Culture of Life – Culture of Death

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21

The culture of life and the quality of life ethic: an either/or?

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IT IS A DAUNTING TASK to talk about quality of life. "An on-line search of the phrase QOL in Medline, Cinahl, Psyc-Info, Eric, and Social Science Abstract provided a list of 16,021 articles published between 1993 and 1998.... Since 1993, there have been over 4,000 articles published about QOL relating to health."[1] The term arose in sociological discussions, spread to psychology, and entered health care ethics. Health related quality of life considerations inform, at least for some ethicists, medical judgments on a wide range of issues. Quality of life judgments have played a role in the discussion of prenatal diagnosis and selective abortion, in treating or failing to treat handicapped newborns, and in the care of the elderly. Scholars have also adduced these judgments in the discussion of how to treat PVS patients as well as those with terminal diseases. Negative quality of life judgements have been the cry of those who consider themselves compassionate and in a German version (*lebenunwertes Leben*) the cry of the Nazis. As James Walter and Thomas Shannon have suggested its meaning "ranges from judgments about whether one should live at all, to the conditions under which one will live, to evaluations of life-style, and to considered judgments by patients about how medicine corresponds to their beliefs and aspirations."[2] Quality of life considerations pertain to at least three different issues: (1) the definition of, judgments about, and uses of quality of life, (2) the criteria that guide and establish the assessment of quality of life,[3] and (3) the mode by which we know the criteria have been fulfilled.[4] This paper hopes to differentiate different senses and uses of the term 'quality of life' and discuss which of these senses are compatible with a health care ethic advancing the culture of life as described by John Paul II in *Evangelium vitae*. Thus, my discussion will focus primarily on judgments, definitions, and uses of quality of life in coming to

[1] B. Haas, 'A multidisciplinary concept analysis of quality of life' 21 (1999) *Western Journal of Medicine:* 728 ff.

[2] J. Walter and T. Shannon (eds) *Quality of Life: The New Medical Dilemma.* New York: Paulist Press 1990: 1.

[3] Cf. T. Gill and A. Feinstein, 'A critical appraisal of the quality of quality of life measurements'. 272 (1994) *Journal of the American Medical Association:* 619.

[4] This hermeneutic is suggested in J. Walter, 'Proportionate reason and its three levels of inquiry: structuring the ongoing debate', in C. Kaczor (ed.) *Proportionalism For and Against* Marquette: Marquette University Press 2000: 393.

decisions in health care and not the clinical criteria or modes of knowing the criteria have been fulfilled.[5] First I will say a word about inappropriate uses of quality of life, uses that exclude certain human beings from being considered persons or that deem them to have a 'wrongful life'. Secondly, I will address suffering and dependency in the culture of life, and finally there will be a word about how quality of life considerations might legitimately enter into discussions of health care ethics.

The term 'quality of life' appears just twice in Pope John Paul II's encyclical *Evangelium vitae*. The term's use in the encyclical reflects the ambiguity of the phrase in the literature. Quality of life is first used as a term of reprobation, as a way of devaluing suffering human persons. John Paul II writes:

> The eclipse of the sense of God and of man inevitably leads to a practical materialism, which breeds individualism, utilitarianism and hedonism. Here too we see the permanent validity of the words of the Apostle: "And since they did not see fit to acknowledge God, God gave them up to a base mind and to improper conduct" (*Rm* 1:28). The values of being are replaced by those of having. The only goal which counts is the pursuit of one's own material well-being. The so-called "quality of life" is interpreted primarily or exclusively as economic efficiency, inordinate consumerism, physical beauty and pleasure, to the neglect of the more profound dimensions – interpersonal, spiritual and religious – of existence.[6]

On this view, only those actually or potentially living this "good life" merit our concern and consideration. Those human beings that lack this actuality or potentiality have a life not worth living.

However, the passage in question does not indicate that it is quality of life as such that is problematic but rather a certain interpretation of it, the "so called 'quality of life'" as the pope says. Indeed, later John Paul II suggests a more positive meaning of quality of life:

> Another welcome sign is the growing attention being paid to the *quality of life* and to *ecology*, especially in more developed societies, where people's expectations are no longer concentrated so much on problems of survival as on the search for an overall improvement of living conditions.[7]

Quality of life in this context includes the quest to make life worth living, to humanize our way of life above mere survival. This quest must be understood not merely in terms of material well being but also social, moral, and religious

[5] On this, see A. Leplege and S. Hunt, 'The problem of quality of life in medicine'. 278 (1997) *Journal of the American Medical Association:* 47–50; T. Gill and A. Feinstein, 'A critical appraisal of the quality of life measurements'. 272 (1994) *Journal of the American Medical Association:* 619–624; and G. Guyatt and D. Cook, 'Health status, quality of life, and the individual', 272 (1994) *Journal of the American Medical Association:* 630–631 for an introduction to these complex questions.

