

"...وَقُلْ رَبِّ زِدْنِي عِلْمًا" سورة طه: 114

“O my lord! Advance me in knowledge”

The Glorious Qur'an: Taha 20: 114

**FIMA
Year Book 2016**

Federation of Islamic Medical Associations

الاتحاد العالمي للجمعيات الطبية الإسلامية

ENCYCLOPEDIA OF ISLAMIC MEDICAL ETHICS- PART III

موسوعة الأخلاقيات الطبية الإسلامية- الجزء الثالث

MEDICAL CARE AT END OF LIFE

العناية الطبية في مراحل نهاية الحياة

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موسوعة الأخلاقيات الطبية الإسلامية: الجزء الثالث

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EDITORIAL

Dear FIMA members
Assalamu Alaykum
Bismillah al-Rahman al-Rahim

All praises be to Allah (ﷻ) the Most Beneficent, Most Merciful.

Peace and blessings be upon Prophet Muhammad (ﷺ), his family, companions and followers until the end of time.

The cardinal purposes of the Muslim's individual, community and global life experiences have been comprehensively defined by *maqassid al-shari'ah*, the highest objectives of Islamic jurisprudence. The wellbeing and welfare of the community is protected by the preservation of the five essentials (*daruriyyat*) in human life, namely faith and morality (*din*), life (*nafs*), intellect ('*aql*), progeny (*nasl*) and wealth (*mal*)¹.

In the hierarchy of *maqassid al-shari'ah*, the sanctity of human life is prioritized, second only to the preservation of *din*. Life is a divine gift and trust from Allah (ﷻ) and its protection and continuation is of utmost urgency and importance.

*"And if anyone saved one life, it would be as if he had saved mankind entirely"*².

Allah, the Life Giver (*al-Muhyi*) is also the Life Taker (*al-Mumit*).

*"He gives life and causes death (yuhyi wayumit), and to Him you will be returned"*³.

The following prayer taught by the Prophet (ﷺ) reiterates the fact that only Allah (ﷻ) decides and determines the timing of life and death:

"O Lord! Please let me live if that is for my good and please let me die if that is better for me"⁴.

Death marks the departure from the continuum of temporal life here on earth and a journeying towards eternal life in the hereafter. We are exhorted to invest our life righteously so as to enjoy the fruits in the life hereafter. We are regularly reminded to prepare for the afterlife, and central to this exhortation is the constant preparedness for death.

Life and death issues became more pronounced and complicated with end of life care and the myriad of clinical choices available. Advances in medicine and surgery have revolutionized the care of patients with cancer, cardiac disease and others with major organ failures. There has been improvements in the morbidity and mortality rates of the critical and terminal patient, however with variable and questionable betterment of their quality of life. The power of the science of healing has somewhat overwhelmed the art of healing and has unwittingly unleashed new sets of clinical, ethical, legal, cultural and religious issues which now challenge our objectives and ethics of end of life care.

Physicians, patients and their families are faced with extremely perplexing and painful dilemmas which include among others:

- How much more should we allow our loved ones to suffer?
- Should we explore all treatment options even though the prognosis is poor?
- Should we allow the respirator, and other life support modalities, to be disconnected upon the advise of the attending clinicians?
- Should we consent to Do Not Resuscitate orders (DNR)?
- How much longer can we afford the care of our loved ones in the ICU?

FIMA first formally addressed these difficult yet important end of life issues in our 2002 and 2005-06 Year Books^{5,6}. With the plethora of life saving interventions, sophistications of therapeutics and intensive care modalities, we felt that it was pertinent to re-examine a wider range of these end of life issues, from the perspectives of *maqassid al-shari'ah*, as the third part of the Encyclopedia of Islamic Medical Ethics.

Sixteen articles were submitted to address various aspects of end of life care. The authors of these chapters come from various countries of the world, from USA in the west to Indonesia in the east. We sincerely thank all them for their ideas, thoughts, diligence and hard work in preparing their submissions. They have comprehensively addressed and updated the scientific and medical developments as well as analyzing the psychosocial, ethical, legal and Islamic perspectives. Virtually all of these chapters are relevant to the daily practice of physicians who care for the critically ill or terminal patient.

A few practical and key messages can be derived from these excellent reviews of major issues related to end of life care.

- Global life expectancy in 2015 was 71.4 years, ranging from 60.0 years in the WHO African Region to 76.8 years in the WHO European Region. Global average life expectancy increased by 5 years between 2000 and 2015. A thorough and contemporary understanding of the effects of aging on the various systems in the human body is a basic essential towards framing a holistic program for end of life care and its unique challenges. Apart from addressing their physical, cognitive and psychological needs, we must not neglect their continuing roles in society and benefit from their talents, experience and wisdom (see chapters 1,2,3,4,5).
- Like all other specialties of medicine and surgery, a Muslim physician's approach to the specific issues related to end of life management must be understood within the context of disease and its treatment in the Islamic paradigm.
- "There is no disease that Allah has created, except that He also has created its remedy"⁷. This narration and several other Prophetic traditions emphasize the Islamic tradition for research into cures for ailments, thus urging believers to

be at the forefront of medical research and the treatment and elimination of diseases.

- If the medical intervention is shown to be effective and safe and strongly correlated with a cure or recovery, Muslim scholars have opined that it is mandatory (*wajib*) to undertake the treatment⁸.
- Otherwise, the default rule for all forms of treatment is optional (*ikhtiyari*) and not mandatory (*wajib*) according to the four schools of thought in Islam (*madhahib*). A few scholars hold the opinion that seeking treatment is supererogatory (*sunnah*). Very few scholars opine that it is obligatory (*wajib*)^{8,9}.
- If the specialist physician counsels his patient and/or family that the chances of a cure or recovery are virtually nil, then there is clearly no religious rationale for ruling that it is *wajib* or *sunnah* to offer or to continue with the said treatment modality.
- Therefore, not beginning or discontinuing the treatment modality (e.g. intubation, ventilation etc) is nothing more than choosing not to operationalize the *ikhtiyari* ruling. Thus, the physician cannot be penalized according to the laws (*ahkam*), nor should he/she feel any guilt when choosing not to execute an action which is *ikhtiyari* (see chapters 9,10,11,12,13).
- Since the preservation of life is a priority of *maqassid al-shari`ah*, we should always endeavor our very best to preserve and maintain life.
- When we recognize that a cure or recovery is not a realistic expectation, or the treatment options are an exercise in futility, or the treatment entails extreme measures, we may opt to withdraw or withhold such treatment modalities and should counsel the patient or family accordingly (see chapter 10).
- We should ensure our patients continue to enjoy appropriate medical and nursing care, maintaining their fluid and nutritional requirements and provide optimal pain relief (see chapter 4).
- We should encourage hospice care of the terminally ill as it is consistent with the teachings of Islam. The palliative care advocates a holistic approach, caring for the physical, psychological, social and spiritual wellbeing (see chapter 4).
- We should check with the patient or the immediate relatives about any advanced medical directives that stipulate the patient's choice of medical care or interventions, should clinical circumstances (e.g. coma or dementia) render him/her incapable of decision making when the need arises (see chapters 6,7).
- Apart from healing the physical aspects, we should manifest our empathy by comforting our patients and encouraging them to beseech healing, patience, perseverance, and mercy from Allah (ﷻ) (see chapters 5,8).
- The definition and diagnosis of death, has significant importance and many implications from the medical, legal, ethical and Islamic perspectives (reviewed in chapter 14).
- Euthanasia is categorically prohibited (*haram*) in Islam, even though it is increasingly advocated and legalized in a few Western countries (see chapter 15).

- Encourage the practise of *Talqeen* to ensure that our patients' critical and end of life moments are righteous with the remembrance of Allah (ﷻ) (see chapter 16).

We hope our readers would enjoy reading the various chapters of this 2016 Year Book and would obtain much benefit from them, as much as we in the Editorial Board enjoyed the task of reviewing and editing the writings.

The exemplary and experienced stewardship of Prof Hossam Fadel, the wisdom and consistency of Prof Abul Fadl and the tenacity and untiring efforts of Dr Aly Mishal and his staff, namely Ms. Elham Mohammad Swaid, merits special mention because otherwise, this work would not reach fruition.

We welcome our new colleagues in the Editorial Board, namely: Profs/Drs. Sohail Akhtar, Muhammad Irfan, Abu Kholdun Al-Mahmood and Abdul Rashid bin Abdul Rahman. We thank them for their efforts and we trust they will uplift the quality of the FIMA Year Book to a higher level.

Finally, we pray and hope that Allah (ﷻ) will accept this effort as *amal salih*, and that everyone who contributed in one way or another to this Year Book project would be bountifully blessed by the Almighty and be rewarded abundantly in this world and in the life hereafter.

May Allah (ﷻ) guide us to the right path and have mercy on us. Amin.

Wassalam
Musa Mohd Nordin
On behalf of the Editorial Board

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Federation Of Islamic Medical Associations (FIMA) in Brief

- Established at the outset of the 15th Hijrah century, December 1981, in Orlando, Florida, USA, where senior leading medical professionals representing ten Islamic medical organizations, from various parts of the world, convened and laid down the foundation of the Federation.
- Subsequently, in March 1999, FIMA was incorporated in the State of Illinois as a non-profit organization, and a tax-exempt status was acquired. FIMA acquired the special consultative status with the United Nations Economic and Social Council (UN-ECOSOC).
- Since that time, FIMA membership progressively expanded to include more than 40 full and associate members, and more than 15 prospective and collaborating organizations from all over the world.
- Most FIMA activities and achievements are based on the endeavors of its member Islamic Medical Associations (IMAs), in constructive mutual cooperation, and harmonious understanding.
- Islamic medical activities of FIMA have a holistic nature. Leadership, mutual cooperation and innovation are prerequisites for the welfare of our communities, our Ummah and humanity at large.
- These activities include, but are not limited to:
 1. Cooperation in humanitarian medical relief work, where and when needed in disaster stricken countries, regardless of ethnicity, religion or race. The FIMA Save Vision Program was initiated in early 2005. To date more than 120,000 eye surgeries were performed by volunteer ophthalmologists and teams from IMAs in several countries, in Africa, South and Southeast Asia, where visual impairments are rampant. The program included training of local medical professionals to continue and widen this activity by qualified local talents. The program also included establishment of local eye hospitals or eye sections in existing general hospitals, in deprived communities.

This activity qualified FIMA for a distinguished award from the American College of Physicians (ACP), designated for outstanding humanitarian medical achievements.

Over the past five years, two new humanitarian activities were launched: The cleft lip/palate (Save Smile) and the vesico-vaginal fistula (Save Dignity) projects, both highlighted as significant medical and psychosocial problems in several needy communities.
 2. Collaboration with regional and international organizations in areas of preventive medicine and community health education.
 3. Scientific, professional and ethical jurisprudence-related conferences, seminars and publications.
 4. Establishment of the Consortium of Islamic Medical Colleges (CIMCO), to foster cooperation in improvement of curriculum, training, research, administration, and up-bringing of model medical practitioners.

5. Establishment of the Islamic Hospitals Consortium (IHC), to pursue cooperation and coordination among medical professionals and hospital administrators in areas of experience exchange, benchmarking, improvement of health care delivery, ethical, administrative and operational activities, to meet the most advanced international standards, in the context of Islamic principles.
6. Publication of FIMA Year Books, which address biomedical, scientific, ethical, and other related issues that are needed for medical practitioners, educators as well as Jurists.
7. In 2013, FIMA committee on Bioethics embarked on the project of Encyclopedia of Medical and Health Ethics. In view of the extensive effort needed, this project is expected to span over several years.
8. Medical students' activities, including conferences, seminars, publications, camps, Umrah and Ziarah programs, pioneered by IMA-Saudi Arabia.
9. Collaboration to extend a helping hand to Muslim medical practitioners in underprivileged countries, to work together and organize professional medical societies, to serve their communities.
10. Activities to combat HIV/AIDS and sexually transmitted infections (STIs): FIMA established long standing educational, prophylactic and capacity building activities in many countries, especially in Africa and Asia, which was pioneered by Uganda IMA in the 1980s. Ten years ago, FIMA launched the parallel project [Protection of Our Youth From STIs and AIDS], pioneered in Jordan, with wide spread activities of education, nurturing and preparation of thousands of local youth leaders in around 30 countries in various regions of the world.
11. Activities to combat all forms of addiction. The project is organized and directed by the Green Crescent Society, based in Istanbul-Turkey, with programs conducted in several countries. The theme of FIMA Yearbook in 2014 was on addiction.

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AGING: MEDICAL, ETHICAL AND ISLAMIC PERSPECTIVES

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Abstract

Nearly one fifth of populations, in most world countries, live after the arbitrarily estimated retirement age.

Chronological and biological aging are different entities, with significant health and socioeconomic implications.

Aging is characterized by progressive and predictable changes that include gradual, unrepaired accumulations of biochemical tissue alterations that compromise cell and tissue systems, rendering individuals to become less fit to reproduce, and survive.

The complex processes of aging are not homogenous among individuals and in various tissue systems, and are influenced by genetic, lifestyle and environmental factors.

Aging can be healthy or pathological. The Concept of successful aging is related to opportunities for continued activity and productivity that should represent an essential strategy from both social and medical perspectives.

The heterogenous deterioration of functions are initially detectable as loss of reserve capacity to restore homeostasis under stress, followed by altered functions at rest.

This article will present contemporary knowledge of normal and pathological aging on various body systems, implications on healthcare, socioeconomics, and the ethical and Islamic perspectives of aging. Hopefully, it will help to positively enhance the outlook of medical caring of the elderly.

Keywords: Aging, chronological aging, biological aging, successful aging, retirement, homeostasis.

Introduction

Worldwide, the retirement age is between 60 and 67 years, which has been arbitrarily estimated with no supporting evidence.

It is known that chronological age fails to provide an accurate indicator of the aging process. Human aging is a complex and irreversible process, which is manifested at different rates in different individuals¹.

The Biological age concept was introduced by many workers in gerontology².

Biological aging is characterized by a progressive loss of coordinated cell and tissue function, a process that is manifested, at variable extents, across body organs and systems that renders individuals to become gradually less fit to reproduce and survive. Deterioration of function is heterogeneous among systems and individuals. It is initially observed as a gradual loss of reserve capacity, and the ability to restore homeostasis under stress, followed, later in life, by altered function even at rest.

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Biological age is synonymous with functional and physiological age, and it is an indicator of the general health status of individuals, their remaining healthy life span and active life expectancy.

Biological age may help in identifying individuals at risk for age-related disorders, serve as a measure of relative fitness, and predict disability in later life and mortality, independent of chronological age².

People who function poorly are looked upon as being “biologically older” than their chronological age. Conversely, people who function well are deemed as “biologically younger”.

This concept may be best represented by construction of an index derived from biological markers (called biomarkers of aging)¹.

Different researchers have developed several types of biomarkers. But because different tissues and organs age at different rates, there is a need to obtain different biomarkers for different body systems.

Some of the newly developed biomarkers include:

- Changes in telomere length.
- Cross-linking of collagen.
- Glycosylation and glycoxidation.
- Pulse wave velocity.
- Sarcopenia (changes in muscles).
- Inflammatory markers.
- Clotting markers.
- Immune function markers.

Such biomarkers may be looked upon as only predictors of more relevant regulatory mechanisms and systems, which need time and effort to elucidate¹.

Moreover, most biomarkers are under substantial genetic influence, which strengthens the concept that longevity is heritable. This concept does not negate the importance of environmental influences.

The development of biological age estimates, using a combination of

reliable biomarkers, together with the search for genes which contribute to aging, will benefit in extending a healthy life span, and maintaining well-being, both physical and psychological.

Although the basic mechanisms underlying aging processes are unknown, available evidence is consistent with accumulation of a variety of biochemical alterations that impair functions of nucleic acids, proteins and lipid membranes.

These alterations probably include, but are not limited to:

- Oxidation by free radicals³.
- Non-enzymatic glycosylation⁴.
- Epigenetic changes, such as DNA methylation and histone acetylation⁵.

The extent to which differentiated cells are affected by aging determines physiologic function, while the extent to which stem and precursor cells (the reserve cells) are affected determines the capacity to replace and repair damaged cells and tissues⁶.

Some studies suggest the presence of circulating factors (?cytokines) that inhibit stem cell mobilization and compromise damage repair^{6,7}.

Aging is accompanied by widely distributed deterioration of signal transduction efficiency. Examples include reduction in the vasodilatory response of the endothelium to estrogen, possibly induced by progressive methylation of the estrogen receptor gene⁸.

Another example is reduced Leydig Cell responsiveness to gonadotropin stimulation, caused by probable altered cell membrane biochemistry^{9,10}.

In studying of changes in older people, it is important to distinguish between effects of aging per se, and those caused by age-related illnesses.

A twin study found that genetics accounted for about 25% of the variation in longevity among twins, and environ-

mental factors accounted for about 50%¹¹.

However, with greater longevity (to age 90 or 100 years), genetic influences become more important.

Frailty:

This is an advanced stage in the process of aging, which needs special care in management.

Its presence is often subtle or asymptomatic. It is evident over time through an excess vulnerability to various stressors, with reduced ability to maintain or regain homeostasis following any destabilizing event.

The term "frail" has varied clinically relevant meanings, including: muscle weakness, bone fragility, very low body mass index, susceptibility to falling, vulnerability to infection and high risk for delirium, depression and dementia.

The term usually describes a condition in which a critical number of these specific impairments occur in parallel, individually or in various combinations¹².

This stage of elderly life necessitates different approach by the medical professionals, family members, and society at large.

One of the aims of care is to delay this stage as long as possible, by maximizing the healthy and productive years in later life. But once this stage finally sets in, compassion, help and kind loving care are needed, from family members in particular, and society in general.

Age-associated physiologic changes:

- **Physiologic rhythms:**

Age impacts the circadian patterns of body temperature, and sleep patterns.

The pulsatile secretion of growth hormone, gonadotropins, thyrotropin, melatonin, adrenocorticotropin hormone, is attenuated with age^{13,14}. These changes are related to factors such as

neuronal loss in the supra-chiasmatic nucleus in the hypothalamus.

- **Loss of complexity :**

May be a general principle of all aging systems, and may result in decreased heart rate variability, blood pressure variability, electroencephalographic frequency and response to stress¹⁵.

- **Homeostenosis:**

A concept that refers to gradual age-related diminishing physiologic reserves leading to increased vulnerability to disease. As frailty sets in, the smallest challenge overwhelms the available reserves and results in disasters¹⁶.

Confusion or delirium can be a similar presentation for a urinary tract infection, gastrointestinal bleeding or a myocardial infarction. With old age, the "anti-confusion reserves" are exhausted.

Age effects on various body systems

Endocrine system

Aging is accompanied with significant shifts in timing and magnitude of circadian rhythms of almost all hormonal systems. The following are main outlines of various system changes.

Parathyroid (PTH) hormone, vitamin D and Calcium balance

Serum PTH levels become slightly higher in older subjects¹⁷. This may be secondary to mild vitamin D deficiency, and phosphate retention caused by declining renal function.

Mild vitamin D deficiency is common among older adults, which is ascribed to decreased dietary vitamin D intake, decreased absorption, decreased sun exposure, decreased generation of endogenous vitamin D, decreased conversion of 25 (OH) vitamin D to 1,25-dihydroxyvitamin D in kidneys^{18,19}. This milieu predisposes to osteoporosis, falls, and fractures in older subjects²⁰.

It is also associated with increased risk of cardiovascular diseases²¹, declining strength²², and risks of certain cancers²³. Calcium balance is also negative in older subjects, due to decreased dietary calcium intake, and decreased absorption of ingested calcium.

Fuel regulation

Insulin and glucose metabolism:

Older adults have decreased insulin sensitivity (50% reduction), with hyperinsulinemia and some decrease in glucose tolerance^{24,25}.

Insulin resistance is, at least partially related to decrease in the muscle content of the glucose carrier protein, GLUT-4²⁶. Not all older individuals have hyperinsulinemia²⁵ and some have sluggish serum insulin response to glucose ingestion²⁷.

Decreased tissue responsiveness to insulin, and slight impairment in insulin secretion may contribute to those age-related derangements. These are similar to changes that precede development of type 2 diabetes mellitus in middle age. The incidence of type 2 diabetes is higher in older individuals.

Leptin: A hormone produced by adipose tissue, in proportion to body fat mass. It decreases appetite.

Serum leptin concentration decreases with age²⁸. This may contribute to increased adiposity in older persons.

Adiponectin: Is a hormone secreted by adipocytes. It reduces insulin resistance, associated with lower risk of atherosclerosis, and has anti-inflammatory properties. Higher levels are associated with lower risk of diabetes in older individuals²⁹.

It seems these changes apply to men over age of 70 years, but less significant in women³⁰.

It seems higher adiponectin levels in older men could reflect enhanced

survival, but further studies are needed to elucidate that.

Growth hormone (GH):

There are shifts in the timing and magnitude of the circadian rhythms of growth hormone in older subjects.

Serum GH concentrations fall with age, both at basal state, and upon provocative stimulation. This change is attributed to decreased secretion of hypothalamic GH releasing hormone (GHRH)³¹⁻³³, and decreased responsiveness to GHRH, somatostatin and ghrelin.

Normally, most GH is secreted during slow-wave sleep. The relationship of GH to age-associated sleep disturbances is relevant.

There are some controversies surrounding GH therapy in older subjects. GH therapy induces increases in lean body mass, and in bone density and muscle strength³⁴.

In men, with the addition of testosterone, this benefit is increased, but not in women treated with estrogen-progestin therapy.

Adverse effects of GH therapy include edema, carpal tunnel syndrome, arthritis, impairment in glucose tolerance and gynecomastia.

Given these side effects, GH therapy should be reserved for subjects with documented GH deficiency.

Pituitary-adrenal axis:

Variable, mostly non-significant changes take place with aging^{35,36}.

They may, however, have some chronic effects. Examples include:

- The higher evening cortisol secretion may be related to sleep disorders³⁷.
- Poorer memory in women³⁸.
- Lower bone density in men with increased fractures^{39,40}.
- Greater body fat⁴¹.

Aldosterone serum concentrations fall with age⁴², probably secondary to decrease in renin secretion. This relative hypoaldosteronism may induce hyponatremia and hyperkalemia. Deydroepiandrosterone (DHEA) and its sulfate (DHEAS) declines with age, starting from the third decade⁴³⁻⁴⁵. These are the most abundant circulating steroids, but with no known functions except as precursors to other hormones (androgens and estrogens). DHEA therapy for the elderly has no documented benefits. Most experts do not recommend such therapy⁴⁶⁻⁴⁷.

Pituitary- Thyroid axis

Slight changes in thyroid functions take place with aging. Serum T3 may be lower, but with no indication to measure it routinely.

TSH may be slightly elevated indicating suspicion of subclinical hypothyroidism⁴⁸⁻⁴⁹.

There is, however, lack of evidence this represents true subclinical hypothyroidism.

On the other hand, low levels of TSH should be looked upon as possible evidence of hyperthyroidism⁵⁰, which is more common with aging, and may not be manifested by the usual symptomatology. Subclinical hyperthyroidism in old subjects may cause osteoporosis, atrial arrhythmias, cognitive dysfunction and dementia^{51,52}.

Female reproductive system

The endocrine system for which there is a well-defined, abrupt, and universal change in function, is the hypothalamic-pituitary-gonadal axis in women.

Decline of ovarian oocyte numbers proceeds as women enter their fourth decade, and menopause occurs at an average age of 51 years. Other postmenopausal processes include vaginal atrophy, dryness, decrease in

cervicovaginal secretions, and increased vaginal pH which predisposes to colonization by enteric microflora⁵³.

Male reproductive system

Changes are mainly due to age-related neurological, vascular and endocrine-logical dysfunction⁵⁴. They are manifested gradually and at variable extents in different individuals⁵⁵.

Male hypothalamic- pituitary-gonadal axis declines progressively with age in most people.

Age adjusted decrease of total and free testosterone (T) has been observed to be relatively constant in men from their twenties onward at a rate just over 1% per year for total T, and nearly 2% for free T. This decline is termed "andropause".

However, unlike "menopause", where complete estrogen deficiency, with known clinical consequences, "andropause" varies from modest to severe, and unclear clinical consequences⁵⁶.

Sperm production is stable to approximately age 70 years, after which it declines progressively by approximately 50% by age 90 years. This is accompanied by tubular fibrosis, shrinkage of testicular volume and modest elevations of follicle stimulating hormone (FSH).

Sperms suffer from increased chromosomal abnormalities, impaired motility, and decreased ability to fertilize, even with intrauterine artificial insemination⁵⁷.

seminiferous tubules degenerate, and leydig cell number decreases with age, with amyloid depositions.

The prostate gland enlarges (benign prostate hyperplasia) with age.

Central nervous system

The brain volume decreases by about 7 cm³ per year after age 65, with greater loss in the frontal and temporal lobes⁵⁸,

white matter more than grey matter⁶¹, with decreases in cerebral blood flow of 5-20%⁵⁹.

Neuron loss proceeds gradually, most likely due to programmed cell death (apoptosis)⁶⁰.

Variable changes take place in brain enzymes, receptors and transmitters. Acetylcholine and dopamine may decrease with normal aging⁶¹⁻⁶².

Dopamine may facilitate memory persistence, and providing dopamines, as L-DOPA, to normal old subjects can improve performance of some cognitive tasks⁶³⁻⁶⁴.

The older brain seems to work harder, with recruitment of more neurons and higher energy expenditure⁶⁵.

Cognitive and behavioral task parameters are usually well preserved through the seventh decades, but begin to decrease with further aging⁶⁶.

The ability to recognize familiar objects and faces and to maintain visual perception of objects remain stable.

Late-life changes, including episodic and working memory, processing speed, and executive function are most affected by normal aging⁶⁷, and specifically, executive function declines more dramatically after age 70⁶⁸.

Other cognitive functions that decrease with normal aging include: problem solving, reasoning about unfamiliar things, processing, learning new information, manipulating one's environment, language abilities, attention span⁶⁹, the ability to focus on a task in a busy environment and ability to perform multiple tasks at one time⁶⁹.

The impact of cognitive loss can often be compensated by non-cognitive factors that do not decline with age⁶⁶.

Despite all these changes, the successfully aging 95-year-old individual may remain able to function at home, in society and the workplace.

The concept of "cognitive retraining" was used to recruit additional skill-specific brain regions/functions⁷⁰⁻⁷³.

This process, referred to as "compensatory scaffolding" could be utilized by more engaging in social, leisure and cognitive activities (e.g. learning a new language or pursuing higher education ...etc), which may decrease the risk of Alzheimer disease or delay its onset⁷⁴.

In healthy volunteers, cognitive training can lead to increases in brain grey matter volume in the "exercised" areas⁷⁵.

Psychological disturbances

Older individuals gradually experience general attitudes of lack of ability to adjust and cope with various life circumstances, with limited flexibility, feelings of despair and lack of self esteem.

The main psychological disorders of old age include⁷⁶⁻⁷⁸:

Depression: A common, but under-recognized and undertreated disorder in the elderly. In the United States, depression is present in 5% of men, and in 7% of women aged 60 years and older.

Depression should be suspected in older adults if there are more than expected mood symptoms, low motivation, and lack of engagement with care providers. Selective serotonin reuptake inhibitors are considered first-line pharmacotherapy for the elderly.

Dementia affects more than 35% of subjects over 90 years of age. It is characterized by progressive decline in at least two cognitive domains: memory, attention, language, visuospatial and executive.

Mild cognitive impairment does not affect daily functioning, but should be carefully screened and evaluated by treating physicians.

Other psychological disturbances of old age include anxiety and suicide tendency.

Cardiovascular system

Both hypertension and ischemic heart disease increase with age.

At autopsy, coronary heart disease may reach 75% after 60 years of age, in men, and two decades later in women.

Left atrial enlargement and left ventricular wall thickness take place with old age⁷⁹⁻⁸¹.

Calcific deposits develop in aortic valve and mitral annulus⁸².

Heart rate decreases as a reflection of combined effects of sympathetic and parasympathetic tones⁸².

The prevalence of atrial premature beats increases with age, but is not associated with increased cardiac risk^{82,83}.

Increase in isolated ventricular ectopic beats is seen in healthy older people, and is considered part of the normal aging process⁸⁴, and so is the presence of an atrial gallop(S4).

Atrial fibrillation is more likely to precipitate heart failure in older adults, partly due to impaired left ventricular filling⁸⁵.

In general, the old heart is a vulnerable heart.

Respiratory system:

The lung undergoes significant age-related anatomic changes⁸⁶:

- Alveolar ducts enlarge due to loss of elastic tissue, resulting in decreased surface area for gas exchange.
- Around one-third of the surface area of lung is lost over the life span.
- Anatomic dead space increases⁸⁷.
- Increased ventilation-perfusion mismatching, with decline in arterial PO₂ with age. This is caused by airways in dependent portions of the older lung that become closed during all or part of the respiratory cycle. Normally

these portions are better perfused than elsewhere.

- The chest wall also changes with age, with increased stiffness⁸⁸.
- The diaphragm flattens and becomes less efficient⁸⁹⁻⁹⁰.
- Pulmonary function tests demonstrate decreases in functional reserves, decreases in forced vital capacity (FVC) and in forced expiratory volume in one second (FEV1) decrease gradually, with deeper decline in the seventh to eighth decades⁹¹⁻⁹².

Age-related decreases in maximal inspiratory force and maximally expiratory force have been found in older subjects who have sedentary lifestyle, but not in active old subjects⁹³⁻⁹⁴.

Cough, and mucociliary clearance are less vigorous in older subjects, with slowed recovery after insults, e.g viral infection⁹²⁻⁹³.

Older subjects, who lack exercise, have decreased responses to hypoxemia, hypercapnia and decreases in central drive to the respiratory muscles. All these changes are minimized by exercise⁹⁵⁻⁹⁷.

Gastrointestinal Tract

- Epithelial lining of the oral mucosa thins with age, gums recede exposing teeth for decay⁹⁸.

Main salivary glands suffer up to 50% decrease in maximal saliva production⁹⁹. Transfer and food bolus to the pharynx is usually altered, with loss of esophageal muscle compliance resulting in resistance to flow of food across the upper esophageal sphincter, and increased aspiration.

- Esophagus: Hypertrophy of skeletal muscle at the upper third, with decrease in myenteric ganglion cells that coordinate peristalsis. Reduced secondary esophageal contractions, combined with

decreased lower esophageal sphincter tone may result in increased gastric acid exposure¹⁰⁰.

- Stomach:

Several age-related physiologic changes take place, with decreased prostaglandin synthesis, decreased bicarbonate and nonparietal fluid secretion, delayed gastric emptying and impaired microcirculation^{101,102}.

These factors are instrumental in causing increased rates of gastritis and sensitivity to gastric irritants and other insults, such as nonsteroidal anti-inflammatory drugs, and increased infection with *H. pylori*.

- Small intestine:

Moderate villus atrophy which may induce malabsorption of several micronutrients.

Vitamin D receptors, as an example, are decreased, with decreased calcium absorption¹⁰³.

Intestinal bacterial overgrowth and associated malabsorption can adversely affect nutritional status. Compromise of barrier function and decrease in myenteric neurons may induce painless ulcerations¹⁰⁴⁻¹⁰⁶.

- Large intestine: More prevalence of mucosal atrophy, mucosal glands abnormalities, hypertrophy of muscularis mucosa, altered coordination of contractions with reduction of colonic propulsive motility that underly chronic constipation.

Older women are more predisposed to fetal incontinence, due to decreased anal sphincter tone¹⁰⁷.

Formation of colonic diverticuli increases with age, due to decreased muscle wall strength and increased intra-abdominal pressure¹⁰⁸.

The risk of colon cancer increases with age, most likely attributed to increased proliferation and decreased apoptosis of colonic mucosa¹⁰⁹.

- Hepatobiliary system: There is reduction of perfusion and blood

flow to the liver, with decreased liver mass, up to 40% with age¹¹⁰⁻¹¹³.

Many liver functions decline, including cytochrome P450, with diminished elimination of drugs and other materials, e.g. erythromycin, galactose and reduced caffeine clearance¹¹⁴.

LDL receptors and LDL metabolism decrease with age, and serum LDL levels increase¹¹³.

Synthesis of vitamin K-dependent clotting factors are decreased, due to lower amounts of vitamin K antagonists needed for anticoagulation in older people¹¹³.

The bile composition has higher lithogenic index, which predisposes to gallstone formation¹¹⁵⁻¹¹⁶.

Genitourinary system

Renal mass decreases up to 30%, with the steepest decline after age 50. Diffuse sclerosis causes destruction of 30% of glomeruli. Fat and fibrosis replace renal parenchyma. Changes affect the renal cortex, especially nephrons responsible for maximal urine concentration¹¹⁷.

Intrarenal vascular changes, with narrowing, intimal fibrosis, shunting between afferent and efferent arteriols (causing bypass of blood flow), and nephrosclerosis take place gradually¹¹⁷⁻¹¹⁸.

Risks of renal injury due to certain drugs (e.g. nonsteroidal anti-inflammatory drugs-NSAIDs) are precipitated due to the above factors, and to increased vasodilating prostaglandins¹¹⁹⁻¹²².

Creatinine clearance decreases with age, with individual variations¹²².

Serum creatinine may remain stable despite decreases in GFR, due to decreased production of creatinine in old age¹²³.

The ability to maximally dilute urine and to excrete a water load is impaired, and compromises volume regulation under stressful situations¹²³. Older kidneys

have impaired ability to retain water, solute, amino acids and glucose.

Older kidneys have reduction of ability to acidify urine, with impaired ability to excrete an acid load. They are more prone to:

- Nephrotoxicity due to medications, or intravenous contrast¹²⁴.
- Less likely to recover from acute insults¹²⁵.
- More vulnerable to ischemic insults.
- Tubular cells have diminished ability to regenerate and populate the tubes after acute ischemic insults.

Increased risk of urinary incontinence, urinary tract infection, erectile dysfunction and female dyspareunia.

Urinary incontinence is related to decreased contractility in detrusor muscle, and decrease of maximal bladder capacity, with decreased ability to withhold voiding, and increased postvoid residual¹²⁶. These changes are partially caused by decreased innervations of the detrusor muscle and changes in the brain.

In women, topical estrogen with pelvic floor exercises, may lead to restoration of urethral function¹²⁶⁻¹²⁸.

Urinary incontinence has adverse impact on the quality of life, social and work functioning and psychological disturbances. Women over 60 years of age are affected twice more often than men.

Risk factors include age, obesity, parity, gynecologic surgery, prostate disorders, diabetes mellitus, pelvic floor muscle weakness, high caffeine intake, tobacco and cognition disorders¹²⁹.

Urge incontinence is characterized by loss of urine accompanied by sense of urgency. Stress incontinence is induced by cough, sneezing or exertion. Both disorders can be mixed.

Overflow incontinent is characterized by continuous dribbling, and is more prevalent in men with prostate enlargement.

Treating physicians should ask their patients about this disorder, since many subjects are hesitant to volunteer reporting this problem.

Evaluation and management should start by exclusion of reversible causes, e.g. medications-induced, infectious, metabolic and cognitive disorders.

Treatment generally proceeds in a stepwise manner, starting lifestyle and behavioral measures, in the form of pelvic floor muscle training, bladder training, weight loss for obese subjects, exercise followed by medications, special devices, then surgeries¹³⁰⁻¹³³.

Musculoskeletal System

Muscle mass decreases (sarcopenia) at variable rates with age. This is considered an independent risk factor for mortality¹³⁴.

Fat and connective tissue infiltrate muscles with advancing age (myosteatosis)¹³⁵⁻¹³⁶, which is greater in legs than in arms. Innervation of skeletal muscle decreases.

The loss of muscle mass contributes to insulin resistance, and changes in volume of distribution for water soluble drugs.

Active lifestyle with exercise plays significant roles in minimizing age effects on muscles.

Age-related hormonal changes, e.g. growth hormone and androgen, may contribute to these alterations.

Bone loss proceeds, with increases in fracture rate and slower rate of repair. Bone loss is promoted by the increased proinflammatory environment. Both trabecular and cortical bone are affected, with decline in osteoblast numbers and activity.

Cortical bone loss proceeds, with enlargement of marrow lumen that is infiltrated with fat¹³⁷. Vitamin D deficiency further accelerates bone loss. Supplementation with vitamin D, Calcium, parathyroid hormone, vascular

endothelial growth factor, have all shown promise to promote bone healing.

Hematopoietic system

Red cell life, iron turnover, and blood volume are unchanged with age. However, bone marrow mass decreases and fat contents increase¹³⁸⁻¹³⁹.

This leads to reduction of functional reserves with advancing age. The compensatory hematopoietic responses to various challenges, e.g. hypoxia, bleeding, is delayed and less vigorous^{138,140}.

The circulating white blood counts do not change with normal aging, but the function of several cell types is reduced. There is more propensity for clonal expansion, which may produce hematologic malignances¹³⁹.

The number of platelets remains stable with age, but platelet responsiveness to some thrombotic stimulators is increased^{141,142}.

Age-associated platelet hyperresponsiveness may be caused by:

- Reduced nitric oxide.
- Increased oxidative damage.

This may cause decreases in bleeding time with age. Old age is considered a pro-coagulant state

Fibrinogen, factors V, VII, VIII, IX, all increase with age, possibly related to the low-grade inflammation, which is part of normal aging¹⁴³.

Overall, age is an important factor for deep vein thrombosis.

Hearing loss is common in the elderly and may lead to depression and social isolation. It usually starts as age-related decrements in high-frequency hearing acuity impaired speech recognition and loss of hearing acuity.

The outer ear develops thinning of the external auditory canal and accumulation of dry cerumen.

The inner ear develops structural changes, neurological, vascular,

ligaments and membranous components, that result in variable degrees of hearing loss, difficulty with speech discrimination, and localizing the source of sounds¹⁴⁴.

The eye

Visual impairment may be unrecognized by patients and their physicians. Main underlying causes are cataract, macular degeneration, presbyopia and glaucoma. The periorbital tissues atrophy, eyelids become more relaxed, which predisposes to entropion and ectropion.

The conjunctiva atrophies and yellows. Deposition of cholesterol esters and neutral fat in the cornea causes arcus senilis.

The iris becomes more rigid with more sluggish responsive pupil.

The lens undergoes photo-oxidation of lens proteins¹⁴⁵ and accumulation of insoluble proteins.

Changes in lens and iris lead to presbyopia. Lens alterations increase light scattering, which renders older persons more sensitive to glare.

The vitreous humor and body shrinks with collagen changes, that manifest as flashes of light¹⁴⁶. Retina becomes thinner because of neurons loss.

Skin

Normal aging leads to atrophy, decreased elasticity and impaired metabolic/repair responses.

The epidermis becomes thinner, the dermo-epidermal junction flattens, resulting in increased fragility¹⁴⁷. Removing an adhesive dressing may dislodge the epidermis. Bleeding into the space between the dermis and epidermis occurs more frequently.

Other skin changes include:

- Dry skin (xerosis), reduction in nail growth, sweat and sebaceous gland activities¹⁴⁸.

- The ability to deliver heat to the skin for excretion is impaired.
- Loss of subdermal fat decreases insulation and ability to conserve heat¹⁴⁹.
- Decrease in sensory perception¹⁵⁰.
- Decrease in vitamin D synthesis¹⁵¹.
- Photoaging, due to chronic sun exposure, specifically sun ultraviolet light, produces most of the cosmetically undesirable skin changes. These changes are partially reversible by topical retinoic acid.

Topical administration of all-trans-retinoic acid (tretinoin) appears to reverse many of these age-related skin change¹⁵².

Drug Prescribing for the Elderly

Age-related changes in pharmacokinetics and pharmacodynamics make it mandatory for physicians to optimize drug therapy for their older patients. This should include deciding whether a drug is indicated, choosing the most appropriate drug, determining the proper doses, monitoring for effectiveness and toxicity and educating the patient and family about expected side effects and indications for seeking medical consultation.

Avoidable adverse drug effects should always be borne in mind when elderly people complain of new symptoms. Any new symptom should be considered drug-related until proven otherwise¹⁵³.

The greater risks of hospitalizations, adverse drug events and increased morbidity-mortality are significant consequences of inappropriate drug prescribing.

Geriatric clinical pharmacology addresses:

- Pharmacokinetics: i.e., absorption, distribution, metabolism and excretion.
- Pharmacodynamics: i.e., the physiologic effects of drugs.

- Adverse drug reactions.
- Drug interactions.
- Rational drug therapy for older persons.

Old Age and Pharmacokinetics:

Age related increase in the proportion of body fat causes increase in volume of distribution for lipid-soluble drugs: e.g. benzodiazepines.

Age-related decrease in lean body mass (muscles) causes 10-15% decrease in total body water. The volume of distribution declines for hydrophilic drugs e.g. alcohol.

Plasma albumen concentration decreases in the elderly malnourished subjects, especially those with advanced cancer.

The plasma-binding of some drugs decreases and the unbound fraction may exceed 50%, which results in increased free drug concentrations and toxicity. Examples include: salicylates, naproxen, acetazolamide, valproate.

Age-related decrease in liver mass reaches up to 20-50% during the age span up to 80 years. This is accompanied by decreased amounts of drug-metabolizing enzymes.

Associated with that is gradual decrease of hepatic blood flow, and decrease in clearance of drugs and decrease in elimination by conjugation of some drugs by up to 25%. e.g. theophylline.

Also there is decreased first-pass metabolism of some drugs that are highly extracted by the liver, e.g. Labetalol, Propranolol, Verapamil and Morphine. This results in decreased systemic bioavailability and decreased concentration.

Older smokers develop decreased hepatic metabolizing enzymes with possible increased mortality.

Malnutrition, as occurs in cancer patients with anorexia, causes impairment of drug metabolism. Adjusting of dosage is important.

In old frail subjects there is decreased clearance of acetaminophen up to 42%.

Warfarin: Age-related decline in liver volume results in decrease in warfarin dose requirement from the age of 50 years.

