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Virtual Mentor

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From the Editor

Measuring the Unmeasurable? Quality of Life and Medical Decision Making

The traditional objective indicators of clinical success and effectiveness, from which the physician drew his treatment decisions in the past decades, were based on quantitative parameters like mortality rate or length of survival, biological or physiologic measures, or improvement in clinical findings. Recently, however, a paradigm shift has taken place: traditional objective measures and the judgement of the physician are being replaced by patients' evaluations of physical functioning and overall health as the main factors in the decision making process and the assessment of a treatment's success [1, 2]. This change was accompanied by a philosophical shift in health-related thinking: while previous medical thinking emphasized disease and focused on physician appraisal of health states, this new line of thought emphasizes health, functioning, and well-being that is centred around the patient's coping resources and evaluation of health [3-7]. The physicians' job, as professor M. Sullivan from the University of Washington said, is "to focus on patients' lives rather than patients' bodies" [8].

This paradigm shift arose from an awareness that neither objective medical outcome measures nor we as physicians can say unequivocally what is the best for the patient. When engaging in clinical decision making, physicians tend to value primarily information about the effect of treatments on physiological functioning and disease progression, rather than information about the impact on the patient's quality of life [9-11]. Without having some idea about how the patient values his or her quality of life at present, however, physicians cannot determine what treatment will most benefit the patient [12-13]. What we view as best for the patient must inevitably include a quality-of-life component because what we call medically indicated treatments presuppose certain values and certain standards of quality of life that may not be true for every patient. Quality-of-life considerations do not only take place in extreme medical situations such as withdrawal of treatment in severely disabled newborns or in patients in a persistent vegetative state, but are part of every treatment consideration for each physician in everyday clinical life. This issue of *Virtual Mentor* explores subtle quality-of-life considerations as well as the philosophical claims about measuring such perceptions and the practical aspects of using quality-of-life rankings when attempting to allocate resources.

Our clinical cases illustrate the importance of quality-of-life considerations at the beginning, middle, and end of life. The question of how certain health states and treatments impact our quality of life spans across the years: how should we, for example, decide about a treatment that, statistically, confers benefit but may impair the quality of our successful, busy lives as adults during our best years?

In clinical decision making, quality of life serves not only as an ethical guide but also as a valid and reliable empirical measure of health status that supplements traditional objective measures. The clinical pearl exemplifies the role that quality-of-life scores play in both clinical research and especially in the individual patient-physician relationship and in the decision-making process.

One of the major challenges for physicians when dealing with quality-of-life measures is that many patients with serious and persistent disabilities report that they experience a good or excellent quality-of-life, when to external observers these individuals seem to have a diminished quality of life. Two articles examining this disability paradox [14] are critiqued here by 3 researchers. Following those discussions, we invited an author of one of the target articles to respond to the critique.

In Oregon's attempt to cover more people on its government-funded Medicaid plan and find an ethically justifiable way of fairly distributing scarce health care resources, the concept of quality-adjusted life years (QALYs) was employed. The question of using the QALY approach as the basis of an effective and just health care allocation system is analyzed by 3 authors; from the public health and the philosophical perspectives and from the point of view of its practical use as a policy tool.

In looking over the entire issue, there seems to be a specific dilemma surrounding quality-of-life assessments: On one side, physicians implicitly use quality-of-life measures in treatment decisions and also integrate the patients' own evaluation of health status into clinical decision making. On the other side, the idea that one can measure quality of life seems to be an incoherent, or, at least, a flawed one, whose variables are very difficult for the physician to analyse, to control, and, thus, to integrate into clinical decision making.

So how do you think we should resolve this dilemma? Should we abandon quality-of-life scores as a valid and promising clinical tool, or should we continue looking for disease and population-specific measures that can help us to integrate the patient's best interest into our clinical decision making? Read this issue and make up your own mind.

Matthis Synofzik

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Clinical Case

Quality of Life and Prenatal Decisions

Commentaries by L Schöls, MD, and Georg Marckmann, MD

Dr Berkman welcomes his long time patient, Sue Nichols, to the clinic. Today she is accompanied by her 17-year-old daughter, Marie, and Marie's boyfriend, Tom. Marie is 8 weeks pregnant, and the 3 have come for genetic counseling.

Dr Berkman is familiar with the Nichols' family history of Huntington's disease and understands Marie's desire to know the fate of her child. A review of the patient's history shows that Huntington's is present on the paternal side of the Nichols' family; Marie's father and his sister have both been diagnosed with the disease. Marie's father is in the end stage of the disease with Sue as his primary caregiver. Marie's aunt committed suicide 15 years ago after receiving her diagnosis.

Dr Berkman talks with the 3 about the decisions they may face when the results are in and supports Marie's decision to go forward with the test. Dr Berkman informs Marie that a positive result for her fetus would mean that she also carries the genetic trait. This information further convinces Marie that she must have her fetus tested. There is approximately a 2-week waiting period for the return of the results. Dr Berkman encourages the family to consider the various options that a positive result would present during the wait time and offers his continuing counseling and clinical expertise.

Upon receiving the test results Dr Berkman informs Marie, Sue, and Tom that the fetus does indeed contain the Huntington gene. Marie is adamant that she does not wish for her child to suffer through the progressive deterioration of the disease in the same manner as her father. Marie states that she wants to abort the fetus because of the positive result.

Sue acknowledges that the consequences of the disease are terrible and is sympathetic to the views of her daughter, but is nostalgic and optimistic with regard to the years preceding the disease. Sue believes her future grandchild should have an opportunity to live a fulfilling life prior to the onset of symptoms just as her husband did. Sue and Marie look to Dr Berkman for help in resolving their difference of opinion.

Commentary 1

by L. Schöls, MD

Medical counselling and predictive genetic testing are difficult tasks in the case of an inherited, life-limiting illness like Huntington's disease (HD). There are several and diverse reasons why individuals at risk desire to know in advance whether or not they will get the disease. Planning of life—especially decisions regarding children and

profession—is a frequent reason for testing, but others seek advice because they can no longer stand the uncertainty. In such situations, the genetic counsellor sometimes gets the impression that individuals will use the test to predict how their lives will unfold. The genetic test, however, offers an answer for only a single disease and cannot predict an individual's overall quality of life in the future.

On first glance, it seems appropriate that a parent-to-be is entitled to know whether or not her child will have HD and to decide whether to abort the pregnancy on the basis of that information. However, this case illustrates a number of problems which complicate a decision for or against prenatal testing and abortion. In a late-manifesting disease like HD, the time before the onset of symptoms could be the span of a normal life. Predictive testing can change this otherwise normal healthy life into a period of anxious waiting for the appearance of symptoms, and this may especially be the case for individuals who have sought predictive testing because they cannot stand the uncertainty.

Similarly important, it is difficult—if not impossible—to predict quality of life for another person. People cope differently with illness, handicaps, and reduced life span. Severely handicapped patients quite often have an impressive will to live, are happy, and are grateful about their ability to participate in life. In contrast, some people who are generally healthy and have almost no limitations are unable to find satisfaction, and instead, they despair, despite all their abilities. Without doubt, it is a severe burden to carry the seed of a disease like HD that most likely will cause premature death after a phase of progressive degeneration that destroys mobility, independence, cognitive capability, and personality. Nevertheless, a disabling disease is not *per se* the reason for an insufficient quality of life. At most, the mother may be able to imagine her own quality of life with HD, but even that attitude might change if she were to live with the disease. Since nothing certain can be said about quality of life for the unborn, it is not an adequate reason for abortion.

In general, quality of life for those with HD, is not necessarily dependent on the severity of individual symptoms, but, may be worse in the beginning of the disease when personality and other individual-defining traits are affected: sometimes severe initial depression—which in HD patients often is a primary psychiatric manifestation of the disease itself—even drives patients to commit suicide (as probably happened to the aunt in this case). Later in the disease, a much stronger will to live commonly returns to patients, as well as to their relatives, who frequently seek advice for gastric tubes and other measures meant to prolong life.

In this case, the statement that quality of life would be so poor for the nascent child that an abortion is an act of humanity has to be challenged. Would the mother state that her life so far has not been worth living? If not, why should it be different for her child? The prospect of a life-limiting disease cannot be the reason for abortion. We all are proceeding to death, and a disabling disease of some sort is the most likely way we will perish. How much time must be passed in a healthy state to justify the assumption that this life is worth living? Moreover, the progress of research has been impressive during the last decade, especially for neurological diseases like HD. Is it completely unrealistic to think that there will be a cure for HD in the next 30 years in the light of

increasing pathogenic understanding and transgenic animal models that make therapeutic trials possible? How will the mother feel if she aborts this child and therapy becomes available in the not too distant future?

An important point that is only mentioned in passing is that the positive genetic test result of the fetus means that the mother carries the mutation, too, and will develop the disease if she lives to or beyond middle age. This adds an additional dimension to the decision of abortion. What is the unbearable point for the mother? Is she trying to abort her own despair of the prospective disease? Is she afraid that she may not be able to bring the child up properly? Can her partner cope with such a disease in his mate and in his child?

Consideration of the mother's life—not the prospective quality of life of the fetus—must drive the abortion decision. During genetic counselling, this fact should be communicated carefully to the mother as a clear but non-accusing message.

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Commentary 2

by Georg Marckmann, MD

Prenatal genetic testing for late onset disorders like Huntington's disease (HD) is particularly controversial and creates difficult ethical issues.

First, because there are currently no effective preventive or therapeutic measures for HD, prenatal genetic testing for this disorder is inevitably linked to the question of selective abortion: is carrying the HD gene an ethically justified reason for abortion? The role that prospective quality of life plays in the decision depends on the ethical position one takes about abortion. There are 3 dominate points of view: (1) According to the *conservative*—commonly known as the “pro life”—view, the fetus has the same moral status, privileges, and rights as an adult human being. Hence, abortion is morally impermissible under all but the most extreme circumstances. In this deontological position, the prospective quality of life is irrelevant. (2) According to the *liberal view* known also as the “pro choice” view, the fetus does not have the same right to life as an adult person, therefore abortion is permissible if it is the autonomous choice of the pregnant woman. Under this premise, the unborn child's prospective quality of life might factor into the pregnant woman's decision of whether or not to carry a pregnancy to term. In this particular case, using the liberal viewpoint, how other people—eg, the genetic counsellor or Marie's mother—evaluate the prospective quality of life does not matter (3). More interesting from an ethical perspective, seems to be the *intermediate view*, which is often based on a gradualist position on the moral standing of the fetus: the moral status gradually increases as the fetus develops. Thus, abortion is permissible under certain circumstances but forces one to ask: what are morally legitimate reasons to terminate a pregnancy?

In general, using the intermediate view, abortion might be justified if it is able to prevent substantial harm and suffering to the child. So we must decide whether carrying the HD gene is a substantial harm and, hence, a sufficient reason to justify

abortion. To answer this question, we inevitably must make assumptions about the future quality of life of the unborn child. These predictions are especially difficult to make in late onset diseases like HD, since there are 2 distinct phases of life: before and after the onset of the disease. During the first decades of life, individuals with the HD gene can live physically unimpaired lives. However, they have to live with the psychological burden either of uncertainty or, after predictive genetic testing, of anticipation of the disease onset. HD has devastating physical and psychological consequences for both the patients and their family members. We would certainly all agree that HD is a severe neurological disease and that we would do anything to prevent or cure the disease if we could. On the other hand, people can live with a reasonable or even good quality of life before the onset of symptoms. Unfortunately, when considering the termination of a pregnancy we must make an integral evaluation of the prospective quality of life. In other words, we must balance the relatively good quality of life during the first decades against the increasingly poor quality of life after the onset of the disease. Two facts complicate this quality-of-life judgment even further: First, subjective quality of life assessments of HD patients before the onset of the disease vary greatly, and, second, it is difficult for others to estimate how much patients suffer with manifest HD. Accordingly, it is almost impossible to make objective and ethically compelling assessments of the prospective quality of life for a fetus with the HD gene.

Should, then, quality-of-life considerations be excluded completely from the decision-making process? In a world in which reproductive autonomy is a fundamental value, this appears unrealistic. Pregnant women with the Huntington's mutation and a 50 percent risk of transmitting it to their offspring, will continue to request prenatal genetic testing and consider selective abortion. In many cases, these individuals, like Marie in our case, will have experienced the suffering of other family members with HD, both before and after the onset of the disease. These experiences will influence their evaluation of the prospective quality of life for their offspring. However, the results of these assessments can be quite different, even in the same family, as we can see from Marie and her mother Sue. Without an objective reference, we cannot decide whose estimate is "correct," Marie's or Sue's. Perhaps there is nothing—no instrument or system—that is adequately able to provide an objective and accurate quality-of-life estimate.

In the face of this substantial ethical uncertainty, we have no other choice than to proceed to the formal question: Who shall decide about the continuation of the pregnancy? Certainly, the pregnant woman—in this case Marie—must have the final decisional authority. Is this decision the end of the story? Probably yes, but there is still some more to say about the process that takes place before we reach the end. Marie's ultimate decision will be informed not only by her own experience but also by the genetic counselling she receives from Dr Berkman. This brings us to question of how dominant of a role a genetic counsellor should play. There is wide agreement that genetic counselling should be non-directive and ought to promote the client's reproductive autonomy. But autonomous choices must be informed by professional knowledge and other arguments that might influence the client's decision. This is the challenge of genetic counselling: how to provide full factual information and support

the difficult decisions a patient faces without making explicit (or implicit) value judgements or directing the clients to a preconceived opinion. The guiding question should be: what decision is in the best interest of the unborn child all things considered? In my opinion, the burden of the disease on other family members or on society should only play a minor role in the decision. Even if we personally think that carrying the HD gene is not an ethically justified reason for abortion, we should grant the pregnant woman (together with the future father) the decisional autonomy about continuing or terminating the pregnancy.

Georg Marckmann, MD, studied medicine and philosophy at the University of Tübingen and public health at Harvard School of Public Health. He is also an assistant professor at the Institute of Medical Ethics and History of Medicine at the University of Tübingen.

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Clinical Case

Optional Treatments and Quality of Life

Commentaries by Mary Jane Massie, MD, and Johannes Meran, MD, MA

Dr Brooks completed a routine breast exam on Ms Civali and found a suspicious mass. After running necessary tests, Dr Brooks discovered that Renee Civali has early stage breast cancer. Ms Civali is a 40-year-old, petite woman who is single and works as a successful car salesperson. Ms Civali has been seeing Dr Brooks for the past 5 years, and chart notes indicate that Ms Civali has been occasionally emotionally unstable and has made most decisions based on what others tell her to do.

