

## PAPER

# 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

See Editorial Commentary, p 467

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See end of article for authors' affiliations

Correspondence to:  
Dr J T King Jr, Section of  
Neurosurgery, VA  
Connecticut Healthcare  
System/112, 950  
Campbell Ave, West  
Haven, CT 06516, USA;  
Joseph.KingJr@  
med.va.gov

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**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 ( $\kappa=0.51$ , moderate agreement). Among the neurosurgeons, agreement with their patients ranged from 82% ( $\kappa=0.77$ , almost perfect agreement) to 52% ( $\kappa=0.37$ , 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.

There are numerous treatment options for patients with unsecured cerebral aneurysms, including surgical clipping, endovascular embolisation, no intervention, serial imaging, or combinations of the above. During the process of clinical decision making, neurosurgeons are the healthcare providers most often faced with the task of informing patients with cerebral aneurysms about their aneurysms and the treatment options. Informing patients about complex medical problems and treatments can be challenging, and, despite the best efforts of the doctor, patient comprehension is often imperfect. Most patients prefer to be informed about available treatment options and the associated risks,<sup>1–4</sup> and such information generally improves compliance with the treatment plan and treatment outcomes without increasing anxiety.<sup>3,5</sup> In contrast with the almost universal desire for information, patients vary in their desire to participate in decision making—younger patients tend to prefer more active involvement, whereas older patients often prefer a more passive role.<sup>4,6</sup>

To obtain a better understanding of communication between patients with cerebral aneurysms and their neurosurgeons, we studied patients and their neurosurgeons in a vascular neurosurgery clinic. We administered surveys immediately following clinic visits to assess what information had passed between the neurosurgeons and their patients about the natural history, treatment options, and expected outcomes of cerebral aneurysms. We then compared the responses of patients and their neurosurgeons for insights into communication about this complex topic.

## 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),<sup>7</sup> 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.<sup>8</sup> 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,  $p \geq 0.274$ ). 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,  $p \geq 0.102$ ). 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 ( $\kappa = 0.51$ , 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 ( $\kappa = 0.77$ , substantial agreement) to 67% agreement ( $\kappa = 0.52$ , moderate agreement) and to 52% agreement ( $\kappa = 0.37$ , fair agreement). In the secondary analysis adjusting for possible patient confusion among similar treatment options, the 64% agreement ( $\kappa = 0.54$ , moderate improvement) was only slightly improved compared with the baseline analysis. Patients with a high school diploma showed better agreement with their neurosurgeon ( $\kappa = 0.56$ , moderate agreement) than patients with less education ( $\kappa = 0.38$ , 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 1** Characteristics of the study population (n = 44)

Age (years)	
Mean (SD)	56.9 (12.5)
Range	25–90
Sex: women (%)	75
Race (%)	
Non-Hispanic white	93
African American	7
Education: high school or technical school graduate (%)	84
Mini Mental State Exam (mean (SD))	23.5 (3.3)
Cigarette use (%)	
Current	29
Past	71
Hypertension (%)	60
Number of aneurysms (%)	
1	57
2	27
3	14
4	2
Aneurysm locations (%)	
Anterior circulation	87
Posterior circulation	13
Previous subarachnoid haemorrhage (%)	30
Previous aneurysm treatment (%)	34

The **neurosurgeon** reports that they and their patient agreed to this aneurysm treatment plan

		Endovascular embolisation	Surgical clipping	Combined surgical and endovascular	Serial imaging	No intervention	Defer decision	Totals
The <b>patient</b> reports that they and their neurosurgeon agreed to this aneurysm treatment plan	Endovascular embolisation	4	0	0	0	1	0	5
	Surgical clipping	0	11	0	0	0	0	11
	Combined surgical and endovascular	0	0	1	0	0	0	1
	Serial imaging	0	4	0	4	6	2	16
	No intervention	0	0	0	1	5	0	6
	Defer decision	0	0	0	2	1	2	5
Totals		4	15	1	7	13	4	44

**Figure 1** Matrix of patient and neurosurgeon responses when asked to select the consensus “best” treatment for the patient’s aneurysm. Shaded cells indicate agreement between patients and neurosurgeons existed on 27/44=61% of survey pairs ( $\kappa=0.51$ , moderate agreement).

the mean estimates of the risk of stroke or death over the next 20 years without any intervention were: patient 63% versus neurosurgeon 25% ( $p<0.001$ ).