Anesthesia

There is increased brain sensitivity to I.V fentanyl and altentanil. This should be carefully taken into consideration when dealing with older subjects.

Polypharmacy

Approximately 50% of patients over age 65 years take five or more medications each week.

The use of multiple medications increases the risk for inappropriate use, drug-drug interactions, duplication of therapy, adverse reactions, and medication errors. Polypharmacy is clearly associated with increased outpatient visits, increased risk for hospitalization, increased health care costs, and decrease functional status. Additionally, the risk for non-adherence increases, which can lead to treatment failure and disease progression.

Polypharmacy increases the risk of “Prescribing Cascades”: When an adverse drug event (ADE) is misinterpreted as a new medical condition, and more drugs are prescribed¹⁵⁴.

Certain medications have been found to particularly incur high risk for geriatric patients. The American Geriatrics Society has compiled a list of high-risk drugs that must be carefully considered in terms of risk-to-benefit ratio in the elderly¹⁵⁴.

Summary and Recommendations

- The possibility of adverse drug events (ADE) should always be borne in mind. Any new symptoms should be considered drug-related until proven otherwise.
- Physicians must always review all medications used. Special attention

must be paid to non-prescription drugs, herbs and supplements.

- Various criteria sets exist in the literature that identify medications to be avoided, or prescribed with caution.
- Physicians should avoid under-utilization, as much as over-utilization of drugs.
- ADEs result in 4 times as many hospitalizations in older compared with younger adults.
- Causes of preventable ADEs include, among others: prescribing cascades, Drug-drug interactions and inappropriate drug doses.
- Follow a step-wise approach to prescribing for older adults.
- Discontinue any potentially unnecessary therapy.
- Consider non-pharmacological approaches.
- Substitute with safer alternatives.

Fall prevention

Falls are significant source of morbidity and mortality in older adults. Thirty to 40% of subjects older than 65 years, experience falls annually. The prevalence increases with advancing age and cognitive dysfunction.

The American Geriatric Society developed guidelines and recommendations to prevent falls in older subjects¹⁵⁵.

The following multifactorial risk factors were identified:

- History of falls.
- Medications.
- Gait, balance and mobility.
- Visual acuity.
- Other neurologic impairments.
- Muscle strength.
- Heart rate and rhythm.
- Postural hypotension.
- Feet and footwear.
- Environmental hazards.

In addition to adopting case-specific interventions to deal with these risk factors, the recommendations included other parameters, e.g. modifications of home environment, provision of proper education and vitamin D supplementation.

The concept of "successful aging"¹⁵⁶⁻¹⁶⁰

Remaining active physically, cognitively, and socially, with continued generativity and making a contribution, are the main parameters of successful aging².

Remaining active has specific health benefits, both in the physical and cognitive domains. There is evidence to support the old saying "use it or lose it": to live longer and also healthier.

Being able to make a contribution has been described as an essential element of "successful aging". It has been reported that women who participated in voluntary work or activity had greater longevity than those who did not. Moreover, this voluntary work is essential to psychological well-being in late life. Physical and cognitive activity, along with social engagement, are related to improved health and function with aging.

In addition to the generativity and contributions, elderly individuals can ensure their legacy through defining one's life contributions and achievements.

Staying cognitively active helps to protect memory in older people.

Regular physical activity, both of moderate and high intensity, are associated with lower frequency of heart disease, diabetes mellitus, maintenance of proper weight, more beneficial levels of cardiovascular disease risk factors, and lower likelihood of disability and dependence. Much has been learned recently regarding the adaptability of

various biological systems by exercise¹⁵⁸.

Regular exercise is effective to reduce or prevent a number of functional declines associated with aging, and contributes to an increase in healthy life expectancy.

Additional benefits include:

- Improved bone health with reduction in risk of fractures.
- Improved postural stability, with reduction in falls.
- Increased coordination, flexibility and range of motion.
- Psychological benefits: related to preserved cognitive function and alleviation of depression.
- Improved concept of personal control and self-efficacy, independent lifestyle, functional capacity and quality of life.

A good number of clinical studies showed significant benefits of exercise and community involvement^{159,160}.

Those who live long lives, and are vibrant until shortly before death, may provide the best possible example of successful aging.

From the psychological domain, aging is seen as a life-long adaptive process, an ongoing dynamic of selective optimization with compensation, involving the following three elements, which provide a general framework for understanding the developmental changes and resilience across the life span¹⁵⁷.

1. Selection: as a result of physical and cognitive limitations, individuals select, or optimize, their efforts into areas of high priority.

2. Optimization: individuals continue to engage in behaviors that enrich and augment their physical and mental reserves.

3. Compensation: individuals compensate by using psychological and technological strategies.

Psychological strategies may involve using external memory aids.

Technological strategies may include a hearing aid.

The three elements interplay with one another so that a person may suffer from a reduction in general capacity and losses in specific functions, but creates a transformed and effective life, and thereby the older person maximizes and attains positive or desired outcomes, and minimizes or avoids negative or undesired ones.

The role of society/state

It may be very difficult for old individuals to get involved in activities that produce successful aging. It is hard to accomplish in a retirement setting or in isolation.

In most countries, very few efforts are made to open organized avenues for old people to play meaningful roles as they age².

The experiences, abilities and time of older adults are largely not harnessed, and most efforts are limited to the variable needs of the elderly, without making use of their contributions to their societies. Some workers in this area describe the older generations as the only increasing natural resource, but the least used one!².

In the post retirement years, more than half of people aged 65 and older are without significant disabilities, although 80% of them have one or more chronic disease².

Such chronic diseases are usually managed successfully, and most affected people lead near normal life. Most of them are, however, marginalized from productivity, while having plenty of time and experience.

The family, society and the state need to develop modalities, policies, strategies and legislations to achieve this, in active efforts towards maximizing productive and healthy years of life, side by side with minimizing the number of years of late life lived sick and disabled. Such modalities also help to decrease costs.

It is the duty of society to create widely accessible opportunities for older adults to remain active and productive.

Positive social support, and social activity of the older adults have been related to improving their health, functioning and happiness.

A prominent example of opportunities for older people to accomplish is the field of children education².

In most societies there is a two way deficiency of time and attention provided by working parents, as well as by the school systems to provide various types of care to the young generation. This deficiency includes teaching and education, as well as areas of culture and general knowledge.

With their wide knowledge and experiences, together with their valuable support, advice and helping hand, both at home and school levels, the older generation can provide valuable contributions and role models.

In addition, it provides them with the joy of giving and happiness of more achievements.

Programs must be designed that are attractive and convenient to old people, to maximize their effectiveness and contributions, as long as possible.

This educational model could be conveniently and actively extended to include other areas of health, environment, social and charitable work to serve and support their communities.

Islamic perspectives of aging

There is a wealth of references that address aging in the Glorious Qur'an, the Tradition of the Prophet (ﷺ), and Muslim scholarly heritage. They characterize the Islamic vision of human life with its various stages.

Whether old age is associated with frailty or not, there are special moral considerations of respect and dignity entitled to the elderly in Islamic teachings.

When old age is accompanied with frailty, these consideration become more clearly manifest, and various rights are clearly enjoined on family members and society at large.

Many Qur'anic verses provide definitions and obligations of this stage of human life:

"اللَّهُ الَّذِي خَلَقَكُمْ مِنْ ضَعْفٍ ثُمَّ جَعَلَ مِنْ بَعْدِ ضَعْفٍ قُوَّةً ثُمَّ

جَعَلَ مِنْ بَعْدِ قُوَّةٍ ضَعْفًا وَشَيْبَةً يَخْلُقُ مَا يَشَاءُ وَهُوَ الْعَلِيمُ الْقَدِيرُ"

*"It is Allah, who created you (in a state) of weakness, ordains strength (on you) and then, after a period of strength, ordains (old age), weakness and gray hair. He creates whatever he wills, and he alone is all-knowing and infinite in His power"*¹⁶¹.

The word "weakness" in this verse pertains to utter helplessness of the human being during infancy. Then life evolves gradually to the stage of strength, followed by old age and frailty, which affects different individuals at different times and patterns of body and/or intellectual deterioration.

Biological aging eventually leads to utter senescence and compromise of all capabilities. The human being will then be reduced to a state of complete or near complete dependence on others.

A second Qur'anic verse states:

"وَاللَّهُ خَلَقَكُمْ ثُمَّ يَتَوَفَّاكُمْ وَمِنْكُمْ مَنْ يُدْرَأُ إِلَى أَزْدَلِ الْأَعْمُرِ لِكَيْ لَا

يَعْلَمَ بَعْدَ عِلْمٍ شَيْئًا إِنَّ اللَّهَ عَلِيمٌ قَدِيرٌ"

*"and Allah has created you, and in time will cause you to die, and many a one of you is reduced in old age to a most object state, ceasing to know anything of what he once knew so well"*¹⁶².

This deterioration of knowledge represents a more advanced stage of intellectual frailty that may lag in time after physical frailty. At a certain stage some elderly people may suffer senility or other forms of dementia, behavioral disturbances and susceptibility to various illnesses.

The realization of our weaknesses, and the eventuality of death, ought to make

our minds and hearts open for proper reasoning and contemplation to utilize the remaining times of our lives for deeds and achievements that benefit us and mankind at large, in various aspects, within the framework of what pleases Allah (SWT). The Glorious Qur'an and the Prophetic Tradition, continuously remind us of a time in the hereafter when some of us will painfully beg for a return to life to work and rectify what we failed to do when we were granted the opportunity of life prior to death:

"وَلَوْ تَرَى إِذِ الْمُجْرِمُونَ نَاكِسُو رُءُوسِهِمْ عِنْدَ رَبِّهِمْ رَبَّنَا أَبْصَرْنَا

وَسَمِعْنَا فَارْجِعْنَا نَعْمَلْ صَالِحًا إِنَّا مُوقِنُونَ"

*"If only you could see when the guilty ones on the day of judgment will bend low their heads before their lord! (saying): Oh Lord! We have (now) seen and we have (now) heard: now then send us back (to the previous life): we will work righteousness: for we do indeed (now) believe"*¹⁶³.

Life span: Islamic view

The Prophet (ﷺ) stated: "The life span of my *Ummah* (nation) is between sixty and seventy, and a minority of them will exceed that"¹⁶⁴!

It was, however, repeatedly reported that the Prophet referred to longer life spans in favorable terms. These are but few examples:

"The best among you are those who live longer lives with good deeds"¹⁶⁵.

He was reported to recite a *Duaa* (supplication) whenever he concluded a meeting or gathering, saying: "Oh Allah! bestow on us a fear from you that prevents us from disobeying you ..., and grant us the enjoyment of our (senses of) hearing, seeing and energy, as long as you grant more life to us, and make this everlasting for us"¹⁶⁶.

The Prophet (ﷺ) prayed for one of his companions, and said:

“Oh Allah ! Grant him blessing and increase his wealth and progeny, prolong his life and grant him forgiveness”¹⁶⁷.

It was reported this companion lived more than one hundred years.

The Prophetic Tradition established the concept that the devoted believer continues to gain favorable outcomes as he/she proceeds in age. This is evident from the *Hadith*”: “Do not express your desire to die, and do not make *Du'a* for death before it comes on you, because death will terminate your good deeds, while prolonged living will further increase good deeds of the faithful”¹⁶⁸.

Old age and our responsibilities

It is pertinent to address the mutual obligations between the elderly and their society.

Islam places a duty on every individual to practice healthy lifestyle, and to seek remedy from ailments. Moreover, healthy and competent old people have significant roles to play in their society, their nation and humanity at large. With their knowledge, experiences and wisdom, they can provide valuable functions at various levels.

On the other hand, the society has obligations to adopt various arrangements to keep open avenues for the older generation to play their proper roles. As frailty clouds finally set in, their rights on society gradually expand. Ultimately the frail elderly individual becomes totally dependent. Family and society are morally and religiously enjoined to provide the proper caring. In Islam, this caring is looked upon as an act of worship, that Muslims expect the best level of reward by their Creator. He/she also expects the same level of devoted loving care, if he/she is destined to live to the stage of frailty.

Religious concessions to the elderly¹⁶⁹

Older people, who become incapable to perform religious duties, are exempted, or their compliance is compassionately modified. This includes daily prayers (*Salah*):

"الَّذِينَ يَذْكُرُونَ اللَّهَ قِيَامًا وَقُعُودًا وَعَلَىٰ جُنُوبِهِمْ ..."

"And celebrate Allah's praises, standing, sitting and lying on your sides"¹⁷⁰.

They are entitled to pay monetary or material substitution (*fidyah*) for untolerated fasting in *Ramadan*. Such substitution is directed to charitable support of needy people:

"يَا أَيُّهَا الَّذِينَ آمَنُوا كُتِبَ عَلَيْكُمُ الصِّيَامُ كَمَا كُتِبَ عَلَى الَّذِينَ مِن قَبْلِكُمْ لَعَلَّكُمْ تَتَّقُونَ، أَيَّامًا مَّعْدُودَاتٍ فَمَن كَانَ مِنكُم مَّرِيضًا أَوْ عَلَىٰ سَفَرٍ فَعِدَّةٌ مِّنْ أَيَّامٍ أُخَرَ وَعَلَى الَّذِينَ يُطِيقُونَهُ فِدْيَةٌ طَعَامُ مِسْكِينٍ..."

"Oh you who believe! Fasting is prescribed to you as it was prescribed to those before you, that you may (learn) self restraint. (Fasting) for fixed number of days, but if any of you is ill or on a journey, the prescribed number (should be made up) from days later. For those unable to fast, a substitution (*fidyah*) by feeding of one who is indigent"¹⁷¹.

These exemptions or modifications of religious duties extend to *Hajj* (pilgrimage), *jihad* and other demanding acts of worship.

The Prophet (ﷺ) advised leaders of prayers (*Imams*) to be considerate for the weak and the elderly, "if one of you leads people in prayer, he should be easy on them, for among the people are the weak, the sick and the aged"¹⁷².

On the other hand, elderly competent people are enjoined to display exemplary character and behavior. They are expected to utilize their remaining years for more pure and piety deeds. These remaining years are invaluable and uncompensatable if used to add to their favorable acts, and to wipe away their unfavorable ones. Such years could be looked upon as favors granted by their Creator if properly utilized with pure

intention (*niyyah*) to be blessed with life in paradise (*Jannah*) by the mercy and grace of Allah (SWT).

Elderly people should be extremely careful and weary of committing sins or immoral behaviors in their advanced years. The Prophet (ﷺ) said: "Three persons whom Allah will not speak to, nor purify, nor look at them on the day of resurrection, and they will be afflicted with a painful torment: An old person who is an adulterer, a king (ruler) who is a liar, and a beggar who is arrogant (proud)" ¹⁷³.

One of the most overwhelming pleasures on the day of judgment is when the Creator looks at the believer or speaks to him/her.

Failure of cognition- An Islamic perspective

Muslim scholars believe that true and faithful believers may not reach the stage of cognitive compromise.

Al-Qurtubi stated: Senescence and mental deterioration do not apply to the knowledgeable believer ¹⁷⁴.

According to Al-Suyuti, those who are reciters of Al-Qur'an are the most who will enjoy cognitive preservation ¹⁷⁵.

Al-Shanquiti stated: Those who memorize and repeatedly recite Al-Qur'an will not suffer from dementia or delirium ¹⁷⁶.

Mohammad Bin Ka'ab Al-Qurathy reported: He who repeatedly recites Al-Qur'an will enjoy preservation of cognitive power, even if he lived two hundred years ¹⁷⁷.

Rights of the elderly are obligations on the society

Parent and child in Islam are bound together by mutual obligations and reciprocal responsibilities ¹⁷⁸.

When a frail, senile parent, or grandparent, repeats his old memoirs over and over, and expects audience to

listen, his/her caring son/daughter remembers childhood times when he/she persistently requested stories from the parent or grandparent, over and over.

When the frail elderly suffers and cries of pains, the caring offspring remember their childhood illnesses, and the havoc on their parents.

Principles of elderly care in Islam

Family and society care for the elderly is based on the following principles of faith and morality:

- (1) The dignity and respect of the human being:

"وَلَقَدْ كَرَّمْنَا بَنِي آدَمَ..."

"and we glorified the progeny of Adam" ¹⁷⁹.

Allah (SWT) ordered the angles to kneel to Adam, as a sign of respect and glorification. This status is extended to all mankind, including the elderly.

- (2) The Muslim society is distinguished with mercy, solidarity and caring, especially towards those in need. The Prophet (ﷺ) said: (He does not belong to us who does not show mercy to our young, and respect to our old ones) ¹⁸⁰.
- (3) Elders who spent their lives in services and accomplishment, are duly entitled for reward and return of favor by family and society. The Prophet (ﷺ) said (whenever a young person provides a favor for an old person, Allah will provide people to provide favors for him when he becomes old) ¹⁸¹. He also said: (One of the great favors from Allah is for those who provide favors and respect for an elder Muslim) ¹⁸².
- (4) Caring for the elderly in the Muslim society is a moral and religious obligation on capable

relatives and the society, in case no capable offspring is available.

Friends and relatives of parents

Not only parents, but also their friends and relatives are entitled for care and respect. The Prophet (ﷺ) said: (One of the purist deeds is for a person providing care for the beloved ones of his parents)¹⁸³.

This practice was widely implemented by companions of the Prophet (ﷺ) and their successors. As one *sahabi* advised a young man: My son! Preserve the love of your father's beloved ones.

This society-wide behavior has extremely favorable outcomes on minimizing social isolation and psychological disturbances among the elderly.

The Prophet (ﷺ) listed parent's neglect together with worshipping partners to Allah (*shirk*) and to murder¹⁸⁴.

When the Prophet (ﷺ) was asked about the best deeds in the eyes of Allah (SWT), he answered: (Performing timely prayers), then (caring to the parents), then (*jihad* for the cause of Allah)¹⁸⁵. Caring for parents was given priority over *jihad*.

This care was not limited to Muslim parents, but also to non-Muslim ones. This is clear in the Qur'anic verse:

”وَوَصَّيْنَا الْإِنْسَانَ بِوَالِدَيْهِ حَمَلَتْهُ أُمُّهُ وَهْنًا عَلَى وَهْنٍ وَفُضِّلَ فِي عَامَيْنِ أَنْ أَشْكُرَ لِي وَلِوَالِدَيْكَ إِلَيَّ الْمَصِيرُ” ”وَأِنْ جَاهِدَاكَ عَلَى أَنْ تُشْرِكَ بِي مَا لَيْسَ لَكَ بِهِ عِلْمٌ فَلَا تُطِعْهُمَا وَصَاحِبُهُمَا فِي الدُّنْيَا مَعْرُوفًا وَاتَّبِعْ سَبِيلَ مَنْ أَنَابَ إِلَيَّ ثُمَّ إِلَيَّ مَرْجِعُكُمْ فَأُنَبِّئُكُمْ بِمَا كُنتُمْ تَعْمَلُونَ”

“And We have enjoined on man (to be good) to his parents: In travail upon travail did his mother bear him, and in years twain was his weaning (hear the command): Show gratitude to Me and to your parents: To Me is (your final) goal (return)”

”But if they strive to make you join in worship with Me things to which you has

no knowledge, obey them not, yet bear them company in this life with justice (and consideration), and follow the way of those who turn to Me (in love and obedience). In the end the return of you all is to Me, and I will tell you the truth (and meaning) of all that you have done”¹⁸⁶.

Obligations to respect, value, serve and support the elderly are exemplified by a wealth of Qura'nic verses and Prophetic sayings.

A man asked the Prophet (ﷺ) permission to strive in *jihad*. The Prophet said, “Are your parents alive?” He said yes. The Prophet said, “Then strive in their service”¹⁸⁷.

The elderly right to be remembered in Du'a'

One of the most answered (honored) *Du'a'* (Supplication) is that of a son/daughter for his/her parent. Unpaid debts, *Zakat*, and unfulfilled *Hajj* can be performed by the offspring of a person who is unable to do so, or even after his death.

The Prophet (ﷺ) said. (When a person dies, his actions come to an end, except in respect to three matters that he leaves behind: *Sadaqah jariyah* (a continuing charity), knowledge from which people benefit, and a pious child who makes *Du'a'* for him”¹⁸⁸.

Old age homes in Muslim society¹⁸⁹

Old age is the time when people need loving care, which is best performed by their beloved ones. The current trend of abandoning the elderly and placing them in old age homes is not consistent with this concept, and contradicts basic Islamic teachings.

In some instances, the contemporary lifestyles may necessitate utilizing Muslim old age homes for people in special circumstances. In such cases, their relatives, friends and society at

"And that you be dutiful to your parents. If one of them or both attains old age during your life, say not to them a word of disrespect (not shout at them), not repel them, but speak to them with gentleness and generosity. And out of kindness, lower to them the wing of humility and say: my lord! Bestow on them your mercy even as they cherished me in childhood"¹⁹⁰

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OLD AGE PSYCHIATRY

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Abstract

Old age psychiatry is a vital topic in old age medicine. In this chapter, a review of the most prominent disorders is explored. Namely, organic brain disorders, the dementias, delirium, anxiety, mood disorders and psychotic disorders, including schizophrenia and bipolar disorder. Aspects of management and rehabilitation are discussed. The psychological trends that govern the behavior of the old are discussed. Old age poses a challenge to the medical profession in general and to psychiatry in particular. As longevity is increasing and the number of older people and their likely disabilities demonstrate clearly the importance of mental disturbances in the elderly and especially in the very old. As most old people are retired, they require attention by society, and families. They require special medical and psychological care. Their management requires an air of optimism by all concerned. They might be subjected to all kind of ailments whether in the field of medicine or psychiatry. Old age psychiatry nowadays bears an air of optimism and the elderly ill are looked after as well as the young. Scrutiny is required to delineate the organic from the psychiatric origin of the signs and symptoms. The elderly person needs sympathy, care and establishment of a good rapport rather than alienation and demotion of his/her morale.

Keywords: Aging, dementia, delirium, anxiety, depression, rehabilitation

Introduction

Studies in the area of normal aging have found that working memory declines with aging, as does long-term memory¹, with decrements more apparent in recall than in recognition capacities. Slowing or some loss of other cognitive functions takes place, most notably in information processing, selective attention, and problem-solving ability, yet findings are variable¹. These cognitive changes translate into a slower pace of learning and greater need for repetition of new information.

Vocabulary increases slightly until the mid-70s, after which it declines². In older people

whose IQ declines, somatic illness is probably implicated³.

One large longitudinal study found high cognitive performance to be dependent on four factors, ranked here in decreasing order of importance: education, strenuous activity in the home, peak pulmonary flow rate, and self-efficacy, which is a personality measure defined by the ability to organize and execute actions required to deal with situations likely to happen in the future⁴. Education, as assessed by years of schooling, is the strongest predictor of high cognitive functioning.

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This finding suggests that education not only has salutary effects on brain function earlier in life, but also foreshadows sustained productive behavior in later life, such as reading and performing crossword puzzles⁵.

A new model postulates that successful aging is contingent upon three elements: avoiding disease and disability, sustaining high cognitive and physical function, and engaging with life⁵, the latter encompasses the maintenance of interpersonal relationships and productive activities⁵. These three major elements are considered to act in concert, for none is deemed sufficient by itself for successful aging. This new model broadens the reach of health promotion in aging to entail more than just disease prevention⁵.

Change, Human Potential, and Creativity

Research reveals evidence of the capacity for constructive change in later life.

The capacity to change can occur even in the face of mental illness, adversity, and chronic mental health problems. Older persons display flexibility in behavior and attitudes and the ability to grow intellectually and emotionally. They embark upon new social, psychological, educational and recreational pathways, as long as the individual retains good health and material resources. Fear of death is not present in absence of depression, encountering a serious loss or having a terminal illness. Periodic thoughts of death are usually associated with the death of a dear friend or family member.

Coping with Loss and Bereavement

Many older adults experience loss with aging; loss of social status and self-esteem, loss of physical capacities, and death of friends and loved ones. But in the face of loss, many older people have the capacity to develop new adaptive strategies with the help of supportive family and friends. Loss frequently leads to

depression if not properly managed. Religious beliefs are the mainstay of help towards all kinds of thoughts regardless of age. Strong faith leads to stability of emotions⁶.

The Glorious Qur'an says:

"قُلْ لَنْ يُصِيبَنَا إِلَّا مَا كَتَبَ اللَّهُ لَنَا هُوَ مَوْلَانَا وَعَلَى اللَّهِ فَلْيَتَوَكَّلِ الْمُؤْمِنُونَ"

*"Say: Nothing will happen to us except what Allah has decreed for us: He is our protector": and on Allah let the Believers put their trust"*⁶.

"كُلُّ نَفْسٍ ذَائِقَةُ الْمَوْتِ وَإِنَّمَا تُوَفَّقُونَ أُجُورَكُمْ يَوْمَ الْقِيَامَةِ فَمَنْ رُخِّعَ عَنْ التَّارِ وَأُدْخِلَ الْجَنَّةَ فَقَدْ فَازَ وَمَا الْحَيَاةُ الدُّنْيَا إِلَّا مَتَاعُ الْغُرُورِ"

*"Every soul shall have a taste of death: And only on the Day of Judgment shall you be paid your full recompense. Only he who is saved far from the Fire and admitted to the Garden will have attained the object (of Life): For the life of this world is but goods and chattels of deception"*⁷.

"كُلُّ نَفْسٍ ذَائِقَةُ الْمَوْتِ وَنَبْلُوكُم بِالشَّرِّ وَالْخَيْرِ فِتْنَةً وَإِلَيْنَا تُرْجَعُونَ"

*"Every soul shall have a taste of death: and We test you by evil and by good by way of trial. to Us must ye return"*⁸.

Psychiatric Disorders in Older Adults

Classification:

- Cognitive Disorders; i-dementia, ii delirium.
- Schizophrenia and related disorders.
- Mood Disorders; depression and bipolar disorder.
- Anxiety Disorders.

There are challenges regarding assessment of these disorders in old age:

First, the notion of senility causes a delay in asking for consultations. Second, elderly patients mainly present with somatic symptoms and usually seek the consultation of primary care physicians or different specialists and undergo extensive unnecessary investigations. Psychiatric stigma plays a role. Thirdly, the assessment is further complicated by high rate of comorbidity with other

medical disorders. All this leads to under-diagnosis and under-treatment. Furthermore, cognitive decline, both normal and pathological, can be a barrier to effective identification and assessment of mental illness in later life. Many older adults present with somatic complaints and experience symptoms of depression and anxiety, that does not meet the full criteria for depression or anxiety disorders. Failure to detect the disorders poses serious public health problems. In addition, they prefer being managed by a medical doctor. On the other hand, doctors do not take older adults seriously. Cognitive decline, both normal and pathological, can be a barrier in effective identification and assessment of mental illness in later life.

Cognitive Disorders

Dementia

If not the most common, dementia is surely the most serious psychiatric disorder of old age. Ten percent of those over 65 years of age are demented, and in half of these, the condition is at least cared for in some kind of institution (e.g. nursing home, hospital or rehabilitation center).

The essential features of dementia, the status produced by chronic and extensive (global) brain disease, are persisting intellectual deterioration, an impaired memory for recent events and disorientation, all occurring without any drowsiness (clouding of consciousness). Most definitions of dementia emphasize its insidious onset, chronic and progressive course and irreversibility.

Lipowski⁹ defined dementia as a global cognitive disorder that is relatively stable and unaccompanied by fluctuating disturbance of wakefulness and attention and has lasted more than three months. Marsden's definition¹⁰; is a syndrome of global disturbance of higher mental functions in an alert patient.

Dementia can be a devastating disease eroding personality as well as intellect and damaging of relationships irreparably.

Sometimes it seems as if the true self dies long before the body's death, and in the intervening years, a smudged caricature disintegrates noisily and without dignity into chaos. Until recently, the challenge presented by this tragic condition has been largely ignored. The close identification of dementia with irreversible ageing has meant that clinicians and research scientists have turned their backs, looking for more rewarding scope for their skills. Having made the dreadful discovery of cerebral atrophy neurologists have lost interest, while physicians and surgeons resent the blocking of an acute bed when dementia delays discharge. Residential homes tended to shun the confused elderly, and the burden of care has been left to families, general practitioners and social services in the community, and to the backwards of geriatric and psychiatric hospital. Here, far removed from the centers of excellence, like the teaching hospitals, where diverse experts meet and can fruitfully discuss complex problems to which no single specialty can have the answer (and dementia is, par excellence, one such) barely basic care is given, while detailed observations, investigations and appraisal to understand the course of the condition and how it may be influenced is very scanty.

Recognition, however, that with the inexorable aging of the population, and especially the increase in those over 65, who are most at risk, dementia threatens to overwhelm the health and social services. This led Britain's Department of Health and Social Services in 1972 to issue a document "Services for Mental Illness Related to Old age". It has clear guidance about where demented persons should be looked after, by whom and the scale of provisions to be made for them. In 1977, after a conference including neurologists, neuropathologists,

neurobiochemists, geneticists, and immunologists, psychiatrists and geriatricians, the Medical Research Council publicized its interest in dementia research to the scientific community. Very soon afterwards, the discovery that there is a specific neurotransmitter deficit in the most serious dementia of old age, Alzheimer's disease (AD), sharpened this interest by shifting its focus from the dead or dying nerve cell to a potentially remediable biochemical abnormality. In the United States, rehabilitative techniques to improve the memory of the demented were developed by Folsom¹¹ and have now been enthusiastically adopted elsewhere. The growth of the subspecialty of psychiatrics, particularly in Britain, has meant that now many more psychiatrists are actively interested in the condition. The development of computerized axial tomography (CT) and magnetic resonance imaging (MRI) are enabling wonderfully clear pictures to be taken of the brain.

Gradually, dementia is getting the attention it demands. The main forms of dementia in old age are Alzheimer's disease (senile dementia) and the multi-infarct (or atherosclerotic) dementia. There is probably a third, more benign form, which is closely related to aging.

Alzheimer's Disease (AD) (Senile Dementia)

This, the worst form of dementia, appears to predominate in women, and as women outnumber men the older they get, it is unfortunately also the most common. It pursues, usually, an unremitting course over few or several years, from impairment of the higher mental abilities, such as judgment, self-criticism and abstract thinking in personality and an ultimate state of incoherent incontinence. Forgetfulness is an early sign and rapidly becomes extensive and disabling. The oldest memories tend to be the last to go

(Ribot's law) and hence the characteristic dwelling in the past: many dementing old wives or widows, when asked who they are? will give their maiden names, forgetting all about the forty odd years of their marriage! This dysmnnesia is usually soon accompanied and complicated by dysphasia (difficulty in finding the right words, or understanding what is said) which impedes speech and comprehension. Typical, too, of Alzheimer's disease is dyspraxia, a difficulty in putting movements together due to malfunction of the parietal lobe of the brain, which is a severe handicap in, say, dressing and feeding. Gross neurological signs, however, such as spasticity or paralysis, are rare and late. Interest rapidly dwindles, and is replaced by vacant apathy. Emotions may become labile, tears, laughter and anger being easily provoked, and as readily subside. Usually there is little or no insight into what is happening. The patient blandly disclaiming the defects in her memory and her capacity to care for herself, which are so evident to others. Sometimes self-awareness is kept away by the mental mechanisms of denial: there is nothing wrong with my memory (the memory gaps may be filled by confabulation, or making up stories) and projections: the reason I cannot find my things is that everybody keeps taking them. Thus, there can be a very troublesome paranoid- phase during which the family and friends can be very hurt by vigorous, if irrational accusations; eventually, though, with the continuing progress of the dementia, the patient is no longer able to form her delusions. Habits deteriorate partly because of apathy and not caring, and partly because of loss of social behavior and dyspraxia. Food is slopped; dress is careless and slovenly, washing perfunctory and reluctant and control over the bladder (less often of the bowel) erratic. Incontinence and unexplained aggression are very hard for households to tolerate. However, the demented patients' hostility is

the least dangerous aspect. Wandering can be a great problem; sometimes the patient insists that the home in which she has lived for the last 30 years is not hers, and that her husband is a stranger, and she goes off in search of her mother. She may knock up her neighbors' doors in the middle of the night, causing great annoyance, or, more seriously, gets lost. Leaving the gas on unlit and interference with electrical appliances are, understandably, other causes of great anxiety.

The demented old person living alone is in obvious danger of self-neglect. If she is with her spouse or children, the problem is more theirs-how they are to manage her and cope with their own mixed feelings. If admitted because of dementia to a hospital or an old people's home, the patient is likely to survive two years or so; the more helpless she appears on admission, the less likely she is to live long. It used to be thought that the natural end of dementia was to be bedridden, with contracted limbs and bedsores. We now know that this was the effect of putting the patient to bed, and since that policy has been to keep her up and about, death is more often due to a bout of pneumonia, a heart attack or (the inevitable and entirely acceptable occasional consequence of encouraging activity) a fractured femur.

Alzheimer's disease is a disease and by no means simply due to aging, though dementia (like heart and respiratory disease) becomes a greater hazard with advancing years. It is rare before the age of 65, though the disease originally described by Alzheimer¹² occurred in much younger patients, and was thought to be a separate disorder with a stronger family history; however, the abnormalities in the brains of older and younger victims are identical. Kay et al¹³ showed that dementia exists in two to three per cent of those aged between 65 and 74, in twice as many of those 75 to 79, and in no less than 22 per cent of those over 80. It has long been assumed that the dementia is the consequence of accelera-

tion in the death of nerve cells or neurons so that too few survive for thoughts, memories, intentions and reactions to be mediated normally. The loss of grey matter in the demented brain, with shrinking and smoothing of the surface or cortex, the loss of clefts or grooves or gyri and enlargement of the ventricles and a lower brain weight than is normal at that age certainly suggest, but do not prove that there is a loss of neurons, which are exceedingly difficult to count. At a colloquium about Alzheimer's disease in Edinburgh in 1979, the eminent neuropathologist Wiesniowski observed that the neuron is sick, but not beyond recovery.

The characteristic abnormalities in the brains of sufferers from Alzheimer's disease, visible only with a microscope, are neurofibrillary tangles and senile plaques. The former is due to changes in the tubular fibers or nerve processes radiating from the nerve cell to connect at the synapses with the processes of other nerve cells. The electron microscope has shown that the normally strait neurotubules are replaced by a pair of filaments coiled round each other (PHF paired helical filaments) which give the tangled appearance. The likely cause of this is an alteration in the protein of the neurotubule. Plaques are infiltrations of amyloid, a waxy starchy substance that fills the space between the capillaries or tiny blood vessel to the brain. Plaques could be collections of degenerated nerve fibers, damaged by the process described above, or a response to some toxin derived from the blood. There is certainly a hereditary factor in senile dementia, for if one of a pair of non-identical twins develop the condition, the risk of the other twin getting it is 8 per cent; whereas if the twins are identical, the risk increases to 43 per cent¹⁴. In addition, a Scandinavian study has shown that one's risk of suffering senile dementia is four times as great as that of general population if one has close relative with the disorder¹⁵. There is a connection

between Down's syndrome and Alzheimer's disease. Almost all Down syndrome patients over 35 show the characteristic changes in their brains¹⁶.

It has been suggested that senile dementia particularly afflicts the lower classes and those with an already abnormal personality. However, it is very probable that the underprivileged will be more readily admitted to mental hospitals. It has also been alleged that the changes found in the brain post mortem are often inconsistent with the degree of dementia shown during life, and the suggestion has been made that it is not so much the degree of brain damage, but the personality reaction to it which determines the severity of dementia. However, elegant work by Corsellis¹⁷ in London and Blessed, Tomlinson and Roth¹⁸ at Newcastle-upon-Tyne has shown a quite close relationship between the severity of dementia in life and pathological changes (chiefly the quantity of neurofibrillary tangles and senile plaques) in the brain after death.

Neurochemical and Histopathological Changes in AD

Most biochemical studies of AD relied on information derived from the post mortem brain, which typically represents the late stage of the disease. There is considerable brain atrophy and selective neurotransmitter abnormalities affecting many brain regions¹⁹.

Acetylcholine

In samples from AD patients, presynaptic markers of the cholinergic system were reduced. Thus, choline acetyltransferase activity, choline uptake and acetylcholine synthesis are all reduced up to 60% of control values. The clinical correlates in AD are cognitive dysfunction. This is due to disruptive effects of basal forebrain cholinergic lesions on cognitive function.

Furthermore, cholinergic deficit in AD occurs to greatest extent in cortical areas primarily concerned with memory and cognition-the hippocampus, adjacent temporal lobe regions and select frontal areas. All lead to loss of cholinergic enzyme activity²⁰.

Glutamate

Uptake of glutamate markers are reduced in many cortical areas in the brain. However, Glutaminergic neurons of the neocortex and hippocampus are influenced by acetylcholine through nicotinic and muscarinic receptors. Thus, treatment of patients with cholinomimetics is likely to increase glutaminergic function. Serotonergic faulty neurotransmission leads to depression while faulty noradrenergic transmission leads to aggressive behavior. A highly consistent receptor abnormality in AD is the loss of the nicotinic receptor, which is associated with reactive neuropil threads, tangles and plaques¹⁹.

Links between Neurotransmission and Neuropathology

Increased production of beta-amyloid is the critical event in AD causing other changes (tangles, neuron loss, synaptic loss and neurotransmission dysfunction). It is suggested that compounds that reduce the production of beta-amyloid must have an alleviating effect in AD²¹.

Cholinergic Approaches to Treatment

It has been shown that a presynaptic cholinergic deficit is found in AD, which correlates with cognitive impairment. This together, with the emerging role of acetylcholine in learning and memory, clearly suggest a rational approach to treatment. The use of acetyl cholinesterase (ChE) inhibitors is the most developed approach to the

treatment of AD. In present time, the available ChE Inhibitors are donezapil, rivastigmine and galantamine²².

Multi-Infarct (Atherosclerotic) Dementia

This results from the clogging of arteries supplying the brain by atheroma. The course is typically a series of 'little strokes'--episodes of confusion sometimes associated with minor neurological signs (slurring of speech, weakness of one side of the body, or in a single limb) due to sudden inadequacy of the cerebral circulation, either because a vessel has become completely blocked, or because for some reason the blood pressure has dropped below the level necessary to force the blood through some of the narrowed arteries. The network of arteries to the brain is very rich, and after a few days or weeks, the circulation is restored. There is then clinical improvement, or even full recovery, until the next episode, which takes place in a matter of weeks, months or sometimes not for more than a year. Eventually, however, after a succession of such bouts, there is less and less recovery, until, by a process of "stepladder", deterioration dementia as profound as the senile variety develops. Other signs of brain damage than dementia indicate the atherosclerotic process. Complaints of dizziness are quite common, in the early stages, actual blackouts are not uncommon, and later there may even be fits. High blood pressure is present in about half the cases. Slurring of speech, Parkinsonism (stiffness and shakiness of the voluntary muscles) weakness of one side of the face and/or body, defects of the visual field (hemianopia) and spasticity of the limbs are common neurological signs. Typically, the patient who has atherosclerotic dementia has a shuffling gait, with little steps the *Marche a petit pas*. There are frequently, also, signs of heart disease and of atherosclerosis in other blood vessels in the body than those supplying the

brain. Nevertheless, it is often surprising that, on the one hand, a man can suffer severe atherosclerotic dementia with only minor physical disability, while on the other a patient with a serious stroke may show no intellectual impairment. The explanation is probably that in dementia the blockage mainly affects the smaller vessels, nearer to the brain's surface, and thus spares the tracts lying deeper in the brain which govern movement, whereas major strokes result from obstruction of a major vessel while the other arteries may be relatively free from disease.

Although the disease is widespread in the brain, the cortex is less uniformly affected than in senile dementia, and the patchiness of the lesions, together with the tendency towards some return of function after an incident of occlusion, makes for fluctuations, inconsistency and an intriguing variety of clinical pictures.

Confusion is inconstant; an old man may be muddled in the morning, lucid and alert in the afternoon, rambling and disorientated again in the evening. It is therefore important, if one is required to assess such a patient, not to rely exclusively on how he performs at a single interview but to pay close attention to the history, otherwise one may have unfair suspicions that he is being willfully misrepresented. Emotionalism is sometimes very marked. The patient experiences uncontrolled emotional outbursts with laughing and weeping. However, the distress is not always shallow. The personality is relatively well preserved until a late stage in the dementia, and the consequent insight into the failing memory can cause profound depression and even suicide. Apparently, though, this depression is not wholly reactive to the dementia, for there is a family history of depressive illness in atherosclerotic depressive illness alone²³.

There may be a constitutional link between atherosclerosis and depression; anyway, the

dementia can precipitate true depressive illness in the predisposed.

A paranoid phase is as common as senile dementia. Paranoid delusions in dementia are always directed against those at hand, and never achieve the elaborate consistent quality of those, which characterize paraphrenia. Though relatively well preserved, the personality is not undamaged. Impairment of judgment and self-criticism sometimes precede memory failure. Sometimes the usual pattern is reversed, and personality degenerates while the memory is relatively unimpaired. Presumably, in such cases the frontal lobes of the brain, which seem to have much to do with the finer features of personality such as unselfishness, the moral sense and restraint, are affected earlier by the atherosclerosis. A common complaint is that the patient is never easy to live with but he/she becomes impossible to live with, that he becomes— completely self-centered, callous, cruel, coarse, crude and explosively irritable; yet performance of intellectual tests is within normal limits for the age²³.

The final picture of multi-infarct dementia is that of any advanced dementia, with severe loss of memory and dysphasia, dyspraxia to the point of helplessness and incontinence. Physical infirmity is more marked than at the comparable stage of senile dementia, and death, quite often from a serious stroke, is not long delayed.

Post mortem, the brain may present a moth-eaten appearance, the surface being marked by many infarcts (soft, discolored areas of tissue which died before the patient because of an insufficient blood supply). On the other hand, the brain may seem quite normal to the naked eye and the effects of the disease are only detectable under the microscope.

Table 1 shows comparison between Alzheimer's disease, multi-infarct dementia and benign senescent forgetfulness²⁴.

