

INVITED PAPER

QUALITY OF LIFE AND ETHICAL DECISIONS IN MEDICAL PRACTICE

QUALITÀ DELLA VITA E DECISIONI ETICHE NELLA PRATICA MEDICA

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Abstract – Quality of Life (QoL) is one of the most controversial construct in bioethics. In general QoL is considered as freedom from emotional and physical discomfort. This view is inconsistent with the basic principle of medical ethics, that life is a “*bonum onticum*” that has a value on its own. In an ethical perspective, preservation of QoL should be considered an important means to preserve a person’s dignity, that is the ability to pursue his/her own unique mission.

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Introduction: goals of medicine and the ambiguity of the expression “quality-of-life”

The time-honoured duty of physicians is to act in the best interest of their patients. However, in some situations it may result very difficult to identify the patient’s best interest. Competing treatment goals generally include prolongation of survival versus preservation of function and *in primis* of cognitive activity. There is a tendency among physicians, the public, family, and patients themselves to believe that quality of life (QoL) is so deeply compromised that life is not worthy preserving when a patient is dependent in bodily function or when cognition is irreversibly impaired. Then QoL considerations become the primary compass of clinical decisions. In a well-known treatise of medical ethics¹, QoL considerations are included among four topics that determine the ethics of a clinical decision. Other authorities in medical ethics, such as Pellegrino and Thomasma disagree with such conclusion and warn against QoL based judgements except in limited and well-defined circumstances. Their main concern is the difficulty to translate an intellectual construct such as QoL into concrete situations and hence the practical application of QoL to clinical decisions. This difficulty persists despite the myriad of instruments available to gauge QoL, none of which is able to provide an objective measure.

An additional area of concern is the attempt to base health policies on QoL. Although QoL considerations are voiced by politicians, economists, sociologists and planners of health administration to justify health care plans, it is difficult to escape the impression that QoL

has become a code word for limited care and facilitated death. After all, these plans are more palatable when presented as a way of promoting the patient’s QoL instead of care rationing due to limited resources.

The main goal of this article is to illustrate the terms of the dilemma of whether QoL should or should not be a basis for clinical decisions and health care policies from an ethical viewpoint.

Quality of life and quality of health

As we try to explore the question whether QoL should direct medical decision, it is important to underline that no agreement exists on the meaning of QoL. The term embraces a large array of constructs, from symptom management to the preservation of basic activities of daily living, to maintenance and restoration of higher functions, including independent living and the full experience of the most consequential emotions, such as pleasure, suffering, joy and sadness. A source of further confusion is the overlapping of QoL with other constructs including autonomy and dignity, whose interpretation is also controversial. For example: is the autonomy of a demented person compromised by the inability to drive, or is the dignity of a bedridden person compromised by fecal incontinence?

From a medical ethics standpoint a discussion of quality of health appears more appropriate than that of QoL, as health is the primary goal of medical care. As highlighted by J. Seifert², all human lives must be considered of the same value from an ontological standpoint. Ontology, the study of the being, holds that life is a supreme

good that cannot be measured and consequently cannot be graded. At the same time health can be assessed and graded. Physicians are constantly establishing whether the health of a certain person is getting better or worse. If the value of human life cannot be measured clearly it is not determined by the quality of an individual's life at a particular time point. At the same time, the view of human life as a supreme good irrespective of its quality mandates the pursuance of the best possible health for each and every person. In this perspective, quality of health, rather than quality of life should direct end-of-life decisions. It is reasonable to withhold life-prolonging treatment from a patient whose health has been irreversibly damaged. It is not acceptable to hasten the death of a person who is severely depressed just because he or she complains of a miserable QoL.

To better illustrate this point, medical decisions based on QoL would consider physical life as a '*bonum utile*' something of conditional value, not unlike a car or a refrigerator that are dispensed with when they cease to function. This concept is at odds with the basic principle of medical ethics, that considers physical life as a *bonum onticum*, something whose value is determined by the very fact that it exists and that is independent from its level of functioning. All physical lives are of equal *ontic* value and all persons are of equal *moral* worth³. Without the acceptance of this principle medicine would cease from being a healing profession and would become an instrument of discrimination aimed to preserve the life and the function only of people judged worthy of surviving and thriving. This judgement could only be issued by a totalitarian government.

