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Work-in-Progress Toward Incorporating Patients' Preferences in Practice Guidelines for Imaging Aneurysmal Subarachnoid Hemorrhage¹

Pina C. Sanelli, MD, MPH, Rachel L. Gold, BA, Edward D. Greenberg, MD, Melissa B. Reichman, MD, Igor Ugorec, MD, Alan Z. Segal, MD, and Matthew Fink, MD

¹Departments of Radiology (E.D.G., M.B.R., P.C.S.), Public Health (P.C.S.), and Neurology (A.Z.S., M.F.), Weill Cornell Medical College, New York Presbyterian Hospital, 525 East 68th Street, Starr 630, New York, NY 10065; New York College of Osteopathic Medicine, Old Westbury, NY (R.L.G.); Atlantic Neurosurgical Specialists, Morristown, NJ (I.U.)

Abstract

Rationale and Objectives—Patient-centered care has become a primary focus in clinical practice. In developing practice guidelines for clinical care, the patients' perspective is an important component.

Materials and Methods—Patients' preferences are represented in a decision analytic model as quality-of-life weights for different health states associated with the aneurysmal subarachnoid hemorrhage population. The time–tradeoff method is used to obtain the individual patients' preferences, which are directly measured in quality-adjusted life years. An individualized care model is explained as a means of implementing a patient-centered approach into practice guidelines for clinical care. A method for calculating the expected value for societal benefit from improved decision making using an individualized care model is reviewed.

Results—We discuss our work-in-progress towards incorporating patients' preferences in a decision analytic model for aneurysmal subarachnoid hemorrhage patients. The main methodologic concerns for using patients' preferences in cost-effectiveness analyses for developing practice guidelines are discussed.

Conclusion—Emphasis is placed on using patients' preferences and patient-centered outcome measures in cost-effectiveness analyses.

Keywords

Patient preferences; decision analysis; aneurysmal subarachnoid hemorrhage

In recent years, there has been improved awareness and effort to implement patient-centered care in clinical practice. With the advent of patient involvement in addressing health care issues and government policy making, patient-centered care has become a primary focus in developing practice guidelines. In this setting, the patient is considered as the ultimate judge of the quality of medical care services. By applying this concept specifically to radiology

practice, the patient is regarded as the authority on determining an imaging experience as acceptable care, including the outcome management from the examination performed. Thereby, patients' preferences and patient-centered outcomes are an important component in developing practice guidelines for clinical care.

Practice guidelines have been defined as systematically developed statements to assist both physicians and patients in making decisions about appropriate health care for specific clinical circumstances (1). Issues related to costs, benefit, quality, access, patients' preferences, and utilization are some factors considered in developing practice guidelines. Emphasis is placed on developing systematic practice guidelines using evidence-based medicine, such as conclusions drawn from decision analyses to determine quality of life and cost-effectiveness.

Decision analysis is a method used to evaluate the value of diagnostic tests or treatment strategies by assessing patient outcomes. In this model, the risks, benefits, and costs of performing a diagnostic test or treatment are included in the decision branches for each strategy being investigated. Selecting the optimal strategy is not based on imaging criteria for improvement or resolution of disease, rather it is a patient-centered approach based on the patients' clinical outcomes and health states. Traditionally, a cost-effectiveness analysis (CEA) determines the optimal strategy based on a societal approach by weighing the benefits and costs of each decision branch for the entire population represented in the model. The strategy that yields the maximum expected health benefits for society is considered the single best choice for every patient. However, at an individual level, these decisions are not necessarily the most appropriate strategy for each patient because of the heterogeneity in the population for personal preferences and individual perspectives on quality of life. For example, a health state described as minor disability with loss of function of only two fingers on the left hand would be considered as minimal loss of quality of life using a population level approach. However, on an individual basis, patients with occupations that require intact fine motor skills, such as a pianist, would consider this health state as a greater loss of quality of life because it interferes with both financial stability and personal happiness. In clinical practice, an individualized care model can be used to select the most appropriate strategy for each patient based on their own personal preferences incorporated into a CEA (2). The basic concept is for physicians to individualize care and choose different strategies for different patients that maximize the health benefits for each patient given their individual value assigned as their preference (2). Applying cost-effective treatment for individual patients based on their own personal preferences can potentially result in overall benefits for society with improved health outcomes and costs.