Following the diagnosis of breast cancer, Dr Brooks explained to Ms Civali that she had 2 main treatment options: a total mastectomy or breast-conserving surgery, both options followed by chemotherapy and radiation. Dr Brooks told Ms Civali that both treatment plans would most likely rid her body of the cancer, but each would carry a specific consequence. Ms Civali, admittedly overwhelmed and unsure of what decision to make, asked Dr Brooks to make a therapeutic decision on her behalf. Dr Brooks ultimately suggested the breast conserving surgery and justified the decision by reasoning that this was a less intrusive method with lower chances for a loss of body image, self-esteem, and other psychological issues that often affect younger women with this type cancer. Dr Brooks believed that, if followed by chemotherapy and radiation, the less radical surgery would achieve the same medical results as the more radical total mastectomy.

Several months after the surgery, chemotherapy, and radiation treatments—all of which appear to have been successful—Dr Brooks raises the possibility of Ms Civali's beginning an orally administered hormone-based therapy, telling Ms Civali that this could help reduce the risk of the cancer's recurring. Dr Brooks however, admits to Ms Civali that research suggests that many women may not actually need the hormonal treatment in order to remain in remission because their initial surgery coupled with the follow-up therapies were sufficient. Dr Brooks explains the various side effects of a hormone-based regimen and states that some women find that the potential benefit is not worth the distressing side effects when there are no signs of aggressive disease. After listening to this proposal, Ms Civali discloses her feelings of depression about the status of her disease and questions whether or not the partial mastectomy was most effective in eliminating her cancer. Ms Civali also acknowledges significant frustration with her current medical situation, saying she feels worn down by the constant trips to the hospital and other reminders of her recent medical history and wishes that she could return to the life she led prior to the discovery of her cancer. After hearing Dr Brooks discuss the next possible round of treatment and expressing her concerns—both physical and psychological—Ms Civali reports that she is

unwilling to make an independent decision with regard to the hormone treatment and asks Dr Brooks for her recommendation.

Commentary 1

by Mary Jane Massie, MD

This case demonstrates some of the problems that many young women with breast cancer experience. The problems Ms C is having are common reasons for referring a patient with cancer to a psychiatrist.

Only 5 percent of breast cancer occurs in women under the age of 40. Although Ms C was unlucky to have breast cancer at such a young age, her cancer was caught at an early stage, and she was fortunate to have treatment choices. Dr Brooks had a 5-year relationship with Ms C prior to her cancer diagnosis, is aware of this patient's emotional instability and indecisiveness, and is well positioned to help Ms C continue with her cancer treatment.

Although we don't have precise knowledge about the estrogen and progesterone hormonal receptivity of the tumor, since antiestrogens are being recommended, we can assume that Dr Brooks has evidence that this regimen can provide a relatively significant benefit to Ms C. Chemotherapy and antiestrogen therapies are frequently described to patients as an "insurance policy" and given that Ms C is a "successful car salesperson" she probably advises her clients about their need for insurance to protect their investment when they purchase a valuable machine, Dr Brooks may have used this analogy when describing the role of antiestrogens to Ms C. Although Dr Brooks knows that the most difficult part of Ms C's treatment is behind her, Ms C is feeling overwhelmed and uncertain as to whether she can go on. It's unclear whether she understands that antiestrogen treatment is merely the ingestion of a pill daily, albeit for 5 or more years.

Ms C also appears to be questioning the previous treatment decision and asks Dr Brooks for another "recommendation." The best advice, I believe, that Dr Brooks can give is that Ms C consult with a mental health professional (a psychiatrist or psychologist) who specializes in working with women with breast cancer. These professionals, known as psycho-oncologists, commonly consult with women who have just completed surgery, irradiation, and chemotherapy. Many women like Ms C describe feeling depressed, emotionally "worn out," and unable to move forward with their life after 6 to 9 months of cancer treatment. Dr Brooks will explain that the referral to the psychiatrist is not being made because she thinks Ms C is "crazy," but because she appreciates how long and difficult the treatment has been for Ms C and how arduous breast cancer treatment is for all women. Dr Brooks knows that starting an antiestrogen immediately is not vital for Ms C's health, and allowing Ms C time to discuss the treatment with another professional may make her more comfortable with her final decision. The psychiatrist also has ample time to: better understand the range of problems that Ms C is struggling with, provide support, treat depression, and, ultimately, help Ms C think through her decision to take or not take an antiestrogen.

When Ms C meets with the psychiatrist, he or she will want to know her family history of breast cancer. Is part of her depression related to the personal tragedy associated with losing 1 or several family members to breast cancer or other cancers? Is part of the reason she feels depressed or emotionally depleted because she has undergone treatment alone, without enough people available to provide support and practical assistance? Did she continue to work during chemotherapy without telling her employer or business colleagues about her breast cancer because she wished to maintain her privacy?

Dr Brooks has noted previous emotional instability and a pattern of “making decisions based on what others tell her to do.” Many patients ask their doctors to recommend the best treatment and then defer to their physician's clinical judgment. To better understand Ms C's current psychological state, the psychiatrist will ask her about her personal history of depression, anxiety, insomnia, substance use, and her current emotional symptoms. The psychiatrist will also ask how she has made other important decisions in the past. As a successful salesperson, Ms C knows how to “close” or “complete a deal” and must have experience observing others make significant decisions when there is an element of uncertainty. The psychiatrist will probably tell Ms C that Dr Brooks has really only asked her to start this final phase of breast cancer treatment because, to the best of our current knowledge, doing so will “complete the deal,” offering her the best chance of a “cure.” The psychiatrist will acknowledge that considering an antiestrogen is difficult when one is overwhelmed, exhausted, depleted, and has decreased ability to concentrate after chemotherapy and then will explain that there are people and strategies available for Mrs C to use so the decision-making process does not feel so overwhelming.

Ms C is 40, single, presumably without children, and was likely premenopausal prior to chemotherapy. If chemotherapy has made her prematurely menopausal, some of her current emotional distress and depression may be related to fluctuating or reduced estrogen levels and insomnia resulting from vasomotor instability. Part of her concern about antiestrogen use may be her knowledge that some women describe having insomnia, weight gain, and depressed mood when taking antiestrogens, and she may view this as intolerable or worse than her current symptoms.

Maybe Ms C hopes to become pregnant and sees taking 5 years of antiestrogens as dashing an important dream. The psychiatrist will explore her previous plans, thoughts, and hopes about child bearing or child rearing and her current hopes and fears in the aftermath of chemotherapy.

Symptom management to improve Ms C's quality of life will be an important first step before any final decision regarding antiestrogens is made. If her anxiety is severe, the psychiatrist will prescribe a benzodiazepine to manage daytime anxiety and a hypnotic for insomnia. Reducing anxiety to acceptable levels permits many patients to think more clearly and better participate in the decision making process.

Additionally, if Ms C is depressed or has disabling menopausal symptoms, the psychiatrist may prescribe an antidepressant such as fluoxetine, sertraline, paroxetine,

or venlafaxine to treat the depressed mood and to reduce the frequency and intensity of hot flashes and night sweats that she may be experiencing.

Although pharmacologic therapy is likely to benefit Ms C significantly, psychotherapy, which has many components including support, will give her a private space in an unhurried setting to voice her frustration, sadness, disappointment, and mourning for the “loss of good health” at a young age. During or after breast cancer treatment younger women commonly want to discuss fears of death, body image concerns, sense of themselves as women, desirability as sexual partners, future sexual relationships, fertility, career, and relationship issues.

In individual psychotherapy, Ms C can discuss her most intimate fears and concerns and how those fears affect her decision making about further treatment. In addition to talking “one-on-one” with a trained professional, many women appreciate the opportunity to participate in support groups for women who are undergoing breast cancer treatment. In a group setting, Ms C is likely to hear other women describe their cancer treatment experiences and say that antiestrogens are, in fact, very tolerable and viewed as an important component of breast cancer treatment to ensure that the cancer “will never come back.” Both her psychiatrist and support group members will ask her to think through how she would feel about not trying an antiestrogen if her cancer returned; many women report they would be very disappointed if they had not accepted all anticancer treatment available to them and their cancer recurred. Women who attend breast cancer groups benefit from seeing that they are not alone and that others have and are successfully completing cancer treatment.

In summary, an antidepressant combined with support and encouragement delivered in both individual and group therapy settings are likely to help Ms C feel more in control and better able to think through the pros and cons of future decisions. Dr Brooks will point out that only rarely does a woman become so uncomfortable on antiestrogens that she chooses to discontinue them. Both Dr Brooks and the psychiatrist can reassure Ms C that there is good evidence that young women who have been treated for breast cancer achieve good physical and emotional recovery and ultimately have psychological, social, and sexual health equal to that of their peers.

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Commentary 2

by Johannes Gobertus Meran, MD

The case of Ms Civali evokes questions that physicians need to reflect on when dealing with early stage breast cancer and its potential psychosocial implications.

Initially, the physician has to give priority to providing sound medical advice and counseling. This clinical step should always be based on a risk-benefit assessment, which requires a complete and detailed medical characterisation of the respective cancer: one would like to know, for example, the localisation, histology, TNM staging, grading, hormone-receptor status (ER, PR), and additional risk factors, at least the HER2/neu overexpression. Primary treatment of localized breast cancer, which is what Ms Civali has, consists, in most cases, of breast-conserving surgery, followed by radiation and systemic adjuvant therapy according to the particular risks of the cancer. In this case these prognostic and predictive factors are unknown, but it may be assumed that Dr Brooks' decision to perform a breast-conserving surgery followed by chemotherapy and radiation was the most appropriate first step of Ms Civali's cancer treatment.

Now the next treatment questions are: why was hormone treatment not suggested earlier, and should the physician recommend Ms Civali start the hormone treatment several months after completing chemotherapy and radiation? With respect to medical facts, Dr Brooks' proposal of a hormone therapy allows us to conclude that the carcinoma cells are receptor-positive. The benefit of hormone therapy is about 5–10 percent reduction in the 10 year mortality rate. Although Tamoxifen—the most popular hormone treatment drug—is associated with an increased risk of venous thromboembolism and endometrial cancer, the statistical gain is widely believed to greatly outweigh the medical risks. Thus, based on statistical and diagnostic trends, Dr Brooks is justified in recommending the hormone treatment. Recent data suggest using Anastrozole instead of Tamoxifen as the preferred treatment, because it significantly prolongs disease-free survival and has fewer side-effects [1].

A physician's advice should not be based solely on general statistical outcomes, but should always include a personalized risk-benefit assessment that takes into account the unique circumstances of the individual patient. Clear and sensitive communication about the anticipated long-term outcomes and acute effects must be discussed openly and within the context of the patient's life. In this case, Ms Civali feels unable to make an independent, personal decision and asks Dr Brooks for a recommendation. This situation is an analogue to the earlier instance in which Ms Civali asked Dr Brooks to decide whether or not she should have breast surgery. When considering her unwillingness to actively participate in the decision making process, it is important to recognize that Ms Civali's attitude indicates early symptoms of clinical depression. These symptoms require specific medical treatment and psychological support.

So how should Dr. Brooks advise Ms Civali about the adjuvant therapy? Adjuvant therapies are often thought to present considerable restrictions on patients' quality of

life. Thus, 2 criteria of medical decision making compete with each other: general statistical benefit has to be weighed against possible changes in individual quality of life. The basis for assessing the patient's quality of life is the patient's subjective evaluation of her own condition. These subjective perceptions cannot be derived authentically from the outside. They depend on personal values and moral principles that reflect the very individual experiences and understandings each person has had in her or his life. If, for example, a patient who has a chronic disease and has received extensive medical treatments views taking drugs and making regular visits to the hospital as a significant burden, this presents a serious and important decision making consideration for the consulting physician. Sometimes fatigue, frustration with the medical situation, and the need for prolonged inpatient hospital care, may justify a decision to forgo specific forms of treatment. Here, Ms Civali is obviously frustrated with her current situation. She feels worn down by the constant trips to the hospital and wishes to return to the life she led before her cancer was detected. So should Dr Brooks *not* recommend hormone therapy to Ms Civali in light of her individual psychosocial situation and the fact that there are currently no signs of cancer in her body?

This scenario also has to take into account the possibility that Ms Civali may just be temporarily overwhelmed by emotions related to her medical condition and treatment. These reactions may pass after a short time when the patient has gained some rational, reflective distance on her situation. Therefore it seems to be important to rule out true depression as well as a temporary emotional state that may unduly influence her quality-of-life assessment. In such fragile situations it is not only the right of the patient to waive the active role in decision making, it may even be wise to do so by asking the physician for advice, as Ms Civali has done—especially when the physician appears to have led the decision-making process very responsibly. Although time is scarce in everyday clinical life, good quality care and empathy require the doctor to find out about patients' preferences and wishes and to disclose potential agonizing symptoms and side effects of treatment options. As physicians, we need this kind of normative and psychosocial cooperation from the patient in order to reach a patient-centered treatment decision.

The alternatives to adjuvant hormone treatment should also be openly discussed with the patient. In the case of Ms Civali one of the alternatives is no further treatment at all. But would the denial of hormone treatment allow her to live a “normal life” again, ie, the life she led prior to the discovery of her cancer? Although Ms Civali hopes so, cancer patients usually do not forget the disease and their changed status of life simply by avoiding the hospital. The anxiety of cancer recurrences or possibly undetected metastases remains. Some periodical follow-up is usually requested by the patients to confirm the remission of the cancer. Hence, the hope of Ms Civali to escape her disease merely by rejecting a hormone treatment seems to be illusionary. Nevertheless, if her fatigue of treatment is so strong that she wants to avoid any more external medical reminders of her disease, Dr Brooks should accept these feelings while assuring her that she is welcomed whenever she feels the need to communicate with or be seen by a doctor.

If I were in Dr Brooks' place, I would try to make Ms Civali aware of her particular risk-benefit ratio, including the statistical advantages of adjuvant therapy. Assuming a hormone-receptor-positive tumour and considering the given psychosocial facts, the justification for a hormone treatment seems preponderant. Anastrozole (or Tamoxifen) is usually well-tolerated, and its benefits will almost certainly outweigh its potential side effects (eg, hot flashes and vaginal discharge). These side effects are rather mild given that the patient has already tolerated the much harsher side effects of chemotherapy. If the assumption that the benefits will outweigh the individual side effects turns out to be wrong in Ms Civali's case, it is still possible to either modify or discontinue the treatment after evaluating the regimen together with the patient.

