

## Patient Power? Medical Perspectives on Patient Use of the Internet<sup>1</sup>

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**ABSTRACT** *Patients and carers now have unprecedented access to health information via specialist journals and the popular media, while the worldwide web has revolutionised public access to clinical information. Levels of patient demand for information about health have grown and there is evidence to suggest that patients wish to receive more information than is sometimes currently provided by clinicians. In secondary care, some specialisms have more readily adopted the use of information communication technologies (ICT) in clinician/patient communication than others. This paper focuses on clinicians' perceptions of client Internet use for psychiatric conditions and studies the influence this has had on the consultation process in the United Kingdom. The research method consisted of a postal questionnaire distributed to the members of the Women in Psychiatry Group on the register of the Royal College of Psychiatry. Telephone interviews were conducted, employing the critical incident method, as well as a brief additional questionnaire. The data show that psychiatrists who used the Internet discerned client usage more readily. Where the client sought to discuss information acquired electronically with the consultant this tended to extend the consultation period, but a number of psychiatrists reported a greater sense of partnership as a result. The paper explores consultant perceptions of client motivations for Internet use and the perceived advantages and disadvantages for both client and psychiatrist. Overall, the psychiatry profession appears to be following the lead of clients in the use of ICT. Policy recommendations are offered with respect to the provision of profession-validated information on the Internet and psychiatrists' training in IT.*

**Keywords:** ICT, Internet, psychiatrists, clients, consultation.

### Introduction

Information transfer is an essential element in the relationship between clinician and patient. Notwithstanding a shift in clinical perspectives towards a recognition of the need for patients to be involved in decision making and for greater partnership between clinician and patient in therapeutic care (from compliance to concordance), the asymmetric power relationship, while more overt in compliance, is still present in concordance. This involves the lay patient and expert practitioner

and encompasses 'the cognitive, affective, ethical, legal and existential elements intrinsic to the human nature of medicine'.<sup>2</sup> An assumption made in the literature on patient education/information is that the patient is 'reasonable' and has 'sufficient mental competence to assess as a layman [sic] the likely benefits and harms . . . of the physician's proposed innovation'.<sup>3</sup> In these circumstances, the patient is expected to understand, assess and freely decide whether to accept the proposed treatment. The implication seems to be made that, despite the fact that patients/carers are suffering and upset, at least some individuals are able to draw on the rational selves of their earlier state of well being.

Patients are likely to seek information to aid their understanding, not only from the clinician, but from other sources such as newspapers, magazines, radio/television and, particularly, the Internet. Patients also gossip, as the proliferation of Internet chat rooms testifies; likely reasons being for comfort, to check on a clinician's competence or to seek information for self-care. The attention of physicians is being drawn to the Internet by, amongst other sources, a regular short note in the *British Medical Journal* entitled 'Website of the Week',<sup>4</sup> while a Web chat-site for the exclusive use of registered pharmacists (Private RX) has been established by a UK community pharmacist.<sup>5</sup> And UK clinicians are now more aware of the influence of websites on patients and the population at large. For example, child psychiatrists have been warned of the potential effect of suicide websites on vulnerable young people,<sup>6</sup> a search on popular search engines, such as Lycos, Northernlight and AltaVista using the keyword 'suicide' typically yielding 50,000–100,000 pages.

Much of the published research on clinician and patient use of the Internet is American, although the number of UK studies is increasing. There has been no recent study of the effect of patient/carer Internet use on consultation style in either the USA or the UK. The aim of this study is to explore UK psychiatrists' reactions to patient/carer use of the Internet; to consider how client use of the Internet is growing and to what extent the clinician's recognition of client Internet use is determined by his/her own level of confidence in IT. We seek to determine to what extent and in what ways perceptions of client Internet usage influence the consultation process. The term 'client' is used inclusively for both patient and/or carer.