We describe our work-in-progress towards incorporating patients' preferences in a decision analytic model for aneurysmal subarachnoid hemorrhage (A-SAH) patients to evaluate imaging strategies for improving patient outcomes.

DECISION ANALYTIC MODEL

We are developing a decision analytic model in A-SAH patients using TreeAge Pro 2006 software program (Tree-Age Software, Inc., Williamstown, MA). The decision analytic

model is a visual representation of the complex management of A-SAH patients displayed in a branching diagram called a decision tree. The possible alternatives and consequences that are considered in making decisions for imaging and treatment of vasospasm constitute the fundamental composition of the model. The decision tree is designed to compare 2 diagnostic strategy branches for A-SAH patients using a strategic approach for the model construction in the organization of the options, consequences, treatments and outcomes. Figure 1 is a simplified outline of a decision tree demonstrating its basic structure. The decision tree is in chronological order of events from left-to-right. The first segment contains the 2 diagnostic strategy options leading from the decision node (square symbol). The standard strategy currently used in clinical practice is compared to the new strategy proposed in this study. In the second segment, the diagnostic options leading from the chance nodes (circle symbol) are presented as vasospasm and no vasospasm. The third segment contains the options for the patients' outcome health states, which are determined at the end of hospitalization. The triangle symbol represents a termination node, indicating the end of this sequence of options. A measure of quality of life and/or costs resulting from that particular chain of events is assigned to each branch at the termination node. These outcome measures provide a means of evaluating and comparing the value of each diagnostic strategy.

In more detail, the standard diagnostic strategy branch is further divided by chance nodes in a sequential format to include the diagnostic modalities currently used to detect vasospasm such as clinical examination, transcranial Doppler ultrasound (TCD), and digital subtraction angiography (DSA). The new diagnostic strategy branch differs from the standard strategy by including CTP instead of TCD imaging. The diagnostic accuracy, complications, and costs associated with each imaging modality are included into the diagnostic strategy branches. The imaging results lead to management and treatment options along with its associated consequences, which are separated by chance nodes. These options include patient observation, further testing using DSA with the possibility of intra-arterial treatment, or immediate medical treatment of vasospasm. The second segment of the decision tree yields the diagnostic options of vasospasm for each branch, indicating whether or not the patient had the disease. The long-term clinical outcome is represented in the third segment as the main health states associated with A-SAH patients, such as full recovery from A-SAH, stroke, and death. The probabilities of these health states occurring in this population are determined from literature review for both treated and untreated A-SAH patients (3–5). Each health state is assigned an established utility score and expected life years (6–8). Quality-adjusted life years (QALYs) are used as the outcome measure to assess both quality of life and length of life. QALYs are determined by multiplying the utility score and estimated life years for each health state.

Rollback analysis of each branch in the decision tree yields an expected value. The expected value is measured in QALYs and represents the weighted sum of the QALY values of all its branches, which contain the possible options and consequences of that strategy. The QALY values are also weighted by the probabilities of the imaging and treatment options assigned to each branch. The diagnostic strategy with the greatest expected value represents the preferred strategy in A-SAH patients because it balances all possible harms and benefits of the outcomes, weighted by the probability of its occurrence, yielding the most QALYs

gained. CEA will also be performed using this decision tree with the expected value now measured in dollars lost per QALY gained. Calculation of an incremental cost-effectiveness ratio will yield the added cost per unit of added benefit of the new diagnostic strategy relative to the standard strategy.

From a traditional perspective, the overall goal in managing A-SAH patients is to maximize QALYs, minimize costs, and maximize societal net health benefit. The net health benefit (NHB) can be interpreted as the effectiveness of a strategy adjusted for its associated costs expressed in units of health by taking into consideration the society's willingness-to-pay threshold. The willingness-to-pay threshold is the monetary equivalent of a single QALY for A-SAH patients. A commonly used value of \$50,000 per QALY and an acceptable range of \$20,000–\$400,000 per QALY may be used. If the incremental NHB exceeds zero, then the strategy is considered cost-effective compared to its comparator.

Incorporating Patients' Preferences

Patient-centeredness can be achieved in a decision analytic model by incorporating patients' preferences and patient-centered outcomes. In our work, we are incorporating patients' preferences for the different health states associated with A-SAH, including full recovery from the hemorrhagic event, stroke with major disability (such as aphasia, hemiplegia, memory dysfunction, gait instability), stroke with minor disability, and death. Patients' preferences are determined as quality of life weights for these different health states. Individual patients will have variable preference weighting according to their relative desirability of these health states. The patients' preferences are then represented in the model as the QALYs assigned to each health state. By incorporating the patients' preferences into these outcome measures, the decision making for imaging and treatment of vasospasm in A-SAH will ideally be driven by the patients themselves.