Delirium

Delirium is a state of acute confusion due to an underlying physical cause. Associated with the disorder of cognition and attention, there is frequently disturbed psychomotor behavior and disturbance to the sleep-wake cycle. It is a common feature in those, particularly old patients, who present as acute medical emergencies. It is a common, potentially treatable condition. It is also under-recognized. Confusion, or cognitive impairment, commonly occurs in three conditions; delirium, dementia and depression. Two of the 3Ds are eminently treatable.

Delirium occurs in 14-56% of older hospitalized patients²⁵. Its incidence is lower in admissions for elective surgery and higher in admissions for acute medical conditions. Patients who have suffered delirium during a hospital admission tend to stay in hospital for longer and have greater requirements for rehabilitation and require increased home care services²⁶.

Risk Factors

Inouye et al²⁵ propose a multifactorial model for delirium, including predisposing factors and precipitating factors. The study identifies four predisposing factors for delirium; visual impairment, severe physical illness, cognitive impairment and high blood urea nitrogen (BUN): creatinine ratio i.e. an indicator of dehydration. Using complex methodology, they identified a hierarchy of precipitating factors, the most significant of which were major surgery, stay in intensive care, multiple medications and sleep deprivation. Their conclusion was that the etiology of delirium is multifactorial, but certain predisposing factors, combined with a weighting of precipitating factors can make the likelihood of delirium much more predictable. Elie et al²⁷ similarly identified risk factors that included dementia, advanced age and medical

illness. Robertson et al²⁸ looked at the onset of delirium and showed that late-onset was more likely to induce it, compared to early onset. Vascular dementia was more likely to induce delirium, compared to early-onset AD.

Clinical Features

Diagnostic Criteria: Diagnostic and Statistical Manual of mental disorders (DSM) (IV-TR)²⁹:

- A) A disturbance in attention (i.e., reduced ability to direct, focus, sustain, and shift attention) and awareness (reduced orientation to the environment).
- B) The disturbance develops over a short period of time (usually hours to a few days), represents a change from baseline attention and awareness, and tends to fluctuate in severity during the course of a day.
- C) An additional disturbance in cognition (e.g., memory deficit, disorientation, language, visuospatial ability, or perception).
- D) The disturbances in Criteria A and C are not better explained by another preexisting, established, or evolving neurocognitive disorder and do not occur in the context of a severely reduced level of arousal, such as coma.
- E) There is evidence from the history, physical examination, or laboratory findings that the disturbance is a direct physiological consequence of another medical condition, substance intoxication or withdrawal (i.e., due to a drug of abuse or to a medication), or exposure to a toxin, or is due to multiple etiologies.

Investigations

Delirium, particularly in the elderly tends to have a multifactorial etiology. It can be due to almost any underlying physical problem. These are likely to be infections, cardiac problems, iatrogenic medications, dehydration, stroke, diabetes, cancer and various metabolic disorders (renal or hepatic failure)³⁰.

Treatment

Identifying the cause is the mainstay of management. If the cause is identified and can be treated delirium can be resolved. Otherwise the suffering can be alleviated. Lipowski³¹ has recommended an appropriate environment for managing patients with delirium. He has described a well-lit room with familiar items and clearly visible clock and calendar. Inouye³² described a multicomponent intervention to prevent delirium in hospitalized older patients. In addition, psychopharmacological treatment is needed. Haloperidol and Quetiapine are the drugs of choice³³. Benzodiazepine is considered in alcoholics. The duration of delirium is shorter in cases which occur in the postoperative period than when it is associated with acute medical problems³⁴. However, the long-term prognosis after delirium is poor³⁵.

Schizophrenia and Related Disorders

Although schizophrenia is commonly thought of as an illness of young adulthood, it can both extend into and first appear in later life³⁶. Diagnostic criteria for schizophrenia are the same across the life span. Symptoms include delusions, hallucinations, disorganized speech, disorganized or catatonic behavior (the so-called positive symptoms), as well as affective flattening, logia, or volition (the so-called negative

symptoms). Symptoms must cause significant social or occupational dysfunction, must not be accompanied by prominent mood symptoms, and must not be uniquely associated with substance use.

Late-onset Schizophrenia

Studies have compared patients with late onset (age at onset 45 years or older) and similarly aged patients with earlier onset of schizophrenia³⁶. Both were very similar in terms of genetic risk, clinical presentation, treatment response, and course. Among key differences between the groups, patients with late-onset schizophrenia were more likely to be women in whom paranoia was a predominant feature of the illness. Patients with late-onset schizophrenia had less impairment in the specific neurocognitive areas of learning and abstraction/ cognitive flexibility and required lower doses of neuroleptic medications for management of their psychotic symptoms. These and other differences between patients with early and late-onset illness suggest that there might be neurobiological differences mediating the onset of symptoms^{36,37}. The older patients experienced less severe symptoms overall and were on lower daily doses of neuroleptics than middle-aged patients who were similar in demographic, clinical, functional, and broad cognitive measures. In addition, positive symptoms were less prominent in the older group.

Mood Disorders

Depressive and Bipolar Disorders Late Onset Depression

The patient displays greater apathy, cognitive deficit with more impaired executive and memory functioning. The risk factors of recurrence include widowhood, physical

illness, low school attainment and impaired functional status.

Barriers to Diagnosis and Treatment

- The nature of the disorder.
- Attribution of symptoms to old age.
- Being looked after by a non-psychiatrist. This results in mis-diagnosis and maltreatment
- The older adult amplifies physical symptoms distracting from diagnosing depression. In addition, to avoid the stigma of diagnosing depression, relatives or even physicians might consider symptoms as part of old age.

Depression is usually comorbid with ischemic heart disease, stroke, cancer, chronic lung disease, arthritis, Alzheimer's disease and Parkinson's disease.

The most serious consequences of depression are increased mortality either from suicide or from somatic illness.

Treatment of Depression in Older Adults

The elderly patient responds to anti-depressive drug treatment. In addition, psychosocial treatment contributes to improvement. Warm relationship with raising the patient's morale, a medium characterized by interactive atmosphere, dealing with persistent insomnia and grief following the death of a loved one, all help to combat depression. Severe depression with suicidal thoughts might warrant electroconvulsive therapy.

Bipolar Disorder

Mania in the elderly is characterized by hyperactivity, grandiose delusions, insomnia, flight of ideas, irritability, persecutory delusions and insomnia. Cognitive dysfunction is also common. Mania can have its onset either earlier or later in life.

Sometimes it can be induced by anti-depressive therapy in patients with major depression.

Depressive episodes are characterized by agitation, mixed states, psychotic features, and cognitive impairment.

Anxiety Disorders

Anxiety disorders constitute generalized anxiety disorder, panic disorder, social anxiety disorder, posttraumatic stress disorder and obsessive-compulsive disorder. Any anxiety disorder can be a continuation of the disorder at a younger age, since 40 percent of anxiety disorders are chronic. Yet, any anxiety disorder can afflict old age. For instance, a panic attack can affect older adults for the first time. Phobic anxiety disorder is among the most common mental disturbances in late life. Anxiety, both as a symptom and as a disorder is common among the elderly. The nature of worry and its clinical manifestations, however, change with advancing age. The intricate relationships among psychosocial stress, physical illness, depression and anxiety in late life make the recognition, diagnosis and classification of neurotic disorders in the elderly quite complex. The elderly worries about ill-health, senility and dependency. Multiple somatic complaints are common usually accompanied with lot of fears and worries, all of which warrants extensive, repeated, sometimes unnecessary investigations. It appears that anxiety disorders run a chronic course, usually lasting into old age. The higher rate of medical co-morbidity, mixed picture of anxiety depression can make accurate assessment and management difficult at times.

Rehabilitation:

Rehabilitation of the older person with a psychiatric disorder means restoring and

maintaining the highest possible level of psychological, physical and social function despite the disabling effects of illness. More broadly, it also means preventing unnecessary handicap associated with illness, and combating the negative effects of low expectations of older people amongst care holders, families and society in general. Managing chronic disease and disability is the greatest challenge to modern medicine. Yet many get cured and require little rehabilitation. Physical factors are important in dementia. Multiple disabilities are common. Functional disorders and delirium can be cured, while multiple disorders such as heart disease, hypertension, and stroke are quite disabling and cannot be cured.

Principles of Rehabilitation³⁷:

- Focus on the home
- Ensure comprehensive assessment
- Encourage normal function
- Treat the treatable
- Analyze disabilities and chart progress
- Clarify career's goals for help and support
- Teach what can be learned.
- Coordinate support
- Promote flexibility and realistic optimism.
- Positive attitude must be enhanced by all concerned with elder adults including family members, nurses, social workers, general practitioners, geriatric specialists, psychiatrists, and geriatric psychiatrists.

General Conclusions

- Important life tasks remain for individuals as they age.
Older individuals continue to learn and contribute to the society, despite physiologic changes due to aging and increasing health problems.

- Continued intellectual, social, and physical activity throughout the life cycle is important for the maintenance of mental health in late life.
 - Stressful life events, such as declining health and/or the loss of mates, family members, or friends often increase with age, however persistent bereavement or serious depression is not normal and should be treated.
1. Normal aging is not characterized by mental or cognitive disorders. Mental or substance use disorders that present alone or co-occur should be recognized and treated as illnesses.
 2. Disability due to mental illness in individuals over 65 years old will become a major public health problem soon because of demographic changes. Dementia, depression, and schizophrenia, among other conditions, will all present special problems in this age group:
 - a. Dementia produces significant dependency and is a leading contributor to the need for costly long-term care in the last years of life;
 - b. Depression contributes to the high rates of suicide among males in this population;
 - c. Schizophrenia continues to be disabling in spite of recovery of function by some individuals in mid to late life.
 3. There are effective interventions for most mental disorders experienced by older persons, for example; depression and anxiety, and many mental health problems, such as bereavement.

Islamic Perspectives

Islam emphasizes respect for all elders in society, children have a special responsibility towards their parents.

The Glorious Qur'an says:

"وَقَضَىٰ رَبُّكَ أَلَّا تَعْبُدُوا إِلَّا إِيَّاهُ ۚ وَبِالْوَالِدَيْنِ إِحْسَانًا ۖ إِنَّمَا يُبَلِّغُكَ عَنْكَ الْكَبِيرُ
أَحْلَاهُمَا أَوْ كِلَاهُمَا فَلَا تَقُلْ لَهُمَا أُفٍّ وَلَا تَنْهَرْهُمَا وَقُلْ لَهُمَا قَوْلًا
كَرِيمًا" ۚ وَخَفِضْ لَهُمَا جَنَاحَ الذُّلِّ مِنَ الرَّحْمَةِ وَقُلْ رَبِّ ارْحَمْهُمَا كَمَا رَبَّيَانِي
صَغِيرًا"

*"And that you be dutiful to your parents. If one of them or both attains old age during your life, say not to them a word of disrespect (not shout at them), not rebel them, but speak to them with gentleness and generosity. And out of kindness, lower to them the wing of humility and say: my lord! Bestow on them your mercy even as they cherished me in childhood"*³⁸.

In the Islamic world, one rarely finds "old people's homes." The strain of caring for one's parents in this most difficult time of their lives is considered an honor, a blessing, and an opportunity for great spiritual growth. In Islam, it is not enough that we only pray for our parents, but we should act with limitless compassion, remembering that when we were helpless children, they preferred us to themselves. Mothers are particularly honored. Serving one's parents is a duty second to prayer, and it is their right to expect it.

The organization of Islamic Medical Sciences (IOMS) addressed mental and psychiatric disorders in three conventions in 1981, 1984 and 1997.

Outcomes of the latter convention were published in the International Islamic Code for Medical and Health Ethics in 2005³⁹, as follows (Taking in consideration that what is referred to as "psychological" applies to "psychiatric disorders"):

The eleventh seminar, held in 1997, dealt with psychological health legislation and recommended that theories, applications, methods, and instruments of psychotherapy should be applied in accordance with the rulings of Islamic Law. The seminar's recommendations say:

The seminar concludes that efforts should be made to adopt an Islamic perspective in theories, applications, methods, and instruments of psychotherapy to make it compatible with rulings of Islamic Law and with the values and circumstances of Islamic

societies. There are two categories that should be observed:

The first category: Principles of Extending Care to a Psychological Patient and the Rights of such a patient. This category consists of five principles:

The First principle is that efforts should be augmented and made adequate for the maintenance of psychological health and prevention of psychodisorders.

The Second principle is that every human being has the right to receive basic psychological health care.

The Third principle is that the evaluation of psychological health should be compatible with recognized international medical principles.

The Fourth principle is that when there is any need to restrict the freedom of patients with psychological and physical disorders as a precaution against any threat they may pose, this restriction should be minimal, and the necessary instruments should be provided to the patient to enable him to perform his religious obligations and take care of himself.

The Fifth principle is that a patient should enjoy the freedom to choose for himself, and, therefore, his consent must be obtained for any medical intervention that concerns him.

The second category: Principles of Determining the Responsibilities of a Psychological Patient. This category consists of three principles:

The First principle is that a psychological disorder affects an individual's civic responsibility if it causes him to lose the ability to distinguish good from evil, impairs his ability to make the right judgment, and results from a mental disorders, inadequate discretion, or a weakness of some self-control faculties.

The Second principle is that a psychological disorders affects criminal responsibility if the psychological patient suffers, at the time of the crime, a mental disorder affecting his will, awareness, reasoning, or mood, and

consequently impairing his ability to make sound judgments.

The Third principle concerns the legal consequences of a disorder that affects responsibility: When it is established that a disorder affects responsibility, the patient's competence should be limited and he should be placed under a guardian who protects the patient's right to defend himself.

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Table 1: Comparison between Alzheimer's disease, multi-infarct dementia and benign senescent forgetfulness

	Alzheimer	Multi-infarct	Benign
Age of onset	45 onwards	45 onwards	After 80
Sex	Commoner in women	Commoner in men	Commoner in women
Course	Progressive and global	Step ladder and focal	Slow, mainly affecting memory
Dysphasia and dyspraxia	Soon	Sooner or later	Absent
Impairment of insight, intellect and personality	Early	Late	Late
Physical symptoms	Absent	Present (headache, dizziness)	Absent
Physical signs	Few and late (e.g. grasp reflex)	Frequent (tremors, paralysis, spasticity)	Absent

AGING AND THE IMMUNE SYSTEM – NEW INSIGHTS

*Ammar K. Daoud**

Abstract

The human population is aging with increasing numbers of humans living longer years worldwide, imposing an urgent need to understand the changes that affect the body systems and organs. The core source of mechanisms of aging and its final result: death, is the limit on cell division and replacement. The Immune System has different components or arms that are affected by the aging process differently and called in general: immune-senescence. The hematopoietic cell reserve is decreased as well as naïve T and B lymphocytes repertoire (cells for the Adaptive Immunity) with decrease in the ability to recognize new antigens, while the myeloid series (cells of Innate Immunity) are generally maintained. These changes give rise to a picture similar to changes seen in Immunodeficiency disorders, of increased rate of infections' mortality, morbidity and decreased efficacy of new vaccines. Also, there is evidence for decreased ability to fight cancers (Immune-surveillance) and thus increased incidence of cancers and increased tendency for certain autoimmune diseases.

Keywords: Aging, Immune system, Immune senescence, Adaptive Immunity, Innate immunity.

Introduction

Humans are living longer and there is a rapidly increasing population on earth reaching old age than ever before. However, till now there is a limit to age that humans can reach, even with the most advanced and sophisticated medical interventions, because of the inability of cells to regenerate, repair and expand. This is an area of extensive research for the secrets of longevity and the ability to delay frailty and death. All types of cells, tissues, organs and systems are affected differentially with aging, and there is need to appreciate and accommodate these changes and devise interventions to preserve health and functionality as long as possible.

The Immune System is no exception to these rules, and in this review I will attempt to discuss the Immuno-aging or Inflammation-aging (The Immune System or Inflammation changes with aging) concepts in a simple language suited for the general practitioner.

The Immune System

The Immune System is a vital system as evidenced by the HIV/AIDS epidemic that, without a normal functioning immune system, we cannot survive. It is needed to fight and deal with foreign invaders and microbes, abnormal self-cells, like cancers and limit foreign cells as in organ transplantation. Any arm of the immune system has first to recognize the foreignness or danger of the substance it attacks, become activated then launching an attack on it to get rid of it. So, the immune response passes through three stages; recognition, activation then killing mechanisms. The classifications of immunity into types is meant for clarification and

simplification as there is a lot of cooperation and dependency among the different arms of this system.

The immune system can be looked at as 2 types; non-Specific (or innate or natural), or specific (acquired or adaptive), depending on its characteristics. The innate immunity is fast and ready to act immediately against many invaders and uses receptors that recognize things found only on the foreign cells. However, this type of immunity lacks the capability to amplify its responses on repeated exposures to the same invader as it lacks immunologic memory.

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The adaptive immunity starts slowly as it needs to be exposed to the invaders first to be mobilized, and is highly specific to its target (in the range of 10^{11} to 10^{18} different receptors)¹, and only a subset or clone of it become activated. This system remembers its targets even after many years, with long lived memory cells that can start a quick and amplified immune attack on repeated exposure (Amplification and Immunologic Memory). There is a chance for the antigen (target for the immune attack), in the case of adaptive immunity, to be self-antigen, so at an early stage (from embryonic period) these cells or arms must be "educated or selected" not to cause autoimmune diseases by attacking or recognizing self-antigens. This process of education and selection is performed in the thymus for T lymphocytes, and in the bone marrow for B lymphocytes before release of the cell in peripheral tissues.

Another way of looking at the immune system is to look at it being cellular or humoral (products of cells), and Table-1 summarizes the components of each of the four arms of the immune system. There is a great deal of control, cooperation and dependencies among these arms and many signals, molecules and hormones called cytokines, are used to achieve that. The killing mechanisms are mostly done by components of the innate, especially after being activated by the adaptive immunity¹.

Aging and the Immune System

Changes in the immune system with advancing age have been discussed by several authors, including extensive details by Ahmad Massoud², and Corony³ who summarized aging as an etiology of immunodeficiency.

These changes can be viewed as observations from the basic science, as well as from the clinical-epidemiologic aspects.

Basic Science Changes of Aging affecting the Immune System

As a human ages, there are observed changes in the ability of cells to regenerate, and an increased defective cell cycles. This is called cell senescence and is probably related to telomeric length at the ends of the chromosomes that track how many times the cell divides³. Similar processes occur for immune cells that are termed: immune-senescence. The number of the Hematopoietic Stem Cells, the source of all hematologic cells, is decreased in the bone marrow and even in the peripheral blood. This is associated with a decreased capability to produce

new cells. It affects the lymphoid division of cell production more than the myeloid part (affecting the adaptive immune system type of cells more than the ones of innate immunity). Elderly people can increase the number of their neutrophils and monocytes, the same as younger people, when needed to fight infections, but have fewer new T and B lymphocytes and these cells might not have the ability to get educated or programmed as the thymus undergoes atrophic changes with advancing age beginning in late childhood. Elderly people maintain most of their Lymphocyte cells as veterans of memory cells from past exposures and lack the needed diversity to fight new pathogens if they are exposed^{4,5}. There is decrease in the naïve T and B lymphocytes and there is also slow gradual decline in the memory cells.

Other changes in elderly persons affecting the immunity include the increased risk of malnutrition (a well-known cause of Immunodeficiency due to calorie / protein malnutrition or trace elements like Zinc deficiency) with extremes of age due to many factors (social, economic, psychological or physiologic). There are defects in the protective barriers like the skin or intestinal mucosa allowing easier access for invaders. In general, there is increased levels of inflammatory mediators in the elderly. Serum levels of Tumor Necrosis Factor alpha (TNF α), Interleukin-6 (IL-6) and C-Reactive Protein (CRP) are increased. These increases are associated with chronic inflammatory environment and accelerated degenerative processes like coronary artery disease, Alzheimer disease and frailty⁶. There is also an increase in Pathogen Associated Molecular Pattern Molecules (PAMPs) and alarmins which leads to, or indicates, a defect in the innate immune response³.

Clinical Effects of Aging on the Immune System

The clinical behavior of aging individuals is like those expected in immune-deficient patients, i.e. increased incidence of infections, cancers and autoimmune diseases. For infections, there is evidence for increased morbidity and mortality from bacterial (e.g. pneumococcal) and upper respiratory tract infections, infective endocarditis, cholecystitis and lower urinary tract that may become serious and persistent and difficult to treat^{2,3}. Similarly, for viral infections, there is increased mortality, morbidity and reactivation of latent infections like VZV and CMV. Especially when there are emerging infections, like the SARS (Severe Acute Respiratory Syndrome) epidemic, the elderly are the most severely affected. This is due to

the inability to deal with new antigens. There is also decreased efficacy of vaccines either to new antigens or even booster doses in the geriatric age compared to younger individuals. There is a decreased response to the annual influenza virus vaccine seen by decrease in the production of interferons *in vitro* in the laboratory and a decrease in the clinical protection from it⁷.

Many cancers are seen in the elderly, but this is multifactorial with important environmental exposures to radiation, chemical carcinogenic toxins or infections with oncogenic viruses, but also in part due to a decrease of immune-surveillance and anticancer function. Natural killer cells (an important anticancer type of cell) is generally maintained in numbers in healthy aging, but its subsets are altered with decreased responses to stimulatory cytokines reflecting decrease in its functionality against cancers². In immunodeficiency states, we expect an increase in autoimmunity associated with dysregulation of the function. Although certain autoimmune diseases increase in older age, some conditions like Giant Cell Arteritis, Polymyalgia Rheumatica and Rheumatoid Arthritis, do not. So far, the changes seen in the experiments on regulatory mechanisms are contradictory with increased T reg cells as opposed to a decrease⁸.

Conclusions

Aging is an increasing phenomenon that requires the medical profession to understand it and deal with it efficiently. Dealing with this age group

needs awareness of its unique characteristics, susceptibilities and requirements. The immune system, like the whole body, cells or organs, changes with aging with a decrease in its capacity to respond to new threats or regenerate its cells, termed immune-senescence. Better vaccines are needed to fit the special changes in the elderly with a stimulatory and protective results to be achieved.

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Table – 1 Components of each arm of the immune system

	Adaptive	Innate
Cellular	T Lymphocytes T Helper T Cytotoxic	Neutrophils Monocytes / Macrophages Natural Killer Cells
Humoral	Immunoglobulins from B Lymphocytes 5 classes and 9 subclasses	Complement System Lysozyme Lactoferrin

PALLIATIVE CARE THROUGH THE AGES AND WITHIN FIMA MEMBER COUNTRIES

Diana Katiman*

Abstract

Palliative Care is an interdisciplinary approach to care that aims to relieve suffering and improve quality of life for patients with advanced illness and their families. It is offered simultaneously with all other appropriate medical treatments. Although the concept of holistic care was fairly recently popularised as ‘Palliative Care’ in conventional medicine, the spirit of looking after the sick and tailoring care to their psychosocial circumstances, dates as old as medicine itself. Islamic history in the field of medicine documented that institutions, similar to that of modern hospitals and hospices, were built to accommodate patients from all backgrounds, and not only to those who were dying. Regardless of its origin, palliative care services should be made available to all. The mapping of palliative care services and provisions by the World Health Organisation (WHO) and Worldwide Palliative Care Alliance (WPCA) allows each nation, and especially member countries of the Federation of Islamic Medical Associations (FIMA), to benchmark against sister nations with similar cultural and economical background. This will help each country identify barriers to provisions of good palliative care services, and subsequently overcome these barriers according to local priorities.

Keywords: Palliative, Palliative care history, Barriers, FIMA.

Introduction

“...She was EXHAUSTED. Just simply tired all the time. Also, very sensitive and moody. Her cough started to sound weird, percussive, deep and continuous. I had an inkling something was wrong. She felt it too. When I pushed her to go see a doctor, she said “It is my body!”. I was angry then. Now I realized how fearful she must have felt knowing that the Big C was a likely cause. If you look at my mom at this time, you could not have known how ill she felt. She was chubby and she put on such a strong front – calm, collected and graceful.

In February 2015, I made an appointment at a local clinic that provided a full range of health screens. I just got her through them. Didn’t ask her if she wanted it. Just made sure it was done. When the x-ray came out and we saw a white mass in her right lung, I thought it was

pneumonia. The Doctor thought differently. Of course, we got an earful because he was of the opinion we waited too long to get the tests done. I’ll admit, the fella scares me a bit – so fierce!

I cried in the car with mama next to me all the way home. It was tears of anger. So very angry because we tried to get her to do a test for ages. So, angry she was stubborn, strong willed, “It is my body!”, she said. Mama was sitting next to me in fear, and there I was being angry. She kept saying sorry and I wasn’t appeased. I felt like I was losing her already. So, desperate that feeling it was consuming me. I managed to calm down once we got home but by then the damage is done. I will learn to regret this later on in our journey like I regret many things I should have done better”.

(Adapted with permission from the author¹).

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The excerpts above hopefully depict the physical, emotional, social and spiritual interplay of a family touched by the diagnosis of cancer on its mother-figure. It also tells of the many distresses the patient and family went through, notwithstanding the feeling the author had following consultation with a doctor. The author has not gotten around to update her blog, but it will continue to say that “Mama” will have failed 3 lines of targeted chemotherapy, developed pathological fractures and was referred to the Palliative Care service.

What is Palliative Care?

The World Health Organisation (WHO) defined Palliative Care as “an approach that improves the quality of life of patients and their families facing the problem 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 spiritual²”.

In short, palliative care aims to holistically help patients AND their families to live life to the fullest despite all the challenges of a life-threatening illness.

Palliative care does not necessarily mean that the patient has to have the diagnosis of cancer. In fact, the WHO has outlined several diseases that sufferers, adult or children, may require some form of palliation one way or another². These include advanced stages of human immunodeficiency virus infection and acquired immune deficiency syndrome (HIV/AIDS), cardiovascular diseases, complications of diabetes mellitus, advanced organ failures^{2,3}, and many other disease entities in adults and children.

A recent publication by the Worldwide Palliative Care Alliance (WPCA)³ and WHO stated that in 2011, over 29 million people died from diseases requiring palliative care. Ninety four percent of these were adults and six percent were children. Figure 1 depicts the distribution of adults in need of palliative care at the end of life by WHO regions and disease categories (Figure 1).

History of Hospices and the Modern Palliative Care movement

The tradition of caring goes way back to the history of medicine. History documented that as early as 2500 BC, in ancient Egypt, India and China, there were institutions that possessed some of the attributes of hospitals and medical home visits^{4,5}. Hippocrates (460-371 BC) is reported to have visited and treated patients in their homes⁵, similar to what some hospice services are offering now.

The words “Hospice” and “Palliative” have their linguistic origins from the Latin words ‘*Hospitium*’ and ‘*Pallium*’. ‘*Hospitium*’ means “entertainment, hospitality, lodging or inn”^{4,6}. This is thought to have come from medieval times of the crusades in the 11th century, when the crusaders would have set up a place of shelter and rest for the weary or ill travellers on a long journey⁷.

‘*Pallium*’ meanwhile, means ‘to cover’ or ‘to cloak’, similar to a cloak giving comfort and a sense of security to the wearer^{4,6}. It was the desire to comfort people facing death, to relieve their pain and suffering, that brought the founder of modern palliative care movement to her professional calling.

The modern palliative care movement was attributed to Dame Cicely Saunders, a British nurse and social worker, who had to witness terrible pain and suffering during the second World War. She also cared for patients sickened with cancer who were in so much pain and saw the need to help them with their psychological and spiritual well-being, and preserving their dignity towards their end-of-life. It was when she was volunteering in the “St. Luke’s Home for the Dying Poor” in London that she resolved to pursue a medical degree to be able to do more to ease the pain suffered by such patients. She qualified as a doctor in 1957⁴. This accreditation allowed her to better manage pain and increased her commitment towards caring for the terminally ill. She questioned the practice of physicians then to give intermittent sedation to terminally ill patients when in pain, thus coming up with a novel pain control which allowed patients to be pain-free but conscious, and

maintaining a good quality of life. She perfected the use of oral morphine before pain appeared, giving it to patients as the previous morphine dose's analgesic effect is wearing off, thus staying ahead of the pain. Ten years later, in 1967, Dame Cicely Saunders opened St. Christopher's Hospice in London, the first modern hospice dedicated to caring for the terminally ill⁷.

As the concept of caring for the terminally ill became more widely accepted, hospices mushroomed and with it came the negative connotations of the word hospice with 'death' and 'dying'. To reclaim the ideas of what holistic comfort care was all about, Dr. Balfour Mount, a surgical oncologist at The Royal Victoria Hospital of McGill University in Montreal, Canada, coined the term 'Palliative care' in 1974 to be used in a hospital-based palliative care service he helped set up⁸. The term has since been generally accepted and used worldwide.

Although history highlighted Dame Cicely Saunders' efforts in caring for the terminally ill, there were other institutions in France, Ireland and America in the late 19th century which were documented to give refuge to patients with leprosy and cared for patients dying of tuberculosis and cancer⁴.

History of Medicine and Palliative Care in Islam

The role of Islamic heritage in promoting humane care was also documented in Western literature, but elaborations were scarce. In the sixth century, during the time of the Prophet Muhammad (ﷺ), tents were pitched in the yard of the Prophet's mosque in Madina, as a field hospital, where a *sahabiah*, by the name of *Rufaidah al-Aslamiyah* nursed the wounded and cared for homeless newcomers to Madina⁹.

As Europe went through the medieval era and the 'Dark Ages', Muslim and later, Jewish and Christian physicians, functioning under the folds of Islamic civilization, enhanced the earlier works of the Greek and Roman physicians. Works of *Abu Bakr Muhammad ibn Zakariyya al-Razi*, known in the West as Rhazes (865-925) in Baghdad, *Abu al-Qasim al-*

Zahrawi, Latinised as Abulcasis (936-1013) in Cordoba, *Ibn Sina*, also known as Avicenna (980-1037), *Abu Walid Muhammad ibn Ahmad ibn Rushd* or Averroes in the West (1126-1198) and rabbi *Musaibn Maymoun*, also known as Maimonides (1138-1204) were compiled and taught in universities and via apprenticeships in Islamic hospitals across the regions¹⁰.

In the ninth and tenth centuries, five teaching hospitals were built in Baghdad, placing it as the dominant centre to produce the Islamic medical tradition. The most famous of these was the Al-'Adudi Hospital, established under *Buyid* rule in 981¹⁰. Subsequently, other medical institutions flourished in the nearby regions, such as the *Nuri* hospital of Damascus (twelfth century), the *Mansuri* hospital of Cairo (thirteenth century), as well as those in *Qayrawan*, *Mecca*, *Madina* and *Rayy*, to name a few¹¹.

Although literature searches revealed no designated place to care for terminally ill patients in the early Muslim healthcare era, medical institutions were made available to everyone who needed medical care, regardless of gender, religion, age, social class and wealth, or whatever disease they suffer from. Care was also provided to prisoners and people in remote villages via mobile clinics. The hospitals were divided into sections. Men and women were treated in separate halls. There were areas reserved for the treatment of contagious diseases; separate areas for surgical cases, and other areas for the mentally ill¹¹.

The holistic approach to care of terminally ill patients, as envisioned by Dame Cicely Saunders, should resonate well with Muslim physicians. As mentioned earlier in this article, palliative care advocates for whole patient care, which consists of these four aspects: physical, psychological, social and spiritual well-being. Islam taught us that a human being consists of a spiritual soul encompassed in a material body. In the Glorious Qur'an, we read:

"الَّذِي أَحْسَنَ كُلَّ شَيْءٍ خَلَقَهُ وَبَدَأَ خَلْقَ الْإِنْسَانِ مِنْ طِينٍ، ثُمَّ جَعَلَ نَسْلَهُ مِنْ سُلَالَةٍ مِّنْ مَّاءٍ مَّهِينٍ، ثُمَّ سَوَّاهُ وَنَفَخَ فِيهِ مِنْ رُّوحِهِ وَجَعَلَ لَكُمُ السَّمْعَ وَالْأَبْصَارَ وَالْأَفْئِدَةَ قَلِيلًا مَّا تَشْكُرُونَ"

"He is the one who excelled in everything He created, and He started creating man from clay

*and then made man's progeny from a worthless fluid, then He made him and breathed into him from his soul, and made for you the hearing, the visions, and the hearts, and little thanks you give"*¹².

Thus, when a Muslim physician treats a patient, whether for life-limiting illness or not, he or she must always remember the Islamic perspective of an individual as being a soul and a body. The physician should not only consider the patient's physical being, but also emotions, spiritually and the social circumstances. Does this not resonate with what palliative care is all about?

Palliative Care in FIMA member countries

Palliative Care has developed in leaps and bounds over the decades since its modern inception. However, there are still many countries in the world where the provisions of palliative care do not really penetrate the core of the society that needs it most. These barriers are multifaceted with various levels of confounding issues whether it is the role of the authorities, or that of the health-care providers or the societies that it wants to protect.

A recent literature review¹³ identified key barriers to palliative care integration into three main domains, as outlined by the World Health Organisation. These are:

- (1) Policy domain: fragmented healthcare system, need for greater funding for research, lack of adequate reimbursement for palliative care, and regulatory barriers.
- (2) Education domain: lack of adequate education/training and perception of palliative care as end-of-life care.
- (3) Implementation domain: inadequate size of palliative medicine-trained workforce, challenge of identifying patients appropriate for palliative care referral, and need for culture change across settings.

Over the years, interests have developed in the comparative analysis of palliative care development worldwide^{14,15}. These analyses were aimed mainly to facilitate cross-national comparative analysis and stimulate advocacy, policy making and service development.

One of the most comprehensive reviews¹⁵ published was that by the International

Observatory on End of Life Care (IOELC) based at Lancaster University in the United Kingdom. The team systematically reviewed data from all 234 United Nation recognised countries or areas, and categorised their development regarding palliative care services into 4 categories as shown in (Table 1).

This initial study was further developed by researchers at the Worldwide Palliative Care Alliance (WPCA) and the WHO. When the services were mapped in a global view, as in Figure 2, one can appreciate that there are still many parts of the world that are left wanting of palliative care provisions and services (Figure 2).

Although these categorisations allow some degree of standardised comparison between countries, the assessments were mainly based on various degrees of physical presence of a service as reported by published journal articles and interviews of 'key figures' in palliative care in the respective countries^{14,16}.

A systemic review comparing the 'western' and Muslim Middle East (MME) models of palliative care provisions highlighted four major differences, namely cultural differences, legal/policy differences, differences in the understanding of palliative care, and the availability of resources and support for palliative care¹⁷. Knowing that these differences exist, will allow us to view these categorisations of countries, not as one country 'better' than another, or 'more developed' than another, but rather, each country will have different sets of challenges to overcome, in its own unique pace, before palliative care becomes accessible to all who need it.

For example, in the United States of America (U.S.A.) (Category 4b), although having a very low palliative care service to population ratio (1:48,000), there are concerns of disparities in the form of geographical access to care, type of care received and availability of hospice care according to medical insurance coverage¹⁸. However, for Malaysia (Category 4a), where the palliative care service to population ratio is 1: 250,000, opioid consumption (a surrogate to effective pain control) is relatively low. In 2014, the total morphine consumption in Malaysia was 0.7392 mg/capita, which was way

below the global mean of 6.24mg/capita¹⁹.

Challenges for Zimbabwe (another Category 4a country) is somewhat different. The Zimbabwe National Cancer registry recorded that in 2005, 60% of cancer diagnosis in Zimbabwe, were Human Immunodeficiency Virus (HIV)-related, with low survival rates attributed to limited access to early detection and treatment²⁰. However, with a comprehensive approach to address these challenges, Zimbabwe (alongside Uganda in Category 4b) is now seen as a beacon of hope in Sub-Saharan Africa in terms of public health management. Zimbabwe outlined priorities for cancer prevention and control which focused on prevention (HIV infection control efforts to reduce Kaposi sarcoma, vaccination for Hepatitis B and Human Papilloma Virus, HPV), early detection and treatment of cancer including human capital and infrastructure development; and the establishment of a critical mass of activists and providers for palliative care. The decades of work seem to have paid off with a reduction of HIV prevalence from 18% in 2004, to 15% in 2011²⁰, and a decent palliative care service to population ratio of 1:963,000¹⁶.

The Jordan Palliative Care Initiative (JPCI) initiated in 2001, has since been declared a WHO Demonstration Project. It falls in 'Category 3b' of the IOELC/WPCA typology of palliative care development. Challenges in terms of policy and human resources trained in palliative care were overcome by a consolidated effort by various stakeholders. These include the Jordanian Ministry of Health, the King Hussein Cancer Center (KHCC- a non-governmental and not-for-profit institution), a Jordanian pharmaceutical company (HIKMA- who produced cost-effective morphine tablets), the WHO and several Palliative Care Institutions and Hospices from the United Kingdom and United States of America²¹. The success story of JPCI, as well as other WHO Demonstration Projects (in Catalonia, Spain; Wisconsin, U.S.A.; Kerala, India and Mongolia) in starting up a palliative care service 'from scratch' serves as a model for developing countries, especially those with similar cultural and religious background, to emulate.

These are some examples of palliative care developments in the Federation of Islamic Medical Associations (FIMA) member countries. FIMA was formed on December 31st 1981 and subsequently incorporated in the State of Indiana, United States of America (USA) as a (not-for-profit) entity in 1982. Currently, there are more than 40 full and associate member countries in FIMA, representing about 50,000 Muslim medical and health professionals from 41 countries^{22,23}.

Based on the categories of palliative care reported by Lynch *et. al*^{17,19}, progress of palliative care development in FIMA member countries in 2011 can be mapped out as shown in (Table 2).

Several articles related to palliative care in Muslim majority countries quoted cultural and religious influences as factors that needed to be tactically addressed by health care professionals involved in providing palliative care services there. These factors include the concept of suffering and treatment of illness and their relation to one's spirituality, the inherent belief of the unseen contributing to an individual's physical health and thus the role of spiritual healers, and the importance of family and society in some aspects of care and decision-making^{9,16,17,24,25}.

Members of the Federation of Islamic Medical Associations (FIMA), do not necessarily come from countries with a majority Muslim population, nor do they have similar levels of national economic growth. Members are bound by common objectives²² of the organisation, which include promoting the understanding and the application of Islamic principles in the field of medicine, promoting health services, education and research - through cooperation, coordination and exchange of medical information and technical expertise among member organizations.

By setting a benchmark amongst member countries and with the rest of the world, we will be able to gauge where a country stands and what more needs to be done to ensure that palliative care can be delivered to all those who require it.

Moving forward:**Empowering palliative care provisions in FIMA member countries**

The Worldwide Palliative Care Alliance (WPCA), in its 2013 report¹⁶, stated that there was a 9% increase in the number of palliative care services established globally, from 115 countries in 2006 (49% of 234 countries) to 136 countries in 2011 (58% of 234 countries). This change in direction from group 1&2 (no known activity/capacity building) to group 3a (isolated provisions) are countries from Africa (+9 countries including Sudan, Morocco, Nigeria) and the Middle East (+5 countries including Lebanon).

Multiple studies and systematic reviews have summarised the barriers that hinder the development of palliative care. As mentioned earlier in the article, the World Health Organisation's (WHO) Public Health Strategy for Palliative Care outlined several barriers to the development of palliative care. The barriers may be about policies, medication availability, education and training, implementation and psychological/social/cultural barriers³.

However, these barriers may not be applicable to all countries, as there are geo-political, cultural and human resources differences. To ensure that palliative care is made available to all, interested parties in FIMA member countries must identify and prioritize which barrier to overcome first. Some of these barriers in FIMA member countries have been described earlier in this writing.

A recently published article¹³ summarised the policy-related barriers in the U.S.A. These include the fragmented structure of the US healthcare system, the need for greater funding for palliative care research, the lack of adequate reimbursement and incentives for palliative care for individuals with complex medical problems and regulatory barriers to greater palliative care integration in the nursing home setting. In the Middle East, Turkey is the only FIMA member country that has a national palliative care policy²⁶.

A case series in the U.S.A. and a study of several European countries, reported barriers in the areas of prescribing and dispensing opioids,

linked directly to the insurance company²⁷ or government policies²⁸. Whereas, in some Asian countries, like Bangladesh and Indonesia^{29,30}, the limited access to opioids, hinders delivery of adequate pain management to palliative care patients. In some Middle Eastern countries, such as Egypt, Morocco and Jordan, although there is no prohibition on prescribing morphine for home use, there are limitations to the length of morphine prescription²⁶.

Barriers in education and training of human resources in palliative care are evident in many researches worldwide. A study done in one tertiary care centre in the US reported, the stigma of the term 'palliative care' among oncologists and hematologists prevented earlier referral to specialised palliative care service³¹. A comprehensive undergraduate curricula and postgraduate training in palliative care also needs to be looked at in several countries where lack of knowledge among medical students and doctors are noted to be high. This is true in several FIMA member countries such as the Nepal, the U.S.A., United Kingdom, Germany, Australia, Oman, Egypt, Morocco, Turkey, India, Pakistan and Malaysia^{26,32,33}. Limited research data from other FIMA countries may indicate the need to enhance the research culture in palliative care in some member countries.

Cultural and social perception of death and dying, and of 'palliative care' in general, in some Muslim majority countries, need to be respected and considered when planning for a nationwide strategy for palliative care development. In some countries, the view that an illness is a test from God and the protective role of family or community members in caring for one of their own, may influence how soon patients present to their medical professionals to seek treatment. In some cultures, the strong belief of probable involvement of supernatural beings in causing the illness may also cause the delayed treatment seeking behaviours. Thus there is a high incidence of late presentations of most diseases in these countries^{9,17,20,24,25}. However, the existing stigmas and taboos in some countries may not always be a cultural barrier, but rather of limited understanding and exposure to holistic healthcare. Thus, the importance of education and training for all

sectors of society including patients, caregivers, health care professionals, religious leaders and policy makers, cannot be underestimated. Moving forward, understanding where we stand with regard to palliative care accessibility in our respective countries, and benchmarking ourselves to countries with similar economic and cultural background, may help us prioritize which areas we need to focus on. As mentioned earlier, palliative care goes hand in hand with the concept of holistic care in Islam. So, it is only prudent of Muslim healthcare professionals to ensure that palliative care is practiced by all, for all.

