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VIEWPOINT

From Quality of Life to Value of Life: An Islamic Ethical Perspective

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Abstract
Many factors contribute to the conceptualization of health related quality of life. These same factors seem to influence the medical decision-making in a manner that reflects competing principles and interests. The overall trend, however, may appear to be skewed toward weighing "worthiness" of patients for treatment according to their current or expected quality of life. Such position is in contrast to the whole concept of health related quality of life, which was meant to help improve health care access and delivery rather than limit it based on prognosis. This article aims to reiterate the absolute value of life from my understanding of Islamic perspective, and argues against belittling the value of life based on poor health-related quality of life.

Introduction

Health-related quality of life (HRQOL) is a concept that addresses the impact of disease on a person's overall perception of both physical and mental health (1). Health care providers can utilize HRQOL to gain a broader perception of how disease state affects their patients, and perhaps more importantly, understand what interventions can improve the overall health in susceptible patient groups (1). Such interventions may include improved access to healthcare, and fair allocation of resources, just to name a few.

The concept of health-related quality of life, however, is somewhat subjective, since it relies heavily on the "perception of health" (2). This, in itself, is a summation of several variables that form a triad of personal experience, beliefs, and expectations. In this context, it is important to understand how an association has formed between poor HRQOL

and worthiness of treatment; we – the health care providers - need a moment of truth to fully examine the prevalence of such an attitude. Ironically then, we find that HRQOL may become a tool for limiting, as opposed to improving access to healthcare. The advancements in biotechnology that allows supportive and life sustaining interventions have allowed for a growing burden of chronic incurable diseases in individuals who cannot contribute to society while draining societal resources to cover expenses of such technologies. But instead of the later becoming the "moral" justification for limiting interventions for patients with poor HRQOL, the efforts of the Muslim healthcare systems should be focused on the challenge of adopting healthcare advances and supporting rational healthcare spending that enable us to value every single life no matter how impaired by disease.

The critical pitfall in this relationship between HRQOL and worthiness of treatments is most evident in patients requiring some form of life sustaining devices; where the underlying disease is incurable, the HRQOL is extremely poor, and the only measurable outcome of the medical interventions seems to be life sustenance. According to the American Medical Association's "Code of Ethics," there is no ethical obligation for physicians to deliver futile care; futility, as determined by the physician's best professional judgment, is care that will not have a reasonable chance of benefiting a patient (3). Considering life sustaining devices, for example, if the physician determines that the use of such devices is futile because it will have almost no beneficial impact for the patient or for improving his perceived HRQOL (despite the undeniable "benefit" of survival as may be perceived by the patients, their families, or their surrogate decision makers), then this situation may have the potential for a serious ethical conflict. Moreover, one cannot help wonder whether the physician's judgment of futility represents an opinionated position of worthiness of sustaining the life of patients who are severely compromised by the burden of incurable disease, especially that this resource hemorrhage is not counterparted by any measurable "payback" to the society. When we look at the value of life in Islam, there is no distinction between the value of life of a fully productive individual and that of a bedridden comatose person; the benefit and moral value of sustaining both lives is virtually the same. The Muslim scholar Ibn Al Munzer reports the consensus among Islamic Jurists that a person who kills another person deserves the capital punishment even if the murdered one was handicapped, or blind, or has both upper limbs paralyzed, and the murderer has a healthy body (4), this clearly reflects the equal value of life in Islamic jurisprudence.

More extreme examples of such situations have emerged based on a diagnosis of irreversible vegetative states, so much so that it was ruled – by the power of court - appropriate to withhold the most basic human needs of nutrition and hydration. In the highly publicized case of Terri Schiavo, her feeding tube was removed for a third time after several legal battles between her husband and her family. The U.S. Congress then passed an "emergency measure" that was signed by the President in an effort both to force federal courts to review Ms. Schiavo's case and to create a legal mandate to have her feeding tube reinserted yet again. The U.S. District Court in Florida denied the emergency request to reinsert the feeding tube, and the decision was upheld on appeal. Multiple subsequent legal appeals were denied, and Ms. Schiavo died of starvation 13 days after the feeding tube was removed (5). From an Islamic perspective, starving an innocent creature, let alone human being, to death is prohibited. Narrated 'Abdullah bin 'Umar: Allah's Apostle Peace be upon him said, the meaning: "A lady was punished because of a cat which she had imprisoned till it died. She entered the (Hell) Fire because of it, for she neither gave it food nor water as she had imprisoned it, nor set it free to eat from the vermin of the earth"(6). We can readily extrapolate that starving a human being to death is as sinful and tabooed as starving an animal to death.