The large majority of UK psychiatrists are employed by NHS trusts, although they work in a variety of specialties and settings. Psychiatric training follows a general medical degree, postgraduate qualifications in psychiatry being conferred by the Royal College of Psychiatrists, membership of which is a requirement for consultant status. Many psychiatrists work with adult patients in the context of community mental health teams and hospitals; others specialise in a particular age group, psychiatry for the elderly being generally a separate specialty, as is child and adolescent psychiatry. Other psychiatrists may specialise in particular problems; for example, services for people with drug and alcohol problems are often separate from general psychiatry services. There are also special areas of psychiatry defined partly by the location of the work; for example, some psychiatrists work in general hospitals in which they see patients together with other medical colleagues; while forensic psychiatrists work with patients who are in contact with the criminal justice services. From this variety of specialties and settings, the degree to which relatives and carers are involved in consultations varies widely. In child and adolescent psychiatry, the involvement of parents and carers is the norm, whereas in some other services such involvement may be limited for reasons of location or the

nature of the problem (e.g. people with drug and alcohol problems). Thus, the dynamics between sources, mediators and users of information may be expected to change with respect to different situations. Within the psychiatric profession, consultants will be at different times not only sources of information, but also mediators and users.

### **Patient Access to Health Information: A Literature Review**

The empirical focus of this paper is the effect of patient/carer Internet searches on UK consultant psychiatrists' perceptions of their relationships. The global nature of the Internet, however, necessitates a world-wide literature search of patient/carer Internet usage. While no single clinical specialty has attracted many studies of patient Internet use, collectively they provide a comparative framework within which to locate the present study.

The level of patient demand for health information has grown in the UK,<sup>7</sup> there being some evidence that patients desire more information than is currently provided by clinicians.<sup>8</sup> Research on general practitioner prescribing, for example, has shown that while some patients wish to know about side effects, GPs, on the whole, give this relatively low priority.<sup>9</sup> Another study showed that leaflets on the benefits and risks of screening and interventions in pregnancy were well-received by women, but less so by health professionals, some of whom blocked access to the information.<sup>10</sup> The Internet, however, largely renders human and distance barriers to information transfer obsolete, and although this may influence a client's attitude towards the clinician, it may not significantly shift the balance of power and trust relationships between clinician and client.<sup>11</sup>

The increased use of Information and Communication Technologies (ICT) by patients has been highlighted by a number of researchers. A study conducted in the USA on e-mail communication between physicians and patients found e-mail to have the potential to increase patient involvement in the supervision and documenting of their health, the authors noting that 'these new linkages may have profound implications for patient/physician relationships'.<sup>12</sup> Patient use of the Internet appears to be particularly developed in the area of oncology; after the establishment of the website OncoLink in March 1994, visits to the site averaged over 36,000 per month from around the world within a very few months.<sup>13</sup> Studies conducted in the USA and Germany have shown motivation for patient use to be particularly high in areas of patient support, as well as for information to supplement that obtained from physicians.<sup>14</sup>

While there is good evidence that patients wish to receive more information than previously,<sup>15</sup> linkages with a desire for involvement in decision-making are less clear,<sup>16</sup> although it has been shown that patients who feel more involved in treatment decisions are generally more satisfied with their treatment visit.<sup>17</sup> It is recognised, however, that patients' preference for involvement is not static and is likely to vary according to the condition and the various stages in its development and treatment.<sup>18</sup> Moreover, the patient's preference is likely to vary with his/her psychological make-up and life experiences.

In UK primary care some 90% of general medical practices and almost 100% of community pharmacies were computerised by 1997, using computers for tasks directly related to work requirements (e.g. data entry of diagnosis and treatment by the GP; data entry to permit medicine label production in the pharmacy). But health professionals' use of the Internet is variable. A 1998 study showed that only

17% of UK-based GPs had access to the Internet in their surgeries, and 29% at home.<sup>19</sup> There is some evidence to suggest that Internet usage varies among health disciplines as well as among countries.<sup>20</sup> A study of clinician and medical student attitudes to ICT categorised the types and degrees of resistance to these technologies. Some physicians accepted ICT with no apparent difficulty, while others appeared to resent the technologies, adopting rationalising behaviours by expressing concern for the depersonalisation of medical care.<sup>21</sup>

