

WIDER WORKING PAPERS

**Quality of Life Measures in
Health Care and Medical Ethics**

Dan W. Brock

WP 66

August 1989

*World Institute for Development Economics Research
of the United Nations University*

QUALITY OF LIFE MEASURES IN HEALTH CARE
AND MEDICAL ETHICS

Dan W. Brock
Brown University
USA

January 1989

QUALITY OF LIFE MEASURES IN HEALTH CARE AND MEDICAL ETHICS

Dan W. Brock
Brown University

I. Introduction

There has been considerable philosophical work during the last two decades, especially in the United States but not limited to there, in a relatively new field called medical ethics. My aim in this paper is to explore what illumination that body of work might offer to our understanding of the quality of life. If one looks only to the medical ethics literature explicitly addressing the notion of the quality of life, there are few sustained analyses of it and of its role in various medical and health care contexts. Consequently, it is necessary to look more broadly to issues and areas of research that often do not explicitly address the quality of life, but that nevertheless importantly bear on it. I believe there are two main areas of work in medical ethics that fit this criterion. The first is work on ethical frameworks for medical treatment decisionmaking in a clinical context, including accounts of informed consent and life-sustaining treatment decisions. The second relevant area is the development of valuational measures of outcomes of health care treatments and programs; these outcome measures are designed to guide health policy and so must be able to be applied to substantial numbers of persons, including across or even between whole societies. The two main parts of this paper will address these two main bodies of work. However, before doing so several preliminary issues need to be briefly addressed.

I have mentioned that the literature that I will be summarizing and drawing on often does not explicitly address the concept of "the quality of life," but instead uses other notions that are either closely related or roughly equivalent in the context. Sometimes a notion of "health" is employed, particularly in its broader interpretations

as exemplified in the World Health Organization definition of "health" as a state of complete physical, mental and social well-being.¹ The notion of patient "well-being," independent of its use within a definition of health, also is often employed for evaluation of outcomes in health care. Another conceptual framework commonly employed for evaluating health care outcomes is the assessment of the benefits and burdens of that care for the patient (and sometimes for others as well). Still another common conceptual framework often employed looks to the effects of health care on patients' interests, with a best interests standard particularly prominent for patients whose preferences cannot be determined. These and other conceptual schemes are not fully interchangeable in health care, much less in broader contexts. Nevertheless, they all have in common their use in evaluating health care outcomes for patients and their employment as at least a part of a comprehensive account of a good life for persons. I shall freely draw here on each of these conceptual frameworks, and others, though indicating where differences between them become important.

The "quality of life" of persons can be given a number of more or less broad interpretations, depending on the scope of the evaluative factors concerning a person's life that it is taken to include. Medicine and health care often affect a person's life in only some limited areas or respects. Nevertheless, my concern will be with the broadest conception of, in Derek Parfit's words, "what makes a life go best," and I shall try to show that medicine and health care may affect and illuminate more aspects of that question than might at first be thought.² No concept is entirely apt or widely accepted in either philosophical or common usage for this broad role, but I shall use the concept of a "good life" to refer to the quality of life of persons in its broadest interpretation.

It is common in much philosophical work on theories of the good for persons or of a good life to distinguish three broad kinds of theories. While this classification misses some distinctions important for my purposes here, it provides a natural initial

starting point. These three alternative theories I will call the hedonist, preference satisfaction, and ideal theories of a good life.³ Much of the philosophical work on these theories has been in the service of developing an account of "utility," broadly construed for employment in consequentialist moral theories.⁴ What is common to hedonist theories, as I will understand them here, is that they take the ultimate good for persons to be the undergoing of certain kinds of conscious experiences. The particular kinds of conscious experience are variously characterised as pleasure, happiness, or the satisfaction or enjoyment that typically accompanies the successful pursuit of our desires. Particular states of the person that do not make reference to conscious experience, such as having diseased or healthy lungs, and particular activities of the person, such as studying philosophy or playing tennis, are part of a good life on this view only to the extent that they produce the valuable conscious experience.

Preference satisfaction theories take a good life for persons to consist in the satisfaction of their desires or preferences. I here understand desires or preferences as taking states of affairs as their objects; for example, my desire to be in Boston on Tuesday is satisfied just in case the state of affairs of my being in Boston on Tuesday obtains. This is to be distinguished from any feelings of satisfaction, understood as a conscious experience of mine, that I may experience if I am in Boston on Tuesday. The difference is clearest in cases in which my desire is satisfied, but I either do not or could not know that it is and so receive no satisfaction from getting what I desire; for example, my desire that my children have long and fulfilling lives, a state of affairs that will only fully obtain after my death. For preference satisfaction theories of a good life for persons to be at all plausible, they must allow for some correcting or "laundering" of a person's actual preferences.⁵ The most obvious example is the need to correct for misinformed preferences; for example, my desire to eat the sandwich before me not knowing that its ingredients are spoiled and will make me ill. Other corrections of preferences have also been supported by proponents of the preference

satisfaction theory that are compatible with its underlying idea that ultimately what is good for persons is that they get what they most want or prefer.

The third kind of theory holds that at least part of a good life for persons consists neither of any conscious experience of a broadly hedonist sort nor of the satisfaction of the person's corrected preferences or desires, but instead consists of the realization of specific, explicitly normative ideals of the person.⁶ For example, many have held that one component of a good life for persons consists in being a self-determined or autonomous agent, and that this is part of a good life for a person even if he or she is neither happier as a result or desires to be autonomous. Ideal theories will differ both in the specific ideals the theories endorse together with the place they also give to happiness and preference satisfaction in their full account of the good for persons. There is a strong tendency in much of the philosophical literature to seek a simple, comprehensive theory, such as the hedonist or preference satisfaction theories: proponents of ideal theories commonly acknowledge a plurality of component ideals of the person that place constraints on and/or supplement the extent to which happiness and/or preference satisfaction serves a person's good. The account I will develop of quality of life judgments in health care strongly suggests that it is a mistake to let the attractions of a simple, unified theory of a good life for persons force a choice between the hedonist and preference satisfaction theories. Instead, these quality of life judgments suggest the importance of giving independent place to the considerations singled out by each of the three main alternative theories, as ideal theories do in any adequate overall account of the quality of life or of a good life for persons. The quality of life judgments made in medicine and health care also help some to fill in the content, especially of one central ideal of the person, of a theory of a good life.

A major issue concerning ethical judgments generally, and judgments concerning a good life for persons in particular, is the sense and extent to which such

judgments are objective or subjective. A number of different senses have been given to the notions of "objectivity" and "subjectivity" in these contexts, and other essays in this volume take up some of these general theoretical issues and will develop some of these alternative senses.⁷ I will attempt no extended analysis of this general theoretical issue here. Nevertheless, one sense in which what constitutes a good life for a particular person is believed to be subjective or objective mirrors the distinction between hedonist and preference satisfaction theories on the one hand, and ideal theories on the other. Hedonist and preference theories are each subjective in the sense that each holds what is good for a particular person depends on what in fact makes that person happy or is what that person (with appropriate corrections) desires. (This is compatible, of course, with acknowledging that what will make a particular person happy or satisfy his or her preferences is an "objective matter of fact," even if often an extremely difficult one to determine.)

Ideal theories are objective, or at least contain objective components, in the sense that they hold a good life for a person is, at least in part, objectively determined by the correct or justified ideals of the good life for persons, and does not in those respects depend either on what makes that person happy or on what that person's (even corrected) preferences happen to be. In this understanding, the question of whether accounts of a good life for persons are objective or subjective is an explicitly normative issue about what is the correct or most justified substantive theory of a good life for persons. This sense of the objective-subjective dispute has been a central concern in the debates in medical ethics and health care about the quality of life. Interestingly, I believe that medicine and health care provide some of the most persuasive instances both for the objective and subjective components of a good life, and so point the way towards a theory that incorporates hedonist, preference, and ideal of the person components.

Haavi Morreim has distinguished a different sense in which quality of life judgments in medicine are either objective or subjective.⁸ In her account, objective quality of life judgments are made on the basis of intersubjectively observable, material facts about a person (facts concerning his or her body, mind, functional capabilities, and environment) together with a socially shared evaluation of those facts, specifically of how those facts determine the person's quality of life. Subjective quality of life judgments also appeal to material facts about a person and his or her condition (though these may also include facts about the person's private psychological states) together with that person's value judgments about how those facts affect his or her quality of life. In this account the essential difference that makes a quality of life judgment either objective or subjective is whether the evaluative judgments concerning a particular individual's quality of life are and must be those shared by some wider group or are instead only the individual's own. Since there are many possible wider social groups, one respect in which one could make sense of degrees of this kind of objectivity is in terms of the size, breadth or nature of the wider social group; important variants include an individual's community or larger society, and a maximally wide group might be all humans or rational agents. It should be obvious that my and Morreim's senses of the objective-subjective distinction are independent: the individual whose quality of life is in question might hold any of the three substantive theories of the good for persons distinguished above, as might any wider social group.

A full conception of a good life for a person that does not reduce to a single property like happiness or preference satisfaction must assign a weight to the various components that contribute to that life's being good, though there may not be full comparability between different components and so in turn only partial comparability between different possible life courses for a person. Amartya Sen has suggested in several places the formal device of understanding these different components as

independent vectors, each of which contributes to an overall assessment of the degree to which a person has a good life.⁹ There are several benefits to an analysis of what constitutes a good life into a number of independent vectors. First, it allows us to accept part of what proponents of each of the three traditional theories of a good life have wanted to insist on, namely the theoretical independence of those components. The three components of happiness, preference satisfaction, and ideals of a good life can each be represented by their individual vectors, or subdivided further into distinct vectors within each component, having independent weight within an overall account of a good life. Second, the vector approach quite naturally yields the possibility of two senses of partial comparability of the quality of different lives. For a single individual, alternative possible lives may be only partially commensurable if one alternative life provides a greater value on one vector, but also a lesser value on another vector, than another possible life. But for two different persons it is important that at least partial comparability between their lives may be possible, contrary to the dogma about the impossibility of interpersonal comparisons of utility, by comparing common vectors or by comparing different changes in common vectors making up a good life for each. Medicine and health care provide strong grounds for insisting on these independent vectors and, perhaps more important, also suggest a content and structure to the ideals along the lines proposed by Sen in his work on agency and capabilities that drew on settings largely outside of health care.

We also need to distinguish between the relative importance of a particular feature or condition, say as represented by a specific vector, in its contribution to a person having a good life, compared with what I shall call its broader moral importance. A simple example will suffice. One condition that may plausibly contribute to persons' quality of life or good life is their physical mobility. It may be possible to specify roughly a normal level of physical mobility for persons of a similar age at a particular historical stage and in a particular society, and then to specify

roughly levels of mobility say 25% below and 25% above the norm, such that the effect on a person's quality of life in moving from 25% below the norm up to the norm is quantitatively roughly the same as moving a person from the norm to 25% above it. While the degree or importance of the two changes in a person's quality of life or good life may be roughly the same, it can nonetheless be consistently held that these two comparable effects on the person's quality of life have different moral importance or priority. For example, it might be held that on grounds of equality of opportunity there is greater moral priority to bringing a person's mobility from 25% below the norm up to the norm than to increasing his or another's mobility from the norm to 25% above it. The general point is that aspects of a person's quality of life may play a role not only in judgments of his quality of life or of how good a life he has, but also in other distinct moral and political judgments, or in the application of independent moral principles such as a principle of equal opportunity. This is, of course, a thoroughly familiar point in moral and political philosophy generally, and concerning consequentialist moralities in particular, against which it is often objected that they ignore the moral importance of whether the good is fairly or justly distributed. In the present context its importance is in reminding us to distinguish judgments concerning the improvement or reduction of people's quality of life from other independent moral evaluations of those same changes in people's conditions, so as not to confuse needlessly the nature of quality of life judgments in health care.

