal, the burden of healthcare expenditures will be higher in countries with ageing populations. However, outlays on healthcare are influenced also by healthcare structures and modes of healthcare delivery.

The health care system in US is complex, non-socialized and individualistic. The US spends a relatively large proportion of its GDP (17.9%) on health and has a large and increasing aged population. As a result, the Federal and state governments are coming under increasing pressure to increase spending on health and welfare services. Medical futility can be regarded to some extent as an opportunity cost problem -that is, care needs to be taken to ensure that resources consumed by one person, say a person over the age of 80 with multiple complex health problems, rather than several younger persons who require health maintenance interventions to stave off chronic illness. Allocating resources in the proper place decreases health expenditure burden on the government, and the decision for this allocation needs a framework that shape the practice of healthcare workers which enable them to take decisions freely without constraints from policies and regulations. Lebanon spends 6.3% of its GDP on health that is considered high compared to its total area and have a good number of physicians compared to its population. Nevertheless, Lebanon has a good number of aged population 9.4% meaning that this proportion may consume healthcare benefits rather than young population and place a burden on the government health expenditures.

The differences noted in Tables 2.3- 2.5 bring out the differences in relevant socio-economic and cultural factors among countries and provide context for considering issues of medical futility.

The evolution of medical futility guidelines started in the United States when the debate started between patients and physicians about providing aggressive treatment.

Some thought from patient's right perspective, patients can gain access to life prolonging treatment even if futile or against the physicians' wishes. Those cases in the late 1980's led to court cases, and because of the nature US law many cases were decided by states rather than federal courts. Because of the lack of a unified jurisprudence on medical futility and the absence of U.S. Supreme Court decisions on the subject two states of the US Texas and Virginia have attempted to approach futility through legislation and developed state law to protect futility practices (Eskildsen, 2010). In Virginia, "Baby K" case (1992-1994) led to federal court decisions that required an emergent treatment in the state. Nevertheless, Texas is the second largest area in US with largest population, it spends 13.1% of its GDP on health and constitutes 24.6% the highest uninsured rate in US (Nighohossian, Rettenmaier & Wang, 2013) and Texas policy integrated into Texas Advance Directives Act in 1990 and became part of the Texas Health and Safety Code (1990).

Other countries do not have a formal definition on medical futility since each country is limited to its government type, culture and legal system. Australia has not adopted a clear policy but its legal system is flexible enough to enable healthcare providers to practice end-of-life care and to exercise discretion about medical futility decisions without fear of prosecution. The flexibility available provides for informed decisions made of full-consultation and within the patient's interest, and consistent with his or her preferences while creating time for continuing public and professional debate aimed principally towards policy development and possibly legislation. However, political opinions on end-of-life care in the country remain conservative. It should not be forgotten that the Northern Territory in Australia was the prominent in legalizing euthanasia although the decision was later reversed by the Australian Federal

Government. Even more conservative Iran and UAE lack the audacity to discuss futility from a legal perspective because espoused religious beliefs and related legislation place narrow constraints on medical practice, at least officially.

B. Lebanon

Literature on 'medical futility is lacking in Lebanon. Consequently, it is worthwhile to consider current challenges in the context of Bagheri's edited book (2013). Perspective can be gained on medical futility in Lebanon by comparing its status in the country with that in other countries. However, time and space does not permit comparison of Lebanon with the 13 countries analysed in by the contributors to Bageri's book. Only four of the 13 countries have been selected for comparative analysis: the United States, Iran, UAE and Australia. United States was selected as a basis for comparison because services available in most academic medical centers in Lebanon follow same accreditation standards as US. Iran and the UAE were chosen as a basis for comparison to Lebanon because both are eastern countries with great similarity in the religion of population and factors affecting medical futility discussion. Australia was selected for comparison because it is one of the most developed countries outside Europe that is breaking new ground in discussions about medical futility. The Netherlands was excluded from the comparative analysis because it is among the most liberal of countries and has long established legislation and practices relevant to medical futility and permits euthanasia within the law. Lebanon is neither as liberal as the United States or as conservative as Iran and the UAE, nor as progressive as Australia, which makes these four countries acceptable comparators.