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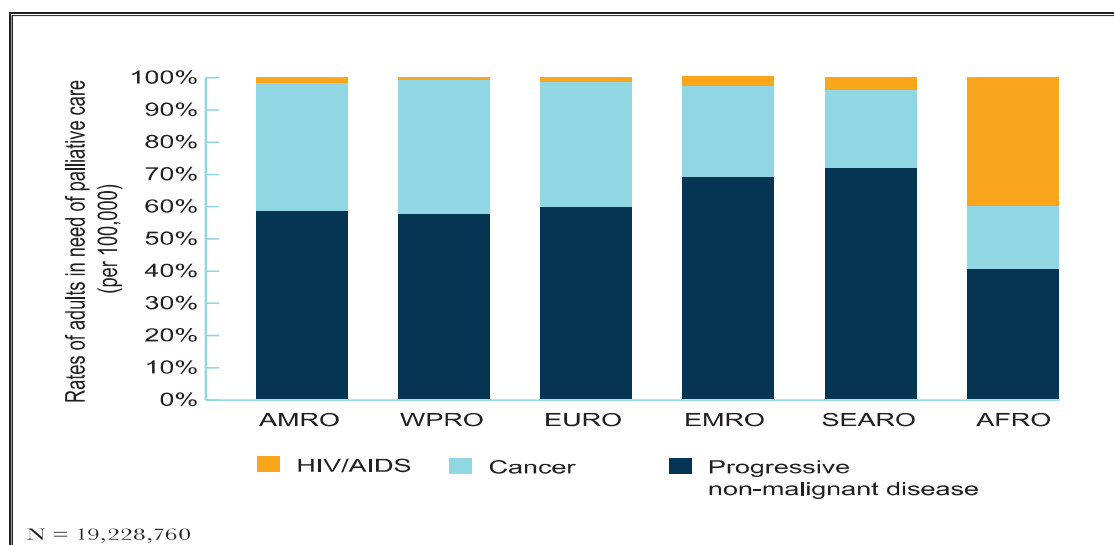


Figure 1: Distribution of adults in need of palliative care at the end of life by WHO regions

AMRO= Regional Office for the Americas of the WHO.
 WPRO= Western Pacific Region of the WHO.
 EURO= European Region of the WHO.
 EMRO= Eastern Mediterranean Region of the WHO.
 SEARO= Southeast Asian Region of the WHO.
 AFRO= African Region of the WHO.

(Permission to republish obtained from the World Health Organisation)

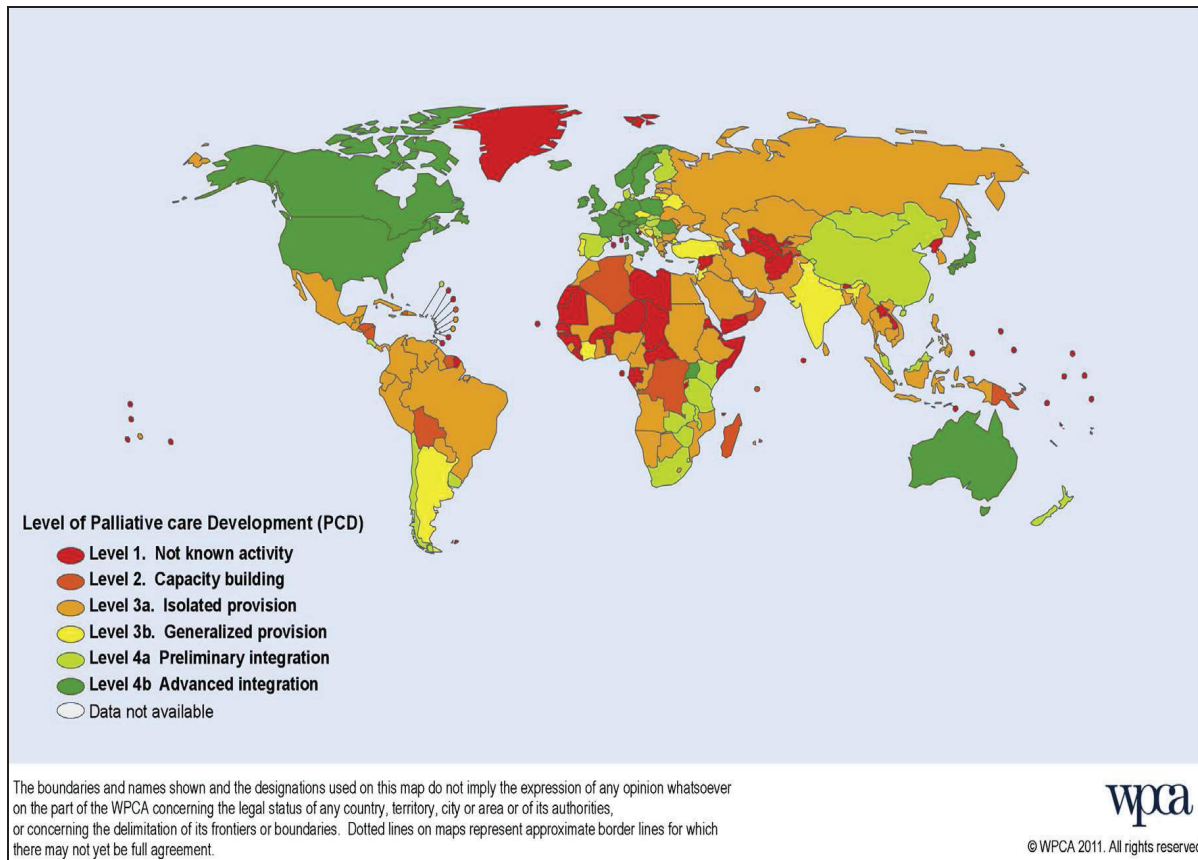


Figure 2: The Level of Palliative Care Development as mapped out by the Worldwide Palliative Care Alliance (WPCA) in 2011.

* The WPCA has since changed to the Worldwide Hospice and Palliative Care Alliance

Table 1:
Categorization of countries in the world according to their development in Palliative Care Services

Group 1	No known Hospice-Palliative Care Activity
Group 2	<u>Capacity Building Activity.</u> Evidence of wide-ranging initiatives designed to create the organizational, workforce and policy capacity for the development of hospice-palliative care services although no service has yet been established.
Group 3	<p><u>3a: Isolated Palliative Care Provisions.</u> Palliative Care activism that is patchy in scope and not well-supported; source of funding that is often heavily donor-dependent; limited availability of morphine; and a small number of hospice-palliative care services that are often home-based in nature and limited in relation to the size of the population.</p> <p><u>3b: Generalized Palliative Care Provisions.</u> Palliative Care activism in several locations with the growth of local support in those areas; multiple sources of funding; the availability of morphine; several hospice-palliative care services from a community of providers who are independent of the health care system; and the provision of some training and education initiatives by the hospice organizations.</p>
Group 4	<p><u>4a: Hospice-Palliative Care Services are at a stage of Preliminary Integration into mainstream service provisions.</u> There is a critical mass of palliative care activism in a number of locations; a variety of palliative care providers and types of services; awareness of palliative care in the part of health care professionals and local communities; the availability of morphine and some other strong pain-relieving drugs; limited impact of palliative care on policy; the provision of a substantial number of training and education initiatives by a range of organizations; and existence of (or at least an interest in the concept of) a national palliative care association.</p> <p><u>4b: Hospice-Palliative Care Services are at a stage of advanced intergration into mainstream service provisions.</u> There is a critical mass of palliative care activism in a wide range of locations; comprehensive provision of all types of palliative care by multiple service providers; broad awareness of palliative care on the part of health professionals, local communities, and society in general; unrestricted availability of morphine and most strong pain-relieving drugs; substantial impact of palliative care on policy, in particular on public health policy; the development of recognized education centers; academic links forged with universities; and the existence of a national palliative care association.</p>

Table 2:
FIMA Member countries and level of Palliative Care Development

NO	COUNTRY	FIMA MEMBER / ASSOCIATE MEMBER	COUNTRY CATEGORY (GROUP)	Ratio (1:000s) of PC Service: Population
1	Australia	Islamic Medical Association of Queensland (IMAQ)	4b	67
2	United States of America	Islamic Medical Association of North America (IMANA)	4b	48
3	Singapore	Muslim Healthcare Professionals Association (MPHA)	4b	206
4	Sweden	Swedish Islamic Medical Association (SWIMA)	4b	66
5	Uganda	Islamic Medical Association of Uganda (IMAU)	4b	962
6	United Kingdom	British Islamic Medical Association (BIMA)	4b	48
7	Kenya	Islamic Medical Association of Kenya (KMMP)	4a	905
8	Malaysia	Islamic Medical Association of Malaysia (IMAM)	4a	250
9	South Africa	Islamic Medical Association of South Africa (IMASA)	4a	239
10	Tanzania	Sunshine Medical Society	4a	2,187
11	Zimbabwe	Islamic Medical Association of Zimbabwe (IMAZ)	4a	963
12	Bosnia	Bosnian Islamic Medical Association (BIMA)	3b	942
13	India	Islamic Medical Association – India	3b	4,218
14	Jordan	a- Islamic Hospital- Jordan b- Jordan Society of Islamic Medical Sciences	3b	1,579
15	Nepal	Islamic Medical Association- Nepal	3b	4,889
16	Turkey	Hayat Foundation for Health & Social Services Turkey	3b	5,344
17	Bangladesh	National Doctors Forum Bangladesh (NDF)	3a	23,174
18	Egypt	Islamic Medical Association of Egypt	3a	27,666
19	Indonesia	a- Islamic Medical Association and Network of Indonesia (IMANI)- Perhimpunan Profesi Kesehatan Muslim Indonesia (PROKAMI) b- The Indonesian Forum for Islamic Medical Studies (FOKKI)	3a	22,996
20	Iraq	Islamic Medical Association of IRAQ	3a	30,747
21	Khmer Republic of Cambodia	a- Islamic Medical Association of Cambodia (Assoc Member)	3a	7,402

22	Lebanon	a- Islamic Medical Association of Lebanon (IMALB) b- Al-Amal Society c- Al-Shifaa Society	3a	2,112
23	Morocco	Justice and Development Medical Society-Morocco	3a	31,993
24	Nigeria	Islamic Medical Association of Nigeria (IMAN)	3a	22,104
25	Pakistan	Pakistan Islamic Medical Association (PIMA)	3a	90,404
26	Philippines	Bangsamoro Medical Society (Associate)	3a	852
27	Saudi Arabia	Islamic Medical Association of Kingdom of Saudi Arabia (IMAKSA)	3a	8,573
28	Sri Lanka	IMA-Sri Lanka	3a	20,238
39	Sudan	Sudanese Islamic Medical Association (SIMA)	3a	21,136
30	Thailand	Thailand Islamic Medical Association (TIMA)	3a	5,212
31	Tunisia	United Doctors for Tunisia	3a	5,136
32	Algeria	Association of National El Razi Algeria	2	N/A
33	Azerbaijan	Azerbaijan Medical Association (AzMA)	2	N/A
34	Palestine	a- Scientific Medical Association of Palestine b- Al-Wafa Charitable Society –Gaza-Palestine (Assoc Member) c- Medical Aid Society- Gaza-Palestine (Assoc Member)	2	N/A
35	Afghanistan	Afghanistan Islamic Medical Association (AIMA)	1	N/A
36	Mauritania	Islamic Medical Association of Mauritania	1	N/A
37	Somalia	Somali Young Doctors Association (SOYDA)	1	
38	Yemen	Islamic Medical Association, Republic of Yemen (IMARY)	1	N/A
39	Germany (hq), France, Ireland, Austria, Poland, Italy	Union Arabischer Mediziner (ARABMED)		

SPIRITUAL CARE AT THE END OF LIFE: WESTERN VIEWS AND ISLAMIC PERSPECTIVES

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Abstract

The concept of spiritual and religious care, as core components of palliative care for patients at end of life stages, has achieved significant organized applications and advances in modes of intervention and tools. Specifically in western countries, there is increasing professional contributions from chaplaincy, nursing, social workers and medical professionals.

The past two decades have witnessed waves of secularization with impacts of the concepts of spirituality and chaplaincy that diverged away from religion, more so in the UK and some European countries as compared to US applications. Spirituality became more generic and broad that revealed itself in helping and education of patients and families to earth and think of meaning and purpose of life, suffering death and dying.

The issues of spirituality and religiousity in the Islamic culture, teachings and attitudes towards patient care at terminal stages of life, is distinguished by clarity and harmony in view of clarity of Muslim beliefs and interpretations concerning purpose, meaning and mission of human life on this earth, end-of-life care and the afterlife.

This paper will address the contemporary western diverse concepts of spirituality, its relationship with religiousity in terminal patient care, and will elaborate on the holistic Islamic views and attitudes towards this stage of human life.

Keywords: End-of-life care, spirituality, religiousity, chaplaincy, Islamic end-of-life teachings.

Introduction

The past three decades have witnessed proliferation of interest in areas of palliative, spiritual and end of life care¹. There is a wealth of literature on concepts of spirituality, religiousity, well-being, quality of life care and achieving a "good death".

Significant developments have been achieved in chaplaincy, nursing and social guidelines and practices at the stages of end-of-life¹.

An extensive review of this topic¹ has covered the English-language literature from 2000 to 2010, which included spiritual care at end of life settings,

spiritual assessment tools and ongoing intervention modes, with the contributions coming from the professional disciplines of chaplaincy nursing, social work, and interdisciplinarity studies.

Historically, a chaplain was seen as the representative of a particular faith, a clergyperson commissioned to provide pastoral services in institutions or governmental entities, which may include crisis management, counseling, worship, education, help in ethical decision making, staff support and church coordination².

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In the past, a healthcare chaplain was appointed by the church, or by other religious authority, to minister people suffering from illness, and to bridge the gap between hospital, community and church.

More recently, however, with the movement towards secularization, and the changes in definition of spirituality, the mission of chaplaincy has changed³.

Chaplains are no longer perceived as representing any particular faith or religion. They became responsible for spiritual care of people belonging to all faiths, and to those with no faith^{4,5}.

They focus on a generic form of spirituality, offered to a broad range of people with diverse beliefs^{5,6}.

The mode of spirituality practice of chaplaincy in the UK and US became broad, generic and inclusive.

In the UK and some other western countries, the concept of spirituality and spiritual needs is open for debate^{5,7}.

Spirituality is perceived as a generic characteristic of human being, that reveals itself in search for meaning (of life, illness, death...etc)⁸, especially when humans are faced with trauma, ill health or sadness. This search for meaning extends to search for purpose, hope, self worth and relationships. All people are spiritual beings, and all have something to hold on to¹.

The Nursing profession and spiritual care:

The nursing profession has a long historical association with spirituality and religiosity⁹, with historical heritage of tending to patient suffering, emotions and spiritual needs of the sick, the dying and the destitute.

This spiritual heritage of nursing has gradually eroded in UK health care system run by the National Health Service (NHS), and expectedly in other western countries in the increasingly

secular and materialistic societies, but survived in the context of charitable-run hospices¹⁰.

The concept and claims that spiritual patients care has therapeutic benefits, with enhancement of quality of life, there is pioneering work, educational and practice-oriented to support these previously unsubstantiated thinking¹¹⁻¹³. Research into spirituality has been extended to followers of various religions, ethnicities and culture denominations^{14,15}.

Social workers and spiritual care

The first work looking at social work in end of life situations and bereavement was published in UK in 1997¹⁶.

This national study revealed that majority of social workers acknowledge existential issues as significant.

In the UK, social work literature continues to distinguish psychosocial from spiritual care, in contrast to that in US¹⁷.

There is an increasing use of the psychosocial-spiritual model for social work directed to people who are dying or bereaved¹⁸.

In many western countries, particularly in the UK, literature is more concerned with mental health and well-being¹⁹.

Some studies in older adults report on importance of religiosity and spirituality to mental health and well-being²⁰, including the importance of belief for a "good death"²¹.

A US study showed a range of practices such as yoga, prayers and meditation frequently used by some social workers.

Western narratives which distinguish religion from spirituality, and develop a secular perspective²² are critiqued in the context of social work practice in multi-cultural settings, and the exporting of western models of education and practice to postcolonial contexts²³.

On the other hand, study of older African Americans highlighted spiritual

resources and strength of belief as the most significant factors in end of life decisions²¹.

Comparing of the role of social workers with that of chaplains found considerable overlap in perceptions of role and task, except in the provision of spiritual care.

Social workers were found to be more concerned with personal fulfillment and well-being, where chaplains focused on providing religious services and exploring psychological meanings²⁴.

Social workers are often seen to take a "problem solving" approach Y, where chaplains start from acceptance of mystery and paradox²⁶.

Spirituality and Religiosity

Significant debates continued in the area of definition and exploring the relationship between spirituality and religion.

In US literature, spirituality is commonly equated to religiosity. This is not the case in the UK where a complex exercise of broader understanding of spirituality focuses health outcomes and well-being¹.

The First Annual Report of the End of Life Care Strategy²⁷ identified concerns that many of the available tools for the end of life care have been developed in the US, regarded as more religious than in the UK, and may not transfer well in the UK.

Spirituality is more generic, basic, and has wider implications than traditional religiosity²⁸. it relates to the way in which people look at their lives, values, and perception of meaning and purpose of life, illness, wellbeing and death^{29,30}.

This renders spirituality as a diffuse term that is quite difficult to tie down³¹.

The UK guidelines, however, do not ignore identifying religious beliefs and spiritual practices of the dying patient and relatives, in order that health care practice does not offend or contravene tenets of religions practices of specific

religious groups. Guidelines work to facilitate the needed environment for patients to die in the manner prescribed by their religion³².

Religiosity is defined as participation in beliefs, rituals and activities of one of the traditional religions³³.

Religion is considered as a mode of spirituality, but both are not considered synonymous³⁴.

Not all western writers agree on the benefits of religion within the context of end of life care³⁵. On the other side, however, some experts consider religious spirituality to have clear benefits in the form of the coping with illness and impending death³⁶.

The significance of both religion and spirituality is in providing people with capabilities to make sense of their lives, to cope with their health experiences and suffering, and maintaining hope, inner harmony and peacefulness at this final days of suffering and challenges of life³⁷.

The sense of well-being during terminal illness may be the fruit of religious belief in the "afterlife" and that God is caring for the patient in the midst of the current suffering.

In US literature, it is believed that religion and spirituality have positive impact on how patients perceive illness and end of life issues, and can be beneficial in terms of mental and physical health and well being³⁸.

This is not reflected in UK literature which centers on a much broader definition of spirituality.

The raising of spiritual needs must come from the patient, rather than from the health care professional. Patients during their terminal times, may express their spiritual needs to talk about meanings of life, suffering and death.

Even patients who do not have specific faith (religion), may use religious vocabulary, because there is no secular language of spirituality. Religious language remains the grammar of

suffering¹, which may indicate that the majority of people who say they have no religious beliefs, are not truly secular.

In the UK literatures, a study showed most terminal patients expressed their top six spiritual needs, which are psychological in nature⁷:

- To have time to think.
- To have hope.
- To deal with unresolved issues.
- To prepare for death.
- To express true feelings without being judged.
- To speak of important relationships.

The UK standards for Hospice and Palliative Care Chaplaincy⁸, were careful to affirm the need to make available the spiritual and religious needs to all, even for those of no faith:

- Explore the individual's sense of meaning and purpose in life.
- Explore attitudes, beliefs, ideas, values and concerns about life and death issues.
- Affirm life and worth, by encouraging reminiscence about the past.
- Explore the individual's hopes and fears regarding the present and future for themselves and their families.
- Explain the way questions in relation to life, death and suffering.

One of the required skills for health care professionals is to learn companioning and listening skills³⁹ that focus on hearing the patient's spiritual dynamics, that reveal concerns and worries⁴⁰:

- Being a burden others.
- Abandoning loved ones.
- Regrets about unfinished duties and business.
- Fears of dying alone.

The carer becomes familiar with patients' needs in meditation,

contemplation, and prayers that may bring them peace and well-being⁴².

Majority of patients would like their spiritual needs addressed by health care professionals, but this is not happening in practice⁴³, inspite of the fact that spiritual care is a core component of palliative care⁴⁴.

Spirituality and Religiosity: Islamic attitudes at the end of life

At the "end-of-life" stage, Islamic teachings and guidance are based on a set of foundational beliefs, as clearly outlined in Islamic original primary sources, namely: The Qur'an and the Prophetic Tradition (*Sunnah*)⁴⁵.

This guidance forms the basis of medical and spiritual care provided to patients and their families at this terminal stage of human life which is rampant with sufferings, fears, emotions and hopes.

The first cornerstone is the belief in the one God of all, the Creator of humans and Universe. *Allah* (the Arabic equivalent to God) Has the divine attributes of glory (*Jalal*), grace (*jamal*) and immanence, yet He is loving, forgiving, merciful and very close to the human, even closer than his/her jugular vein^{45,46}:

"وَلَقَدْ خَلَقْنَا الْإِنْسَانَ وَنَعْلَمُ مَا تَشْوِشُ بِهِ نَفْسُهُ وَنَحْنُ أَقْرَبُ إِلَيْهِ
مِنْ حَبْلِ الْوَرِيدِ"

*"We created the human being, and We know what his soul whispers to him. We are nearer to him than his jugular vein"*⁴⁶.

The second concept: Allah (SWT) is the owner of everything and the ultimate of all. This concept implies that humans do not "own" their lives, health or wealth in the absolute sense⁴⁵.

The Human body is a trust from Allah (SWT). The humans ownership is temporary, a trustee-type of ownership⁴⁵. The Qur'an states that Allah (SWT) created the human being to be His trustee on earth.

"وَإِذْ قَالَ رَبُّكَ لِلْمَلَائِكَةِ إِنِّي جَاعِلٌ فِي الْأَرْضِ خَلِيفَةً قَالُوا أَتَجْعَلُ فِيهَا مَنْ يُفْسِدُ فِيهَا وَيَسْفِكُ الدِّمَاءَ وَنَحْنُ نُسَبِّحُ بِحَمْدِكَ وَنُقَدِّسُ لَكَ قَالَ إِنِّي أَعْلَمُ مَا لَا تَعْلَمُونَ"

"Behold, thy Lord said to the angels: "I will create a vicegerent on earth." They said: "Wilt Thou place therein one who will make mischief therein and shed blood?- whilst we do celebrate Thy praises and glorify Thy holy (name)?" He said: "I know what ye know not."⁴⁷

This principle of trusteeship implies a trustee is not at full liberty to make life decision such as suicide or active euthanasia, or to unjustly behave in health and wealth decisions⁴⁵.

The Qur'an is quite clear in answering universal questions pertaining to the human being, the human nature, mission on this earth, and where the human is going from here?.

"الَّذِي أَحْسَنَ كُلَّ شَيْءٍ خَلَقَهُ وَبَدَأَ خَلْقَ الْإِنْسَانِ مِنْ طِينٍ، ثُمَّ جَعَلَ نَسْلَهُ مِنْ سُلَالَةٍ مِّنْ مَّاءٍ مَّهِينٍ، ثُمَّ سَوَّاهُ وَنَفَخَ فِيهِ مِنْ رُّوحِهِ وَجَعَلَ لَكُمُ السَّمْعَ وَالْأَبْصَارَ وَالْأَفْئِدَةَ قَلِيلًا مَّا تَشْكُرُونَ"

"Such is He, the Knower of all things, hidden and open, the Exalted (in power), the Merciful";-"He Who has made everything which He has created most good: He began the creation of man with (nothing more than) clay", "And made his progeny from a quintessence of the nature of a fluid despised: "But He fashioned him in due proportion, and breathed into him something of His spirit. And He gave you (the faculties of) hearing and sight and feeling (and understanding): little thanks do ye give!"⁴⁸

Human Life, health, wealth and all resources available in this universe are means to help humans to fulfill that trust.

"وَسَخَّرَ لَكُم مَّا فِي السَّمَاوَاتِ وَمَا فِي الْأَرْضِ جَمِيعًا مِّنْهُ إِنَّ فِي ذَلِكَ لَآيَاتٍ لِّقَوْمٍ يَتَفَكَّرُونَ"

"And He has subjected to you, as from Him, all that is in the heavens and on earth: Behold, in that are Signs indeed for those who reflect"⁴⁹.

The Qur'an states that Allah (SWT) Has created death and life, to test the human as to his/her conduct in this earthy life, which is but a temporary stage of human life. The real and eternal life is the life hereafter.

"كُلُّ نَفْسٍ ذَائِقَةُ الْمَوْتِ وَإِنَّمَا تُوَفَّقُونَ تُجْرَتَكُمْ يَوْمَ الْقِيَامَةِ فَمَن زُحْزِحَ عَنِ النَّارِ وَأُدْخِلَ الْجَنَّةَ فَقَدْ فَازَ وَمَا الْحَيَاةُ الدُّنْيَا إِلَّا مَتَاعُ الْغُرُورِ"

"Every soul shall have a taste of death: And only on the Day of Judgment shall you be paid your full recompense. Only he who is saved far from the Fire and admitted to the Garden will have attained the object (of Life): For the life of this world is but goods and chattels of deception"⁵⁰.

"يَا قَوْمِ إِنَّمَا هَٰذِهِ الْحَيَاةُ الدُّنْيَا مَتَاعٌ وَإِنَّ الْآخِرَةَ هِيَ دَائِرُ الْقَرَارِ"

"O my people! This life of the present is nothing but (temporary) convenience: It is the Hereafter that is the Home that will last"⁵¹.

"الَّذِي خَلَقَ الْمَوْتَ وَالْحَيَاةَ لِيَبْلُوَكُمْ أَيُّكُمْ أَحْسَنُ عَمَلًا وَهُوَ الْعَزِيزُ الْعَلِيمُ"

"He Who created Death and Life, that He may try which of you is best in deed: and He is the Exalted in Might, Oft-Forgiving;"⁵².

The third central belief is the certainty of death, resurrection, the life hereafter, accountability before Allah (SWT), reward, forgiveness and punishment⁴⁵.

The fact that everybody is going to die is absolutely certain, even to those who do not believe in God, or are unaware about the existence of God⁴⁵.

Allah (SWT) predestines the moment and place of death for all. No one can delay or hasten his/her own death, or that of others.

"وَلَن يَجْزِيَ اللَّهُ نَفْسًا إِذَا جَاءَ أَجَلُهَا وَاللَّهُ خَبِيرٌ بِّمَا تَعْمَلُونَ"

"But to no soul will Allah grant respite when the time appointed (for it) has come; and Allah is well acquainted with (all) that ye do"⁵³.

"وَمَا كَانَ لِنَفْسٍ أَنْ تَمُوتَ إِلَّا بِإِذْنِ اللَّهِ كَتَبَهَا مُؤَجَّلًا وَمَنْ يُرِدْ ثَوَابَ الدُّنْيَا نُفُوتِهِ مِنْهَا وَمَنْ يُرِدْ ثَوَابَ الْآخِرَةِ نُفُوتِهِ مِنْهَا وَسَنَجْزِي الشَّاكِرِينَ"

"Nor can a soul die except by Allah's leave, the term being fixed as by writing. If any do desire a reward in this life, We shall give it to him; and if any do desire a reward in the Hereafter, We shall give it to him. And swiftly shall We reward those that (serve us with) gratitude"⁵⁴.

"وَلِكُلِّ أُمَّةٍ أَجَلٌ فَلِذَا حَسَاءُ أَجَلُهُمْ لَا يَسْتَأْذِنُونَ سَاعَةً وَلَا يَسْتَعْتَمُونَ"

"To every people is a term appointed: when their term is reached, not an hour can they cause delay, nor (an hour) can they advance (it in anticipation)"⁵⁵.

The Qur'an has vivid pictures of this eternal life in the hereafter:

"مَنْ عَمِلَ صَالِحًا مِمَّنْ ذَكَرْنَا يُؤْتِيهِمْ أَجْرَهُم بِأَحْسَنِ مَا كَانُوا يَعْمَلُونَ"

"Whoever works righteousness, man or woman, and has Faith, verily, to him will We give a new Life, a life that is good and pure and We will bestow on such their reward according to the best of their actions"⁵⁶.

"دَعْوَاهُمْ فِيهَا سُبْحَانَكَ اللَّهُمَّ وَتَحِيَّتُهُمْ فِيهَا سَلَامٌ وَأَخْرَجْنَاهُمْ مِنْ دَعْوَاهُمْ أَنْ الْحَمْدُ لِلَّهِ رَبِّ الْعَالَمِينَ"

"This will be) their cry therein: "Glory to Thee, O Allah." And "Peace" will be their greeting therein! and the close of their cry will be: "Praise be to Allah, the Cherisher and Sustainer of the worlds!"⁵⁷.

"تَحِيَّتُهُمْ يَوْمَ يَلْقَوْنَهُ سَلَامٌ وَأَعَدَّ لَهُمْ أَجْرًا كَرِيمًا"

"Their salutation on the Day they meet Him will be "Peace!"; and He has prepared for them a generous Reward"⁵⁸.

"قُلْ يَا عِبَادِيَ الَّذِينَ أَسْرَفُوا عَلَى أَنْفُسِهِمْ لَا تَقْنَطُوا مِنْ رَحْمَةِ اللَّهِ إِنَّ اللَّهَ يَغْفِرُ الذُّنُوبَ جَمِيعًا إِنَّهُ هُوَ الْغَفُورُ الرَّحِيمُ"

Say: "O my Servants who have transgressed against their souls! Despair not of the Mercy of Allah. for

Allah forgives all sins: for He is Oft-Forgiving, Most Merciful"⁵⁹.

This eternal life is glorified and distinguished by human dignity, forgiveness, purity, peace, love, harmony and complete absence of injustice or tyranny, as exemplified by many Qur'an verses:

"فَأَنَّا الَّذِينَ آمَنُوا بِاللَّهِ وَاعْتَصَمُوا بِهِ فَسَيُدْخِلُهُمْ فِي رَحْمَةٍ مِّنْهُ وَفَضْلٍ وَيَهْدِيهِمْ إِلَى صِرَاطٍ مُسْتَقِيمًا"

"Then those who believe in Allah, and hold fast to Him, - soon will He admit them to mercy and grace from Himself, and guide them to Himself by a straightway"⁶⁰.

"... نَكْفُرْ عَنْكُمْ سَيِّئَاتِكُمْ وَنُدْخِلْكُمْ مُدْخَلًا كَرِيمًا"

"... We shall expel out of you all the evil in you, and admit you to a gate of great honour"⁶¹.

"الْيَوْمَ نُجْزِي كُلُّ نَفْسٍ بِمَا كَسَبَتْ لَا ظُلْمَ الْيَوْمَ إِنَّ اللَّهَ سَرِيعُ الْحِسَابِ"

"That Day will every soul be requited for what it earned; no injustice will there be that Day, for Allah is Swift in taking account"⁶².

The Qur'an makes it clear that every soul shall taste death, including the greatest prophets.

That in itself is a sort of consolation and alleviation of human fear of death, and of better coping in the critical times of suffering, grief and mourning⁴⁵.

Muslim's beliefs of death and the afterlife has deep influence on patients and families' attitudes in consolation, harmonious/coping, and confidence of trust, belonging and connection to their Creator.

"هُمْ دَارُ السَّلَامِ عِنْدَ رَبِّهِمْ وَهُمْ وَلِيُّهُمْ بِمَا كَانُوا يَعْمَلُونَ"

"For them will be a home of peace in the presence of their Lord: He will be their friend, because they practised (righteousness)"⁶³.

"نَحْنُ أَوْلَاؤُكُمْ فِي الْحَيَاةِ الدُّنْيَا وَفِي الْآخِرَةِ وَلَكُمْ فِيهَا مَا تَشْتَهُي أَنْفُسُكُمْ وَلَكُمْ فِيهَا مَا تَدْعُونَ"

"We are your protectors in this life and in the Hereafter: therein shall ye have

all that your souls shall desire; therein shall ye have all that ye ask for!"⁶⁴.

A terminally ill patient who is used to performing his/her daily prayers and other acts of worship, including charity, is likely to pursue this conduct whenever and however possible, even during terminal illness, and feels more connected to his Creator with no intermediary⁴⁵.

These times are appropriate to remember certain obligations and debts for other people and work to fulfill them, either directly or through his/her advance directive.

As for the rights and obligations toward Allah (SWT), there are many divine assurances to forgive and wave them after death of the believer.

"يَا أَيُّهَا الَّذِينَ آمَنُوا عَلَى أَنْفُسِهِمْ لَا تَقْنَطُوا مِنْ رَحْمَةِ اللَّهِ إِنَّ اللَّهَ يَغْفِرُ الذُّنُوبَ جَمِيعًا إِنَّهُ هُوَ الْغَفُورُ الرَّحِيمُ"

Say: "O my Servants who have transgressed against their souls! Despair not of the Mercy of Allah. for Allah forgives all sins: for He is Oft-Forgiving, Most Merciful"⁶⁵.

The medical practitioners and all concerned in caring and counseling of terminally ill patients have leading roles to provide caring and proper communication to alleviate distressing symptoms, fear, anxiety of patients and family members, guided the above holistic Islamic guidance.

Conclusions

Spiritual care has risen in health services over the last two decades, and became an integral part of health care systems across the world particularly so in palliative care at end of life care, towards patients, their families, and their carers. This review uncovered a substantial literature on spirituality and spiritual care at the end of life issues in Western countries reaching two main conclusions.

First, there is work to be done in applying conceptual debates and theoretical models with specific illustration on end of life care in practice.

Second, there is a need for end of life care training programs at all levels to build knowledge and understanding (and by implication, confidence) in spiritual care, focusing on the rising objective of enabling more people to die at home (including care homes) for all, regardless of religion, belief, or affiliation.

On the other hand, the issues of spirituality and religiousity in the Islamic teachings and guidance towards patient's care at terminal stages of life is clearly outlined in the Islamic original primary sources namely: the Qur'an and the Prophetic Tradition (*Sunnah*) as basis of medical and spiritual care, with clear fundamental concepts of faith and outlook towards life, death and the hereafter.

Following this holistic guidance, medical practitioners and all concerned in caring and counseling of terminally ill patients, are qualified to provide communications and vision in alleviating distress, fear, anxiety and emotions of patients and families.

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THE ETHICAL, LEGAL AND ISLAMIC PERSPECTIVES ON ADVANCE MEDICAL DIRECTIVES

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Abstract

Advance medical directives emerged due to increased focus on greater patient autonomy which has now taken the forefront in medical decision making. An advance medical directive seeks to preserve a patient's right of self-determination and acts as a guide for doctors to determine medical treatment that represents the patient's values and wishes when he/she is unable to partake in the decision-making process. It not only fulfils the ethical obligation of doctors in respecting patient's autonomy, but also facilitates the application of the principle of justice in terms of managing health care resources, and helps to alleviate the psychological burden experienced by family members and health care providers. The position of advance medical directives in furtherance of these aims must thus be examined from the ethical, legal and religious perspectives, in order to properly comprehend the nature of such an instrument, and ensure its legitimacy and effective implementation in medico-legal practice.

Keywords: Advance directives; autonomy, euthanasia, DNR (Do Not Resuscitate), medical ethics, legal aspects, Islam.

Introduction

Since the turn of the 20th century, the increase in the degree of medical conditions, particularly at the end of life, has redefined the dimensions between life and death. Medical treatment and equipment are now able to prolong life expectancy of patients suffering from life-limiting illnesses, even in the absence of any brain activity. Consequently, patient autonomy has taken precedence over medical paternalism in medical decision-making, amidst the fears that one's dying phase would be suspended indefinitely by medical interventions. Advance medical directives were developed as a response to address this concern, providing a means for patients to preserve their right to self-determination in situations where they might lose the ability to decide

on the course of their medical treatment. As an embodiment of a patient's anticipatory medical decisions, as well as his or her values in relation thereto, advance medical directives not only enhance patient autonomy, but also serve to facilitate doctors in performing their ethical obligations towards the patient at a time when the latter might not be able to participate in the decision-making process. The development of advance medical directives is seen to be more prominent in its place of origin, that is, the United States than other parts of the world. In most countries, particularly Malaysia, the use of advance medical directives is still in its infancy, and no legislative instrument exists to specifically address the matter.

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Definition of Advance Medical Directives

Advance medical directives are oral or written statements made by persons while they are competent, pertaining to future medical treatments in the event that they become incapable of decision-making when the need arises. They consist of anticipatory instructions and decisions as to the extent of treatment in which a person agrees or refuses to receive, the circumstances in which treatment may or may not be provided and may also include the appointment of a proxy who is authorised to make health care decisions on the person's behalf¹. The discussion process between doctor and patient, which may also include family members, to develop and document a valid projection of the patient's wishes with regard to the type of medical care in situations where he/she becomes unable to communicate, is referred to as advanced care planning². Proper advanced care planning, which includes the formulation of advance medical directives, serves to enhance patient autonomy as it entails the consequential involvement of the patient in expressing and validating his values and wishes in anticipation of a situation where he might lose his decision-making capacity. It stems from the theoretical rationale that if patients have the right to refuse treatment even when such refusal might endanger their lives, then they should be entitled to exercise the same right when they become incompetent, which is facilitated by the use of advance medical directives³.

Types of Advance Medical Directives

There are two types of advance medical directives:

(i) Living will

Advance medical directives usually take the form of a living will. A living will, also described as an "anticipatory decision"⁴, is a list of preferences and instructions expressed by a person in respect to the type of treatment that

should or should not be provided to him/her in different circumstances⁵. It allows people to indicate and document their wishes in advance as to how they would want their medical care to be carried out, in the event that they lack the competency to decide in the future. For example, a person may express his/her refusal to receive cardiopulmonary resuscitation or blood transfusion, or request for life-sustaining treatment such as a respiratory ventilator to be withheld or withdrawn. In order for a living will to be implemented, it is sufficient to have proof that it was indeed made by the person himself. Therefore it needs not necessarily require endorsement by a third party, although a verification by the doctor and/or attestation by family members may indeed serve to further affirm the reliability of the document.

(ii) Lasting power of attorney

A lasting or continuing power of attorney, also referred to as a "durable power of attorney for health care", "health-care proxy", or "medical treatment attorney" is an instrument that allows a person to appoint a surrogate or proxy who is authorised to decide on his behalf on health care matters should he lose the ability to do so.³ This legal document takes effect only when the person appointing, that is, the donor becomes incompetent and no longer has the capacity to decide for himself.¹ Due to the scope and nature of such an appointment, it is important that the person appointed i.e. the health care proxy to be someone who is very familiar with the values and wishes of the donor⁵. The difference between a living will and a lasting power of attorney is that while the former is an expression of the patient's wishes and preferences, a lasting power of attorney allows the appointed health care proxy to replace the incapacitated donor in the medical

decision-making process. Thus, it is suggested that an effective way to ensure that an advance directive serves a two-fold purpose is by integrating a lasting power of attorney into the living will⁶.

Circumstances in which Advance Medical Directives are Applicable

Since advance medical directives are the manifestation and extension of a patient's autonomous choices when he/she is unable to make decisions pertaining to his/her medical care, the circumstances in which advance directives are operative are very much related to the issue of capacity. Doctors may have recourse to an advance medical directive to determine the course of medical treatment for a patient who does not have the capacity to consent or refuse. This may include situations where the patient's ability to decide is impaired by a temporary loss of consciousness^{7,8}, or when the patient becomes insensate or is in a vegetative state due to a severe injury or terminal illness⁹. Some experts contend that the full measure of autonomy is also compromised in patients with serious illness although they may still possess basic decision-making capacity¹⁰⁻¹³. Factors such as pain, systemic weakness, delirium, depression and anxiety could distort the cognitive function of terminally ill patients, and impair their ability and perception to make autonomous decisions¹². An advance medical directive may also be applicable in cases where the patient suffers from a mental disorder such as dementia¹⁴ and schizophrenia⁸.

The Ethical Perspective on Advance Medical Directives

Autonomy, which is synonymous with self-determination, is one of the important bioethical principles in medical practice¹⁵. The word autonomy is derived from Greek terms, *autos* (the ability to decide by oneself) and *nomos* (governance or the law to which one complies)¹⁶. An individual is

capable of determining his own life in accordance with his values, goals and beliefs. In health this refers to a special form of personal liberty, where individuals are free to choose and implement their own decisions, free from deceit, duress, constraint and coercion. Therefore, it is the fundamental right of the patient to conduct and manage his own affairs, including the decision about what should be done with his body¹⁶. Where medical treatment is concerned, patients' preferences are to be given pre-eminence since medical decisions reflect value judgments, and patients are therefore the best authority to decide their own values and goals rather than doctors^{12,17}. The doctor-patient covenant will be seriously breached if the doctor offers medical procedures that conflict with the patient's values¹³. Respect for autonomy or the right to self-determination constitutes an important precept in ethical medical conduct, and thus the doctor "may not restrict nor negate the free wishes of an individual with respect to his/her own body...one must facilitate any desired action acceptable to a person's own judgment and in accordance with his/her own choice"¹⁵. Accordingly, to infringe a patient's autonomy is "to deprive him of one essential component of his own good"¹⁸ and this violates the aim of medicine to act for the good of the patient¹⁸. This is further reiterated in the Patient's Charter issued by the Malaysian Medical Association, which lists the rights of patients to include the "Right to Choice of Care" under Clause II: "A patient shall have the right to know the investigations conducted, the results of these investigations and a copy of the medical reports and have them explained. The patient shall also have the right to authorize in writing another health professional to obtain a copy of the same and inform him or her of what they contain. *A patient who has received adequate information about his or her condition during consultation shall have the right to accept or to refuse treatment*".

A similar obligation to respect patient autonomy is also highlighted in Clause 1.1 of the Malaysian Code of Professional Conduct for Nurses. A nurse is to work co-operatively with patients and their families and should respect decisions about a patient's care and maintain informed consent in the provision of nursing care to all patients. If a patient refuses treatment, it is the duty of a nurse to continue to provide the necessary support.