II. Ethical Frameworks for Health Care Treatment Decisionmaking

The first broad area of work within medical ethics bearing on the concept of the quality of life concerns the aims of medicine and the account of medical treatment decisionmaking appropriate to those aims. It may be helpful to begin with a natural objection to thinking that these issues in medical ethics will illuminate any broad

notion of the good life. On the contrary, as Leon Kass has argued, medicine's proper end is the much narrower one of health, or the healthy human being, and other goals such as happiness and gratifying patient desires are false goals for medicine.¹⁰ Kass understands health to be a naturalistically defined property of individual biological organisms, organisms which must be understood as organic wholes, and whose parts

"have specific functions that define their nature as parts: the bone marrow for making red blood cells; the lungs for exchange of oxygen and carbon dioxide; the heart for pumping the blood. Even at a biochemical level, every molecule can be characterized in terms of its function. The parts, both macroscopic and microscopic, contribute to the maintenance and functioning of the other parts, and make possible the maintenance and functioning of the whole."¹¹

What constitutes well-functioning varies with the particular biological species in question, but Kass is at pains to argue that "health is a natural standard or norm -- not a moral norm, not a 'value' as opposed to a 'fact,' not an obligation -- a state of being that reveals itself in activity as a standard of bodily excellence or fitness."¹²

Kass' work constitutes one of the more ambitious attempts to justify two commonsense beliefs about the "objectivity" of medicine: that the aim of medicine is and should be the patient's health, and that health is a biologically determined, objective matter of fact. If so, then physicians with their impressive body of scientific knowledge concerning human biologic functioning and the impact of therapeutic interventions on diseases and their natural courses, would seem to be the proper judges of whether we are healthy and, if we are not, what therapeutic interventions will likely make us more so. This hardly begins to do justice to the subtlety of Kass' view, though it is a view that I believe to be fundamentally mistaken, but it does bring out why one might think medicine, properly aimed only at human health defined in terms of biological functioning, has little to teach us regarding broader social issues about the quality of life. I believe it is fair to say that the main body of work in medical ethics within the last two decades has rejected Kass' view of the sole proper aim of medicine as health, defined in naturalistic, biological terms, and of the ethical

framework for medical treatment decisionmaking that it would seem to imply. We need to see how the alternative, broader view of the aims of medicine that should guide medical treatment decisionmaking bears on an understanding of the quality of life.

It has become a commonplace, at least in the developed countries, that medicine has achieved the capacity commonly to offer to patients suffering from particular diseases a number of alternative treatments and to extend patients' lives in circumstances in which the benefit to the patient of doing so is increasingly problematic. In the United States this has led to patients pursuing various means of gaining control over decisions about their treatment. In the case of competent patients, a broad consensus has developed that such patients have the right to decide about their care in a process of shared decisionmaking with their physicians and to reject any proffered treatment. In the case of incompetent patients, an analogous consensus has been developing that an incompetent patient's surrogate, seeking to decide as the patient would have decided in the circumstances if competent, is likewise entitled to decide about the patient's care with the patient's physician and to reject any care the patient would not have wanted, though this consensus concerning incompetent patients is less broad and deep and more ringed with qualifications. Each consensus is reflected in a large medical ethics literature, a growing body of legal decisions, legal mechanisms such as Living Wills and Durable Powers of Attorney for Health Care whose purpose is to insure patient's control over their care, pronouncements and studies of authoritative bodies and commissions, policies of health care institutions, and the practice of health care professionals.¹³

The common view has become that health care decisionmaking should be a process of shared decisionmaking between patient (or the patient's surrogate in the case of an incompetent patient) and physician.¹⁴ Each is seen as indispensable to sound decisionmaking. The physician brings his or her training, knowledge and expertise to bear for the diagnosis of the patient's condition, the estimation of the

patient's prognosis with different alternative treatments, including the alternative of no treatment, and a recommendation regarding treatment. The patient brings the knowledge of his or her aims, ends and values that will likely be affected by different courses of treatment and that enable the comparative evaluation of different possible outcomes. As alternative treatments have multiplied and have become possible in circumstances promising increasingly marginal or questionable benefits, both physicians and patients are called upon to make increasingly difficult judgments of the effects of treatment on patients' quality of life. It is worth noting that proponents of shared decisionmaking need not reject the functional account of health as a biological norm defended by Kass and others. What they can reject is the claim that the only proper goal of medicine is health. Instead, medicine's goal should be to provide treatment that best enables patients to pursue successfully their overall aims and ends, or plans of life. It is the relative value of health, and of different aspects of health, as compared with other ends, that varies for different persons and circumstances.

Most decisions of patients about life-sustaining treatment will be based on their judgment of the benefits and burdens of the proposed treatment and the life it sustains, though in some instances patients may give significant weight to other factors such as religious obligations, the emotional burdens and financial costs for their families, and so forth. Except for patients who hold a form of vitalism according to which human life should or must be sustained at all costs and whatever its quality, these decisions of competent patients must inevitably involve an assessment of their expected quality of life if life-sustaining treatment is employed, though, as I shall note shortly, of only a very restricted sort.

Some have rejected the acceptability of quality of life judgments in the case of incompetent patients unable to decide for themselves and so for whom others must make treatment decisions.¹⁵ One version of the objection is that no one should decide for another whether that other's quality of life is such that it is not worth continuing

it. More specifically, the objection is that it is unacceptable to judge that the quality of a person's life is sufficiently poor so as to be not worth the cost and effort to others to sustain the person's life. This objection, however, is not to making quality of life judgments in this context generally, but only to concluding that a person's life is not worth sustaining because its poor conditions or quality make it not of value, but instead a burden, to others. The sound point that this objection confusingly makes is that quality of life judgments concerning a particular person should address how the conditions of a person's life affect its quality or value to that person, and not its value to others. Moreover, persons might judge their quality of life to be low and nevertheless value their lives as precious. In economic and policy analysis one version of the so-called human capital method of valuing human life, which values a person's life at a given point in time by his or her expected future earnings minus personal consumption, in effect values a person's life in terms of its economic value to others.¹⁶ But there is no reason to reject the soundness of any evaluation by one person of another's quality of life simply because some might draw a further unjustified conclusion that if its quality is sufficiently low to make it on balance a burden to others, it ought not to be sustained.

The quality of life judgment appropriate to life-sustaining treatment decisions, whether made by a competent patient or an incompetent patient's surrogate, should thus assess how the conditions of the patient's life affect the value of that life to that patient. Nevertheless, even properly focused in this way, the role of quality of life judgments in decisions about whether to withhold or withdraw life-sustaining treatment is extremely limited. This quality of life judgment focuses only on which side of a single threshold a person's quality of life lies. The threshold question is, "Is the quality of the patient's life sufficiently poor so that for that person continued life is worse than no further life at all?" Or, in the language of benefits and burdens commonly employed in this context, "Is the patient's quality of life so poor that the use

of life-sustaining treatment is unduly burdensome, that is, such that the burdens to the patient of the treatment and/or the life that it sustains are sufficiently great and the benefits to the patient of the life that is sustained sufficiently limited, to make continued life on balance no longer a benefit or good to the patient?"¹⁷ The only discrimination in quality of life required here is whether the quality of the life is on balance sufficiently poor to make it worse than non-existence to the person whose life it is.

Some have objected that this judgment is incoherent since, though it is possible to compare the quality of two lives, or of a single person's life under different conditions, it is not possible to make the quality of life comparison needed here because one of the alternatives to be compared is non-existence. If a person no longer exists, there is no life that could possibly have any quality so as to enter into a comparison with the quality of the life sustained by treatment. This objection does correctly point out that the judgment in question cannot involve a comparison of the quality of two alternative periods of life, though it could compare two possible lives, one that ends at that time and another that continues longer. However, it does not follow that there is no sense to the question of whether the best life possible for a person with some form of life-sustaining treatment is of sufficiently poor quality, or sufficiently burdensome, to be worse for that person than no further life at all. Perhaps the most plausible example is the case of a patient suffering from an advanced stage of invariably fatal cancer, who is virtually certain to die within a matter of days whatever is done, and whose life will be filled in those remaining days with great and unrelievable pain and suffering. (With the appropriate use of presently available measures of pain relief, it is in fact only very rarely the case that great pain and suffering in such cases cannot be substantially relieved.) The burdens of those remaining days may then be found by the patient to be virtually unbearable, while the life sustained provides nothing of value or benefit to the patient. This judgment addresses the quality of the life sustained

and appears to be a sensible judgment. It is just the judgment that patients or their surrogates commonly understand themselves to be making when they decide whether to employ or continue life-sustaining treatment.

Alternatively, the objection to someone ever making such a judgment for another may be based not on any putative incoherence of such judgments, but may express instead a concern about the difficulty in ever reliably deciding how another would in such circumstances decide, due perhaps to the diversity and unpredictability of persons' actual decisions for themselves. Moreover, if the difficulty in reliably making such judgments for others is in fact this great, then we might well have a related practical concern that the interests of others, which may be in conflict with those of the patient, may consciously or unconsciously infect judgments about what is best for the patient.

Despite these difficulties, there have been attempts to formulate some general substantive standards for when an incompetent patient's quality of life is so poor that withholding or withdrawing further life-sustaining treatment is justified. For example, Nicholas Rango has proposed standards for nursing home patients with dementia.¹⁸ He emphasizes the importance of being clear about the purposes for which care is provided and distinguishes three forms of care: 1) palliative care aimed at relieving physical pain and psychological distress; 2) rehabilitative care aimed at identifying and treating "excess disabilities, the gap between actual level of physical, psychological or social functioning and potential functioning capacity"¹⁹ 3) medical care aimed at reducing the risk of mortality or morbidity. He emphasizes the importance of therapeutic caution because a seriously demented patient will not be able to understand the purpose of painful or invasive interventions, and so presumably cannot choose to undergo and bear burdensome treatment for the sake of promised benefits.²⁰ Rango proposes two conditions, either of which is sufficient to justify forgoing further treatment of a chronic medical condition or a superimposed acute

illness: a) when the patient is burdened by great suffering despite palliative and rehabilitative efforts; b) when the dementia progresses "to a stuporous state of consciousness in which the person lives with a negligible awareness of self, other, and the world."²¹ Even within the relatively narrow focus of life-sustaining treatment decisions for demented patients, Rango's proposal can be seen to include three different kinds of components of quality of life assessments. The first, covered by treatment aim 1 and patient conditions a and b, concerns the quality of the patient's conscious experience. The second, covered especially by treatment aim 2 and patient condition b, concerns the patient's broad functional capacities. The third, covered especially by patient condition b and by the patient's ability to understand the purpose of treatment and in turn to choose to undergo it, concerns the centrality to quality of life of the capacity for the exercise of choice in forming and pursuing an integrated and coherent life plan. I shall argue below that each of these three kinds of conditions are essential components of an adequate account of the quality of life.

At the other end of life, the debate in the United States about treatment for critically ill newborns has also focused on the role of quality of life considerations in determining when life-sustaining treatment is a benefit for the newborn. One influential attempt to bring quality of life considerations into these decisions is the proposal of the moral theologian, Richard McCormick, that a newborn's life is a value that must be preserved only if the newborn has the potential for a "meaningful life."²² A meaningful life is one that contains some potentiality for human relationships; for example, anencephalic newborns wholly lack this potential, while newborns with Down's Syndrome or Spina Bifida (to cite two of the most discussed kinds of cases) normally do not. Nancy Rhoden has developed a more detailed proposal along similar lines regarding life-sustaining treatment for newborns

"aggressive treatment is not mandatory if an infant: (1) is in the process of dying; (2) will never be conscious; (3) will suffer unremitting pain; (4) can only live with major, highly restrictive technology which is not intended to be temporary (e.g., artificial ventilation); (5) cannot live past infancy (i.e., a few

years; or (6) lacks potential for human interaction as a result of profound retardation."²³

Rhoden's proposal is typical of those accepting the use of quality of life considerations in life-sustaining treatment decisions for newborns in its focus on: the infant's at least minimal capacity for positive conscious experience (conditions 2 and 3); the infant's capacities for physical, mental, and social functioning (conditions 2, 3, 4 and 6), and; the infant's capacities to live far enough into childhood to begin a life that can be viewed and experienced "from the inside" by the child as a life lived in a biographical, not biological, sense (conditions 1 and 4; I will say more about this special feature of infant "life years" below in discussing the relevance of mortality data to good lives). However, the very limited, single threshold character of the quality of life assessments required in decisions whether to forgo or to employ life-sustaining treatment, whether for adults or newborns, takes us only a little ways in understanding quality of life assessments in health care treatment decision making.

