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The Well-Year of Life as a Basis for Patient Decision-Making

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Medical decision-making requires the integration on costs, risks, and benefits of treatment. Clinical side effects and benefits are typically expressed in terms of symptoms and clinical states of diseases. Integrating probabilistic information about different categories is often difficult from both the patient's and the clinician's perspectives. We offer a General Health Policy Model that expresses the benefits and side effects of treatment within a common unit. The model takes into consideration mortality, function (morbidity), and preference for health states. In addition, the model uses probability information to describe the prognosis or likelihood of transition among states over the course of time. The output of the model is a well-year which is defined as the equivalent of a completely well-year of life. The well-year is a comprehensive expression of benefits minus side effects that may be useful for individual patient decision-making.

Key words: decision-making; well-year; quality of life; cost/effectiveness.

Introduction

Decision analysis is a process of organizing information so that systematic rules can be applied to the decision process. Medical decisions are often complex, since they frequently involve information about various treatment alternatives, each with its own associated probabilities of positive benefits and negative side effects.

Consider the case of mild hypertension. Elevated blood pressure is a known risk factor for mortality. Thus, patients with mild hypertension are well advised to bring their blood pressure within normal limits. They have several alternatives. Thiazide medications may bring blood pressure under better control, although they may be associated with increased serum cholesterol levels

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and a variety of side effects. These side effects include dizziness and impotence in males. Alternative treatments, such as beta blockers, may effectively control blood pressure with lesser effect on cholesterol. Yet they may be associated with vertigo and blunting of emotional responses. Elevated blood pressure is associated with the probability of a bad health outcome sometime in the future. Patients who experience side effects of their medications are trading the reality of current problems against change in the chances of developing a problem later. Indeed, for those with mild hypertension, the odds are that the patient will not die of heart disease or suffer a stroke even though their risks are elevated. The choice before patients is clearly complex. Thus, systematic schemes to help the patients organize information will be important to develop.

The patient's choice

Discussions in the medical decision-making literature often describe how the physician should use information to make his or her choice about treatment [1]. These decisions are typically based on the expected efficacy of a procedure or test. They may also depend upon the physician's expectation about patient compliance or convenience. Often there is a choice between several alternatives. Even when there is evidence that one treatment has a higher benefit than another, the second alternative may still be preferred. By noting the comparative efficacy of a treatment in two groups, a comparison of relative value is being made. There may be advantages to a slightly less effective treatment that is substantially less difficult to use or is much less expensive.

Clinical articles often make the paternalistic assumption that physicians are entitled to make treatment decisions for their patients. Despite a growing consensus that patients should be involved in decisions affecting their health care [2], recent studies suggest that patients rarely report being advised of their options regarding surgical procedures [4]. This failure to inform is all the more indefensible because many interventions affect quality of life rather than life expectancy. Determining potential benefit requires the integration of the patients' utilities and the accurate assessment of probability outcomes.

It is interesting that in the 2118 page 11th edition of *Harrison's Principles of Internal Medicine* [4] the issue of patient input is discussed in only one paragraph. Although that one paragraph recognizes patient values, it appears to discount the patient's views as less meaningful than those of the physician. It states, ". . . the final plan should reflect an agreement between a well-informed patient and a sympathetic physician who has detailed knowledge of the relevant medical issues and of the impact of the various possible outcomes on the specific patient" [1].

Decision theory approaches

Within the last few years there has been growing interest in using Quality of Life data to help evaluate the cost/utility or cost effectiveness of health care programs. In this paper, we suggest that these models may be usefully adapted to aid patients in individual decision-making. The benefits of medical care, behavioral interventions, or preventive programs can be expressed in terms of well-years. These outcomes have also been described as quality adjusted life years [5], discounted life years [6] or healthy years of life [7]. Since the term quality adjusted life years has become most popular, we will use it interchangeably with well-years in this presentation. QALYs integrate mortality and morbidity to express health status in terms of equivalents of completely well-years of life.

If a man dies of heart disease at age 50 and we would have expected him to live to age 75, it might be concluded that the disease was associated with 25 lost life years. If 100 men died at age 50 (and also had a life expectancy of 75 years) we might conclude that 2500 (100 men × 25 years) life years had been lost. Yet, death is not the only outcome of concern in heart disease. Many adults suffer myocardial infarctions leaving them somewhat disabled over long periods of time. Although they are still alive, the quality of their lives has diminished. Well-years take into consideration the quality of life consequences of these illnesses. For example, a disease that reduces quality of life by one half will take away 0.5 well-years over the course of each year. If it affects two people, it will take away 1.0 year (equal 2 × 0.5) over each year period. A medical treatment that improves quality of life by 0.2 for each of five individuals will result in the equivalent of one well-year if the benefit is maintained over a 1-year period.