It follows that since an advance medical directive is representative of a patient's wishes, it is incumbent on doctors to respect and abide by the content of the advance medical directive. By doing so, and doctors would be acting ethically in terms of respecting the patient's right to self-determination. However, respect for autonomy does not entirely necessitate complete discretion at the hands of the patient. Information sharing and discussions between the parties involved in the patient's care facilitate ethical decision making and concomitantly enhance patient autonomy. It is to be noted that doctors have a moral obligation that may outweigh their duty to respect a patient's wishes, particularly where end-of-life decisions are concerned¹²; a doctor's obligation to his patient extends beyond the prevention of harm, and includes restoration and improvement of the quality of life¹⁸. Further, patients' preferences are not decisive unless a beneficial medical perspective is present¹⁷. Therefore, doctors are not obliged to honour requests for interventions that confer no medical benefit to the patient or treatments that would expose the patient to more harm than good, as this would constitute a direct violation of the values of the medical profession, and a disrespect towards the concept of patient autonomy^{13,17}. Some ethicists argue that doctors should not encourage active participation by the patient in technical aspects of medical decisions and non-beneficial interventions should not even be offered in the first place, as this would "promote the appearance of autonomy when in fact the patient may be harmed"¹³.

Correspondingly, it has been largely advocated that a patient's right to autonomy does not extend to even more complex situations such as assistance in dying^{12,19}. It is considered unethical for doctors to undermine their commitment to professional integrity, at the core of which stands their moral obligation to primarily protect the patients' best interests, by succumbing to a patient's request to die. Although such refusal to accede to the patient's wishes may be seen as an infraction to the patient's individual liberty, it is argued that terminating one's life is in fact antithetical to his right to wilful and free consent as it puts an end to the possibility of the patient's right to exercise autonomy^{19,20}.

The Legal Perspective on Advance Medical Directives

In Malaysia, the use of advance medical directives is a novel concept, which could be primarily attributable to the cultural conditions and lack of exposure on the subject matter among the local communities. In a local study conducted by *Htut, Shahrul* and *Poi* on advance directives and advance care planning, it was found that none of the respondents had heard of advance directives or advance care planning². The majority were also hesitant to decide on issues relating to future medical care due to religious reasons and were of the view it was premature or unnecessary to formally decide on related matters. In recent years however, issues regarding its importance and calls by the medical community for increased awareness as well as the wider implementation of advance care planning made local newspaper headlines. Malaysian doctors have voiced the need for advance directives to assist them in managing their patients in a more effective manner, especially in dealing with disputes among family members as to what would be the best course of action for the patient²¹. There are also calls from religious groups in Malaysia for proper guidelines be issued in respect of advance directives and the right of

family members to decide on a patient's behalf²². Concomitantly, the legal fraternity have acknowledged the evident need for advance directives or living wills to be recognised as a legally binding instrument, although at this point of time a proper legal pathway has yet to be developed to integrate it into the structure of Malaysian legal practice²³.

Currently, there is no regulatory instrument that specifically addresses the issue of advance care planning or advance medical directives in Malaysia. General mention is made under Clause 5 of Section II of the Code of Medical Ethics of the Malaysian Medical Association ("CME"), which states that in the case of a dying patient, "one should always take into consideration any advance directives and the wishes of the family in this regard." The CME also makes reference to numerous declarations and statements made by international bodies such as the World Medical Association (WMA), the World Psychiatry Association and the United Nations in Appendix IV. The WMA Declaration of Venice on Terminal Illness for example, recognizes the right of patients to develop advance medical directives that describe their preferences regarding medical care in the event that they are unable to communicate and the designation of a substitute decision-maker to make decisions that are not expressed in the advance medical directive²⁴. It also highlights the importance of advance care planning, particularly, with respect to life-sustaining treatment and palliative measures that might hasten death.

It is clear from the CME that doctors must give precedence to advance medical directives, in deciding whether a particular medical treatment is to be administered during the patient's incapacitated state. The obligation to abide by a patient's wishes and preferences is accordingly subject to the condition that the advance medical directive in question must be valid, which as previously discussed, necessitates determination of the patient's competency. This is reflected in the guideline on

"Consent for Treatment of Patients by Registered Medical Practitioners" issued by the Malaysian Medical Council ("Consent Guideline")²⁵. The relevant details under clause 18 ("Advance Care Directives (or Living Wills)" of the Consent Guideline can be summarised as follows:

- (a) A doctor must comply with an unequivocal refusal to treatment in a patient's written directive in the circumstances specified therein;
- (b) A doctor must not comply with an advance directive that contains instructions that are unlawful such as euthanasia or the termination of pregnancy;
- (c) A doctor should determine the validity of an advance directive by considering the following factors:
 - (i) Whether it is sufficiently clear and specific to apply to the clinical circumstances which have arisen;
 - (ii) Whether it can be said to have been made in contemplation of the current circumstances (for example, whether the directive was made before or after the diagnosis of the current illness); and
 - (iii) Whether there is any reason to doubt the patient's competence at the time that the directive was made, or whether there was any undue pressure on the patient to make the directive;
- (d) If the doctor is in doubt about the validity of an advance directive, he should consult the patient's spouse or next of kin, and the doctor should also consider the need to seek legal advice and to discuss the issue with his or other clinicians involved in the patient's care;
- (e) In emergency cases, the doctor can treat the patient in accordance with his professional judgment of the patient's best interests until legal advice can be obtained on the validity or scope of the patient's advance directives.

The Consent Guideline however does not address all relevant aspects pertaining to advance directives such as the considerations in ascertaining the patient's competency and best interests. It is accordingly unclear how these guidelines can be effectively carried out in practice by Malaysian doctors in terms of seeking legal advice as to the validity of an advance directive, having regard to the paucity of clear, precise and enforceable legal standards on the matter.

As there are no specific guidelines or legislation governing the validity of advance directives under Malaysian law, the principles of common law may be applied in order to determine its legality. This is due to the fact that the right to determine what shall be done with one's own body is a basic human right firmly entrenched in and protected by the common law, upon which Malaysian medical law is based. The reliance on the common law is attributable to the fact that Malaysia inherits much of its legal system from the common law in England, having been under British colonial rule in the 19th and 20th centuries. The prevailing influence of the laws of England is codified in section 3 of the Malaysian Civil Law Act 1956, which states that Malaysian courts shall apply the common law of England and rules of equity where no provision on the matter has been made by any written law in Malaysia. It is an established principle in common law that it is unlawful for doctors to administer treatment to a competent adult unless the latter has validly consented to such treatment. A doctor, who proceeds to do so without the consent of an adult of sound mind would be committing battery. The patient's right to choose is accordingly "not limited to decisions which others might regard as sensible". It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent"⁷. Likewise, this principle covers refusals to treatment; a competent patient has the right, either for rational or irrational reasons or for no reason at all, to refuse any

medical intervention, even though the consequence of such decision may lead to his death²⁶.

The validity of an advance medical directive which may include patient's consent or refusal to medical treatment essentially rests on whether he/she did so upon being properly informed²⁷⁻²⁹, that it was done voluntarily⁷, and whether he possessed the capacity to make the decision at the time when it was made. In *Re T (Adult: Refusal of Treatment)*⁷, the test of competency as laid down by the House of Lords necessitated the following conditions to be fulfilled: at the time when the decision was made, (1) the patient must have had the legal capacity and possessed the requisite competence to consent or refuse treatment. In other words, the patient must be an adult and must not suffer from any impairment that may undermine his ability to make up his own mind. It is important to note that a person with reduced capacity does not however *ipso facto* render him incapable of making a decision as to the treatment in question. Doctors must consider whether the patient had a capacity which was commensurable to the gravity of the decision which he purported to make; (2) the patient must have been aware and intended for the scope and basis of his consent to be applicable in that particular situation. In the *Bland* case⁹, the court drew attention to the need for special care in ensuring that a prior anticipatory refusal could still be regarded as relevant to the situation at hand; and (3) the patient must have known the nature, purpose and effect of the treatment to which he is consenting. This third element was further clarified in *Re C (Adult: Refusal of Medical Treatment)*⁸; in order to determine whether the patient has sufficient understanding. It must first be proven that he understood and is able to retain the information given pertaining to the treatment; secondly, that the patient believes it, and thirdly, that the patient is able to internalise and weigh such information by balancing the need for such treatment with

the risks that may be involved, before making a choice.

The conditions of a valid consent as set out above are therefore applicable in determining the legitimacy of an advance medical directive that is, whether the person making the advance directive was provided the necessary information and was indeed competent at the time when he expressed his preferences. In the event that the person does not satisfy the aforementioned criteria for competency, his advance medical directive will not be valid and therefore any act or decision pertaining to the person's medical treatment during his period of incapacity must be made in his best interests. Originally, under the common law, the courts applied the same standard in the *Bolam*³⁰ test that was used to determine the standard of reasonable care in cases of medical negligence, in ascertaining a patient's best interests. This classical assessment provides that a doctor would have acted in the best interests of his patient if his actions were in accordance with a practice accepted as proper by a responsible body of medical men skilled in that particular form of treatment. The House of Lords in *Re F (Mental Patient: Sterilisation)*³¹ adopted the test in relation to the power vested in the court to make a declaration regarding health care decisions on behalf of an incapacitated adult. The judgment in *Bland*⁹ indicated however, that the formulation in *Bolam* by itself was not an adequate basis and the decision-making process should encompass wider considerations, particularly in the case of persistent vegetative state (PVS) patients.

Consequently, the English courts began to recognise that the benchmark in the *Bolam* test could not be applied for determining "best interests" as it was confined to medical interests, which led to a shift in the legal landscape on the subject matter. In *Re MB (An Adult: Medical Treatment)*²⁶, it was held that the test of a patient's best interests was not limited to best medical interests and should be broadened to include a welfare-based assessment. This formulation was

applied in *Re A (Medical Treatment: Male Sterilisation)*³² and subsequently *Re SL (Adult Patient: Medical Treatment)*³³. The Court of Appeals in the latter case expressed in its judgement that in deciding what would be best for an incapacitated patient, the test should encompass issues that were far wider than medical interests, and that paramount importance had to be given to the welfare of such patient. The notion that the principle of best interests extended beyond the elements set out in the *Bolam* test was reiterated in *Re S (Adult Patient: Sterilisation)*³⁴. It was held that judicial opinion must incorporate "broader ethical, social, moral and welfare considerations", and that in cases where a declaration is sought by health care practitioners as to the legality of a proposed treatment, it is for the judge (rather than doctors) to decide whether such treatment would be in the patient's best interests.

The Islamic Perspective on Advance Medical Directives

For Muslim patients, even though the importance of patient autonomy is duly recognized in Islamic law, the advancement of this concept is not without its limitations as it has to be applied within the parameters of the religion. The right and ability to make their own choices and decisions about medical care and treatment for Muslims must be within the defined limitations of the *Shari'ah*. The *Shari'ah*, or Islamic law, is based on two primary sources, the *Qur'an* and the *Sunnah* of the Prophet (ﷺ). In the absence of any direct ruling on a specific matter in the primary sources, Islamic jurisprudence allows for the application of *ijtihad*, generally translated as deductive reasoning. The guiding principles, rules and regulations in the main sources govern all aspects of the Islamic way of life, and together with *ijtihad*, provide a comprehensive moral and juridical framework to address and resolve issues relating to human conditions. It prescribes for a balanced way of life in both its materialistic and spiritual aspects, which is

firmly based on the concept of monotheism i.e. belief in the Oneness of Allah (SWT)³⁵. In Islamic jurisprudence, each deliberation towards resolving any given issue must be consistent with and founded upon the principles laid down in the *Glorious Qur'an* and the *Sunnah*, and accordingly observe the fundamental objectives of the *Shari'ah*, which are properly known as *maqāsid al-Shari'ah*. These comprise the protection of one's faith and belief, preservation of life, protection of progeny, maintenance of intellect, and preservation of property or wealth³⁶.

Islam upholds the sanctity of life and places the priority of protecting and maintaining life only second to the preservation and safeguarding of religion. Accordingly, the sanctity of life forms the substratum of Islamic bioethics. The importance of this principle has been mentioned and emphasized numerous times in the *Glorious Qur'an* and *Hadith* of the Prophet (ﷺ) where it is ordained that life and death is strictly an exclusive prerogative that belongs to Allah (ﷻ) and that life cannot be taken away except by His Will. For example:

"...فَإِذَا جَاءَ أَجْلُهُمْ لَا يَسْتَأْذِنُونَ سَاعَةً وَلَا يَسْتَقْدِمُونَ"

"And when their term has come, they will not remain behind an hour, nor will they precede [it]"³⁷; and

"وَمَا كَانَ لِنَفْسٍ أَنْ تَمُوتَ إِلَّا بِإِذْنِ اللَّهِ كَيْتَابًا مُّجَرَّدًا..."

"and it is not [possible] for one to die except by permission of Allah at a decree determined"³⁸.

It is accordingly forbidden for anyone to deliberately end a life, either his own or that of another; to intentionally commit any act which threatens and violates the sanctity of life is to blatantly defy the will of Allah and would place the wrongdoer in grave sin. This is stated in the following Qur'anic verses:

"وَلَا تَقْتُلُوا النَّفْسَ الَّتِي حَرَّمَ اللَّهُ إِلَّا بِالْحَقِّ..."

"Do not take life, which Allah made sacred, other than in the course of justice"³⁹; and

"...مَنْ قَتَلَ نَفْسًا بِغَيْرِ نَفْسٍ أَوْ فَسَادٍ فِي الْأَرْضِ فَكَأَنَّمَا قَتَلَ النَّاسَ جَمِيعًا وَمَنْ أُخْيَاهَا فَكَأَنَّمَا أَحْيَا النَّاسَ جَمِيعًا..."

"Whoever kills a soul unless for a soul or for corruption [done] in the land - it is as if he had slain the entire mankind. And whoever saves one - it is as if he had saved the entire mankind"⁴⁰.

The inviolability principle is accordingly substantiated in several *Ahadith*. The absolute prohibition and severity of consequences upon committing suicide and murder are illustrated in the following narrations:

"It was narrated by *Thabit bin al-Dahhak* that the Prophet (ﷺ) said, "...And whoever commits suicide with piece of iron will be punished with the same piece of iron in the Hell Fire"⁴¹. In the same *Hadith*, it was narrated by *Jundab* that the Prophet (ﷺ) said, "A man was inflicted with wounds and he committed suicide, and so Allah said: My slave has caused death on himself hurriedly, so I forbid Paradise for him".

The above authorities cited from the *Glorious Qur'an* and the *Hadith* are examples of clear evidences on the Islamic viewpoint towards the sanctity of human life. Islam values life and regards it to be sacred, acknowledging it as a gift from God that must be treated with the highest respect. Accordingly, Islam forbids the infliction of harm and intentional killing of a person; the commission of suicide and murder are considered to be major sins which are heavily punished in this world and the Hereafter. Thus, a Muslim patient cannot refuse medical treatment if such voluntary refusal is done for the purpose of committing suicide. Likewise, killing a person to ease his suffering even though it is at the request of the person is strictly prohibited by Islamic law.

The bioethical principles of autonomy, beneficence, non-maleficence and distributive justice which form the fundamentals of Western bioethics are similarly imbued in the Islamic precepts relating to medicine. While there are many similarities in the approach adopted by the Western and Islamic systems, there exist

some notable differences between the two models with regard to the application of patient autonomy. Such differences emanate from the disparate sources that form the substratum of Western and Islamic bioethics respectively. As highlighted in the preceding paragraphs, the Islamic model is derived from a divine order, from which moral principles applicable to medicine are acknowledged and legislated. The Western concept is on the other hand secular and primarily drawn from human reason and experience, and there exist variable ethical theories on the validity of moral cognition.¹⁵ Autonomy is recognised and held high in Islamic teachings in that no one is entitled to dispose of the right of an individual without the latter's permission^{19,42,43}. However, the right to autonomy in Islam including the refusal of medical treatment is not absolute and is qualified in the following respects:

- (1) **Decision making must concede and be based on knowledge.** Autonomy can only be exercised if the patient participates in the decision-making process with the ability to understand and make intelligent decisions,¹⁹ following an informed discussion with his doctor. If there is a prevailing standpoint on the matter in Islam, the doctor and the patient are obliged to comply and act accordingly with it,⁴² overriding any conflicting preference that they may personally have;
- (2) **Public interests supersede individual considerations.** In Islam, individual welfare is intrinsically connected to one's family and community^{35,44}. A person's freedom of choice is thus contingent upon the responsibilities that he has towards others; to form an ethical decision, there must accordingly be a balance between the right of the individual, the wishes of family members and the concerns of society as a whole¹⁹. This is in accordance with the principle of *istislah*, which is one of the methods applied in Islamic jurisprudence to seek the best solution

in order to serve the general interest of the community;

- (3) **Limitations of autonomy in end-of-life decisions.** In cases of active euthanasia, the Islamic position on the sanctity of life makes it clear that there can be no concept of free consent and personal liberty⁴⁵. Where other aspects of end-of-life decisions are concerned, such as withdrawal and withholding of futile treatments, apart from the principle of *istislah*, the Islamic legal maxim, "no harm shall be inflicted or reciprocated"⁴⁶ governs the approach to autonomy. Islam thus holds it permissible for doctors to withhold or withdraw treatment which are harmful, non-beneficial and futile⁴⁷. In such situations, the decision should not be an individually autonomous decision, but rather one which is jointly made pursuant to discussions between all of those concerned, such as the medical team, the patient, his family members, and at times religious authorities^{19,44,48}.
- (4) **Obedience towards God supersedes the obligation to respect patient's wishes.** The general philosophy in Islamic medicine is that God is the Ultimate Healer and the doctor is the instrument that God uses to treat people and alleviate suffering.^{19,49,45} The doctor-patient relationship therefore takes on a more meaningful dimension than the Western model; in Islam a doctor is not only accountable to the patient in the performance of his duties, but more importantly, is answerable to God for his actions.⁴⁹ Therefore, he cannot use patient autonomy as a justification to commit that which is forbidden in Islam⁴⁵, for example to commit or assist a patient in active euthanasia; and
- (5) **Duties of beneficence and non-maleficence may in certain situations take precedence over autonomy.** It is the duty of a doctor to do what is in the best interests of the patient as a

whole and prevent the patient from harm. In emergency cases for example, doctors are allowed to proceed with treatment or interference to save the patient's life although it may be against the patient's wishes, as long as they follow the proper medical procedures. The justification of such course of action is explained in the Islamic Code of Medical Ethics⁴⁵:

"The 'bad' inherent in not saving the patient outweighs the presumptive 'good' in leaving him to his self-destructive decision.

The Islamic rule proclaims that 'warding off' the 'bad' takes priority over bringing about the 'good'.

The Prophetic guidance is "Help your brother when he is right and when he is wrong". When concurring with helping a brother if right but surprised at helping him when wrong, the Prophet (ﷺ) answered his companions: "Forbid him from being wrong...for this is the help he is in need of".

A doctor may also in exercising his duties of beneficence and non-maleficence, refuse to accede to the request of a patient to administer therapy that would be futile.³⁵ Further, in Islam, individual liberty "is constrained by the harm it causes others",^{19,35} which substantiates the subservience of autonomy to non-maleficence in certain cases. To this end, guided paternalism is required in certain respects to ensure that the best interests of the patient and society at large are preserved.

In the case of incompetent patients i.e. those who are unable to provide consent for medical treatment, the consent of their next of kin or legal guardian is an imperative consideration in Islam. This is based on the concept of *wali* (guardian) in Islam, which is mentioned in the following Qur'anic verse:

"وَابْتَلُوا الْيَتَامَىٰ حَتَّىٰ إِذَا بَلَغُوا النِّكَاحَ فَإِنْ آنَسْتُمْ مِنْهُمْ رُشْدًا فَادْفَعُوا إِلَيْهِمْ أَمْوَالَهُمْ وَلَا تَأْكُلُوهَا إِسْرَافًا وَبِدَارًا أَنْ يَكْبَرُوا وَمَنْ كَانَ غَنِيًّا فَلْيَسْتَعِظْ وَمَنْ كَانَ فَقِيرًا فَلْيَأْكُلْ بِالْمَعْرُوفِ فَإِذَا دَفَعْتُمْ إِلَيْهِمْ أَمْوَالَهُمْ فَأَشْهَدُوا عَلَيْهِمْ وَكَفَىٰ بِٱللَّهِ حَسِيبًا"

*"And test the orphans [in their abilities] until they reach marriageable age. Then if you perceive in them sound judgement, release their property to them. And do not consume it excessively and quickly, [anticipating] that they will grow up. And whoever, [when acting as guardian], is self-sufficient should refrain [from taking a fee]; and whoever is poor - let him take according to what is acceptable. Then when you release their property to them, bring witnesses upon them. And sufficient is Allah as Accountant"*⁵⁰.

This ruling concerning the guardianship of a child's property is equally applicable to medical treatment and other cases involving patients who are incapable of partaking in decision making. Accordingly, at the 23rd session of the Council of Senior Scholars in Riyadh, it was unanimously decided that "it is not permissible to operate on a patient without his or her permission provided the patient is pubescent and sane, whether the patient is male or female. If the patient is not of age or insane, the permission of their *wali* (guardian) must be obtained"⁵¹. It is incumbent upon a *wali* to carry out his or her responsibilities in the best interests of his or her ward. In this respect, the opinion and recommendation of doctors are of paramount importance in determining what would be in the best interests of an incompetent patient, and thus there is an evident need for medical experts to be consulted in each situation³⁵. If the *wali* refuses to consent to medical treatment and such refusal is detrimental to the latter, then the *wali*'s decision shall not be taken into account. In such a case, the right of permission will be transferred to the next *wali* and ultimately to the ruler of the Islamic state⁵² (in modern practice this would be a court of law).

In terms of the validity of advance medical directives, some jurists have contended that

the concept is consistent with Islamic teachings and was practised even at the time of the Prophet (ﷺ). When the Prophet (ﷺ) became terminally ill, there were times in which he would lose consciousness. In one such occasion, his companions tried to force feed him medicine, pursuant to which the Prophet (ﷺ) indicated his disapproval by waving his hand at them. When the Prophet (ﷺ) came to his senses, he reproached the companions and voiced his displeasure at their actions⁵³. The following principles can thus be derived from this *Hadith*: (a) A patient's right of autonomy must be respected; (b) It is permitted for a patient to refuse treatment particularly at the end of life and when such treatment would be futile; and (c) Islam recognises the effect of an anticipatory refusal and doctors should give effect to the patient's wishes⁴⁷. Accordingly, the issuance of advance directives are incorporated in the recommendations made by the Islamic Medical Association of North America (IMANA) for the health care of Muslim patients⁵⁴. The IMANA Ethics Committee also endorses the appointment of a case manager to assist doctors in clarifying and carrying out the wishes of patients who are unable to partake in the decision-making process relating to their care. Further, consistent with the limitations of patient autonomy, the purport and content of an advance medical directive cannot be antithetical to Islamic principles.

Another approach to advance medical directives is that the validity of any pre-emptive refusal to treatment is subject to the approval of the patient's *wali* upon obtaining the opinion and advice of doctors⁵⁵. Proponents of such a view have based this on the role of the *wali* expounded in the Glorious Qur'an; they accordingly argue that during a period of incapacity, the *wali* is conferred the right to decide on behalf of the patient, and this cannot be overridden by the issuance of an advance medical directive. It is nevertheless

submitted that this does not negate the importance of an advance medical directive in helping doctors to respect the patient's wishes and decide on the most viable medical course of action. The appointment of a patient's *wali* as the case manager in the preparation and implementation of the patient's advance medical directives fulfils both the Islamic role and responsibility to be undertaken by a *wali* on behalf of his incompetent ward, as well as the obligation to respect the patient's wishes regarding his medical treatment. Further, Islam does not give unqualified power to a *wali*; a *wali* is duty-bound to act in the best interests of the patient, and this is achieved through consultation and a mutual decision-making process with medical experts.

Conclusions

Evidently, the most challenging aspect for the effective implementation of advance care planning and advance medical directives is the lack of knowledge and understanding of the subject matter not only on the part of those on the receiving end of health care, but also those involved in the provision of medical services. This makes it difficult for advance medical directives to be made part of a patient's medical routine. Although advance care planning is a process that should be initiated earlier when the patient is healthy, many medical practitioners affiliate advance medical directives with medical crises and thus discussions take place when the patient may not be in the right frame of mind to make important decisions concerning his treatment preferences should he lose the capacity to consent¹. Another difficulty is that even though the patient may have executed a valid advance medical directive, the doctor or family members may not be able to trace where it is located in order to identify the patient's actual wishes when the need arises^{1,56,57}. Accordingly, there is an apparent need to establish legal standards and proper rules of conduct in order to address the various issues pertaining to

advance medical directives. It is submitted that this is best addressed by means of statutory reform, supported by other regulatory instruments such as practice guidelines. This will accord proper direction to both doctors and patients in formulating advance medical directives and guide doctors in its proper implementation. Legislating the use of advance medical directives will thus provide assurance to doctors that their actions in relation thereto are ethically and legally valid, and operate as a safeguard in the preservation of a patient's autonomous rights and best interests during both periods of competency and incapacity, thus preventing potential abuse.

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THE PATIENT'S RIGHT TO ACCEPT OR DECLINE THERAPY- INFORMED CONSENT

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Abstract

The ethical doctrines of respect for autonomy and self-determination raises the question of the extent to which current legal norms are consonant with Islamic theology. . Recent trends in the understanding of informed consent imply a shared decision by both physician and the patient that serves the patient's best interests. It also acknowledges the essential contributions from other segments of society including religious perspectives. Basic human rights are guaranteed in every political system, and the rights of patients are specifically assured by governments and healthcare institutions. In the Islamic context, the patients' rights are safeguarded in *Shari'ah*. It is the fiduciary duty of the physician to provide the patient with the material facts that will empower him to make an informed choice.

Islam emphasizes the ethical facets of healthcare, protecting the patient's rights and privileges and similarly highlighting the patient's responsibilities. The limitations of informed consent and the right to agree or refuse a diagnostic, therapeutic or research proposal by a caregiver are well defined in Islam. This is part of a holistic health care system which addresses the physical, emotional, moral and spiritual aspects of humanity.

This article addresses the Islamic *Shari'ah* guidance pertaining to the patients' right to accept or decline diagnostic and therapeutic procedures, and to bear the responsibilities associated with them.

Keywords: Human rights, ethics, humanism, professionalism, culture, Islam, Shari'ah, informed consent.

Introduction

Basic human rights are moral principles or rules, which describe certain ethics of human behavior, and are regularly protected as legal rights by national and international law. These rights are commonly implicit as inalienable fundamental privileges "to which a person is inherently entitled, simply because he/she is a human being". These rights also imply that all human beings are born free and equal in dignity and rights. The first document entirely

dedicated to Human Rights was issued by the United Nations in 1948, that was called "Universal Declaration on Human Rights"¹.

Human Rights were identified, implemented and stressed in Islamic *Shari'ah*, over 1400 years ago, 700 years before the appearance of the first western human rights document. Since human rights are conferred by Allah (ﷻ), they are permanent.

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On the other hand, rights granted by governments, or authorities can be withdrawn in the same way they are conferred². They can confer them when they please, withdraw them when they wish; and openly violate them when they like. In Islamic *Shari'ah*, none has the right to abrogate or withdraw the rights bestowed by Allah (ﷻ).

In the International Islamic Code for Medical and Health Ethics, the general juridical rules have confirmed the principles of patient autonomy based on the *fiqhi* rules³:

-The right of a human being cannot be disposed of, or relinquished without his/her permission.

-Man's rights cannot be nullified without his consent.

Autonomy: Right to accept or refuse therapy

One of the fundamental rights of any patient is the right to accept or refuse the proposed diagnostic or therapeutic procedure offered by health care providers⁴.

This notwithstanding clear, concise explanation of his/her condition, proposed interventions, mortality, risks, problems related to convalescence, and the probability of success⁵. The patient or his/her legally authorized representative should not be subjected to any intervention without his/her voluntary, competent, and informed consent. Where medically significant alternatives for proposed care or treatment exists, the patient shall be so informed and the treating physician's preferences⁶. The patient may refuse treatment to the extent permitted by law. When refusal of treatment by the patient or his/her legally authorized representative without duress, deception or exploitation prevents the provision of appropriate care in accordance with ethical and professional standards, the relationship with the patient may be terminated upon reasonable notice⁷. These rules are not absolute and exceptions

are permitted in life threatening conditions, where the law allows the physician when the patient or relatives are unable to provide the consent, to proceed with appropriate treatment. When the patient is unconscious or is determined to be mentally incompetent and no consent can be obtained from an appropriate family member, a court order may be obtained for diagnostic and therapeutic procedures⁸.

The patient's right to determine his or her treatment is fundamental and reflects our respect for the autonomy of the individual. However, a strict adherence to the principle of autonomy can be problematic when patients appear to be cognitively competent but unable to make use of the information because of their emotional state⁹. It is essential not to abandon these patients but to work closely with them in determining why they are making decisions that do not appear to be promoting their wellbeing. This exploration, combined with ongoing education by all members of the health care team, is fittingly desirable¹⁰. Further research is required on the concept of competence to determine how it could be broadened to include emotional factors.

According to Islamic teachings, though the importance of patient autonomy is duly recognized, the advancement of this concept is not without its limitations as it must evolve within the perimeters of *Shari'ah*. The importance of individualism, personal gratification and the denial of faith in medical decision-making is inconsistent with Islamic values^{10,11}. From the Islamic perspective, autonomy represents one of the four basic principles often used in analyzing ethical issues in medicine. The others are beneficence, non-maleficence, and justice.

Failure of the treating physician to secure the informed consent of the patient, or his/her legal representative/guardian is considered as one form of medical negligence, and represents grounds for retribution (*daman*),

for any complication that results thereby. Other forms of disciplinary actions would also be imposed¹².

There are exceptions to this rule and these must be clearly understood by the treating physician. They should not be used merely to seek exceptions or excuses for not providing sufficient information to the patient before asking permission in the language the patient can properly comprehend¹³. The exceptions include an emergency situation, where the doctor may provide immediate treatment, but only to overcome the emergency, which, again, is defined as "an imminent danger to self or others¹⁴". Whatever treatment provided in the emergency setting cannot be continued after the immediate danger has passed, unless the patient agrees and gives informed consent, the patient has the right to decide whether to continue or not¹⁵.

One must be aware that the treatment provided in an emergency is vital for safety and recovery and the benefits of treatment far outweigh the risks. Even then, in certain conditions a court order may be required to continue the treatment process in the best interest of the patient¹⁶, provided that the delay should not jeopardize the patient's condition. The exception to the rule will also prevail in the care of the mentally sick who are incompetent to accord permission, care of minors, unconscious and unknown subjects brought to the emergency room without any accompanying next of kin or legal guardian¹⁷. Refusal of therapy based on religious beliefs, such as when a Jehovah's Witness, refuses a blood transfusion, could potentially lead to death¹⁸. He can refuse if his decision is free and informed. A Muslim can refuse *Haram* (not permissible) ingredients of a drug, particularly when *Halal* (permissible) substitutes are available¹⁹. In the case of absolute necessity, where *Halal* alternatives do not exist, Islamic teachings allow for the Sacred Law to be temporarily suspended, and

the non-permissible is allowed as mentioned in the following verse:

"وَمَا لَكُمْ أَلَّا تَأْكُلُوا مِمَّا ذُكِرَ اسْمُ اللَّهِ عَلَيْهِ وَقَدْ فَصَّلَ لَكُمْ مَا حَرَّمَ عَلَيْكُمْ إِلَّا مَا اضْطُرُّرْتُمْ إِلَيْهِ وَإِنَّ كَثِيرًا لَيُضِلُّونَ بِأَهْوَائِهِمْ بَعِيرَ عِلْمٍ إِنَّ رَبَّكَ هُوَ أَعْلَمُ بِالْمُعْتَدِينَ "

*"And why should you not eat of that (meat) on which Allah's Name has been pronounced (at the time of slaughtering the animal), while He has explained to you in detail what is forbidden to you, except under compulsion of necessity?"*²⁰.

Another right is the right to get treatment from a physician of his/her choice. The patient has the right to be informed by the responsible practitioner or his/her delegate about any continuing healthcare requirements following discharge from the hospital²¹⁻²². The patient may not be transferred to another facility unless he/she has received a complete explanation of the need for the transfer and the alternatives to such a transfer²².

The patient's responsibilities

The patients are responsible to provide accurate and complete information about medical complaints, previous illnesses, hospitalizations, medications, and other matters relating to their health as far as this is possible. The patient is also responsible to follow the treatment plan recommended by those responsible for his care. The care provider may take appropriate action if patients refuse treatment or do not follow the healthcare team's instructions. The patient must follow the hospital rules and regulations for smooth transaction of the business including respect of other patients and hospital personnel²².

Informed consent

The doctrine of informed consent partly comes from the fiduciary duty of the physician to inform the patient. The

relationship between a doctor and his patient is one of trust calling for a recognition by the physician of the ignorance and helplessness of the patient regarding his own physical condition²³. The doctor must supply the patient with the material facts to enable the patient to make an informed decision.²⁴ The patient's right to autonomy should always be respected and steps should be undertaken to make the consent truly informed. There is, however, no absolute right to consent based on philosophical, ethical, legal and practical considerations²⁵. Consent is valid when it is free, informed and voluntarily given: This means that the patient is not forced into consenting²⁵. If a patient gives consent because a doctor or the patient's relatives are applying pressure, then the consent is not free. A physician must always explain the risks of not receiving treatment, without exerting undue pressure on the patient. Instead, it is for the patient's education. It is the right of an individual patient to get all the relevant information including risks and benefits that normally go with the proposed treatment before he finally decides²⁶. The right to consent to health care includes the right to refuse health care. One must understand that consent is given by the patient only. Consent given for someone else is called substituted consent. Before asking for that, a physician must make sure the patient is incompetent to consent for the treatment²⁷.

It is also important to determine whether someone qualifies to make decisions and therefore it is the duty of a caregiver to make the conscious patient understand about the nature of illness, nature and purpose of therapy or diagnostic procedure, and the risks of not getting such therapy or diagnostic information²⁸. It is also important that the patient's illness must not affect the patient's understanding of these issues²⁹. Some people are unable to care for themselves or their property on their own but still can have some say about their medical care. These people are

referred to as being legally "incapable"³⁰. If an incapable patient refuses medical care, a physician alone cannot decide in a non-emergency situation whether to institute therapy or not. It may be referred to an institutional review board or to solicit a court order to continue with treatment³¹⁻³². In the case of minors, the legal guardian can offer substituted consent.

Conclusions

The general *Shari'ah* rules are based on the established fundamental principles of respect for the human being, personal autonomy and free will of competent individuals, irrespective of their faith, gender or ethnicity, in seeking medical care, accepting or declining diagnostic and therapeutic interventions, or participating in scientific health research. In exercising this autonomy, patients should bear the consequences of their decisions.

Treating physicians have the duty to fully enlighten their patients about their illness, nature of diagnostic therapeutic undertakings, their advantages and risks, and any alternative undertakings, with their advantages and risks, without any sort of pressure, duress, coercion, deception or exploitation.

Exception to this principle include emergency situations, communicable diseases that threaten the community, when the patient is a minor or incompetent, according to prevailing laws, in which case the consent should be provided by a properly appointed surrogate decision-maker, the institutional review board or the court.

The treating physicians needs to be reassured that their meticulous patient care, skills, empathy, comforting and alleviation efforts and attitudes, are all considered acts of worship (*Ibadah*).

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PHYSICIAN'S ROLE AT TIME OF DEATH

Sohail Akhtar^{}, and Abdul Majeed Memon^{**}*

Abstract

Physicians deal with dying patients frequently. A lot is expected from them. Apart from managing the illness including making the last moments of the patient's life pain-free as much as possible, the physician is responsible for counseling the relatives, breaking the news, and for consolation. Most doctors do not get training on these aspects in either the medical schools or afterwards and find such situations difficult to handle. Physicians need to avoid doing too little when it can matter, or too much when there is no hope. Restoring faith can help the patient as well as the family in coping with such extreme situations. One can learn from Prophet Muhammad (ﷺ) how to deal with a dying person on a human level, as well as how to be prepared for death by supplication and reading Qur'an.

Keywords: Death, dying, comfort care, hospice, terminal care.

Introduction

Death is an eventuality to which most are not prepared to face. Belief in the hereafter life changes the entire perspective of death, from the dying person's point of view as well as of those caring for him/her, including the physician.

Physicians are involved in the end of life of most people and they have an important role to help patients and their families to cope with such a stressful event. Physicians also are in a better position to decide, or to advise, the patients or their families on the best possible approach, going all out for possible cures on one hand and avoiding futile therapies and investigations on the other. They should avoid themselves being overenthusiastic, emotional or defensive for fear of litigations, and should make the patient's wellbeing and comfort the top priority. A continued and meaningful conversation on illness and death-related

issues between the physician and the dying patient and his/her family is of utmost importance in clearing confusions and comforting both parties. Lack of training of physicians in these issues is one of the major factors that disrupt the ease/harmony that can be drawn in such situations.

The modern world is focused on providing plenty of pain medications and tranquilizers, with the belief that this will give comfort in the last moments of life. Most people in the Western world die in institutions, often in intensive care, out of sight of their beloved ones. There is overshadowing of 'doing everything possible' over rational, comfort-based approach due to multitude of reasons.

Financial resources constraints or overuse, attain an important role in such situations especially in societies where patients have to bear the cost themselves.

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Physicians should take the most rational path using all possible resources to save human life which is most precious, but at the same time avoiding draining resources when there is little hope.

Muslim physicians should help spiritually guide a dying patient, even if a nonbeliever, so that he/she reverts to goodness and repents (*tauba*) before dying.

Directions from Qur'an and Sunnah

The Glorious Qur'an teaches us that:

"كُلُّ نَفْسٍ ذَائِقَةُ الْمَوْتِ"

"Every soul shall have taste (experience) of death"¹.

It also states:

"اللَّهُ يَتَوَفَّى الْأَنفُسَ حِينَ مَوْتِهَا وَالَّتِي لَمْ تَمُتْ فِي مَنَامِهَا فَيُمْسِكُ الَّتِي قَضَىٰ عَلَيْهَا الْمَوْتَ وَيُرْسِلُ الْأُخْرَىٰ إِلَىٰ أَجَلٍ مُّسَمًّى إِنَّ فِي ذَٰلِكَ لَآيَاتٍ لِّقَوْمٍ يَعْتَمِدُونَ"

"It is Allah that takes the souls (of man) at death, and those that do not die (He takes) during sleep; those on whom He has passed the decree of death, He keeps back (from returning to life) while the rest He sends (to their bodies) for a term appointed. Verily in this are signs for those who reflect"².

Death occurs when the soul leaves the body. What is the nature of soul? We have been given only the information that we need to know.

"وَيَسْأَلُونَكَ عَنِ الرُّوحِ قُلِ الرُّوحُ مِنْ أَمْرِ رَبِّي وَمَا أُوتِيتُمْ مِنَ الْعِلْمِ إِلَّا قَلِيلًا"

"And they ask you, [O Muhammad, ﷺ], about the soul. Say, 'the soul is the affair of my Lord'. And mankind has not been given of knowledge except a little"³.

The time of death is difficult for every human being. Allah says:

"سَاءَ إِذَا بَلَغَتِ التَّرَاقِيَ، وَقِيلَ مَنْ رَاقٍ، وَظَنَّ أَنَّهُ الْفِرَاقُ، وَالْتَقَمَتِ السَّاقُ بِالسَّاقِ"

"When the soul (of a person) reaches the collar bone, and it is said, who is an enchanter (that can save him?). And he realizes that it is (the time of) departure (from

the world.). And one shank is intertwined with the other shank"⁴.

Aayeshah (RAA) reports "After witnessing the difficulties experienced by Rasulullah (Prophet Muhammad ﷺ), I do not doubt that anyone does not experience difficulties at the time of death"⁵.

For a Muslim, death reflects a change, the soul is leaving the physical body forever and is starting of the eternal life. Ma'qil bin Yasar (RAA) narrated that the messenger of Allah (ﷺ) said: "Recite Surat Yaseen over those who are dying"⁶. Scholars believe that the idea is that the person is listening to verses which give him/her glad tidings about what is ahead and he/she can look forward to it.

Breaking Bad News: different perspectives

In the Western world, the concept of "truth telling" has contributed to a reduced physician role in the patient's health related decisions. On the other extreme outside the United States, physicians tend to conceal serious diagnoses from patients. It has been observed that many African and Japanese physicians, often choose terms such as "growth," "mass," "blood disease," or "unclean tissue," when discussing the diagnosis of cancer. Whereas Hispanic, Chinese, and Pakistani communities, and family members tend to actively protect terminally ill patients from knowledge of their condition⁷. In the critical care settings emotions tend to run high. Communicating bad news is especially more challenging as one of the authors witnessed a brother collapsing and dying as soon as the news of his sister's death in ICU was communicated to him in the waiting room. A mother died in same manner as soon as news of her son's death was conveyed to her.

Physician and patient dynamics have also changed with times. With the introduction of modern technology and multispecialty medicine, the strong relationship or "sacred trust" between patient and family physician

has gradually eroded. Various subspecialists are now entrusted with patient care at different phases of evaluation and treatment. Because of the transient nature of these physician-patient interactions, a strong bond is often not established before critical decisions must be made concerning ongoing patient care. As a result, multiple members of the different healthcare teams may be confronted with addressing end-of-life discussions, while in the past this was the responsibility of the family physician. Because of this need to move into a previously viewed private territory, communicational conflicts may arise between members of the healthcare team⁸.

Proper training of doctors starting from medical school, in this difficult area of communication, is necessary to cope with difficulties. One should keep cultural and personal, cognitive factors in perspective while adopting an 'open' or modified policy in these situations, but one should not try to hide facts when they need to be communicated. The scope of this article is too narrow to discuss even the basics of this area.