CHAPTER 3

MEDICAL FUTILITY IN LEBANON

Few countries around the world have recognized late-life care in their policies and medical education. Lebanon has a highly rated educational level of medical and paramedical population and is characterized by its diversity of graduate health professionals that are graduates of different education systems mainly graduates of the USA, Western Europe, Latin America and Eastern Europe (Strategy for National Health Care Reform in Lebanon 2007). This diversity of learning schools made the Lebanese health care providers more open to the end-of-life discussions and decisions. This is reflected by the progress Lebanon has made toward the definition and acceptance of palliative care concept as well as defining it legally in law number 240 (dated October 22, 2012) because it is more acceptable culturally. This chapter discusses the factors that affect Lebanon approach to medical futility despite the absence of studies in the Lebanese literature regarding futility.

A. Introduction

Lebanon is a middle-income country, its aging population is 9.4% relatively high compared other Eastern Mediterranean countries, but low compared with the United States, Japan, and most European Countries. Lebanon spends 6.3% of its GDP on health, equivalent to 924$ per capita and has a good hospital bed density and high physicians density relative to its geographical size and demography. Advances in medical technologies and high quality services are available in the academic medical centers in the country, which have standards comparable to other US accredited

institutions. However, the number of people with chronic illnesses and complex medical needs in the country is increasing (Lebanon baseline information, 2013). As a result, more patients require end-of-life care, which raises complex problems for physicians and nurses due to cultural and religious beliefs. In general, death is accepted as God's will, but at the same time there is a general expectation that every available treatment should be used to improve the patient's condition and if possible restore them to health. Unlike other countries, families of end-of-life-care patients regard themselves as the primary decision makers about medical interventions. Whereas, patients may want to know their diagnosis and prognoses, many would prefer not to know, trusting that their physicians will do what is best for them. Consequently, patients are not routinely told that they are at the end-of-life stage, and relatives are an important influence in deciding what their patient can be told.

Unlike countries where autonomy in health care decisions is regarded as the prerogative of the patient, in Lebanon, with exceptions, the concept of autonomy is commonly misinterpreted by family members who'd rather take decisions on behalf of the patient or his physician regarding interventions that should be implemented or withheld. Consequently, when it comes to discussions about whether a treatment or intervention is futile, families consider their right to take decisions that sometimes can be contradictory with their physician's advice. Although, Lebanese law number 240 (dated October 22, 2012) emphasizes the importance of patient autonomy in statements such as "The physician should always respect the patient's will", the patient's will is not always directly sought. More often, the family's understanding of the patient's will is the most important reference point because close family members including spouses, adult sons and daughters, fathers and mothers, elder male siblings are taken as being

most informed about what the patient wants, or would want if she or he were aware of their poor prognosis and the likely futility of any further active treatment other than that required for palliative care.

The influence of families in making decisions about end-of-life care and accepting advice about the probable futility of further medical intervention is a highly complex phenomenon in Lebanon due to its sectarian and cultural characteristics. There are a minimum of 17different religious sects in Lebanon, recognized mainly as variations of Islam and Christianity. Each sect has its creeds and traditions, history and teachings, spiritual sensibilities and moral code; which may overlap and have much in common, but are nonetheless cultural markers that define to a considerable degree communal and personal identity. The Eastern culture found in Lebanon encourages people to identify strongly with moral and religious teachings during periods of serious ill health. This response commonly drives people to disregard medical advice. The result is insistence on sustaining medical interventions that may prolong life and suffering, but are incapable of restoring health.

B. Health care systems in Lebanon

The Lebanese health care system is pluralistic and for the most part unregulated; although the Ministry of Public Health accredits public hospitals. . The war of 1975-1990 had a major negative impact on the Lebanese economy and particularly on the public health care system. The sector remains under-regulated, has uncontrolled expansion, and includes a variety of private and public organizations for financing (Strategy for National Health Care Reform in Lebanon 2007). The system is financed by seven public funds, 71 mutual funds, 56 private medical insurance companies,

numerous Non Governmental Organizations and out-of-pocket expenditure. The Ministry of Public Health is the planner, supervisor, regulator and evaluator of health, and the health care system (Ministry of Public Health mission by law Decree 8377 dated 30/12/1961 –Article 2). However, the scarcity of financial and human resources is making it impossible for the Ministry of Public Health to perform its role (Strategy for National Health Care Reform in Lebanon 2007). A report published in 2000 by the World Health Organization ranked Lebanon as 101 out of 191 countries in relation to fairness in financial distribution.

