Original Contributions

Patient Preferences for Stroke Outcomes

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Background and Purpose  In clinical trials stroke is reported as a major morbid outcome, but the impact of stroke on patients is not directly assessed. This study examines patient preferences for different outcomes of stroke, including death.

Methods  We presented patients with written case scenarios of stroke outcomes. The scenarios represented four categories of stroke severity (mild, moderate, severe, and fatal), and for nonfatal strokes the scenarios described motor, language, and cognitive deficits. Patients reported values for each of the 10 stroke scenarios using a rank-and-scale method over a 100-point range, with 100 representing perfect health and 0 corresponding to the worst possible health state.

Results  One hundred seventeen of 209 consecutive patients at risk for stroke participated in this study. Severe strokes were uniformly rated as having low preference weights (mean±SD [median]: 3±4 [1] for disabling hemiplegia, 8±9 [5] for confusion, and 15±14 [10] for global aphasia), and severe motor impairment (a disabling hemiplegia) was rated as significantly worse than death. Even mild deficits resulted in substantial loss to patients (54±21 [55] for dysarthria and 53±21 [50] for mild anomia).

Conclusions  Strokes may result in a wide variety of post-stroke consequences for patients. Severe strokes may be viewed by patients as tantamount to or worse than death. Even mild strokes may cause significant declines in patient preferences for health states. These data are useful in interpreting studies that report stroke and death, in designing new studies that measure stroke in at-risk populations, and in helping patients reach treatment decisions about therapies designed to prevent strokes. (Stroke. 1994;25:1721-1725.)

Key Words  • carotid endarterectomy  • quality of life  • stroke outcome  • stroke prevention

Stroke is a major morbidity reported in the recently completed trials of anticoagulation for atrial fibrillation and endarterectomy for carotid stenosis. While these trials report the overall clinical benefit of therapy, the treatment choice for any individual patient should include a consideration of that individual's own preferences for risks and benefits of therapy.

The current and recently completed trials provide no means of weighing patient preference for two of the major risks of the interventions, stroke and death. The ability to quantify patient preference for various stroke outcomes would allow more precise evaluation of the risks and benefits of these interventions. If one strategy led to a greater fatality rate but fewer severe strokes, for example, the intervention's value could be assessed using decision analytic techniques.

One difficulty with quantitatively evaluating stroke outcome is that strokes result in a variety of handicaps, differing both in type and intensity of residual deficit. Most of the recently completed randomized trials grade strokes according to broad classifications that are not uniform among the studies. Some investigators categorize strokes according to the patient's level of independence, others draw a distinction between "disabling" and "nondisabling" events, while still other researchers rely on functional scores such as the Rankin scale.

Quality of life can be measured using functional status scales that quantify the physical and emotional health status of patients. These measures may take the form of detailed descriptive scales of the many different dimensions of health: clinical status, physical functioning, mental health, social interaction, and general health perception. Although many measures of quality of life have been used to assess outcomes of patients with strokes, these scales do not report on patients' overall preferences for these stroke outcomes. Such scales therefore cannot be used by economists to calculate quality-adjusted years of life resulting from treatment.

Measurements of patient preferences for treatment outcomes, by contrast, allow the conversion of functional status assessments into a single measure of personal values for the physical and emotional states of patients with strokes. To date, few attempts have been made to assess the severity of strokes using patient preferences. Ahlqvist and colleagues evaluated quality of life over time in a population of patients who had already suffered strokes by using a visual analogue scale. They did not report their results, however, in a way that allows for measurement of specific health states. Watson and coworkers assessed attitudes toward different aspects of stroke disability in patients rehabilitating from stroke with three commonly used techniques. They presented preliminary findings but never published their completed results. Our goals in this research were to create a classification system for common stroke outcomes and to measure patient preferences for these health states.
Subjects and Methods

In this section we describe the development of our preference assessment measure, the administration of the survey instrument to patients at risk for stroke, and the methods of data analysis.

Preference Assessment Instrument

For the purposes of our assessment, we grouped the consequences of strokes into three types of isolated neurological deficits: motor, language, and cognitive. We developed case scenarios for each of these deficit types in three severity levels: mild, moderate, and severe impairments. (See Table 1 for a summary of the scenarios and the “Appendix” for the full scenarios.) Efforts were made to ensure that the scenarios were descriptive, explicit, targeted to a ninth-grade reading level, and were nonjudgmental. In addition to these nine scenarios, we included scenarios for a painless fatal stroke and for a state of perfect health.

We tested the scaling validity of the severity classifications by asking three neurologists who specialize in stroke care to rate the severity of each stroke scenario on a 9-point scale. To qualify for inclusion, a scenario rating had to meet two criteria. First, the range of physicians’ ratings had to be no larger than 2 points. Second, the mean score needed to be ≤3 points for mild, between 4 and 6 for moderate, and ≥7 for severe categorization.