Too much at the End?

As physicians, it is our innate nature to keep trying to remedy our patient. When the patient is at the stage where death is imminent, many of us tend to provide treatment that may be characterized as "futile". In these cases, the patient may get operated upon, and, hooked up to machines and be started on expensive medications which may be of little or no benefit and end up being very costly⁹.

Physicians can play a very important role in leading the families towards selecting a comfort oriented treatment instead of futile attempts to cure at the end of life. The training of a physician is to intervene and correct the obvious abnormal lab results or visible findings on physical examination or imaging studies. It is very tempting to drain a pleural

effusion seen on chest x-ray of a patient who is close to dying from metastatic lung cancer. This will make sense if he appears short of breath; however, if the dyspnea can be relieved by simple oxygen supplement, one needs to resist the temptation to perform the procedure. Similarly, ventilating a patient slowly fading away from a prolonged untreatable disease often does nothing but prolongs misery. These unnecessary measures also consume lot of financial and temporal resources which can be best directed at managing treatable illnesses. In poor settings health care spending overtakes many people's life savings; people selling their homes to pay for hospital bills are not uncommon. If it is for a futile course in hospital for a very poor survival chance, such heroics may even be considered unethical. Health care spending takes major share in out of pocket spending in many countries with long term effects on the whole family¹⁰.

On the other hand, neglecting pain relief and providing oxygen and similar simple comfort measures for an apparently incurable case is also unethical. Physician should also not write off a potentially treatable case simply because of lack of resources. The state and society have a moral responsibility to provide such support. A God-fearing doctor goes all the way in such cases to find out a practical solution.

It is worthwhile to note physicians' personal attitudes towards this subject. Interestingly more physicians choosing to remain out of hospital in the last part of their lives, compared to the rest of the population¹¹.

Role of Family

Ethically it is correct that patients be given an opportunity to decide for themselves as to how much treatment is to be provided to them in terminal time. Often the patient is unable to understand or unable to stand up to the reality of the impending inevitable. He or she expects

the physician to guide and discuss various alternatives and their relevance. Once the patient comes up with a decision agreed upon by his physician, the family needs to play a strong role. If the family is not briefed or not kept informed of the decision of the patient, unanswerable questions may arise after the patient departs. The physician can find himself in an awkward situation while the patient would not be there to defend the treatment approach adopted by the physician at the patient's directive. The physician will have to gently guide the patient and his family toward humane sensible approach. Identifying a family member who can control his or her emotions will be helpful. Often under strong emotional stress, the spouse or closest relative asks to "do everything". This is frequently the case when a third party is paying for the care. Occasionally the family wishes to withdraw life support because of expected financial gains from inheritance. Sometimes the family or the patient decides to have the family physician play a strong role in making the decisions for care. These issues are addressed more easily if the physician knows the family's background and knows the key members to communicate with. In the US and many Western countries, this has now become impossible as often the family meets the emergency room physician or the intensivist for the first time. There is no bond or trust. The media also plays its role. The family expects the physician to be able to treat every disease as seen on TV or internet.

Fear of Litigation

One of the reasons for over-treatment, particularly in the West, is to avoid future questions about under treatment. Do-everything approach appears to reassure the physician and the family that every possible measure was adopted, including repeated attempts at Cardio Pulmonary Resuscitations (CPRs) in a person having cardiac arrest as a

terminal event of a long protracted incurable illness.

Empathy

Death is an occasion that demands utmost empathy, respect and comfort. For many physicians, dealing with dying patients becomes a common occurrence, still they should never be casual about death. Even if death was expected for long, like in an incurable disease, the attitude of the treating physician towards the patient and the family should be serious and caring. Repeated blood tests just to show physician's 'concern' of the patient, are simply pain inflicting exercises close to death. Simple presence of the physician at the bedside and being available, may comfort all those involved much more. One should provide calm atmosphere of *dua'a* (prayers), closeness with the beloved ones and comfort. This may not always be possible especially in intensive care settings (ICU).

The doctor may decide in case of a patient with no possibility of cure, to remove him from isolated ICU beds to one where his close relatives may recite Quran, *dua'a*, and be close to him/her. Those involved in care of the terminally ill may find the experience to be of great satisfaction and enrichment particularly observing the courage of many dying patients¹². Physicians themselves should refresh their spirituality (*Iman*) by remembering the occasion which is inevitable to them as it is to the patient they are treating.

Last Chance of *Da'wah*

Abu Saeed al- Khudri (RAA) reported the messenger of Allah (ﷺ) said:

"Exhort (urge or advice) your dying persons to recite *La Ilaaha illa Allah* (there is no true god except Allah)"¹³.

Abu Saeed and *Abu Hurairah* (RAA) narrated that the messenger of Allah (ﷺ) said:

"Remind those that are on their death bed, of the *Shahadah: La Ilaaha illa Allah*"¹⁴.

As much as a physician lifts up the morale of the patient and his family, close to death, he/she should not be shy to bring the patient close to belief. Some, especially those not so close to religion, would argue not to 'impose' belief on the patient at the time of dying¹⁵. Muslims know by teachings of Qur'an and the acts of Prophet Muhammad (ﷺ), that this is absolutely vital to save a person from hellfire in the hereafter.

Anas narrated: A Jewish boy used to serve the Prophet and became ill. The Prophet went to pay him a visit and said to him, "Embrace Islam," and he did embrace Islam.

Al-Musaiyab said: When *Abu Talib* was on his deathbed, the Prophet visited him and kept asking him to declare the *shahada*¹⁶. Near the time of death may be the last chance a person has!.

Remembering Allah may be the most comforting 'pill' for a distressed person. Sometimes persons with even the weakest of faith get softer and revert to the eventuality of meeting their Creator. A physician is perhaps in the best of positions at times, to judge how close the eventuality is; there he/she should revitalize the dying person with Iman.

One of the authors witnessed a situation during morning rounds when a lady in a US nursing home was seen sitting alone appearing worried. Upon inquiring, the patient said that she did not know what will happen to her after she died. Using this opportunity, the physician gave *da'wah*. After asking a few questions and trusting the physician, the patient took *shahadah* (embraced Islam). Two days later she died on correct belief. For something like this to happen, there needs to be a bond built by a caring physician over a period of time. We have a responsibility not only to provide excellent medical care but to be involved in the overall wellbeing of patients and their families, including their lives after death.

Conclusions

Physicians have a very important role in the last stages of their patients' life. Free and open communication with the patient and his family are very important. The physician can be more effective if he has been given a chance to have some rapport with the patient beforehand, but this is not always possible given the changes in health care delivery system. Every possible support will need to be provided to alleviate visible suffering. Avoidance of futile measures which increases the patient's suffering and drain the family's resources can be achieved by guiding the patient and his family by a physician who is perceived to be very involved. "Do everything" from the caring family may sweetly be converted to "Do everything useful" by a sensible physician. Duty of a Muslim physician is also to try that his patient dies with correct belief and gets to the highest level of paradise.

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DECISION MAKING AT THE END OF LIFE

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Abstract

Communication and decision making at the end of life (EOL) is a challenging process for physicians and patients, as well as patients' families. Failure to provide communication properly at the EOL may increase psychological distress, inconsistent medical treatment with patient's preference, utilization of burdensome treatment, and adversely impact post-bereavement outcome. Therefore, discussing EOL is preferably executed early in the course of life threatening illnesses with a subsequent periodic review, and it requires good approach to both values, patient's preferences and their background. The important step before starting the discussion is estimating the prognosis to guide goals of care while still relying on God's will as the owner of every human's life. Amongst approaches of decision making, shared decision making (SDM) is the ideal model in complex situations. It is important to maintain hope during discussing the EOL phase by providing sufficient information about prognosis, giving empathy, and offering desirable approach of decision making for the patient. Since, in Islamic perspective, life determines afterlife, discussing death can arise anxiety for some patients. Encouraging patients to think positively of Allah while communicating EOL is important to achieve a "good death".

Keywords: communication, decision making, Islamic perspective, end of life, palliative

Introduction

Communication and decision making at the end of life are critical aspects of EOL care. Both communication and decision making represent the clinical interactions focusing on death and dying issues as parts of illness progression or a potential outcome despite treatment efforts. Although health care practitioners (HCP) often apply it near the end of life, the discussion often precedes care issues in terminal stages of a disease process.

Communicating EOL care is also pertinent in the setting of advanced chronic diseases or with healthy people who are planning for care related to unexpected illnesses¹.

Death, in the Islamic perspective, is Allah's prerogative as stipulated in the Qur'an:

"... فَإِذَا جَاءَ أَجْلُهُمْ لَا يَسْتَأْجِرُونَ سَاعَةً وَلَا يَسْتَأْذِنُونَ"

*"When their specified time arrives, they cannot delay it for a single hour nor can they bring it forward"*².

To face the inevitable together and to help the patient achieve a good and meaningful death, communicating it in advance is a key point in the EOL care.

The goal of communication and decision making in EOL is not to avoid death or prolong life, but to create a shared understanding of a person's values and treatment preferences that will lead to a plan of care that is consistent with these values and preferences¹.

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Communication and decision making at the end of life may occur in various settings, such as homes, physicians' offices, or hospitals. It may result from a sudden illness/injury or deterioration of chronic diseases. Providing effective communication and decision making is often a challenging task because of the emotions involved within the physician, the patients and the patients' families. Failure to provide adequate and effective communication during the EOL phase may result in unintended psychological suffering for both the patients and their caregivers, unpreparedness in facing the future, inconsistent medical treatment with personal preference, utilization of burdensome and expensive health care resources of little or no therapeutic benefit, and may adversely impact bereavement³⁻⁵. Yet, the fulfillment of information needs is among the biggest unmet needs in EOL care.

Initiating the Discussion of EOL Care

Decision making in EOL is a complicated process and often emotionally burdening. Various issues may arise from either HCPs, patients or their families. End of life care discussion is an ongoing process over time which is time-consuming and requires more than a single session. In addition to the long and complicated processes, the patient may also avoid discussing EOL related issues. Instead of waiting for patients to raise the issues, HCP should tactfully raise EOL issues should occur early in the course of the disease with a subsequent periodic review. There are some routine and urgent clinical indications for discussing EOL care (Table 1)⁶.

Physicians who have a long-standing history of good doctor-patient relationships with dying patients are in the ideal position to initiate and maintain the palliative care discussion with patients and families⁶.

Formulating and Delivering the Prognosis

Providing an accurate prognosis is vital, especially concerning treatments and goals

of care to avoid inappropriate therapy and assist in the care and personal planning. From the Islamic perspective, even though the essential duty of the HCPs is to preserve health and life, they believe that death is the inevitable destiny predetermined by Allah (SWT). We believe that life is sacred and will end at a time that is predetermined by Allah. Therefore no one knows exactly when he will die, or in what land he will die⁷.

"إِنَّ اللَّهَ عِنْدَهُ عِلْمُ السَّاعَةِ وَيُرْسِلُ الْغَيْثَ وَيَعْلَمُ مَا فِي الْأَرْحَامِ وَمَا تَدْرِي نَفْسٌ مَآذَا تُكْسِبُ غَدًا وَمَا تَدْرِي نَفْسٌ بِأَيِّ أَرْضٍ تَمُوتُ إِنَّ اللَّهَ عَلِيمٌ خَبِيرٌ"

*"Verily, Allah! With Him (Alone) is the knowledge of the Hour, He sends down the rain, and knows that which is in the wombs. No person knows what he will earn tomorrow, and no person knows in what land he will die. Verily, Allah is All-Knower, All-Aware (of things)"*⁸.

Estimating and delivering the accurate prognosis is important since it determines goals of care which may shift the emphasis from cure to palliation. However, less than 25% of the physicians can give accurate estimates, and most would tend to be overly optimistic⁹. Also some physicians admit that they prefer not to communicate any prognostic information to the patients and their families. Both overestimation and reluctance can arise because of unwillingness to deliver bad news, desire to maintain hope, and not wanting to worry patients or their family. However, this concept of protecting patients or their families is now falling out of favor. Avoiding EOL discussion may deprive patients of the opportunity to make such advance care planning, working on issues of life closure such as healing a family relationship or fulfilling their unfinished business⁶. At present, several tools can aid the formulation of prognosis including the Medical Guidelines for Determining Prognosis in Selected Non-Cancer Diseases, developed by National Hospice and Palliative Care Organization (NHPCO), and Palliative Prognostic Scale (PPS). Despite the importance of delivering prognosis, keep

in mind that every patient and family have the right to refuse this information. The HCP has to explore their preference before finally communicating it in an appropriate way to those who are willing.

The most important thing for a Muslim physician is the capability to deliver the estimation of prognosis based on medical knowledge while still relying on God's will as the owner of every human's life.

Delivering bad news is difficult, time-consuming, and emotionally exhausting, nevertheless HCPs should develop the skill on how to properly deliver the bad news. There are several principles or steps in delivering bad news. One of the protocols that are easy to understand and apply is SPIKES (Table 2)¹⁰.

Content of Issue Discussed in EOL Decision Making

Despite significant research findings on various cultural and other particular backgrounds' impact on decision making and preferences, it is not recommended to make assumptions based on patients' demographic characteristics or cultural background. Since generalizations are not always applicable, HCPs should clarify patient's and caregiver's information needs based on their preference and tailor it accordingly. Even the same individual will demand different supports in various time points through the course of their illness. After confirming and communicating the state of EOL and prognosis, EOL decision-making process should discuss several important issues. Clayton *et al.* explored various issues of EOL according to patients', carers', and HCPs' view explained below¹¹.

1. Treatment at the EOL

From the Islamic viewpoint, human life is sacred and so valuable that the Holy Qur'an equates saving one life to saving the life of all humankind¹².

"مَنْ أَجَلَ ذَلِكَ كَتَبْنَا عَلَى بَنِي إِسْرَائِيلَ أَنَّهُ مَنْ قَتَلَ نَفْسًا بِغَيْرِ نَفْسٍ أَوْ فَسَادٍ فِي الْأَرْضِ فَكَأَنَّمَا قَتَلَ النَّاسَ جَمِيعًا وَمَنْ أَحْيَاهَا فَكَأَنَّمَا أَحْيَا النَّاسَ جَمِيعًا"

وَلَقَدْ جَاءَهُمْ رَسُولُنَا بِالْبَيِّنَاتِ ثُمَّ إِنَّ كَثِيرًا مِّنْهُمْ بَعَدَ ذَلِكَ فِي الْأَرْضِ لَمُسْرِفُونَ

"We ordained for the Children of Israel that if any one slew a person - unless it be for murder or for spreading mischief in the land - it would be as if he slew the whole people: and if any one saved a life, it would be as if he saved the life of the whole people"¹².

On the other hand, people's lives do not belong to themselves, rather are divine loans entrusted to them which ought to be protected¹³. Allah gives and takes life, and all life and death are by His permission.

"وَمَا كَانَ لِنَفْسٍ أَنْ تَمُوتَ إِلَّا بِإِذْنِ اللَّهِ كَتَبْنَا مُوَجَلًّا وَمَنْ يُرِدْ ثَوَابَ الدُّنْيَا نُؤْتِهِ مِنْهَا وَمَنْ يُرِدْ ثَوَابَ الْآخِرَةِ نُؤْتِهِ مِنْهَا وَسَنَجْزِي الشَّاكِرِينَ"

"It is not [possible] for one to die, but with the permission of Allah at a decree determined"¹⁴.

Therefore any decisions in this respect should be made by referring to values in Islam which state that the process of dying should not be prolonged, and that accepting death as the Will of God is something that a Muslim should keep in mind. This understanding is expected to help patients and families cope with serious and life-limiting illnesses. However, HCPs should consider that any efforts to relieve suffering are highly valuable in Islam¹⁵.

Many patients and carers expect to get the information about current treatments available as well as the pros and cons of each treatment from many sources.

Communicating every possible treatment option is, therefore, a paramount responsibility of the HCP¹¹. Further discussion of various issues of treatment at the EOL are described elsewhere in this book (refer to Chapters: Withdrawing and Withholding Treatment; Do Not Resuscitate (DNR), Euthanasia, Hydration; etc.). Muslim HCPs should put Islamic values when determining the advantages and objectives of treatments for different patients in addition to the medical science. Procedures or treatments should be useful and beneficial for patients, while at the same time should comply with Islamic jurisprudence rules, such as the principle of

the illegitimacy of harm (*la darar wa la dirar*, or the use of haram substances). Islam also does not encourage wasting resources that allow physicians to stop offering futile treatments.

"وَأَبْذَرَ خَلْقَهُ وَالْمُسْكِينَ وَأَبْنَى السَّبِيلِ وَلَا تُبَذِّرْ تَبْذِيرًا، إِنَّ الْمُبَذِّرِينَ كَانُوا إِخْوَانَ الشَّيَاطِينِ وَكَانَ الشَّيْطَانُ لِرَبِّهِ كَفُورًا"

"... and do not spend wastefully. Indeed, the wasteful are brothers of the devils, and ever has Satan been to his Lord ungrateful"¹⁶.

2. Future symptoms

Clayton *et al.* revealed that most HCPs address the importance of providing adequate information about possible deterioration to avoid patients misconception that their condition will remain stable during the progress. The information needed includes predominant symptoms that are likely to occur due to their illness such as gradual decrease in energy to perform previously daily activities and the need for more rest. Patients showed the need for a broader picture rather than detailed information and expected support through whatever problems that may arise. On the other hand, carers prefer a more comprehensive information so that they can be prepared and know what to do¹¹.

Muslims believe in divine destiny and regard any joy and suffering as the will of Allah. They perceive suffering as a way of redemption for one's sins, as the Prophet (ﷺ) said:

"No fatigue, no disease, nor sorrow, nor sadness, nor hurt, nor distress befalls a Muslim, even if it were the prick he receives from a thorn, but Allah expiates some of his sins for that"¹⁷.

This belief can help the patients and families to cope with suffering in EOL.

3. Preferences for place of death

Knowing a patient's and carer's preference on the place of death earlier before the last days can be helpful for the HCP. While many patients may be reluctant to discuss this topic directly, carers are often eager to know whether it is realistic to take care of the patient at home so that when death occurs it will be at home. The HCP should, therefore, discuss the possibility to die at home considering the patient's medical condition, family support, facilities at home, and available services in their local area, and types of support and care that can be given at home¹¹. Muslims believe that only Allah knows and has the right to determine the time or place of death. However, some patients may wish to die in their preferred place, particularly which they consider holy such as Makkah and Madinah. In this case, the HCP should respect their wish and help accommodate it¹⁸.

4. Terminal Phase/Dying

Although patients and families often are frightened to discuss the dying process, they often express relief after discussion EOL issues. Patients and their family members may have different concerns related to the dying issue. Patients often need the reassurance of symptom control (pain) in the period of dying, dignity, and sufficient support from HCPs during the process. Families or carers tend to expect more detailed information on what to expect and how to manage and whether any support and help are obtainable¹¹. In addition to specifically address patients' and families' concerns, health care providers may also remind a dying person about the great generosity of Allah and encourage patients and families to look forward to Allah's blessing and forgiveness.

"فَتَلَقَّى آدَمُ مِنْ رَبِّهِ كَلِمَاتٍ فَتَابَ عَلَيْهِ إِنَّهُ هُوَ التَّوَّابُ الرَّحِيمُ"

*"Then Adam received from his Lord [some] words, and He accepted his repentance. Indeed, it is He who is the Accepting of repentance, the Merciful"*¹⁹.

5. Unfinished business

Both patients and families are usually emotional and seek forgiveness from each other upon realisation of imminent death. In this phase, HCPs are urged to recognize and support any unfinished business or the last will of their patients²⁰. Discussing patients' wishes with respect will also improve the serenity during EOL. To provide the opportunity to finish the unfinished business is also one of the main reasons to disclose the prognosis to the patient as part of respecting the patients' rights to prepare for death.

6. Exploring perceptions about dying and dispelling myths

Before discussing dying, the HCP needs to assess the patient's perception of death and any myths that he / she believes. As an example, patients may perceive that they will suffer as did others with the same illness. Some may be afraid of burdening their family in their last days and worried about losing control of their bodily functions. Allowing patients to express their fears is important to alleviate their concerns¹¹.

7. Describing the final days and unconscious period

Many HCPs describe the last days of their patients as being gradually weaker and needing longer resting period followed by a reduced consciousness of what is happening around them. Some also describe it as a sleep-like state while at the same time reassuring patients that it is not the same as night-time sleep, so it is not necessary to be afraid of going to bed at night. Never forget to state

that dying can be a slow process but that it may also happen suddenly and unexpectedly¹¹.

8. Dilemma to discuss complications around the last days of life

Some complications may occur during the last days of life and may vary according to the illness, such as seizures, massive hemorrhage, suffocation, etc. Since discussing complications with patients may create anxiety, HCPs should communicate this issue appropriately. Because of the difficulty, HCPs often face dilemmas whether or not to discuss this topic. Most HCPs will tell the patients or their families that complications can occur but are very rare. However, if a complication would occur, patients can be sedated to prevent or eliminate their suffering. Discussing this issue with patients' carers is also imperative since they expect the information to be able to accept the worst eventualities.. However, most of the carers perceive that the information should be retained by them and not be delivered to patients to avoid the emergence of anxiety¹¹.

9. Foods and fluids for dying person

Carers mainly address this issue. The most important duty of the HCP in this context is to assure that food and fluid intake will naturally decrease in the dying person and it is not necessarily their failure. The aim is to reduce carers' anxiety about their loved ones dying of starvation and dehydration when they are no longer able to eat or drink¹¹.

10. What needs to be done immediately after death/funeral HCPs think that this discussion can be helpful, especially for carers, by disclosing what would happen to the body after death, how they can tell that the patient has already died, and who to call. However, this topic will be delivered in response to a question¹¹.

11. Existential issues

Discussing existential issues and listening to the patients' spiritual concerns are critical factors to address patient concerns of dying¹¹. In Islam, death means separation of the soul from the body that does not result in the annihilation of a man¹³. The Qur'an explains that death is a transition from one existence to another form of life which is eternal and the true life of Muslim. Faith in life after death and resurrection is one of the six fundamental beliefs in Islam besides faith in Allah and His last Messenger. This passage will be smooth and satisfying for faithful people while difficult for the sinful who rather disbelieve in the day of judgment since the only life they knew has ended²¹.

"فَكَيْفَ إِذَا تَوَفَّيْتُهُمُ الْمَلَائِكَةُ يَضْرِبُونَ وُجُوهَهُمْ وَأَذَانَهُمْ، ذَلِكَ بِأَنَّهُمْ اتَّبَعُوا مَا أَسْخَطَ اللَّهَ وَكَرِهُوا رِضْوَانَهُ فَأَحْبَطَ أَعْمَالَهُمْ"

*"But how -will it be- when the angels take their souls at death, and smite their faces and their backs? This is because they followed that which called forth the wrath of God, and they hated God's good pleasure, so He rendered worthless their deeds"*²².

"يَا أَيُّهَا النَّفْسُ الْمُطْمَئِنَّةُ، ارْجِعِي إِلَىٰ رَبِّكِ رَاضِيَةً مَّرْضِيَّةً، فَادْخُلِي فِي عِبَادِي، وَادْخُلِي جَنَّاتِي"

On the other hand, *"the righteous souls will return to Allah in a well-pleased (with him) and well-pleasing (Him) manner, entering His garden"*²³.

Since life decides afterlife, discussing death and life after death may bring peacefulness in some patients while arising anxiety in others. Reminding of the infinite mercy and forgiveness of God may help relieve the fears caused by this issue.

Type of Decision Making Approach Based on Participation Preferences

Care at the EOL should recognize, assess, and address the psychological, social, spiritual/religious issues, and cultural taboos. Different cultures may require

significantly different approaches. Therefore stereotyping the approaches should be avoided. Even generalization about the same cultures is not always applicable for specific patients. By paying attention to the patient's values, spirituality, and relationship dynamics, the physician can elicit and follow cultural preferences.

Many types of research showed that the majority of adolescent patients prefer to be involved in decision making in the EOL. However, the degree of participation may vary and depends on various factors. The way they see their role or assess their capabilities for participating in future treatment decision-making is one of the factors. Patients who doubted their ability to make the treatment decisions by themselves preferred to give a more decisive role to their physician or families. However, this function is not static and can change along the illness trajectory. There are several approaches of decision making based on participation preferences²⁴:

1. Patient-centered decision making

This approach is the implementation of autonomy and the consequence of patient-centered care in palliative care. This method allows patients to make decisions of caregiving by themselves and commonly take place when patients are familiar with their illnesses. Although this manner may cause more anxiety for patients, it can be minimized by an appropriate way of communication and support from loved ones and healthcare providers.

2. Family-centered decision making

This is the most common approach in Asian and southern European cultures by which the family, and not the patient, formulate decisions with the physician, commonly without disclosing the diagnosis to the patient to protect him/her. This particularly happens when the prognosis is poor or if the patient is unable to communicate or are very elderly patients. To decide which is the best approach for our patients is to ask

him/her whether he/she would like the family to take over.

3. Physician-centered decision making

The physician makes the decisions with the implicit agreement from the patients and their families. Although patient input may be asked, it is not necessarily the same as the decision made by the physician. This approach has many disadvantages. However, in several conditions, it may be appropriate, such as when the patient, or sometimes the caregiver, is unable or unwilling to participate in decision making.

Shared Decision Making (SDM)

In a complex situation, SDM has become the ideal model for decision making, where the HCP provides information to patients and families and share their opinions regarding decisions, while patients and families make informed decisions regarding their medical care in conjunction with their providers²⁴. A family conference can be used to improve the communication in SDM about EOL care. Even though the majority of patients wished an SDM, there are some who prefer a more active or passive approach. This suggests that personal preference should be carefully considered.

Sustaining or Reframing Hope While Communicating About EOL

The idea of maintaining hope is critical for patients, caregivers, and providers. However, physicians frequently interpret this as to prolonging survival and improving treatment response to enhance hope in their terminal patients²⁴. In fact, hope is not necessarily restricted to escaping death. It can also mean enjoying their final moments with their loved ones. Therefore support may include lessening their fears of pain, suffering, and loneliness. Touching patients not only physically but also emotionally would also be of benefit. The feeling of being abandoned by their physicians or suspecting any information

being withheld from them may potentially diminish the patients hope.

HCPs behaviors that instill hope include offering the most up-to-date treatment, having extensive knowledge about their patient's disease, and assuring them that their symptoms (example: pain) will be well controlled. On the other hand, HCP behaviors that depressed hope are nervous appearance, disclosing the information to the family rather than the patient, and applying euphemism. However, it is common and expected that patients would try to maintain a sense of hope. There are several steps that we can do to keep this hope alive in severely ill patients.

First, formulate the accurate prognosis. For most patients, being reassured about timing will provide hope. Therefore, knowing that death will not occur in the next minutes or hours is important. Once this anxiety is relieved, patients start the struggle to embrace life while preparing to breathe their last breath²⁶. There are several tools for this purpose, such as palliative performance scale (PPS), life expectancy tables, and National Hospice and Palliative Care Organization hospice criteria. Collaborating with a multidisciplinary team can better improve the prognostication²⁵.

Second, communicate with empathy. Knowing their values can help patients' feeling of being treasured. Empathic communication include having conversation about patients' relationship with their loved ones, what life means to them, how they want to be remembered, their hope for not being such a burden for their family, their worries on those who they will leave behind, their fear of dying, etc²⁶.

Thirdly, provide the models of decision-making approach which are most desirable for the patient, for example, patient-centered decision making, etc.

A Good Death in the Islamic Perspective¹⁸

A study by Tayeb et al. showed that the main aspects of the quality of a Muslim

death which are regarded as important for Muslims can be categorized in three domains.

1. Religious faith and belief:
 - Knowing that somebody will be by their side to guide them to enunciate Shahadah in the last breath,
 - The attendance of someone at the bedside to recite chapters of the Glorious Qur'an,
 - To die in a position facing the holy mosque in Makkah,
 - To die in a sacred place (e.g., Madinah, Makkah, or mosque) or in a divine time (e.g., in Ramadhan or on a Friday).
2. Self-esteem and body image
Preserve patients' body from post-mortem distortions, deformities, septic wounds, or bad odors by nurturing continence and keeping patients' environment free of dirt and making sure the body has a normal appearance after death.
3. Concern about family security
Patients need to feel free of worry that their family will face trouble after their departure particularly related to economic and social issues.

Other studies suggested that the common measures of good death include adequate pain and symptom management; clear decision making by patient, family, and physician; preparation for death; being afforded dignity and privacy; having access to any spiritual or emotional support; access to hospice care; ability to issue advance directives, which ensure wishes are respected; having time to say goodbye and control over other aspects of timing; ability to leave when it is time to go; avoiding prolonged dying process; and ability to retain control of what happens²⁷.

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Table 1. Clinical indications for discussing EOL care

Routine Indications	
	Discussing prognosis
	Discussing treatment with low probability of success
	Discussing hopes and fears
	Physician would not be surprised if the patient died in 6-12 months
Urgent Indications	
	Patient is facing imminent death
	Patient who is talking about wanting to die
	Patients' or families' request for hospice or palliative care
	Recent hospitalization for severe progressive illness
	Severe suffering and poor prognosis
Source: Quill TE ⁶	

Table 2. SPIKES Protocol	
S	Setting up the interview: arrange private room, few interruptions, and so forth
P	Assessing patient's <i>P</i> erception: "what have you been told about your medical condition so far?"
I	Obtaining patient's <i>I</i> nvitation: ask how patients want to get informed
K	Deliver <i>K</i> nowledge and information to the patient
E	Addressing patient's <i>E</i> motions with empathic responses
S	<i>S</i> trategy and Summary

Source: Baile W, Buckman R, Lenzi R, et al¹⁰.

FUTILITY OF MEDICAL TREATMENT

Mohammed Ali Albar and Hassan Chamsi-Pasha***

Abstract

Medical and technological resources allow many patients affected by advanced diseases to receive more aggressive and expensive treatments than ever before. This wide range of available options can frequently lead to complex end-of-life decisions, such as when to start palliative care programs. Medical futility refers to interventions that are unlikely to produce any significant benefit for the patient. Medical futility is a daily problem, with significant ethical implications and concerns about the respect of the main ethics principles: beneficence, non-maleficence, patient's autonomy, and justice. Proceeding with futile treatment is neither in the best interests of the patient nor of the healthcare system.

This paper examines the definition of futility, applications of the concept of medical futility, the complexities of management when care is considered futile.

Keywords: Futility, End-of-Life, Medical Ethics, Withhold treatment, Withdraw treatment.

Case History

Mrs M is an 82-year-old Somali woman (living in London) with diabetes, on hemodialysis; she had a right below-knee amputation six months previously and has been in hospital for a week with an ischemic left foot; she has evidence of sepsis with multiresistant organisms on blood culture. She is now hypotensive and confused.

Hemodialysis is complicated by the loss of upper central venous access and poor blood flow rates on repeated femoral lines. The vascular surgeons have stated that no procedure is possible to improve blood flow to the left leg and that she is too unwell even for an amputation. A discussion is held with her family about Mrs M's poor prognosis and inevitable death. The family state that they want full treatment as demanded by their religion and that 'Allah decides when death

happens'. Two days later, the femoral line clots. A further meeting is held with the family; it is explained that it would be futile to attempt another femoral line insertion, and that attempting to do so could be very uncomfortable and distressing for Mrs M. Subsequently, a family member phones the hospital patient affairs department and states that if their mother is not put back on to dialysis, they will contact Somali radio and accuse the hospital of racism.

Following this, the renal team elects to maintain Mrs M on dialysis after further femoral line insertion. Over the next two weeks, Mrs M is maintained on hemodialysis, intravenous antibiotics and inotropes. She eventually has a cardiac arrest during dialysis and dies after an extended attempt of resuscitation¹.

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This case history illustrates the potential conflicts that emerge when considering end-of-life management for patients from minority ethnic groups in a Western healthcare system that is dominated by the principles of patient autonomy, beneficence, non-maleficence and avoiding futile care. The outcome of this case history was far from ideal from the viewpoint of both the patient (inappropriate prolongation of dying, pain and discomfort from repeated femoral line insertions and dialysis attempts) and society (inappropriate use of limited healthcare resources)^{1,2}.

Case # 2

A well-known example of futile cases from the USA is the case of a baby, widely referred to as “baby K” who was born in Virginia on October 30, 1992, and had been diagnosed prenatally as having anencephaly. The mother, who believed that her baby was the son of the (God moon)!, insisted that life support is continued. The physicians believed that ventilatory support was not warranted as the baby would never recover consciousness, and sought legal authority in the federal court to forgo it. The court ordered continuation of ventilation and resuscitation as the white mother of the baby requested. “Baby K” continued to receive high-quality medical care and survived for two and a half years before succumbing to an infection. The tax payers lost millions of dollars on futile treatment.

Introduction

The concept of futility has been debated for many years, and a precise definition remains elusive. This is not entirely unsurprising given the increasingly complex and evolving nature of modern medicine. Progressively more complex decisions are required when considering the increasingly sophisticated diagnostic and therapeutic interventions. Allocating resources appropriately amongst a

population whose expectations continue to increase raises a number of ethical issues not least of which are the difficulties encountered when consideration is being given to withholding “life-preserving” treatment³.

The debate about when a life-sustaining medical treatment for a critically ill patient should be discontinued is linked to, but distinguishable from, the right-to-die debate. It is often stated in terms of who gets to decide. Can a physician decide to stop treatment, or does the decision belong to the patient, or the next of kin or proxy?⁴.

Definition

Futility of end-of-life treatment can be difficult to define. This is due to several factors such as the effect on the quality and length of life, financial costs, emotional costs and likelihood of success⁵. The American Thoracic Society states that a treatment should be considered futile if it is highly unlikely that it will result in “meaningful survival” for the patient.

The multiorganization statement (entitled: An official American Thoracic Society (ATS) / American Association for Critical Care Nurses (AACN) / American College of Chest Physicians (ACCP) / European Society for Intensive Care Medicine (ESICM) / Society of Critical Care (SCCM) Policy Statement: Responding to Requests for Potentially Inappropriate Treatments in Intensive Care Units) provides examples of potentially inappropriate treatments; however, no clear definition is provided⁶.

The Society of Critical Care Medicine and four other major critical care organizations have recently endorsed a seven-step process to resolve disagreements about potentially inappropriate treatments and provided a clear definition of inappropriate interventions in the intensive care units (ICU) environment⁷. ICU interventions should generally be considered inappropriate when there is no reasonable

inappropriate when there is no reasonable expectation that the patient will improve sufficiently to survive outside the acute care setting, or when there is no reasonable expectation that the patient's neurologic function will improve sufficiently to allow the patient to perceive the benefits of treatment. This definition should not be considered exhaustive; there will be cases in which life-prolonging interventions may reasonably be considered inappropriate even when the patient would survive outside the acute care setting with sufficient cognitive ability to perceive the benefits of treatment⁷.

Impact of Futility

Futility is still a much discussed topic, and as any clinician, ethics consultant, or ethics committee member knows, the concept has hardly left the clinic. It is still apparent in clinical decision making and is one of the most common reasons for an ethics consult or ethics committee review⁸. A major debate in medical ethics is the topic of requesting futile medical care. This issue can threaten the physician-patient relationship⁹. Dissipation of medical resources, elimination of or reduction in the opportunity for other patients in need of medical services, erosion of trust in the medical team, and the emergence of legal complexities for the medical team are only a few examples. Although the requests for medical futility compose only a small part of the health system in its totality, they can cause severe psychological and ethical tension for the patient, their family, and the medical team¹⁰.

This challenge also presents a major logistic problem as well: the allocation of health resources. For example, the ICU bed and the ventilator are aiding a patient whose imminent death is expected while concurrently, there is a patient in the hospital with a disease amenable to treatment (e.g. Guillain-Barré, a disease that paralyzes the muscles, including

the respiratory muscles, for a while, but is reversible and curable) and there is no possibility of setting up another bed and another device. The ventilator is connected to a patient who will die within a few days while another patient is in dire need of the same device to regain his health¹¹.

Clinicians mostly overestimate survival, and are not always accurate to the date of death. Many physicians in Saudi Arabia, for example, who may be less experienced than American physicians in distinguishing end of life issues, are unwilling to declare their certainty of an impending death¹².

In Saudi Arabia, for example, futile treatment is often requested by relatives¹³. The concept of "Cure-all", requested at times by the patient or his family, has led to extraordinary demands on the part of patients or substitutes (surrogate decision makers) to the effect that "anything possible will be done", which can create conflict and disagreements between the health care team and the patient or the relatives¹⁴.

Futile treatments and medical interventions should be considered in light of patients' outcome, and resource utilization in end-stage patients^{15,16}.

Islamic views

This is a subject of great dispute, even among Islamic scholars. Some actively do not advocate treatment if it is to merely prolong the final stages of life. The Qur'an states that death does not happen except by God's permission. Life is a divine trust and cannot be terminated by any form of active or passive human intervention, as its term is fixed by an unalterable divine decree. The Qur'an encourages the recognition of one's own limits. The ethical rule 'No harm shall be inflicted or reciprocated in Islam' expounded by Prophet Muhammad (ﷺ) has been evoked by Muslim jurists to allow withdrawal

of futile treatment after consultation with patient, family and others involved^{17,18}.

Decisions about aggressive invasive treatment to extend life are jointly made by all associated with the patient, including religious leaders. Withdrawal of life-sustaining treatments, when considered futile, is seen as allowing death to take its natural course; delaying the inevitable death is neither in the patient's nor in the public's best interests because of distribution of healthcare and financial resource¹.

Despite these clear Islamic teachings, Muslims believe in the reward they would be getting for enduring the suffering of the disease. Some Muslims strongly believe in God's miraculous cures and that it is within God's power to heal and cure even if the health care workers believe the case is futile or hopeless¹⁹.

Christian and Muslim patients and families may provide religious justifications for insisting on aggressive medical treatment at the end of life. Brett and Jersild consider that there are four commonly invoked reasons: (1) hope for a miracle, (2) refusal to give up on faith in God, (3) a conviction that every moment of life is a gift from God and is worth preserving at any cost, and (4) a belief that suffering can have redemptive value. For each of these 4 reasons, however, there are alternative Christian interpretations that point in the direction of limiting medical intervention under certain circumstances²⁰. Although these points were raised from a Christian perspective, they may be useful for physicians dealing with Muslims as well²¹. However Muslims should not cling to life at any cost, as death is considered a passage to eternal life.

For Muslims, treatment can be withheld in the case of a terminal illness such as widespread metastatic cancer. However, reversible illnesses should normally be treated (e.g. pneumonia), whereas terminal manifestations of an illness should not^{17,22}.

With respect to suffering, Muslims also hold that it may have redemptive value. Moreover, relief of suffering, if it does not conflict with the preservation of life, is a duty of Muslim patients and physicians²³.

When clinicians believe that an intervention is medically inappropriate or inhumane, they are not necessarily obligated to provide it simply because it is demanded on religious grounds. Instead, clinicians, preferably assisted by cleric, should discuss alternative religious interpretations with the patient or family, and should attempt to reach a consensus on the most appropriate limits to life-sustaining treatment²⁰. Some words are emotionally disturbing and detract from a rational discussion. Rather than referring to the patient's continued treatment as being futile — a word that implies that the patient himself is no longer useful — doctors can speak about the appropriateness of his care, which is more objective and considers what is in his best interest²⁴.

Relatives of Muslim patients, and occasionally physicians also, may come up with arguments similar to those outlined by Brett and Jersild to justify futile therapy. Therefore, their recommended approach and proposed counterarguments may be applicable²¹.

Fortunately, Muslims believe all healing comes ultimately from God and recognize that no cure is possible except by God's will. Although denying the possibility of a miracle is a sin and may be an expression of disbelief in God's power and sovereignty for Muslims, praying for a miracle does not obligate Muslims to demand treatment if an expert has deemed it of no benefit²³.

Resource utilization and outcomes in gravely ill patients must be observed. Futile treatments and medical interventions must be considered in light of outcomes. According to Islam, the physician needs to be certain of the inevitability of the impending death or else life should be sustained¹⁷.

Conclusions

Medical futility is a term used to describe medical interventions that are expected to result in little or no benefit to a patient. Some Muslims strongly believe in God's miraculous cures even if the physicians believe the case is futile or hopeless. In health service settings, any action that is not beneficial to the patient based on narrative or rational and empirical evidence is unacceptable and the patient and service providers need to cease pursuing it. Accordingly, since medical futility is not beneficial to the patient, it is inconsistent with the two principles of beneficence and non-maleficence and is, as such, wrong. The patient-centered care, based on physician-patient communication, seems to be the best approach to this problem, even with a patient with advanced heart failure or metastatic carcinoma.

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WITHDRAWING OR WITHHOLDING TREATMENT: CONTEMPORARY STANDARDS AND ISLAMIC PERSPECTIVES

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Abstract

Muslims believe that all healing comes from God, so they have the obligation to search out medical care and right to receive appropriate medical treatment. Islam considers disease as a natural phenomenon and a type of tribulation that expiates sin. Unfortunately many elder patients with chronic illness spend their last few weeks or months in hospitals. Life support is not required if it prolongs the agony and suffering associated with final stages of a terminal illness. The decision to withhold life support from a patient in the intensive care unit (ICU) is a modern medico-legal issue. When considering end-of-life decision making, both withholding and withdrawing life support are considered to be ethically and legally equivalent. Islamic law permits withdrawal of futile treatment on the basis of a clear medical decision by at least three Physicians.

Keywords: Withdrawing treatment, Withholding treatment, Do-not-Resuscitate, Medical ethics, Islam, ICD Deactivation.

Introduction

The tremendous technological advances of modern medicine have increased physicians' capability to carry out a wide spectrum of clinical interventions near the end-of-life. These new procedures have led to new "types" of living where a patient's cognitive functions are severely impaired while many physiological functions remain active. Patients, surrogate decision-makers, and physicians all struggle with decisions about what clinical interventions to pursue and when therapeutic intent should be replaced with palliative care. Some countries have an established legal frame work for withholding and withdrawing treatment with widely accepted standards for both competent and incompetent patients, but many developed countries do not¹⁻⁵.