For clinical specialists, the Internet increases the potential to inform evidence-based patient management,<sup>22</sup> a study of the use of the Internet by paediatric surgeons showing that the surgeon 'gains enormous information that can be useful for patient care'.<sup>23</sup> It has been asserted that IT is now sufficiently mature that every health provider 'should consider incorporating some type of computer-based patient education into his or her practice' in order to promote patient empowerment in making concordant individual decisions.<sup>24</sup> And in certain specialties (e.g. rheumatology), it has been found that an effective outpatient service can be provided over the Internet.<sup>25</sup> However, utilisation of the Internet by health care professionals has been alleged to lag behind that of managers/professionals in other areas of employment such that an important gap is created between 'the Internet-fuelled empowerment of consumers and their expectations for speed, access, and convenience' and the current readiness of health professionals fully to embrace telemedicine.<sup>26</sup> More patients are seeking participation in decisions concerning their treatment and have turned to the Internet to confirm diagnosis, validate physicians' recommended treatment, and to explore alternative therapies.<sup>27</sup> On the premise that patients are benefiting where practitioners seek clinical guidance on the Internet, an increasing number of guides is being provided for clinicians to search online sources.<sup>28</sup>

Patients have differing expectations of consultations; some desire straightforward answers, while others seek a partnership in decision-making with the clinician.<sup>29</sup> Glode suggests that clinicians 'will increasingly act as information guides, rather than information resources, for patients and their families with cancer'.<sup>30</sup> It has been a matter of anecdotal debate that a more informed client may seek a longer consultation—that the transition between diagnosis and treatment may become a contested terrain through a growing self-perception of the patient/client as informed consumer, rather than passive recipient of healthcare. There is likely to be a range of health professionals' attitudes towards 'well informed' clients. Some may see such patients as time-consuming, threatening, a nuisance, and/or the source of a challenging—even enjoyable—discussion. Some writers have assumed that patients are uniformly satisfied by specific physician behaviours,<sup>31</sup> although the consultations of some GPs are known to be more patient-centred than those of others.<sup>32</sup> Such a supply-side perspective ignores patient diversity in socio-economic status, gender and ethnicity, besides cognitive style.<sup>33</sup>

Such studies as exist of the quality of information available on the Internet within any single specialty raise questions about accuracy and consistency. Information on how to treat childhood fever, for example, was found to range from acceptable to inaccurate, while some treatments were dangerously out of date.<sup>34</sup> The overall quality of information on common vascular diseases was found to be poor and difficult to access, one study showing a third of the sites relevant to patient education on the subject to be either misleading or unconventional.<sup>35</sup> A project using two Internet search engines for information on kidney disease yielded the conclusion that 'the number of websites providing complete, non-biased

information continues to represent only a small portion of the total'.<sup>36</sup> A study of Internet sources on the treatment of childhood diarrhoea showed that, of the treatments described, there was a low percentage of concurrence with professional guidelines, the authors concluding that 'patients must be warned about the voluminous misinformation available on medical subjects on the Net'.<sup>37</sup> However, Internet censorship is not only difficult but also, in all probability, counter-productive. It has been pointed out that clinicians need to become more proactive in the design and evaluation of Internet-based interventions directed at health behaviour change.<sup>38</sup> More opportunities exist than have currently been realised for clinician input to websites both from the point of view of mediating information, as well as in the development of interactive networks.

## **Method**

A 20-item postal questionnaire, consisting largely of closed questions, was devised to explore psychiatrists' perceptions of client use of the Internet for information on psychiatric conditions. Evidence was sought on the pattern and perceived reasons for client Internet use. We explored the extent to which reported client use of the Internet had influenced approaches to clinical consultation and in what ways consultation format and style had changed as a consequence. Evidence was sought on the level of clinicians' own use of the Internet and their perceptions of the advantages and disadvantages of client use of the Internet both to clients and themselves. Clinicians were asked to indicate if they would be prepared to grant a 30-minute telephone follow-up interview.

The questionnaire was mailed to 448 UK psychiatrists, all registrars or consultants and members of the Royal College of Psychiatrists, the majority being consultants. A reminder was mailed five weeks after the first, enclosing a tear-off slip inviting those respondents who had had no contact with patient use of the Internet to return the slip only. Respondents were not asked to identify themselves by name unless they agreed to the follow-up interview. This paper does not consider the question of Internet usage from the patient's perspective. Rather it addresses the under-researched theme of psychiatrists' constructs of patient/carer Internet use and how this influences consultation interactions.