The Lebanese Ministry of Public Health has implemented a series of interventions to improve equity and efficiency of health care spending because in 1998 Lebanon spent the highest amount of its GDP 12.4% on health sector and out-of-pocket payments at 60% of total health spending among the Eastern Mediterranean region. The interventions included improving the rational use of medical technologies and medicines, restoring of the public-sector primary-care network, and improving quality in public hospitals (WHO report 2010 on Health Care Financing; National Health Statistics Report in Lebanon, 2012 edition).

Thus, Lebanon has to cautiously dispense services and cover treatment for patients who really need it for the sake of preserving scarce resources and decreasing the burden on the government. Therefore, palliative care is the basis for culturally acceptable end-of-life care in the country; although this is not always acknowledged explicitly because relatives if not patients themselves demand aggressive medical intervention, however futile. Consequently, medical futility has to be considered from the perspective of how unnecessary and non-beneficial treatments can be withheld while

avoiding euthanasia and providing the patient with the highest standard of end-of-life care possible.

1. End-of-Life Ethical Issues in Lebanon

The perspective to death has changed with the advance of medicine, and improving quality of life when curative care is no longer effective is a widely accepted concept among everybody. The nature of the health care system, legal structures, and diverse cultures has an impact on end-of-life decisions. Physicians from Lebanon seem to consider within the legal framework, that withdrawal and withholding of life-sustaining treatment are not ethically the same and are unwilling to withdraw therapies in critically ill patients (Kronfol & Sibai, 2012). The major principles of medical ethics are nonmaleficence, beneficence, autonomy, and justice. Nonmaleficence and beneficence are Hippocratic principles in which physicians are expected to cause no harm for patients and alleviate patient's suffering. Suffering is personal, individual, and commonly expressed as a narrative. For many centuries, these two principles have maintained medical paternalism in which physicians have held the primary decision-making authority for their patients (HINSHAW, 2008). In Lebanon, the law state that physicians should always respect the patient's will, but strictly prohibit them from assisting to put an end of life to the patient. Decisions on withholding or withdrawing life sustaining treatment in the Lebanese ICU are the most difficult decisions for the patients, families, and physicians, those decisions depend on ethics related to moral, social, cultural and religion. Hence, cultural difference and lack of official guidelines implicate ethical limitations in the decision-making processes (Yazigi, Riachi & Dabbar, 2005).

In Lebanon, most medical students pursue their education in the United States and a number of medical centers follow American associations' guidelines in their practice. American University of Beirut Medical Center stated a clear policy related to end-of-life care, this policy is based on the Lebanese law 240 and it defines medical futility as any treatment believed to be without benefits, palliation or restoration of cure within a rational degree of medical certainty. It describes clearly that the patient/ guardian/ legal representative can request to withhold resuscitative services and shall discuss it with the attending physician when the patient's condition is futile. This practice shall be documented and witnessed by the head of medical department and any conflicts in discussions or decisions, the case shall be referred to the ethical committee of the hospital. The role and responsibilities of nurses are also described; the nurse is responsible to inform the attending physician about patient/ guardian/ legal representative requests, they are encouraged to be present during discussions, and communicate "Do not resuscitate"/Do not intubate" orders during shifts among each others. Nevertheless, nurses' beliefs are respected and nurses are given the chance to be assigned to other patients if decisions to refuse life-sustaining treatments conflict with their beliefs.

2. Attitudes Towards Futility

No studies of medical futility have been published in Lebanon. Withholding and withdrawing futile treatment is practiced because of the unilaterality of decision making of some physicians and the tendency of patients and families to put the onus for decision making on physicians than to make decisions and be accountable for themselves. For some family members this might happen because they want to avoid the guilt they would experience if they were the ones who made the decision not to

continue intensive medical intervention. Futility is either physiologic or normative and both are distinguished from the nature of disagreement between the physician and patients. It is physiologic when a treatment will never achieve its goal and normative when a treatment may achieve its goal but will not restore life based on medical fact example of giving treatment to a brain dead patient (Velasco, 2013). The majority of health care givers tend to withhold life-sustaining treatments rather than to withdraw it because of the religious constrictions and obligations. Nevertheless, the ambiguity of the Lebanese law towards end-of-life decisions makes physicians more reluctant to document unilateral decisions when deciding on not to provide a treatment deemed futile. Medicine is traditionally considered a healing profession, and modern medicine claims legitimacy to heal through its scientific approach to medicine and cure not care became the primary purpose of medicine, and the physician's role became "curer of disease" rather than "healer of the sick" (Egnew, 2005). From that perspective, people expect to receive the maximal medical treatment to prolong life and physicians disregard the concept of healing during their practice making the concept of medical futility more important to be discussed.