[6] John Paul II, *Evangelium vitae*: 23.

[7] John Paul II, *Evangelium vitae*: 27. Emphasis in the original.

development. The meaning here is not so much medical as social, not clinical but personal and interpersonal.

Evangelium vitae thus reflects various meanings of the term quality of life, some noxious to an ontological valuing of each human person; others entirely commensurate with and even demanded by an affirmation of the unique value of every human being. But what of quality of life in health care ethics? Are the so called sanctity of life and quality of life ethics completely opposed or might they be in some respects reconciled?

Illustrating uses of quality of life that undermine recognizing the dignity of all human beings are those arguments denying that respect is due human beings in early stages of development. Pro-abortion and pro-infanticide arguments of Mary Anne Warren, Michael Tooley, and Peter Singer have presupposed a functional evaluation of human beings and used it to justify their ethical views.

Typically, it is noted that the fetus lacks some capacity, for instance rationality, or does not excercise this capacity to the requisite degree, and hence the unborn child cannot be considered as worthy of the respect given to other human beings. Thus, abortion is morally permissible and should be legal on demand and without limit.

From the perspective of the culture of life, judgments about the humanity and the personhood of any member of the class *homo sapiens* should be inclusive rather than exclusive. The human person must be accorded an ontological value rather than a functional one. The ontological view has a decisive advantage over the functional view insofar as any functional view arbitrarily excludes human beings from being considered truly persons. First, the functional view must choose some standard by which to separate those that are merely human beings from those who are also persons. Recently, the proposed standard has been rationality. Different cultures have proposed other standards, however, such as the ability to reproduce, attractiveness, racial or sexual characteristics, usefulness to the community, or some other desired characteristic. Given this standard, further choices must be made about the degree of the characteristic needed by the human being if that human being is to count legally and/or morally as a person, a being due respect. In so far as characteristics such as rationality are matters of degree, invariably an arbitrary standard must then be chosen to distinguished the protected and valued class of human beings from the unprotected and unvalued class. Of course, a standard of morality based on arbitrary choices hardly merits the title, and so functional evaluation is incompatible with right reason.

Secondly, from an historical perspective, the arbitrariness of these choices has led to innumerable catastrophic injustices by whites against blacks, men against women, rich against poor, Aryans against Jews, etc. The lessons of history indicate the gross danger of adopting an exclusive rather than an inclusive point of view with respect to the personhood of any human being. The authors of the U.N. Declaration on Human Rights crafted it precisely to avoid such arbitrary and exclusive judgments.

One might also add that from the perspective of Christian belief the mission of Jesus indicates that the poor, rejected, and unloved, just as much as the rich,

accepted, and loved, merit our respect and kindness. As John Paul II writes in *Evangelium vitae*:

> In a special way, believers in Christ must defend and promote this right [to life], aware as they are of the wonderful truth recalled by the Second Vatican Council: "By his incarnation the Son of God has united himself in some fashion with every human being". This saving event reveals to humanity not only the boundless love of God who "so loved the world that he gave his only Son" (*Jn* 3:16), but also the incomparable value of every human person.[8]

Christ's interaction with various 'marginalized' human beings, such as tax collectors, prostitutes, the Samaritan woman, lepers, and so forth offers a model of Christian interaction with those whom society deems 'unwanted', especially the so called unwanted child.

Unfortunately, quality of life concerns, understood as judgments about which humans have personhood and which lack personhood, are not confined to discussion about abortion. Quality of life judgments, understood as the functional evaluation of human beings who must merit personhood, run through many other concerns of medical ethics. Ethicists have used functional evaluation of human beings in justifying active euthanasia, in not treating handicapped infants as persons, in removing organs from living but neurologically damaged patients, and in removing nutrition and hydration in order to kill PVS patients. Functional evaluation of human beings is one way of describing what John Paul II calls the "culture of death". Clearly, this sense of quality of life is incompatible with the inclusivity of a culture of life that affirms the intrinsic dignity and fundamental equality of every human being regardless of circumstance.

This malignant sense of quality of life is not the only way in which the term can be used. Understood within the context of the culture of life, quality of life, on my view, can be an element in making decisions about what sorts of treatments should be given to a patient. It is here that a sanctity of life ethic parts from a vitalistic ethic which demands that we extend the duration of human life as much as possible regardless of the burdens or benefits of the treatment to the patient and others.[9] If a patient's condition or quality of life is such that treatments provide no real benefit but rather impose a heavy burden, the treatment need not be given even if such treatment would extend the life of the patient.

