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# Self-diagnosis and attitude change through the 'information super highway'

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The Internet provides information on virtually any subject. This is readily accessible to the public, although of variable quality. The Internet also plays an important role in contemporary psychiatry with the dissemination of information on disorders, research and clinical practice. Our patients may have access to mental health web-sites, consulting electronic sources when making decisions that affect their health. The implications of patient power on the Internet are discussed.

The Internet is an unregulated community of people who communicate freely across an international electronic computer network. Also described as the 'Global Information Super Highway' by enthusiasts, the Internet appears to have heralded the birth of the information age, providing vast quantities of information on virtually any subject matter.

Through the Internet, the lay public has access to a growing supply of information on health and disease, often of variable quality and relevance (Bower, 1996; Coiera, 1996). Several authors (Fung, 1993; Coiera, 1996; Pallen, 1996) have questioned the preparedness of the medical profession to participate in this exponential technological growth, alerting doctors to the potential demands and consequences on clinical practice. In fact in some areas more patients than doctors have access to the Internet.

The development of medical informatics (the application of information technologies in medicine), electronic journals and more recently informatics sections in medical journals, highlights an advance towards improving the management of clinical information and helping doctors understand the demands that will be made of them.

In psychiatry, the important role of the Internet in research, clinical practice and information dissemination has been emphasised (Green, 1996; Littlejohns & Briscoe, 1996). On the World Wide Web users are able to create and exchange text, images and video documents of high quality. The number of psychiatry-related sites are

rapidly expanding as are overlap disciplines such as sociology, anthropology, neuroscience and pharmacology. Using computerised searching tools to explore the Internet (surfing the net), on one occasion we located several hundred English language resource sites covering mental health, psychiatry and psychology alone, all accessible to the public. Widely diverse, web-sites included electronic publications of psychiatric and psychological journals, clinical practice, molecular psychiatry, history, ethics, institutions, agencies, substance misuse and psychopharmacology to mention but a few. Also available were sites specifically providing information to patients and their carers on subjects as varied as attention deficit disorders, trauma, bereavement, depression, bipolar affective disorders, schizophrenia, learning disabilities, sleep, anxiety, eating disorders, medication tips and even virtual reality therapy (an interactive computer generated environment that stimulates real situations applied in the treatment of a variety of psychological disorders). While some web-sites are structured as frequently asked questions, others are support, discussion or news groups allowing interactive participation. On-line forums allow doctors and patients all over the world to carry out dialogues about psychopathology, problems and the possible treatment options (Johnson, 1996). Patient groups also encourage the exchange of information and perspectives among patients (Nally, 1996). Interestingly one site provided a check-list of characteristics to look out for in a psychiatrist when seeking treatment, stressing the patient's role in the decision-making process. It suggested that patients clarify with their prospective doctors their understanding and beliefs about aetiology, opinions on psychotherapeutic treatment, medication and the psychiatrist's degree of experience in dealing with the disorder presented with.

With the emergence of so much detailed and comprehensive information on the Internet, health professionals will need to think ahead to the future as many patients and their families

will also consult electronic information when making decisions that affect their health.

The following case report illustrates a lay member of the public's self-diagnosis, referral and attitude change through the Internet.

### Case report

A university student in her 20s registered with a general practitioner complaining of a two-year history of frequent mood swings, each lasting a few weeks or months, and requested to be referred to a psychiatrist. She described depressive episodes characterised by low mood, tearful spells, social isolation, poor sleep and appetite with weight loss. During these periods of being in 'a dark pit' she had seriously contemplated suicide several times. A few months later she would then report feeling 'too good', in an ecstatic mood associated with irritability, hyperactivity, racing thoughts, excessive spending and disinhibition. These episodes had caused a deterioration in her social and academic functioning. While in college she had discovered a 'Depression news group' while on the Internet which she then joined and exchanged mail with members. Occasionally she came across the phrase 'manic-depressive' which she assumed to be a very severe form of depression. While reading frequently asked questions on depression on a web-site, symptoms of manic-depressive (bipolar affective) illness were described which she immediately recognised as what she had been experiencing over the past two years. Through electronic mail (e-mail) facilities she discussed her symptoms with a 'psychiatrist' in America, who enlightened her about the possible nature of her disorder and advised that she sought a psychiatry consultation. The psychiatric assessment was facilitated by the knowledge she had acquired of her disorder, medication and side-effects, which she had also printed out. She had also prepared questions for clarification. The diagnosis of a rapid cycling bipolar affective disorder was made and lithium was commenced as the most appropriate treatment. Following treatment, her condition stabilised and she resumed college without further major disruption. Initially, her condition had not been helped by the negative attitude of her family who were bewildered by her behaviour. From the Internet she printed out information pages for her family members who now have a better understanding of her unstable behaviour as an illness and this has improved their relationship.