**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

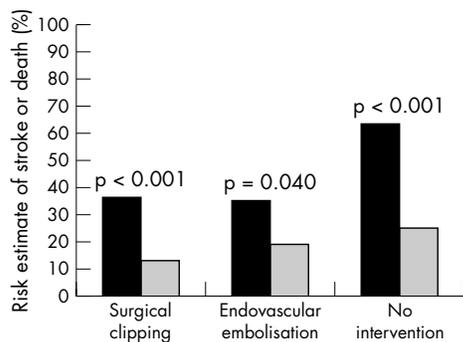
was the best. In addition, patients consistently overestimated the stroke and death risks from an untreated aneurysm or the risks from surgical or endovascular treatment by a factor of 2–3 compared with risk estimates offered by their neurosurgeon.

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.<sup>9,10</sup> 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%).<sup>11</sup> 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

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

\*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.



**Figure 2** Risks estimates by patients (black bars) and neurosurgeons (grey bars) for management of aneurysms by surgical clipping, endovascular embolisation, or no intervention.

imaging, no intervention, defer decision). The need to discuss and consider a greater number of treatment options may explain the relatively poorer communication seen in our study. Given the role of surgical consultant as patient educator and counsellor, our goal was to measure how well the neurosurgeon had conveyed crucial information to the patient about aneurysm treatment options, treatment risks, and expected outcomes.

Our data further indicate that vascular neurosurgeons and patients often do not recognise when there is a communication problem. Both parties thought that the patient understood their treatment options and knew the best treatment option, yet approximately 40% of patient–neurosurgeon pairs disagreed about the consensus treatment plan. One would hope that the vast majority of patients would understand the plan for their aneurysm treatment immediately after walking out of their doctor's office, yet apparently, this was not the case. Consistent with the inter-physician variability seen in other studies, we found substantial variation among the neurosurgeons in their ability to communicate the treatment plan to the patient successfully.

The patient responses indicate that most patients see aneurysms and aneurysm treatments as quite dangerous. Compared with their neurosurgeons, patients overestimated the risks of surgical treatment, endovascular treatment, and the untreated natural history of their aneurysm by a factor of 2–3. The mean patient risk estimates of stroke or death related to their aneurysm were impressively high: 36% for surgical clipping, 35% for endovascular embolisation, and 63% for the untreated natural history. Many patients have difficulty understanding probabilities and risks, tending to inflate large risks and minimise smaller risks.<sup>12</sup> If patients perceived that the chances of a poor aneurysm outcome are high, then we would expect their numerical risk estimates to be elevated. Problems with numeracy may also contribute to misunderstanding.<sup>13–14</sup> For example, many patients may not have had a good understanding of the annual rate of rupture of an unsecured aneurysm, let alone the cumulative long term risks. The shock of recently learning the details about the dangers of aneurysms and aneurysm treatments from the neurosurgeon may also have contributed to these elevated risk estimates.

Compared to their neurosurgeons, patients perceive that aneurysm natural history and treatment is two to threefold riskier. The outcomes estimates of the patients and neurosurgeons were doubtless influenced by multiple factors, including knowledge of aneurysm natural history and treatments; attitudes towards risk, disease, surgery, and death; and the effectiveness of communication between neurosurgeon and patient. All the neurosurgeons considered

aneurysms 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,<sup>15–16</sup> but others have met with less promising results.<sup>17–18</sup> One solution may be to teach better communication skills during medical school.<sup>19</sup> 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,<sup>20</sup> benign prostatic hypertrophy,<sup>21–22</sup> menopausal symptoms,<sup>5</sup> and ischaemic heart disease.<sup>23</sup> 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 utilising 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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