Inadequate Website Disclosure of Surgical Outcome of Intracranial Aneurysms
—Survey of 1225 Sites in Japan—

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Abstract

Social demand for the disclosure of medical information is increasing, especially the treatment for unruptured intracranial aneurysms. This study investigated to what extent information on the treatment for unruptured intracranial aneurysms is disclosed on websites in Japan. We surveyed 1225 institutions authorized by The Japan Neurosurgical Society. The following factors were analyzed: percentage of institutions with websites, disclosure of number of surgeries, and disclosure of outcome of treatment for ruptured and unruptured intracranial aneurysms. Of the 1225 institutions surveyed, 1097 (89.6%) had their own websites. The total number of websites was 1262 since some institutions have several homepages in different websites. The annual number of surgeries was shown in 274 of the 1225 institutions (22.4%). The outcome of treatment for ruptured intracranial aneurysms was disclosed in 104 of the 1225 institutions (8.5%). The outcome of treatment for unruptured intracranial aneurysms was shown in only 32 of the 1225 institutions (2.6%). Disclosure of outcome of treatment for unruptured intracranial aneurysms on websites is not common. To improve disclosure of the outcome on websites, guidelines should be established.

Key words: Internet, unruptured intracranial aneurysm, outcome

Introduction

The disclosure of medical information has become one of the most significant issues for the public. This disclosure involves a wide range of information, including both basic medical science and medico-social problems such as medical liability issues and medical accidents. Information on the outcome of the treatment is the most important for the public, since it is directly related to the behavior and decision-making of the patients. In particular, individual data on specific hospitals and physicians is useful for patients to select a hospital and physician.

The World Wide Web is becoming the most convenient source of healthcare information due to the remarkable development of the Internet and information technology. However, disclosure of outcome of treatment involves many complicated problems.

In this study, the disclosure of outcome of treatment for intracranial aneurysms in Japan was extensively analyzed based on data on the websites of 1225 institutions authorized by The Japan Neurosurgical Society. This is the first study investigating the extent of the disclosure of outcome of treatment for intracranial aneurysms on websites.

Subjects and Methods

I. Subjects

Most intracranial aneurysms are treated in hospitals authorized by The Japan Neurosurgical Society. There are 1225 hospitals registered by The Japan Neurosurgical Society (home page, http://jns.umin.ac.jp/) in October 2003. Briefly, the requirement for this authorization is that total number of surgeries has to exceed 100 cases per year and there should be more than two neurosurgeons qualified by The Japan Neurosurgical Society.

To survey the extent of disclosure of information...
### Table 1 Database on Excel file

<table>
<thead>
<tr>
<th>Number</th>
<th>Institution</th>
<th>District</th>
<th>Website</th>
<th>URL</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Asahikawa Med. Univ.</td>
<td>Hokkaido</td>
<td></td>
<td><a href="http://www.asahikawa-med.ac.jp/dept/mc/neuro/">http://www.asahikawa-med.ac.jp/dept/mc/neuro/</a></td>
</tr>
<tr>
<td>2</td>
<td>Hokkaido Univ.</td>
<td>Hokkaido</td>
<td></td>
<td><a href="http://www.med.hokudai.ac.jp/neuro/index.html">http://www.med.hokudai.ac.jp/neuro/index.html</a></td>
</tr>
<tr>
<td>5</td>
<td>Iwate Medical Univ.</td>
<td>Iwate Pref.</td>
<td></td>
<td><a href="http://www.iwate-med.ac.jp/univ/kouza/nouge.html">http://www.iwate-med.ac.jp/univ/kouza/nouge.html</a></td>
</tr>
<tr>
<td>6</td>
<td>Tohoku Univ.</td>
<td>Miyagi Pref.</td>
<td></td>
<td><a href="http://www.hosp.tohoku.ac.jp/">http://www.hosp.tohoku.ac.jp/</a></td>
</tr>
</tbody>
</table>

Only the first eight academic websites of 1225 institutions are shown.*

### Disclosure of Outcome on Website

by these 1225 hospitals, their websites were searched using the Internet search engines Yahoo! and Google. This survey was performed from May 2004 to June 2004.

