Utility of Databases and Information Technology in Pediatric Neurology

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Summary

Significant number of neurological patients in the pediatric age group have genetic and/or metabolic basis. It is difficult to remember details of each of them as their number is very large and the disorders are encountered infrequently. This impracticality necessitates the use of various websites and data base search. The internet has become a tool by which one can obtain and disseminate information. It has enhanced the medical person’s ability to know at the earliest the developments in different medical specialities. Furthermore, these rare disorders are being recognized on the basis of specialized tests available only at selected centres which deal with few of these disorders. Our objective is to provide pediatric neurologists easy access to the expanding body of medical information and also to make them aware of the advancements in information technology, which is likely to facilitate telemedicine as a future consultancy service. Information about these diseases can also be facilitated by e-consultations.

Key words : Internet, Neurology, Pediatrics, Telemedicine, Websites.

Introduction

The medical information systems are improving day by day. Though the recent expansion of the internet services has yielded systematic compilation of large amount of useful information, it has not reached the real users in many developing countries, including India, due to lack of knowledge regarding its retrieval. The users include medical doctors, paramedical personnel, patients and patient’s family members. The information is most useful in newly evolving medical fields. Pediatric neurology is an upcoming medical subspeciality. The pediatricians and neurologists working in this area need to be able to receive updated information about the latest diagnostic techniques, management and research. Management of the individual cases can be facilitated by case discussions on the net and telemedicine consultations. Moreover, parents and family members of the patients can clear their queries regarding specific diseases by visiting certain websites. In view of these facts, an attempt has been made here to provide the latest information about the relevant websites and data bases and also to make
the fraternity aware of its utility. The usefulness of the whole information can be described as follows.

Information for Family / Caregivers

A large number of neurological diseases have been identified. The genetic basis of many of these has been unraveled and new information is increasing each day. In a busy clinic, the neurologist does not have enough time to explain various aspects of the disease in detail. The knowledge of the people in general has also improved with better educational facilities and access to television, internet etc. Hence, when a child is diagnosed to have a disease, the physician should be able to convey up-to-date information and also the options by which parents can learn more about the disease. The internet enables easy and fast access to medical information. Some of the sites are free, whereas some require registration and/or online subscription. Some of the sites provide separate information for physicians and patient/patient’s relatives. The child neurology home page site http://www.waisman.wisc.edu/child-neuro/index.html is one such site which has online resources for both professionals and patients. Information and guidelines for parents to talk to their children about their concerns and questions regarding adolescent mental disorders is available at www.aboutourkids.org/. Some of the recently discovered diseases have separate websites. A site especially dedicated to Rett syndrome is www.bundlings.com/irsg.htm. Several chronic diseases need interaction among the patients. For example, interactive pages for children with epilepsy are available at http://www.eqi.org.au/intro.htm and http://www.epilepsy.org.uk/kids/index.html. Patient and their relatives can participate in self-help at http://www.cafamily.org.uk/ and http://www.rare diseases.org. Such facilities are needed in developing world. Several options are now available for the family members to satisfy their queries that are otherwise not possible due to the busy schedule of the treating physician. In addition, telecom services, emails and personal website of the consulting physician can facilitate homecare for chronic neurological disorders like stroke, epilepsy, mental retardation etc.

Information for Physicians

Internet gives unlimited information regarding hundreds of diseases. Anatomy, physiology, radiology and genetic information can be accessed and one can increase one’s knowledge about ongoing research in the field. The website www.neuro.wustl.edu/neuromuscular/lab/patterns.html gives general approach to neuromuscular diseases with nice diagrams in addition to disease specific information. The Baylor College of Medicine website www.bcm.tmc.edu/neuro/ is especially for scientists working on DMD/BMD and Duchenne like muscular dystrophies. The genes and proteins involved and the diagnostic techniques are in updated form. The human gene mutation database http://www.uwcm.ac.uk/uwcm/mg/hgmdO.html is available through the Institute of Medical Genetics at Cardiff. Latest news on epilepsy is accessible at http://www.neuro.wustl.edu/epilepsy.currentnews.html website. Another valuable website is www.neuroguide.com has detailed data for over 100 neurological and psychiatric disorders along with links to other sites and several neurological journals. The site http://www.neuroscience.center.com/book store/bstore 06.htm provides information about books on neurology.