Survey Administration

Our patient population consisted of all outpatients referred to the neurodiagnostics laboratory at the Hospital of the University of Pennsylvania for ultrasound evaluation of their carotid arteries. One of us (C.J.R.) conducted all of the interviews, including asking patients for consent to participate, collecting demographic data, and administering the preference assessment instrument.

Each subject was given cards in random order describing the 10 stroke scenarios. The subjects were asked to rank the scenarios in increasing order of aversion. Subjects were told that the scenarios were intended to represent the final consequences of strokes (ie, these conditions would be permanent). They then scored the 10 stroke outcomes on a 100-point scale in the following manner. They were told to assign scores of 0 and 100, respectively, to the worst scenario and a scenario describing a perfect state of health. Next they were asked to choose the scenario that fell halfway between those two extremes and score it as a 50. This scenario could have been found on any of the remaining cards, not necessarily the card in the middle of the ranking sequence. If no scenario fell midway between, the subjects were instructed to find the one that came the closest to the midpoint and give it the score they felt appropriate. The rest of the scenarios were then valued according to the anchor score that the participants had created. The subjects reviewed their choices to allow for reevaluation once all scenarios had been considered. In the resulting preference assessments, low rankings and high absolute scores correspond to more favorable stroke outcomes.

Data Analysis

The data are reported as both rankings and scores for the descriptive analysis, but statistical analysis was performed only on the scores. The data were analyzed for differences in scoring between individual case scenarios, for differences in scoring across severity categories and stroke types, and for differences in scoring by demographic characteristics. Evaluation of individual scenario scores was performed using paired t tests. Data were aggregated using the arithmetic means of individual scenario scores as appropriate (ie, the nonfatal outcome score was the arithmetic mean of all of the nonfatal scenario scores). Comparisons of aggregated scenario scores were made using ordinary least-squares multiple regression analysis where scores were used as the dependent variable and dummy variables were constructed as the independent variables.

Because of the large number of comparisons made in the analysis, we required a probability value of .01 to consider a difference statistically significant for this study.

Results

One hundred seventeen of 209 eligible subjects agreed to participate (Table 2). The mean age was 73 years. Most subjects reported themselves as being chronically ill, and none had suffered a previous stroke. Forty-four percent were women. Participants were similar to those who declined inclusion in average age (P=.4) and ethnicity (P=.2). However, women were more likely to refuse to participate in the survey (P=.03). Level of education and level of chronic illness could not be compared reliably between the two groups because of the high rate of refusal to provide such information among those declining to participate in the preference assessment. The majority of participants had completed high school, half had some education beyond high school, and few had graduated from college. The most common reason for refusing to take part in the experiment was discomfort with the study protocol (73% of refusers), followed by time constraints (15%).

The mean rankings of all 117 participants are presented in Table 3, and the corresponding mean scores are displayed in Table 4. For Table 3, the worst rankings are represented by the highest absolute numbers. For Table 4, the worst raw scores are represented by the lowest absolute numbers.

There was a progressive decline in acceptability from the mild to the severe stroke scenario in each of the three categories of deficit, both according to rank and absolute scores. Consensus was lacking among patients regarding preferences for the mild and moderate deficits, however, as is reflected by the large standard deviation in scores on the mild and moderate deficit scenarios.
deviations for these scores. By contrast, the severe deficits are rated as uniformly undesirable by patients, as reflected by their small standard deviations. The score for fatal stroke was 10±14.

Motor deficits were the least preferable of the impairments. Mean motor deficit scores were 6 points less than language deficit scores (P<.01). Severe motor deficit had a lower score than the painless fatal stroke (P<.01). Severe language deficit had a higher score than death by absolute score (P<.01). We failed to detect a statistically significant difference between severe cognitive deficit and death (P=.20).

There was a difference in stroke preferences between the sexes. Women assigned scores with lower values (ie, more undesirable) than did men to eight of the nine nonfatal scenarios. This difference approached significance when all nonfatal outcome scores were summarized and compared by sex (P=.04), but we failed to detect statistically significant differences for individual outcomes. In contrast, men scored the fatal stroke 6 points lower (ie, worse) than did women (P=.03).

**Discussion**

Our study evaluated patient preferences for the common consequences of stroke and death in at-risk patients. The aggregate scores for each severity level (51.0 for mild, 40.2 for moderate, and 8.4 for severe strokes) can be used to quantify more accurately the alternatives in the management of diseases that may lead to stroke. These results can be used in decision analytic models to evaluate medical therapies or can be used to help patients make more informed decisions about their care.