In conclusion, I would recommend the hormone treatment to Ms Civali, but acknowledge her concerns by accompanying the treatment with psychological support, specifically a program to enhance self-esteem and to provide all possible help for reintegration in her life and work. As argued above, communication between patient and physician remains the most important guide to achieving shared decision making which depends heavily on excellent medical information and the personal risk-benefit assessment. The latter is usually best expressed by the patient, who is the only one in a position to make the individual risk-benefit assessment since this has to be done according to her very own way of living, her experiences, and her preferences.

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Clinical Case

Helping the Patient Achieve Quality-of-Life Goals

Commentaries by Thomas Finucane, MD, Alfred Simon, PhD, and
Muriel Gillick, MD

Mrs McGoldrick was admitted to the local hospital from a local nursing home with a urinary tract infection (UTI) and multiple chronic diseases including diabetes and a history of heart attacks. Mrs McGoldrick is 81 years old, has an adult daughter, Regan, and an elderly sister, Emily. During the admission process, Mrs McGoldrick reported that she could walk only with pain and therefore spent most of her day sitting in a chair. She was evaluated by a psychiatrist immediately after admittance and was prescribed antidepressants to combat symptoms of clinical depression. She was also observed to have indications of early stage dementia.

After spending 3 days in the hospital, Mrs McGoldrick appeared to have been successfully treated for the UTI but remained weak and lethargic. In an effort to elevate her mood, the anti-depressant dosage was increased, but after several days there were no marked signs of improvement. One of the most distressing trends noted by the clinical staff was Mrs McGoldrick's intake of foods and liquids. Several tests revealed that she was suffering from hypoprotein anemia which suggested that she had not been properly nourished for a sustained period of time. The hospital staff, however, observed Mrs McGoldrick eating and drinking well when Emily fed her during one of her regular visits.

Prior to Mrs Goldrick's release from the hospital, her primary care physician, Dr Misenti, spoke privately with Mrs McGoldrick's daughter, Regan, who stated that her mother had expressed a "wish to die," believing that there was nothing more that she wanted from this life. After considering Regan's information, Dr Misenti suggested continuing the anti-depressants and giving Mrs Goldrick the option of a percutaneous endoscopic gastrostomy (PEG), which might help raise her mood and nutritional status and, hence, her quality of life. It was Dr Misenti's hope that by improving the quality of Mrs McGoldrick's life, he would also encourage her to want to live. Regan believed that this was an idea that should be explored and implemented, but Mrs McGoldrick refused to consider the option.

Commentary 1

by Thomas Finucane, MD

Mrs McGoldrick was admitted to hospital with an acute and totally reversible illness—a urinary tract infection. Once treated, she'll presumably be about as well as she was before admission. (This is in contrast to an illness like stroke, fracture or major myocardial infarction where the patient would probably not return to her previous

health state.) Her baseline functioning seems limited by chronic ambulation-related pain, and there is no evidence of recent deterioration.

During this admission, Mrs McGoldrick comes under the scrutiny of the acute medicine team, with its bias towards intervention. Had she not become infected, none of the questions now on the table would have arisen. The team notices depression, perhaps early dementia, poor food and liquid intake, and some abnormal “markers of nutritional status.” The record shows that she is not dysphagic, however, and with her sister present her oral intake is adequate and otherwise problem-free.

Mrs McGoldrick's daughter reports that her mother has expressed a wish to die. This statement of course requires that the patient be carefully evaluated for suicidal ideations. Often, however, this “wish” is presented as a fairly nonspecific expression of suffering, rather than an actual desire. In LaFontaine's *Death and the Woodcutter*, an elderly man is enveloped by hardships: hunger, exhaustion, wife, kids, debt, servitude, taxes, and soldiers. He calls on Death to come and release him. But when Death arrives and asks what he wants, he says he just needs some help moving this bundle of branches. LaFontaine concludes, “Plutot souffrir que mourir, C'est la devise humaine” [1].

PEG feeding is then suggested by the patient's primary care physician, who gives 3 reasons for his recommendations. The first is that Mrs McGoldrick's mood will improve with PEG feeding. Second, her nutritional status will be raised, “and, hence, her quality of life.” Third, with improved quality of life, the patient may be encouraged to want to live. The first issue, her mood, is discussed in an accompanying piece (see commentary by [Muriel Gillick](#)). Understanding and treating depression in dementia are very complex matters. In any case, a sick patient who's received 3 days of antidepressant medication has not been treated effectively for depressive symptoms.

What about her nutritional status and quality of life? First of all, there is a profound misunderstanding about malnutrition, and there is a vigorous promotional campaign designed to sell nutritional supplements. A human being needs calories for 3 main purposes: basal metabolism, activity, and the thermal expenditure of feeding—the energy required to digest and absorb nutrients. Basal metabolic rate depends in large part on muscle mass. If a patient is thin, slightly wasted, and sedentary, as Mrs McGoldrick is, her muscle mass will be low. Confined to bed and chair, Mrs McGoldrick's activity level is also low; she eats little; and will need only minimal energy to digest and absorb her food. In the days before PEGs, many very skinny, bedfast patients survived for years with an astonishingly small caloric intake. Lawyers and vendors of nutrition products would have us believe that such a situation is untenable.

We all want our patients to be properly nourished, but what does this mean? Although studies of feeding tubes in those with mild dementia are not available, other data show that thin patients with advanced dementia who are eating little do not live longer with PEG feeding. For a physician to tell a family member of such patients, “Well, we can either put in a feeding tube or let your mother starve to death” is both dishonest and

coercive. A truer sentence is, “Your mother is not doing well despite our best efforts. We can put in a feeding tube, but no real evidence suggests it will help her live longer, and the best evidence shows a high chance that she would die in the near future.” Similarly, no evidence whatsoever suggests that risk of infection is reduced by PEG feeding and “proper” nutrition. To the contrary, tube feeding is cited as a risk factor for pneumonia and has been shown to cause life-threatening infections of the lung, pleura, gut, peritoneum, abdominal wall, bloodstream, and more. Children with poor access to food live longer and have fewer infections when they are provided with food; adults with advanced dementia who eat little even when it is offered do not live longer, have no fewer infections, and may well have more, once PEG feeding is begun.

What do the data show about quality of life with PEG tube feeding? Most of the data concern more severely demented patients, and they are usually unable to report their inner experience. Patients who undergo PEG feeding are more likely to be restrained, which seems to contradict the suggestion that quality of life is better. But most importantly for this case, PEG feeding might reduce mealtimes with the sister—who is one of the patient's only sources of socialization—and this would be a real loss to both women. PEG might improve the quality of life for patients with severe dysphagia who cannot keep food and fluid out of the airway and who react vigorously with coughing and gagging. In general, eating is one of life's great pleasures. PEG feeding is not eating.

Finally, what is the relationship between quality of life and the desire to stay alive? LaFontaine's story refers to an important drive: the widespread and deeply held desire not to be dead. In the large, sophisticated SUPPORT initiative, quality of life had no effect on patients' desire for resuscitation [2]. Of surveyed patients with C4 quadriplegia, stable for at least 1 year, with clear cognition, 90 percent are glad to be alive [3]. This desire not to be dead is often underestimated by physicians and family members.

In conclusion, there is no physiologic basis for placing a feeding tube in this patient. She has been stable in the nursing home and should recover completely from her acute illness. She is able to protect her airway and when her sister is present, Mrs McGoldrick's intake is adequate. Tube feeding will not solve any of the problems for which it is proposed; imprecise references to “proper nutrition” should be clarified explicitly.

Beyond the uncertain and, frankly, unlikely medical benefit, an even stronger reason not to place a feeding tube exists. In many ethical decisions near the end of life, tension develops between 2 fundamental values. On one hand is reverence for life. The value of human life is the North Star by which ethical decision making should steer. On the other hand is the basic human right to say, “Keep your hands off of me,” which our patient has already expressed. Unless we are willing to counter that she is incapable of realizing the consequences of this decision, and to deprive her of her basic right to control her own body, placing a PEG would be assault. This would be

true even if PEG feeding were life-sustaining, which it is not. To undertake this intrusion based on someone else's assessment of her quality of life is simply untenable.

My approach to this patient would be to discontinue all medications that might interfere with appetite or attentiveness, including cholinesterase inhibitors, bisphosphonates, nonsteroidal anti-inflammatories, sedatives, narcotics, and many others. She should be formally evaluated for major depression. If this diagnosis is established, she should be properly treated. Meals and mealtimes should be attractive, pleasant experiences with the nursing home staff and family spending meaningful time helping Mrs McGoldrick to take nourishment. Truly caring for the patient is at the heart of good care for so vulnerable and frail a person.

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Commentary 2

by Alfred Simon, PhD

In order to justify any medical intervention, eg, placing a feeding tube as in this case, there must be *medical indication* for the treatment and the *consent of the appropriately informed patient*.

Medical indication is decisive in determining the clinical foundation for the intervention, ie, whether it should be offered to the patient at all. A physician determines whether a treatment is indicated based on his or her *medical knowledge* of the course of a disease and the effects of certain interventions on that course. Indication also depends on the physician's knowledge of the *diagnosis and prognosis* specific to this individual patient and on the *aim of treatment*. Finally, the physician must consider whether the expected benefit is in due proportion to the harm that may be expected. If a measure has little or no benefit for the patient or if the benefit causes disproportionate risk of harm, the measure has to be considered *medically futile* and should not be offered to the patient.

The fact that an intervention is medically indicated, however, does not mean that the physician is automatically authorized to carry it out. It is not the physician but rather the patient who decides on the implementation of a measure because patients with decision-making capacity have the *right to self-determination*. If a patient refuses or withdraws consent after learning about both the benefits and the risks, treatment is

not justifiable. The prerequisites for providing informed consent are decision-making capacity and appropriate *patient information*. If the patient does not have decision-making capacity, the physician should ask whether he has given his opinion on the situation at an earlier date when he was determined to be of adequately sound mind, perhaps in the form of a living will. If this is not the case, the patient's interests must be represented by a proxy or “surrogate” decision maker or, if this is an emergency situation, by the physician himself.

Application to the Present Case

The first question the physician should ask himself is whether Mrs McGoldrick presently has *decision-making capacity*. If she does, he should offer her the opportunity to reconsider her decision against a PEG; coercion and, especially, treatment of the patient against her will would interfere with her right to self-determination and would therefore be ethically unacceptable. Whether Mrs McGoldrick has decision-making capacity cannot be answered definitively based on the information presented in this case. Her age, treatment with antidepressants, and early stage of dementia do not exclude decision-making capacity but do require the medical staff to be aware of possible compromised decision making. The determination of her competence must also consider whether she is presently capable of understanding the consequences of her refusal for additional treatment. To decide this, it might be helpful to investigate whether the refusal of the treatment is *authentic*— in other words, consistent with her other known values and goals. If the physician has any doubts regarding Mrs McGoldrick's decision-making capacity, he should consult a psychiatrist.

The aim of the proposed procedure is to raise the patient's mood and nutritional status and hence, her quality of life. Yet it is questionable whether a PEG is a suitable means to this end. The fact that Mrs McGoldrick eats and drinks sufficiently when fed by her sister suggests that her insufficient nutritional status has a social and caregiving explanation rather than a medical basis. The staff at the local nursing home probably does not have enough time to feed Mrs McGoldrick, and this further perpetuates her social isolation. Maybe the food is not presented in an appealing way (eg, big portions) or Mrs McGoldrick finds this previously shared time very lonely. Instead of considering PEG, those in charge should first try to improve the social situation and nursing care of Mrs McGoldrick through greater involvement of her older sister and her daughter.

The other rationale offered for inserting the PEG is that artificial feeding would counteract imminent malnutrition and thus contribute to life extension. Without improving the social and caregiving situation, this seems to be a futile goal, since Mrs McGoldrick has made it clear—explicitly to her daughter and implicitly by refusing to eat and drink—that she does not want to live that way.

Conclusion

Application of PEG in this case seems to be *neither medically reasonable nor in the patient's best interest*. PEG is not an appropriate means for solving social or caregiving deficits. Should it not be possible to improve Mrs McGoldrick's quality of life by social and caregiving measures, it seems to make little sense to extend the situation artificially by

PEG since the patient herself obviously does not wish for this lifestyle. Apart from the questionable medical indication, Mrs McGoldrick's refusal to even discuss the possibility of PEG clearly speaks against taking this measure. If Mrs McGoldrick is still able to grasp the consequences of her decision, and is determined to have decision-making capability, her refusal is binding for the physician. If she is deemed to lack decision-making capacity, her refusal would at least be an important indicator that PEG was not her preference, which is supported by her refusal to eat and her earlier statements to her daughter, and should be taken into account by surrogates and physicians when making treatment decisions.

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Commentary 3

by Muriel Gillick, MD

The case of Mrs McGoldrick stimulates us to think about the meaning of patient autonomy for a patient with cognitive impairment and about how surrogate decision makers should evaluate quality of life. Before we consider the ethical dimensions of the case, however, we must consider the medical aspects.

The first area that should be addressed is Mrs McGoldrick's physical pain. We are told that her pain is severe enough to prevent her from walking and to confine her to a chair. It is essential to try to establish the etiology of the pain and to treat it vigorously. Pain control is the foundation of good palliative care, and lack of treatment may be at the heart of the patient's depressive symptoms and apparent lack of interest in life [1].

The second domain that requires further exploration is Mrs McGoldrick's depression. She was started on antidepressants at the time of admission to the hospital, and, when she remained weak and lethargic after 3 days, the dose was increased. Tricyclic antidepressants take 4-6 weeks to become effective; selective serotonin reuptake inhibitors typically require 2 weeks, and, while we are not told what medication is prescribed, almost all take longer than 3 days to work. If Mrs McGoldrick's depression is contributing to her anorexia, then she should probably be treated with a stimulant such as methylphenidate. The dose can be increased rapidly, and, if the patient continues to have depression with life-threatening consequences, electroconvulsive therapy should be considered.

Third, the question of dementia ought to be further pursued. We are told that Mrs McGoldrick has early dementia and, while truly reversible dementia is rare, it is important to rule out hypothyroidism and, especially in view of the patient's poor nutrition, pernicious anemia. If Mrs McGoldrick has mild Alzheimer's disease, treatment with Donepezil should be considered. Although controversy persists over whether anti-cholinesterase inhibitors produce clinically meaningful benefits, if they have any role, it is in the early stages of Alzheimer's [2].