On the other hand, patients with much worse health-related quality of life due to more severe neurologic devastation, i.e. brain death, are kept on life sustaining devices not for their own "benefit" of course but in order to arrange to harvest their organs for the benefit of other patients. And even though the 1986 Islamic jurisprudence resolution by the council of Islamic Fiqh Academy in Amman- Jordan equated brain death

to death (7), the fact remains, as stated by Dr Al Bar, that there remains a lot of resistance to accepting the concept of equating brain death to death among Islamic scholars, the general public, and some physicians (8). As a matter of fact, the 1987 Islamic Jurisprudence resolution of the Islamic Jurisprudence Council in Makah, Saudi Arabia, allows only for removing life support equipment from brain dead patients, but rules that such a person is not legally dead until his cardiorespiratory functions irreversibly stop after the removal of such equipment (9). Therefore, it is not allowed to procure organs while the brain dead patient remains on life support equipment since he/she is not legally dead according to this resolution.

So there really is no consensus on equating brain death to death from an Islamic Jurisprudence position, the difference of positions hinging around the fact that the brain dead patients' vital signs and functions do not cease until their life support devices are removed, or until their bodies are cut open and their vital organs anatomically severed. Dr Al Bar equates poor quality of life with human suffering when he emphasizes the importance of avoiding inappropriate use of intensive care and resuscitative measures in order to "reduce human suffering of the patient" (8). However, brain-dead patients are kept on life sustaining devices that prolong their suffering and prolongs the death process according to his statement (8).

If the argument for Terri Schiavo's discontinuation of artificial tube feeding was for her "benefit" in avoidance of prolonged suffering, which is a reasonable quality of life concern one might argue, then why is it that the "suffering" of brain dead patients is prolonged against their "benefit" (the benefit being, one can argue, putting an end to their suffering and not prolonging their death process) in favor of the benefit of others (receiving the harvested vital organs of the brain dead person)? In addition, what does this tell us about our society's moral values as related to equally weighing the value of each life? Moreover, if Ms.Schiavo,, who was diagnosed as being in an irreversible vegetative state, was still alive today when we now have protocols for controlled cardiac death, at least in some countries, would she have been left to an agonal death of starvation and dehydration, or would she have had her life fully supported pending arrangements for her death hastened at the door steps of an operating room ready to harvest her organs?

Quality of life

The perception of the health of the individual appears to be a collective contribution of physical, psychological, and social domains modulated by individual beliefs, expectations, and subjective perceptions (2). Marcia et al, presents a model for measuring each domain both objectively and subjectively, and makes an argument for using such measures when estimating the advantage or cost effectiveness of one treatment versus another (2). This may be of great value when planning public health policies and prioritizing limited resource allocations, however, applying this model in the day-to-day medical practice that involves individual patients is a different story. Here the subjective perception of health by the patient has a significant weight in the decision making process, even if such decisions go against the health care providers' view of what intervention is worthwhile and what is not from a HRQOL perspective. Moreover, the belief system of the society as a whole may well put limits on what one individual chooses to do in response to a perceived poor quality of life, such as requesting physician-assisted suicide. The later represents an example of autonomy being overridden by the value system of the society as a whole.

To that extent, Islam provides a comprehensive foundation of beliefs and regulations that govern such perceptions and the actions taken in response. Islam clearly defines the human being as a combined entity of body and soul, and defines good life as maintaining a fine balance between enjoying the bounties of life and fulfilling the purpose of existence, that is the servitude and worship of the One and only Creator. The domains of quality of life then are the body and the soul; this gives rise to four possible combinations of quality: good quality for the body and the soul, poor quality of both, good quality for the body and poor quality for the soul, and finally poor quality for the body and good quality for the soul. When weighing the quality of life of body versus soul, the issue in Islam is settled in favor of the soul. A verse of the Holy

Quran criticizes a category of people for have they not travelled in the land, and have their hearts wherewith to feel and ears wherewith to hear, the verse then states that indeed it is not the eyes that grow blind, but it is the hearts, which are within the bosoms, that grow blind (10). Therefore, these are individuals with intact body parts: heart, ears, and eyes, but, from an Islamic perspective, have dysfunctional souls. To put things in perspective, a Muslim may be blind sighted but has the tranquility of faith in his soul that provides an unparalleled quality of life, as opposed to a full sighted person whose distorted way of life may leave his soul distraught and in agony, a very poor quality of life that may even lead to suicide.