#### II. Investigated items

**Percentage of institutions with websites:** The percentage of institutions with websites was examined. Some institutions had two or more homepages (one homepage included in the website of the main institution and another independent homepage). In such cases, the websites were considered as one.

**Disclosure of number of surgeries:** Disclosure of the annual number of surgeries was examined.

**Disclosure of outcome of treatment for ruptured intracranial aneurysms:** Whether outcome of treatment for ruptured intracranial aneurysms was disclosed or not was examined.

**Disclosure of outcome of treatment for unruptured intracranial aneurysms:** Whether outcome of treatment for unruptured intracranial aneurysms was disclosed or not was examined.

The enormous amount of data obtained from these websites of more than 1000 institutions was analyzed in an Excel spreadsheet (Microsoft Co., Redmond, Wash., U.S.A.) as shown in Table 1.

#### III. Additional analysis

Many interesting questions can be answered based on the vast database of information on the websites of these 1225 institutions. The following three questions were investigated.

Firstly, we considered whether urban institutions located in densely populated and competitive areas may disclose their outcome more than those located in underpopulated areas. To answer this question, the Tokyo metropolitan area as a sample of a densely populated area and the Hokkaido area, exclusive of Sapporo, as a sample of an underpopulated area were selected. The second question is whether academic institutions, such as university hospitals, disclose their outcomes more than other institutions. Finally, we speculated that high-volume hospitals disclose their outcome more than low-volume hospitals. Therefore, the third question is whether institutions that disclose outcomes on their websites have a greater number of surgeries compared to those that do not.

Initially we planned to analyze the outcome data, including mortality and morbidity of unruptured aneurysm treatment in Japan, based on the data obtained from websites. However, not enough quantitative data was obtained from the websites as disclosed in this paper.
Results

I. Main analysis

Percentage of institutions with websites: Out of 1225 institutions, 1097 (89.6%) had their own homepage. The total number of websites was 1262 since some institutions have several homepages in different websites.

Disclosure of number of surgeries: Among these 1225 institutions, the annual number of surgeries was disclosed in only 274 websites (22.4%).

Disclosure of outcome of treatment for ruptured intracranial aneurysms: Among the 1225 institutions, outcome of treatment for ruptured intracranial aneurysms was disclosed in 104 websites (8.5%).

Disclosure of outcome of treatment for unruptured intracranial aneurysms: The outcome of treatment for unruptured intracranial aneurysms was disclosed in only 32 websites (2.6%).

II. Additional analysis

Comparison between densely populated and underpopulated areas (Fig. 1): There were 68 institutions (27 “A ranked” and 41 “C ranked” hospitals) in the Tokyo area (23 districts) and 57 institutions (29 “A ranked” and 28 “C ranked” hospitals) in the Hokkaido area. There is no significant difference between the Tokyo and Hokkaido areas in the density of the neurosurgical institutions per unit population. However, the institutions in the Tokyo area had a greater percentage of websites (92%) compared to the Hokkaido area (76%) (p = 0.009, chi-square test).

Comparison between academic and other institutions: All academic institutions had websites (100%). This was significantly higher than other general neurosurgical institutions (84.0%) (p < 0.001, chi-square test). However, the content on the academic institution websites was not always satisfactory since disclosure of the annual number of surgeries was only 10% and disclosure of outcome of treatment for ruptured and unruptured aneurysms was 7% and 3%, respectively.

Disclosure of outcome of treatment for unruptured intracranial aneurysms as related to number of surgeries (Fig. 2): A significant difference was seen between 45 institutions that disclosed outcome of treatment for unruptured intracranial aneurysms and those that did not. Institutions that disclose their outcome had a significantly larger number of annual surgeries than those that did not. Values are given as mean ± SD (p < 0.001, Mann-Whitney U test). Median value was 264 and 170 and interquartile range (IQR) was 220 and 134, respectively.
Disclosure of Outcome on Website

The brain check-up system called “Brain Dock” is well developed in Japan. People who want to check for asymptomatic cerebral infarction and unruptured aneurysm can select hospitals that provide the “Brain Dock.” The “Brain Dock” includes both imaging examinations such as brain magnetic resonance (MR) imaging, neck vascular imaging using MR angiography, and/or Doppler ultrasonography, and general medical checks such as blood examination, blood pressure, and other options. There are requirements for the quality of imaging regulated by the Japanese Society for Detection of Asymptomatic Brain Diseases (homepage, http://www.snh.or.jp/jsbd/).