Finally, Mrs McGoldrick's nutritional status warrants further examination. Her physician states that improved nutrition, delivered through a gastrostomy tube, will improve her quality of life and mood. While this assertion is intuitively appealing, there is little data to support the beneficial effect of artificial nutrition in the frail elderly: in a community study of 150 older individuals who received gastrostomy tubes, there was no improvement in health-related quality of life among those who survived more than 60 days [3]. In the same study, there was no change in depression scores or functional status which might contribute to quality of life. Drawing inferences about the effects of gastrostomy tubes on quality of life from our intuition has proved hazardous in other, clinically distinct, situations such as that of patients with advanced dementia. In this setting, feeding tubes are often presumed to enhance quality of life by preventing aspiration pneumonia, improving function, and decreasing pressure ulcers, but in fact they have not been proven to reliably achieve any of these surrogate markers [4]. While the role of artificial nutrition remains controversial, the only circumstances where there is consensus regarding benefit are isolated dysphagia and other non-progressive conditions that Mrs McGoldrick does not manifest [5]. The physician's suggestion that artificial nutrition would likely benefit Mrs McGoldrick also fails to take into consideration such adverse consequences of a gastrostomy tube: diarrhea, infection, and the need for restraints if the patient tries to pull out the tube.

If, after the caregiving team responds to these unresolved medical problems, Mrs McGoldrick continues to eat poorly and to express the wish to die, it is time to grapple with the ethical issues. Can the patient be compelled to accept a potentially life-saving intervention against her will? To answer this question, we must first ascertain whether Mrs McGoldrick has decision-making capacity. The fact that she has mild cognitive impairment—assuming she has early dementia rather than delirium from her infection—does not necessarily mean that she is incapable of making decisions about a gastrostomy tube. She needs to be able to communicate her understanding of the nature of the proposed procedure, the alternatives to the procedure, and the consequences of both inserting and not inserting a gastrostomy tube [6]. We do not have sufficient information about Mrs McGoldrick to know whether she meets this standard. The effect of her depression on her ability to make decisions is also a concern. The presence of depression, however, does not automatically deprive a person of the ability to participate in his or her own medical care [7].

Let us suppose that Mrs McGoldrick has had her pain and depression vigorously and successfully addressed. Let us suppose, in addition, that her primary care physician and the consulting psychiatrist assess her to be incapable of making life and death decisions. When she is told that she might feel better—and feel differently about living longer—if she had a feeding tube, she just repeats that she doesn't want it and she does not seem to be able to process the possibility that she might have a new attitude towards life if her nutrition were improved (a claim which, as mentioned above, is entirely speculative and not grounded in any persuasive data). Under these circumstances can a surrogate decision maker authorize the intervention against her will?

One standard for determining whether a surrogate can demand an intervention that the patient opposes is a *sliding scale* of decision-making capacity [8]. We commonly accept that a patient may refuse to have her blood drawn, even if she fails to fully understand the benefits of the test, because she does grasp its burdens and, at the same time, the test is very unlikely to be a matter of life and death. We also acknowledge that when a patient who is deemed incapable of making his own medical decisions and says he does not want a surgical intervention, but fails to understand that he will die without it, his decision can be overridden by his surrogate (assuming that the patient, when decision-capable, did not decline life-prolonging medical treatment). In the case of Mrs McGoldrick, who says she doesn't want a gastrostomy tube but may not fully appreciate the consequences of the choice, the ultimate decision may be left to a surrogate if it has been formally established that the patient lacks the capacity to make her own decisions. The actual benefits of artificial nutrition are not well-established, the burdens are significant, and, most importantly, there is a less invasive alternative: the patient's sister, who has been successful in feeding her or coaxing her to eat, can be asked to play a more active role in her care. The patient's daughter can be recruited to share in caregiving tasks by visiting more regularly and providing greater support. The medical profession is often eager to find a quick fix; this is a situation that will take time to sort out. As Mrs McGoldrick's depressive symptoms improve, as her pain resolves, as she engages in life review with a social worker or a chaplain, and as she spends more time socializing with her family—and eating as she socializes—perhaps her assessment of her quality of life will change. The medical team and Mrs McGoldrick's family must avoid “conflating...the meaning of caring for the patient with the provision of a feeding tube” [9].

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Journal Discussion

Evaluating the “Disability Paradox” in Conjunction with Resource Allocation

by John Brazier, PhD

Introduction

An important component in assessing the cost-effectiveness of health care interventions is the valuation of the outcomes using a quality-adjusted-life-years (QALYs) instrument [1-3]. The QALY is calculated by multiplying the number of years a patient is expected to live by a health state co-efficient that ranges from 0 to 1, where full health is valued at 1 and death or states regarded as equivalent to death are rated 0. These health state values are usually assigned by members of the general public who try to imagine what the quality of life in the given state would be rather than by patients who are actually in that state of health [4-6]. The source of values has important implications for allocating resources in health care because patients who are in a given health state tend to give higher values to their quality of life than members of the general population who are asked to rate that health state [7-11]. This commentary considers 2 papers that challenge the orthodoxy of using general population values [12, 13].

Explaining Discrepancies Between Patient and General Population Values

The paper by Ubel and his colleagues explores the reasons for the discrepancies between patient’s valuation of their own state and valuations made by members of the general population trying to imagine the state [12]. It provides the most complete set of explanations yet to be published on this topic, dividing them into 3 broad categories. The first set of explanations concerns discrepancies that arise from poor descriptions of the condition and the tendency of the general public to focus on the negative aspects of a given health state while ignoring the fact that many other aspects of health and quality of life will be unaffected. The second set of explanations concerns the psychometric phenomenon that people’s rating of their health states may shift over time due to changing internal standards. Finally, there are the explanations that concern adaptation to the circumstances by patients and the fact that many members of the general public fail to accurately predict this process.

Whilst the distinction between these categories may blur, Ubel’s approach does provide a useful framework for thinking through, and informing future research into, the different causes of the discrepancies. However, Ubel et al do not consider the implications of these explanations for resource allocation.

Examining the Implications for Resource Allocation in Health Care

The paper by Menzel and his colleagues provides a slightly different framework for explaining the discrepancy because their aim was to highlight the normative

implications that the discrepancies have on resource allocation [13]. Rather than consider explanations rooted in the problems of measurement (such as Ubel's incomplete descriptions and “focusing illusion”), Menzel and colleagues examine 8 explanations, for these valuation differences, dividing them into those that support the use of adapted (ie, patient) values and those that appear to argue against using patient values, instead, favouring general public valuation. The former category—explanations that argue for use of adapted values—include skill enhancement, activity adjustment (in line with ones abilities) and goal adjustment. The latter category—reasons why patient values might be suspect—encompass such adaptations such as cognitive denial, suppressed recognition of full health, and lowered expectations. While the latter set of explanations might be cause for concern, the authors argue that there is a strong case for using patient values since they are a more accurate reflection of what it is actually like to be in a given state. While members of the general public might be able to predict what a new state would be like initially, we are often poor at predicting the extent of our adaptation [14]. Menzel and colleagues consider the arguments against using patient values that appear in philosophical literature, which draws analogies in health to the idea of the happy slave and entrenched deprivation. At the risk of over-simplifying the arguments made in the paper, it appears that many of the claims in the literature seem to neglect the fact that simply because people adapt to their circumstances does not mean that given the choice, they would choose their current health state over full health. Menzel et al responded to the philosophical arguments by pointing out that many of them were constructed outside of the health arena and have little relevance here, and, even where they do have legitimacy (eg, the fact that some deaf persons give the same value to their state as those with full hearing give theirs) it does not mean that patient values should be entirely ignored. Menzel and colleagues make an important and clear distinction between the role of an individual assessment of utility, that best comes from patients, and role of the social perspective or valuation that may include other considerations such as the role of adaptation. Societal assessment of utility, for example, might exclude utility gains based on what society views as less laudable causes of adaptation—eg, a patient’s denial of his or health state.

Policy and Research Implications

It seems difficult to justify the exclusive use of patient values or the current exclusive use of values assigned by uninformed members of the general population. Menzel and colleagues therefore suggest a possible third way. In this model, values of the general population would inform resource allocation in a public system, but the public respondents would be provided with more detailed information as to what the states they are rating are like for patients experiencing them. This would require the development of an explicit system for providing better ways of conveying information about various health states to the general population. Methods for doing this could include improvements in the descriptions of the different states and providing more information on the process and nature of the adaptation experienced by patients over time. These considerations represent major challenges for future research. Even asking patients to value their own health raises major practical research problems.

Menzel and colleagues and, less directly, Ubel and colleagues challenge the current orthodoxy recommended initially by the Washington Panel on Cost Effectiveness and adopted by many of the health technology reimbursement agencies (such as the National Institute of Clinical Excellence). Many health economists, philosophers, and health professional and patient advocacy groups have been rightly concerned about the use of largely uninformed general population values in decision making. While the authors of these papers are not in agreement about the extent to which patient values should be taken into account, and while neither offers specific methods, they have identified the need for greater debate and more research. Discussion needs to be informed by an understanding of the causes of the differences between patient and general population values and the role of value judgements. The research agenda must be expanded to explore the way we describe health states, the elicitation of patient values, and how to develop methods for obtaining informed general population preferences by providing more comprehensive information on what it is like for people in various health states.

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Journal Discussion

Quality of Life and the Problem with QALY Researchers: Comments on 2 Papers

by Tom Koch, PhD

In 2 distinct papers published in different journals, Menzel et al [1] and Ubel et al [2] confront the same, seemingly “paradoxical” problem [3]. As Menzel and his colleagues put it: “Chronically ill and disabled patients generally rate the values of their lives in a given health state more highly than do hypothetical patients imagining themselves to be in such states” [4]. Stated declaratively, the issue is that people who live with difference perceive their life quality as better than mundane folk and most academics believe is possible. Both authors seek, using a QALY-style (quality-adjusted life year) test, first to document the perceived difference, and then to understand the phenomenon. Menzel attempts to explain the perception of persons of difference through consideration of the adaptive process by which people accommodate to their altered states. Ubel takes a different but not incompatible approach, using the construction of a “focusing illusion” [2] to explain the judgments of mundane respondents.

The real question, implicit in Ubel’s paper and explicit in Menzel’s, is whether ethicists, lawyers, physicians, or policy analysts can accept the seemingly counterintuitive notion, advanced by persons of difference, that a physically or cognitively restricted life is as potentially full, fruitful, and worthy as a life without these obstacles. It is not that these generally healthy people dismiss the self-reported valuations of persons of difference. It is, however, that to the mundane public and, one assumes, members of the authorial teams themselves, the result is counterintuitive. Menzel, after all, describes the set of persons of difference as “thoroughly deprived” [6]. How can one credit a positively self-reported life quality by persons whose life context is thus described?

From the perspective of difference—I abjure use of “disability” as both inadequate and prejudicial—the real problem is with assumptions inherent in the researchers’ questions and the methodology employed in their work that result in a presumably unintentional lack of respect. With what are undoubtedly the best of intentions, the motive themes of these papers and the general methodology employed limit the usefulness of the papers’ conclusions and call into question the paradigms both research teams employ.

I would argue that predictive quality-of-life instruments impose a range of assumptions, typically implicit, that are not credible [7]. The first assumption is that a simplistic medical model with the descriptions of physical conditions can serve as a linear predictor of life quality for those living with that condition. But a wealth of

literature insists that such a medical model serves neither to address the complexity of the lived life or the life quality that may result from difference [8]. For example, research of social worker Young and colleagues, involved with patients with ALS (Lou Gherig's disease), offers one sample from a broad, if largely non-quantitative, literature [10].

Both Ubel and Menzel's teams impose a version of the simple medical model using QALY-style, health-related quality-of-life (HRQoL) instruments that ask mundane persons to make prospective judgments about life quality expected from different physical states. There is, however, no simple equivalence between changed physical condition and a resulting life quality [8]. Irrespective of a person's physical state, life quality is a complex outcome based on a daunting range of factors including but not limited to: age, education, employment, expectations and goals (familial, personally, and professional), experience, family structure, income, and social support. For persons of difference, the latter includes accessibility to the urban environment (curb cuts, transportation services, etc.), social and financial support if needed, as well as counselling and outreach services as appropriate.

To assume that the life quality for persons of difference can be predicted based solely on a single clinically defined difference is to suggest that any single, limiting condition solely defines the quality of our lives. It also assumes that persons with no understanding of life lived in a given health state can adequately predict what their life quality might be in that state. Further, to make even a moderately educated guess would require that subjects have some first-hand knowledge of the life that results, both its richness and its challenges. Most do not, and, thus, they judge out of ignorance [7].

In this vein, Ubel et al [2] consider a "focusing illusion" in which mundane people are assumed to "overestimate" the emotional impact of events by "disproportionately focusing on the narrow domains influenced by the events" [2]. When asked about blindness, most people will think as sighted persons about being unable to see; asked about paraplegia, people respond as ambulatory persons talking about being unable to walk. In other words, when faced with questions about states they have never been in, mundane people answer from the only perspective they have.

Ubel et al then argue that the goal of HRQoL "measurements should be to reduce this source of discrepancies" without suggesting how this reduction might occur [12]. While recognizing that patients and the public may not view HRQoL measures in the same way, Ubel assumes that this is a modest difficulty [12]. These "discrepancies" are, in fact, a fundamental flaw of the instrument that is built into the model and contributes to the arrogant assumption that mundane folks can judge complex states on the basis of a simple catalogue of physical differences.

Rather than looking at why people overestimate the impact of health events they have not experienced, Menzel et al, seek instead to explain the higher-than-expected life quality reported by persons of difference. To do so, they describe 8 modes by which persons of difference are assumed to adapt to their "damaged" circumstances. This

means that to understand a future quality of life in a specific circumstance, one must first consider which modes of adaptation he or she would follow. No QALY can do that. Hence, Menzel's study undermines rather than explains the QALY approach.

Certainly, people—mundane and distinguished alike—adapt to changes along the life course [13]. Unfortunately, Menzel does not draw upon the extensive and pertinent experiential literature, written by persons of difference or those who live with them [7, 8]. With great specificity recent literature documents the experiences of formerly mundane persons who have developed sensory limits (eg, blindness, deafness), mobility disorders (eg, paraplegia or quadriplegia), and severely limited neurophysical states [14]. A secondary literature describes the experiences of family members who live with and care for those persons and who reflect upon their own life quality within families of difference [8, 15, 16].