Solutions to Diagnostic Problems

a) Phenotypic and genetic variability : Medical information/communication technology can aid in the diagnosis of diseases in an individual patient. Phenotypic variability in several diseases may pose a diagnostic dilemma. In case of rare disorders also, it is necessary to do a thorough literature and database search before making a final diagnosis. The neurological disease database is available at http://www.neurologie.uni-duesseldorf.orf.de/~witte/disease.html and http://www.acsiom.org/nsr/neuro.html sites. Whole brain atlas can be visualized at www.med.harvard.edu/AANLIB/home.html site. Similarly, CNS pathology images site is http://www.med.jhu.edu/pathology/aid/images/cns/. MEDLINE(http://www.ncbi.nlm.nih.gov/Pubmed) is the world’s premier biomedical database. It is possible to search MEDLINE fields (author name, MESH term,
Information Technology and Pediatric Neurology

Table II

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Floppy Infant
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http://www.fsma.org
http://www.fightsmsa.com
*http://www3.oup.co.uk/nls.supplements/brain/hdb/Volume_81/Issue_04/810461.sgm.abs.html
http://www.psycweb.com/Dictiom/floppyi.html

Muscular Dystrophy
http://www.mdausa.org
http://www.musculardystrophy.org.uk
http://www.mdac.ca/
http://www.dmd.nl
http://www.users.neworld.net/woliver/md.html

CNS Infections
http://www.vh.org/Providers/TeachingFiles/CNSInfDisR2/Paren.html
http://www.surgical-tutor.org.uk/core/trauma/cns_infection.htm
http://www.leeds.ac.uk/mbiology/ug/ugteach/micr3290/cns1/index.htm
http://www.cdc.gov/epo/mmwr/preview/mmwrhtml/00053675.htm
http://www.worldmedicus.com/server/Controller/3700002709beOOO_O.s/j
http://jennifer.mi.uky.edu/mi598/lecture1/cns%20infections%20598-2.htm

Epilepsy
http://www.epilepsy.org.uk/
http://www.freeinet.edmonton.ab.ca/epilepsy/index.html
http://www.efa.org/index.htm
http://phy.hal.kagoshima-u.ac.jp/EPNET/index.html
http://www.neuro.wustl.edu/epilepsy/currentnews.html
http://www.geocities.com/HotSprings/2836/epilepsy.html
http://www.neo.wustl.edu/epilepsy/pediatric/Information.html

Stroke
http://www.stroke.org
http://www.amhr.org/catalog/Stroke_catpage30.html
http://www.stroke.wustl.edu
http://sites.netscape.net/pedstrokepdf/index.html
*http://archneur.ama-assn.org/
*http://mitpress.mit.edu/e-journals/CONE/
*http://www.neurology.org/
The websites with an asterisk (*) denote sites from the journals

Another database with some overlap with MEDLINE is EMBASE, the Excerpta Medica database i.e. http://www.healthgate.com/help/price/embase.shtml. It indexes greater number of European and Asian journals than its MEDLINE counterpart. ‘EMBASE Drugs and Pharmacology’ is especially useful. Online registration is free, but for detailed articles a fee is charged.

Online Mendelian Inheritance in Man (OMIM) is a database that has a catalog of genes and genetic disorders and contains textual data, pictures and references. The website is www.ncbi.nlm.nih.gov/omim and is edited by Victor A McKusick and his colleagues. Another important database for genetic neurological disorders is London neurogenetics database developed by Baraitser and Winter and available on CD-Rom with its photo-library. Presently, several companies are providing updated information on neurological diseases in periodic CD versions which can be ordered on payment. One such example is MedLink-Neurobase by Arbor Publishing Corporation, USA.