The paramount aversion to a severe motor impairment was perhaps our most surprising result. Patients scored the dense disabling hemiplegia as significantly worse than general confusion, global aphasia, and death. This preference held regardless of the patient's level of education. This finding may reflect a fear of dependence and isolation among this elderly urban cohort who likely rely heavily on mobility to preserve their autonomy.

**Clinical Application**

Our findings have direct reference to several clinical problems. For example, several recent trials of endarterectomy for carotid stenosis have shown clinical benefit in both mortality and morbidity when stenosis is symptomatic and high grade.6 8 Trials in asymptomatic patients or those with less severe stenosis, on the other hand, appear to have found that the procedure has no clinical benefit.30 However, these trials did not report breakdowns of strokes by severity or type of dysfunction; if differences existed, applications of preference weights might provide insight into the appropriateness of endarterectomy for asymptomatic patients.

Second, while the five recent trials of anticoagulation in atrial fibrillation all demonstrated reduced risk of embolic events and low bleeding rates for patients who take warfarin, there may be subpopulations whose conditions are worsened as a result of therapy. The studies compared embolic strokes to bleeds (including intracerebral hemorrhage) but did not compare the overall damage from these two types of events. If hemorrhagic events are more severe, some patients might wish to risk a potentially less disabling event by substituting aspirin or by not taking medication. For example, young patients with lone atrial fibrillation, who might wish to risk a potentially less disabling event by substituting aspirin or by not taking medication. For example, young patients with lone atrial fibrillation, who might wish to risk a potentially less disabling event by substituting aspirin or by not taking medication.

The magnitude of the aversion to stroke found in our study is surprisingly large. Previous physician estimates of the average disutility caused by strokes are found in published decision analyses. Both Naglie and Detsky and Eckman and colleagues (CASANOVA Study Group) assumed the utility for victims of disabling strokes to be 0.5 on a scale of 0 to 1 (where 1 is the perfect state of health analogous to our score of 100). Desbiens estimated utility of life with stroke to be 0.67 on the same scale. The values assigned by Matchar and Pauker (a utility of 0.8 [80 on our scale] to minor and 0.2 [20 on our scale] to major strokes) come closest to the scores that we measured empirically.

**Table 3. Results of Utility Assessment for Nonfatal Strokes: Rankings**

<table>
<thead>
<tr>
<th>Deficit</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language</td>
<td>2.6±1.4 (2)</td>
<td>4.4±1.6 (4)</td>
<td>7.4±1.6 (7)</td>
<td>4.8±2.5 (5)</td>
</tr>
<tr>
<td>Cognitive</td>
<td>2.8±1.6 (3)</td>
<td>4.8±1.6 (5)</td>
<td>8.3±1.4 (8)</td>
<td>5.5±3.1 (5)</td>
</tr>
<tr>
<td>Motor</td>
<td>3.6±2.2 (3)</td>
<td>3.9±2.0 (4)</td>
<td>9.2±0.9 (9)</td>
<td>5.6±3.1 (5)</td>
</tr>
<tr>
<td>Total</td>
<td>3.0±1.8 (3)</td>
<td>4.3±1.8 (4)</td>
<td>8.3±1.5 (8)</td>
<td></td>
</tr>
</tbody>
</table>

Values are expressed as mean±SD (median). Rank ordering of stroke scenarios by patients from best to worst. Perfect health was assigned a ranking of 1. Death had a ranking of 8.2±1.8 (9).

**Table 4. Results of Utility Assessment for Nonfatal Strokes: Raw Scores**

<table>
<thead>
<tr>
<th>Deficit</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Language</td>
<td>54±21 (55)</td>
<td>40±21 (40)</td>
<td>15±14 (10)</td>
<td>36±25 (35)</td>
</tr>
<tr>
<td>Cognitive</td>
<td>54±21 (50)</td>
<td>37±21 (40)</td>
<td>8±9 (5)</td>
<td>33±26 (25)</td>
</tr>
<tr>
<td>Motor</td>
<td>45±23 (45)</td>
<td>43±22 (50)</td>
<td>3±4 (1)</td>
<td>31±27 (25)</td>
</tr>
<tr>
<td>Total</td>
<td>51±22 (50)</td>
<td>40±22 (40)</td>
<td>8±11 (5)</td>
<td></td>
</tr>
</tbody>
</table>

Values are expressed as mean±SD (median). Average scores assigned for stroke scenarios by patients. Perfect health was assigned a score of 100. Death had a score of 9.8±14 (5).
cerebral bleeding may be higher than that of patients who were followed in the trials.