Across this range of writings and literatures, the message is simply profound and damningly complex. Life changes and people change with it [13]. Adaptation is a part of a process, individual and social—by which everyone accommodates to changes across the life course. Learning to live with difference is a subset of a more fundamental process with its specific challenges and boons as hard to perceive as the reality of a successful 20-year marriage is to a dating teenager. Why some are better able to change than others is a subject of our communal ignorance, one that extends into the greater realms of psychology and philosophy.

On the basis of the broader literature, professional experience with the families of hundreds of persons accommodating to changing realities, and my own psychophysical experience, I believe that there is much to learn about the human condition from persons of difference. These lessons cannot be reduced to a QALY-style questionnaire, however. They will not be discovered by assuming that lessons come easily to those unprepared to delve beyond the simple categorization of physical states as if they expressed a lived reality. The first lesson of difference, one that needs to be incorporated into research paradigms and the mind of the general public alike, is that life quality is not a simple outcome. Understanding that would inform the future research of these authorial teams and the work they hope in the future to present.

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Journal Discussion

Values for Resource Allocation Should Expose the Adaptation Process, Not the Outcome

by Elly A. Stolk, MSc, Floortje E. van Nooten, MSc

Ubel PA, Loewenstein G, Jepson C. Whose quality of life? A commentary exploring discrepancies between health state evaluations of patients and the general public. *Qual Life Res.* 2003;12:599-607.

Menzel P, Dolan O, Richardson J, Olsen JA. The role of adaptation to disability and disease in health state valuation: a preliminary normative analysis. *Soc Sci Med.* 2002;55:2149-2158.

Patients may succeed in reaching high levels of well-being despite chronic illness or impairment because they eventually learn to adapt to their situation. As a result, these patients generally rate their own health higher than the general public rates the health of patients in these circumstances. This phenomenon has attracted the attention of quality-of-life experts like Menzel [1] and Ubel [2], who have explored these differences further. From their analyses, we get a clearer picture of the psychological processes that contribute to the discrepancies between a patient's own health rating and the general public valuations of that patient's health state. An unresolved issue, however, is the question of whose values and rankings are more appropriate to use as the basis of health care allocation—those of patients or those of the general public? It is usually assumed that resource allocation decisions should be guided by societal preferences, because they affect the entire society [3]. However, Menzel and his co-authors questioned the appropriateness of this approach, arguing that if social values fail to anticipate and account for the adaptation process, they are factually mistaken and can misrepresent a patient's quality of life [1]. This raises the question of whether pervasive social values should be considered invalid for use in resource allocation with adapted patient values used instead. In this contribution we make clear our position in the ongoing debate on this matter.

The term “adaptation” refers to the instability of internal standards by which people evaluate certain outcomes or health states. For most people, an improvement in health constitutes an improvement in well-being, and vice versa: loss of functioning decreases quality of life. This is reflected in the way unaffected members of society rank quality of life for less-than-full-health states. Patients without hope for recovery from a particular problem, however, often adapt to that state of health. They learn to cope with their disabilities or lower their expectations in order to achieve a more stable state of well-being. But does this ability to adapt mean that our health care systems should

try less diligently to resolve the health problems of these patients? Contrary to what we believe, Menzel, indeed seems to think so. According to him, a person's contentment with his or her health state—not the health state itself—should be the relevant outcome measure [1]. This idea originates from the moral argument about the worth of an individual life, which objects to stigmatisation of disabled persons' lives as inherently less valuable. Every additional year of life provided for a disabled person, Menzel suggests, should receive the same value as a year lived by a generally healthy person, irrespective of their different health states [1]. Menzel also objects to using quality-of-life values determined by healthy members of the public because their lower quality-of-life estimates for health states of chronically ill patients would imply that life-saving treatments for this group are valued less [1].

We object to Menzel's position, first, because patients' internal “reference points” may turn out to be rather flexible. Patients with no hope for recovery will probably reach an adapted state. If, however, they have the opportunity to improve their health, they will probably recognize and appreciate the capabilities that can be regained after treatment, so, from the reference point of their anticipated improved health state, the perceived value of their current health drops [4]. This so-called “response shift” illustrates the instability of subjects' internal standards of measurement and leads us to conclude that patients give invalid and unreliable values for their own health states when compared to a wider set of (attainable and unattainable) health states. Although we agree that stigmatisation of handicapped persons is unwarranted and that handicapped persons should have equal claim to life-saving treatments, we do not agree that it is appropriate to concentrate on subjective measures of happiness and to ignore real differences in patients' health states. Surely there must be better ways to address the problem of stigmatisation.

The second reason why we disagree with Menzel is that inequalities in health generate inequalities in opportunities, regardless of whether or not these translate into inequalities in happiness [5]. Disabilities reduce a person's opportunities in life and should therefore be considered relevant in the decision-making process that concerns resource allocation. For example, patients with stool problems who are incontinent may regain control over defecation using enemas. However, compared to healthy people, their achievement of continence requires consumption of resources. In this case, time is invested, and perhaps a diet is prescribed to control bowel movements. Time and resources expended in managing one's health cannot be used in pursuit of other goals, resulting in reduced opportunity and choice, and thus making patients less capable than healthy persons to get what they want from life. This capability perspective motivates us to argue that, from a distributive justice point of view, social values, not adapted patient values, should inform resource allocation.

The capability perspective offers an explanation for the discrepancies between patient-derived values and those derived from non-patient members of society. Patient values seem to represent the “state” of being adapted, whereas the values of others may acknowledge that an “act” of adaptation will be required. It is interesting to consider whether other inconsistencies between quality-of-life measures can also be explained by the concept of capability. The capability perspective turns our attention to the

question of how quality of life is accounted for in techniques that elicit preference. According to Verkerk et al, existing measures lack a uniform basis. Some preference elicitation instruments concentrate on contentment with functionings whilst others are also sensitive to the capabilities of the patients [6]. We therefore believe that the debate about values that aim to inform resource allocation should go beyond the question of whose values count; it should also consider the conceptual implications of the process in which values can be generated.

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Thoughts on Koch's Postulates

by Peter Ubel, MD

Six months ago at a departmental meeting, I presented a series of research studies I had led, exploring the happiness and quality of life for people with a wide range of illnesses and disabilities. In these studies, our research group had developed several novel ways of testing the validity of subjects' self-reports, an important task because numerous studies have shown that people are not always able to provide accurate assessments of their global well-being [1]. On sunny days, for example, people report significantly higher overall well-being than on cloudy days, with their current mood strongly influencing their global assessment. Our studies confirmed several flaws in people's self-reports. For example, Parkinson's patients report different levels of well-being when they participate in studies of "people with Parkinson's" than when they are approached as "members of the general public"[2]. In another study, we found that dialysis patients overestimate the frequency with which they experience extremely good and bad moods in a typical week [3].

Despite these misreports, I presented detailed evidence that people with chronic illness and disabilities report very high levels of life satisfaction and positive mood and very low levels of negative mood; that they are largely happy, and, in fact, report levels of happiness equivalent to those of healthy control subjects.

Upon completing my presentation, one of the leaders of my health institution burst out: "You've done a brilliant job, Peter, of showing just how deep these people's denial runs!"

Here is a fact: many people with chronic illness and disability report higher levels of happiness and well-being than healthy people believe is possible. This clearly bothers Dr Koch, and his anger is both palpable and understandable. The unfortunate truth is that many members of the general public hold terrible views of what life with any disability must be like. Discrimination, bias, and stigmatization are all too common. In such a climate, research on the quality of life of people with chronic illness and disability will generate strong emotions, and will often be misinterpreted.

It is still crucial to figure out why people with severe illness or disability often report negligible declines in their overall quality of life, even if such research will ruffle some feathers. Quality of life measurement is an imprecise, but necessary, business. Without quantitative measures, like QALYs, SF-36 scores, and the like, it is impossible to measure the impact of clinical interventions or determine the cost-effectiveness of new health care technologies.

As a primary care physician, I care for hundreds of chronically ill patients, many of whom amaze me with their emotional resilience. However, a substantial minority experience mood disorders and chaos in their lives because of their health problems. In fact, regardless of how disability and illness have influenced their lives, most of my patients are very clear that they want my help in *improving* their health and function. I believe this phenomenon deserves serious inquiry.

About 10 years ago, I experienced rapid onset of repetitive strain injury in both of my arms, leaving me unable to hold a pen, type at a computer, or practice piano (a passionate hobby I had been pursuing for 30-odd years). For 6 to 9 months, I was forced to stay away from the piano, hoping the pain in my hands would subside. My pain did eventually subside. But in the interim, I have to tell you, I was not miserable. Rather than practice piano, I read books and listened to music. Rather than type at a computer, I began dictating manuscripts into a tape recorder, a practice I continue to this day. By any measure of quality of life, my life was just as good as ever.

And yet, when my hands healed and I was able to resume piano practicing, I did so with renewed passion.

Would my life be diminished if I had never been able to resume my hobby? Of course not. Did learning the Liszt piano sonata improve my quality of life? Of course it did. And that is a paradox worth studying.

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Clinical Pearl

Assessing Quality Of Life In Patients With Lumbar Sciatica

by Bernd E Will, MD, and Matthis Synofzik

Evaluating Sciatica

Sciatica, a very common and costly medical condition, describes a *set of symptoms* rather than a *diagnosis*, and it is difficult to find criteria for successful treatment. To evaluate success of surgery for lumbar degenerative disc, for example, one might repeat the radiological diagnostics and compare them with the preoperative findings, observe physiologic changes (eg, nerve conduction) or look for improvement in clinical findings (eg, weakness). But there is increasing doubt among clinicians that these traditional, objective measures of medical success present a valid and sufficient indication of outcomes from the *patient's* perspective. Of what worth are radiological findings if they do not sufficiently represent the patient's evaluation of the sciatic symptoms—either because the patient's subjective impairment is much greater than suggested by the radiological findings [1] or vice versa, the radiological findings show lumbar nerve compression but the patient's impairment is mild [2,3]? Objective measures do not always correlate with subjective experiences. To assess the functional impact of sciatica for patients more validly, quality-of-life (QoL) scores have been developed for use in research and clinical settings. The improvement in health-related QoL as measured by these scores can be seen as the main goal of sciatica treatment [4, 5].

QoL Considerations in the Evaluation of Treatment of Spinal Disorder

Although the concept of QoL and the methodology of its assessment still remain controversial, there is enough agreement on the core set of measures to assess QoL. All good QoL questionnaires have in common that they can be easily understood by the patients, easily interpreted by the physician, and administered quickly (1-10 minutes [6]), which is a prerequisite for successful application in hasty clinical life. Criteria for an effective QoL measure are [4]:

- Specificity to disease, setting, and population
- Content validity (What domains and items are included?)
- Face validity (Do patients and physicians agree that these questions are relevant to their complaint?)
- Feasibility (Is it easy to understand and to use?)

Back-specific function scores ask about impairments that are particular to patients with spinal disorders: standing, walking, bending down, getting dressed, etc.

For every questionnaire there is a simple algorithm for adding the single item points together to obtain an overall score that broadly classifies patients into the categories of “unimpaired,” “mildly impaired,” “strongly impaired,” or “very heavily impaired” by

the disease. Since the various QoL questionnaires correlate highly with each other, they can be used by physicians in different specialties. QoL scores typically assess quality of life in 5 domains [6]:

- Function (back-specific questionnaires employ Roland-Morris [7], Oswestry [8])
- Work disability (work status, days off work, etc.)
- Pain (Bodily Pain Scale of SF 36 [9], Chronic Pain Grade [10])
- Satisfaction (back-specific Patient Satisfaction Scale [11]; global questions).
- General health status (e.g. SF-36 [12])

Whereas measures of function and work disability are related to physical capabilities (house work, mobility, dressing, etc), the general health status and satisfaction measures also include dimensions like social function, emotionality, and so on [6]. The former measures have a more objective and descriptive character, which makes them more similar to the traditional clinical physiological measures and easier to integrate into the clinical decision-making process. The latter are more subjective and prescriptive in character, making it harder for the physician to control and evaluate the variables and overall outcomes [13].

Using QoL in Sciatic Patients for Clinical Decision-Making

In the clinical decision-making process for patient's with lumbar sciatica, quality-of-life measures aid in:

- *The assessment of the severity of the low back disorder at baseline,*
- *The assessment of the individual response to specific treatment over time,* eg, postoperative improvement of low back pain; follow-up of an individual patient under conservative therapy when comparing the QoL score at patients' admission with later score evaluations; final evaluation of patients' progress while in the hospital through a QoL score before admission and after admission,
- *Exposing evaluation discrepancies between physicians and patients.* For example, when comparing the individual patient's score with his or her own clinical impression, the physician should be highly alerted by certain discrepancies: why does the patient perceive his health state significantly worse than the physician thinks it is? Or vice versa: why does it appear to the physician that the patient is strongly impaired whereas the patient himself reports being quite well? In clinical life the former discrepancy probably occurs more often, but the latter scenario might illustrate a general misinterpretation of patients' own view of their lives (See the journal discussion of the disability paradox in this issue [14,15]).
- *Evaluating outcome of general treatments,* eg, one-level discectomy compared to two-level discectomy [16],
- *Guiding decision making about hospital care options,* eg, all patients with lumbar disc surgery who afterwards still affirm more than half of the questions of the Roland-Morris questionnaire should be given extended stationary therapy.
- *Evaluating cost-effectiveness,* eg, for patients with clearly defined indications for surgery, lumbar disc surgery is generally more effective than continued medical treatment only in the short-term, but not when long-term outcomes are considered [17].

Putting QoL in Sciatica Patients into Practice: the Maine-Seattle Back Questionnaire

An example of an instrument for determining QoL for a specific disease like sciatica is the Maine-Seattle back questionnaire portion of the Roland-Morris Disability Questionnaire [6], one of the most respected and frequently used back-specific functional status measures. A portion of the questionnaire is shown below.

Instructions: As you read this list of statements from the Maine-Seattle portion of the Roland-Morris Disability Questionnaire, think of yourself today. When you read a sentence that describes you today, put a check in the “yes” column. If the sentence does not describe you today, you put a check the “no” column.

