Key Points

1. Newspapers are a trusted source of medical information
2. Study analyzed major newspaper coverage of 10 neurological conditions for stigmatizing language and errors
3. Found no correlation between the prevalence of a disease and the amount of coverage
4. Alzheimer's/dementia was the most covered condition with 400 stories out of 1203 total
5. Stigmatizing language was found in 15% of the stories
6. Epilepsy and migraines had the highest frequency of stigmatizing language
7. 20% of stories had medical errors or exaggerations

Definitions

cerebellar tonsils - portion of the cerebellum located at the bottom, so named because of their shape

cerebellum - part of the brain located at the bottom of the skull, near the opening to the spinal area; important for muscle control, movement, and balance

cerebrospinal fluid (CSF) - clear liquid in the brain and spinal cord, acts as a shock absorber

Chiari malformation I - condition where the cerebellar tonsils are displaced out of the skull area into the spinal area, causing compression of brain tissue and disruption of CSF flow

decompression surgery - general term used for any of several surgical techniques employed to create more space around a Chiari malformation and to relieve compression

Source

Media Of Neurological Conditions Error Prone

May 20, 2006 -- Despite recent dramatic declines in circulation, newspapers are among the most trusted sources of medical information for most Americans. According to a Gallup poll (from a couple years ago), TV and the internet are a frequent source of health news and information, but people remain cautious about its credibility.

Not surprisingly, doctors are the number one trusted source of health information, followed by books and newspapers. By being put in a position of trust, and given the serious nature of medical news, reporters - whether they want to or not - have a duty and responsibility to accurately portray medical conditions. This is especially true in local papers because medical stories often focus on the situation of specific individuals and families.

To see how well newspapers do in this regard, a group of researchers from the Arizona State School of Journalism and the Mayo Clinic neurology department at Scottsdale (Caspermeyer et al) analyzed the coverage of 10 neurological conditions in 8 major newspapers (see Table 1) for the year 2003. They published their results in the March, 2006 issue of the journal Mayo Clinic Proceedings.

Table 1
Newspapers Used In Study

Paper	Weekday Circulation
Arizona Republic	449,000
Atlanta Journal-Const.	461,000
Boston Globe	448,000
Chicago Sun-Times	314,000
Houston Chronicle	552,000
New York Times	1,055,000
San Diego Union-Tribune	373,000
Seattle Times	215,000
Virginia Pilot	220,000

The research team used Lexis-Nexis, a commercial database service, to search the 2003 issues of the newspapers (all with circulations over 200,000) for articles on the following conditions: Alzheimer's/dementia, Parkinson's, stroke, MS, epilepsy, Creutzfeld-Jakob, brain tumor, migraine, ALS, and traumatic brain injury. To check the accuracy of the articles, two neurologists independently reviewed a statistical sampling of the stories for medical errors and exaggerations.

The team was also interested in the way specific diseases were depicted and every article was reviewed by two independent coders for the use of stigmatizing language. For the purposes of the study, stigmatizing language was defined as wording that portrayed a patient with the condition as socially undesirable, less desirable, or reduced in physical worth. The researchers felt this was important because many people with a chronic illness - especially one that involves the brain - can feel marginalized and struggle with identity issues. It should be pointed out, however, that in reviewing the articles the accuracy of stigmatizing language was not considered, just that it was used.

Their analysis identified 1,203 articles from the eight newspapers during that year. Interestingly, there was no real association between the prevalence of a condition - meaning how many people have it - and the number of articles that were written about it (see Table 2). In fact, some of the most common neurological problems, such as migraines and traumatic brain injury, were the least covered in the selected papers. In contrast, Alzheimer's/dementia was written about the most and accounted for nearly one third of the total articles. Parkinson's, stroke, and MS were also at the top of the list.