This system has the advantage of considering both benefits and side effects of programs in terms of the common QALY units. The need to integrate mortality and quality of life information is clearly apparent in studies of heart disease. Consider the case of hypertension. People with high blood pressure may live shorter lives if they are untreated. Thus, one benefit of treatment is to add years to life. However, for most patients, high blood pressure is not associated with symptoms for many years. Conversely, the treatment for high blood pressure may cause a variety of symptoms. In other words, in the short run, patients taking medication may experience more symptoms than those who avoid it. If a treatment is evaluated only in terms of changes in life expectancy, the benefits of the program will be overestimated because side effects are not taken into consideration. On the other hand, considering only current quality of life will underestimate the treatment benefits since information on mortality is excluded. In fact, considering only current function might make the treatment look harmful because the side effects of the treatment might be worse than the symptoms of hypertension. A comprehensive measurement system may take into consideration side effects and benefits and provide an overall estimate of the net benefit of treatment [7].

Information presented to patients can be very confusing because it includes current health status, and probabilities of changes in health status and death in the future. In addition, the patient must consider side effects. Any decision implicitly or explicitly integrates patient values or preferences. Ultimately, the decision maker engages in tradeoffs. For example, he or she may exchange an increased probability of side effects now for a decreased probabil-

TABLE I

QUALITY OF WELL-BEING GENERAL HEALTH POLICY MODEL, ELEMENTS AND CALCULATING FORMULAS (FUNCTION SCALES, WITH STEP DEFINITIONS AND CALCULATING WEIGHTS)

Step No.	Step definition	Weight
Mobility scale (MOB)		
5	No limitations for health reasons	– 0.000
4	Did not drive a car, health related; did not ride in a car as usual for age (younger than 15 years), health related, and/or did not use public transportation, health related; or had or would have used more help than usual for age to use public transportation, health related	– 0.062
2	In hospital, health related	– 0.090
Physical activity scale (PAC)		
4	No limitations for health reasons	– 0.000
3	In wheelchair, moved or controlled movement of wheelchair without help from someone else; or had trouble or did not try to lift, stoop, bend over, or use stairs or inclines, health related; and/or limped, used a cane, crutches, or walker, health related; and/or had any other physical limitation in walking, or did not try to walk as far or as fast as others the same age are able health related	– 0.060
1	In wheelchair, did not move or control the movement of wheelchair without help from someone else, or in bed, chair or couch for most or all of the day, health related	– 0.007
Social activity scale (SAC)		
5	No limitations for health reasons	– 0.000
4	Limited on other (e.g. recreational) role activity, health related	– 0.061
3	Limited in major (primary) role activity, health related	– 0.061
2	Performed no major role activity, health related, but did perform self-care activities	– 0.061
1	Performed no major role activity, health related, and did not perform or had more help than usual in performance of one or more self-care activities, health related	– 0.106

Calculating formulas

Formula 1. Point-in-time well-being score for an individual (W):

$$W = 1 + (\mathrm{CPX}wt) + (\mathrm{MOB}wt) + (\mathrm{PAC}wt) + (\mathrm{SAC}wt)$$

where wt is the preference-weighted measure for each factor and CPX is symptom/problem complex. For example, the W score for a person with the following description profile may be calculated for 1 day as:

CPX-11	Cough, wheezing, or shortness of breath, with or without fever. chills, or aching all over	– 0.257
MOB-5	No limitations	– 0.000
PAC-1	In bed, chair, or couch for most or all of the day, health related	– 0.077
SAC-2	Performed no major role activity, health related, but did perform self-care	– 0.061

$$W = 1 + (-0.257) + (-0.000) + (0.007) + (-0.061) - 0.605$$

Formula 2. Well-years (WY) as an output measure:

$$WY = [\text{No. of persons} \times (\mathrm{CPX}wt + \mathrm{MOB}wt + \mathrm{PAC}wt + \mathrm{SAC}wt) \times \text{Time}]$$

ity of a stroke later. Yet, these decisions are difficult. A formal decision model may be a useful aid because it quantifies the components of the decision and integrates them in a comprehensive fashion.