It is necessary, consequently, to broaden the focus from life-sustaining treatment decisions to medical treatment decisions generally. Here, as noted earlier, there is a widespread consensus that competent patients are entitled, in a process of shared decision-making with their physicians, to decide about their treatment and to refuse any proffered or recommended treatment. In the United States, the doctrine of informed consent, both in medical ethics and the law, requires that treatment not be given to a competent patient without that patient's informed and voluntary consent.²⁴ What does this doctrine, which lodges decision making authority with the patient, imply about the nature of judgments concerning the patient's quality of life? An argument that it presupposes the normatively subjective, preference satisfaction account of a good life might, in rough outline, go as follows.

Each of the requirements of the informed consent doctrine can be understood as designed to provide reasonable assurance that the patient has chosen the treatment

alternative most in accord with his or her own settled preferences and values. If the patient's decision is not informed, specifically, if the patient is not provided in understandable form with information regarding his or her diagnosis, prognoses when different treatment alternatives (including the alternative of no treatment) are pursued, including the expected risks and benefits with their attendant probabilities of treatment alternatives, then the patient will lack the information needed to select the alternative most in accord with his or her settled preferences. If the patient's decision is not voluntary, but is instead forced, coerced, or manipulated by another, then it will likely not be in accordance with the patient's settled preferences, but instead will forward another's interests, or another's view of what is best for the patient. If the patient is not competent to make the choice in question, then he or she will lack the abilities to use the information provided to deliberate about the alternatives and to select the one most in accord with his or her settled preferences. When all three requirements are satisfied, others will have reasonable assurance that the patient's choice fits the patient's own conception of a good life, as reflected in his or her settled preferences.²⁵ Viewed in this way, the informed consent doctrine may appear to be grounded in a preference satisfaction account of the good for persons or the quality of life, and so not to require any more complex vector account of the sort suggested earlier. Even in this very crude form, however, this argument can be seen to be unsound by asking what values the informed consent doctrine and the account of shared decisionmaking in medicine are usually thought to promote, what values support their acceptance.

The most natural and obvious first answer has already implicitly been given -- the informed consent doctrine in health care treatment decisionmaking is designed, when its three requirements are satisfied, to serve and promote the patient's well-being, as defined by the patient's settled, uncoerced and informed preferences. If this were the only value at stake, or at least clearly the dominant value, then it would be

plausible to argue that the informed consent doctrine rested, at least implicitly, on a preference satisfaction account of the good life. However, it is not the only value. Usually regarded as at least of roughly commensurate importance is respecting the patient's self-determination or autonomy.²⁶ I understand here the interest in self-determination to be the interest of persons, broadly stated, in forming, revising over time, and pursuing in their choices and actions their own conception of a good life; more narrowly stated for my specific purposes here, it is persons' interest in making significant decisions affecting their lives, such as decisions about their medical care for themselves and according to their own values. Sometimes this is formulated as the right to self-determination.

Whether interest or right, however, the greater the moral weight accorded to individual self-determination as one of the values underlying and supporting the informed consent doctrine, the weaker the basis for inferring that the doctrine presupposes the normatively subjective, preference satisfaction account of the good life. This is because the greater the moral weight accorded to individual self-determination as support for the informed consent doctrine, the more that same self-determination can explain the requirement of informed consent, even assuming the patient chooses in a manner sharply contrary to his or her own well-being. Moreover, there is substantial reason to suppose that the doctrine does in fact substantially rest on patient self-determination. In the celebrated 1914 legal case of *Schloendorff v. Society of New York Hospitals*, usually cited as the first important enunciation of the legal requirement of consent for medical care, Justice Cardozo held that: "Every human being of adult years and sound mind has a right to determine what shall be done to his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages."²⁷ I shall make no attempt here to trace the development of the legal doctrine of informed consent since *Schloendorff*, but it is probably fair to say that no other subsequent case has been as influential or as

often cited in that development. And the later cases, in one form or another, repeatedly appeal to a right to self-determination to support that developing doctrine.²⁸ For example, nearly half a century later in the important 1960 case of *Natanson v. Kline* the Kansas Supreme Court made an equally ringing appeal to self-determination:

"Anglo-American law starts with the premise of thorough-going self-determination. It follows that each man is considered to be master of his own body, and he may, if he be of sound mind, expressly prohibit the performance of life-saving surgery, or other medical treatment. A doctor might well believe that an operation or form of treatment is desirable or necessary but the law does not permit him to substitute his own judgment for that of the patient by any form of artifice or deception."²⁹

The philosophical tradition on the problem of paternalism is equally bound up in a commitment to the importance of individual self-determination or autonomy. Here, the locus classicus is John Stuart Mill's renowned assertion of the "one very simple principle" that

"the sole end for which mankind are warranted, individually or collectively, in interfering with the liberty of action of any of their number is self-protection. That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not a sufficient warrant. He cannot rightfully be compelled to do or forbear because it will be better for him to do so, because it will make him happier, because, in the opinions of others, to do so would be wise or even right."³⁰

The voluminous subsequent philosophical literature on paternalism certainly suggests that this principle is not as simple as Mill supposed, but it also makes clear that, even for one like Mill who in other contexts was an avowed utilitarian, the case for non-interference with individual self-determination and liberty of action does not rest on any claim that doing so cannot be for a person's "good," understood in a normatively subjective interpretation. Quite to the contrary, Mill and the many who have followed him have been at pains to insist that such interference is not justified even when it would truly be for the good of the one interfered with.³¹ The result is that it is not possible to draw any firm conclusion from the doctrine of informed consent in medicine that patients' well-being or quality of life is understood in a

normatively subjective interpretation. Instead of that normatively subjective account of the good for persons, individual self-determination can serve as the foundation for the informed consent doctrine and can make that doctrine compatible with any of the three main alternative accounts of the good for persons or quality of life that I have distinguished.

What is the relation between these two values of patient self-determination and well-being, commonly taken as underlying the informed consent doctrine, and the broad concept of a good life for persons? The conventional view, I believe, is that the patient's well-being is roughly equivalent to the patient's good and that individual self-determination is a value independent of the patient's well-being or good. Respecting the patient's self-determination then at least sometimes justifies respecting treatment choices that are contrary to the patient's well-being or good.³² Respecting self-determination is commonly held to be what is required by recognizing the individual as a person, capable of forming a conception of the good life for him or herself. If personal self-determination is a fundamental value, fundamental in what it is to respect persons, however, then I suggest that our broadest conception of a good life for persons should be capable of encompassing it rather than setting it off as separate from and in potential conflict with a person's well-being, as in the conventional account of informed consent. What we need is a distinction between a good life for a person in the broadest sense and a person's well-being, such that only personal well-being is independent of and potentially in conflict with individual self-determination.

We should think of being self-determined as central to, a central part of, having a good life in the broadest sense. It is in the exercise of self-determination that we maintain some control over, and take responsibility for, our lives and for what we will become. This is not to deny, of course, that there are always substantial limits and constraints within which we must exercise this judgment and choice. But it is to say that showing respect for persons through respecting their self-determination

acknowledges the fundamental place of self-determination in a good life. I take this to be essentially what Rawls intended in his claim that persons have a highest order interest in autonomy and what Sen means with his notion of agency freedom.³³ We do not want this broad conception of a good life, however, to prevent our making sense of persons freely and knowingly choosing to sacrifice their own personal well-being for the sake of other persons. To cite an extreme case, a parent might knowingly and freely choose not to pursue expensive life-sustaining treatment such as a heart transplant in order to preserve financial resources for his children's education. Given his love and sense of responsibility for his children, he would judge his life to be worse if he had the transplant at the expense of his children's education, though certainly his health and his personal well-being would be improved. We might say here that he values his personal well-being in these circumstances less than the well-being of his children. In its requirement to respect such a choice, the informed consent doctrine implicitly accepts that the best life for a person is a life of self-determination or choice, even if the exercise of that self-determination or choice results in a lessened state of personal well-being. Precisely how to make this distinction between a good life, as opposed to the personal well-being, of an individual raises difficulties that I cannot pursue here. The rough idea is that personal well-being makes essential reference to the states of consciousness, activities, and capacities for functioning of the person in question (I will pursue this further in Section II of this paper), and it is these that are worsened when the parent pursues his conception of a good life in sacrificing his personal well-being for that of his child.³⁴

Medical treatment decisions often must be made for patients who are not themselves competent to make them. There has been considerable discussion in medical ethics and in the law regarding appropriate ethical standards for such decisions.³⁵ Since quality of life considerations are virtually always relevant to these decisions, the ethical frameworks developed for these decisions must employ, either

explicitly or implicitly, a conception of the quality of life of patients. There is considerable consensus that if the patient in question, while still competent, formulated and left an explicit advance directive clearly and unambiguously specifying his or her wishes regarding treatment in the circumstances now obtaining, then those wishes should be followed, at least within very broad limits, by those treating the patient. At the present time in the United States, most states have adopted legislation giving the force of law to one or another form of so-called Living Will which allow persons to give binding instructions about their treatment should they become incompetent and unable to decide for themselves. Several other states have more recently enacted legislation permitting persons to draw up a Durable Power of Attorney for Health Care which combines the giving of instructions about the person's wishes regarding treatment with the designation of who is to act as one's surrogate decisionmaker, and so to interpret those instructions, should one become incompetent to make the decisions oneself.

In the usual case in which an incompetent patient has left no formal advance directive, two guidance principles for those who must decide about treatment for the patient have been supported -- the Substituted Judgment principle and the Best Interests principle. The Substituted Judgment principle requires the surrogate to decide as the patient would have decided if competent and in the circumstances that currently obtain. The Best Interests principle requires the surrogate to make the treatment decision that best serves the patient's interests. This has the appearance of a dispute between what I earlier called normatively subjective and normatively objective accounts of a good life since the only point of the Best Interests principle as an alternative to Substituted Judgment might seem to be that it employs a normatively objective standard of the person's good that does not depend on his or her particular subjective preferences and values. However, this appearance is misleading. These two principles of surrogate decisionmaking are properly understood, in my view, not as

competing alternative principles to be used for the same cases, but instead as an ordered pair of principles to cover all cases of surrogate decision-making for incompetent patients in which an advance directive does not exist, with each of the two principles to apply in a different subset of these cases. (This is not to say that these two principles are always in fact understood in medical ethics, the law, or health care practice as applying to distinct groups of cases -- treatments of these two principles are rife with confusion.)

The two groups of cases are differentiated with regard to the information available or obtainable concerning the patient's general preferences and values that have some bearing on the treatment choice at hand. The two principles are an ordered pair in the sense that when sufficient information is available about the relevant preferences and values of the patient to permit a reasonably well-grounded application of the Substituted Judgment principle, then surrogate decisionmakers for the patient are to use that information and that principle to infer what the patient's decision would have been in the circumstances if he or she were competent.³⁶ In the absence of such information, and only then, surrogate decisionmakers for the patient are to select the alternative that is in the best interests of the patient, which is usually interpreted to mean the alternative that most reasonable and informed persons would select in the circumstances. Thus, these two principles are not competing principles for application in the same cases, but alternative principles to be applied in different cases.

Nevertheless, it might seem that the Best Interests standard remains a normatively objective account when it is employed. However, this need not be so. If the Best Interests standard is understood as appealing to what most informed and reasonable persons would choose in the circumstances, it employs the normatively subjective preference standard. And it applies the choice of most persons to the patient in question because in the absence of any information to establish that the patient's relevant preferences and values are different than most peoples, the most reasonable

presumption is that the patient is like most others in the relevant respects and would choose like those others. Thus, the Best Interests standard, like the two other standards of choice for incompetent patients -- the Advance Directive and Substituted Judgment standards -- can be understood as requiring the selection of the alternative the patient would likely have selected, with the variations in the standards suited to the different levels of information about the patient that is available. Just as with the informed consent doctrine that applies to competent patients, so these three principles -- Advance Directives, Substituted Judgment, and Best Interests -- guiding surrogate choice for incompetent patients can all be understood as supported and justified by the values of patient well-being and self-determination. Thus, these three principles to guide surrogate choice for the treatment of incompetent patients each implicitly employ an account of a good life that is a life of choice and self-determination concerning one's aims, values, and life plan.