3. Related Laws and Regulation

Lebanon is still in its early stages of end-of-life discussions, some institutions have developed policies to guide practice of health professionals aligning with the Lebanese law. Lebanese law number 240 defines the physician's mission "as to maintain the physical and mental health of human beings, in terms of precautions to be taken and treatments to be undergone, to rehabilitate and relieve the pain." The law clearly states that patient's will must be respected in every medical intervention. Nevertheless, if a Patient suffers from a hopeless disease of recovery, the physician

shall reduce the patient's physical and mental pain through providing giving appropriate treatments, and physicians are encouraged not to have recourse to technical means and to excessive treatment upon the consent of the parents according to a joint report of the treating Physician and the Head of the concerned department. It remains necessary to help the patient until the end, in a manner that preserves the patient's dignity.

4. Futility and Euthanasia

"A Physician may not put an end to the life of a patient due to compassion even if the patient required him to do so, that is euthanasia" (Law no.240). This law also states that the physician's mission shall be limited to reducing the physical and mental pain to patients suffering from a hopeless disease for recovery and giving them appropriate treatments for protecting life as much as possible, and It is better not to have recourse to technical means and to excessive treatment upon the consent of the parents according to a joint report of the treating physician and the Head of the concerned department. Even though, the law protected the patient's right to choose their treatment, it forbids any act that helps in intentionally terminating life, that is because euthanasia labeled as "mercy killing" is unacceptable culturally, morally and ethically. Muslims and Christians occupies the highest portion of religions in Lebanon and both the Qur'an and bible forbid people from ending their own lives as committing suicides because their lives are owned by God and it is impossible to justify euthanasia decisions from a religious perspective. If the patient's medical condition is critical with no hope for survival or treatment can't restore previous quality of life the physician can discuss this situation with the patient or his legal directive to agree on a treatment that can lessen suffering and prevent futile treatments that can prolong life associated with pain or suffering.

In summary, Lebanon as an Eastern Mediterranean country with a complex health care system and a diverse population with different ethical values has made a start in discussing end-of-life issues but this is still in its infancy and need more studies to assess the health care knowledge, perspective and practicing of medical futility. Practicing medical futility is even placing more burdens on the health sector that already suffers scarcity of resources. Lebanon lack the clarity in the law about medical futility and this evokes the need to have clear guidelines for practice. There is an emergent need to understand whom to decide on treatment? Are physicians allowed to decide unilaterally on behalf the patient on providing treatment? Moreover, what are the ethical implications of practicing medical futility in Lebanon? Those speculations with the Lebanese laws and regulations will be discussed in more details in the next chapter.

CHAPTER 4

CURRENT LAWS AND IMPLICATIONS

A. Lebanese laws and culture

Perceptions, beliefs and attitudes of caregivers and family members in Eastern countries seem to be in favour of avoiding telling the truth to the patient (Bou Khalil , 2013); which contradicts the espoused commitment to 'truth telling' expressed in Western bioethics (Pentheny O'Kelly, Urch & Brown, 2011; Blackhall, Frank, Murphy & Michel, 2001). However, patients in Lebanon have the right to know their medical condition and participate in decision making related to recommended interventions. Lebanese law 574 article 6 states that "No medical act may be performed or treatment be effected without securing the prior consent of the person concerned, except in cases of emergency and impossibility and the consent must be clearly given, be preceded by all necessary information". In addition, Lebanese law 240 article 3 states that the "patient's will must be respected in every medical intervention" and patients have the right to refuse treatment. The law protects the patient's rights to know and to refuse interventions consistent with best practice in Western countries. However, the right to know and the right to choose are often withheld from patients in Lebanon, for well-intentioned reasons. Family members themselves assume to protect their patient from life threatening diagnosis and from knowledge of poor prognosis. Furthermore, family members compel physicians to withhold information about life threatening diagnoses and terminal stages of illness. Physicians do provide this information to patients when thought appropriate, but physicians, too, are sometimes sympathetic to the case for non-disclosure. As a result, patients cannot articulate their wishes especially when it comes

to making decisions about possible or probable medical futility. Lebanese law is of little help because it is ambiguous about obtaining the patient's will. Nothing is clear about how the patient's will is to be obtained, whether verbally or in writing and nor about whether families are allowed to control information, and act contrary to the patient's known desires and wishes. Some health centers have developed internal policies in conformity with the Lebanese law regarding end-of-life care and decisions. Nevertheless, medical futility is not defined in Lebanese law and policy makers are reluctant to formalize a clear policy related to this concept, since the Lebanese culture is a combination of multiple religions that follow their individual teachings, customs, and practices.