Although there are several different approaches for obtaining well-years, most of them are similar [8]. The approach that our group prefers involves several steps. First, patients are classified according to levels of functioning. These levels are represented by scales of mobility, physical activity, and social activity. The dimensions and steps for these levels of functioning are shown in Table I. The reader is cautioned that these steps are not actually the scale, only listings of labels representing the scale steps. Standardized questionnaires have been developed (Table II) to classify individuals into one of each of these scale steps [9].

The questionnaires used to classify individuals into these levels ask about actual performance of specific activities, rather than more subjective ratings of capacity. For example, the performance questions ask, "Did you drive your car or use public transportation yesterday?" If the response is "no", a probe question asks if the reason was health related. Capacity questions ask if the respondent could have driven or used public transportation. We prefer the more complex performance questions because systematic studies have shown that they are more capable of identifying dysfunction [9].

TABLE II

EXAMPLES OF QWB6A QUESTION AND FOLLOWUP PROBE PATTERNS

PAGE 6
C. PHYSICAL ACTIVITY SCALE

PAC1. On which of the past 6 days, if any, did (you/ . . .) spend most or all of the day in a wheelchair?

[IF NONE, X NONE BOX AND GO TO PAC2; IF SOME OR ALL, X DAYS IN WHEELCHAIR, AND FOR FIRST X DAY, ASK]

PAC1A. Did (you/ . . .) move or control the movement of the wheelchair without help from someone else on (day/date)?

[CODE M/N; FOLLOWUP (And on . . .) ALL X DAYS; IF R/OS CONFINED TO A WHEELCHAIR ALL 6 DAYS OR PERMANENTLY, "INAP" ALL FURTHER PAC SCALE QUESTIONS AND GO TO ROL1, PAGE 7]

PAC2. On which of the past 6 days, if any, did (you/ . . .) spend most or all of the day in bed?

[X DAYS IN BED; FOR FIRST X DAY, ASK]

PAC2A. On (day/date), were there reasons related in any way to (your/ . . .) health that (you/ . . .) stayed in bed? [WHETHER YES OR NO, ASK] What were the reasons?

[RECORD RESPONSE; FOLLOWUP (And on . . .) FOR ALL X DAYS; GO TO PAC3)

In addition to classification into these observable levels of function, individuals are also classified by the one symptom or problem that bothered them most (see Table III). More than half of the population reports at least one symptom on any day. Symptoms may be severe, such as serious chest pains, or minor, such as the inconvenience of taking medication or a prescribed diet for health reasons. The symptoms are obtained using a standardized list that is part of the questionnaire. The questionnaire asks about the last 6 days, which is the memory window we have identified as reliable. The functional classification (Table I) and the accompanying list of symptoms or problems (Table III) was created after extensive reviews of the medical and public health literature [6]. Over the last decade, the function classification system and symptom list were repeatedly shortened until we arrived at the current versions. With structured questionnaires an interviewer can obtain classifications on these dimensions in 11 – 16 min.

Once observable-behavioral levels of functioning have been classified, a second step is required to place each individual on the 0 – 1.0 scale of wellness. To accomplish this, the observable health states are weighted by "quality" ratings for the desirability of these conditions. Human value studies have been conducted to place the observable states onto a preference continuum with an anchor of 0 for death and 1.0 for completely well. In several studies, random samples of citizens from a metropolitan community evaluated the desirability of over 400 case descriptions. Using these ratings, a preference structure that assigned the weights to each combination of an observable state and a symptom/problem has been developed [6]. Cross validation studies have shown that the model can be used to assign weights to other states of functioning with a high degree of accuracy ($R^2 = 0.96$). The regression weights obtained in these studies are given in Tables I and III. Studies have shown that the weights are highly stable over a 1-year period and that they are consistent across diverse groups of raters [10].

Finally, it is necessary to consider the duration of stay in various health states. For example, 1 year in a state that has been assigned the weight of 0.5 is equivalent to 0.5 of a quality adjusted life year. Table I provides an illustrative example of a calculation. Various future states must also be considered. In the case of high blood pressure, expert judgment would be used to estimate the probability of different outcome states, including stroke, heart disease, etc. Epidemiologic data are used to simulate the probability of reaching these various outcomes under different treatment options.