Not only the patient who suffers in dignity will be rewarded in the hereafter, but also his family who bear with him the ordeal⁶. Muslim therefore believe that illness is a test of person's faith in God, and saving a life and caring for

someone is considered one of the highest imperatives in Islam.

The Glorious Qur'an says:

"مَنْ أَجَلِ ذَلِكَ كَتَبْنَا عَلَى بَنِي إِسْرَائِيلَ أَنَّهُ مَنْ قَتَلَ نَفْسًا بِغَيْرِ نَفْسٍ أَوْ فَسَادٍ فِي الْأَرْضِ فَكَأَنَّمَا قَتَلَ النَّاسَ جَمِيعًا وَمَنْ أَحْيَاهَا فَكَأَنَّمَا أَحْيَا النَّاسَ جَمِيعًا وَلَقَدْ جَاءَهُمْ رَسُولُنَا بِالْبَيِّنَاتِ ثُمَّ إِنَّ كَثِيرًا مِّنْهُمْ بَعَدَ ذَلِكَ فِي الْأَرْضِ لَمُسْرِفُونَ"

"Because of that, We decreed upon the Children of Israel that whoever kills a soul - unless for a soul or for corruption done in the land - it is as if he had slain the entire mankind. And whoever saves one - it is as if he had saved the entire mankind"⁷.

Death is inevitable and occurs only with a command from God. Muslims also believe that God is the ultimate healer of any physical and psychological illness. At the same time, Muslims are obligated to seek treatment, and should not terminate life.

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Patient's religious affiliation constitutes a key component in medical decision making. This is particularly pertinent in issues involving end-of-life decisions such as withdrawing and withholding treatment, medical futility, nutritional feeding and do-not-resuscitate (DNR) orders. These issues affect not only the patient's values and beliefs, but also the family unit and members of the medical profession⁸.

Seeking remedy

Seeking remedy in Islamic jurisprudence may be obligatory (mandatory) in certain life-saving situations or may be preferred or encouraged (*Mandoob*) in other situations. It may be facultative or (optional) (*Mobah*), or it may be (*Makrooh*) i.e. not preferred or discouraged. In some situations and with certain types of treatment it may be prohibited (*Haram*).

Seeking remedy may not be preferred (*Makrooh*), when therapy is unlikely to bring benefit, where harm or even inconvenience from therapy may exceed its benefit, and in end-of-life cases. Many companions of the Prophet Muhammad (ﷺ) refused therapy in their last illness, as they felt it would be futile e.g. *Abubakr al-Siddiq*-the first caliph, and *Muath ibn Jabal*⁶. Seeking remedy is facultative (optional) or (*mobah*) where the benefit is not proved or even doubtful and where ill effects of that mode of therapy are uncertain. It may be (*makrooh*) when therapy is unlikely to bring benefit and where harm or even inconvenience from the therapy may exceed its benefit.

The dominant position in the *Hanafi*, *Maliki* and *Hanbali* schools is that seeking medical treatment is permissible but not obligatory, while *Shafi* jurists hold seeking medical treatment to be a recommended act. All of the four schools of Sunni law regard that leaving medical treatment becomes sinful under exceptional circumstances and in the minority of cases. *Hanafi* jurists consider forgoing medical treatment, even if this non-action results in death, does not carry the weight of sin, while *Shafi* and *Maliki* authorities suggest that Muslims would be considered sinning should they not seek medical treatment when the

malady is treatable and will cause death if not treated^{6,9}.

Prophet Muhammad (ﷺ) said: "Seventy Thousands would enter paradise without being questioned. When asked who are they? He said: "those who refused *Ruqia* (Incantation) and treatment" (*Sahih Al-Bukhari*). He also praised the lady who agreed not to be treated for epilepsy and told if she remains patient she will enter paradise (*Sahih al-Bukhari*).

These two *Hadiths* do not contradict the Prophet *hadith* stating: "Verily, Allah sent down the disease and the cure, and for every disease he made a cure. Seek treatment, but do not seek treatment by the unlawful." (*Sunan Abi Dawud* 3874) for the following reasons:

1. As a general rule, if a person has an ailment, he/she should be treated. However, some people want to have "*Rukaya*" in advance, as a form of protection of possible disease in the future, which is Islamically acceptable. Others refuse to have such "*Rukaya*" to prevent a possible disease in future. These are the seventy thousands people mentioned in the *Hadith*.
2. Certain groups of people have strong belief in God, and they refuse to expose themselves to any kind of physical treatment. They consider trust in Allah (*Twakkul*) as a real treatment¹⁰.
3. At the end of life, and when treatment is considered futile, patients have the right to refuse such a futile treatment.
4. As for the lady with epilepsy, there was no available treatment for this illness at that time.

Medical advances make it possible to restore health and sustain life in circumstances previously regarded as hopeless. This capability brings with it considerable clinical, moral, legal, socio-cultural, and economic issues that challenge the values and goals of patient care.

Generally, patients whose conditions are expected to improve with intensive care measures are admitted to the intensive care unit (ICU). In other words, patients are not admitted to the ICU to die. However, families of patients

in the ICU are agonized with several dilemmas. Some of these dilemmas related to: (a) the justification for “prolonging” the suffering of their loved ones; (b) to what extent they should exhaust their financial resources in order to keep their loved ones in the ICU; (c) whether or not to give their consent to disconnect the ventilator once their patient is diagnosed to be brain dead; and (d) the validity for seeking extraordinary therapeutic measures for their patient when the prognosis is poor¹¹. Terminally ill patients may consume significant resources, including nursing care, and medications. Spiritual care is not necessarily religious, but religious care should always be spiritual.

The Family Role

Until recently, families in Muslim countries used to live together, children taking care of their parents until they die. Now, in affluent Muslim countries and with increasing employment of men and women, family members may live in different cities, or different locations and the time devoted to take care of parents particularly with disabilities or chronic illness is less. Increasingly and unfortunately many elder patients with chronic illness spend their last few weeks or months in hospitals¹². In most of Muslim cultures, illness is considered as a whole-family affair, and it is not unusual that the family members prefer that their patient is not informed about a life threatening diagnosis or prognosis. They may even demand to be the decision makers regarding end of life medical decisions, intubation and ventilation, cardiopulmonary resuscitation (CPR), admission to ICU and may often request heroic measures for their patients. Unfortunately, this may subject the patients to medical interventions and procedures that may be contrary to their wishes or preferences¹².

The ethics of a number of Asian and Eastern countries require that any fatal diagnosis or prognosis to first be disclosed to a family member. Following discussion with the treating physician, the family judge whether communicating the truth is in the best interests of the patient. The truth is often concealed for fear that it will extinguish the patient’s hopes,

leading to desperation, physical suffering, anxiety and a hastened death. Most families then tend to withhold crucial information that—in their best of knowledge—might lead to psychological suffering of their loved ones. It is narrated by Ibn Majah that the prophet ﷺ said: “When you enter upon one who is sick, cheer him up and give him hope of a long life, for that does not change anything (of the Divine Decree), but it will cheer the heart of the one who is sick.”

It is acceptable in Islam that the physician can withhold information from the patient if he has good reason that divulging the information to that patient is going to cause great harm, impair management or cause distress. The physician should document this fact in the patient’s file and should get the consent of the substitute decision maker (legal representative)⁵.

When the terminally ill patient is deemed to lack the capacity for decision making, he/she loses the right to autonomy. A substitute decision maker will have to make the necessary decisions.

This decision maker might have been designated previously by the patient. If no substitute decision maker has been previously designated, a member of the family (next of kin) could be the decision maker. An intriguing problem arises when there are several family members with different points of view. In principle, the doctors should not be involved in family disputes; the family should be told to discuss among themselves and come back with one unanimous decision. If family consensus fails, some order of precedence among family members can be used based on their respective strengths as inheritors. For example, the decision of the son takes precedence over the decision of the brother². This is agreed upon by Muslim Jurists in the Islamic Jurisprudence as “Rules of Guardians” (أحكام الولاية والوصاية).

Withdrawal of life-sustaining treatments

Withholding medical therapy in terminally ill patients is now been widely accepted around the world on medical, legal, ethical, and moral grounds. Critical care physicians and other health care providers have to base their

recommendations on scientific data and to limit treatment in case of medical futility¹³. A Questionnaire study conducted on 847 ICU physicians in 10 low-middle-income countries and 618 physicians from ICUs in six high-income countries showed that physicians from low-middle-income countries were less likely to limit cardiopulmonary resuscitation, mechanical ventilation, vasopressors and inotropes, tracheostomy and hemodialysis than those from high-income countries. They were more likely to involve families in end-of-life care discussions and to perceive legal risks with limitation of life-sustaining treatments and DNR orders¹⁴.

Withholding or withdrawing life support is still an area of controversy. Its applicability is weighed with benefits and risks and how futile the treatment is for the terminally ill patient. Withdrawing and withholding treatment can be "voluntary", where the conscious patient authorizes it, or if unconscious, the patient had expressed to his next of kin that he would prefer not to be kept alive on life support. It can also be "non-voluntary", where the decision to withdraw life support is made by the family of the patient, provided that it is suggested by the treating team.

Issues arising from the withdrawal and withholding treatment have not reached total consensus amongst the Muslim jurists. However, the article 62 of the Islamic code of medical ethics (Code of Conduct 1981) stated that, "the treatment of a patient can be terminated if a team of medical experts or a medical committee involved in the management of such patient are satisfied that the continuation of treatment would be futile or useless." It further stated that "treatment of patients whose condition has been confirmed to be useless by the medical committee should not be commenced"¹⁵.

The Saudi *Ulema's Fatwa* is a landmark in regulating resuscitative measures, stopping of machines in cases thought to be not suitable for resuscitative measures. The decision should be based on medical criteria and decided by at least three competent physicians. The family should be approached and the facts discussed fully with them^{5,16}.

Terminally ill Muslim patients are permitted to have life-sustaining treatments withheld or withdrawn when the treatment is futile, does not improve the patient's condition or quality of life, involves great complications, delays the dying process, or involves suffering¹⁶. In Saudi Arabia, for example, futile treatment is often requested by relatives¹⁷. A study from Lebanon, looking at withholding and withdrawal of treatment in an intensive care unit, highlighted concerns that the shift of focus to palliative care was taking place inappropriately late in the course of the patients' illnesses¹⁸. Delaying the inevitable death of a patient is neither in the patient's nor in the public's limited resources best interests. Western trained physicians have more exposure to medico-legal aspects and interpretation of these different medical terms to limit therapy. Further awareness and education is needed among Middle Eastern trained physicians to clarify the difference between of DNR/no code and comfort care.

The basic human rights of the patient, which include food, water, nursing, and painkillers, must still be provided and this can be done at home or hospice. The patient should be allowed to die peacefully and comfortably. Social workers and religious affairs personnel will be needed for the social and religious requirements of the patient and his family^{5,16}.

Health-care professionals need to be clear about the law and ethics of death and dying, as well as practice standards developed by their local regulatory body to prevent potential errors.

Deactivation of Cardiac Devices

At the end of life, the chronic heart failure patient often becomes increasingly symptomatic, and may have other life-limiting comorbidities as well. Implantable cardioverter defibrillator (ICD) is the treatment of choice for patients with poor left ventricular function who are at risk of sudden cardiac death due to ventricular arrhythmias.

However, patients who have an ICD may be denied the chance of a sudden cardiac death, and instead are committed to a slower terminal decline, with frequent DC shocks that can be painful and reduce the quality of life of the

patients, contributing to major distress for the patient and family.

When a patient with an ICD approaches the end of life, discussion with regard to ending ICD treatment may be indicated. ICDs can create an extra burden for patients, particularly from inappropriate discharges and prevention of a rapid death.

Deactivating an ICD or not performing a generator change is both legal and ethical, and is supported by both American and European guidelines. The respect for autonomy and individual personhood support a patient's right to dictate decisions about their treatment, and detailed informed consent to a procedure is a fundamental right. The patient has the right to refuse any treatment or to withdraw a previous consent to a treatment if it no longer satisfies his health care goals or if the perceived hardship of such treatment outweighs its perceived benefits¹⁹.

There is disagreement within the medical community with respect to deactivation²⁰. *Rady et al.* consider such an act either patient-assisted suicide or euthanasia²⁰. The American Heart Rhythm Society clearly affirms that "carrying out a request to withdraw life-sustaining treatment is neither physician-assisted suicide (PAS) nor euthanasia" and that "the right to refuse or request the withdrawal of a treatment is a personal right of the patient and does not depend on the type of the treatment".

Management of ICDs and Cardiac Resynchronization Therapy-Defibrillator (CRT-D) as patients near the end of their lives creates ethical dilemmas. Decisions about deactivation of implantable cardioverter defibrillators (ICDs) are complicated. Unilateral DNR orders (against patient/family wishes) have been ethically justified in cases of medical futility. Unilateral deactivation of ICDs may be seen as a logical extension of a unilateral DNR order. Few patients consider device deactivation at end-of-life, although a large majority believes that unilateral deactivation is not ethical/moral, even in the setting of medical futility. Advance care planning for these patients should address device deactivation²¹.

Left ventricular assist devices (LVADs) were initially used as bridge in patients awaiting heart transplantation, but they are currently implanted as destination therapy (DT) in patients with end-stage heart failure, who have failed to respond to optimal medical therapy, and who are ineligible for cardiac transplantation.

For heart failure patients at the end of their lives, continued circulatory support by an LVAD may become undesirable. Consensus is being developed within the transplant ethics community that deactivation of a LVAD is appropriate. Grounds for ethical permissibility are usually based on the well-established ethical and legal consensus that competent, informed patients (or their surrogates) have the right to request the withdrawal of any life-sustaining intervention they perceive as excessively onerous relative to benefits²². Some ethicists, however, remain opposed to device deactivation in many circumstances²³.

End-of-life care practice and decision making should be grounded in clinically trustworthy guidelines rather than opinions that are short of scientific validation and potentially cause more harm than benefit to LVAD patients. Although the technical, emotional, and psychological aspects of turning off or removing these devices are challenging, these aspects of care should not confuse the ethical considerations for how best to manage these devices at the end of life⁵.

In Islam, seeking remedy is facultative (optional) where benefit is not proved or even doubtful and where ill effects of that mode of therapy are uncertain. The person should have autonomy and decide for himself, whether to accept or refuse that modality of treatment⁶.

Conclusions

Although Muslims believe that all healing comes ultimately from God, they have a duty to seek out medical attention when ill and a right to receive appropriate medical care. The patients' and their families' trust in God may therefore deter some of them from making decisions about withdrawal of life-sustaining therapy. Many dying patients suffer prolonged and painful deaths, receiving unwarranted, invasive and expensive care, which affects their

physical, psychosocial and spiritual integrity. In Islam, the sanctity of human life is paramount, but life support is not required if it prolongs the final stages of a terminal illness. Islamic law permits withdrawal of futile treatment on the basis of the consent of the immediate family members who act upon the professional advice of the physician in charge or, as the Saudi *Fatwa* implies, it should be a clear medical decision by at least three Physicians. Muslim jurists also recognize the patient's right of refusal of futile treatment. The removal of basic necessities of life such as food and water will amount to actively killing the patient. The Prophet Muhammad (ﷺ) discouraged forcing the sick to take food or drink. However, Muslim families tend to express great concern when the nutritional intake of a patient is jeopardized. Some Muslim families may demand for a medical intervention to compensate for this decreased nutritional intake. Reference to the teachings of the Prophet (ﷺ) on this matter may alleviate the concerns of families. Ibn Qayyim al-Jawziyya in his book of "Tibi Nabawi" states that forcing a patient to have feeding is sometimes mandatory, particularly in cases of mental disturbances, confusion or unconsciousness²⁴. (For further details, please refer to our chapter "Artificial nutrition and hydration") in this yearbook.

Anything short of aggressive resuscitative measures will be applied to ease pain and relieve symptoms.

Explaining the truth about diagnosis, prognosis and treatment options generates the basis for freedom of the individual's choice. However, in serious illness, Muslim family members are usually closely connected, and the family often decide whether and how much to tell the patient. Many believe medically, legally, morally, and ethically there is no difference between withholding and withdrawing life-sustaining treatment. Withholding a treatment may seem more acceptable to healthcare professionals, patients, and their families.

There is a need for the medical profession to be guided on the ethical obligations, legal demands and religious expectations prior to handling difficult end-of-life decisions. The development

of comprehensive ethical codes in congruence with developing legal standards may offer clear guidance to the medical profession in making sound medical decisions.

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DO-NOT-RESUSCITATE ORDERS: ISLAMIC VIEWPOINT

Mohammed Ali Albar and Hassan Chamsi-Pasha***

Abstract

It is imperative to seek remedy in life-threatening situations. When treatment benefit is doubted, seeking remedy becomes facultative. If the treatment is futile, there is no need to continue. Resuscitation has the ability to reverse premature death. It can also prolong terminal illness, increase discomfort, and consume resources. The do-not-resuscitate (DNR) order and advance directives are still a debated issue in critical care patients. The DNR order in the case of terminal illness is encouraged in Islam.

Keywords: Terminal illness, medical futility, cardiopulmonary resuscitation, medical ethics.

Case history

Mrs. M. was a 56-year-old woman who was looked after by a physician in the hospital for 145 consecutive days. Her physician stated that he had some disagreements with her family and, therefore, would like to pass on the case to another physician. In addition, this patient was Muslim, and he thought a Muslim physician would be in a better position to understand and manage the social issues that had become challenging in the care of this patient.

She was in hospital for a protracted period because of multiple complications after being admitted initially for abdominal pain and anemia. She had gastrointestinal bleed secondary to erosive gastritis, respiratory failure, and then nosocomial pneumonia. She subsequently had multiple other infections with full blown sepsis that led to acute renal failure requiring dialysis. She finally ended up having a tracheotomy, peg tube feeding, and

continued hemodialysis. She continued to have multiple organisms and recurrent pneumonias and, therefore, no nursing home would admit her. The family refused a DNR for the patient. She continued to survive for a few more months in the hospital on dialysis and continued tracheotomy care. She ultimately died from worsening sepsis. A DNR order was entered in her medical records when the treating physicians and the family concurred that she was terminally ill¹.

Introduction

In the 40 years since its introduction, the do-not-resuscitate order (DNR) has become part of our society's ritual for dying.²

A well informed competent patient has decision-making capacity and has the right to refuse medical therapy, including treatment that will sustain life artificially.

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During critical illnesses and in case of sustained coma, such decision would be taken on his behalf by physicians and or next of kin. In Islamic societies, euthanasia and assisted suicide are forbidden. But the wishes of a patient not to have his dying process prolonged artificially in the presence of hopeless prognosis, are to be respected. Such wishes may be declared in an advance directive or by accepting a standing Do Not Resuscitate (DNR) order³.

Cardiopulmonary Resuscitation

Cardiopulmonary resuscitation (CPR) is now routinely performed on any hospitalized patient suffering a cardiac or respiratory arrest. The frequent performance of CPR on patients who are terminally ill or who have a remote chance of survival has raised concerns that resuscitation efforts may be utilized too broadly. The health care providers soon realized that CPR was not appropriate for every patient, and this led to the emergence of Do Not Resuscitate (DNR) policy to identify patients who would not benefit from CPR.

Concerns were raised that many patients were kept alive through futile medical therapy. This contributed to further worries about the emotional and financial burdens imposed on the patients and their families. Advanced invasive procedures and treatments that may sustain life may not confer any foreseeable benefit, and in fact may invoke further suffering to the patient and the family⁴. Therefore, CPR may be withheld if, in the judgment of the treating team, an attempt to resuscitate the patient would be futile.

Do Not Resuscitate

“Do Not Resuscitate” (DNR) is a medical order to provide no resuscitation to individuals for whom resuscitation is not warranted. The American Heart Association in 2005 moved from the traditional do not resuscitate (DNR) terminology to (do not

attempt resuscitation) (DNAR). DNAR reduces the implication that resuscitation is likely and creates a better emotional environment to explain what the order means. Allow natural death (AND) is the name recommended in some settings to make the meaning even clearer. Most hospitals still use the obsolete DNR term. Medical staffs should consider moving to DNAR and in some settings to AND, appropriate use of as language here is extremely important⁵. A Do Not Treat (DNT) order relates to treatment of the primary disease condition, such as cancer, when that treatment is considered futile. A DNT order is sometimes misunderstood to mean that resuscitation is not carried out for cases of reversible cardiorespiratory arrest⁶.

Do not resuscitate (DNR) is an important entity of medical practice. However, only a few studies from Arab Muslim countries have addressed this issue⁷. A cohort study of data prospectively collected from 15/10/2008 through 15/01/2009 for patients where DNR was initiated in a tertiary care center in Saudi Arabia. DNR was initiated in 65 patients referred to the intensive care unit (ICU). DNR was initiated by ICU physician in 80% of cases and by most responsible physician (MRP) in 20% of cases. Documentation of discussion with the family was absent in 53.8% of cases. The authors concluded that ICU physicians have a role in initiating DNR⁷. The need for education of the public is an essential part of DNR practice. The global medical community must educate patients and families to realize that there often comes a point when best medical care will not result in survival and will only prolong the suffering of patients and their loved ones.

Islamic view

The Islamic perspective regarding DNR decisions is a moving target. In a *Hadith*, Prophet Muhammad (ﷺ) said:

“None of you should wish for death because of a calamity be falling him but if he has to wish for death, he should say: ‘O Allah! Keep me alive as long as life is better for me, and let me die if death is better for me’”⁸.

There is no relevant distinction between withholding and withdrawing life-sustaining treatment. The Islamic religion’s concept concerning DNR decision has been clarified by the Presidency of the Administration of Islamic Research and *Ifia*, Riyadh, Kingdom of Saudi Arabia (KSA), in their *Fatwa* No. 12086 issued on 28/3/1409 (1989). The *Fatwa* states that: “if three knowledgeable and trustworthy physicians agreed that the patient condition is hopeless; the life-supporting machines can be withheld or withdrawn. The family members’ opinion is not included in decision-making as they are unqualified to make such decisions”. The *fatwa* was based on questions raised on using resuscitative measures on the following conditions:

1. If the medical file of the patient is already stamped: “Do not resuscitate”, according to the patient’s or his proxy’s will and the patient is unsuitable for resuscitation, as agreed by three competent specialized physicians, then there is no need to do any resuscitative measures.
2. If three physicians have decided that it is inappropriate to resuscitate a patient who is suffering from a serious irremediable disease and that his death is almost certain, there is no need to use resuscitative measures.
3. If the patient is mentally or physically incapacitated and is also suffering from stroke or late stage cancer or having severe cardiopulmonary disease and already had several cardiac arrests, and the decision not to resuscitate has been reached by three competent specialist physicians, then it is permissible not to resuscitate.
4. If the patient had irremediable brain damage after a cardiac arrest and the condition is authenticated by three competent specialist physicians, then there is no need for

the resuscitative measures as they will be useless.

5. If resuscitative measures are deemed useless and inappropriate for a certain patient in the opinion of three competent specialist physicians, then there is no need for resuscitative measures to be carried out. The opinion of the patient or his relatives should not be considered, both in withholding or withdrawing resuscitative measures and machines, as it is a medical decision and it is not in their capacity to reach such a decision”⁹.

In summary, the *fatwa* delineates six situations where a DNR is granted: if the patient arrives dead at the hospital, if the panel of physicians determines that the condition is untreatable and death is imminent, if the patient’s condition does not make him or her fit for resuscitation, if the patient is suffering from advanced heart or lung disease or repeated cardiac arrest, if the patient is in a persistent vegetative state, and if resuscitation is considered futile⁹.

Although, according to the *fatwa*, families and guardians cannot decide on the application or removal of resuscitation measures or procedures, as they are not considered qualified, the medical practice in Saudi-Arabia involves the guardians and families in the discussion of DNR. The DNR Form is valid only when it is signed by three qualified physicians (mainly 2 consultants, and 1 staff physician), and only acceptable within the hospital during the patient’s admission. When signed, the form is kept in the patient’s record, and it has to be reviewed by the physicians according to the institution’s policies.

The *Fatwa* of this Permanent Committee in Saudi Arabia should be explained to the family. If the family still insists on doing everything possible then they should be offered the possibility of transferring their patient to whichever hospital agrees to accept the patient^{10,11}.

Based on the *Fatwa*, some hospitals in KSA have implemented a “No Code” policy. The policy had led to a dramatic reduction in futile CPR. In fact, DNR orders was shown in one study to be written for 66% of patients who die in ICU and 82% of patients who die in the wards in a tertiary care hospital in Saudi Arabia. However, there is still a great variability in DNR practices. For example, DNR orders are more likely to be written on day one of hospitalization in cancer patients with widespread metastasis, and on the last hospital day in cirrhotic patients, underscoring the delays in recognizing the futility of the treatment in some patients¹².

A decision on DNR, particularly early in the hospital stay, can bring about significant resource use reduction for an identifiable group of patients¹³. Identifying these patients early and carefully evaluating them based on objective and well-validated criteria would allow conducting therapeutic limits reducing unnecessary patient suffering and medical care costs. CPR should only be performed on patients, who are likely to benefit from it. Similarly, admission to ICU should be offered only to patients who are likely to benefit from the admission.² Not all patients have to be admitted in the ICU for dying; the ICU is not a “dying place” but rather an area where life support is provided to patients with reasonable chance of recovery.

The implementation of this *Fatwa* may vary among different Muslim countries. This *Fatwa* is contrary to the practices in the United States where patient wishes and family involvement are considered a top priority¹⁴. According to this *Fatwa*, a DNR order or withdrawal of care is a physician-based decision that does not need involvement of families. However, in a survey among 461 Muslim physicians in the US and other countries, more than half of the respondents did not agree with this and nearly one-third felt that families could over rule the patient’s decisions despite his wishes¹⁵.

We believe that it would be impractical not to discuss the issue of DNR with the family, since it is not uncommon for a member of the family to be around when the patient sustain a cardiac arrest and it would be very difficult for the doctor not to react to the patient’s cardiac arrest as he is bound by the DNR policy. Poor explanation to the family resulted in family dissatisfaction in most of the cases, as reported in Western studies¹⁶.

In a cross-sectional study conducted between May and December 2013 in Jeddah, Saudi-Arabia, a total of 140 questionnaires were sent to interns and residents to find out whether they are familiar with these policies and their attitudes toward DNR. While more than half of both interns and residents were familiar with the term DNR, the greatest proportion of both were not sure whether a clear DNR policy exists in their hospitals and whether a DNR policy exists at a national level. The authors concluded that there was a lack of familiarity with DNR’s policies and the *fatwa* and also a lack of understanding when it comes to treating DNR-labeled patients. The majority opinion was to include the patient in the decision-making process despite the fact that the patient is excluded according to the *fatwa*¹⁷.

The Islamic Medical Association of North America (IMANA) believes that when death becomes inevitable, as determined by physicians taking care of terminally ill patients, the patient should be allowed to die without unnecessary procedures. While the patient is still alive, all other ongoing medical treatments can be continued. IMANA does not believe in prolonging misery on mechanical life support in a patient in a vegetative state, when a team of physicians, including critical care specialists, have determined that no further attempt should be made to sustain artificial support. Even in this state, the patient should be treated with full respect, comfort measures and pain control. The patient should be allowed to die

peacefully and comfortably. No attempt should be made to enhance the dying process in patients on life support¹⁸.

IMANA also recommends that the patient 'be permitted to die naturally with only the provision of appropriate nutrition and hydration' and any medications and procedures that are necessary to provide comfort and alleviate pain. The patient should not be neglected or left to die in agony⁷.

Furthermore, the Islamic Organization for Medical Sciences (IOMS) has recommended the following: In his defense of life, however, the doctor is well advised to realize his limit and not transgress it. If it is scientifically certain that life cannot be restored, then it is futile to diligently keep on the vegetative state of the patient by heroic means of animation or preserve him by deep-freezing or other artificial methods. It is the process of life that the doctor aims to maintain and not the process of dying. In any case, the doctor shall not take a positive measure to terminate the patient's life¹⁹.

If the patient is competent enough (which is rare in such cases), it should be discussed with him. He should be assured of receiving all necessary care and medication to alleviate pain and distressing symptoms. If the patient is not competent enough, DNR should be discussed with the family members especially the most appreciative and comprehending person¹¹.

Physicians' beliefs

Physicians' religiosity affects their approach to end-of-life care (EOLC) beliefs. Studies exist about end-of-life care beliefs among physicians of various religions. However, data on Muslim physicians are lacking. Saeed et al studied the beliefs centering on aspects of end-of-life care among 461 Muslim physicians in the US and other countries¹⁵. The survey was targeted toward Muslim physicians practicing in the United States,

Pakistan, India, Bangladesh, United Kingdom, and Kingdom of Saudi Arabia. Nearly 66.8 % of the respondents believed that DNR is allowed in Islam, compared to 7.4 % of the respondents who did not believe that it is allowed. Muslim physicians' beliefs on EOLC issues are affected more by the area of practice, country of origin and previous experience in talking about comfort care, than by the religious beliefs¹⁵. There is a gap of knowledge on EOLC beliefs with respect to do not resuscitate (DNR) orders and advance directives in this group of physicians.

Ur Rahman et al²⁰ designed a questionnaire which was sent to members of the Pan Arab Society of Critical Care. The majority of responders were trained in Western countries. Admission of DNR patients to the ICU was acceptable for 47.7% of respondents. DNR was considered equivalent to comfort care by 39.5%. They concluded that the training background and level of seniority in critical care provider does not impact opinion on most of end of life issues related to care of terminally-ill patients²⁰.

DNR in Practice

Withholding Medical therapy at the end of life has now been widely accepted in many countries around the world on medical, legal, ethical, and moral grounds²¹. However, there is no worldwide DNR policy. It is clear that there is a need for standardization. To improve the attitude about DNR orders, it is necessary to achieve several goals such as: increased communication, consensus on law, increased trust among patients and health care systems, and improved standards and quality of care to respect the patient's will and the family's role²¹.

Hospitals are required to have a (DNR) policy in place. Practitioners are advised to first consider what is best for the patient and, when in doubt, to communicate with patients or surrogates and with colleagues to arrive at the

most appropriate care plan. If irreconcilable conflicts arise, consultation with the institution's bioethics committee, if available, is beneficial to help reach a resolution²².

Unfortunately, the advance directive is not a usual practice in Middle Eastern countries. DNR is never discussed with patients but rather with the family, and only when the situation is critical.

Cultural, educational, and religious issues were found to be the main reasons for poor communication between staff and family members emphasizing the need to continuously evaluate DNR practice in Arab and Muslim countries⁷.

Conclusions

It is important to note that a DNR order implies that a DNR patient is to receive all treatments except for cardiopulmonary resuscitation. All interventions that ensure patient's comfort and dignity continue to be undertaken. The DNR order is a physician decision, but the family must be informed and the medical and religious *Fatwa* explained fully to them (without seeking their involvement in the decision).

A clear policy from the ministry of health regarding DNR and end of life issues is urgently needed for all hospitals and health care providers in most, if not all, Arab and Muslim countries.

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ARTIFICIAL NUTRITION AND HYDRATION

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Abstract

Hydration and nutrition are essential for the maintenance of life. Discontinuation of artificial support can result in distress for patients, family members, and healthcare providers.

Proponents of maintaining hydration argue that hydration is a basic human need and can reduce and prevent dehydration-induced delirium, opioid neurotoxicity, and/or fatigue in terminally ill patients. Opponents have argued that parenteral hydration is burdensome and prolongs the dying process.

Islamic law does not allow the withholding or withdrawal of basic nutrition because this would result in death by starvation. Terminal patients continue receiving nutrition, hydration, and general supportive care without discrimination.

Keywords: Hydration, nutrition, terminal illness, medical ethics.

Illustrative case #1:

Mrs F 82 years old, is in a nursing home, where she exists in a near-vegetative state. She had previously worked as a nurse for many years, caring for patients with Alzheimer's disease. Before being diagnosed with the disease herself, she had stipulated in a written advance directive that she be allowed to die if she was ever in a state of advanced dementia. In spite of this, the facility's nurses and care aides were instructed to continue to give her food and fluids, as doing otherwise would constitute neglect.

When challenged by her daughter, the facility argued that Mrs.F opened her mouth when being fed, which they saw as a sign that she wanted food. They rejected the notion that this could be a reflex action. Mrs. F's daughter

filed a lawsuit arguing that this continued feeding constituted battery¹.

Case # 2

An 89-year-old woman with vascular dementia lives in a nursing home. She is able to walk, talk, and feed herself, but needs assistance with dressing and toileting. She is transferred to the hospital for a large ischemic stroke; MRI confirms diffuse hypoxic brain injury.

Four days later, she withdraws to pain, has unintelligible speech, does not respond to commands, but has corneal and gag reflexes. Being unable to swallow, a nasogastric tube is placed for nourishment.

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Her son, the healthcare proxy, is hopeful she will return to her previous state, wants aggressive resuscitative efforts, and is adamant that a percutaneous endoscopic gastrostomy (PEG) tube be placed; otherwise, his mother will starve. Her primary team is concerned that a PEG will not achieve the son's goals for the patient².

In both cases an ethical conflict between the patient's proxy and the primary team exists. In the first case, the patient's daughter is refusing feeding while in the second case the son is demanding the tube feeding.

Introduction

In patients at the end of life (survival days or weeks), artificial hydration and nutrition pose clinical, ethical, and logistical dilemmas in the Western culture resulting in debates for and against such interventions³. Currently, there are differences in perceived benefits of artificial nutrition/hydration between healthcare providers and the general public⁴. Wide variations in practice patterns exist depending on the setting (inpatient versus hospice), and culture. A qualitative study examining the attitudes of healthcare providers regarding artificial nutrition and hydration at the end of life, compared the different attitudes of physicians from Australia with Dutch doctors. The Dutch physicians often take primary responsibility for providing artificial nutrition and hydration while the Australian doctors are more likely to let the patient's family make the decision⁵.

Consequently, communications provided by the healthcare providers about artificial nutrition/hydration is inconsistent which may cause confusion for patients and family members. Patients and family members are often not involved in the decision-making; and when involved, their decisions are influenced by their treating physicians' recommendations⁶.

Although discussions about withholding or withdrawing of life-sustaining treatments often include decisions about stopping or never starting artificial nutrition and hydration (ANH), feeding issues continue to be among the most emotional and value laden for patients and families. The decisions are often considered separately from decisions around the use of 'machines'. The ethical decision-making process is difficult when considering the risks and benefits of feeding tubes in patients with advanced dementia².

The majority of terminally ill patients will derive no clinical benefit from parenteral nutrition, with some exceptions that include patients with a good functional status and a nonfunctional gastrointestinal tract or a slow growing tumor³. Dehydration in turn can cause or aggravate pre-existing symptoms such as fatigue, sedation, and delirium. Withdrawal of nutrition and hydration, on the other hand, causes physiological responses which are, at the very least, unpleasant for those caring for the patient to witness^{7,8}. A 2016 study out of Taiwan suggests caregivers often prefer life-sustaining treatments more so than patients; it is suspected that caregivers tend to feel guilt over 'not having done enough' for their parents⁹.

Arguments for hydration state that hydration provides a basic human need, provides comfort and may prevent uncomfortable symptoms: e.g. confusion, agitation, and neuro-muscular irritability, may prevent complications (e.g. neurotoxicity with high-dose narcotics), relieves thirst, and provides minimum standards of care; not doing so would break a bond with the patient.

Those arguing against hydration state that intravenous therapy is painful and intrusive, it interferes with acceptance of the terminal condition, prolongs suffering and the dying process, and leads to less fluid in the gastrointestinal tract with less vomiting, and less pulmonary secretions and less cough, choking, and congestion³.

There is scarcity of scientific evidence to support either approach, with only a few prospective or randomized controlled trials conducted in patients at the end of life. Controlled clinical trials addressing the potential symptomatic and survival benefits of artificial hydration are difficult to conduct because of methodological and ethical reasons.

Consensus statements from both the American Geriatric Society and the American Academy of Hospice and Palliative Medicine (AAHPM) do not recommend feeding tubes in advanced dementia, and instead recommend oral assisted feeding. However, both professional societies stressed the importance of respecting cultural beliefs and having high-quality patient-centered meetings. They recognize families will consider ANH as basic sustenance for faith-based, cultural, and personal reasons, and these views should be explored, understood, and respected^{10,11}.

The American Society for Parenteral and Enteral Nutrition's (ASPEN) position paper emphasizes that, although from scientific, ethical, and legal perspectives there should be no differentiation between withholding and withdrawing of ANH, withdrawing is more emotionally laden than withholding, especially within specific cultures.

It recommends learning relevant religious positions and cultural attitudes one will encounter in the regional population².

The decision about withholding and withdrawing artificial nutrition and hydration includes the clinical course of the disease, religious beliefs, cultural identity of the patient, family, and healthcare provider, the cost of treatment, legal, ethical and moral issues^{12,13}.

Islamic View

A recent position paper of the American Society for Parenteral and Enteral Nutrition advises respect for the religious, ethnic, and

cultural background of patients and families 'to the extent it is consistent with other ethical principles and duties. However, little data is found in the English literature about religious and cultural attitudes regarding the ethics of withholding and withdrawing artificial nutrition and hydration, apart from Jewish and Catholic perspectives^{14,15}.

Prophet Muhammad (ﷺ) discouraged forcing the sick to take food or drink. However, Muslim families tend to express great concern when the nutritional intake of a patient is jeopardized. Some Muslim families may demand for a medical intervention to compensate for this decreased nutritional intake. Reference to the teachings of the Prophet (ﷺ) on this matter may alleviate the concerns of families and facilitate their understanding of the anorexia/cachexia syndrome associated with malignancy, for example. However, in patients who are slowly deteriorating, one should maintain the required amount of nutrition and hydration until the last moment of life^{16,17}.

In Islam, nutritional support is considered a basic care and not a medical treatment, and it is a duty to feed people who are no longer capable of feeding themselves¹⁵. Islamic law, therefore, does not allow the withholding or withdrawal of basic nutrition because this would result in death by starvation, which is a crime according to Islamic law and contrary to both the fundamental importance of the sanctity of life and the duty to provide nutrition to a fellow Muslim, and a human being¹⁶.

If hydration and feeding is stopped, the patient will suffer from dehydration and hunger for 10-14 days, and it would be more humane to inject him with a medicine that will let him die in seconds rather than torturing him for 2 weeks. However, this is considered Euthanasia which is emphatically prohibited by Islamic Jurists¹⁷.

The Islamic Medical Association of North America (IMANA) states that: "when death

becomes inevitable, the patient should be allowed to die without unnecessary procedures. However, no attempt should be made to withhold nutrition and hydration¹⁸.

The Saudi Council for Health Specialties has advised that “intravenous fluids and nutrition should not be withheld from a patient who cannot otherwise be fed normally, regardless of the nature of his disease or its duration”¹⁹. In a prolonged terminal phase, active disease treatment may be determined to be medically futile and patients are transferred to palliative care where they receive nutrition, hydration, and pain control, as well as social and psychological support²⁰.

Conclusions

Discontinuation of artificial nutrition or hydration results in distress for patients, family members, and healthcare providers. Research showed no clear benefits of parenteral hydration on symptom burden or survival for terminally ill patients. However, dehydration can cause or aggravate pre-existing symptoms such as fatigue, sedation, hunger and delirium. The Islamic view on this subject is that nutrition and fluids should not be withheld from a patient who cannot be fed normally, regardless of the nature of the disease or its duration.

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DEFINITION OF DEATH: CONTEMPORARY CONCEPTS AND ISLAMIC PERSPECTIVES

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Abstract

Death is a universal fact of life. In this article I present its different concepts. The simple definition of death as being permanent and irreversible cessation of cardio-respiratory function has been challenged by technological advances in today's world, and brain death concept has been introduced. It would have been no problem except that it is inseparably linked with organ removal and transplantation, resulting in hesitation or reluctance of acceptance. Some reject the definition altogether, others accept it wholeheartedly, and many are in between. Scientific explanations of brain function and brain death are discussed along with criteria and methods used for the diagnosis of brain death with their complications and pitfalls. Acceptance/rejection of the concept of brain death in Islamic Jurisprudence, discussions and rulings of Islamic *Fiqh* councils and in other religious-cultural settings is presented.

Keywords: Brain Death, brainstem death, transplantation, definition of death, Islamic jurisprudence, diagnosis of death

Introduction

Death is easy to see or diagnose, but defining it requires a more careful and calculated approach. Simply put, it is "irreversible and permanent loss of ability of the lungs and heart to function"¹. Because of the technical ability to maintain these functions for any length of time, we have to come up with additional definition of some kind giving rise to the development of the concept of brain death.

This was necessitated by the first heart transplant performed in 1967 in South Africa², which was immediately followed by a world-wide publicity, along with the associated religious, moral, ethical and legal questions³.

For example, in the USA, a president's commission was established "for the study

of ethical problems in medicine and biochemical and behavioural research" that provided these "guidelines for the determination of death"⁴. Its definition of a dead individual is: "an individual who has sustained; a) permanent and irreversible loss of cardiac and respiratory functions, and b) who has developed a complete loss of whole brain function including brain stem, is dead". The inseparable question of organ transplantation from brain death forced the world scientists and ethicists to make more definitive statements.

Also it forced religious and legal entries to race toward some kind of understanding of 'brain death' as death. That brought out varying statements in favor (accepting it) or against (rejecting it) that we will discuss.

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Diagnosis of Death

We will consider the accepted criteria and methods established for diagnosis of death in today's practice of medicine and then take up the discussion, as to how these criteria have evolved and how are they accepted in the cultures and courts of the rest of the world.

When a physician examines a patient in complete coma and finds no function of heart and lungs he declares the patient dead. We then discuss "Brain Death" as death and how to diagnose it.

We start with American Academy of Neurology that had proposed standard methods for diagnosis of brain death in 1995⁵ and updated them in 2010⁶.