Lebanon is a mixture of multiple religions, although the majority of the population is Muslim. Families tend to refer to religious orthodoxy when faced with sensitive moral dilemmas. Even when they know that further treatment will probably be futile, they insist on intervention to avoid feeling guilty about taking end-of-life decisions that acknowledge that death is imminent (Pentheny O'Kelly, Urch & Brown, 2011). Although to have life prolonged pointlessly and to be able to issue advance directives that ensure respect of patient's wishes are among the principles of good death in Islam (Tayeb, Al-Zamel, Fareed & Abouellail, 2010), debate continues about the pointlessness of further information. Key in this regard, is interpretation of Quran **45**:26, "It is God who gives you life, then causes you to die". In Islam, people are expected to look within themselves for the cause of illness and treat it with lawful medical treatment and to supplicate with a humble heart and a crying eye asking God to cure them (Gulf Times, 2014). Moreover, Prophet Mohammad, Sallallahu 'Alaihi Wa Sallam, said: "No one among you should wish to die because of distress. But if he must do so, then he

should say, ‘OAllah give me life as long as life is better to me, and cause me to die as long as death is better for me”. [Al-Bukhari](Gulf times 2014). Deciding on whether to withhold or withdraw treatment is, therefore, a complex matter, because the obligations of the family when a person is in the terminal stage of an illness could conflict with tenets of faith. Nevertheless, Islamic scholars continue to debate about the interpretation of those principles. Islamic jurisprudence principle “certainty cannot be prevailed by uncertainty,” as it is certain (100% probability) that withdrawing a treatment will deprive the patient from any possible benefit associated with it, whereas it is uncertain (less than 100% probability) that maintaining that particular treatment will cause harm (Zafir al-Shahri & al-Khenaizan, 2005). Families called upon to participate in decisions about end-of-life care are faced with believing either that their contribution to decision making is irrelevant because all that matters is God’s will, or that by expressing an opinion, they are reflecting preferences that they have no right to express.

For Christians, there are similar sentiments. The Bible, Job, **1**:21 ‘The Lord gave, and the Lord hath taken away; blessed be the name of the Lord.’ The dilemmas involved in decision making at end-of-life are different in Lebanon because unlike western countries, the concept of individual agency is less well established. This is due to commitment for the importance of the collective agency, of the family over the individual, and the community over the family. The ethos of individualism necessitates that patients must be informed about their disease process, prognosis and treatment options. In Arab countries, including Lebanon, a shared notion of agency predominates. Decisions are shared among the family; people do not usually follow only their personal choices. They refer to and often defer to their families when making major decisions.

This complicates the relationship between healthcare professionals and the patient. The Lebanese law 240 mentions that if informed consent cannot be obtained from a patient, the legal representative shall be designated, but the legal representative is not clearly defined. When physicians' judge on treatment as futile based on medical facts the challenge arise on how and with whom to discuss the facts of the case and how to agree on not exploiting heroic measures. Most problems occur when the family members disagree among themselves and when the patient is kept out of the discussion. This process overwhelms health caregivers including nurses and physicians. They become unable to decide whether to follow the family wishes on providing aggressive treatment or to avoid prolonging suffering by providing care and comfort that allow peaceful death.

B. Prospects for legislation in Lebanon

Current Lebanese legislation describes the patient's rights to be informed before any medical act can be done; it does not discuss the obligation of families and physicians to inform patients about their medical condition, prognosis and treatment options. The culture and religion dominates the law and health care providers tend to respond to the family's wishes and hinder the truth form the patients. Although, patients' will and right to refuse treatment is stated in the law, the family and religious obligations often compromise patients' requests and wishes. Most of the times medical interventions cannot restore or improve quality of life but health providers insist in managing aggressively to sustain life because of fear from the legislative law, personal beliefs or to moral and ethical obligations of not forbidding the family to achieve their wishes. Nevertheless, euthanasia is forbidden in the Lebanese law and physicians are

strictly prohibited from assisting to put an end to the life of the patient. There is often a misconception of medical futility among people where they consider not initiating a treatment even if futile is the same of supporting a patient to put an end to his life. Lebanese law must define the meaning of medical futility to have legislations that differentiate the practice of health providers and guide them in discussing futility decisions.