The importance of symptoms is worthy of comment. Symptoms have an impact upon the score in at least two ways. First, there is an adjustment for the symptom that bothered the respondent most. A minor cold may bring the score from 1.0 down to 0.83 while burns over major portions of the body would bring the score down to 0.61. Only the most troublesome symptom is scored because that is the one most expected to influence outcomes. The second way symptoms influence the score is through their impact upon function. A cough that keeps a patient in bed, for example, will get the adjustment on the mobility scale (in

TABLE III

QUALITY OF WELL-BEING GENERAL HEALTH POLICY MODEL, SYMPTOM/PROBLEM COMPLEXES (CPX) WITH CALCULATING WEIGHTS

CPX no.	CPX description	Weights
1	Death (not on respondent's card)	– 0.727
2	Loss of consciousness such as seizure (fits), fainting, or coma (out cold or knocked out)	– 0.407
3	Burn over large areas of face, body, arms, or legs	– 0.387
4	Pain, bleeding, itching, or discharge (drainage) from sexual organs — does not include normal menstrual (monthly) bleeding	– 0.349
5	Trouble learning, remembering, or thinking clearly	– 0.340
6	Any combination of one or more hands, feet, arms, or legs either missing, deformed (crooked), paralyzed (unable to move), or broken — includes wearing artificial limbs or braces	– 0.333
7	Pain, stiffness, weakness, numbness, or other discomfort in chest, stomach (including hernia or rupture), side, neck, back, hips, or any joints or hands, feet, arms, or legs	– 0.299
8	Pain, burning, bleeding, itching, or other difficulty with rectum, bowel movements, or urination (passing water)	– 0.292
9	Sick or upset stomach, vomiting or loose bowel movement, with or without fever, chills, or aching all over	– 0.290
10	General tiredness, weakness, or weight loss	– 0.259
11	Cough, wheezing, or shortness of breath, with or without fever, chills, or aching all over	– 0.257
12	Spells of feeling upset, being depressed, or of crying	– 0.257
13	Headache, or dizziness, or ringing in ears, or spells of feeling hot, or nervous, or shaky	– 0.244
14	Burning or itching rash on large areas of face, body, arms, or legs	– 0.240
15	Trouble talking, such as lisp, stuttering, hoarseness, or being unable to speak	– 0.237
16	Pain or discomfort in one or both eyes (such as burning or itching) or any trouble seeing after correction	– 0.230
17	Overweight for age and height or skin defect of face, body, arms, or legs, such as scars, pimples, warts, bruises, or changes in color	– 0.188
18	Pain in ear, tooth, jaw, throat, lips, tongue; several missing or crooked permanent teeth — includes wearing bridges or false teeth; stuffy, runny nose; or any trouble hearing — includes wearing a hearing aid	– 0.170
19	Taking medication or staying on a prescribed diet for health reasons	– 0.144
20	Wore eyeglasses or contact lenses	– 0.101
21	Breathing smog or unpleasant air	– 0.101
22	No symptoms or problem (not on respondent's card)	– 0.000
23	Standard symptom/problem	– 0.257

house), yielding a lower score than a cough that does not influence function. Duration also affects the well-year calculation. A runny nose may only last a few days and will have only a minor effect on the well-year calculation. For example, the impact of 3 days would be [3(1 – 0.83)]/365 = 0.001 well-years. By contrast, burns over the body would be excepted to last throughout the year. Thus, the loss of well-years would be [365(1 – 0.61]/365 = 0.39 well-years.

In evaluating patient decision-making, it is important to separate the various components of the decision process. These include current status, preferences, duration of stay and probabilities. Often, empirical components of health outcome get confused with preferences. For example, the probability that a patient with high blood pressure will have a stroke or a heart attack is not a matter of preference. It is determined empirically through epidemiologic studies. On the other hand, the desirability of these outcomes is a preference matter. In decision-making, it is important to separate these preferences and probabilities. The components of the decision process involve assessing current status of the patient and then applying preferences or values to these states. Then, it is important to determine the expected duration or stay in various states and the probabilities of these outcomes. Only the preference component is a matter of patient value. For example, people often become confused when given probability information. Yet, a systematic model can be used to include actual probabilities for various outcomes. The outcomes themselves are weighted by patient preference. A state that is valued 0.5 by the patient, but has a probability of 1/100, ultimately has little effect on well-years (0.01 × 0.5 = 0.005). In most analyses, current health status is obtained from the patient. Preferences are obtained either from the general population or from the patient him- or herself. The duration of stay and the probability information is estimated from the published literature.