The spread of this system has affected Japanese society, including the diagnosis of unruptured intracranial aneurysms in healthy people and treatment to prevent subarachnoid hemorrhage. Unruptured intracranial aneurysms have been identified in more than 6% of people who underwent the “Brain Dock” using high quality MR angiography.

The Japanese Society for Detection of Asymptomatic Brain Diseases recommends that the outcome should be disclosed in the homepage of each hospital (http://www.snh.or.jp/jsbd/). The present study has shown that this advice has not been followed. Necessary information for patients who have unruptured intracranial aneurysm identified by the “Brain Dock” is not well disclosed on websites. Websites that offer information on the outcome of treatments are not common. While patients can directly ask physicians in the outpatient clinic for general information on unruptured intracranial aneurysms, it is not always easy to ask directly about the outcome of treatment. Other sources such as “Guide of Best Hospitals” and “Guide of Best Doctors” do not always provide correct information. Therefore, websites are an important source of information for patients, since it is easy to access and the cost is low. On the Internet, patients can see the outcomes and strategies of other hospitals. However, our results revealed that this important source of information is not widely available.

Unruptured intracranial aneurysm is not a newly established disease, but has been one of the most important diseases for neurosurgeons for a long time. However, the swift spread of high resolution MR angiography revealed an unexpectedly high incidence of unruptured intracranial aneurysms in healthy people. This disease has provoked controversy among medical professionals and the public. The natural history of unruptured intracranial aneurysms also remains controversial, and is still under investigation.

Discussion

On the other hand, outcome disclosure is not easy from the viewpoint of hospitals and physicians that are subject to disclose information to the public. Complicated problems arise when information about medical outcomes are disclosed. For example, if no guidelines for the disclosure of medical outcome on the Internet exist, physicians may be hesitant to do so. In addition, outcome evaluation in surgery is also controversial. There is no gold standard to evaluate outcome of treatment for unruptured intracranial aneurysms. In addition, some data may be involved in ongoing lawsuits or medical liability cases. Even in the absence of legal problems, institutions may hesitate to publish their data, unless the outcomes have been excellent. In addition, since each institution and any individual can set up a homepage without restriction or control, there is a risk of deliberate modification of data. It is easy to spread biased information for commercial purposes on the Internet.

The present study revealed that only 2.6% of 1225 institutions in Japan disclosed outcome data of treatment for unruptured intracranial aneurysms on websites. This number is lower than we had expected when we launched this study. In other words, at present it is practically impossible for patients to obtain data on unruptured intracranial aneurysms.
from individual institutions using the Internet. This problem does not seem to be specific to Japan, although there is no international comparative study on websites of medical information. Surgery for unruptured aneurysms is likely to increase in Europe, North America, and Korea. To provide the best information to patients, the creation of the websites is important. For this purpose, we need to establish minimum guidelines and ethics for the disclosure of outcome on websites.

There is no question that establishment of the appropriate guidelines is indispensable for improved treatment for unruptured intracranial aneurysms. However, at present, we do not have any reliable or scientific standards to compare the complicated outcome of such treatment. It is true that the outcome is seriously affected by the expertise of surgeons and endovascular surgeons. However, other factors such as the characteristics of the patient including the aneurysm size, location, and risk factors are strongly related to the outcomes. In other words, simple exposure of the outcome without adequate guidelines may invite unfair interpretation of the competence of hospitals and neurosurgeons. In order to prevent this unfavorable trend, the establishment of adequate guidelines based on the peer review system is required without delay.

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References

1) [Anonymous]: The web of information inequality. Lancet 349: 1781, 1997 (editorial)

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Disclosure of Outcome on Website


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