Lebanese law is characterized by its ambiguity, in that it gives the primary treating physician the responsibility to shift s practice towards reducing physical and mental pain and providing comfort to patients with life threatening conditions and no hope of recovery, but it does not state how this can happen or who is the responsible to decide on the hope of recovery. These uncertainties amplify the physician's responsibility on judging on patient's medical condition and describing alternative treatments because of medical futility.

Barriers to establish a national policy and country law concerning medical futility are several in Lebanon. This country suffers insecurity and the political structure is inconvenient to initiate the start of a new law related to end-of-life decisions. Physicians and nurses need to highlight the importance of this concept and introduce it to the public to start the debate and move it up to higher authorities for review. Nevertheless, policy maker may be reluctant to support this debate because of the multiple Lebanese religious reference, cultural obligations and personal restrictions.

CHAPTER 5

FUTILITY MOVING FORWARD

A. Overview

Some health organizations developed policies about end-of-life to facilitate practice and to protect employees the organization from civil suits aimed at recovering compensation. The prospects for legal action against health professionals in Lebanon is much less because Lebanese laws are ambiguous, and the resulting uncertainty empowers some physicians to take end-of-life decisions unilaterally without fear of prosecution. However, in Lebanon as elsewhere, decisions to withhold or withdraw medical treatment are complex and challenging for all health care providers because ethical issues cannot be resolved by empirical evidence or legal action. Legal action can resolve issues of compensation and culpability, but it cannot determine the rights and wrongs of an event outside the framework of law. The difficulty with the relationship between legal and moral issues is that legislation generally lags behind changing public attitudes towards moral issues. Despite moral conservatism in Lebanon, it is more acceptable, at least among health professionals, to discuss end-of-life issues, and there is increasing use of inter-disciplinary conferences in the leading medical centers to be engage families in the end-of-life management of their loved ones. However, patients are becoming more assertive in expressing their wishes and in giving the responsibility for significant decisions to physicians. This responsibility can and does contradict the wishes families. As a result, there are patients who cannot have their wishes prevail over the dissenting voices of their families. This contradiction in wishes to preserve life at all costs, even after the point that further intervention is medically futile, necessitates

the presence of clear definitions of patient autonomy, physician authority, medical futility and clear criteria for application for the application of these definitions.

Current ambiguities in Lebanese law have both a positive and negative effect on practice. The positive case for ambiguity is that it protects front line providers by leaving the decisions they make during end-of-life care relatively unquestioned. However, the negative effects of the negative impact of ambiguity significantly outweigh its positive effects. Lack of clarity overwhelms nurses and physicians when further intervention is futile because they lack definitions and guidelines to help them to communicate futility to family members. Unlike in Western countries advanced directives have no status in Lebanon. Consequently, patients are prevented from articulating their wishes in ways that would make them binding on their families no less than on physicians and other health care workers. The result can be chaotic because in the absence of family consensus, there is often no one decision family member who can ask the physician to respect the patient's wishes. In such cases, the law is no help because it is silent on the respective roles of physicians and family members. Physicians are guided to consult with family members and that is all. Current legislation does not align with front line practice, and each physician follows his or her own beliefs. As a result, scarce resources are not assigned objectively and are therefore consumed by patients who cannot benefit from them, leaving those who could benefit with no access to interventions that could help them. Lack of legal clarity increase the risk for unethical practice; patient's autonomy can be disrespected by not telling him or her truth or by taking unilateral decisions, to continue or stop resuscitation for example. Legislative reform is required to respect both those who cannot accept the concept of medical

futility and those who can. Applicable law needs amendment to take into account use of scares resources, distribute justice and the primary importance of patient autonomy.