More detailed descriptions of this system are available in other publications [11—13]. In a later section, we will illustrate the potential of the well-year concept for individual decision-making.

Focus on outcomes

It is instructive to consider health care measures in light of the objectives of prolonging life and enhancing life quality. Traditional biochemical measures and diagnoses are important because they may be related to mortality or to life quality. For example, elevated low density lipoprotein cholesterol (LDL-C) over a sustained period of time may predict deaths due to heart disease, heart disease related disability, or stroke. If high serum cholesterol were unrelated to these outcomes, it would be unimportant. In other words, serum cholesterol is important because it correlates with health outcomes although it is not an outcome itself.

We use the term health-related quality of life to refer to the impact of conditions on function. Health often affects quality of life independently of work, housing, air pollution and so forth [14]. Within the last few years, a substantial number of quality of life measures have been proposed. Before reviewing the application of these measures, it will be important to consider some examples of why the focus should be on quality of life and mortality rather than intermediate variables.

An example for patient's with high blood pressure

As many as 20% of the adults in the American population have some degree of high blood pressure. Among these, about one-third have moderate to severe hypertension. These people are faced with several treatment alternatives. They can attempt to control their blood pressure using diet, or they can select from between several alternative medications. Each of these alternatives has some expected benefits and some expected side effects.

In order to estimate the benefits, Weinstein and Stason [5] used data from the Framingham Heart Study. This study followed a substantial number of people over a long period of time. First, they simulated the probability of death. The systematic relationship between diastolic blood pressure and mortality fit a logistic curve. For those with diastolic blood pressures in excess of 110 mmHg, there was a greater increase in the chances of death for each 10 point increase in blood pressure than there was for individuals whose initial blood pressure was 95 mmHg. Thus, any simulation of outcomes must take the patient's initial blood pressure into consideration. In addition to the expected mortality outcomes, epidemiologic data can also be used to simulate the effects on other adverse health consequences, including heart attack and stroke. Stroke has an effect on function and that effect can be estimated using the general quality of well-being scale. A stroke, might be given the value of 0.47. If an adult does not recover from the stroke, for each 2 years they spend in the state, they may have lost the equivalent of approximately 1 year of life.

Epidemiologic data can be used to estimate the expected well-year loss without treatment. However, information on treatment benefits must also be considered. Using data from a variety of sources, such as the Hypertension Dectection and Follow-up Program (HDFP) [15], it is also possible to estimate the treatment benefits under different treatment alternatives. This benefit has been estimated in several trials. It might also be possible to simulate fractions of benefit that might be achieved if the patient is less than 100% compliant. Another component in the analysis is the side effects of the treatment. Very few data are available on the actual numbers of people that experience side effects due to antihypertensive medications. However, the estimated disability associated with drug side effects can be obtained for the model. In Weinstein and Stason's evaluation of antihypertensive medications, they assume that the impact of drug side effects was 0.01 on a 0—1.0 scale. In other words, if a person was in terrific health, but took antihypertensive medication they would go from 1.0 to 0.99. However, these effects might last for many years and accumulate negative consequences. Over the course of 25 years, for example, the cumulative impact of a very small side effect would be a quarter of a year of life (0.01 × 25 years = 0.25 well-years).

Table IV shows an example of the estimated benefit of treatment for high blood pressure. The analysis considers the net expected benefit for blood pres-

TABLE IV

NET EXPECTED TREATMENT BENEFITS IN WELL YEARS FOR HIGH BLOOD PRESSURE IN 40 YEAR OLD MEN AND WOMEN

Notes: numbers are presented for males/females. Assumes treatment begins at age 40. Estimates are adapted from Weinstein and Stason [5, pp. 75–76]. Russel [7] suggests that these treatment benefits are conservative and may underestimate the contribution of current treatment.