In our work, preference-based measures are derived from utility theory, such as the time-tradeoff (TTO) method (9). The TTO method is of particular interest for this purpose to determine utilities based on patients' preferences because it directly measures utilities in terms of QALYs (10). Using the TTO method in a survey design, patients with A-SAH are presented with a hypothetical situation. The patient decides between a longer period of time in less optimal health versus a shorter period in good health (9–11). At the indifference point, the actual calculation of utility for a health state is equal to the time in optimal health the patient is willing to trade divided by the assumed time in the patient's present health. The utility is interval-scaled along a continuum from 0 (equaling death) to 1.0 (perfect health). For example, patients are asked to "Imagine you have 10 years to live. You are in excellent health, except that you have A-SAH." The survey then describes one of the health states in the model, such as stroke with hemiplegia. The patient is then asked, "How many years of your life, ranging from 0 to 10 years, would you be willing to sacrifice to achieve ideal health without this condition?" Patients may answer using a combination of years and months, allowing patients to sacrifice partial years. Responses to these items are converted into QALYs by the following formula: $\text{QALY} = (10 - \text{years sacrificed})/10$. Previous research supports the use of the TTO method for assessing patients' preferences as a validated and reliable technique (11,12).

Measuring The Expected Value Of Individualized Care

In a patient-centered approach, it is assumed that utilizing patient' preferences for individualized care will lead to improved outcomes for individual patients. However, there may also be an added benefit for society with an overall improvement in health outcomes and cost-effectiveness. Basu and Meltzer described a theoretical framework to measure the expected value of individualized care (EVIC) in a CEA model (2). The EVIC represents the net societal gain from improved decision making at the individual level compared to the traditional CEA based on population preferences. For individualized care and treatment decisions, the CEA model incorporates patients' preferences in the decision tree, representing the individual desirability for the possible health states associated with A-SAH patients. The QALY values assigned to these health states are weighting variables according to these individual preferences. Rollback analysis of the model can then reveal the optimal strategy for each individual patient.

The net health/monetary benefit criteria can be used to assess the value of the strategy (2). The net health benefit (NHB) of a strategy is the net value the strategy produces in terms of benefits, often expressed in QALYs. The NHB is the difference between the benefits from the strategy and the benefits-equivalents of the costs of the strategy. The society's willingness-to-pay is incorporated into the NHB value. The willingness-to-pay represents a monetary cost that society accepts to improve a state of health. In other words, it is a societal value attached to a given health benefit. The EVIC is then compared to the value of treatment decisions based on the traditional population-level CEA model.

In the individualized care model, physicians select different strategy decisions for different patients so that the net health benefits are maximized for each patient based on his or her own preference values. The EVIC quantifies the value of individualized care and may be considered as the expected costs of patient-level preference heterogeneity that exists in traditional CEA models (2). Because the estimation of the EVIC includes the society's willingness-to-pay, it also represents the potential value or cost that society is accepting for individualized care (2). However, another relevant factor to consider in estimating the EVIC is the health insurance structure regarding internalization of relative costs of treatment, as further described by Basu and Meltzer.

DISCUSSION

A patient-centered approach is an important component in developing practice guidelines for clinical care. Patient-centered analyses incorporate the patient's perspective on important outcome measures and satisfaction of care. An example of a patient-centered analysis was performed by Sommers et al (11) in patients with prostate cancer. Compared to the traditional CEA model for the treatment of prostate cancer, 30% of patients in this study indicated a different optimal treatment. Treating these patients based on population based preferences would result in sacrifice of 0.13 QALYs on average, which translates into a significant loss of 1.5 months of perfect health. The key message is that an optimal treatment often depends on individual patient preferences, and not merely the clinical scenario viewed by the physicians or policy makers. In another study of patients with prostate cancer,

Wennberg reported that doctors cannot predict patients' preferences unless they explicitly ask the patients for their preferences (13).