As John Keown has pointed out, it is the *treatment* and not the *life of the human person* that is burdensome. Even if the duty to prolong life is not without exception, human life is always a gift and never a burden. Thus the idea of life itself being a burden, 'wrongful life' as it is sometimes called, must be rejected. Many ethicists maintain that life in itself has no intrinsic value but only instrumental value. Living as such, they maintain, is not beneficial or good especially

[8] John Paul II, *Evangelium vitae*: 2.

[9] J. Keown, 'The legal revolution: from "sanctity of life" to "quality of life" and "autonomy"', in L. Gormally (ed) *Issues for a Catholic Bioethic*. London: The Linacre Center 1999: 233–260.

when life is connected with severe suffering and when death would bring release from this suffering as well as, hopefully, rest with God. Even some who explicitly reject a merely instrumentalist account of the value of human life, sometimes speak as if life itself were burdensome. For example, James Walter and Thomas Shannon state: "The specific issue here is whether the burdensomeness of the life preserved by the offering of nutrition/hydration can or should be part of the overall assessment of burden in the determination of ordinary/extraordinary...[10]" Typically, such beliefs in 'wrongful life', or the idea that some lives are not worth living, rest on at least two philosophical mistakes.

The first mistake is a Cartesian/Neo-Platonic conception of the person as a duality of two substances, body and soul. Death, it is argued, is ontologically evil for the body of a person but good for the Christian person brought into a new life.[11] Human persons, however, are a unity of body and soul; they are ensouled bodies.[12] Since human beings are not pure spirits merely using or possessing their own bodies, but rather human beings *are* their bodies (but not, of course, *merely* their bodies), what is evil for the human body is evil for the human person. Since death is not a good for the human body, but rather a privation of a due good, the death of a person's body is not a good for that person. Hence, in an ethics in which one is enjoined to want and seek the good for oneself and others (love your neighbor as yourself), in the realm of commutative justice, intentional killing of human beings has no place.[13]

The second mistake in speaking of persons with low quality of life as having a 'wrongful life' is the lack of requisite conceptual distinctions between good and evil. The fact that some evil brings about some good or some good brings about some evil does not change the nature of evil into good or good into evil. Let us say that I am tortured, imprisoned, and blinded by captors from whom I eventually escape. Following my escape, I become a more loving, generous, and sensitive person. It does not follow that because good resulted from my experience that being tortured, imprisoned, and blinded are goods for my captors or me. The forgiveness of sins is a great good, and forgiveness of sins comes about only *because of* sin, but we certainly cannot conclude from these observations that sin itself is a good. In a similar way, we cannot reason that since eternal life is a great good, and death brings about eternal life, then death is a good. We cannot reason that since relief of pain is a good, and death brings a relief of pain, death is a good. Although many evils may be connected with life (severe

[10] J. Walter and T. Shannon, 'The PVS Patient and the Forgoing/Withdrawing of Medical Nutritian and Hydration'. In Walter and Shannon (eds) *Quality of Life: The New Medical Dilemma.* New York: Paulist Press 1990: 214.

[11] D. Thomasma, 'Assisted Death and Martyrdom'. 4.2 (1998) *Christian Bioethics:* 112–142, at 130.

[12] P. Lee, 'Human Beings are Animals', in R. George (ed) *Natural Law and Moral Inquiry.* Washington D.C.: Georgetown University Press 1998: 135–151.

[13] I cannot defend this claim here, but interested readers should see Christopher Kaczor, *Proportionalism and the Natural Law Tradition.* Washington, D.C.: The Catholic University of America Press, 2002.

pain, debilitation, sickness), these evils must all be conceptually distinguished from life. That is, just because an evil such as sickness is found in conjunction with a good such as life does not mean that sickness is a good or life is an evil any more than the pain associated with staring at the sun would make eyesight an evil. Eyesight, like life, is an intrinsic good of human persons even if connected with or a necessary condition for various evils.

However, those in the debates about what does or does not constitute burdensome treatment often implicitly assume the belief that some lives are not worth living both for the dependent individual and for those who care for the dependent individual. Suffering and dependency can be construed as unmitigated evils.

