A failure to communicate: patients with cerebral aneurysms and vascular neurosurgeons

J T King Jr, H Yonas, M B Horowitz, A B Kassam, M S Roberts

Objective: To assess communication between vascular neurosurgeons and their patients with unruptured cerebral aneurysms about treatment options and expected outcomes.

Methods: Vascular neurosurgeons and their patients with cerebral aneurysms were surveyed immediately following outpatient appointments in a neurosurgery clinic. Data collected included how well the patient understood their aneurysm treatment options, the risks of a poor outcome from various treatments, and the consensus ‘best’ treatment. Patient and neurosurgeon responses were measured using Likert scales, multiple choice questions, and visual analogue scales. Agreement between patient and neurosurgeon was assessed with kappa scores. The Wilcoxon sign rank test was used to compare visual analogue scale responses.

Results: Data for 44 patient–neurosurgeon pairs were collected. Only 61% of patient–neurosurgeon pairs agreed on the best treatment plan for the patient’s aneurysm (κ = 0.51, moderate agreement). Among the neurosurgeons, agreement with their patients ranged from 82% (κ = 0.77, almost perfect agreement) to 52% (κ = 0.37, fair agreement). Patients estimated much higher risks of stroke or death from surgical clipping, endovascular embolisation, or no intervention compared with the estimates offered by their neurosurgeons (surgical clipping: patient 36% v neurosurgeon 13%, p < 0.001; endovascular embolisation: patient 35% v neurosurgeon 19%, p = 0.040; and no intervention: patient 63% v neurosurgeon 25%, p < 0.001).

Conclusions: Following consultation with a vascular neurosurgeon, many patients with cerebral aneurysms have an inaccurate understanding of their aneurysm treatment plan and an exaggerated sense of the risks of aneurysmal disease and treatment.

 METHODS

Study population

As part of a study on quality of life in patients with cerebral aneurysms, between June 2001 and February 2004 we surveyed patients and their treating neurosurgeons in neurosurgical clinics at the University of Pittsburgh Medical Center. Informed consent was obtained from all patients prior to data acquisition, and the institutional review boards of the University of Pittsburgh and Yale University approved the protocol. Using structured interviews, surveys, and medical record extractions, we collected data on demographics, education, cognitive function using the Mini Mental State Exam (MMSE), medical history, habits, and aneurysm characteristics and treatments. Immediately following their appointment with a vascular neurosurgeon, patients with an unsecured aneurysm (whether or not previously treated) were given a one-page written questionnaire about aneurysm natural history, treatment options, treatment decisions, and expected outcomes. The treating neurosurgeon was asked to complete a similar questionnaire. Three vascular neurosurgeons participated in this study—one of whom was also fellowship-trained in interventional neuroradiology.

Questionnaire design

The questionnaires asked patients and neurosurgeons to rate:

Abbreviation: VAS, visual analogue scale
(1) the patient’s understanding of treatment options
(2) the “best” treatment as agreed upon by the patient and neurosurgeon
(3) the risk of stroke or death from attempted treatment or the future risk of death and stroke with no intervention (see appendix online at http://jnnp.bmjournals.com/supplemental/).

We used six point Likert scales ranging from “strongly agree” to “strongly disagree” to assess the appropriateness of various treatment options and how well the patient understood them. Patients and neurosurgeons were next asked to specify which treatment option they had agreed was best for that patient. Finally, the patients and neurosurgeons marked 10 cm horizontal visual analogue scales (VAS) to indicate their estimate of the risk (0–100%) of stroke or death for the patient from surgical clipping and endovascular embolisation, and cumulative risk of stroke or death over the next 20 years with no aneurysm treatment intervention.

Data analysis
Demographics, education, cognitive function, medical history, habits, and aneurysm characteristics and treatments were tabulated, and medians, quartiles, means, and standard deviations were calculated for continuous variables. Likert scale responses were collapsed into three categories: agree (strongly agree, moderately agree), unsure (mildly agree, mildly disagree), and disagree (moderately disagree, strongly disagree). Paired patient–neurosurgeon Likert scale responses and consensus treatment responses were compared using unweighted kappa scores. Kappa scores assess how closely two raters agree beyond that expected from chance alone and quantify agreement as follows: 0–0.20, slight agreement; 0.21–0.40, fair agreement; 0.41–0.60, moderate agreement; 0.61–0.80, substantial agreement; and 0.81–1.00, almost perfect agreement. In a secondary analysis of paired patient–neurosurgeon responses, we combined the options that did not involve immediate action and that might be confused by patients (“leaving it alone” and “think about it more and decide later”). Paired patient–neurosurgeon VAS responses were compared using the Wilcoxon signed rank test. The characteristics of patient respondents and non-respondents were compared using the Wilcoxon sign rank test. Differences in responses across the neurosurgeons were assessed with the Kruskal–Wallis test. Results were formatted to preserve the anonymity of the neurosurgeons. Two tailed p values <0.05 were considered significant.