Before leaving the ethical frameworks that have been developed in the medical ethics, legal, and medical literatures for treatment decisionmaking for competent and incompetent patients, I want to make explicit an indeterminacy in those frameworks concerning the nature of the ethical theory they presuppose. I have noted that it is common to base those ethical frameworks on two central values in a good life -- patient well-being and self-determination. What is commonly left unclear, however, is the foundational status of the ethical value of individual self-determination in the underlying ethical theory supporting those decisionmaking frameworks. Self-determination might be held to have only derivative or instrumental value within a broadly consequentialist moral theory. Specifically, it might be held to be instrumentally valuable for the fundamental value of happiness or preference satisfaction within normatively subjective theories of a good life of a hedonist or preference satisfaction sort. If, as seems true at least for many social conditions and historical periods, most persons have relatively strong desires to make significant

decisions about their lives for themselves, then it is at least a plausible presumption that their doing so will generally promote their happiness or the satisfaction of their desires. If self-determination is only valuable at bottom in so far as it leads to happiness or preference satisfaction, then it will not be part of an ideal of the person that is objective in the sense of its value not being entirely happiness or preference dependent. Since on most plausible theories of the good for persons, persons' happiness and desire satisfaction is a significant part of their having a good life, and since self-determination does commonly make a significant contribution to persons' happiness or desire satisfaction, self-determination will commonly have significant instrumental value on any plausible theory of a good life.³⁷

As a result, to single out self-determination as one of the two principal values underlying the informed consent doctrine in medical ethics as it applies both to competent and incompetent patients is not to make clear at a foundational level of ethical theory whether self-determination is held to have only instrumental value, or also significant non-instrumental value as an important component of an objective ideal of the person. The vast majority of ethical discussions of informed consent and health care treatment decisionmaking simply do not either explicitly address this foundational question of ethical theory nor even implicitly presuppose a particular position on it. From a practical perspective, this foundational indeterminacy has the value of allowing proponents of incompatible ethical theories, for example consequentialists and rights-based theorists, to agree on the fundamental importance of a life of self-determination and choice in a good life for persons.

There is one final difficulty to be noted in attempting to infer the account of a good life at the level of basic ethical theory from the ethical frameworks for treatment decisionmaking advocated for and employed in medical practice. The general difficulty lies in inferring the underlying values or ethical principles that support social practices. A social practice like that of informed consent and shared

decisionmaking in medicine must guide over time a very great number of treatment decisions carried out in a wide variety of circumstances by many and diverse patients, family members, and health care professionals. A well-structured practice must take account of and appropriately minimize the potential in all involved parties for well-intentioned misuse or ill-intentioned abuse of their roles. Thus, institutional constraints may be justified, though on some particular occasions they will produce undesirable results, because in the long run their overall results are better than those of any feasible alternatives. For example, even if we appeal only to the value of patient well-being and leave aside any independent value of self-determination, a strong right of patients to refuse any treatment might be justified if most of the time persons themselves are the best judges of what health care treatment will best promote their happiness or satisfy their enduring preferences and values. Alternatively, that same strong right to refuse treatment might be justified within a normatively objective ideal theory of a good life for persons because, though individuals can be mistaken about their own good when they pursue their happiness or seek to satisfy their desires, no reliable alternative social and legal practice is feasible that in the long run will produce better results, even judged by that ideal theory of a good life. The imperfections and limitations of persons and institutions may lead supporters of quite different accounts of a good life for persons to support roughly the same institutions in practice. In a more general form, this is a thoroughly familiar point in moral philosophy where defenders of fundamentally different moral theories, such as consequentialists and rights theorists, may converge on the institutions justified by their quite different theories. Without explicitly uncovering the justificatory rationales for specific social institutions accepted by particular persons, we cannot confidently infer the ethical principles or judgments, and specifically the conception of a good life, that they presuppose.

III. Health Policy Measures of the Quality of Life

I want now to shift attention from the account of the quality of life presupposed by ethical frameworks for medical treatment decisionmaking to more explicit measures used to assess health levels and the quality of life as it is affected by health and disease within larger population groups. Early measurement attempts focused on morbidity and mortality rates in different populations and societies. These yield only extremely crude comparisons, since they often employ only such statistics as life expectancy, infant mortality, and reported rates of specific diseases in a population. Nevertheless, they will show gross differences between countries, especially between economically developed and underdeveloped countries, and between different historical periods, in both length and quality of life as it is affected by disease. Major changes in these measures during this century, as is well known, have been due principally to public health measures such as improved water supplies, sewage treatment and other sanitation programs and to the effects of economic development on improved nutrition, housing, and education; improvements in the quality of and access to medical care have been less important. In recent decades, health policy researchers have developed a variety of measures that go substantially beyond crude morbidity and mortality measures. Before shifting our attention to them, however, it is worth underlining the importance of mortality measures to the broad concept of a good life.

When quality and quantity of life are distinguished, both are relevant to the degree to which a person has a good life. Persons whose lives are of high quality, by whatever measure of quality, but whose lives are cut short well before reaching the normal life span in their society, have had lives that have gone substantially less well, because of their premature death, than they might have had or than reasonably might have been expected. People typically develop, at least by adolescence, more or less articulated and detailed plans for their lives; commonly, the further into the future

those plans stretch, the less detailed, more general, and open ended they are. Our life plans undergo continuous revision, both minor and substantial, over the course of our lives, but at any point in time within a life people's plans for their lives will be based in part on assumptions about what they can reasonably expect in the way of a normal life span.³⁸ When their lives are cut short prematurely by illness and disease they lose not just the experiences, happiness, and satisfactions that they would otherwise have had in those lost years, but they often lose as well the opportunity to complete long-term projects and to achieve and live out the full shape, coherence, and conclusion that they had planned for their lives. It is this rounding out and completion of a life plan and a life that helps enable many elderly, when dying and near death, to feel that they have lived a full and complete life and so to accept their approaching death with equanimity and dignity. Thus, the loss in the goodness of a life from premature death is not simply the loss of a unit of a good thing, a desired and expectably happy life-year, but the cutting short of the as yet incompletely realized life plan that gave meaning and coherence to the person's life.

The importance of life plans for a good life suggests at least two other ways in which different mortality rates within societies affect the opportunities of their members to attain good lives. Citizens of economically underdeveloped countries typically have shorter life expectancies than do citizens of the developed countries. Thus, even those who reach a normal life span in underdeveloped countries will have less time to develop and enjoy a richly complex and satisfying life than will those who reach a normal, but significantly longer, life span in the developed countries. Mortality data indicate that citizens of underdeveloped countries typically have less good lives as a result of inadequate health care both because of their shorter life expectancies and because of their increased risk of not living to even the normal life span in their own society.

One final relation between mortality data and the importance of life plans in a good life concerns infant and extremely early childhood mortality. It is common to view such early mortality as particularly tragic both because of the greater amount of expected life years lost to the the individual and because the life was cut short just as it was getting started. The loss is often deep for the infant's or extremely young child's parents, in part because of the hopes and plans for the infant's future that they had for the infant. But the death of an infant or extremely young child before he or she has developed the capacity to form desires, hopes and plans for the future cuts that life short -- "life" understood as a connected plan or unfolding biography with a beginning, middle and end -- before it has begun; the infant is alive, but does not yet have a life in this biographical sense.³⁹ From the perspective of this biographical sense of having a life as lived from the "inside," premature death in later childhood, adolescence, or early adulthood commonly makes a life that has gotten started go badly by that death, whereas infant death does not make a life go badly, but instead prevents it from getting started. Thus, as we shift attention to quality of life measures, which commonly seek to evaluate a life at some point in time or during some stretch of time, it is important not to lose sight of some of the complex ways in which mortality rates in a society can affect the extent to which its members enjoy a good life.

There is a voluminous medical and health policy literature focused on the evaluation of persons' quality of life as it is affected by various disease states and/or treatments to ameliorate or cure those diseases.⁴⁰ The dominant conception of the appropriate aims of medicine focuses on it as an intervention aimed at preventing, ameliorating or curing disease and its associated effects of suffering and disability, and thereby to restore, or to prevent the loss of, normal function or of life. Whether the norm be that of the particular individual, or that typical in the particular society or species, the aim of raising peoples' function to above the norm is not commonly accepted as an appropriate aim of medicine equal to restoring function up to the norm.

Problematic though the distinction may be, quality of life measures in medicine and health care consequently tend to focus on individuals' or patients' dysfunction and its relation to some such norm. At a deep level, medicine views bodily parts and organs, individual human bodies, and persons from a functional perspective. Both health policy analysts and other social scientists have done considerable work constructing and employing measures of health and quality of life for use with large and relatively diverse populations. Sometimes these measures explicitly address only a part of an overall evaluation of persons' quality of life, while in other instances they address something like overall quality of life as it is affected by disease. A closely related body of work focuses somewhat more narrowly on the evaluation of the effect on quality of life of specific modes of treatment for specific disease states. This research is more clinically oriented, though it too has some range in the breadth of impact on quality of life researchers seek to measure, depending often on the usual breadth of impact on the person of the disease being treated. As a general matter, the population wide measures tend to be less sensitive to individual differences in either the manner or degree to which a particular factor affects persons' quality of life. It will be helpful to have before us a few representative examples of the evaluative frameworks employed.⁴¹

The Sickness Impact Profile (SIP) was developed by Marifyn Bergner and colleagues to measure the impact of a wide variety of forms of ill health on the quality of persons' lives.⁴² Figure 1 below enumerates the items measured.

Figure 1

Vol. XIX, No. 8

THE SICKNESS IMPACT PROFILE

Table 1. Sickness Impact Profile Categories and Selected Items

Dimension	Category	Items Describing Behavior Related to:	Selected Items
Independent Categories	SR	Sleep and rest	I sit during much of the day I sleep or nap during the day
	E	Eating	I am eating no food at all, nutrition is taken through tubes or intravenous fluids I am eating special or different food
	W	Work	I am not working at all I often act irritable toward my work associates
	HM	Home management	I am not doing any of the maintenance or repair work around the house that I usually do I am not doing heavy work around the house
	RP	Recreation and pastimes	I am going out for entertainment less I am not doing any of my usual physical recreation or activities
	I. Physical	A	Ambulation
M		Mobility	I stay within one room I stay away from home only for brief periods of time
BCM		Body care and movement	I do not bathe myself at all, but am bathed by someone else I am very clumsy in body movements
II. Psychosocial	SI	Social interaction	I am doing fewer social activities with groups of people I isolate myself as much as I can from the rest of the family
	AB	Alertness behavior	I have difficulty reasoning and solving problems, for example, making plans, making decisions, learning new things I sometimes behave as if I were confused or disoriented in place or time, for example, where I am, who is around, directions, what day it is
	EB	Emotional behavior	I laugh or cry suddenly I act irritable and impatient with myself, for example, talk badly about myself, swear at myself, blame myself for things that happen
	C	Communication	I am having trouble writing or typing I do not speak clearly when I am under stress

A second example is the Quality of Life Index (QLI) developed by Walter O. Spitzer and colleagues to measure the quality of life of cancer patients.⁴³

Figure 2

QUALITY OF LIFE INDEX

SCORING FORM

Study No. _____

Age _____ Sex M / F (ring appropriate letter) _____ OO

Primary Problem or Diagnosis _____ OOO

Secondary Problem or Diagnosis, or Completion If appropriate) _____ OOO

Score's Specialty _____ OOO

Score each heading 2, 1 or 0 according to your most recent assessment of the patient.