Of course QoL considerations play an important role in medical decisions in more than one way. First they should be one of the goals, albeit not the only one, of all medical interventions. Second, they should determine the course of action associated with the preferential outcome: for example breast preservation would be preferable over mastectomy in the management of breast cancer if it allows a patient to preserve her self image and sexual function. Most important, QoL considerations may indeed help a provider to make an ethical decision by indicating benefits and burdens of health care in individual patients. For example, the same ventilator may be considered a benefit when it allows a patient's recovery from life-saving surgery and a burden when it prolongs the dying of a terminally ill individual.

Quality of life and medical decisions

With this background let's try to explore uses and abuses of QoL in current medical practices. An appropriate

use involves the best symptom management of all patients, and especially of those who are dying. Optimal symptom management involves prolongation of a person's function in addition to symptom relief. An inappropriate use involves the termination of lives that somebody declares unworthy living through euthanasia or physician assisted suicide. For this purpose we will study some specific cases.

I. QoL as criterion of patients' selection: the case of severely ill newborns

Life and death decisions for incapacitated subjects are particularly vexing. The temptation to judge their lives unworthy living, based on personal opinions, personal preferences and societal standards is becoming more and more pervasive and is a reflection of the so called "creed of greed" inspiring the Western societies. Profit, rather than human life is considered the supreme good and consequently all lives that may compromise profit are seen as an evil to extirpate. Paradoxically, these decisions based on QoL contradict the basic principle of QoL, holding that nobody has the right to judge the QoL of another person. There are abundant examples in the medical literature of patients who judged their own QoL quite differently from the external judgment of a provider or of a family member. Also, the original goal of QoL was to bring back the patient perspective in the practice of medicine. Instead this construct has been deformed to become an instrument to justify the elimination of people considered undesirable. Not few people believe that, even though correct diagnostic and prognostic evaluation should inform clinical decisions in incapacitated subject, external assessment of QoL should represent the ultimate decisional criterion.

Perhaps the best example of this paradox is the management of newborns with severe pathologies, which represents one of the most controversial aspects of current neonatal and pediatric care. When a complete recovery is unlikely, physicians as well as parents may assume in absolute good faith that continuation of treatment represents a burden rather than a benefit for the patient. The basic question is: is it ethical, compassionate, and clinically sound to stop the treatment of very early preterm infants or of those suffering from severe and irreversible congenital problems? Is it ethical to prolong a life that will be marred by serious handicaps and poor quality, by all estimations?

This dilemma has been approached in the so-called 'Groningen Protocol' approved and adopted by the Dutch Association of Pediatrics in 2005⁴. QoL is one of the criteria for inducing euthanasia. In particular the

protocol states that “unbearable and hopeless suffering” would make termination of life acceptable and goes to affirm that the decision to terminate the life of these fragile children would be more “human” than letting them live. This view is clearly contrary to the view of life as a *bonum onticum*, something that is worthy in itself, and may be used to justify the elimination of any human being considered undesirable. Medical progress consistent with ethical principles would rather involve an empathic and compassionate attitude toward the most fragile and needy human beings and toward their families who carry most of the burden of their care.

In an interesting review article R. De Jong⁵ offers a critical reappraisal of the concept of QoL adopted in the Groningen Protocol. According to him, it seems impossible to predict with certainty the future quality of life of newborns with severe malformations. Indeed the self-reported QoL of life of children with handicaps does not differ from that of children without disabilities. While it is true that spina bifida may cause unbearable pain, it is not true that all patients with spina bifida will experience this pain. Thus ethical medical progress consists in learning how to manage the pain of spina bifida patients, not in eliminating the bearers of this anomaly. This seems tantamount to eliminating a patient in order to eradicate his/her cancer or his/her HIV infection⁶.