RESULTS
Study population
A total of 122 patients with one or more unsecured aneurysms consented to participate in the research study. Of these, 74 patients completed crucial elements of the post-appointment questionnaire and neurosurgeons completed the questionnaire for 73 patient visits; the resulting 44 paired patient–neurosurgeon responses are the basis for this analysis. Deficiencies in data collection were caused by refusal to complete surveys because of lack of interest or time constraints, illegible written responses on survey forms, or scheduling conflicts that prevented research staff from administering the survey forms. The 44 analysable patients were predominantly women (75%) and white (93%) with a mean (SD) age of 56.9 (12.5) years (table 1). Of these, 43% of patients had multiple aneurysms, 87% of aneurysms were located in the anterior circulation, 30% had a history of subarachnoid haemorrhage, and 34% had undergone a previous attempt at aneurysm obliteration. There were no significant differences between the non-respondents and the patients included in the analysis with respect to age, sex, race, education, cognitive function, smoking, hypertension, number of aneurysms, aneurysm locations, history of subarachnoid haemorrhage, or previous aneurysm treatment (for all, p>0.274). The patient populations of the three neurosurgeons were similar with respect to demographics, education, cognitive status, hypertension, past cigarette use, number of aneurysms, and previous aneurysm treatment (for all, p>0.102). One neurosurgeon had more patients who currently smoked cigarettes (p=0.005) and one neurosurgeon had a greater proportion of patients with posterior circulation aneurysms (p=0.026).

Agreement was surprisingly low when patients and neurosurgeons were asked to select what treatment they had agreed upon together (fig 1). Overall, only 61% of patient–neurosurgeon pairs agreed on the treatment plan (k = 0.51, moderate agreement). There were large differences between how closely each neurosurgeon and their patients agreed on the consensus treatment plan. Concordance for the three neurosurgeons ranged from a high of 82% agreement (k = 0.77, substantial agreement) to 67% agreement (k = 0.52, moderate agreement) and to 52% agreement (k = 0.37, fair agreement). In the secondary analysis adjusting for possible patient confusion among similar treatment options, the 64% agreement (k = 0.54, moderate improvement) was only slightly improved compared with the baseline analysis. Patients with a high school diploma showed better agreement with their neurosurgeon (k = 0.56, moderate agreement) than patients with less education (k = 0.38, fair agreement). When asked to focus on a particular treatment (for example, surgical clipping), patients and neurosurgeons were in agreement from 49% to 60% of the time about the appropriateness of each treatment plan, with the corresponding kappa scores in the slight to fair agreement range (table 2).

Patients estimated much higher risks of stroke or death from surgical clipping, endovascular embolisation, or no intervention compared with the estimates offered by their neurosurgeons (fig 2). The mean estimates of the risk of stroke or death from surgical clipping were: patient 36% versus neurosurgeon 13% (p<0.001). The mean estimates of the risk of stroke or death from endovascular embolisation were: patient 35% versus neurosurgeon 19% (p = 0.040; and

<table>
<thead>
<tr>
<th>Table 1</th>
<th>Characteristics of the study population (n = 44)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>56.9 (12.5)</td>
</tr>
<tr>
<td>Mean (SD)</td>
<td>25–90</td>
</tr>
<tr>
<td>Range</td>
<td>75</td>
</tr>
<tr>
<td>Sex: women (%)</td>
<td>93</td>
</tr>
<tr>
<td>Race (%)</td>
<td>African American</td>
</tr>
<tr>
<td>Education: high school or technical school graduate (%)</td>
<td>84</td>
</tr>
<tr>
<td>Mini Mental State Exam (mean (SD))</td>
<td>23.5 (3.3)</td>
</tr>
<tr>
<td>Cigarette use (%)</td>
<td>Current 29</td>
</tr>
<tr>
<td>Past 71</td>
<td></td>
</tr>
<tr>
<td>Hypertension (%)</td>
<td>60</td>
</tr>
<tr>
<td>Number of aneurysms (%)</td>
<td>1 57</td>
</tr>
<tr>
<td>2 27</td>
<td></td>
</tr>
<tr>
<td>3 14</td>
<td></td>
</tr>
<tr>
<td>4 2</td>
<td></td>
</tr>
<tr>
<td>Aneurysm locations (%)</td>
<td>Anterior circulation 87</td>
</tr>
<tr>
<td>Posterior circulation 13</td>
<td></td>
</tr>
<tr>
<td>Previous subarachnoid haemorrhage (%)</td>
<td>30</td>
</tr>
<tr>
<td>Previous aneurysm treatment (%)</td>
<td>34</td>
</tr>
</tbody>
</table>
the mean estimates of the risk of stroke or death over the next 20 years without any intervention were: patient 63% versus neurosurgeon 25% (p

DISCUSSION
Cerebral aneurysms are a potentially devastating disease requiring consideration of complex information by neurosurgeons and patients before arriving at a treatment plan. There is no precise algorithm for selecting the “best” treatment plan, and several treatment options may be equally suitable. Clinical decision making requires the consideration of multiple factors, including aneurysm characteristics, the skill set and experience of the neurosurgeon, and patient preferences. We surveyed patients with cerebral aneurysms and their neurosurgeons following neurosurgery clinic appointments to obtain information on how well neurosurgeons communicated with their patients about treatment options, expected outcomes, and the treatment plan. In approximately 40% of encounters, the patient and neurosurgeon disagreed about which aneurysm treatment option was the best. In addition, patients consistently overestimated the stroke and death risks from an untreated aneurysm or the risks from surgical or endovascular treatment by a factor of 2–3 compared with risk estimates offered by their neurosurgeon.