b) Resolution of queries: There are several websites for different childhood neurological disorders. Some of these have been listed in table II. Queries about patient diagnosis and management can be cleared through e-mails/websites of experts and answers can be received in a short span of time. Though much of electronic communication is one-to-one, it is also possible to communicate with hundreds (or thousands) of users with a common interest. Discussion lists (or mailing lists) facilitate such communication. Matters of mutual interest can be discussed. No charges are levied for subscription to any discussion list. However, there are a set of rules governing issues such as who can join and post
messages, and whether or not the messages have to be moderated by the list owner. It is important to note the difference between the address of the mailing list and address of the listserver. Messages that relate to joining, leaving etc. are sent to the listserver, whereas contributions to the discussion should be sent directly to the mailing list. Names and description of Mailbase lists can be obtained at http://www.mailbase.ac.uk/search.html. With improvement in technology, computers are being being linked to other independent media like telephone and TV networks, and these are growing together. E-convergence may be useful in transfer of large amounts of data that may at times be needed during e-consultations. However, privacy of individuals and legal implications are to be addressed while making dealings/discussions through e-convergence.

The essence of telemedicine is the exchange of information at a distance, whether the information is voice, an image, and elements of a medical record or commands to a surgical robot, i.e. remote communication of information to facilitate clinical care. The telemedicine system provides interactive audio and video network, enhancing effective delivery of health care in addition to health education.6,7 Special software is available to connect a central site, i.e. a tertiary hospital to distant sites numbering up to 200 (as on today), say peripheral hospitals so that expert guidance can be given as and when required. The equipment has attached camera and scanner for recording images and scanning X-rays, ECGs and CT scan etc for easy transmission.

c) Laboratory/molecular diagnosis : Diagnosis of several rare disorders is not possible at a single centre due to technical limitations and financial constraints. Even in the developing countries, rare diagnostic tests are available only at few specialized centres. The investigations for new diseases under research are done only at the institutions where the research is being carried out. The diagnostic facilities available at various laboratories can be known from specific websites of the institutes. As for example, http://www.neuro-oas.mgh.harvard.edu/neurogenetics is affiliated to the Massachusetts General Hospital and has diagnostic facilities for infantile NCLF, NF2, tuberous sclerosis, Friedrich’s ataxia etc. Detailed information can be obtained by contacting the involved persons by e-mails.

Drug Information

Information on the therapeutics i.e. antibiotics, other drugs, speech therapy, physiotherapy, gene therapy etc. is also accessible through the net. The drug database site is http://about.onhealth.com/conditions/resourced/pharmacy/index.asp. Other sites include http://neuroscience.about.com/science/neuroscience/cs/drugs/index.htm and http://pharmacology.about.com/healthpharmacology/cs/nervous_system/index.html. An important website on gene therapy is http://mrcr2.med.nyu.edu/murphp01/genereth.htm. Similarly, site on supportive management of cerebral palsy is http://www.hbotoday.com/treatment/cp.shtml.

Information for Researchers

Several sites are available for those involved in research related to neurological disorders. These include databases and sites of journals.


Health Statistics

Several countries have their own statistics. The more important ones are http://www.cdc.gov/nchswww (National Center for Health Statistics, USA), http://www.ons.gov.uk (Office of National Statistics, UK), and http://www.who.int/whr (WHO Health Report 1999). In developing countries, it is difficult to obtain up to date health statistics. Hence, the third site mentioned above becomes more relevant in these conditions. There are also disease-specific statistics available on the net e.g. http://www.cjd.ed.ac.uk/ for Creutzfeldt-Jakob disease.

Medical Education

Information on online CMEs, fellowship, conferences and meetings is available and can be fruitfully utilized to one’s use. The sites for CME include http://www.medscape.com/ and http://omni.ac.uk/cme/search-cme.html and the information about conferences can be obtained at http://www.pslgroup.com/MEDCONF.HTM and www.mediconf.com.
Conclusion

Thus, medical information and communication technologies provide not only extensive information on diagnosis of a disease but also help in the management of individual cases. In recent future, the telemedicine system is likely to play a major role in health care delivery. However, the prudent neurologist should take optimum care to shield the identity of any patient whose data has been supplied to any website or other institute. Though the site may be secure, the use of information by persons accessing the data cannot be predicted.

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References


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