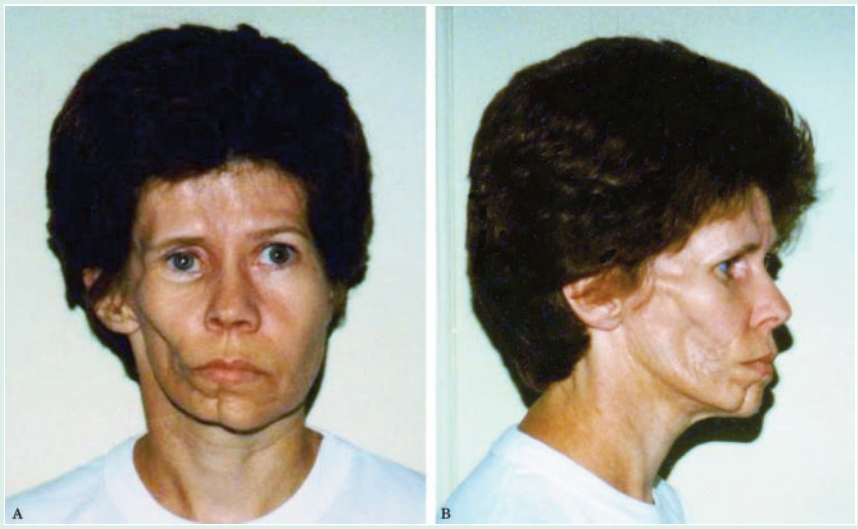
Parry-Romberg syndrome: Use of the Internet for clinical research

Jon Stone briefly notes the clinical features of 205 patients with the rare Parry-Romberg syndrome, demonstrating the potential value of the Internet for identifying patients with rare diseases and inviting them to participate in research on their disorder.

see page 674

Commentary by Michael H. Rivner, MD

The Internet now reaches over 500 million people worldwide, a number that may grow to 5 billion people within the next generation. We use the Internet as a source of medical information, either from sponsored sites or from medical journals. But the Internet can be a tool in research: its global reach allows wide dispersion of information about studies and allows medical information to be transmitted back to the research team.



This can be a powerful approach, particularly, as in this case, when the entity studied is relatively rare; however, caution should be exercised by both researcher and reader.[1] Although the Internet makes it easy and inexpensive to reach subjects who would otherwise be unable to participate in studies, those who choose to answer Web-based surveys are self-selected. Therefore, they may not be a representative subset of the total group.[2] As a result, conclusions based on quantitative data may be inaccurate unless one selects and validates subjects. Patients who are younger, healthier, more familiar with the Internet, and more focused on their disease are over-represented in such a study. The validity of information collected on the Internet may be compromised by subjects who might fraudulently claim to have a disease, fill out the survey multiple times, or not read the questions carefully. The use of cookies, subject validation, and recording the time it takes to complete the survey might help eliminate these problems but will also increase the complexity and cost of Web research.

In short, conclusions based on quantitative data acquired in this way may be inaccurate unless one selects and validates subjects and their information. Data collected on the Internet are less secure than in a more controlled environment. At the very minimum, Web interfaces must use SSL protection to prevent personal information from being intercepted.[3] Research databases must be properly secured to prevent unauthorized access. In order to protect the rights of human subjects and to be HIPAA complaint, Web surveys will need IRB approval. In most cases, informed consent is needed.

We may be seeing more studies using the Internet as a research tool. Whereas this approach has undeniable advantages allowing the researcher to collect data easily from a worldwide cohort of subjects, its limitations—outlined by the author—must be understood and the rights of human subjects must be protected.

References

1. Wyatt JC. When to use web-based surveys. J Am Med Inform Assoc 2000;7:426–430.
2. Eysenbach G, Wyatt JC. Using the Internet for surveys and health research. J Med Internet Res 2002;4:E13.
3. Kelly G, McKenzie B. Security, privacy, and confidentiality issues on the Internet. J Med Internet Res 2002;4:E12.

Glossary Cookies: These are files placed on the client's computer by the Web site host computer that contain information that can be read by the host computer any time the user connects to that site. Using a cookie, it is possible for Web software to know if that client computer has connected before.

SSL: Secure Socket Layer protocol. This is an encryption method that allows sensitive information to be transferred between the client computer and the host computer of a Web site.

see page 674

continued on page 594

MRI predicts MS in clinically isolated demyelinating syndromes

Frohman et al. analyzed prospective studies that utilized a baseline MRI in patients with clinically isolated syndromes to predict clinically definite multiple sclerosis (MS). This evidence-based assessment provides evidence that the presence of disseminated lesions at baseline is a strong predictor of future disease activity.

see page 602

Despite advances in MRI, MS remains a clinical diagnosis dependent on a high level of clinical expertise to distinguish symptoms indicative of a clinically isolated syndrome vs those of ongoing disease activity.

The accompanying editorial by Simon and Thompson notes that despite the potential value of MRI in the evaluation of clinically isolated syndromes, there remain issues to be clarified. In particular, MRI techniques and MRI interpretation are not sufficiently well-standardized to have confidence that MRI alone is sufficient for diagnosis of clinically definite MS. MS must still be considered a clinical diagnosis.

see page 596

Acute motor conduction block neuropathy

Capasso et al. report two patients with an acute, exclusively motor neuropathy, normal or brisk tendon reflexes, motor conduction block, normal sensory conduction, very high titer of immunoglobulin G to GD1a and GM1, and rapid recovery. They classify this neuropathy as a Guillain-Barré syndrome variant.

see page 617

In the accompanying editorial, Yuki and Saperstein review axonal variants of Guillain-Barré syndrome, discussing antecedent infections, associated antiganglioside antibodies, and presumed pathophysiology. They also highlight unique clinical features such as rapid recovery and preserved, or even brisk, reflexes.

see page 598

A cohort study of nonsystemic vasculitic neuropathy

Collins et al. reviewed their 20-year experience with nonsystemic vasculitic neuropathy, reporting that combination corticosteroid/cytotoxic therapy appeared more effective in inducing remission and improving disability than corticosteroid monotherapy and that cyclophosphamide treatment for >6 months decreased relapse rate. Neurologic prognosis was better than anticipated based on earlier reports.

see page 623

Tumoral epilepsy: A potentially curable cause of refractory seizures

Zaatreh et al. found that seizures in patients with refractory temporal lobe tumoral epilepsy responded favorably to surgical resection of the tumor, with better seizure control among patients with total tumor resection. Surgical intervention should be considered early as a therapeutic option in treating refractory tumoral epilepsy.

see page 636

Sterilize the "feebleminded"; Euthanize the "hopeless"?

M. Louis Offen discusses how William Lennox, an epileptologist, argued that "a passion for prolonging all lives, including the genetically unfit . . . violated nature's plans for humanity's improvement." Starting in the 1930s, he and Foster Kennedy, a President of the American Neurological Association, vigorously advocated sterilization for those "feebleminded" deemed potentially productive, and euthanasia for the "hopelessly unfit."

see page 668

continued on page 595

Poststroke pain: Where is the lesion?

Jong S. Kim reports 20 patients who developed poststroke pain after lenticulo-capsular hemorrhage. The symptom was usually severe in the leg, and probably caused by involvement of the thalamo-cortical sensory tract.

see page 679

Teddy bears with epilepsy?

Burneo et al. provide classification statistics on the behavioral observation that toy animals brought from home to an inpatient video/EEG seizure monitoring unit were uniquely associated with psychogenic seizure diagnosis in adults.

see page 714

September 9 Highlights

Neurology 2003;61;593-595
DOI 10.1212/WNL.61.5.593