	Initial diastolic BP (mmHg)			
	90	100	110	120
Expected post-treatment diastolic BP (mmHg)	80	85	90	95
Change in life expectancy (years)	0.30/0.32	0.46/0.44	0.66/0.59	0.90/0.75
QWB benefits of treatment excluding mortality (well-years)	0.02/0.03	0.03/0.05	0.05/0.08	0.08/0.12
QWB side effects including mortality (well-years)	0.15/0.17	0.15/0.16	0.14/0.16	0.14/0.16
Net well-year effects of treatment (life expectancy + morbidity benefits − side effects)	0.17/0.18	0.34/0.33	0.57/0.51	0.84/0.71

sure treatment of men and women. The analysis assumes that treatment begins at age 40 and evaluates potential for patients starting at different initial levels of diastolic blood presssure: 90, 100, 110 and 120 mmHg. Net benefits are the effects of increased life expectancy plus the effects upon quality of life, expressed in well-years, minus the effects (in well-years) of side effects. In this analysis, the treatment always produces a benefit after side effects have been removed. For increasingly higher levels of initial blood pressure, there is an even greater benefit of treatment.

The models described above have been used almost exclusively for policy analysis. They describe how the patient is affected "on the average", yet individual patients may have very different preferences for specific outcomes. For example, a male who is made impotent by an antihypertensive medication may place high weight on that side effect. Thus, using the medication may bring him from a well-being level of 0.9 down to 0.7. Considering the high loss in well-being associated with this side effect, the treatment would need to have profound effects to show a net benefit. Simulation studies can be used to allow patients to place their own values on various states of functioning.

Although there have been relatively few applications of the well-year concept in clinical practice, we feel the system has an important potential. The next phase in the research process will be to begin attacking some of the technical problems. These include the development of methods for assessing preferences, and establishing probabilities for various outcomes.

Patient preferences

Most applications of the model use standardized preference weights that have been obtained from members of the general population. The preferences have the advantage of being stable, and generalizable across groups [10]. Balaban and his colleagues have also shown that patient groups (rheumatoid arthritis) do not differ from general population samples for these preferences [16]. However, methods for the elicitation of patient preferences deserve more study.

Until recently, patient preferences for various outcomes were simply not assessed. An emerging group of studies allow patients to weight the alternatives. McNeil et al. [17], for example, have elicited patient weights for various outcomes in laryngeal cancer. Surgery may extend the life expectancy but might also increase the risk of speech problems. The McNeil study laid out the alternatives and permitted patients to express how much risk of death they were willing to take in order to retain their speech. Barry and colleagues [18] directly involved men in the decision of how to manage their benign prostatic hypertrophy. Although surgery is typically recommended, it carries minor risks of urinary incontinence, impotence, and even death. The choice not to have surgery may be associated with discomfort from urinary retention and some other health risks. Barry presents the possible outcomes using video tapes and allows patients to choose their treatment course. We would recommend that patients rate their preference for different outcomes on simple 10 point rating scales. Then these ratings would be combined with duration and probability information in order to demonstrate which alternative produces the greatest number of well-years.

There is some debate about how preference information should be obtained. We have favored simple rating scales that have the advantage of being easily understood. Some evidence supports the validity of these measurement methodologies [19,20]. Others prefer methods that more explicitly ask patients to trade off alternatives [21]. These methods have the advantage of representing realistic decision processes, but the disadvantage of being so complex that they overwhelm the capacity of the human information processor.

Establishing probabilities

There are many clinical conditions for which simulation is difficult because there is insufficient clinical data. For these conditions the estimation of well-year benefits will be less reliable. However, judgments about clinical treatment almost always require some estimate of probable outcomes. Clinicians are reluctant to make these judgments explicit, yet these assumptions can be elicited. Experts are asked to identify the functional outcomes under different treatment alternatives, the probabilities of each outcome, and the duration of stay in each identified state. Examples of this methodology are available in the literature [22].

Clinical examples

How might this complex system be used to help patients make decisions? To date, most of the applications have been in policy analysis. Policy options that provide the largest yields in well-years at the lowest cost are preferred. We suggest that the same rational can be applied to patient decision making. Using patient preferences, we can select the treatments that, considering both risks and benefits, produce the largest benefit in well-year units.

One clinical example concerns the decision to have a prostatectomy for benign urinary tract obstruction. Resection of the prostate gland is one of the most common surgical procedures in the United States [23]. However, there is widespread variation in the use of this procedure in demographically homogeneous areas, suggesting that there is uncertainty in the indications for surgery. Urologists participating in the Maine Medical Assessment Program suggested that there is little disagreement that patients need to have a prostatectomy if they have chronic urinary retention, large residual volumes of urine in the bladder after a void, and a serious threat of complications such as sepsis and kidney failure. However, there was considerable disagreement about the benefit of the procedure for those who do not experience chronic retention [24].