The sample frame consisted of all members of the Women in Psychiatry Group (WIPSIG) of the Royal College of Psychiatry. Women comprise about 40% of the membership of the College and, although no data are available, female consultants are likely to be, on average, somewhat younger than consultant psychiatrists as a whole. In a profession in which women are increasingly being represented at more senior levels, it can be posited that WIPSIG members are as likely as any psychiatrists to be aware of Internet usage by clients. None of the research discussed in the literature review suggests a gender bias in clinicians' responses to patient Internet use. The questions raised in this paper could have been addressed to any clinical specialty for, as the preceding literature review shows, there is general awareness of patient Internet use across many specialties, as well as general medicine. Psychiatry was selected because of the authors' relative ease of access to the Women in Psychiatry Group of the Royal College of Psychiatry.

The total response to the survey was 279, a response rate of 62.3%. Twenty-six respondents agreed to a follow-up interview and 23 were contacted. Each telephone respondent was asked to provide two critical incidents, namely narratives of episodes from their practice in which they had evidence of a patient/carer

**Table 1.** Number of occasions on which psychiatrists encountered clients using the Internet

| Number of instances | Patients |                | Carers   |                |
|---------------------|----------|----------------|----------|----------------|
|                     | <i>N</i> | % <sup>a</sup> | <i>N</i> | % <sup>a</sup> |
| 1                   | 23       | 24             | 27       | 31             |
| 2–5                 | 54       | 56             | 42       | 48             |
| 6–10                | 16       | 17             | 15       | 17             |
| 11–20               | 2        | 2              | 1        | 1              |
| >20                 | 1        | 1              | 3        | 3              |
| Total               | 96       | 100            | 88       | 100            |

<sup>a</sup>% of those respondents who had encountered patient use and carer use of the Internet.

searching the Internet for information on the condition. After narrating the incidents, respondents were asked 13 supplementary questions concerning their own level of IT literacy; how they rated the Internet compared with other sources of clinical information for patients; the extent to which patients appeared to take information from the Internet on trust; consultants' level of concern regarding patient/carers reactions to the information available on the Internet, and any plans of which they were aware to put new clinical information online. While all 23 contact respondents answered the supplementary questions, not all of them provided critical incidents. In all, 30 incidents were narrated by 16 respondent psychiatrists. Critical incidents were provided on adult conditions which included dementia, depression, drug-induced paranoia, epilepsy, anxiety, gender-identity disorder, and complex regional pain syndrome. Incidents concerning child disorders involved autism, learning difficulties, sleep problems, and attention deficit and hyperactivity disorder (ADHD).

## Results

### *Awareness of Internet Usage*

Forty per cent of responding psychiatrists believed that clients had used the Internet to research their condition. Of these psychiatrists, 76% had encountered more than one instance of client Internet use (see Table 1). The first reported episodes in which consultants recognised client Internet use took place in 1995, 103 psychiatrists having experienced perceived client Internet use by June 1999. Nevertheless, clients known to be using the Internet still represented under 5% of the patient list (see Table 2) of the majority of responding consultants aware of client Internet use. Of clients perceived to use the Internet, 95% were being treated on the NHS and the majority of responding consultant psychiatrists were working within the NHS (88%) (see Table 3). That the proportion of NHS patients known to be using the Internet exceeds the proportion of psychiatrists working in the NHS, reflects the specific circumstances of, for example, prison psychiatrists, university lecturers and researchers.

Some 61% of the psychiatrists who indicated the level of their own ICT skills regularly used the Internet for clinical information. Of the 23 interviewees, only

**Table 2.** Percentage of the 1999 client list that had used the Internet to search for information on their condition

| % of patient list using the Internet | Number of psychiatrists <sup>a</sup> |
|--------------------------------------|--------------------------------------|
| >0% to <5%                           | 95 (78%)                             |
| 5%                                   | 17 (14%)                             |
| 10%                                  | 7 (6%)                               |
| 20%                                  | 2 (2%)                               |
| 30%                                  | 1 (<1%)                              |
| 40%                                  | 1 (<1%)                              |

<sup>a</sup> % of those respondents who had encountered client use of the Internet.

five used the Internet with ease (22%). One respondent claimed to know how to use the Internet but chose not to; several indicated that they were becoming more proficient, while some reported that they were about to learn. One consultant described her first encounter with a carer who had used the Internet in about 1996: 'I was both interested and overwhelmed . . . because at that time I didn't have access to the Internet at all'. She asked the patient for a paper copy of the material and, in a subsequent consultation, discussed the information with the patient, asking for leave to share the material with other patients. Some interviewees acknowledged that patients could trigger their own use of the Internet.