ACTIVITY

- During the last week, the patient _____ 2
- has been making or looking in usual occupation or managing own household or participating in unpaid or voluntary activities, but not having been working or studying in any capacity or not managing own household _____ 0
- has not been working or studying in any capacity and not managing own household _____ 0

DAILY LIVING

- During the last week, the patient _____ 2
- has been performing essential functions of daily living (e.g., eating, dressing, grooming, walking, etc.) _____ 0
- has not been managing personal care (not night tasks and/or not leaving own home or institution at all) _____ 0

HEALTH

- During the last week, the patient _____ 2
- has been feeling "very ill" or "fairly" ill, more than just occasionally _____ 0
- has been feeling "well" or "fairly" well, at least most of the time _____ 0

SUPPORT

- During the last week _____ 2
- support received or expected has been limited from family and friends and/or by the patient's condition _____ 0
- support from family and friends occurred infrequently or only when absolutely necessary or patient was unconscious _____ 0

OUTLOOK

- including surroundings _____ 2
- has been seriously confused or very frightened or consistently anxious and depressed or unconscious _____ 0

OO

QLI INDEX TOTAL _____

How confident are you that your scoring of the preceding dimension is accurate? Passing the appropriate strategy.

Very Confident ₁ Quite Confident ₂ Not Very Confident ₃ Very Doubtful ₄ Not at all Confident ₅

Fig. 2. The format of the final version adopted.

A third prominent measure developed by Milton Chen, S. Fanshel and others is the Health Status Index (HSI) which measures levels of function along the following dimensions.⁴⁴

Figure 3

Scales and Definitions for the Classification of Function Levels*

Scale	Step	Definition
<i>Mobility Scale</i>		
5	Travelled freely	Used public transportation or drove alone. For below 6 age group, travelled as usual for age.
4	Travelled with difficulty	(a) Went outside alone, but had trouble getting around community freely, or (b) required assistance to use public transportation or automobile.
3	In house	(a) All day, because of illness or condition, or (b) needed human assistance to go outside.
2	In hospital	Not only general hospital, but also nursing home, extended care facility, sanitarium, or similar institution.
1	In special unit	For some part of the day in a restricted area of the hospital such as intensive care, operating room, recovery room, isolation ward, or similar unit.
0	Death	
<i>Physical Activity Scale</i>		
4	Walked freely	With no limitations of any kind.
3	Walked with limitations	(a) With cane, crutches, or mechanical aid, or (b) limited in lifting, stooping, or using stairs or inclines, or (c) limited in speed or distance by general physical condition.
2	Moved independently in wheelchair	Propelled self alone in wheelchair.
1	In bed or chair	For most or all of the day.
0	Death	
<i>Social Activity Scale</i>		
5	Performed major and other activities	Major means specifically—play for below 6, school for 6–17, and work or maintain household for adults. <i>Other</i> means all activities not classified as major, such as athletics, clubs, shopping, church, hobbies, civic projects, or games as appropriate for age.
4	Performed major but limited in other activities	Played, went to school, worked, or kept house but limited in other activities as defined above.
3	Performed major activity with limitations	Limited in the amount or kind of major activity performed, for instance, needed special rest periods, special school, or special working aids.
2	Did not perform major activity but performed self-care activities	Did not play, go to school, work or keep house, but dressed, bathed, and fed self.
1	Required assistance with self-care activities	Required human help with one or more of the following—dressing, bathing, or eating—and did not perform major or other activities. For below 6 age group, means assistance not usually required for age.
0	Death	

It would be a mistake, of course, to attempt to infer precise and comprehensive philosophical theories of the quality of life or of a good life from measures such as these. Their developers are commonly social scientists and health care researchers who are often not philosophically sophisticated or concerned with the issues that divide competing philosophical accounts of a good life. The practical and theoretical difficulties in constructing valid measures that are feasible for large and varied populations require compromises and simplifications with, or simply passing over, issues of philosophical importance. Nevertheless, several features of these measures are important in showing the complexity of the quality of life measures employed in health care and, I believe, of any adequate account of the quality of life or of a good life.

First, the principal emphasis in each of the three measures of quality of life is on function, and functions of the "whole person" as opposed to body parts and organ systems. In each case the functions are broadly characterized so as to be relevant not simply to a relatively limited and narrow class of life plans, but instead to virtually any life plan common in modern societies; following the lead of Rawls' notion of "primary goods," I shall call these "primary functions."⁴⁵ In the SIP, the categories of sleep and rest, and of eating, are necessary for biological function. The "independent" categories of work, home management, and recreation and pastimes are central activities common in virtually all lives, though there is adjustment for the relative importance they have in a particular life by making the measure relative to what had been the individual's normal level of activity in each of these areas prior to sickness. The two broad groups of functions, physical and psychosocial, are each broken down into several distinct components. For each primary function, the SIP measures the impact of sickness on it by eliciting information concerning whether activities typical in the exercise of that function continue to be performed, or have become limited. Even for primary functions, about which it is plausible to claim that they have a place in virtually any

life, the different functions can have different relative value or importance within different lives, and the SIP makes no attempt to measure those differences. The QLI likewise addresses a person's levels of activity in daily living, specifically measuring the presence of related behaviors in these areas. In measuring health and outlook, the primary concern is with subjective feeling states of the person, though here too there is concern with relevant behavior. The category of support addresses both social behavior of the individual together with the availability of persons in the individual's environment to provide such relationships. This category illustrates the important point that most primary functional capacities require both behavioral capacities in the individual and relevant resources in the individual's external environment. The HSI addresses three broad categories of primary function -- mobility, physical activity, and social activity -- with evidence of current functional capacity found in current levels of activity. It is noteworthy that even this index, which focuses explicitly on the health status of individuals, does not measure the presence or absence of disease, as one might expect given common understandings of "health" as the absence of disease; like SIP and QLI, it too measures levels of very broad primary functions.

A second important feature of these measures shows up explicitly only in the first two -- SIP and QLI -- and is best displayed in the "outlook" category of QLI, though it is also at least partly captured in the "emotional behavior" category of SIP. Both of these categories can be understood as attempts to capture the subjective response of persons to their objective physical condition and level of function, or for short their level of happiness or satisfaction with their lives, though the actual measures are far too crude to measure happiness with much sensitivity. The important point is that the use of these categories represents a recognition that part of what makes a good life is that the person in question is happy or pleased with how it is going; that is, subjectively experiences it as going well, as fulfilling his or her major aims, and as satisfying. This subjective happiness component is not unrelated, of course, to how

well the person's life is going as measured by the level of the other objective primary functions. How happy we are with our lives is significantly determined by how well our lives are in fact going in other objective respects. Nevertheless, medicine provides many examples which show it is a mistake to assume that the subjective happiness component correlates closely and invariably with other objective functional measures. For example, in one study researchers found a substantial relation between different objective function variables and also between different subjective response or outlook variables, but only very limited relation between objective and subjective variables.⁴⁶ These data reinforce the importance of including both objective function and subjective response categories in a full conception of the quality of life since neither is a reliable surrogate for the other. Given this at least partial independence between happiness and function variables, what is their relative weight in an overall assessment of a good life? Here too, medicine brings out forcefully that there can be no uniform answer to this question. In the face of seriously debilitating injuries, one patient will adjust her aspirations and expectations to her newly limited functional capacities and place great value on achieving happiness despite those limitations. Faced with similar debilitating injuries, another patient will assign little value to adjusting to the disabilities in order to achieve happiness in spite of them, stating that she "does not want to become the kind of person who is happy in that debilitated and dependent state."⁴⁷

There are other important qualifications on the general positive relation between this happiness component of a good life and both the other primary function components as well as the overall assessment of how good a life it is. These qualifications are not all special to health care and the quality of life, but some are perhaps more evident and important in the area of health care than elsewhere. The first qualification concerns persons' adjustments to limitations of the other primary functions. Sometimes the limitation in function, or potential limitation, is due to

congenital abnormalities or other handicaps present from birth. For example, an American television program recently reported on a followup of some of the children, now young adults, born to pregnant women who had taken the drug Thalidomide in the late 1950s.⁴⁸ The persons reported on had suffered no brain damage but had been born with serious physical deformities, including lacking some or any arms and legs. While this placed many impairments in the way of carrying out primary functions such as eating, working, home management, physical mobility and ambulation in the manner of normal adults, these persons had made remarkable adjustments to compensate for their physical limitations: one was able to perform all the normal functions of eating using his foot in place of missing arms and hands; another made his living as an artist painting with a brush held between his teeth in place of missing arms and hands; another without legs was able to drive in a specially equipped car; and a mother of three without legs had adapted so as to be able to perform virtually all the normal tasks of managing a family and home.

These were cases where physical limitations that commonly restrict and impair persons' primary functional capacities and overall quality of life had been so well compensated for as to enable the persons to perform the same primary functions, though in different ways, as well as normal, unimpaired persons do. While a few life plans possible for others remained impossible for them because of their limitations (for example, being professional athletes), their essentially unimpaired level of primary functions as a result of compensations they had made left them with choice from among a sufficiently wide array of life plans that it is probably a mistake to believe that their quality of life had been lowered much at all by their impairments. These cases illustrate that even serious physical limitations do not always lower quality of life if the disabled persons have been able or helped sufficiently to compensate for their disabilities so that their level of primary functional capacity remains essentially

unimpaired; in such cases it becomes problematic even to characterize those affected as disabled.

In other cases, compensating for functional disabilities, particularly when they do not begin at birth but arise later in life, may require adjustments involving substantial changes in the kind of work performed, social and recreational activities pursued, and so forth. When these disabilities significantly restrict the activities that had been and would otherwise have been available to and pursued by the person, they will, all other things being equal, constitute reductions in the person's quality of life. If they do so, however, it will have to be because they significantly restrict the choices, or what Norman Daniels has called the normal opportunity range, available to the persons and not because the compensating paths chosen need be, once entered on, any less desirable or satisfying.⁴⁹ The opportunity for choice from among a reasonable array of life plans is an independent component of quality of life; it is insufficient to measure only the quality of the life plan the disabled person now pursues and his or her satisfaction with it. Self-determination and, more specifically, choice from among the normal opportunity range available to persons in the agent's society is an important and independent component of quality of life. Adjustments to impairments that leave primary functions undiminished or that redirect one's life plan into areas where function will be better -- both central aims of rehabilitative medicine -- can enhance quality of life even in the face of a diminished opportunity range.

In his theory of just health care Daniels uses the notion of an age-adjusted normal opportunity range, which is important for the relation between opportunity and quality of life or a good life. Some impairments in primary functions occur as common features of even the normal aging process, for example, limitations in previous levels of physical activity. The choice to adjust the nature and level of our planned activities to such impairments in function is usually considered a healthy adjustment to the aging process. This adjustment can substantially diminish the

reduction in the person's quality of life from the limitations of normal aging.

Nevertheless, even under the best of circumstances, the normal aging process of the elderly, and especially the old, old (say, beyond age 80), produces limitations in primary functions that will reduce quality of life. Thus, while quality of life must always be measured against normal, primary functional capacities for humans, it can be diminished by reductions both in individual function below the age-adjusted norm and by reductions in normal function for humans as they age.

I have suggested above that adjustments in chosen pursuits as a result of impairments in primary, or previously pursued individual, functions can compensate substantially (fully, in the effects on happiness) for impaired function, but often will not compensate fully for significant reductions in the range of opportunities available for choice, and so will not leave quality of life undiminished. However, in some cases a patient's response and adjustment to the limitations of illness or injury may be so complete in his commitment to and happiness from the new chosen life path that there is reason to hold that his quality of life is as high as before, particularly as he gets further away in time from the onset of the limiting illness or injury and as the new life becomes more securely and authentically the person's own. An undiminished or even increased level of happiness and satisfaction, together with an increased commitment to the new life, often seem the primary relevant factors when they are present. But we must also distinguish different reasons why the affective or subjective component of quality of life, which I have lumped under the notion of happiness, may remain undiminished, since this is important for an evaluation of the effect on quality of life.