Third, our findings may apply to the literature on thrombolytic therapy for acute myocardial infarction. Stroke is one of the major outcomes in these trials, and the rates of stroke differ for the various thrombolytic agents. In circumstances where the difference in efficacy between agents is small, the variation in their stroke rates and types may influence the decision of whether to administer thrombolytic therapy and which agent to use.

Limitations

There are several limitations to our study. Our method did not address strokes that leave patients with combined impairments, such as a memory deficit and hemiplegia. We do not know if preferences for such deficits are additive based on the disutility of each of the individual deficits or are combined by some other complex function. Thus, we cannot comment on patient preferences for combined impairments. We also cannot comment on neurological deficits other than those we directly assessed. We chose motor, language, and cognitive deficits for our study because they represent common consequences of carotid distribution strokes.

In our analysis, we report a large number of comparisons of patients' results, both by severity level and by type of deficit. Thus, we are at increased risk that the associations we detected could have resulted from chance alone. We have attempted to correct for this issue of multiple comparisons by using a conservative threshold of statistical significance, \( P \leq .01 \). However, our correction may not have been sufficient to prevent us from reporting a chance result as a statistically significant finding. Repeat experiments of this type should be performed to validate our findings.

There are several methods currently used to assess preferences. No clear consensus has emerged as to the best technique. We chose to use a rank-and-scale technique, a simple method, to improve patients' understanding of the task required. Other procedures for assessing preference, such as standard reference gamble, ask patients to reveal their preferences under conditions of risk. There is a theoretical distinction between patient preferences assessed using a rank-and-scale method and those assessed using a risk-based preference measure: the results of these differing types of surveys may not represent the same concept of health in the patient's mind. For this reason, preferences reported elsewhere for other medical conditions may not be fully comparable with our findings.

Our results must be considered in light of the large number of nonresponders. We do not know whether patients who refused to take part in the study would have had different preferences, but according to the demographic data that we collected on all eligible subjects, the refusers were not significantly different from the participants.

Our survey assessed patient preferences of patients at risk for stroke. It is these patients who have to make decisions about potential treatment options to reduce their risk of stroke. Patients with completed strokes may have preferences for their health states that differ from those we measured in this study. There may be many reasons for this difference, including patients' adaptation to their clinical condition or belief that their clinical status will improve. However, we believe that the preference assessments we report are important, as it is on these assessments that patients rely when making treatment decisions.

Our patient population was elderly, and we speculate that this factor may have led them to fear severe motor strokes more than any other. For patients enrolled in the recent carotid endarterectomy trials, the range of mean ages for the various trials was 64 to 66 years. Range of mean ages in the atrial fibrillation trials was 67 to 75 years. Our patients were slightly older than the average but not substantially different in age from the typical patient who is at risk for or who has suffered a stroke.

Summary

The results of this analysis help clarify the values that patients assign to common consequences of stroke. By understanding preferences for various stroke outcomes, we can make better decisions for resource allocation in health policy implementation. Furthermore, knowledge of these stroke preferences may give physicians insight into the values of future patients and can provide a reference point for patients considering their own values. In addition, our taxonomy of common stroke outcomes may help future researchers who design trials to clarify their measurements of strokes.

Appendix

Case Descriptions

Mild Language Deficit

You suffer a stroke that causes you to slur your words. Listeners can still understand what you have to say, but it is apparent that your speech is not normal. Your thoughts remain clear and your understanding of language has not changed. Your limbs are not affected.

Moderate Language Deficit

You suffer a stroke that leaves your speech impaired to the extent that others cannot understand your words. You can still write and understand language as well as ever. Your thoughts remain clear, and your limbs are unaffected.

Severe Language Deficit

You suffer a stroke that takes away your ability to understand language. You no longer understand anything being said to you, and when you attempt to reply it makes no sense to the listeners. The rest of your thoughts are clear, but you are unable to express them to others. Your thoughts are otherwise unchanged, and your limbs are not affected.

Mild Cognitive Deficit

You suffer a stroke that leaves you occasionally searching for the word that names an item (such as "television," "spoon," and "apple"). You can still make use of these objects without any difference from before. You are still able to speak with a normal voice and your message is clear, but there are times when you cannot find the word you wish to use. You can still understand language without change, your thoughts are clear, and your arms and legs are unaffected.

Moderate Cognitive Deficit

You suffer a stroke that leaves you with problems remembering recent events. For example, you have difficulty remembering directions to familiar places, where you left your keys,
Fatal Stroke

You suffer a stroke that leaves you unconscious. You feel any pain from the stroke. Several hours later you die without ever waking up. You never recognize family and friends most of the time, but your ability to participate in most activities is limited. Your speech and limbs are unaffected.

Perfect Health

You are in a state of perfect health.

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