AUBMC is one of the leading institutions in end-of-life discussions in Lebanon. It has implemented a policy that recognizes medical futility. However, the policy needs to be implemented effectively and its application requires monitoring. Although medical futility is currently discussed from the perspective of the physician only in Lebanon, nurses are often left in the difficult position of trying to mediate between physicians, patients and family members. Condemned to silence by an organizational prohibition on conveying information about diagnoses or prognoses to patients or family members, nurses need to know the meaning of medical futility and the crucial role they could play if open communication with patients and families was permitted and encouraged. This report can serve as a reference point for any healthcare institution in Lebanon to a debate on medical futility with the aim of arriving at unified criteria that align the practice of physicians and nurses with the wishes of patients and those of family members who support those wishes. Nurses must be involved in the debate if anything is to change because they are the ones who have to navigate personal practice in the gap in legislation that protects physicians and confounds patients who do not want to receive futile treatments.

B. Recommendations

- More studies need to discuss medical futility in Lebanon, including case reports. Further studies need to explain the real situation in the Lebanese hospitals and identify the challenges among nurses and physicians regarding medical futility discussions.

- Scholars should be encouraged to initiate discussions and move forward towards achieving local policies to guide practitioners and define treatment limits.
- Medical futility is an evolving concept to medicine and practice, awareness campaigns and conferences needs to be implemented to support this concept.
- Clear guidelines can be implemented to direct physicians on how to judge a treatment as futile and if they need to consult a second opinion within their specialty.
- Interdisciplinary conferences that include nurses, physicians, patients and family members can be recommended as a part of deciding on medical futility. Communication should be clear among nurses and physicians to provide overlapping of discussions with patients and their families.
- Clear channel of reporting futility cases can help in improving communication processes between the three parties: nurses, physicians, patients and their families. This channel helps in exploring obstacles, difficulties, and recommends further improvements and studies.
- Nurses play a crucial role in medical futility discussions and they are the ones in direct contact with the patients. Nurses should express patient's fears and convey their wishes to public since they know their patients and families better.
- Nurses and physicians need to set clear guidelines on what patients and their families need to know concerning disease process, prognosis, management and medical futility decisions.
- Ethical committees should be established in every heath institution to protect patient's rights and health care givers at the same time. Medical futility discussions should be referred to this committee for review at all times.

- Upon recruitment, nurses shall understand the institution's end-of-life and medical futility policies. Policies shall be discussed during orientation phase so nurses can understand their role in end-of-life and they shall sign on a verification form that they have read, understand and will abide by the policies.
- Nurses need to express their feelings, concerns and distresses. They need to be psychologically supported when dealing with patients during their end-of-life phase and when deciding on futile treatment. Some programs can be implemented in hospitals to prevent nurses burn out and help them ventilating out their worries.

C. Limitations

Literature review is weak about medical futility and almost scarce worldwide. We could not find data in Lebanon to help guide us in medical futility discussions, when it started and if it achieved any progress. However, no case report was published discussing a medical futility argument or a case law related to this issue. Nurses' code of practice and Lebanese order of nurses does not define the role of nurses in medical futility discussion in specific and end-of-life care practice in general. Therefore, data and literature to support this report is very weak.

Some scholars might be reluctant to initiate "medical futility" discussions because it is a complex process influenced by many factors that are subjective to people. Hence, this process is affected by personal beliefs and thoughts, culture and religion, financial and ethical considerations. Medical futility concept is evolving and some people may be resistant. Some may prefer to keep on the unilaterality and control of decision making for physicians.

Lebanese political and economical insecurity are barriers to update the current laws and recommend adding up medical futility definition. More efforts are needed from policy makers to highlight the importance of having clear legislations that direct practice.

Medical Centers rather than AUBMC with different systems were not checked for the presence of end-of-life policies and practice. Further studies are recommended to investigate the practice of other hospitals in Lebanon.

D. Conclusion

Progress in medicine, Lebanese cultural and religious diversity, and ambiguous applicable legislation necessitates the initiation of a national debate on medical futility to guide practice taking into consideration the ethical aspects of end-of-life care. Most nurses do not express their will to take care of patients during their end stage of life; some are trained to give comprehensive, holistic care while others are not. Taking decisions as futile on patients does not mean ending a patient's life; it can be a start for alternative treatments to support patients in minimizing suffering, improving quality of life and ensuring a good death process. Nurses need to know how to take care of patients during their end-of-life phase and they need to understand their role and responsibilities. Future studies ought to look in detail at medical futility issues among health care givers to better understand implications to practice and to move Lebanon forward in medical futility discussions, policies and legislations.

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