Value of life

Life is a gift from God. It is an equal privilege that all humankind enjoy, and all humankind are ordained to preserve this precious life regardless of level of function or contribution to society, let alone the individual state of health. The Holy Quran ordains that if anyone killed a person not in retaliation of murder, or (and) to spread mischief in the land - it would be as if he killed all mankind, and if anyone saved a life, it would be as if he saved the life of all mankind (11). In the state of health, life is preserved by providing essential elements of sustenance, like food and water. When a person is ill, seeking medical treatment is one more way of preserving life, in addition to the basic sustenance by nutrients and hydration. To deprive a person from basic life-sustaining elements, i.e. food and water, is murderous according to Islamic law. The issue of treatments deserves some detailed insight, for unlike food and water, which are essential requirements for life; medical treatments are variable and inconsistent elements that have different outcomes in different persons and circumstances. Dr Al Bar elaborates on the different Islamic jurisprudence positions on seeking remedy, and defines the situation when seeking remedy is obligatory; that is to save lives, or when seeking remedy is better off abstained from, that is when therapy is unlikely to bring benefit (8). Agreeing fully with such stratification, one must acknowledge that certain interventions are of doubtful benefit until actually applied, after which it becomes certainly beneficial or non-beneficial. Such interventions, although not obligatory to start with, may fall into the category of obligatory rule once proven effective, such as the case of a person in respiratory failure responding to mechanical ventilation. At this point then, depriving the ventilated patient from what is now proven to be a life sustaining intervention appears to be as forbidden as depriving the person from nutrients and water. Understanding this matter helps us to understand the difference between withholding and withdrawing medical interventions; from an Islamic perspective, the withheld medical intervention is of doubtful value and hence can be withheld subject to consent on the premise that seeking medical treatment is optional and not compulsory according to Islamic law. Once successfully applied, however, the value of such an intervention is no longer in doubt, and withdrawing such a life sustaining medical treatment or intervention is essentially similar to withdrawing food and water. It is important to note that providing nutrients and water should never be withheld from any person as outlined earlier. So, the difference between withholding and withdrawing life sustaining treatments or interventions is basically the difference between doubt and certainty; withholding life sustaining interventions is only permissible when its success is doubtful, but once applied and proven effective, the doubt is replaced by certainty that the patients life is now as dependent on this life sustaining intervention as it is on food and water.

This is in clear contrast to the frequently quoted ethical standard in current medical literature that describes withholding and withdrawal of life support as ethically equal. According to Luce et al surveys of healthcare professionals indicate that most ICU physicians withhold and withdraw life support on a regular basis, and that they consider these processes ethically equivalent (12). Moreover, these surveys reportedly state that they recommend withholding and withdrawal of life support based upon prognosis (which may be an expression of futility), and that they consider patient and surrogate wishes to be most important in deciding to forego life-sustaining treatment, but place these wishes in the context of their own assessment of prognosis (12). In a prospective

survey over two months, Ferrand et al, followed the frequency of and the process leading to decisions to withhold and withdraw life support in intensive care units in France. According to their interpretation, they found that withholding and withdrawal of life-support therapies was widely practiced in French ICUs, despite their prohibition by the French legislation (13). These are alarming trends in the sense that ethical standards are solidified with no basis other than some surveys of opinions and/or practices, in addition to what appears to be physicians taking the law into their own hands in defiance of local legislation as in Ferrand's study. The findings that prognosis, some times a surrogate for quality of life, plays a role in decisions regarding limitation of life support, is a testimony to the distorted understanding of the concept of HRQOL. The HRQOL, originally coined to represent the patient's interest and comprehensive medical needs, is used against the patient in order to limit access and application of medical interventions based on "worthiness" as measured by prognosis and HRQOL.

A recently published study by Monti et al, used functional magnetic resonance imaging (f-MRI) in a group of 54 patients with disorders of consciousness, and showed that a small proportion of patients in a vegetative or minimally conscious state have brain activation reflecting some awareness and cognition (14). In this study, Monti et al, also showed that in one patient with severe impairment of consciousness, functional MRI established the patient's ability to communicate solely by modulating brain activity, whereas this ability could not be established at the bedside (14). Such a patient is at high risk of being "written off" as a futile case from a perspective of poor quality of life, but how accurate is such a judgment – let alone ethical, if indeed there is a way to communicate with a person captive to his physical disease. As labor intensive as f-MRI studies are, decisions as critical as end of life care and advance directives should respect patient's autonomy, and while such tools obviously need more validation and end user simplifications, the concept should lead proxy decision makers to be much more cognizant of the soul that resides in the incapacitated body we are caring for. Terri Schiavo was at the center of a legal battle between two proxies; an advocate for life support, which in her case was simply the feeding tube, and an advocate of Terri's alleged "right to die," The outcome was a 13 day long slow death process that most will inarguably describe as murderous. I wonder what Terri would have had to say should we have had a "window" of communication with her soul while all those legal battles were fought in her name. However, until that is possible, why should we insist on continuing to ignore and belittle the value of a person's life simply because of a severe incapacitating disease of the body. From an Islamic perspective, all protected lives according to Islamic jurisprudence are equally worthy lives. What we should be doing is to provide whatever reasonable and available reasons possible of sustaining every life, for when it comes to the value of life, its sustenance is not futile.

Conclusion

Health related quality of life is an important concept that stimulates health care providers to ensure a holistic and comprehensive approach to the patient's medical needs. It may prove to be a valuable tool of assuring that the physical, psychiatric, and social needs of the patient are addressed and fulfilled to the best possible extent. Turning the table by using health related quality of life as a value tag for which decisions to intervene are scaled according to prognosis is completely opposite of the very essence of the concept of HRQOL centered patient care, and has the grave potential for dehumanizing the practice of medicine in exchange for a material-value based system of worthiness of intervention. The Islamic perspective on this issue is clear and straightforward: every protected life according to Islamic jurisprudence is an equally valuable life that deserves equal access to life sustaining and/ or preserving interventions. We need to restore the humane spirit of medicine by focusing definitions of quality of life to help improve – not limit – health care delivery while we cherish the value of life gifted by God.

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