From the perspective of religious faith, such a belief cannot be accepted. Suffering can be meaningful when the one suffering offers this suffering for that which is lacking in the Mystical Body. As it says in *Col* 1:24: "I am now rejoicing in my sufferings for your sake, and in my flesh I am completing what is lacking in Christ's afflictions for the sake of his body, that is, the church." As John Paul II wrote in his Apostolic Letter *Salvifici Doloris*:

> Every man has his own share in the Redemption. Each one is also called to share in that suffering through which the Redemption was accomplished. He is called to share in that suffering through which all human suffering has also been redeemed. In bringing about the Redemption through suffering, Christ has also raised human suffering to the level of the Redemption. Thus each man, in his suffering, can also become a sharer in the redemptive suffering of Christ.[14]

Within the Christian experience, suffering can draw one closer to Christ and help the entire Church, indeed the entire world. The one caring for those in need by offering support, love, and treatment follows the model of Jesus and indeed cares for Jesus. "Whatsoever you do for the least of these you did for me" (*Mt* 25:40). The perfection of the mystical body of Christ is accomplished through the suffering of the Body of Christ and the imitation of Christ's care for the suffering, both of which give meaning to suffering.

One might also note that health-related quality of life, understood in its subjective aspect of life satisfaction, rather than as an objective evaluation of biological function (objective health status), remains remarkably high on average even when biological function is poor. In the words of Alain Leplege and Sonia Hunt in a recent article from the *Journal of the American Medical Association*: "There is ample evidence that, as an individual comes to terms with the fact of long-term illness, adjustments occur that preserve life satisfaction, and individuals can consider their quality of life as good even when there are severe limitations on their physical ability."[15] For instance, patients with asthma reported high quality

[14] John Paul II, Apostolic Letter *Salvifici Doloris*: 19.

[15] A. Leplege and S. Hunt, 'The problem of quality of life in medicine'. 278 (1997) *Journal of the American Medical Association:* 48.

of life, regardless of severity of illness or medical condition, if they experienced the giving and receiving of love, had a positive approach to everyday events, and took pleasure in life.[16]

These considerations might be enriched by also calling to mind recent philosophical reflection on why dependency ought not be considered an unmitigated evil to be avoided at all costs. In his recent book, *Dependent Rational Animals*, Alasdair MacIntyre writes:

> We ... need to learn how to dissociate the evaluation of personal qualities and of reasoning from physical appearance and from manner of presentation. In so doing we may discover what we had not hitherto suspected: that we have not up till now been able to separate ourselves from feelings of dislike, disgust and even horror in responding to the facial appearances of certain types of other and so we have not been able to exercise critical judgment in respect of those feelings; that we have been lacking in adequate self-knowledge in failing to understand the full range of judgments that are influenced irrelevantly by such feelings; and that, in responding to those whose appearance has affronted us, we have assumed that from them at least we could have nothing to learn. We discover, that is, in our encounters with the disabled hitherto unrecognized sources of error in our own practical reasoning.[17]

Thus, through such encounters, which would seem to be of benefit only to the one receiving care, the caregiver also learns lessons that might not otherwise be available. Even in the case where the one given care cannot communicate, is passive, gravely disabled, or in a persistant vegetative state, one may recognize opportunities for growth. As MacIntyre argues:

> What they give us is the possibility of learning something essential, what it is for someone else to be wholly entrusted to our care, so that we are answerable for their well-being. Everyone of us has, as an infant, been wholly entrusted to someone else's care, so that they were answerable for our well-being. Now we have the opportunity to learn just what it is that we owe to such individuals by learning for ourselves what it is to be so entrusted.[18]

Such lessons provide those who care for the gravely disabled a great good. The benefit in situations of care for the dependent is simply not one way. Thus, not just theological considerations but also philosophical ones suggest that the dependency of even the most disabled person should be considered not simply as a burden for others.

Although the patient's life is always beneficial to him and often to others, not all treatments are. In order to determine which treatments are beneficial and which are burdensome the condition or, one might say, the quality of the life

[16] Cf. Leplege and Hunt, 'The problem of quality of life in medicine': 50.
[17] A. MacIntyre, *Dependent Rational Animals: Why Human Beings Need the Virtues* Chicago: Open Court 1999: 137.
[18] MacIntyre, *Dependent Rational Animals* 138–139.

of the patient must be taken into account. Determining which treatments offer very little benefit, while imposing significant burdens, requires evaluation of the quality of life, or what one might call both the objective health status and subjective health status of the patient in question.