Most reports of patient–doctor communication have studied encounters between patients and primary care doctors, where the emphasis is on obtaining information from the patient. Surgical consultations are fundamentally different—surgeons usually do most of the talking, focusing on patient education and counselling about treatment options. The literature is sparse on communication between surgeons and their patients. A study of surgeons and their patients with breast cancer found high rates of agreement on the choice of surgical treatment (88%). However, the patients were presented with only two treatment options (lumpectomy and mastectomy), compared with the six options presented to our patients with aneurysms (surgical clipping, endovascular embolisation, combined surgery and endovascular embolisation, serial

Table 2 Agreement between patients and neurosurgeons on specific treatments and comprehension of treatment options

<table>
<thead>
<tr>
<th>Survey question*</th>
<th>% Agreement</th>
<th>Kappa score†</th>
</tr>
</thead>
<tbody>
<tr>
<td>Surgery is the best treatment for my aneurysm</td>
<td>60</td>
<td>0.35</td>
</tr>
<tr>
<td>Coiling is the best treatment for my aneurysm</td>
<td>54</td>
<td>0.23</td>
</tr>
<tr>
<td>Leaving it alone is the best treatment for my aneurysm</td>
<td>55</td>
<td>0.26</td>
</tr>
<tr>
<td>Using MRI, CAT scans, or angiograms to watch my aneurysm is the best treatment for my aneurysm</td>
<td>49</td>
<td>0.17</td>
</tr>
<tr>
<td>By the end of my appointment today, I understood the treatment options for my aneurysm</td>
<td>90</td>
<td>0.16</td>
</tr>
<tr>
<td>By the end of my appointment today, I knew what the best treatment is for my aneurysm</td>
<td>80</td>
<td>0.34</td>
</tr>
</tbody>
</table>

*This is the survey format used for patients. Similar surveys were administered to the neurosurgeons.
†Interpretation of kappa scores: 0–0.20, slight agreement; 0.21–0.40, fair agreement; 0.41–0.60, moderate agreement; 0.61–0.80, substantial agreement; and 0.81–1.00, almost perfect agreement.
CAT, computed axial tomography; MRI, magnetic resonance imaging.
an aneurysm and aneurysm treatments less dangerous than their patients did, however, one neurosurgeon consistently gave the lowest mean risk estimates for surgical clipping, endovascular embolisation, and the untreated natural history. The lower estimates may reflect differences in the neurosurgeon’s patient population and/or a more sanguine view of aneurysm disease and treatment. The difficulties of communication between physicians and patients and the challenges of shared decision making have been the subject of several investigations. Some educational interventions aimed at improving the communication skills of practising doctors have been successful,15 16 but others have met with less promising results.17 18 One solution may be to teach better communication skills during medical school.19 Another approach is the use of computer technology to impart information to patients about their disease and treatment options. Computerised videodisc programs have shown benefit in educating patients with back pain,20 benign prostatic hypertrophy,21 22 menopausal symptoms,5 and ischaemic heart disease.23 Perhaps similar decision aids could be developed for patients with cerebral aneurysms, improving communication and patient decision making.

Although our results are both intriguing and consistent with research on other specialties, this study on communication between vascular neurosurgeons and their patients has two major limitations. Firstly, the survey response rate was relatively low, thus the study sample may not have been representative of the aneurysm patient population at our institution. A thorough comparison of respondents and non-respondents found no differences in demographics, education, cognitive function, habits, medical history, or aneurysm characteristics and treatments. Nonetheless, unmeasured differences in the study population may have biased the results. Secondly, our single site study may not be generalisable to other institutions, neurosurgeons, or aneurysm patient populations. Despite these shortcomings, our results are worthy of consideration and provocative enough to merit further investigation through validation studies performed at other institutions utilizing a broader selection of neurosurgeons.

Authors’ affiliations
J T King Jr, Section of Neurosurgery, VA Connecticut Healthcare System, West Haven, CT, USA
J T King Jr, Department of Neurosurgery, Yale University, New Haven, CT, USA
H Yonas, M B Horowitz, A B Kassam, Department of Neurological Surgery, University of Pittsburgh, Pittsburgh, PA, USA
M S Roberts, Section of Decision Sciences and Clinical Systems Modeling, Division of General Internal Medicine, Department of Medicine, University of Pittsburgh, Pittsburgh, PA, USA
M S Roberts, Center for Research on Health Care, University of Pittsburgh, Pittsburgh, PA, USA
M S Roberts, Division of General Internal Medicine, University of Pittsburgh, Pittsburgh, PA, USA
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REFERENCES
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