Table 2
Coverage By Disease Type

Disease	Prevalence per 100,000	# of Stories (1203 Total)
Alzheimer	250	400

Caspermeyer JJ, Sylvester EJ, Drazkowski JF, Watson GL, Sirven JI.
Evaluation of stigmatizing language and medical errors in neurology coverage by US newspapers.

Mayo Clin Proc. 2006 Mar;81(3):300-6.

Parkinson	200	177
Stroke	625	158
MS	60	128
Epilepsy	650	114
CJD	<1	79
Brain Tumor	60	65
Migraine	2000	34
ALS	6	29
Traumatic Brain Injury	600	19

When the neurologists reviewed the sample of articles for accuracy, they found an alarming 20% contained clear errors or exaggerations. Just like total coverage, Alzheimer/dementia and Parkinson's accounted for a majority of the errors. The types of errors included an exaggeration of symptoms and overstating the promise of new treatments which had only been tested in animals. The sample size used for the error analysis was such that statistically, it is very likely that there was a 20% error rate in all the articles.

Stigmatizing language was found in 15% of the stories overall, and was higher in locally produced stories than ones distributed via the wire services. Articles on epilepsy and migraines contained the highest frequency of stigmatizing language (30% and 29% respectively) followed by MS, dementia, and ALS. Unfortunately, 64% of the articles with stigmatizing language were focused on specific patients.

The researchers also analyzed who used the stigmatizing language and found that in more than half the articles (55%) the reporter was the source. Patients themselves were the source 25% of the time and family members 17%, highlighting how chronic neurological conditions can affect people's perception of themselves and loved ones.
Examples of what were counted as stigmatizing language include:

"I want my father back. This old geezer makes me mad."

"The victims of strokes can be terrible puzzles, a torture to families, and sometimes an ordeal for the courts."

To see where Chiari ranks in media coverage versus the conditions in this study, Chiari & Syringomyelia News used the same database service (Lexis-Nexis) to search for "chiari malformation" in all US newspapers (as opposed to just the 8 in this study) for 2003.

We found 33 references to Chiari, mostly in small local papers. In fact, there was only one article from a major newspaper. Also, 10 of the 33 were simply listing a support group meeting, and 3 were about a person who committed a crime to cover medical expenses. In the end, in every newspaper tracked by Lexis-Nexis, there were only a handful of articles which were really focused on Chiari. To make sure 2003 wasn't just an off year, we repeated the search for 2004 and found only 27 articles for that year.

Table 3
Total Newspaper Coverage Of Chiari Malformation, 2003

Total References = 33

References In Major Papers = 1

Support Group Listings = 10

Ref. In All Papers, 2004 = 27

Source: Lexis-Nexis search by Chiari & Syringomyelia News

Although this quick analysis did not check the Chiari articles for accuracy, that would be an interesting project. One item that jumps out from the media coverage of Chiari is that it is almost exclusively referred to as a rare or very rare condition. A rare disorder is defined by the National Organization of Rare Disorders as affecting fewer than 200,000 people in the US. Given the recent prevalence estimates of 300,000 and higher, it is not clear if Chiari is indeed rare, or if it is a lot more common than most people think.

The media, especially in the age of 24 hours news, hundreds of TV channels, and the ever pervasive internet, has a tremendous influence over how things are perceived. When dealing with topics as delicate, and critically important, as neurological conditions, reporters of all media types must take special care to create accurate stories which are sensitive to the patients they are covering.

Chiari & Syringomyelia News strives to be as accurate, objective, and compassionate as we possibly can. Given the sheer volume of information on the Conquer Chiari site, it is likely there are some errors, however we

have not received a single complaint from a medical professional regarding our content. To the contrary, we receive regular positive feedback from patients, family members, teachers, doctors, nurses, etc. In fact, several times, researchers have contacted us to say how happy they were at how we described their research. We have also heard that some neurosurgeons are now directing their newly diagnosed patients to the site for information.

In summary, we realize how important it is to be fair and accurate (especially given the results of this study), and we will honor our responsibilities.

-- *Rick Labuda*