Recent evidence suggests that prostatectomy may not extend the life expectancy, and may even shorten life expectancy by an average of 1.01 months [18]. The value of the procedure is probably its capability to improve quality of life. A man who is unable to urinate may experience discomfort, and a successful procedure may relieve this problem. Unfortunately, the surgical procedure may also cause some problems. Side effects include incontinence, impotence, and even death. The probabilities of these outcomes have been established [25]. The operation reduces symptoms for 93% of severely symptomatic and 79% of the moderately symptomatic men. However, 24% have short term complications, 4% develop incontinence, and 5% become impotent after the procedure. Death is an extremely rare complication.

How should this complex array of information be used to assist patients to make decisions? This problem has been evaluated by Barry et al. [18]. Although these investigators did not directly measure patient preferences, they assumed that moderate symptoms of prostatism placed a patient at 0.89 of the 0 to 1.0 scale. Incontinence was given a rating of 0.50.

First consider the case of a 70-year-old man who is sexually active and has moderate symptoms. He has at least two choices — to have the operation or "watchful waiting" in which he tolerates the symptoms and avoids any immediate risks or benefits of surgery. Under the assumptions about probabilities of outcomes and preferences for various outcomes, the number of well-years expected was 9.99 for watchful waiting and 10.24 for surgery. In other words, surgery would produce an expected difference of 0.25 well-years (about 3 months). Barry and colleagues demonstrated that this benefit was the composite of an expected loss of 1.01 months due to the risk of surgery, a gain in 0.06 months from the prevention of more severe urological disease, and a gain of 3.95 months associated with the improved quality of life because symptoms that were caused by an enlarged prostate were relieved. A variety of other outcomes were simulated. For example, it was possible to estimate the advantage of watchful waiting with the likely operation 6 months or 1 year into the future. It is also possible to manipulate the assumptions about benefits and side effects. For example, the benefit of surgery was estimated to be higher (0.29 well-years) for men who were already impotent. These patients do not take the risk of losing sexual functioning, since it is already absent.

The foregoing analysis uses standardized preferences. However, it is possible to use the patient's own values in the analysis. For example, men may have different ratings for postoperative impotence. If they rate postoperative impotence without urinary symptoms as 0.50, surgery is estimated to yield 0.085 well-years (1.02 months). However, if quality of life with impotence is rated 0.89, then surgery will yield a benefit of 0.245 well-years (2.94 months). Surgery will provide a benefit of 0.117 well-years if the possible outcome of mild incontinence (wetness) is rated as 0.50, but will give 0.245 well-years benefit if the patient rates mild incontinence as 0.89.

In summary, prostatectomy has advantages for most men with benign enlarged prostate glands. However, it is not of benefit to all men, and some suffer bad outcomes. Using a well-year concept, it is possible to simulate the outcomes of treatment using information about probabilities of outcomes and preferences for these states. Evidence suggests that the operation does not increase life expectancy, and may even shorten it. However, relief of symptoms typically gives the operation a net benefit. As Wennberg and colleagues [26] emphasize in their recent review, "For most patients, the decision to undergo prostatectomy should depend on how they value specific outcomes and their attitudes toward risk. In addition to the information on the chances for outcomes, patients need assistance in understanding their own preferences, and such assistance should be part of the informed-patient decision-making . . ." (p. 3029). Before we can use these methods on a large scale basis, we will need more research on how to elicit this information from patients. For those interested in this well-studied case, the Barry et al. article [18] is highly recommended.

Conclusion

Patient decision-making is a complex process. We have suggested a new model to simplify information used in the decision process. The method, originally developed for policy analysis, separates the components of health outcomes. These components include mortality, morbidity, probabilities, duration of illness, and patient preferences. Integrating this information within a single model can express the net risks or benefits of a treatment in terms of equivalents of completely well-years of life. Many systems of medical decision-making ignore treatment side effects or patient preferences for discomfort. Thus, patients who discontinue their therapy when they become nauseous are labelled as "non-compliant". A general model considers side effects as a health consequence of treatment. We believe that many episodes of non-compliant behavior actually represent the maximization of health outcome. Patients discontinue therapy when the treatment produces poor health outcomes.

As of yet, there have been few applications of well-year concepts to individual patient decision-making. We believe this approach may have potential for applications in clinical care and we encourage patient educators to begin conceptualizing treatment benefits in terms of well-years.

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