A persons' happiness is to some significant extent a function of the degree to which his or her major aims are being at least reasonably successfully pursued. Serious illness or injury resulting in serious functional impairment often requires a major reevaluation of one's plan of life and its major aims and expectations. Over time, such reevaluations can result in undiminished or even increased levels of happiness,

despite decreased function, because the person's aspirations and expectations have likewise been revised and reduced. The common cases in medicine following serious illness in which persons come to be satisfied with much less in the way of hopes and accomplishments illustrate clearly the incompleteness of happiness as a full account of the quality of life. To be satisfied or happy with getting much less from life, because one has come to expect much less, is still to get less from life or to have a less good life. (The converse of this effect is when rising levels of affluence and of other objective primary functions in periods of economic development lead to even more rapidly rising levels of aspirations and expectations, and in turn to an increasing gap between accomplishments and expectations.) Moreover, whether the relation of the person's choices to his aspirations and expectations reflects his exercise of self-determination in response to changed circumstances is important in an overall assessment of his quality of life and shows another aspect of the importance of self-determination to quality of life.

Illness and injury resulting in serious limitations of primary functions often strike individuals without warning and seemingly at random, and are then seen by them and others as a piece of bad luck or misfortune. Every life is ended by death, and few persons reach death after a normal lifespan without some serious illness and attendant decline in function. This is simply an inevitable part of the human condition. Individual character strengths and social support services enable persons unfortunately impaired by disease or injury to adjust their aims and expectations realistically to their adversity, and then to get on with their lives, instead of responding only with despair and self-pity to their misfortune. Circumstances beyond individuals' control may have dealt them a cruel blow, but they can retain dignity as self-determining agents capable of responsible choice in directing and retaining control over their lives within the limits that their new circumstances permit. We generally admire persons who in this way make the best of their lot, and achieve

happiness and accomplishment despite what seems a cruel fate. This reduction in one's aims and expectations, with its resultant reduction in the gap between one's accomplishments and one's aims, and in turn resultant increase in one's happiness, is an outcome of one's continued exercise of self-determination. It constitutes an increase in the happiness and self-determination components of quality of life though, of course, only in response to an earlier decrease in the person's level of primary functions.

Other ways of reducing this gap between accomplishments and expectations bypass the person's self-determination and are more problematic in their desirability and in their effect on a person's quality of life. For example, Jon Elster has written, outside of the medical context, of different kinds of non-autonomous preferences and preference change.⁵⁰ Precisely characterizing the difference between what Elster calls non-autonomous preferences and what I have called the exercise of one's self-determination in adjusting to the impact of illness and injury raises deep and difficult issues that I cannot pursue here. Nevertheless, I believe it is clear that response to illness through the exercise of self-determined choice in the service of protecting or restoring one's quality of life is one of the most important practical examples of the significance for overall assessments of the quality of life of how the reasonable accord is achieved that happiness requires between aims and accomplishments.

IV. Conclusion

Let us tie together some of the main themes in accounts of the quality of life or of a good life suggested by the literature in medical ethics and health policy. While that literature provides little in the way of well-developed, philosophically sophisticated accounts of the quality of life or of a good life, it is a rich body of analysis, data, and experience on which philosophical accounts of a good life can draw. I have

suggested here at least the main outlines of a general account of a good life suggested by that work. The account will be a complex one that, among the main philosophical theories distinguished earlier, probably most comfortably fits within ideal theories. I have suggested that we can employ Sen's construction of a plurality of independent vectors, each of which is an independent component of a full assessment of the degree to which a person has a good life.

The ethical frameworks for medical treatment decisionmaking bring out the centrality of a person's capacity as a valuing agent, or what I have called self-determination, in a good life. The capacity for and exercise of self-determination can be taken to be a, or I believe the, fundamental ideal of the person within medical ethics. The exercise of self-determination in constructing a relatively full human life will require in an individual four broad types of primary functions: biologic, for example including well functioning organs; physical, for example including ambulation; social, for example including capacities to communicate; mental, for example including a variety of reasoning and emotional capabilities. There are not sharp boundaries between these broad types of primary functions and for different purposes they can be specified in more or less detail and in a variety of different bundles. The idea is to pick out human functions that are necessary for, or at the least valuable in, the pursuit of nearly all relatively full and complete human life plans. These different functions can be represented on different vectors and they will be normatively objective components of a good life, though their relative weight within any particular life may be subjectively determined.

There are in turn what we can call agent-specific functions, again specifiable at varying levels of generality or detail, which are necessary for a person to pursue successfully the particular purposes and life plan he or she has chosen: examples are functional capacities to do highly abstract reasoning of the sort required in mathematics or philosophy and the physical dexterity needed for success as a musician.

surgeon, or athlete. Once again, these functions can be represented on independent vectors, though their place in the good life for a particular person is determined on more normatively subjective grounds depending on the particular life plan chosen. The relative weight assigned to agent-specific functions and, to a substantially lesser degree, to primary functions, will ultimately be determined by the valuations of the self-determining agent together with factual determinations of what functions are necessary in the pursuit of different specific life plans. The centrality of the valuing and choosing agent in this account of a good life gives both primary and, to a lesser extent, agent-specific functional capacities a central place in a good life for persons because of their necessary role in making possible a significant range of opportunities and alternatives for choice.

At a more agent-specific level still are the particular desires pursued by persons on particular occasions in their valued aims and activities. Different desires and the degree to which they can be successfully satisfied also can be represented using the vector approach. It bears repeating that the level of a person's primary function capabilities, agent-specific functional capabilities, and satisfaction of specific desires will all depend both on properties of the agent and on features of his or her environment that affect those functional capacities and desire pursuits. The inclusion of primary functions, agent-specific functions, and the satisfaction of specific desires all within an account of the good life for persons allows us to recognize both its normatively objective and normatively subjective components. Analogously, these various components show why we can expect partial, but only partial, interpersonal comparability of the quality of life or of good lives -- comparability will require interpersonal overlapping of similarly weighted primary functions, agent-specific functions, and specific desires. The importance of functional capabilities at these different levels of generality reflects the centrality of personal choice in a good life and the necessity for choice of alternatives and opportunities.

Finally, there will be the hedonic or happiness component of a good life, that aspect which represents a person's subjective, conscious response in terms of enjoyments and satisfactions to the life he or she has chosen and the activities and achievements it contains. These may be representable on a single vector or on a number of distinct vectors if the person has distinct and incommensurable satisfactions and enjoyments. Happiness usually will be only partially dependent on the person's relative success in satisfying his or her desires and broader aims and projects. Once again, it is the valuations of the specific person in question that will determine the relative weight the happiness vector(s) receive in the overall account of a good life for that person.

Needless to say, in drawing together these features of an account of the quality of life or of a good life from the medical ethics and health policy literatures, I have done no more than sketch a few of the barest bones of a full account of a good life. However, even these few bones suggest the need for more complex accounts of the quality of life than are often employed in programs designed to improve the quality of life of real persons.

FOOTNOTES

¹ Breslow, 1972 pp. 347-355.

² Parfit, 1984, cf. especially Appendix I.

³ See T. M. Scanlon's discussion in this volume of these alternative theories. What I call preference satisfaction and ideal theories he calls desire and substantive good theories, respectively.

⁴ Some time ago I discussed these as alternative interpretations of utility (Brock, 1973). The most subtle and detailed recent discussion of these alternative theories is Griffin, 1986, Chs. 1-4.

⁵ Virtually all discussions of desire or preference satisfaction theories of the good for persons contain some provision for correcting preferences. One of the better treatments, with extensive references to the literature, is Goodin, 1986, pp. 75-101.

⁶ What I call ideal theories are what Parfit, 1984, calls "objective list" theories. I prefer the label "ideal theories," because what is usually distinctive about this kind of theory is its proposal of specific, normative ideals of the person.

⁷ See the essays by H. Putnam, R. A. Putnam, and M. Walzer.

⁸ Morreim, 1986, pp. 45-69.

⁹ Sen's main discussion of the "vector view" applied to the notion of utility is in Sen, 1980. I am much indebted to Sen's subtle discussions in a number of places of distinctions important to conceptions of the quality of life and of a good life. Besides his essay in this volume, see especially Sen, 1985a, 1985b, 1987.

¹⁰ Kass, 1985.

¹¹ Kass, 1985, p. 171.

¹² Kass, 1985, p. 173. For a more philosophically sophisticated analysis of the concept of health that also construes it in functional terms as a natural, biological norm not involving value judgments, see the papers by Boorse, 1975, 1977. One of the most useful collections of papers on concepts of health is Caplan, Engelhardt, and McCartney, 1981.

¹³ I make no attempt here to provide any more than a few representative references to this very large literature. Probably the single best source for the medical ethics literature in this area is the Hastings Center Report. In the medical literature, cf. Wanzer, 1984, and Ruark, 1988. For a good review of most of the principal legal decisions in the United States concerning life-sustaining treatment see Annas and

Glantz, 1986. The most influential treatment of these issues by a governmental body in the United States is the report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983. See also the recent report by the Hastings Center, 1987. For discussions of Living Wills and Durable Powers of Attorney see Steinbrook and Lo, 1984, and Schneiderman and Arras, 1985. An application to clinical practice of the consensus that patients should have rights to decide about their care is Jonsen, Siegler, and Winslade, 1982.

¹⁴ An influential statement of the shared decisionmaking view is another report of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1982. A sensitive discussion of the difficulties of achieving shared decisionmaking in clinical practice is Katz, 1984.

¹⁵ For example, Ramsey, 1978, pp. 206-207.

¹⁶ I have discussed some of the ethical implications of different measures for valuing lives found in the economic and policy literatures (Brock, 1986). See also the essay by Besley and Kanbur in this volume.

¹⁷ It has been argued that this is the proper understanding of the distinction between "ordinary" and "extraordinary" treatment. That is, extraordinary treatment is treatment that for the patient in question and in the circumstances that obtain is unduly burdensome. Cf. President's Commission report, 1983, pp. 82-89.

¹⁸ Rango, 1985.

¹⁹ Rango, 1985, p. 836, quoting E. M. Brody.

²⁰ The importance of this factor was stressed in a widely publicized legal decision concerning the use of painful chemotherapy for a man suffering from cancer who had been severely retarded from birth. Superintendent of Belchertown State School v Saikewicz, 1977.

²¹ Rango, 1985, p. 838.

²² McCormack, 1974.

²³ Rhoden, 1985. Another sensitive discussion of the need for quality of life judgments in treatment decisions for imperiled newborns is Arras, 1984.

²⁴ The most comprehensive treatment of the informed consent doctrine is Faden and Beauchamp, 1986. See also the President's Commission report, 1982. The exceptions to the legal requirement of informed consent are discussed in Meisel, 1979.

²⁵ When patients' settled preferences are not in accord with their values, then their informed and voluntary choices may not reflect their conception of their good. One of the clearest examples is the patient who is addicted to morphine, hates his addiction and tries unsuccessfully to resist it, but in the end is overpowered by his desire for the

morphine and takes it. This in essence is Frankfurt's example in his classic paper (Frankfurt, 1971). Frankfurt's analysis is in terms of first and second order desires, but can also be put in terms of the desires a person in fact has as opposed to the desires the person values and wants to have. When these are in conflict his informed and voluntary choice may not reflect the values that define his own conception of his good. There is a sense in which his choice in these conditions is involuntary, and so it would be possible to extend the informed consent doctrine's requirement of voluntariness to include this sense. Alternatively, it might be possible to interpret the requirement of competence in a way that makes the morphine addict incompetent to decide whether to continue using morphine.

²⁶ This account of the principal values underlying the informed consent doctrine as patient well-being and self-determination is common to many analyses of that doctrine; cf. President's Commission report, 1982. I have employed it in Brock, 1987.

²⁷ *Schloendorff v. Society of New York Hospital*, 1914.

²⁸ Cf. Faden and Beauchamp, 1986, Ch. 4.

²⁹ *Natanson v. Kline*, 1960.

³⁰ Mill, 1956, p. 13.

³¹ The most detailed recent account of justified paternalism in the spirit of Mill's position is VanDeVeer, 1986. The most sophisticated development of a Millian position on paternalism in criminal law is Feinberg, 1986. I have explored some of the issues between rights-based and consequentialist accounts of paternalism (Brock, 1983, 1988).

³² This conventional view is reflected in the independent ethical principles of beneficence and autonomy in Beauchamp and Childress, 1979. This book has probably been the account of moral principles most influential with persons in medicine and health care without philosophical training in ethics.