Generally speaking: it may be even acceptable to take medical decisions based on quality of life, if the assessment of QoL were an objective measurement such as the blood sugar or the hemoglobin levels. This is not the case however. Psycho-social measurement, such as QoL, have proven very helpful in population studies, but are untested as criteria to manage the individual patient, because of their subjective nature. Not only do external observers tend to underestimate a person’s quality of life, and may be biased by personal convenience, but since the assessment is subjective, one cannot compare the result obtained from different patients. Whereas a blood sugar of 20 represents hypoglycemia or a systolic blood pressure of 220 represents hypertension for everybody, a quality of life of 3 on a Likert scale may be unbearable for one patient and very tolerable by another.

The Groningen Protocol is just one of the many examples of how discrimination based on social desirability may be covered by the cloak of compassion.

The same protocol may justify the deliberate termination of life of terminally ill patients in lieu of simply withdrawing futile treatment. This is an important distinction. A decision to withdraw life-preserving measures is based on the adequacy of these measures (benefits vs burden), that is on quality of health, which is a le-

gitimate field of ethical decisions for the physician. The decision to terminate life, instead, is based on the adequacy (benefit vs burden) of life itself, that is based on QoL. As demonstrated before this decision is contrary to the basic principle of medical ethics, as life is a “*bonum onticum*” has a value of its own that does not change according to particular conditions. In other words, the question seems to be the existence of life in itself, but, how is it possible to consider life a problem which need to be terminated? Only a distortion of the concept of human dignity supports a perspective seeing life as a problem. Dignity derives from the Latin word *dignus* that means “to be worthy.” It is a direct statement of the unconditional value of human life and cannot be compromised by specific conditions. Human dignity derives from the uniqueness of each human being, endowed with a unique mission and vocation.

Health is certainly an important value and is one of the conditions for the pursuance of one’s mission. It doesn’t represent the only condition, however. History is full of examples of individuals who realized their mission despite poor health (Beethoven) or even because of their disease (Leopardi, Van Gogh, Poe).

Finally, one should underline that therapeutic abandonment is never acceptable from an ethical viewpoint. When life-prolonging treatment is considered too burdensome, because ineffective or undesirable by the patient, still it behooves the practitioner to provide the most effective symptom management to maximize the patient’s health and quality of life.

II. QoL as goal to pursue in medical care: a “dignity model”

Preservation of life and its quality have always represented the main goals of medicine. In the perspective of the previous discussion, QoL represents the condition through which the patient is best able to pursue his or her mission, the fundament of his/her uniqueness, that is of his or her dignity.

Generally, the assessment of Health Related QoL (HRQoL) involves different parameters predominantly of physiological nature – pain control, the preservation of physical and social function – to the degree that is necessary to allow the patient to satisfy the projects and the objectives of his/her lifetime. In other words, HRQoL is not a goal in itself, but rather it is a means necessary to give meaning to a patient’s life, to allow the patient to express his/her uniqueness, to pursue his/her mission.

This statement is valid in all stages of health care, but assumes a special weight in the proximity of death. It is important for terminal patients to make the best use of the limited time they have to survive. The personal needs of

the terminal patient are too often unheard by the practitioner devoting attention only to the organic dimension of the illness. In this way the patient is unable to treasure the illness experience and to find a satisfactory meaning to his/her illness. This approach to the terminally ill is a statement that a life at its end has lost its worth, has become disposable. Such an attitude considers life a *bonum utile*, that is a machine that should be replaced by another machine capable of exercising the same function.

Symptom management considerate of human dignity is aimed not just at relieving the symptom but also at empowering the patient to discover the sense of his/her terminal illness, to become aware of the human aspect of dying. The care of the dying finds its higher expression in the hospice philosophy.

According to the WHO, the aim of the palliative care is the attainment of the best quality of life for the patient and for his/her family. This is most effectively pursued through an integrated approach that also takes into account the emotional, relational, social and spiritual dimensions, together with the control of pain and other causes of physical discomfort.