I have learned about some treatments since patients have told me about information they have found. It has prompted me to look things up.

Another commented 'they often know more than I do and that this has happened more since patient/carers access to the Internet'. Not surprisingly, the more familiar clinicians were with the Internet, the more aware they appeared to be of patients' and carers' Internet use, those using the Internet 'a great deal' encountering 3.9 clients using the Internet compared with 1.4 clients for those consultants not using the Internet at all (see Table 4). One psychiatrist reported:

I am quick to pick up any sign of interest, a client might say 'I am into modern

**Table 3.** Source of patient funding and psychiatrists' professional base

| Source of funding for patient |     |                | Psychiatrist's professional base |     |                |
|-------------------------------|-----|----------------|----------------------------------|-----|----------------|
|                               | N   | % <sup>a</sup> |                                  | N   | % <sup>a</sup> |
| All NHS                       | 123 | 95%            | NHS                              | 119 | 88%            |
| Mostly NHS                    | 2   | 1.5%           | Research                         | 12  | 9%             |
| 50% NHS                       | 3   | 2%             | Prison                           | 2   | 1%             |
| All Private                   | 1   | <1%            | Private hospital                 | 3   | 2%             |

<sup>a</sup> % of respondents to the question.

**Table 4.** Mean number of clients perceived to be using the Internet and psychiatrist's own frequency of using the Internet

| Psychiatrists' use of the Internet | Mean number of clients encountered using the Internet |
|------------------------------------|-------------------------------------------------------|
| A great deal                       | 3.9                                                   |
| Not a lot                          | 2.8                                                   |
| Not at all                         | 1.4                                                   |

developments', I might then ask which ones and this often leads them to talking about the Internet.

Many interviewees suspected that some clients were reluctant to mention Internet use. It was suggested that patients with depression were more likely not to report use of the Internet, although their carers (as well as carers of patients with dementia) were more likely to indicate Internet use. One interviewee thought that those who mentioned using the Internet were 'the tip of the iceberg'.

Interviewed psychiatrists identified four variables that they believed influenced client use of the Internet; socio-economic status, age, gender and patient condition. While one reported that 'Lack of money, lack of education and age mean none of them access the net', another suggested that 'it is not clearly related to social class . . . a lot of people who aren't very highly educated enjoy computers and access to the net'. Interviewees believed that Internet usage was higher amongst the young or the early-retired middle aged. With respect to gender, while some respondents perceived computer literacy to be higher amongst men, another respondent commented, 'my limited experience is that it's women, but then it's mums that come to clinic'. The fourth variable was the clinical condition of the patient. Those consultations in which the patient presented a self-diagnosis on a first visit (e.g. 'I have . . . ME') were likely to have been informed by the Internet. Psychiatrists suggested that the extent to which clients took Internet information on trust was likely to differ by disorder. If the patient suffered from some rare or particularly unpleasant illness, they were more inclined to believe a case report on some remarkable recovery; 'the more they want a cure the more they take things on trust'. This was particularly likely where there is no known cure as, for example, with autism. People who had been 'badly treated by doctors' were more likely to have accessed the Web. The removal of geographical barriers was perceived to be important in allowing interest groups in minority situations to make contact. One psychiatrist drew attention to the 'democratising phenomenon' of the Internet—'it means patients no longer think they are the only ones with a problem'. The reduction of a sense of isolation is also important.