Patients' preferences affect their assigned utility values for different health states in a subjective manner, which is not completely understood or evaluated by physicians. Many personal factors influence these individual preferences, such as cultural, religious, political, and gender-related experiences. In the Beaver Dam Health Outcome study, an age-adjusted utility value of 0.87 was reported for patients without any particular disease, indicating that most patients had other unknown problems of some significance (14) affecting their personal assigned utility values. Specifically in A-SAH patients, the utility values for different health states cannot be comprehensively determined by current established outcome instruments. Kim et al (15) studied six different outcome instruments in patients following treatment for intracranial aneurysms, including the Glasgow Outcome Score, Rankin Scale, Barthel Index, National Institutes of Health Stroke Score, Short Form-36, and the Mini Mental Status Examination. They concluded that a single graded scale does not address all aspects of recovery after aneurysm treatment, particularly cognitive dysfunction and the patient's perception of health (15). In this population, a lower functional status is associated with depression and poor general mental health (16). The patients' perspective and subjective well-being are influenced by their levels of anxiety, depression, functional status, and, importantly, their social support network (17,18). These personal variables affect their assigned utility values for different health states, which cannot be adequately measured by an established outcome instrument.

Incorporating patients' preferences into an individualized care model can begin to address this important public concern of implementing patient-centered care to improve health outcomes and satisfaction. Due to the heterogeneity of patients' preferences, a sensitivity analysis of the QALY estimates may be helpful in determining a distribution of probabilities assigned to each health state from the patients' perspective. The importance of this variability in each health state and a probability threshold value can be determined. Individualized care can potentially be provided by using QALY threshold values in determining the optimal strategy for each patient. Additional analysis may be performed by measuring the EVIC to estimate the overall benefits for society in using an individualized care model. An interesting question has been raised in this model indicating that patients' preferences may possibly lead to patterns of self selection (19). It is conceivable that certain attributes of patients will lead to preferences that drive decision making towards more or less aggressive treatment strategies. It is uncertain whether this may have a significant impact on societal health outcomes.

Several important methodological concerns exist in incorporating patients' preferences in the QALY estimates for CEA methods. First, a standardized method needs to be employed to elicit the appropriate weights to be used for individualized QALY values. There are many advantages to using the TTO method because there is direct calculation of individualized QALYs for each health state and it has been shown to be a validated and reliable technique. However, the main disadvantage of using a TTO method is that it can be conceptually difficult for patients to fully understand or judge a health state they have never experienced (20). Bias may be introduced from the individual patient by underestimating or

overestimating the QALYs assigned for each health state. Other areas of bias may also include the effect of physicians' influence on eliciting patients' preferences. Second, there are challenges in adequately representing the cultural, religious, and social values in the TTO method, which are relevant personal factors that affect the QALYs assigned to these health states. Third, an important consideration in determining QALYs is the source of preferences to be used in the analysis. In patient-centered analyses, the patient is clearly the appropriate source. However, a question may be raised at what time-point in the course of the disease is the patient the most appropriate source. Before treatment is instituted is preferable, however, at this early time-point patients' preferences may reflect a lack of understanding and knowledge of the different health states. Patients with an optimistic attitude may not seriously consider the worst states as true possibilities. In our population of A-SAH patients, many patients are experiencing significant physical and psychological stress in the acute stage prior to treatment, which may interfere with adequately performing a TTO method. An alternative is to survey the preferences of patients and families in the later stage of the disease because they have the most experience with a given health state and are most familiar with implications for quality of life (21). The disadvantage may be that their perspective and values about the illness may change based on their adaptation with the disease. Fourth, using an individualized care model with patients' preferences may be costly and time-consuming in clinical practice. Many issues still need to be addressed, such as accommodating non-English speaking patients and patients with impaired decision making due to medical or psychological issues, as well as determining adequate patient comprehension of the TTO method. It remains uncertain how often patients' preferences should be obtained because the assigned QALY values may change at different time points according to the patients' perspective and subjective well-being.

In conclusion, this decision analytic model establishes the foundation of evaluating diagnostic and therapeutic strategies in A-SAH patients using a patient-centered approach by incorporating patients' preferences. Future work may include extending the model to also incorporate the short-term disutility associated particularly with medical imaging, such as the psychological costs of pain, anxiety, and discomfort from a patient's perspective. This important information can then be used in formulating patient-centered practice guidelines in clinical care.

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Figure 1.
Basic decision tree outline for aneurysmal subarachnoid hemorrhage (A-SAH) patients.
QALY, quality-adjusted life years.