While the disease may worsen a person's QoL in terms of comfort and function, it may allow the patient to discover the spiritual dimension of life and offer the opportunity to recognize the depth and the strength of human bondage. The management of the terminally ill should then be directed toward this end, rather than toward clouding a person's awareness in the attempt to eliminate the symptoms. In our experience as ethic consultants, the most common reason for a patient to seek life termination is a sense of abandonment, the feeling that life has lost its meaning and has become a burden for the family, the society and even the providers. This desperation may represent a unique opportunity to emphasize to the patient how his/her care may enrich family members. The caregiving experience allows family members to discover their own value, their own uniqueness in their ability to provide care. Spouses, parents, children or friends deprived of the care-giving experience are deprived of one of the basic functions of family and friendship, and may therefore be deprived of a unique opportunity to discover themselves, their mission and their vocation, that is their own dignity.

The invitation to also consider these aspects of the assistance does not mean to neglecting the physical, emotional and cognitive aspects of the terminal disease, which should be managed with the utmost compassion. As previously stated, the word "quality" does not and should not refer to a property or attribute of life. Rather, it should refer to the relationship which exists between

the medical condition of the patient, on the one hand, and the patient's ability to pursue life's goals and purposes, understood as the values which transcend physical life, on the other.

Knowing who the patient is, his/her biography, his/her life, his/her choices, are paramount for the provider who is caring for a patient with a disease rather than taking care of a disease in the patient. The answer to human suffering is not only medical. It involves listening and communication, directed to the attention of the human sphere of the patient apart from the illness, a comforting attention to all the worries expressed by the patient and to his/her personal experience of the illness. Some organizational problems and above all resource restrictions may certainly make the relationship with the patient particularly difficult. Even with these practical limitations, the provider can only make ethical decisions by developing a personal relationship with the patient, by coming to know the patient as a person.

Conclusions: towards a new education to a true concept of quality of life

QoL has become a compass of medical decisions. While improvement of QoL is definitely an important goal of medical care, it is important to emphasize that it is not a goal by itself, but rather a mean for the patient to gain a full appreciation of the meaning of life.

To use QoL as a determinant criterion to withdraw life-saving care is unacceptable from an ethical standpoint, as it implies that life is a "*bonum utile*" that is disposable. This attitude opens the door to all possible forms of discrimination and is inconsistent not only with the principles of medical ethics but also of civil relationships. This inconsistency becomes even more obvious when life and death decisions are taken concerning incapacitated individuals, who cannot express the appreciation of their own QoL.

While preservation of QoL as a means to discover meaning is important at any stage of care, it becomes particularly important at the end of life. At that time, the discovery of the human aspect of the patient is necessary to provide compassionate care, consistent with the dignity of human life.

Riassunto – Il tradizionale dovere del medico di agire nel migliore interesse del paziente si scontra oggi con uno dei più discussi termini utilizzati nell'ambito della bioetica clinica, "qualità di vita", introdotto quale criterio che dovrebbe essere seguito nel prendere decisioni mediche che presentano implicazioni etiche, soprattutto quelle agli estremi della vita, per pazienti gravemente

malati. Sebbene il termine non sia in sé in conflitto con il concetto di rispetto della vita, rappresentando un complemento di essa nel senso di stato di salute e benessere, di fatto esso viene sempre più utilizzato per selezionare i pazienti partendo dal presupposto che un grado maggiore o minore di qualità di vita possa condizionare il valore stesso della vita. Il salto “antropologico” non è di poco conto ed esprime un diverso modo di interpretare la persona e la sua vita, considerandola non un bene *ontico*, con un valore vero e reale – sebbene limitato - ma un bene *utile*, di valore condizionato appunto dalla sua “qualità”. È necessario, pertanto, riportare il concetto di qualità di vita nell’alveo dello scopo di beneficenza della medicina, ponendolo come obiettivo da perseguire, attraverso la cura e la solidarietà degli operatori sanitari e della società tutta. Risulta necessaria una proposta educativa verso una corretta interpretazione del significato di qualità di vita.

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