³³ Cf. Rawls, 1980, and Sen, 1985, esp. pp. 203-4.

³⁴ If personal well-being is understood in this way, it suggests that satisfaction of a person's impersonal desires that make no such reference to him do not raise the person's well-being. Consider a loyal fan of the Boston Red Sox baseball team who wants the Red Sox to win the pennant. On the last day of the season, tied for first place with the New York Yankees, the Red Sox beat the Yankees and win the pennant. Suppose the fan is traveling in a remote area of Alaska on the day of the big game and a week later, before getting out of the wilderness area and learning of the Red Sox victory, he is killed by a rock slide. Was his personal well-being raised at all simply because the state of affairs he desired -- the Red Sox victory -- obtained? I believe the answer should be no. The harder question is whether, in our broader sense of a good life, he had a better life even unbeknownst to him. And was the quality of his life any better? Certainly his life as experienced by him was no better and not of higher quality. Even in our broad sense of a good life, his life may seem not to have gone better, but perhaps that is only

because this is a relatively unimportant desire. Suppose instead, to adapt an example of Parfit, 1984, a person devotes 50 years of his life to saving Venice and then, confident that it is safe, goes on vacation to the Alaskan wilderness. While he is there a flood destroys Venice, but, like the Red Sox fan, he never learns of it because a week after the flood and before getting out of the wilderness he is killed by a rockslide. Parfit notes that it is plausible to say of the destruction of Venice both that it has made the person's life go less well because he had invested his life in this goal and his life's work is now in vain, but also that it cannot lower the quality of his life if it does not affect the quality of his experience. This suggests a place where the broad notion of a good life may diverge from the notion of the quality of life. Since I believe that medicine and medical ethics have little illumination to offer on this point, I set it aside here and shall in the body of the paper continue to use the broad notion of a good life largely interchangeably with the quality of life.

³⁵ Allen Buchanan and I have discussed ethical issues in decisionmaking for incompetent persons in our paper (Buchanan and Brock, 1986, 17-94) and in our forthcoming book.

³⁶ Rebecca Dresser has developed a Parfitian challenge to the Substituted Judgment principle as well as to the authority of advance directives in cases in which the conditions creating the patient's incompetence also reduce or eliminate the psychological continuity and connectedness necessary for personal identity to be maintained. Cf. Dresser, 1986. Cf. also, Buchanan, 1988.

³⁷ Scanlon argues in this volume that desire satisfaction is not itself a basic part of individual well-being, but is dependent on hedonistic or ideal (what he calls substantive good) reasons for its support.

³⁸ Two of the more important discussions of life plans and of how they can give structure and coherence to lives are Fried, 1970, Ch. 10, and Rawls, 1971, Ch. 7.

³⁹ The notion of a biographical life is employed in the medical ethics literature by Rachels, 1986, pp. 5-6, by Singer and Kuhse, 1985, pp. 129-39, and by Callahan, 1987. It is also implicit in Tooley's, 1983, account of the right to life.

⁴⁰ Among the useful papers consulted for this third section on health policy measures of quality of life, and not cited in other notes, are: Anderson, 1986, Berg, 1986, Bergner, 1976, Calman, 1984, Cohen, 1982, Cribb, 1985, Editorial, 1986, Edlund and Tancredi, 1985, Flanagan, 1982, Gehrman, 1978, Gillingham and Reece, 1980, Grogono, 1971, Guyatt, 1986, Hunt and McEwen, 1980, Katz, 1963, Kornfeld, 1982, Klotkem, 1982, Liang, 1982, Najman and Levine, 1981, Pearlman and Speer, 1983, Presant, 1984, Report, 1984, Starr, 1986, Sullivan, 1966, Thomasma, 1984, 1986, Torrance, 1972, 1976a, 1976b.

⁴¹ An example of a broad quality of life measure not focused on health care and disease can be found in the Swedish level of living surveys discussed in the essay by Erikson in this volume.

⁴² Bergner, 1981.

⁴³ Spitzer, 1981.

⁴⁴ Chen, Bush and Patrick, 1975.

⁴⁵ Rawls, 1971, pp. 62, 90-95.

⁴⁶ Evans, 1985.

⁴⁷ The main character in the popular play and subsequent movie, "Whose Life Is It Anyway?", having become paralysed from the neck down, displayed this attitude of not wanting to become a person who had adjusted to his condition.

⁴⁸ "60 Minutes," CBS television network program, February 21, 1988.

⁴⁹ Daniels, 1985, Chs. 2, 3.

⁵⁰ Elster, 1982.

REFERENCES

- Anderson, John P. et. al. (1986). 'Classifying Function for Health Outcome and Quality-of-Life Evaluation'. Medical Care 24, 454-71.
- Annas, George and Glantz, Leonard (1986). 'The Right of Elderly Patients to Refuse Life-Sustaining Treatment'. The Milbank Quarterly Vol.64, Suppl. 2, 95-162.
- Arras, John (April 1984). 'Toward an Ethic of Ambiguity'. Hastings Center Report 14, 2, 25-33.
- Beauchamp, Tom L. and Childress, James F. (1979). Principles of Biomedical Ethics. Oxford University Press, New York.
- Berg, Robert L. (1986). 'Neglected Aspects of the Quality of Life'. Health Services Research, 391-5.
- Bergner, Marilyn et. al. (1976). 'The Sickness Impact Profile: Conceptual Formulation and Methodology for the Development of a Health Status Measure'. International Journal of Health Services 6, 393-415.
- et. al. (1981). 'The Sickness Impact Profile: Development and Final Revision of a Health Status Measure'. Medical Care XIX, 787-805.
- Boorse, Christopher (1975). 'On the Distinction Between Disease and Illness'. Philosophy and Public Affairs 5, 49-68.
- (1977). 'Health as a Theoretical Concept'. Philosophy of Science 44.
- Breslow, Lester (1972). 'A Quantitative Approach to the World Health Organization Definition of Health: Physical, Mental and Social Well-being'. International Journal of Epidemiology 1, 4.
- Brock, Dan W. (1973). 'Recent Work in Utilitarianism'. American Philosophical Quarterly 10, 241-76
- (1983). 'Paternalism and Promoting the Good', in Sartorius, Rolf. Paternalism. University of Minnesota Press, Minneapolis.
- (1986). 'The Value of Prolonging Human Life'. Philosophical Studies 50, 401-28.
- (1987). 'Informed Consent', in Regan, Tom and VanDeVeer, Donald, Health Care Ethics. Temple University Press, Philadelphia.
- (1988). 'Paternalism and Autonomy', Ethics 98, 550-65.
- Buchanan, Allen (1988). 'Advance Directives and the Personal Identity Problem'. Philosophy & Public Affairs 17, 4, 277-302.
- Buchanan, Allen and Brock, Dan W. (1986). 'Deciding for Others'. The Milbank Quarterly Vol. 64, Suppl. 2, 17-94.
- forthcoming 1989. Deciding For Others. Cambridge University Press, Cambridge.
- Callahan, Daniel (1987). Setting Limits. Simon and Schuster, New York.
- Calman, K. C. (1984). 'Quality of Life in Cancer Patients -- An Hypothesis'. Journal of Medical Ethics 10, 124-7.
- Caplan, Arthur L., Engelhardt, Jr., Tristram H. and McCartney, James (1981). Concepts of Health and Disease: Interdisciplinary Perspectives. Addison-Wesley, Reading, MA.
- Chen, Milton M., Bush, J. W. and Patrick, Donald L. (1975). 'Social Indicators for Health Planning and Policy Analysis'. Policy Sciences 6, 71-89.
- Cohen, Carl (1982). 'On the Quality of Life: Some Philosophical Reflections'. Circulation 66 Suppl. III, 29-33.
- Cribb, Alan (1985). 'Quality of Life -- A Response to K. C. Calman'. Journal of Medical Ethics 11, 142-5.
- Daniels, Norman (1985). Just Health Care. Cambridge University Press, Cambridge.
- Dresser, Rebecca (1986). 'Life, Death, and Incompetent Patients: Conceptual Infirmities and Hidden Values in the Law'. Arizona Law Review 28, 373-405.

- Editorial (1986). 'Assessment of Quality of Life in Clinical Trials'. Acta Medica Scandia 220, 1-3.
- Edlund, Mathew and Tancredi, Lawrence (1985). 'Quality of Life: An Ideological Critique', Perspectives in Biology and Medicine 28, 591-607.
- Elster, Jon (1982). 'Sour Grapes: Utilitarianism and the Genesis of Wants', in Sen, Amartya and Williams, Bernard, Utilitarianism and Beyond. Cambridge University Press, Cambridge.
- Evans, Roger W. (1985). 'The Quality of Life of Patients with End Stage Renal Disease'. New England Journal of Medicine 312, 553-9.
- Faden, Ruth R. and Beauchamp, Tom L. (1986). A History and Theory of Informed Consent. Oxford University Press, New York.
- Feinberg, Joel (1986). Harm to Self. Oxford University Press, New York.
- Flanagan, John C. (1982). 'Measurement of Quality of Life: Current State of the Art', Archives of Physical Rehabilitation Medicine 63, 56-9.
- Frankfurt, Harry (1971). 'Freedom of the Will and the Concept of a Person', Journal of Philosophy 68, 5-20.
- Fried, Charles (1970). An Anatomy of Values. Harvard University Press, Cambridge, MA.
- Gehrman, Friedhelm (1978). 'Valid Empirical Measurement of Quality of Life', Social Indicators Research 5, 73-109.
- Gillingham, Robert and Reece, William S. (1980). 'Analytical Problems in the Measurement of the Quality of Life', Social Indicators Research 7, 91-101.
- Goodin, Robert (1986). 'Laundering Preferences', in Elster, Jon and Hylland, Aanund, Foundations of Social Choice Theory. Cambridge University Press, Cambridge.
- Griffin, James (1986). Well-Being. Oxford University Press, Oxford.
- Grogono, A. W. (1971). 'Index for Measuring Health', The Lancet, 1024-6.
- Guyatt, Gordon H. et. al. (1986). 'Measuring Disease-Specific Quality of Life in Clinical Trials'. Canadian Medical Association Journal 134, 889-95.
- Hastings Center Report (1987). Guidelines on the Termination of Treatment and the Care of the Dying. The Hastings Center, Briarcliff Manor, NY.
- Hunt, Sonya and McEwen, James (1980). 'The Development of a Subjective Health Indicator', Sociology of Health and Illness 2, 203-31.
- Jonsen, Albert R., Siegler, Mark and Winslade, William J. (1982). Clinical Ethics. Macmillan Publishing Co., New York.
- Kass, Leon (1985). Toward a More Natural Science. Free Press, New York.
- Katz, Jay (1984). The Silent World of Doctor and Patient. Free Press, New York.
- Katz, Sidney et. al. (1963). 'Studies of Illness in the Aged. The Index of ADL: A Standardized Measure of Biological and Psychosocial Function', JAMA 185, 914-9.
- Kornfeld, Donald S. et. al. (1982). 'Psychological and Behavioral Responses After Coronary Artery Bypass Surgery', Circulation 66 Suppl. III, 24-8.
- Klotekm, Frederic J. (1982). 'Philosophic Considerations of Quality of Life for the Disabled', Archives of Physical Rehabilitation Medicine 63, 59-63.
- Liang, Mathew et. al. (1982). 'In Search of a More Perfect Mousetrap (Health Status or Quality of Life Instrument)', Journal of Rheumatology 9, 775-9.
- McCormack, S. J., Richard J. (July 8, 1974). 'To Save or Let Die: The Dilemma of Modern Medicine', JAMA 229 No. 2, 172-
- Meisel, Alan (1979). 'The Exceptions' to the Informed Consent Doctrine: Striking a Balance Between Competing Values in Medical Decisionmaking', Wisconsin Law Review 1979, 413-88.
- Mill, J. S. (1956). On Liberty. Bobbs-Merrill, Indiana/New York.
- Morreim, E. Haavi (1986). 'Computing the Quality of Life', in Agich, G. J. and Begley, C. E., The Price of Health. D. Reidel Publishing Company, Dordrecht.
- Najman, Jakob and Levine, Sol (1981). 'Evaluating the Impact of Medical Care and Technologies on the Quality of Life: A Review and Critique', Social Science and Medicine 15F, 107-15.