How then ought one to evaluate 'quality of life' understood as an evaluation of the worthwhileness of treatment (not of patients)? William E. May's article "Criteria for Withholding or Withdrawing Treatment" offers perhaps the best account so far of how quality of life considerations, understood in the restricted sense, may enter into determinations about which treatments are burdensome. After critiquing Kevin O'Rourke's interpretation of Pius XII's address to a congress of anesthesiologists, May writes:

> [M]edical treatment is 'extraordinary' or 'disproportionate' and hence not morally obligatory if *objectively discernable features in the treatment itself, its side-effects, and its negative consequences impose grave burdens on the person being treated or on others.* Excessive burdensomeness is the major criterion, therefore, for determining whether or not to withhold or withdraw medical treatments. Excessive burdensomeness is, one could say, the genus. Species of excessive burdensomeness include riskiness of the treatment, the excessive pain of the treatment, the severely negative impact the treatment will have on the subject's life, treatments judged morally or psychologically repugnant, and treatments that would be too costly and severely imperil the economic security of the patient, the patient's family, or the community.[19]

The list given by May is helpful, and we might add with him a few more "species." Clearly a treatment that is futile, not medically indicated or even counter-productive, should be considered extraordinary and should be withdrawn. Also classified as extraordinary are treatments that interfere with a person's spiritual duties or aspiriations, as Pius XII noted in his address to anaesthesiologists.[20]

In this way, quality of life considerations are both 'objective' or having to do with the objective health status of a patient or treatment and 'subjective' or having to do with the relationship between the proposed treatment and the pursuit of the vocation or aspirations of the patient. One aspect of quality of life is objective because it involves considerations that might be empirically measured and verified such as a treatment's being medically counterindicated due to the patient's physical condition. What may be beneficial treatment to an otherwise healthy patient might be burdensome treatment to someone with a terminal illness. Similarly, the risk associated with a treatment or the likelihood of its benefit are not connected with the plans, aims, or goals of a patient. The benefit of a proposed treatment is linked with the over-all condition that the patient is likely to have after the treatment. In the words of Germain Grisez, "[E]ven if

[19] W. May, 'Criteria for Withholding or Withdrawing Treatment'. 57.3 (1990) *Linacre Quarterly*: 88.

[20] Pius XII, 'The Prolongation of Life: An Address to an International Congress of Anesthesiologists' 1957 as cited by May, 'Criteria for Withholding or Withdrawing Treatment': 89.

they are not dying, comatose and other severely mentally disabled persons stand to benefit far less from many sorts of treatment than do most other people, and it is reasonable to provide those sorts of treatment only to persons who will benefit more from them."[21] Thus, a given treatment that may be ordinary treatment for an otherwise healthy patient may be disproportionate or extraordinary for a comatose patient not precisely because the burden of treatment differs but because the benefit of treatment differs.

The other aspect of quality of life, the subjective health status of a patient, cannot be determined on empirical grounds alone. One reason for considering a treatment burdensome is the severely negative impact a treatment may have on the patient's lifestyle or vocation, and this will be determined by what sort of lifestyle or vocation a patient has chosen and a considered judgment about how the treatment will impact this lifestyle or vocation. A young father might consider a treatment to be excessively burdensome whose side-effects would be debilitating. On the other hand, an elderly and more sedentary person, without obligations of child care, may consider debilitation as endurable given the alternatives. Similarly, that a treatment is morally or psychologically repugnant must be considered not so to speak a priori but in the concrete situation of the individual who assesses 'quality of life', that is, his or her own condition even as subjectively assessed, in addition to individual goals, beliefs, and aspirations, in coming to a decision about the treatment.

Some aspects of quality of life contain both objective and subjective elements. Excessive pain of the treatment is determined in part by the condition of the patient both physically and mentally. A treatment that causes excessive pain to one patient, due to the patient's physical condition or psychological constitution, may not cause excessive pain to another. Some people bear a great deal of pain well; others are extremely sensitive.

In coming to an evaluation about whether a treatment is ordinary or extraordinary, i.e., obligatory or not obligatory, one should first consider the objective health status of the patient and then the subjective health status. If the treatment is risky, linked to noxious side-effects, or extremely expensive, then that treatment is extraordinary regardless of the subjective health status of the patient. Other treatments may be ordinary in an empirically verifiable sense, but extraordinary due to the vocation, aspirations, sensitivity to pain, or other not empirically verifiable characteristics of a patient. All of these quality of life concerns are fully compatible with an affirmation of the intrinsic dignity of every human being. However, insofar as the noxious meaning of the term is most common, we may not want to speak about quality of life even though the term can be used to capture both the objective and subjective aspects of health status important in coming to decisions about treatment. However in certain objective and subjective senses, 'quality of life' judgments are fully compatible with the culture of life, even if we should for prudential reasons not want to use the term 'quality of life'.

[21] G. Grisez, 'Should nutrition and hydration be provided to permanently comatose and other mentally disabled persons?', 57.2 (1989) *Linacre Quarterly:* 30–43, at 42.