1. I change position frequently to try and get my back or leg comfortable.
2. Because of my back problem, I use a handrail to get upstairs.
3. I get dressed more slowly than usual because of my back problem or leg pain (sciatica).
4. I only stand for short periods of time because of my back problem or leg pain (sciatica).
5. Because of my back problem, I try not to bend or kneel down.
6. I find it difficult to get out of a chair because of my back problem or leg pain (sciatica).
7. My back or leg is painful almost all the time.
8. I sleep less well because of my back problem.
9. I stay in bed most of the time because of my back or leg pain (sciatica).
10. Because of my back problem, my sexual activity is decreased.
11. I keep rubbing or holding areas of my body that hurt or are uncomfortable.
12. Because of my back problem, I am doing less of the daily work around the house than I would usually do [6].

Although the linkage between QoL diagnostics and therapeutic decision making is ethically justifiable [18], it has been poorly investigated or established [13, 19-21], and more research on this link is needed [22-23]. There is also increasing—almost scandalous—evidence that QoL considerations still seem to play a relatively minor role even in the physician's decision to modify or discontinue important, patient-centred treatments such as palliative chemotherapy [24]. The patient's self-reported QoL, however, can and should assist in clinical decision making. Here are several examples of how these scores may guide physician's decision making and improve medical practice:

- When seeing a patient for the first time in a clinical or hospital setting, the patient's QoL rating can indicate the need or urgency for intervention. Hence some intervention can be offered before more costly and time-consuming diagnostic procedures are carried out [25-27].
- If the pain and dysfunction score does not go down after treatment during a hospital stay, the physician reliably knows that the treatment measures applied so far were insufficient and that he or she has to work out a better treatment plan. If the score goes down over a reasonable period of time, the physician

knows that his or her treatment protocol has been successful and has a reliable treatment for this patient.

- If the score goes down during a hospital stay, the physician can demonstrate improvement to the patient and can explain the purpose of the initiated treatment. For example, this may help to convince the patient that it is necessary to go to physical therapy on a weekly basis even after being checked out of hospital. This can help the patient's understanding of the physician's decision-making process [28-29].
- If the score remains high and all neurological therapy options are depleted, the neurologist now has a valid basis to discuss the case with neurosurgical colleagues and argue for the need of a discectomy.

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Case in Health Law

Bouvia v Superior Court: Quality of Life Matters

by Brian Liang, MD, PhD, JD, and Laura Lin, MBA

Introduction

Elizabeth Bouvia was a mentally competent, young, quadriplegic woman who suffered from cerebral palsy, leaving her completely bedridden and dependent on others to perform all her activities of daily living. Despite having a college degree, she was financially unable to support herself, did not have a stable living situation, and relied on public assistance for all aspects of her care. In 1983, at age 26, she expressed a desire to end her life [1]. Ms Bouvia then attempted to accomplish this by self-starvation in a California public hospital, an act which was widely publicized in the media.

A California court denied Ms Bouvia judicial assistance to starve herself to death and issued a court order allowing the hospital to commence force-feeding her by inserting a nasogastric tube [2]. After several unsuccessful attempts to find a publicly funded apartment with visiting nurses to provide care, Ms Bouvia once again became a patient in a public hospital, and in 1986 she was eventually transferred to High Desert Hospital (HDH), another public facility. When Ms Bouvia could no longer be spoon-fed without nausea and vomiting HDH inserted a nasogastric tube against her will to avert potential starvation. The medical staff acted against Ms Bouvia's wishes because of her life-threatening condition, her previous efforts to starve herself, and her prognosis which indicated she could survive an additional 15 to 20 years with adequate nutrition [3]. Her caregivers believed that the state's interests in preserving life compelled such an action.

Ms Bouvia sued the hospital and its staff, seeking a court order from the Superior Court of Los Angeles County, to have the nasogastric tube removed and to stop all medical measures to which she did not consent.

Disposition

The trial court denied Ms Bouvia's request, stating that her prognosis justified the state's interest in preserving her life. The court said that to rule otherwise would be tantamount to aiding and abetting suicide, since Ms Bouvia's motive for refusing treatment was to die. Ms Bouvia immediately appealed the trial court decision.

The appellate court acknowledged that a competent adult has the right, in the exercise of control over his or her own body, to determine whether and to what extent to submit to medical treatment [4]. A competent patient also has a basic and fundamental right to refuse any medical treatment, even if it may save or prolong his or her life [5].

Although the questions of refusing and withdrawing treatment are often considered in the context of terminal prognoses (which Ms Bouvia did not have), the right nevertheless exists under both the state and federal constitutions and is not limited to “terminal” patients [7].

Physicians may establish the medical diagnoses and prognoses of patients, but the competent patient is entitled to make the ultimate decision about what care will be rendered, with the “patients interests and desires...the key ingredients of the decision-making process” [7].

The court further recognized that a patient’s right to self-determination regarding medical treatment is based upon the patient’s being mentally competent and able to understand the consequences of withdrawal or refusal of care. The court noted that Ms Bouvia was mentally competent, understood the risks involved in refusing nasogastric tube feeding, and, hence, any objections to her refusal of the feeding could not be based on those grounds.

The hospital staff argued that the interests of the state should prevail over the rights of the patient to refuse treatment. Traditionally, viable state interests include: (1) preserving life, (2) preventing suicide, (3) protecting innocent third parties, and (4) maintaining the ethical standards of the medical profession, including supporting the right of physicians to effectively render necessary and appropriate medical services.

The court decided that these interests, although valid, were insufficient to overcome Ms Bouvia’s right to refuse medical treatment. The appellate court concluded that the trial court had erred in deciding that, just because Ms Bouvia could live an additional 15 to 20 years with sufficient feeding, the state’s interest in preserving her life for that period prevailed over her individual right to autonomy. The appellate court emphasized that the trial court’s focus on the potential additional *years* of life available to Ms Bouvia without considering her *quality* of life during those years had been erroneous. Indeed, quality is an equal, if not more significant, consideration to be weighed by the court.

The appellate court noted on this basis, that it is not the policy of the state to preserve every life. In this case, if treated against her wishes, Ms Bouvia would have to endure 15 to 20 years of a severely diminished quality of life. The court stated that “[i]n Ms Bouvia’s view, her quality of life has been diminished to the point of hopelessness, uselessness, unenjoyability, and frustration. She, as the patient, lying helplessly in bed, unable to care for herself, may consider her existence meaningless” [8]. Since it is “patient’s interests and desires [that] are the key ingredients of the decision-making process,” the court concluded the decision to forgo medical treatment belonged solely to Ms Bouvia [9]. As an important component to her perception of a high quality of life, Ms Bouvia had the right to live out the remainder of her life in dignity and peace as she herself defined it.

The appellate court also addressed the issue of suicide, holding that Ms Bouvia’s decision to exercise her right to refuse treatment and accept the consequences of that

refusal was not equivalent to an election to commit suicide with the hospital staff aiding and abetting this act [10]. The appellate court ruled that no assessment of the “motive” behind Ms Bouvia’s decision should be performed, and the trial court had been wrong to do so. The appellate court noted that Ms Bouvia could exercise her right to refuse medical treatment regardless of her motive, and no criminal or civil liability would attach to caregivers when honoring a competent, informed patient’s refusal of medical services [11]. However, the court stated that the hospital and staff were free to provide the care to which Ms Bouvia consented, such as alleviation of her pain.

In sum, the appeals court reversed the trial court’s determination and held that Ms Bouvia had the right to have the nasogastric tube removed because: (1) she had a fundamental right to refuse medical treatment; (2) her rights superseded the state’s interests; (3) quality of life was a valid and essential consideration; and (4) fulfilling the patient’s desire to refuse treatment was not equivalent to assisting the patient in committing suicide. After the appellate court’s ruling, the feeding tube was removed and Ms Bouvia was eventually discharged from the facility. In the months that followed, Ms Bouvia continued to lose weight and suffer increasing discomfort from arthritis and other ailments [12]. She then entered a private convalescent hospital, agreeing not to attempt starvation [12].

As a postscript to the case, Ms Bouvia’s attorney and personal confidant, Richard Scott, who led the high-profile fight to give Ms Bouvia the right to refuse treatment, committed suicide 6 years after the decision. Ms Bouvia indicated then that she still wanted to die, but, after receiving pain control for secondary diagnoses, the process of starvation proved too physically painful to carry out. Although she considers herself a “reluctant survivor” and living the life she dreaded, she is still alive today [19].

Commentary

The 2 medical ethics principles of respect for autonomy and beneficence inevitably conflict at some point. The principle of respect for autonomy directs that a patient’s wishes should be honored, including those regarding the nature and extent of his or her health care, while beneficence binds the physician to provide care that promotes the patient’s well-being, including the relief of suffering and the preservation of life [13]. As long as the patient’s wishes are reasonably established, courts usually follow the principle of autonomy when conflict occurs. As seen here, the appeals court upheld Ms Bouvia’s right to make her own medical decisions by requiring the hospital and staff to respect her desire to refuse nutritional treatment while continuing the pain control to which she had consented.

The *AMA Code of Medical Ethics* Opinion 2.20 addresses this conflict between respect for autonomy and beneficence:

The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the preferences of the patient should prevail. The principle of patient autonomy requires that physicians respect the

decision to forego life-sustaining treatment of a patient who possesses decision-making capacity [14].

Hence, the ethical focus in such a conflict should always be on a competent patient's preferences as expressions of his or her autonomy. This means that physicians must understand the wishes and desires of the patient, particularly when it comes to implementing advance directives or the use of health care proxies [15]. The *AMA Code of Medical Ethics* further indicates that quality of life is of specific concern in ethical decision making. Opinion 2.17 states that:

[i]n the making of decisions for the treatment of...persons who are severely disabled by injury or illness, the primary consideration should be what is best for the individual patient and not the avoidance of a burden to the family or to society. Quality of life, as defined by the patient's interests and values, is a factor to be considered in determining what is best for the individual [16].

The opinion goes on to state that quality of life can be considered "when deciding about life-sustaining treatment" [16]. Again, this standard highlights the need for physicians to have excellent communication and relationships with patients so they can understand their interests and values about quality of life in order to carry out the patient's wishes most effectively.

Although Opinion 2.17 stipulates that quality of life should be "a" factor to be considered, it should, in fact, be the *overriding* factor of concern to clinicians. As the court stated about Ms Bouvia, "[s]he herself is imprisoned and must lie physically helpless subject to the ignominy, embarrassment, humiliation, and dehumanizing aspects created by her helplessness" [17]. Only Ms Bouvia could understand what such a prospect meant to her quality of life, and only through her decisions and communications with her caregivers could she express that understanding. As the court stated, it is not, and should not, be the policy of any care provider, "[t]hat all and every life must be preserved against the will of the sufferer" [18]. Unfortunately, although acting in good faith, Ms Bouvia's caregivers were attempting to do just that.

Finally, it should be emphasized that quality-of-life considerations and withdrawal of treatment do not, in themselves, constitute physician-assisted suicide or voluntary active euthanasia. A patient's right to refuse or to withdraw from medical treatment, even at the risk of causing his or her own death, is not only constitutionally protected on the state and federal level, but is ethically distinct from active and knowing efforts to end life. Patients who refuse or discontinue life-sustaining treatment are not committing suicide, but dying—or accepting death—caused by the underlying disease. Hence, physicians who honor their patients' wishes to forgo life-sustaining treatment are not assisting in their patients' deaths.

Overall, the patient's own wishes and best interests must always be considered when deciding on any treatment. It is imperative that this assessment be made when patients refuse treatment. In these situations, assessment must include a strong deferral to the patient's perspective regarding his or her quality of life. This is simply another

expression of patient advocacy and respect for patient autonomy. Through high quality, continuous communication, and trust between the patient and the physician, the expression of the patient's wishes—and the best interests of the patient—can occur both in treatment and treatment refusal situations.

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Policy Forum

What's Wrong with Quality of Life as a Clinical Tool?

by John Wyatt, MD

The concept of measuring a patient's quality of life (QoL) has obvious attractions to clinicians. It seems to be an objective, scientific, and quantitative tool to assist in deciding complex clinical and ethical dilemmas in daily practice. Its use has been promoted in many areas of medicine—from prenatal screening to do-not-resuscitate (DNR) decisions at the end of life.

In this brief article I shall try to sound a health warning. I shall argue that the concept of measuring QoL is fatally flawed, and that, in its current form, it represents a misleading and potentially dangerous avenue for clinical ethics in the context of contemporary social and political pressures.

An Incoherent Concept

Firstly, the concept of measuring QoL is fundamentally incoherent. It is assumed that, by performing an assessment across a series of domains such as material, physical, social, emotional, and productive well-being, a single quantitative score can be obtained [1]. But comparing these different aspects of a human life and assigning an equal weight to each is like comparing apples with oranges. How can you rank the inability to walk more than 10 metres on the same scale with the value of an emotionally close and intimate relationship? How about ranking a moderate deficit in attention compared with outstanding musical abilities? The British philosopher Isaiah Berlin emphasised that, within any one life, each of us has competing values, desires, and goals that cannot be ranked against each other—they are incommensurable, to use philosophical jargon [2]. The attempt to rank one person's experience or values against another's is fraught with similar difficulty. When we try to compare the value of certain components of well-being for individuals from different cultures, it becomes even more obvious that any attempt at quantitative ranking is futile.

It is particularly absurd to attempt to rank the “goods” of human life in some kind of hierarchy. Is physical well-being more important than emotional well-being? Is creativity more important than perfect sensory functioning? Is it possible to have any consensus within our own society on these issues?

Furthermore, our values change as we go through life. To children, physical pain associated with medical procedures may rank as a greater harm than a future loss of fertility. In adolescence, body image and peer group relationships may dominate one's priorities. To an elderly person, social isolation may be seen as a greater loss than cognitive impairment. The concept of QoL rankings becomes even more problematic

when it is used in prenatal screening to predict and put a value on the future life experiences of a fetus that is not yet born.

Each person's experience of living is unique, profoundly complex, constantly evolving, and continually modified by relational and social influences. QoL is not a "thing"—a biological variable which can be measured like plasma sodium or Apgar score.

Misleading

Because the QoL concept is flawed, the use of QoL measures in clinical practice can be misleading. Their use assumes that a physical handicap such as impaired neuromotor function translates automatically into a loss of well-being or satisfaction. Yet many disabled people say that the main problem in their lives is not their functional impairment but social attitudes and political responses to their disability [3]. The question, "Are you able to use the local transport system?" could be rephrased, "Has the local transport system been adapted to meet your requirements?" A reduced QoL score may tell us more about social and political attitudes than about an individual's potential for well-being.