- Natanson v. Kline (1960) 186 Kan. 393, 350 P.2d 1093.
- Parfit, Derek (1984). Reason and Persons. Oxford University Press, Oxford.
- Pearlman, Robert and Speer, James (1983). 'Quality of Life Considerations in Geriatric Care', Journal of the American Geriatrics Society 31, 113-20.
- Present, Cary A. (1984). 'Quality of Life in Cancer Patients', American Journal of Clinical Oncology 7, 571-3.
- President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1982). Making Health Care Decisions. U. S. Government Printing Office, Washington.
- (1983). Deciding to Forego Life-Sustaining Treatment. U. S. Government Printing Office, Washington.
- Program, February 21, 1988. '60 Minutes', CBS television network.
- Rachels, James (1986). The End of Life. Oxford University Press, Oxford.
- Ramsey, Paul (1978). Ethics at the Edge of Life. Yale University Press, New Haven, CN.
- Rango, Nicholas (1985). 'The Nursing Home Resident with Dementia', Annals of Internal Medicine 102, 835-41.
- Rawls, John (1971). A Theory of Justice. Harvard University Press, Cambridge, MA.
- (1980). 'Kantian Constructivism in Moral Theory', Journal of Philosophy 77, 515-72.
- Report (1984). 'The 1984 Report of the Joint National Committee on Detection, Evaluation, and Treatment of High Blood Pressure', Archives of Internal Medicine 144, 1045-57.
- Rhoden, Nancy K. (1985). 'Treatment Dilemmas for Imperiled Newborns: Why Quality of Life Counts', Southern California Law Review 58, 1283-347.
- Ruark, John E. et. al. (Jan. 7, 1988). 'Initiating and Withdrawing Life Support', New England Journal of Medicine 318, 25-30.
- Schloendorff v. Society of New York Hospital (1914). 211 N.Y. 125, 105 N.E. 92, 95.
- Schneiderman, Lawrence and Arras, John (1985). 'Counseling Patients to Counsel Physicians on Future Care in the Event of Patient Incompetence', Annals of Internal Medicine 102, 693-8.
- Sen, Amartya (1980). 'Plural Utility', The Proceedings of the Aristotelian Society 81, 193-218.
- (1985). Commodities and Capabilities. Elsevier Science Publishers, Amsterdam.
- (1985). 'Well-being, Agency and Freedom: The Dewey Lectures', Journal of Philosophy 82, 169-221.
- (1987). The Standard of Living. Cambridge University Press, Cambridge.
- Singer, Peter and Kuhse, Helga (1985). Should This Baby Live? Oxford University Press, Oxford.
- Spitzer, Walter O. et. al. (1981). 'Measuring the Quality of Life of Cancer Patients: A Concise QL-Index for use by Physicians', Journal of Chronic Disease 34, 585-97.
- Starr, T. Jolene et. al. (1986). 'Quality of Life and Resuscitation Decisions in Elderly Patients', Journal of General Internal Medicine 1, 373-9.
- Steinbrook, Robert and Lo, Bernard (1984). 'Decisionmaking for Incompetent Patients by Designated Proxy: California's New Law', New England Journal of Medicine 310, 1598-1601.
- Sullivan, Daniel F. (1966). 'Conceptual Problems in Developing An Index of Health', Vital and Health Statistics 2, 1-18.
- Superintendent of Belchertown State School v. Saikewicz, (1977). 370 N. E. 2d 417.
- Thomasma, David C. (1984). 'Ethical Judgments of Quality of Life in the Care of the Aged', Journal of the American Geriatrics Society 32, 525-7.
- (1986). 'Quality of Life, Treatment Decisions, and Medical Ethics', Clinics in Geriatric Medicine 2, 17-27.
- Tooley, Michael (1983). Abortion and Infanticide. Oxford University Press, Oxford.

- Torrance, George W. (1976). 'Toward A Utility Theory Foundation for Health Status Index Models', Health Services Research , 349-69.
- (1976). 'Social Preferences for Health States: An Empirical Evaluation of Three Measurement Techniques', Socio-Economic Planning Sciences 10, 129-36.
 - et. al. (1972). 'A Utility Maximization Model for Evaluation of Health Care Programs', Health Services Research . 118-33.
- VanDeVeer, Donald (1986). Paternalistic Intervention. Princeton University Press, Princeton, NJ.
- Wanzer, Sidney H. et. al. (April 12, 1984). 'The Physicians Responsibility Toward Hopelessly Ill Patients', New England Journal of Medicine 310, 955-9.

WIDER WORKING PAPERS

- WP 1. Amartya Sen: Food, economics and entitlements, February 1986
- WP 2. Nanak Kakwani: Decomposition of normalization axiom in the measurement of poverty: a comment, March 1986
- WP 3. Pertti Haaparanta: The intertemporal effects of international transfers, April 1986
- WP 4. Nanak Kakwani: Income inequality, welfare and poverty in a developing economy with applications to Sri Lanka, April 1986
- WP 5. Pertti Haaparanta: and Juha Kähkönen: Liberalization of Capital Movements and Trade: Real Appreciation, Employment and Welfare, August 1986
- WP 6. Pertti Haaparanta: Dual Exchange Markets and Intervention, August 1986
- WP 7. Pertti Haaparanta: Real and Relative Wage Rigidities – Wage Indexation* in the Open Economy Staggered Contracts Model, August 1986
- WP 8. Nanak Kakwani: On Measuring Undernutrition, December 1986
- WP 9. Nanak Kakwani: Is Sex Bias Significant? December 1986
- WP 10. Partha Dasgupta and Debraj Ray: Adapting to Undernourishment: The Clinical Evidence and Its Implications, April 1987
- WP 11. Bernard Wood: Middle Powers in the International System: A Preliminary Assessment of Potential, June 1987
- WP 12. Stephany Griffith-Jones: The International Debt Problem – Prospects and Solutions, June 1987
- WP 13. Don Patinkin: Walras' Law, June 1987
- WP 14. Kaushik Basu: Technological Stagnation, Tenurial Laws and Adverse Selection, June 1987
- WP 15. Peter Svedberg: Undernutrition in Sub-Saharan Africa: A Critical Assessment of the Evidence, June 1987
- WP 16. S. R. Osmani: Controversies in Nutrition and their Implications for the Economics of Food, July 1987
- WP 17. Frédérique Apffel Marglin: Smallpox in Two Systems of Knowledge. Revised, July 1987
- WP 18. Amartya Sen: Gender and Cooperative Conflicts, July 1987
- WP 19. Amartya Sen: Africa and India: What do we have to learn from each other? August 1987
- WP 20. Kaushik Basu: A Theory of Association: Social Status, Prices and Markets, August 1987
- WP 21. Kaushik Basu: A Theory of Surplus Labour, August 1987
- WP 22. Albert Fishlow: Some Reflections on Comparative Latin American Economic Performance and Policy, August 1987
- WP 23. Sukhamoy Chakravarty: Post-Keynesian Theorists and the Theory of Economic Development, August 1987
- WP 24. Georgy Skorov: Economic Reform in the USSR, August 1987
- WP 25. Amartya Sen: Freedom of Choice: Concept and Content, August 1987
- WP 26. Gopalakrishna Kumar: Ethiopian Famines 1973–1985: A Case-Study, November 1987
- WP 27. Carl Riskin: Feeding China: The Experience since 1949, November 1987
- WP 28. Martin Ravallion: Market Responses to Anti-Hunger Policies: Effects on Wages, Prices and Employment, November 1987
- WP 29. S. R. Osmani: The Food Problems of Bangladesh, November 1987
- WP 30. Martha Nussbaum and Amartya Sen: Internal Criticism and Indian Rationalist Traditions, December 1987
- WP 31. Martha Nussbaum: Nature, Function and Capability: Aristotle on Political Distribution, December 1987
- WP 32. Martha Nussbaum: Non-Relative Virtues: An Aristotelian Approach, December 1987
- WP 33. Tariq Banuri: Modernization and its Discontents A Perspective from the Sociology of Knowledge, December 1987
- WP 34. Alfred Maizels: Commodity Instability and Developing Countries: The Debate, January 1988
- WP 35. Jukka Pekkarinen: Keynesianism and the Scandinavian Models of Economic Policy, February 1988
- WP 36. Masahiko Aoki: A New Paradigm of Work Organization: The Japanese Experience, February 1988
- WP 37. Dragoslav Avramovic: Conditionality: Facts, Theory and Policy – Contribution to the Reconstruction of the International Financial System, February 1988
- WP 38. Gerald Epstein and Juliet Schor: Macropolicy in the Rise and Fall of the Golden Age, February 1988
- WP 39. Stephen Marglin and Amit Bhaduri: Profit Squeeze and Keynesian Theory, April 1988
- WP 40. Bob Rowthorn and Andrew Glyn: The Diversity of Unemployment Experience Since 1973, April 1988
- WP 41. Lance Taylor: Economic Openness – Problems to the Century's End, April 1988
- WP 42. Alan Hughes and Ajit Singh: The World Economic Slowdown and the Asian and Latin American Economies: A Comparative Analysis of Economic Structure, Policy and Performance, April 1988
- WP 43. Andrew Glyn, Alan Hughes, Alan Lipietz and Ajit Singh: The Rise and Fall of of the Golden Age, April 1988
- WP 44. Jean-Philippe Platteau: The Food Crisis in Africa: A Comparative Structural Analysis, April 1988
- WP 45. Jean Drèze: Famine Prevention in India, May 1988
- WP 46. Peter Svedberg: A Model of Nutrition, Health and Economic Productivity, September 1988
- WP 47. Peter Svedberg: Undernutrition in Sub-Saharan Africa: Is There a Sex-Bias?. September 1988
- WP 48. S.R. Osmani: Wage Determination in Rural Labour Markets: The Theory of Implicit Co-operation, December 1988
- WP 49. S.R. Osmani: Social Security in South Asia, December 1988
- WP 50. S.R. Osmani: Food and the History of India – An 'Entitlement' Approach, December 1988

- WP 51. Grzegorz W. Kolodko: Reform, Stabilization Policies, and Economic Adjustment in Poland. January 1989
- WP 52. Dariusz Rosati and Kalman Mizsei: Adjustment through Opening of Socialist Economies, January 1989
- WP 53. Andrei Vernikov: Reforming Process and Consolidation in the Soviet Economy, January 1989
- WP 54. Adam Török: Stabilisation and Reform in the Hungarian Economy of the late 1980s, March 1989
- WP 55. Zhang Yuyan: Economic System Reform in China, March 1989
- WP 56. Amitava Krishna Dutt: Sectoral Balance: A Survey, March 1989
- WP 57. Robert Pringle: Financial Markets and Governments, June 1989
- WP 58. Marja-Liisa Swantz: Grassroots Strategies and Directed Development in Tanzania: The Case of the Fishing Sector, August 1989
- WP 59. Aili Mari Tripp: Defending the Right to Subsist: The State vs. the Urban Informal Economy in Tanzania, August 1989
- WP 60. Jacques H. Drèze, Albert Kervyn de Lettenhove, Jean-Philippe Platteau, Paul Reding: A Proposal for "COoperative Relief of Debt in Africa" (CORDA), August 1989
- WP 61. Kaushik Basu: Limited Liability and the Existence of Share Tenancy, August 1989
- WP 62. Tariq Banuri: Black Markets, Openness, and Central Bank Autonomy, August 1989
- WP 63. Amit Bhaduri: The Soft Option of the Reserve Currency Status, August 1989
- WP 64. Andrew Glyn: Exchange Controls and Policy Autonomy – The Case of Australia 1983–88, August 1989
- WP 65. Jaime Ros: Capital Mobility and Policy Effectiveness in a Solvency Crisis. The Mexican Economy in the 1980s, August 1989
- WP 66. Dan W. Brock: Quality of Life Measures in Health Care and Medical Ethics, August 1989