### Comment

The Internet's challenge to health care provision (Coiera, 1996) cannot afford to be underesti-

mated. As access to the Internet is largely uncontrolled and the quality of information markedly variable, this may pose problems. The increase in unverified claims (Bower, 1996) is a cause for concern as authorities are often powerless to control or prosecute. Currently, a lot of the material available on the network is from medical web-sites in America and may have little relevance in Britain. Patients may access the latest information on their disorders, raising expectations and insisting on treatment options, some of which may be inappropriate, unavailable or even unknown to the doctors. This quest for best practice may expose doctors to medico-legal confrontation, undermining confidence and trust. Perceiving patients as 'well informed' could also greatly bias objective psychiatric assessment by the psychiatrist making assumptions or taking short cuts.

In this case report the patient consulted a 'psychiatrist' on the Internet who had no direct medico-legal responsibility. Confidentiality aside, unregulated consultations, advice and second opinions from 'professionals' who may not be licensed in the UK has major ethical implications for psychiatric practice.

Exposed to volumes of scientific information, the patient is ill equipped to decipher or recognise what is 'evidence-based' or from an authoritative source. It may also be extremely difficult for patients to realise how much is untried, untested or still in the early stages of research. Misinformation may alter the patient's pathway to care, thereby denying prompt and effective intervention. User groups with an 'anti-psychiatry' focus, describing patients (e.g. as 'survivors' and medication as 'poisons') may well discourage acceptance of psychiatric care. As information processing in the mentally ill may be affected by their psychopathology, the content of some web-sites may be damaging to the more vulnerable.

The need for doctors to increase their awareness of information technology and surf on the super highway cannot be ignored. Recognised medical bodies (e.g. the Royal Colleges, university departments and the Department of Health) should take up the challenge creating guidelines, newsgroups and on-line information resources structured for the patient in this environment. It is only then that patients and carers will be able to benefit from evidence-based medicine, while doctors are not wrong-footed by patients 'more knowledgeable' than they are as we endeavour to surf safely on the information super highway.

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The Royal College of Psychiatrists' Special Committee on Electroconvulsive Therapy is to offer another ECT Training Day at the Royal Horticultural Halls in London. The format will be a combination of presentations and participatory workshops. The Training Day has proved to be very popular in recent years and we have decided to repeat it for a second time this year. It will be of particular interest to psychiatrists, nurses and anaesthetists involved in ECT practice.

Dr Chris Freeman (*Royal Edinburgh Hospital*) will give a presentation on *Recent Developments in the Theory and Practice of ECT*, Dr Karen Simpson (*St James's University Hospital, Leeds*) on *Anaesthesia for ECT* and Dr John Lumsden (*Broadmore Hospital*) on *EEG Monitoring of ECT*. Dr Richard Duffet (*College Research Unit*), Dr Allan Scott (*Royal Edinburgh Hospital*), Dr Susan Benbow (*Manchester Royal Infirmary*), Dr Grace Fergusson (*Argyll and Bute Hospital*) and Mrs Heide Baldwin (*ECT Nurses Forum*) will run a series of morning and afternoon workshops.

The workshops will include stimulus dosing with the Ectron ECT machine, stimulus dosing with the Thymatron machine, ECT in the elderly, audit and a workshop specifically for nursing staff with a special interest in ECT. Delegates will be offered attendance at one workshop in the morning and one workshop in the afternoon.

Further information, a full programme and a booking form can be obtained from Mrs J Carroll, CPD Unit, Royal College of Psychiatrists, 17 Belgrave Square, London, SW1X 8PG, Tel: 0171 235 2351 x 108, Fax: 0171 259 6507, E-mail: [jcarroll@repsych.ac.uk](mailto:jcarroll@repsych.ac.uk)