Secondly, when applied at the beginning of life, QoL assessment is always based on some probabilistic or statistical element. Can I, as a neonatologist, predict how an extremely preterm baby will feel about life as an adult in 20 years time? It is obvious that this kind of prediction is fraught with assumptions and incalculable factors, and yet these huge uncertainties are obscured in the apparent quantitative precision of QoL measures.

Thirdly, advances in neurobiology that are already starting to enter clinical trials, point to the remarkable plasticity of the developing CNS and brain repair strategies. A poor QoL assessment at the beginning of life tends to promote a pessimistic fatalism amongst clinicians and parents alike. Moreover, a predicted low QoL ignores the effective therapeutic and adaptive strategies that are likely to become available over the next decade and beyond and can easily become, instead a self-fulfilling prophecy.

Underlying Philosophical Assumptions

Although QoL appears to be an objective and "value-free" idea, some philosophers believe that the concept can never be separated from an underlying value system or worldview. The questions which comprise a QoL assessment conceal, but do not eliminate, value judgements about the goals, purposes, and "goods" of human life. By not allowing different goals or ideas to have more weight than others, this system forces a utilitarian point of view. In particular these assessments tend to form an ethical calculus where the "positive value" of one life outweighs the "negative value" of another within a population. By contrast, orthodox Christian and Jewish philosophy emphasise the intrinsic value and dignity of each human life, irrespective of different abilities and capacities. In the Judaeo-Christian worldview the value of human life resides in the stuff of our humanity, as beings made in God's image, with no form of ethical calculus that allows us to compare the ultimate value of one life against that of another or to reject one life in favour of another. This perspective was well summed

up by Joseph Pieper, “Love is to say to a person, ‘It’s good that you exist. It’s good that you are in the world’” [4].

Dangers

Finally, I believe that QoL measures are dangerous because of their potential for abuse by political, social, and economic agendas within our society. The concept of a low QoL can perpetuate negative prejudices about the experiences of disabled people and may encourage a eugenic desire to eliminate people with any QoL-reducing impairment from our community. In an economic environment with rocketing health care costs, any approach which can reduce on-going health expenditures is attractive. The danger is that QoL subtly shifts the obligation for improving resources for disabled people away from politicians and economists and puts, on clinicians and parents, the responsibility to ensure that people who are likely to be disabled are not brought into the world or, at the very least, that they accept the consequences of their impairments without expecting legal, social, or economic support. I believe that we, as clinicians, should resist that responsibility and give it back to our democratically elected political leaders. Clinicians are called to act with wisdom, care, transparency, and humane judgement in our dealings with patients and parents. We must resist the concept that medicine is a form of social engineering.

Conclusion

Are there any alternatives to the use of current QoL measures? It is obviously important for clinicians to be concerned about the subjective experience and well-being of their patients, and questionnaires and tools designed to assess subjective well-being may be extremely valuable. I think, however, that we should resist the suggestion that subjective experience can be translated into any form of comprehensive assessment of life quality. We may be able to judge whether a treatment is worth giving, but we can never judge whether a life is “worth living.” Perhaps, as clinicians, we need to relearn how to say to each of our patients, whatever their degree of disability, “It’s good that you exist. It’s good that you are in the world” [2].

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Policy Forum

The Oregon Plan and QALY's

by Fritz Allhoff

The Oregon Plan

In 1989, the state of Oregon began work on a controversial plan for the allocation of health care resources. The goal, noble enough, was to provide Medicaid benefits for *more* people than had previously been covered. But how? One option would obviously be to raise more money for health services, though the corresponding tax increases would have been unpopular. Oregon chose another approach: to make *fewer* services available to an enlarged pool of Medicaid recipients. So, by restricting services, they could afford to grant access to *more* people.

This plan instantly gave rise to controversy. Liberals accused this system of discriminating against the poor, specifically women and children who are most likely to use the program, since Medicaid would not cover certain treatments for them [1]. These criticisms were at least partially misguided since there was not *necessarily* any reason to believe that private health care would provide better financial coverage than Medicaid, though the former did tend to cover more medical services. Regardless of the controversy, we can still ask whether this plan is morally defensible. If the goal was to maximize coverage to the poor, it could be reasonable to think that this would be best accomplished by expanding coverage to *more* people even if this required restriction of some (potentially exotic and esoteric) treatments to some patients. Of course, we might think that, in an ideal world, *all* needed treatments should be provided for *all* patients but, given the political and economic realities, the Oregon plan sought a responsible rationing system.

What Is Covered?

Once Oregon came up with its plan, it had to determine which treatments to cover and which to exclude. The mission of the plan, to provide fewer treatments to more people, now needed teeth. How were they to decide what to cover and what not to cover? In 1991, Oregon developed a list of more than 700 diagnoses and treatments and ranked these in order of merits. For example, "Diagnosis: severe or moderate head injury, hematoma or edema with loss of consciousness; Treatment: medical and surgical treatment" was ranked at the top of the list and "Diagnosis: mental disorders with no effective treatment; Treatment: evaluation" was ranked near the bottom (#741) [2]. The state then decided it would extend Medicaid coverage for treatment of the top 587 items, though this list and the cutoff point has shifted slightly over the years. If the diagnosis/treatment for a particular patient was above the cutoff line,

which is currently at about 578, the treatment would be covered and, if not, coverage would be denied.

The fundamentals of the system should now be clear, except for the obvious question: how were these diagnoses/treatments ranked? What factors, for example, led to the determination that a given diagnosis/treatment was #231 and would be covered while another was #612 and would not? First, the commission established 17 categories of health problems, such as “conditions that can be fatal and for which treatment provides full recovery, acute conditions that are treatable and unlikely to be fatal, maternity and newborn services, and preventive care of proven efficacy” [3]. After diagnoses and treatments were assigned to 1 of these categories, the categories were ranked according to 13 criteria which included: life expectancy, quality of life, the cost and effectiveness of a treatment, and whether it would benefit many people. Treatments that prevented death with a full chance of recovery were ranked first, maternity care was ranked second, treatments that prevented death but did not guarantee full recovery were ranked third, and treatments that led to minimal or no improvements in quality of life were ranked last [3].

QALYs

While any of these elements could warrant further discussion, let's focus on quality of life and life expectancy, the theme of this month's *Virtual Mentor* issue. “QALY” represents “quality-adjusted life years,” and the idea is that life expectancy should be weighted to reflect the quality of life that would be experienced. For example, if treating a patient would lead to a life expectancy of 20 years with a high quality of life (eg, hypertension, which only requires daily pills and rarely manifests negative symptoms), coverage for this patient's treatment should presumably have priority over treatment for a patient who would have a life expectancy of 20 years with a comparatively low quality of life (eg, diabetes, which requires daily injections and often manifests symptoms such as neuropathy, blindness, etc). Conversely, *ceteris paribus*, longer life expectancy should be given priority over shorter life expectancy. Where there is a quality-of-life difference, we might adopt a “quality-of-life coefficient,” ranging between 0 and 1, which could be multiplied by life expectancy to yield QALYs, and we could then prioritize treatments that would promote the maximization of QALYs.

While life expectancy is an objective, biological assessment, measuring quality of life is more challenging. Remember that this measurement is going to be *central* to the legitimacy of the Oregon plan since the quality-of-life coefficient plays a substantial role in the determination of QALYs, which in turn are one of the elements that leads to rankings of treatments/diagnoses. This quality-of-life coefficient has the potential to determine which treatments are going to be covered and therefore is of tremendous importance.

First, let's look at what the Oregon plan commission actually did (through a series of 50 community meetings attended by those in a range of health states): the commission had to consider the quality of life that would attach to any specific diagnosis and an associated treatment. A quality-of-life assessment, unlike a life-expectancy assessment,

is necessarily *subjective* since it reflects the merit (as experienced by the patient) of a life in a specific state. The commission, through community feedback, had to determine the subjective values of various lives (eg, one with diabetes versus one with leukemia), and this is certainly an onerous project. In many cases, the assessments might be obvious, but, in others, they could be less so. Imagine, for example, assessing the quality of life after a leg amputation for an avid runner versus assessing it for a comparatively sedentary individual: presumably the former would suffer more than the latter, and therefore his quality of life might be comparatively lower. Since the Oregon plan ranked health care outcomes based upon generic suppositions, it was not able to be sensitive to such considerations.

One criticism offered against the commission's ultimate rankings was that the invocation of quality-of-life assessments discriminated against the sick and handicapped by saying that their lives were less valuable than those of healthy persons. It could be argued that healthy persons might discount the worth of sick or handicapped lives *more* than the sick or handicapped would discount their own lives because the former group might find the latter group's condition more depressing than those in that state find it. If so, the commission's procedures might be viewed as problematic insofar as healthy people rendered at least part of the assessments and therefore unfairly discounted the lives of the sick and handicapped.

However, I think that we can show that this criticism is misguided: it is only the *relative* assessments and not the *absolute* ones that count because, ultimately, all that matters is the *ordering* of treatments/diagnoses since Oregonians will presumably fund as much as they can afford to without considerations for absolute welfare. Imagine, for example, that a healthy person rates a certain health care outcome with a quality-of-life coefficient of 0.6, and that a person with that outcome rates the quality-of-life coefficient as 0.8. Would these disparities discriminate against the sick and handicapped? Arguably not, because the lower coefficient would not lead to an outright denial of treatment, but merely a lower QALY assessment. So long as these assessments were rendered *consistently* (even if comparatively lower than other procedures would produce), the overall rankings of treatments/diagnoses would be *unchanged*. In other words, the "healthy-person bias" would be present in *each* ranking and, therefore, would make no statistical difference to the comparative ordering; it would cancel out.

Conclusion

While there are some elements of the Oregon plan that might be criticized, the plan as a whole has a certain intuitive appeal. The proximate goal of the plan was to make Medicaid available to more people and, given budgetary and political limitations, this goal was realized by cutting some services which were judged to be expensive or inefficacious, to produce small or no gain in quality of life, to lead to small or no gain in life expectancy, etc [4]. While I surveyed the system as a whole, its incorporation of QALYs has been my focus: quality of life and life expectancy were 2 of the elements used to rate the merits of various treatment strategies. Quality-of-life assessments are intrinsically subjective and are not without moral hazards, but the Oregon plan

arguably takes a responsible attitude toward these considerations or, at a minimum, concludes with defensible results.

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4. Another point worth noticing is that many treatments which fell below the cutoff line were nevertheless covered because Medicaid uses a capitated payment system rather than fee-for-service. In many cases, it was cheaper for health care providers to pay for non-covered treatments which would restore patients to full health rather than to provide covered but less effective treatments which would require the patient to make indefinite or perpetual visits

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Policy Forum

Some Ethical Corrections to Valuing Health Programs in Terms of Quality-Adjusted Life Years (QALYs)

by Erik Nord, PhD

Introduction

Health benefits resulting from preventive or curative interventions may be valued in terms of gained personal utility (improved quality of life) for the individuals concerned. These personal utility gains may be aggregated over time by weighting each affected year of life by the size of the utility gain in that year and adding the weighted years together. The result is an estimate of the value of health benefits in terms of quality-adjusted life years (QALYs).

Most Salient Ethical Problems in Use of QALYs

A question raised by many over the last 15 years is whether health benefits valued in this manner adequately represent the way society values health benefits across different groups of people. Three particularly salient ethical problems have been identified, related to the fact that the QALY approach focuses wholly on quantifying *utility gains*, with no regard to contextual factors and fair distribution of beneficial interventions across different groups [1].

The first ethical problem arises from the fact that QALYs pay no attention to the '*without-intervention-utility-level*' of the individuals concerned. But ethical theory and public opinion in a number of industrialized countries suggest that, in setting priorities for programs and their recipients, society values utility gains expressly on this factor—how bad off the individuals would be if intervention did not take place [1]. That is to say, the worse off an individual would be without a specific intervention, the more highly society tends to value that intervention [2]. The latter way of reckoning is often referred to as an *independent concern for severity*.

Second, valuing health benefits in terms of QALYs strongly favours those with greater capacity to benefit. But here again, ethical theory and public opinion in a number of industrialized countries suggest that, for *groups with the same severity of illness*, society does not wish to give strong priority to those with greater capacity to benefit over those with lesser capacity to benefit, as long as the benefit is substantial in both groups [2].

Third, valuing health gains in terms of QALYs means that life years gained in full health for the otherwise healthy—through prevention of fatal accidents, for example—are counted as more valuable than life years gained by those who are chronically ill or disabled. This conflicts with the idea of an equal right to protection of

life by all, irrespective of their health condition, as long as they themselves have the desire to live [2].

Possible Answers

A solution to the first 2 of these problems is to expand conventional QALY calculations by introducing equity weights to capture differences in illness severity (ie, employ an independent-concern-for-severity approach) and reduce discrimination against those with a lesser capacity to benefit [3].

Another solution is to do an appropriate mathematical transformation of utility measures that derive from a family of QALY-oriented health questionnaires called Multi-Attribute Utility instruments (MAU). These instruments establish a multi-dimensional health profile for each person in a given study group and an algorithm that translates the profiles into a single utility score on the 0-1 scale used in QALY calculations (where 0 = death and 1 = full health). Utilities from MAU instruments can then be transformed into societal weights—valuations of health states that take into account not only disutility of illness and disability from a personal perspective but also the societal distributive concerns mentioned above, ie, society's interest in giving priority to the worst off and its non-discrimination against those with lesser capacity to benefit. In health state valuations consistent with societal concern, scores for severe problems are much higher than 0, and scores for moderate problems are compressed to the upper end of the 0-1 scale. This has 2 consequences. First, it reduces the value of improvements for the moderately ill relative to improvements for the severely ill and, particularly, relative to preventing death. Second, it reduces the value of large improvements relative to small improvements when comparing groups with different capacities to benefit—groups for whom medical technology happens to have different degrees of curative potential.

By way of example, consider the states “blind” and “very near sighted.” Assume that MAU instruments assign them utility scores 0.4 and 0.8 respectively. Assume further that these scores are transformed into societal weights of 0.7 and 0.95 respectively. Three effects may be observed. First, the transformation reduces the value of curing nearsightedness relative to curing blindness (from 0.2 / 0.6 to 0.05 / 0.3). Second, the value of both these cures is reduced relative to preventing fatal illness (eg, for blindness from 0.6 / 1.0 to 0.3 / 1.0). Third, the value ratio between (a) bringing a person from blindness to normal vision and (b) bringing a person from blindness to “very near sighted,” is reduced (from 0.6 / 0.4 to 0.3 / 0.25).