The following brief account is derived from the 2010 updated document. Basically three essential points are required which are basic bedside tests:

1. Evaluation of coma
2. Evaluation of reflexes including brainstem reflexes, and
3. Evaluation of Apnea.

A fourth, iso-electric EEG, is added, but we will consider that in "Ancillary Tests".

1) Evaluation of Irreversible coma:

In an unconscious patient, motor response (such as wincing) to an obnoxious stimulus (such as pinching of TM joints, or supra-orbital bony areas) must be absent which can sometimes be observed in other, reversible comas. Careful evaluation demands that all the conditions that mimic irreversible coma, such as drug overdose of some antidepressants or CNS depressants⁷ or baclofen⁸ or other medical conditions, such as fulminant Guillain-Barre Syndrome⁹ or fulminant de-efferentation¹⁰ must be excluded before "irreversible coma" is diagnosed. Depending upon the history of the patient, the following precautions have been recommended to ensure accuracy of the tests.

* If drug screen has to be performed and blood levels are noted and evaluated: the

time to wait before testing is five times the half-life of the drug (assuming normal hepato-renal function.)

* There should be no recent neuromuscular blocking agent administration or CNS depressant medications or severe electrolyte or acid-base disturbance.

* If the person is or has been hypothermic, hypothermia should be corrected first. The blood pressure must not be lower than 90 Hg systolic, and adequate blood volume must be assured.

Other tests of the brain, such as CT, MRI scan etc. may be required for diagnosis of brain injury or other cerebral or non-cerebral conditions causing coma. It is useful for the physician to evaluate these tests himself. These recommendations are given here to ensure not only accuracy but also uniformity of tests as much as possible.

How much time should have passed after the event or cause for coma before the approach to such diagnosis? There is no satisfactory study for this time interval⁶, as it depends so much upon the neurological evaluation in each case. In addition, the physician must make extra effort to rule out conditions like Vegetative State or Locked-in Syndrome, or other conditions that mimic such coma.

2) Evaluation of Brainstem Reflexes, for brain death:

a) Pupils show no reaction on exposure to light (in order to examine the pupils use magnifying glass if necessary.)

b) Corneal reflexes are absent. Make a swift application with a wisp of cotton wool to exposed cornea. The normal response is a blink. In brainstem death there is loss of the blink reflex.

c) Loss of Ciliospinal reflex. There is an ipsilateral pupillary dilatation in response to obnoxious stimulus applied to each side of cervical skin area. This should be absent.

There are pitfalls here because some patients may have unequal pupils or poorly reacting or non-reacting pupils due to other medical conditions such as diabetic neuropathy or from previous trauma etc. Careful history of

prior pupillary abnormalities should be obtained/ascertained.

d) Oculocephalic reflexes should be absent. Also called "Doll's eye Test or Maneuver". Before undertaking the test, make sure there is no cervical trauma or other contraindications.

In a comatose patient, rapid passive movement of the head to one side or the other is performed while eyes are looked at carefully. If the brainstem function is intact, a slow conjugate movement of the eyes to the opposite side of the head turning will be observed. The eyes exhibit no movement in brainstem death.

e) Caloric test. The head is placed at 30 degree angle flexion to allow the horizontal canal to become vertical. Examine the ear canals to see if they are clear and the drum is not perforated, and then proceed to inject 40 to 50 mls of ice water into the canal. A tonic response of eyes to the injected side is observed in coma. In coma due to brainstem death no movement will be seen. A five minute interval should elapse between the testing of the two sides.

f) Jaw jerk: Place your index finger at the chin and strike with the percussion hammer on your finger. Normally, flexion of lower jaw occurs. In case of brain stem death this reflex is absent.

g) Gag reflex or pharyngeal reflex. Stimulate the posterior wall of the pharynx with a tongue blade. The pharyngeal walls will contract. If the comatose patient fails to gag it indicates failure of the brainstem function.

3) *Evaluation of Apnoea:*

The principle involved in this test is that after adequate oxygenation, the artificial respirator is disconnected so that the comatose patient's arterial CO_2 rises to a sufficient level at which the normal intact brainstem center would trigger the resumption of respirations. If the chest movements fail to appear while the PaCO_2 has gone up to 60 mmHg, the Apnoea test is positive. There are many ways of performing this test and all are satisfactory

and safe but suitable comparative studies for determining evidence-base information are not available. In fact, that is true for most of the tests given above. Briefly, the apnoea test is performed when BP is stabilized, blood volume, PaCO_2 , PO_2 , acid-base balance and electrolyte balance all have been corrected, core body temperature is normal and frequent evaluation of ABG (Arterial blood Gases) is available for keeping a check on PaCO_2 and PO_2 . Baseline PaCO_2 is performed (normal being between 35-45 mmHg). Hyper oxygenate the patient with 100% O_2 for 10 minutes. Check ABG and then disconnect the respirator. Watch the patient carefully for any chest movements of respiration and as the PaCO_2 rises and PO_2 falls wait for 8 minutes and then reconnect the respirator. If there were no movements of the chest, and PaCO_2 had gone up to 60 mmHg, the apnoea test is positive.

The physician needs to be aware of some movements that can be observed in brain dead patients¹¹. These are spinal cord generated or result from other reasons. These include occasional limb movements (not the flexion extension type withdrawal movement), chest movements that can be generated by some technical reasons¹², transient bilateral finger tremor¹³, and ocular micro tremor¹⁴.

4) *Ancillary Tests:*

For diagnosis of brain death, the above is sufficient, but sometimes, due to either the type of injury or some other reasons, full examination cannot be performed and additional tests become necessary. Most commonly, EEG is used. The EEG technician uses a special "brain death montage" for recording for half hour. The absence of brain waves is considered confirmatory for brain death. When isoelectric or flat EEG (absence of brain waves) is recorded, a repeat EEG is required for confirmation after 6 to 24 hours. The effect of drugs that can cause reversible flat EEG need to be excluded. Sometimes we need to record the absence of circulation in

the brain and isotope brain scan or angiogram or magnetic resonance (MR) angiogram is undertaken. More recently, Somatosensory Evoked Potentials which depend upon intact brainstem have also been recommended. The choice of a particular test is made by the evaluating physician.

A word about brain death in children. The younger brain has more potential for recovery, therefore the time intervals required before brain death is confirmed has to be longer for children while the criteria are the same. Another rule that governs most situations is that the brain death is accepted only after an independent second physician's evaluation has been performed, usually 6 to 14 hours later.

Discussion

Ethics of medical practice and for organ transplantation were not unknown before the nineteen sixties¹⁵. The first heart transplant brought these subjects into sharp focus and the scientific world along with the social, religious, and legal sections of the society were driven to look into the questions of life and death more urgently and more seriously. How to define what is life and what is death when technologically we can maintain the circulatory and respiratory functions of a person artificially for endless time? The accepted criteria for diagnosing brain death appeared soon¹⁶ and along with that the "Ethical Guidelines for Organ Transplantation"¹⁷ and a statement for heart transplant was independently issued by "House of Delegates" of the American Medical Association¹⁸ with similar reactions in other parts of the world. The medical world produced well-thought of criteria in most countries where brain death was accepted for scientific justification of organ removal from the brain-dead individuals and for disconnecting the technological support for maintaining life. In the USA, A. Earl Walker, a well-respected neurosurgeon, wrote the American view point¹⁹ and Advances in the determination of cerebral death²⁰. A third generation criteria for brain

death were proposed in 1989²¹. The American Academy of Neurology introduced an updated set of criteria in 1995⁵ that have been tested thoroughly, and 15 years later, the Academy published the same guidelines with "evidence-based" guidelines⁶ that I have used in this article extensively. In the UK, brainstem death was recognized as death of the individual²². The Conferences of Medical Royal Colleges published their methods of diagnosis of death in 1976²³ and again in 1979²⁴. Brain death recognition was reported by the well-known British neurologists, C. Pallis and B. Mac Gillivray who claimed EEG was not necessarily required for diagnosis of brain death and also that brainstem death is enough for the diagnosis as the centers of cardiac and respiratory functions are located in the brainstem²⁵. Bryan Jennett and others, well-respected neurosurgeons in the UK presented their cases of brain death, mainly in support of the concept of brain death²⁶. Similarly, the statements about acceptance of brain death were published by Australia and New Zealand Intensive care society. Japanese criteria appeared late because of immediate controversy and litigation against the second (after the South African first) heart transplant performed by a Japanese surgeon (Dr. Wada) in 1968²⁷, and heart transplant was banned there for 15 years. The cultural orientations in Japan being different, the criteria were introduced in 1987^{28,29} and brain death started getting accepted even though the media and society remained sceptical. Slowly the acceptance of brain death came in Japan in the late nineteen nineties³⁰.

Opposing views:

Opposition for accepting brain death had started as soon as the criteria were proposed, but that was more in the lay media²⁷. Scientific objections came after appraisal of the criteria was published³¹. Bryan Jennet has reviewed the controversies critically more recently³². On 'Brain Death' a status report appeared in 1977³³ that was severely criticised by Paul Byrne and his

collaborators³⁴. Their arguments for rejecting were mainly based on the fact that the brain is not destroyed and therefore it is not death of the individual. That is the same reasoning in USA²⁵ and also in Japanese culture²⁷. Their arguments consider some definitive statements of brain death as doubtful such as "irreversible is a non-empirical confusion" and striking on the very basis of brain death concept. They also attacked the British stand on brainstem death by stating that the death of only a part of the brain cannot be considered as an overall death.

Their cautionary or admonishing statement, that such diagnosis is being hurriedly approached for convenience (for organ removal) by some, must be acknowledged. They argue that certainty of death can only be arrived at when "rigor mortis sets in or putrefaction of the body starts, therefore brain liquefaction must be observed for certainty of brain death". This argument fails to realize that death is a process or a state that has a point of starting, which we as scientists/physicians recognize that absolute irreversibility has set in and the person is no more. That is the way we have been writing the "time of death" in our records. Even non-physicians are aware of the fact that 24-48 hours after death hair growth is still observed in the dead body. "On a similar note some have found minimal pituitary function of releasing some hormones in brain-dead persons which is not considered sustainment of life. The number of scientific work and literature during the past four decades has delineated these aspects with vigour and clarity that cannot be pushed aside for emotional reasons"³². This work has been performed with extreme diligence for that very reason. There was initially some reports in the media about some "brain dead individuals coming back to life", but when scientific investigations were performed, it was found that the brain death diagnosis was incorrect¹⁹. Or that how can a brain dead person give birth to a baby? Media outlets continue to publish such news- "People Magazine"-August 3, 2005 or

Reuters (UK), November 3, 2009. The opposite is more pertinent that there has been no report of "coming back" of any patient diagnosed brain-dead even on the basis of the original "Harvard Criteria" (of 1968). Other viewpoints are non-scientific and appeal to emotions more than human intellect with such statements as, "regrettably the medical myth of brain death would not die though its victims do", and similar media news.

However the scientific considerations definitely have placed a challenge to the concept of brain death because the time of death is only recognised after removal of advanced technical support measures when heart and lung functions come to a complete stop. So, at best brain death is a prognostic statement rather than diagnostic.

A word about the difference between Whole Brain death and Brainstem death:

Is that a real difference of criteria? As stated above, since death has always been diagnosed when a person has been found to have permanently lost the cardiac and respiratory functions, UK neurologists state that the centers for these functions lie within the brainstem and so when these centers are destroyed, death has occurred no matter whether other parts of the brain are still functioning. It is for the same reason that when US neurologists state whole brain function they hasten to add the words including the brainstem. Thus, from a practical stand point, there is no difference and the methods of diagnosis to match these criteria strictly remain well established and well accepted. The problem of brain death in scientific circles remains of the acceptance of the concept of equating it with the death of a person. The debate goes on.

Jewish and Catholic Views on Brain Death:

There has been hesitation in accepting brain death by some Jewish scholars, like Rabbi Roshe Fienstein, while others such as Rabbi Dr. Roshe Tendler accepted it as equivalent to decapitation³⁵. Also Fred Posner gives a

scientific account as well as the Jewish position favoring acceptance of brain death³⁶. Although some Catholics are opposed to accepting brain death³⁷ many are coming around to acceptance with time.

Islamic perspectives on diagnosis of death:

The Glorious Qur'an says:

"كُلُّ نَفْسٍ ذَائِقَةُ الْمَوْتِ ثُمَّ إِلَيْنَا تُرْجَعُونَ"

*"Every soul shall have a taste of death; in the end, to Us shall you be brought back."*³⁸

"وَمَا كَانَ لِنَفْسٍ أَنْ تَمُوتَ إِلَّا بِإِذْنِ اللَّهِ كِتَابًا مُؤَجَّلًا وَمَنْ يُرِدْ ثَوَابَ الدُّنْيَا نُؤْتِهِ مِنْهَا وَمَنْ يُرِدْ ثَوَابَ الْآخِرَةِ نُؤْتِهِ مِنْهَا وَسَنَجْزِي الشَّاكِرِينَ"

*"Nor can a soul die except by Allah's leave, the term being fixed as by writing...."*³⁹

"أَيْنَمَا تَكُونُوا يُدْرِكَكُمُ الْمَوْتُ وَلَوْ كُنْتُمْ فِي بُرُوجٍ مُشِيدَةٍ..."

*"Wherever you are death will find you out, even if you are in towers built up strong and high....."*⁴⁰

"قُلْ إِنَّ الْمَوْتَ الَّذِي تَفِرُّونَ مِنْهُ فَإِنَّهُ مُلَاقِيكُمْ..."

*"Say, the death from which you flee will truly overtake you....."*⁴¹

These selected verses/Ayat indicate that:

1. There is a fixed time of death, and
2. Death will overtake you no matter where you are and you cannot run away from it.
3. Only Allah has the knowledge of time and place of death.

Also, the Glorious Qu'ran states:

"اللَّهُ يَتَوَفَّى الْأَنْفُسَ حِينَ مَوْتِهَا وَالَّتِي لَمْ تَمُتْ فِي مَنَامِهَا فِيمِنْهُنَّ الَّتِي قُضِيَ عَلَيْهَا الْمَوْتُ وَيُرْسِلُ الْآخَرَى إِلَى أَجَلٍ مُسَمًّى إِنَّ فِي ذَلِكَ لَآيَاتٍ لِّقَوْمٍ يَتَفَكَّرُونَ"

*"It is Allah that takes the souls (of Man) at death, and those that do not die (He takes) during sleep: those on whom He has passed the decree of death, He keeps back (from returning to life) but the rest He sends (to their bodies) for a term appointed, Verily in this are signs for those who reflect"*⁴².

That suggests to us that there is a soul (*ruh*) connected with the body which may leave it during sleep though still retaining some indescribable connection with the body and

also at the time of death but that at the time of death the soul leaves the body permanently.

A *hadith* of the Prophet (ﷺ) from *Sahih "Muslim"* and *Musnad "Ahmad bin Hanbal"*⁴³ also suggests the soul-body connection.

From *Umm Salamah*, the Prophet (ﷺ) said, "When the soul is taken the eyesight follows" (implying that the person watches the soul going out, at the time of death).

From a scientific point of view, the 'soul' being a non-material, or of ethereal (Spiritual) nature, is not amenable to observation or experimentation. We do not know where in the human body it resides. We make a diagnosis of death only after the soul has permanently departed from the body and the body is showing signs which we, as human beings (physicians) can recognise and then we record the time according to our scientific understanding and calculation. The Islamic scholars have their own definition of death which is the separation of soul from the body⁴³⁻⁴⁵. Other religious cultures also suggest soul's departure from the body as the indication of death⁴⁵.

As early as 1986, the issue of definition of death which terminates human life, and for which a death certificate is issued, was addressed by the Islamic International *Fiqh* Academy in its third session held in Amman-Jordan, titled:

"Human life: Its Inception and End". Scholars of medical sciences and Islamic Jurisprudence participated.

It was clear to the seminar, after hearing the presentations of physicians, that what they recognize as a sign of human death is the inactivity of the whole brain.

Scholars of jurisprudence (*fiqh*) tend, on the basis of the presentations made by expert physicians, to the view that when a person enters the certain stage of brain stem death, he has departed from life.

In this conference the historic resolution No. 5 was passed with a majority of votes, which

equated brain death to cardiac and respiratory death⁴⁶.

This decree paved the way for extensive organ transplantation projects utilizing organs from brain-dead persons in many Muslim countries, including and starting in Saudi Arabia, and spreading to other Gulf countries, Jordan and other Islamic countries⁴⁶.

The most detailed *Fatwa* on organ transplantation was that of the Fourth International Conference of Islamic Jurists held in Jeddah in February 1988^{46,47}. Resolution No. 1 was issued, which endorsed all previous *Fatwas* on organ transplantation.

In 1996, The Islamic Organization of Medical Sciences (IOMS) revisited the issue of brain death at its ninth seminar titled: Health Policy: The Medical Definition of Death⁴⁸.

This meeting was convened in view of some media reports and opposing medical practitioners in Egypt, opposing view to the definition of brain death, which resulted in disapproval of Al-Azhar jurists of the issue of brain death definition for several years.

Medical specialists presented an update on criteria of brain death as adopted by recognized international scientific forums. Eminent Muslim Jurists opinion was consistent with that of the 1986 *Fiqh* Academy.

The conveners affirmed the impossibility of life being restored to a person whose brain has died, according to the recognized special criteria of the definition of brain death. All the cases used as evidence by those who question this notion have been either cases in which diagnosis criteria were not meticulously observed, or cases in which there was an error in diagnosis, inference or deduction⁴⁹.

The Jurisprudence outcomes were subsequently published in the International Islamic Code for Medical and Health Ethics in 2005⁴⁹.

Jurists recommendations of this seminar were consistent with the 1986 Islamic International *Fiqh* Academy.

The Islamic Jurisprudence (*fiqh*) Academy, in a meeting held in Amman in October, 1996⁵⁰, maintained that it is permissible to remove artificial respirators in the case of a patient whose heart is dead and whose respiration has stopped, even if his brain is not dead yet. Resolution No. 5 D 3/07/6 of the Academy stipulates that,

In Islamic Law, a person is regarded as dead, and all the legal consequences of death become operative, if one of the following symptoms is detected:

1. If his heart and respiratory system stop completely and physicians decide that this cessation is irrevocable, or
2. If all functions of his/her brain cease completely.

When this is the case, the artificial life-supporting equipment attached to the patient may be removed, even if some organs, such as the heart, continue to function automatically by virtue of the attached equipment.

In most Muslim countries, legal standards allow procurement of human organs, for transplantation, from subjects with duly diagnosed brain death. Upon proper consents or advance directives, those procedures are currently common practice^{46, 51}.

A pan-Islamic consensus on brain death, however, is lacking^{46,52}. Comprehensive overviews of Muslim jurists opinion, legal standings applicable after brain death is certified, and opposing views have been published by Farah and Kurdi⁴⁵, and more recently by Padela et al⁵².

The Islamic *Fiqh* Council of the Islamic World League held in Makkah in December 1987, passed Decree No. 2, which did not equate cardiac death with brain death^{46,53}, but the decree did sanction the previous *Fatwas* on organ transplantation. Cardiac and kidney transplantation from brain-dead individuals continued without any hindrance from the jurists⁴⁶.

In Iran, a leading jurist, Ayatullah Tabrizi, expressed the opinion that the brain function may be suspended, but it may not be dead,

and so, removing any organ may be tantamount to killing⁴³.

Iran officials, however, accepted "brain death" in 2003⁴⁶.

Conclusions

Expert medical professional forums have set standards and criteria for defining brain death and equating it to total death, which was adopted in many countries worldwide.

In the Islamic tradition, death means departure of the soul (*ruh*) out of the body, the nature and timing of which are not clarified in the Islamic primary sources of Jurisprudence. Physicians have to depend on certain signs according to levels of their scientific knowledge, and subsequently to present and discuss these issues with Muslim *Shari`ah* scholars for *fiqhi* rulings.

Sofar, there is considerable *Shari`ah* rulings that decide the timing of brain death and equating it to total death, but the lack of unanimous opinion still exists. Jurists will continue to encounter difficulties in making consensus verdicts related to timing of death, if medical professionals are unable to clearly arrive to a unified definition in undisputed certainty. A reasonable continued debate among medical-scientific expert forums and *Shari`ah* scholars is needed.

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EUTHANASIA: CONTEMPORARY VIEWS AND ISLAMIC PERSPECTIVES

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Abstract

Euthanasia, literally meaning “good death,” is causing the death of a terminal patient to save him/her from further pain and suffering. The Qur’an explicitly declares that taking a human life or one’s own life is categorically forbidden. All the *Fatwas* prohibit euthanasia and consider it a crime punishable both in this world and the hereafter. Withholding a treatment because it is futile is acceptable in Islam, but withholding it to hasten the death of the patient, to avoid further suffering, is illegal and forbidden in Islam.

Keywords: Euthanasia, Physician-assisted suicide, Medical Ethics, Islam.

Case History

A 70-year-old man with advanced cancer, with severe pain, was not responsive to morphine, and asked the doctor to kill him and save him from suffering. The doctor refused, claiming that he could not commit illegal homicide. The doctor also refused to give the patient any advice about suicide. Upon the patient’s insistence, the doctor agreed to stop hydration and nutrition to enable slow death¹.

Types of euthanasia

Voluntary euthanasia is defined as: “The intentional administration of lethal drugs in order to painlessly terminate the life of a patient suffering from an incurable condition deemed unbearable by the patient, at the patient’s request.”

Assisted suicide is defined as: “intentionally assisting a person, at this person’s request, to terminate his or her life.”

Non-voluntary euthanasia is defined as: “The intentional administration of lethal drugs to painlessly terminate the life of a patient suffering from an incurable condition deemed unbearable, not at the patient’s request”².

Introduction

Euthanasia is a Greek word composed of two syllables: eu means good or easy, Thanatos means death. Thus, the meaning becomes good death or easy death, and nowadays proponents like to call it “mercy killing.”

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Euthanasia is an intentional act 'that is explicitly intended to end another person's life and that includes the following elements: the subject has an incurable illness; the agent knows about the person's condition; commits the act with the primary intention of ending the life of that person; and the act is undertaken with empathy and compassion and without personal gain.

Physician-assisted suicide, on the other hand, intends to provide the patient with adequate knowledge about means and resources, i.e., lethal drugs, and counseling to commit suicide. According to Islamic sources, euthanasia is also defined as 'ending an individual's life out of compassion for that person's suffering'³.

Euthanasia is increasingly advocated in public discourse as a humane response to a terminal prognosis and distress on the part of selected patients, and their care providers⁴.

Currently, euthanasia or physician-assisted suicide is legal in the Netherlands, Belgium, Luxembourg, Colombia, and Canada (Quebec since 2014, nationally as of June 2016). Physician-assisted suicide, excluding euthanasia, is legal in 5 US states and Switzerland. Public support for euthanasia and physician-assisted suicide in the United States has plateaued since the 1990s (range, 47%-69%). In Western Europe, an increasing and strong public support for euthanasia and physician-assisted suicide has been reported; in Central and Eastern Europe, support is decreasing. In the United States, less than 20% of physicians report having received requests for euthanasia or physician-assisted suicide, and 5% or less have complied^{5,6}.

The number of dementia patients requesting euthanasia in the Netherlands has increased recently. In the Netherlands in 2014, 81 people diagnosed with dementia opted for and were granted euthanasia, their doctors either administered them lethal drugs on request or helped them by handing them the lethal drugs⁷.

However, there is a strong opposition to euthanasia in most states of America and most European countries. McEvoy raised the question "Should doctors allow themselves to become authorized agents of society in ending life? To allow some physicians to perform euthanasia would damage the integrity of the profession. Even the authorized experts in the US penal system are not very good at administering the lethal dose. We should not accede to becoming the bedside analogue of this practice⁴.

Islam and Euthanasia

Life is given by God and cannot be taken away except by Him or with His permission. Taking away life should be the domain of the One who gives life. The Qur'an emphasizes that "it is the sole prerogative of Allah to bestow life and to cause death"⁸.

Preservation of life is one of the five basic purposes of the sacred law. Human beings are considered to be responsible stewards of their bodies, which are viewed as gifts from God.

The sanctity of human life is affirmed in the Qur'an.

One cannot take the life of another unjustifiably:

"...وَلَا تَقْتُلُوا النَّفْسَ الَّتِي حَرَّمَ اللَّهُ إِلَّا بِالْحَقِّ..."

*"Do not take life which God has made sacred except in the course of Justice"*⁹.

The Glorious Qur'an says:

"...أَنَّهُ مَنْ قَتَلَ نَفْسًا بِغَيْرِ نَفْسٍ أَوْ فَسَادٍ فِي الْأَرْضِ فَكَأَنَّمَا قَتَلَ النَّاسَ جَمِيعًا وَمَنْ أَحْيَاهَا فَكَأَنَّمَا أَحْيَا النَّاسَ جَمِيعًا..."

*"...One who has killed a person except in lieu of murder or mischief on earth; it would be as he slew the whole mankind and whoever saves the life of a human being, it is as if he has saved the life of all mankind ..."*¹⁰.

One also cannot take one's own life:

"...وَلَا تَقْتُلُوا أَنْفُسَكُمْ إِنَّ اللَّهَ كَانَ بِكُمْ رَحِيمًا"

*"Do not kill yourselves, for verily God has been to you most merciful"*¹¹.

Allah (ﷻ) says in the Qur'an:

"الَّذِي خَلَقَ الْمَوْتَ وَالْحَيَاةَ لِيُبَيِّنَ لَكُمْ أَيُّكُمْ أَحْسَنُ عَمَلًا ..."

"It is He who created death and life, that He may try which of you is best in deed ..."¹².

He also says:

"... وَلَا يَلْبِثُونَ مَوْتًا وَلَا حَيَاةً وَلَا نُشُورًا"

"... Nor can they control death nor life nor resurrection"¹³.

Thus, the person who intentionally ends his life will be punished on judgment day because of his disobedience to Allah, and for denying His mercy.

The *Sunnah*, and teaching of Prophet Muhammad (ﷺ) describes one such instance. He (ﷺ) said in a *Hadith*:

"Whoever kills himself with an iron instrument will be carrying it forever in hell. Whoever takes poison and kills himself will forever keep sipping that poison in hell. Whoever jumps off a mountain and kills himself will forever keep falling down in the depths of hell"¹⁴.

According to *Sahih Muslim*, for example, in the battle of *Hunain*, a courageous Muslim warrior was fatally wounded and killed himself because of unbearable pain due to his wound. Prophet Muhammed (ﷺ) told his companions, when they praised his courage, that he is not fighting for the sake of Allah, but to be called brave and courageous. When he killed himself, he proved that he is not a good Muslim and that he was fighting for fame!¹⁵.

Life saving is a duty and the unjustifiable taking of life is considered a grave sin. The strong opposition to suicide in the *hadith* literature formed a strong opinion among Muslims that neither repentance (if suicide attempt failed) nor the suffering of the person can remove the sin of suicide or mercy killing even if these acts are committed with a purpose to relieve suffering and pain. Some interpretations of the Islamic sources even

give advantage to murderers as opposed to people who commit suicide because the murderers, at least, may have the opportunity to repent for their sin. However, people who commit suicide are 'labeled' as losing faith in the afterlife without a chance to repent for their act¹⁶.

Islamic law clearly prohibits euthanasia in all circumstances. However, the wishes of the patient not to have his dying prolonged artificially in the presence of hopeless prognosis need to be respected and abided by. Such wishes may be declared in the accepted "standing Do Not Resuscitate (DNR) orders" in certain hopeless medical conditions^{17,18}.

The physician therefore has no right to terminate any human life under his care. This also applies to the unborn baby since clear evidence indicates that human life starts at the time of ensoulment (120 days from fertilization).

These sources from the Qur'an and *hadith* illustrate the sanctity of human life, prohibition of killing a human being with no justification, and prohibition of killing oneself. Thus, killing a person to ease his/her suffering, even though it is at the request of the person, will be inconsistent with Islamic law, regardless of the different names given to the procedure, such as, active voluntary euthanasia, assisted suicide, or mercy killing^{19,20}. A person in such situation is expected to persevere patiently with the available medical treatment as the reward for such patience in the Hereafter is tremendous as promised in Qur'an, in which Allah (ﷻ) stated:

"... إِنَّمَا يُؤْتِي السَّابِرُونَ أَجْرَهُمْ بِغَيْرِ حِسَابٍ"

"And those who patiently persevere will timely receive a reward without measure"²¹.

However, pain-relief or withholding or withdrawing of life-support, in which there is an intention of allowing a person to die when there is no doubt that their disease is causing untreatable suffering, are permissible as long

as the structures of consultation between all the parties concerned about the wellbeing of the patient are in place⁸.

The Islamic Jurisprudence Council held in Jeddah²² in May 1992 declared a strong rejection against so-called euthanasia under all circumstances. And those terminally ill patients should receive the appropriate palliative medication, utilizing all measures provided by Allah in this universe, and one should not despair of Allah's mercy, and that doctors should do their best to support their patients morally and physically, irrespective of whether these measures are curative or not^{23,24}.

The Islamic Medical Association of North America (IMANA) is absolutely opposed to euthanasia and assisted suicide in terminally ill patients by healthcare providers or patients' relatives²⁵.

Killing is a crime whatever its name (mercy killing) and is not allowed in Islam and by the law. The perpetrator will be punished; the type of punishment may be reduced from capital punishment to imprisonment, as the perpetrator did it upon demand by the person himself. Even if the law exonerates him from retribution, he is morally wrong and will be judged by Allah on the final Day of Judgment. The laws in Islamic countries criminalize euthanasia and the physician participating in it is punished. The consent of the deceased or the action on his repeated plea to end his life reduces the punishment from capital punishment to imprisonment and abrogation of his medical practice license¹⁹.

The Saudi regulation of medical profession No 21 clearly criminalizes whoever kills or assists to kill a patient in response to the patient's request. Similarly, the Syrian penal code No 552, criminalizes what is called mercy killing or assisting the patient to kill himself²⁶.

Islamic Jurisprudence exonerates the person who kills himself, if he/she was insane or suffered a serious psychiatric disease.

However, the physician who kills a patient upon his demand, will not face *Qisas* (capital punishment) in *Shafi Mazhab* (*Minhaj Attalibeen* by Imam *Nawawi*). The physician may not face any punishment, the maximum being to pay the *diyyah* (blood fine).

In the *Hanafi* and the *Hanbali* mazhabs (schools), the physician will be ordered to pay *diyyah*. It is only the *Maliki* scholars and some of the *Hanafi's Ulema*, who judge that the killer in cases of euthanasia, even by the request of the competent adult patient should face *Qisas* (capital punishment)²⁷.

The killer will face the wrath of Allah on the Day of Judgment, for which his abode will be Hell fire²⁷.

Conclusions

Mercy killing (euthanasia) is not allowed even if the patient insistently requests it and his family agrees to it. No one is authorized to deliberately end life, whether one's own or that of another human being. Saving life is encouraged, and reducing suffering with analgesia is however acceptable, even if, in the process, death is hastened. This rule is based on the central teaching that "actions are to be judged by their intentions". Withdrawal of food and drink to hasten death is not allowed and is considered as a murder crime.

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THE PRACTICE OF *TALQEEN* STARTING, TERMINATING, AND HOSPITAL POLICY ADVOCACIES FOR MUSLIM PATIENTS IN HOSPITALS

*Pukovisa Prawiroharjo**

Abstract

Towards the end of life, preparations should be made for the Muslim patient to die in faith, dignity and peace. Health Professionals and family members, are expected to facilitate this process and guide our Muslim patients to remember Allah (ﷻ) at this stage. According to the Islamic belief, this is a righteous way to leave this temporal world.

Talqeen is an external effort to provide auditory stimuli in the form of remembrance of Allah (*Dhikrullah*) and the hope that the patient will repeat them. *La ilaaha illa Allah* was recommended by the Prophet Muhammad (ﷺ), whose meaning is powerful yet simple and concise in utterances. Simple devices to deliver *Talqeen* may be incorporated which do not interfere with medical interventions to the patients.

A review of various neuroscience literature suggested that patients, in terminal stages and even in states of loss of consciousness (LOC), can be guided by external auditory stimuli such as *Talqeen*. Some consciousness pathways and other parts of the brain remain intact and maintain certain functions during states of loss of consciousness, general anesthesia, and at end-of-life stages, where palliative care is provided.

We recommend hospitals and medical facilities caring for Muslim patients to introduce policies that advocate the practice of *Talqeen*.

Keywords: end-of-life, neuroscience, auditory stimuli, *talqeen*, Muslim faith.

Introduction

Talqeen is an external effort to provide auditory stimuli to individuals. In this case, the stimulus is in the form of *Dhikrullah* (remembrance of Allah), a practice rooted in the teachings of Prophet Muhammad (ﷺ). This practice is undertaken with the hope that the patient will repeat the words of *Dhikrullah* before he/she actually dies. It is hoped, according to Islamic belief, this will help the patient to end his/her

life in a righteous, pious and peaceful state, to enable him/her to be granted admission to Paradise, and to escape Hellfire, as the Prophet (ﷺ) said:

"من كان آخر كلامه لا إله إلا الله دخل الجنة"

"Whoever at his end-of-life says there is no god but Allah, enters the Paradise"¹

Or in another narration, He (ﷺ) said:

"حرمه على النار"

"...Allah will save him from hellfire"².

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From the neuroscience perspective, we need to better understand how the external auditory stimuli (*Talqeen*) is converted into a verbal response via auditory pathways, cognitive processing, and verbal motor pathways. This will be discussed in order to better understand the neuro-dynamics of the *Talqeen* practice, and to help determine when to start, terminate and how to administer *Talqeen* in the following clinical circumstances:

(1) Loss of consciousness (LOC).

LOC is usually diagnosed if the patient is unable to give an adequate response following a visual, verbal, and pain stimuli. LOC may arise from intracranial lesions or systemic metabolic or toxic events that impair the brain's ascending reticular activation system (ARAS) pathway. Generally, LOC reflects a deterioration of the disease process. However, not all LOC conditions leads to a worsening prognosis that is life threatening.

The essence of *Talqeen* is *Dhikrullah*. *Dhikrullah* does not require any obligate preparations, unlike *sholat* (prayers) which must be preceded by ablution (*wudhu*). *Talqeen* is an external effort of *Dhikrullah* stimulation to the ill Muslim patient, in the hope that he/she will respond accordingly to the auditory *Dhikrullah*.

The commencement of *Talqeen* must precede the events that lead to dying (*sakaratul maut*) and probably even before the onset of LOC.

But, is the LOC patient able to listen and respond to the *Talqeen*?

Some LOC patients, even in the vegetative state, may still be able to process the top-down cognitive process³. Neural correlates of the consciousness theory also revealed that loss of consciousness had specific perceptions, and could be elicited by various joint minimum neuronal mechanisms that

may not interrupt the auditory and cognitive pathways⁴.

Auditory oddball paradigm experiments, giving deviant auditory stimuli during sequences of repetitive stimuli, showed that LOC patients may respond well to these deviant stimuli which were measured by P3b frontoparietal ERP evoked. This experiment showed that clinically diagnosed LOC patients may still have intact attention network⁴.

Clinically diagnosed LOC patients actually may have different neural pathways disruption which may or may not include the auditory pathway and cognitive pathways which are required to process the auditory and create the motor response. Therefore the clinically diagnosed LOC patient may still be able to listen and respond as long as the disruption of the consciousness pathway is limited and not further impacting the auditory pathway. The response itself may not be expressed as verbal response, which is the main objective of the *talqeen* practice, as mentioned by the previous *Hadith*.

This neural process remains a mystery and beyond the human ability to observe in detail. Only Allah knows exactly what is happening in the LOC patients' brain, his efforts to respond is and what response that he/she produces. We are only beginning to understand the physiological processes and role of an auditory stimuli such as *Talqeen*. From our limited understanding, we think the LOC diagnosed patient is still able to process the repetitive *Talqeen* stimuli and respond, even though it may not be in form of repeating the words uttered as hoped.

(2) While attempting Code Blue emergencies.

The emergency code will be activated in the event of a life threatening event in the hospital. The medical perspective of Code Blue should also address the end of life (*akhirat*) perspective. For Muslim

physicians and healthcare providers (HCP), medical emergencies should not be reduced to only emergency management of the physical body. The spirit and soul of the patient also demands our appropriate and effective responses too. So a quick response to the spirit of a Muslim patient should be as quick as our medical response to save our patient's life. *Talqeen* is the quickest method we may provide to save our patient's spiritual life. It will be great if *Talqeen* can be part of the standard operation procedure of the Code Blue operations. The challenge would be to offer *dhikrullah* without disturbing the resuscitation process of the emergency team. Designing special *Talqeen* headsets may be appropriate for this purpose.

(3) Red zone of emergency ward patients.

The emergency ward is usually divided into three colour coded zones, namely green, yellow, and red. The green zone is usually for patients who have least urgency and emergency conditions. The red zone is set for life threatening conditions that need more intensive observations and interventions. The yellow zone serves the in-between two zones conditions. In reality, the conditions among emergency ward patients is dynamic. Yellow listed patient may move to red or green just in seconds and vice versa.

Especially at the red zone of the emergency wards, with impending death, *Talqeen* should be done during this opportune moments.

(4) During general anaesthesia.

During general anaesthesia, it is also recommended to administer *Talqeen*. The patient has no obligation to perform *Ibadah*, but he/she is entitled to *Talqeen*, as in the LOC states. Several publications also provide evidence that patients under general anaesthesia have

the possibility of listening and cognitively responding to repetitive auditory stimuli, maybe not in form of verbal response as hoped.

It is not too difficult to provide headsets to patients to listen to *Talqeen* during surgery, instead of listening to the discussions of the surgical team. Neither would it disturb the medical team from working, nor interfere with the sterile conditions as required in the operation theatres.

(5) End-of-life palliative care.

For many countries, end-of-life palliative care has been provided in nursing homes or homecare with good support from visiting and coordinating medical teams. But for others, the care is only provided in hospitals because of limited resources to perform them in out-of-hospital settings. Part of the end of life palliative care protocols should include *Talqeen* services.

When to Terminate *Talqeen*?

Talqeen for the dead (*mayyit*) is contentious. There are no authentic narrations (*hadiths*) of the Prophet (ﷺ) to recommend this practice. There are similarly no evidence to prohibit this activity.

I cannot state that *Talqeen* practice is recommended, but because with the advancing medical technologies, declaring the precise time of death is becoming difficult, especially in the ICU, emergency ward, and resuscitation settings, *Talqeen* seems to be reasonable. Because there is no clear restriction of doing *Talqeen* for a dead person terminating the *Talqeen* is not as restricted as deciding if the patient has died or not. In other words, *Talqeen* termination could be more flexible than deciding the exact time of a patient's death.

Generally, it is now accepted that brain stem death is the criterion of death. However, this is not universally accepted as synonymous to complete

cardiac-pulmonary death in the Muslim world. In some cases of brain death, the patient may still have positive wave I of Brainstem Auditory Evoked Potential (BAEP)⁵. Based on that, I believe *Talqeen* may continue to be provided for some moments (may be seconds to minutes) after the life support withdrawal.

In my opinion, *Talqeen* may be provided to the patient until after the withdrawal of all life support which is soon followed by cessation of cardiac and respiratory activities in the ICU or emergency ward setting. In resuscitation setting, *Talqeen* may be provided for few moments after the resuscitation has failed and terminated, to let the patient die naturally. In the end-of-life care setting, when the patient stated his desire for DNR (do not resuscitate), *Talqeen* may be provided for few moments after the patient is declared dead. After that it is up to his family if *Talqeen* should be terminated or continued.

Narration of *Talqeen*

The cognitive ability to listen comprehensively, perceive perfectly, and respond accurately differs in various disease states which eventually impact the brain function. During LOC and general anaesthesia, the patient may be able to register the auditory stimuli, but its cognition is at an all time low. The cognitive processing required to understand one word is of course much easier than one sentence which contains many. *Talqeen* takes this in close consideration to ensure maximum register by the human brain.

For the palliative care patient, who is awake and has good cognitive ability, he/she will be able to process and understand much longer sentences and even many sentences perfectly. For these patients, recitation of the Qur'an or longer *Dhikrullah* may be offered. If a person has been pious in his/her living

moments and has regularly uttered *Dhikrullah* repeatedly, *Talqeen* for him/her would be relatively easier because of the familiarity of his working memory with the words recited.

Since *Talqeen* has been advocated by the Prophet (ﷺ), the one short but momentous sentence which he has counselled to read to the terminal patient is: *Laailaahailallah*.

"لقنوا موتاكم لا إله إلا الله"

"Guide someone who is dying to say there is no God but Allah"⁶.

Conclusions

The few major clinical circumstances mentioned earlier warrant the practise of *Talqeen* for the Muslim patient to ensure that their critical and end of life moments are righteous with the remembrance of Allah (SWT). Muslim physicians and health organisations should advocate for the inclusion of *Talqeen* in the standard operating procedures of health facilities which serve Muslim patients. Together with Muslim scholars, they would help create a demand by the Muslim communities for *Talqeen* to be part of the holistic health care of their loved ones in hospitals. Eventually we hope, hospital managements worldwide would consider this request and facilitate *Talqeen* for their Muslim patients.

Technology specialists would also need to create a friendly *Talqeen* device to provide to the patients which, would deliver the auditory stimuli of *Dhikrullah* without interfering with the medical interventions at play, preserving the safety and sterility of the patients and its ambience. It is expected that these devices would be simple, miniaturised, mobile, and wireless so that *Talqeen* can be administered even at a code blue resuscitation setting without interfering with life-saving procedures.

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l. Homepage/web site:

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m. Qur'anic Verse:

Example: The Glorious Qur'an: Mariam: 19: 54.

n. *Hadith* from printed volume:

Example: Ibn Hajar al-'Asqalani. Fath al-Bari bi-Sharh Sahih al-Bukhari (The Creator's Inspiration in Interpreting the Verified Collection of al-Bukhari). Cairo, Egypt: Al-Bahiyah Egyptian Press; 1930. Vol 11, p. 405.

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