A potential solution to the third problem is to count as 1 all life years gained as long as they are desired by the individuals concerned [1]. This has been labelled the “equal value of life” approach (EVL) [4]. Swedish health economist Magnus Johannesson has argued that EVL may lead to societal choices that violate a given individual's preference for quality of life years over quantity of life or vice-versa [5]. I believe Johannesson is right, but I think the inconsistency to which he refers is not specifically related to EVL. Rather, it may be seen as an inevitable consequence of the fact that human preferences change as the context in which the choice is made changes. That is, the decision any individual makes for him or herself may differ from the decision he

or she makes when contributing to collective decisions about health policy where distributive fairness is involved.

Other Ethical Issues

British health economist Alan Williams has argued that, rather than introducing concerns for severity into QALY calculations, one should consider life time health, so that QALYs for people who have already had a reasonable number of life years and health—which Williams calls “fair innings”—should count less than QALYs for people who are looking at below-average lifetime health [6]. With respect to gains in life years beyond the age of 75-80, this is arguably a fair proposal. There may thus be a case for supplementing conventional QALY calculations with some kind of age weighting in health program evaluations that purport to take societal concerns for fairness into account. But when applied to gains in *quality of life* in old people, Williams' proposal is far more problematic. In countries like Norway and Sweden, there is widespread consensus that older people have the same right to relief of pain and discomfort as young people, even those who are past their fair innings in terms of length of life [7]. I would assume that most other countries are no different in this respect.

A final ethical concern is that the conventional QALY approach to resource allocation does not ask whether a particular gain occurs as a substantial benefit to a few or as small improvements to a large number of people. To my knowledge there is not much empirical evidence of societal preferences on this issue. But one could relate this issue to the point made above that most people seem to think that the size of the health increase should *not* be given too much weight when comparing people with different capacities to benefit from an intervention, as long as the people in question have the same severity of illness and the benefit is deemed substantial in every case. One way of interpreting this ethical view is to say that there is diminishing marginal societal value of health increases. This again would lead to the view that a given total QALY gain should be assigned greater societal value if it is distributed among many rather than concentrated on a few. I stress that this is assuming that severity of illness is the same.

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Policy Forum

Quality of Life as the Basis of Health Care Resource Allocation: A Philosopher's Perspective on QALYs

by Richard E. Ashcroft, PhD

The concept of the quality-adjusted life year (QALY) provides a simple technical tool for summarising the impact a medical condition has on someone's life and the impact a health care intervention can have on that medical condition. In the former case, QALYs (and related concepts, such as disability-adjusted life years, DALYs) have been useful in producing summary statistics on the burden of disease, while, in the latter case, QALYs are commonly used in evaluating the effectiveness of health technologies [1-4]. In particular, the QALY is at the heart of initiatives such as the UK 's National Institute for Clinical Excellence (NICE), which provides detailed cost-effectiveness evaluations of medical interventions and technologies [5].

The QALY is not a rationing tool on its own, as its use in burden of disease studies shows. It was developed to assist in decision making about health care resource allocation, and this remains its best known application. From the very beginning it has been controversial, but when handled with care, the concept of QALY can be useful.

First, consider a patient who can be treated with either of 2 interventions. There are many ways to choose which intervention to use. Evidence as to which of the 2 gives the patient the greater number of expected QALYs would be helpful. How this information should be used in practice can be controversial, however. If a particular treatment is greatly superior to the other in terms of QALYs added, the temptation to offer only this treatment is strong, since it would appear that no rational person would choose the less-effective treatment. Yet, because QALYs combine length of life with quality-of-life measures, we may be prejudging trade-offs between factors that affect quality of life, and the patient in front of us may choose differently. This becomes still more difficult if we consider cost-per-QALY gained, rather than merely QALYs gained, as the choice criterion.

Secondly, in the case of chronic illness or disability, time becomes important, and we need to consider the preference a person may have for a year of life now as compared to a year of life in the future. People's "time preferences" differ, and, in particular, the patient's time preferences may well differ from those of her physician. Notwithstanding these and similar difficulties, QALYs can provide useful information for patients who are making choices from among various treatment options [6].

Typically, however, QALYs are not directly used in patients' own decision making, but, rather, they assist in 1 of the following kinds of choice:

- How to allocate a scarce treatment among patients.
- How to allocate a limited budget among different treatments or services.

In either case, QALYs can be used independently or combined with cost data to give estimates of cost-per-QALY gained by each intervention, or by each intervention as assigned to each patient.

The debate about using QALYs to allocate treatments among patients is well known: controversy surrounds the questionable objectivity of the quality-of-life measurement, the ethics of discriminating between patients on age grounds alone, and the lack of sensitivity to equity considerations (even allowing for so-called equity weights) [3]. To all of this, however, the QALY supporter can say: fine, tell me what you want to incorporate into the measure, and I will find a way to do so. Or, more belligerently, she might say, fine, if you don't like QALYs, how *do* you want to prioritise scarce resources and expensive treatments [4]?

Where the QALY approach really gets contentious is in allocating budgets to different classes of treatments. There are 2 problems here. Well known is the problem of choosing between costly but life-saving treatments on the one hand and cheap, high volume, but merely quality-of-life-enhancing treatments on the other. Ongoing controversy exists as to whether the so-called “rule of rescue” can or should be built into decision-making rules. The “rule of rescue” holds, roughly, that where a life can be saved, we should aim to do so, and this should take priority over questions of cost or efficiency. It is frequently invoked in neonatal intensive care, for instance. This is a difficult problem, but it would be premature to assume that it cannot be solved, possibly by use of equity weights or, more likely, by supplementing the QALY approach with a more explicitly normative framework for decision making, such as Daniels and Sabin's “Accountability for Reasonableness” framework [7]. Such an approach uses QALY information as a single source of evidence, only to be supplemented with explicit deliberation over values by stakeholders.

A more serious problem concerns which treatments to rule in for QALY assessment and comparison. An interesting example is medical treatment for infertility, recently considered by NICE [5,8]. The NICE economic evaluation of such treatment explicitly excluded “social” infertility (ie, inability to conceive due to the patient's being single or in a homosexual partnership, in contrast to medical infertility which is due to some biological pathology or deficiency). This raises the interesting problem that we would face if allocating in vitro fertilisation (IVF) to only 1 of 2 women, 1 of whom was single, medically healthy, and 25, and the other of whom was married, 42 years old, and medically infertile. The younger woman would have a greater chance of successful implantation and pregnancy and probably a longer lifespan ahead of her to enjoy raising her child. From a QALY point of view, it appears relatively obvious how we should assign treatment; from a social point of view this may not be the case. Opinions will differ about who would be a “better” mother (and what counts as

“good” in this context), but at least some people would believe that the older woman was a more deserving recipient of treatment, notwithstanding her lower probability of a successful pregnancy and her shorter life expectancy from the present.

Secondly, the NICE evaluation explicitly rules out consideration of the *child's* quality of life, although in this instance NICE did not use QALY criteria, but only “success” criteria (birth of a child following treatment). But a QALY evaluation of IVF would presumably consider the mother's quality of life together with that of the child and perhaps that of the partner or other near relatives. This presents an interesting problem: part of the rationale for QALYs is the pursuit of an objective allocation criteria to escape the legacy of early “social” criteria for treatment allocation (such as or merit or number of dependents), but in this situation, a “social” criteria almost inevitably becomes a factor [2]. The point of an allocation scheme such as the QALY is that it is to be objective by being independent of the preferences and prejudices of the allocator. QALYs certainly are independent of such *personal* biases, but are nonetheless value-laden both structurally (an in-built bias toward the young, for instance) and in how they are used (who and what is counted). The advantage of QALYs is that, as a formal, yet empirically informed, framework, such value-loadings can be inspected and debated.

The IVF example illustrates that many interventions can have an impact on quality of life and that these need not be medically necessary or essential interventions, and so we need to have a non-arbitrary criteria for ruling in particular interventions for consideration. It also illustrates that we need to have rules about *whose* quality of life is to be counted and, if the quality of life of the unborn is to be counted, how it is to be estimated. But finally, it is far from clear how to compare QALYs in the infertility context with QALYs derived in the context of, say, coronary artery bypass grafts (CABG). Even if we could show that the impact of a CABG on the health, quality of life, and life expectancy of a 50-year-old was numerically comparable to that of IVF on the health, quality of life, and life expectancy of an infertile person, it is debatable whether we are really comparing the same kind of thing. This is not to deny that infertility is morally important, or psychologically deeply distressing, or that it can have a medical basis and medical sequelae, but it raises the question of whether “medically needed” and “medically desired” can use the same scale. One way to see this is to consider human well-being from within Amartya Sen's capabilities model: infertility treatment addresses a different capability from that addressed by CABG surgery [10].

The argument I have sketched here is that, while we need decision criteria for rationing, and the QALY is useful in framing them, it will need to be supplemented both explicitly by other rules and more subtly by an understanding of what is being measured and the implicit value judgements that underlie assumptions about what can be compared with what, and whose judgements count. These additional considerations should include changes in both the procedural rules (about who is invited to deliberate over decision criteria or specific decisions) and possibly substantive rules (for instance, the rule of rescue, rules about where to draw the line between health-and-non-health-related interventions, or the “fair innings” rule discussed by Alan Williams. According to Williams each of us has a certain reasonable expectation about lifespan and

entitlement to resources, and when we exceed this expected length-of-life, we should allow others younger than ourselves to have priority in the allocation of resources) [11]. Nonetheless, as Nicholas Rescher argued a generation ago, probably *no* allocation scheme is perfectly efficient or perfectly fair [12]. QALYs should be taken on their own merits—and with a pinch of salt.

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Medicine and Society

Medicine Goes to the Mall: Enhancement Technologies and Quality of Life

by Carl Elliott MD, PhD

Over the past several decades we have seen the emergence of 2 related movements in American health care. The first is an emphasis on improving patients' quality of life. The term "patient" is arguable here, however, because the quality of life in question is not necessarily that of people who are sick. A growing number of medical technologies are employed to improve the looks, performance, and psychological well-being of people who are healthy. Over the past decade or 2 we have seen the development of Paxil for shyness, Rogaine for baldness, Viagra for impotence, Provigil for sleepiness, Adderall for poor concentration, Meridia for excess weight, Botox for wrinkled faces, Humatrope for short stature and Sarafem for premenstrual discomfort—and that short list does not even include the tools in the surgeon's kit, that include rhinoplasty, blepharoplasty, breast augmentation, or ETS surgery for blushing or excessive sweating. Prescription drugs and surgery are not just for sick people anymore. They are for anyone who has a willing physician, good health insurance, and a robust checking account.

The second (and related) movement is the submission of the American health care system to the machinery of consumer capitalism. This is not just a matter of the rise of managed care corporations, for-profit hospital chains, and direct-to-consumer drug advertising. It is a change in the ethos of medicine. American doctors and patients are viewing medical care as a market commodity provided to consumers who are able and willing to pay for it. Now that a market model has taken over, the practice of medicine has become driven not just by what patients need, but also by what consumers want.

In a sense, this shift aligns the ethos of medicine with that of American society as a whole. Many of us now see our identities as projects to be shaped and improved by the things we consume [1]. We buy clothes, houses, cars, and other consumer goods with the expectation that they will express something about our identities. Who we are is reflected by what we own. We also measure the success of our lives through the quality of our experiences, which we also shape through what we buy. For many Americans, the "good life" is a synonym for more and better entertainment, leisure activities, and vacations. Now that medicine has moved into the market economy, it should not be surprising that we would come to think of the tools of medicine not merely as a means to relieve illness and disability but as ways to improve our quality of life.

Once the success or failure of a life is determined solely by the quality of its experience, the shape of that life changes in at least 2 subtle ways. First, the end point for success becomes less clear because there is no cap on just how high our quality of

life can be. We envy people whose quality of life seems better, but we have no reliable way of comparing our quality of life to theirs. This can create the sense of life as an endless race in which one is constantly falling behind [2]. Second, we become hungry for experts to advise us on how our quality of life can be improved. As a result, America has produced a cadre of specialized experts who tell us how to improve our sex lives, increase our financial well-being, produce psychologically healthy children, live longer, make friends, and lose weight [3].

Such experts now include physicians, whose domain of expertise has expanded from the physical to the psychological and social. Today it is seen as entirely fitting and proper for physicians to employ medical technology to remedy the social and psychological problems of stigma, alienation, and poor self-esteem.

Cosmetic surgery is a good example of this shift. At the beginning of the 20th century, cosmetic surgery was a largely marginal practice, performed mainly by quacks and hucksters. Yet by the end of the 20th century, cosmetic surgery had become a multi-billion dollar business. Today it has its own professional societies, and it is practiced by reputable surgeons in elite medical centers.

A key turning point, according to historian Elizabeth Haiken, was the notion of the “inferiority complex,” which emerged from the writings of the psychologist Alfred Adler in the 1930s and 40s [4]. Once Americans began to take on the idea that people could be psychologically damaged because of the way they looked, surgeons had an ethical justification for performing cosmetic surgery. Cosmetic surgery was not merely a matter of aesthetics; it was a medical treatment for the inferiority complex. Haiken calls this practice “psychiatry with a scalpel” [4].

American physicians today use a similar rationale for all varieties of medical enhancement. Medical procedures that used to be seen as cosmetic are now employed to treat the psychological damage that may result from social stigma or poor self-esteem. Pediatricians give short boys synthetic growth hormone to treat the stigma of short stature; dermatologists inject Botox into middle-aged foreheads to treat the stigma of aging; internists prescribe Rogaine to help aging men overcome the stigma of baldness; surgeons perform breast augmentation to prevent the stigma of having small breasts. This is not “psychiatry with a scalpel” as much as “sociology with a scalpel.” Doctors cannot fix social conditions, so they “fix” the patient instead.

In this way, medical enhancement is ideally suited for the market. The market produces images of beauty against which young women measure their own looks; then it sells these women remedies such as breast augmentation and diet drugs. The market creates the conditions for alienation with soulless exurbs, like shopping malls and 24-hour cable TV; then it treats the alienation with Valium and Zoloft. The market reinforces the stereotypes that make many racial minorities feel ashamed of the way they look; then it produces skin lighteners, hair straighteners, and cosmetic surgery to make the minorities look more like the white majority. And so the circle is complete. The market creates the conditions for which it then sells a cure.

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