While some consultants stated that they almost never directed patients to the Internet, others in, for example, child psychiatry, suggested that a fruitful discussion could take place with parents after they had learned more about their child's condition on the Internet. One clinician described how she sat down with the parents of a patient suffering from bi-polar affective disorder and accessed the



**Table 5.** Reason identified by psychiatrists for client use of the Internet

| Perceived reason for client use of the Internet | Use had been by patients only | Use had been by carers only | Users had been a mixture |
|-------------------------------------------------|-------------------------------|-----------------------------|--------------------------|
| Information on condition                        | 27 (79%)                      | 27 (90%)                    | 113 (88%)                |
| Choices of treatment                            | 17 (29%)                      | 11 (37%)                    | 72 (56%)                 |
| Check treatment is correct                      | 12 (35%)                      | 11 (37%)                    | 60 (47%)                 |
| Check diagnosis is correct                      | 5 (15%)                       | 7 (23%)                     | 38 (30%)                 |
| Find how common condition is                    | 3 (9%)                        | 6 (20%)                     | 27 (21%)                 |
| Locate patient networks                         | 8 (24%)                       | 9 (30%)                     | 37 (29%)                 |
| Column totals                                   | 34 respondents                | 30 respondents              | 128 respondents          |

Respondents could select multiple reasons, % is of totals for each column.

Royal College of Psychiatrists' pages on the Internet for them, reporting 'it was very helpful'.

#### *Reasons for Client Internet Use*

The main perceived reason for client use of the Internet (Table 5) was to obtain further information on the illness. The availability and effectiveness of treatments were other given reasons. Clients had access to a larger information base that could save consultant time (in some circumstances), although clients might desire longer consultation in others. The information enabled many patients to 'challenge aspects of care' and 'weigh the pros and cons' of treatment. Clients appeared to have a greater sense of ownership and responsibility for information that they had obtained, besides enhancing their power of judgement and, as one respondent noted, knowledge could be acquired 'at their own pace' (Table 6). Most interviewees, while acknowledging the variability and the uncontrolled nature of information on the Internet, believed that patients were discriminating, that the activity of searching could be beneficial: 'I generally believe the more information the better so long as they could be guided to appraise it'. Another psychiatrist

**Table 6.** Psychiatrists' perceived advantages to clients of using the Internet

| Client advantage gained from the Internet      | Respondents stating |
|------------------------------------------------|---------------------|
| Informing clients about their illness          | 80                  |
| Giving ownership, control & empowerment        | 34                  |
| Support groups                                 | 23                  |
| A sense of partnership in the relationship     | 14                  |
| Clients' increased confidence                  | 7                   |
| An aid to discussion                           | 4                   |
| A means of corroborating treatment & diagnosis | 4                   |
| Saves time in the consultation                 | 3                   |
| Increases compliance                           | 2                   |

**Table 7.** Psychiatrists' perceived disadvantages to clients of using the Internet

| Client problems with the Internet               | Respondents stating |
|-------------------------------------------------|---------------------|
| Misinformation or inaccurate information        | 60                  |
| Misinterpretation of information—confusion      | 22                  |
| Biased information                              | 13                  |
| Raising false hopes                             | 12                  |
| Inappropriate information, e.g. suicide methods | 12                  |
| Self diagnosis or hypochondria                  | 11                  |
| Client's increased anxiety                      | 10                  |
| Too much information                            | 10                  |
| Increased time leads to longer waits            | 3                   |
| Reduced compliance                              | 3                   |
| Reduced trust                                   | 1                   |

reported:

I don't like the plea of doctors being gods and patients being minions—they need to take responsibility and an active role.

Respondents were positive about the role of a number of patient/carer support groups accessed via the Internet: for example, the National Schizophrenia Fellowship and Alzheimers Disease Society. The ME Society, in contrast, was criticised, much of the Internet information being alleged to lack an evidence base, while not all treatments mentioned are available in the UK. Psychiatrists also identified disadvantages to client use of the Internet. The most frequently cited concerns were inaccurate information and the misinterpretation of information (see Table 7). Concern was expressed about the easy availability of information about suicide methods, a point made by Thompson.<sup>39</sup> Some patients may use information to reinforce stereotypes and primitive defence mechanisms. One young female patient, for example, had started taking overdoses, but denied the role of her recreational drug use because she had, she said, 'researched ecstasy on the Internet' and believed it to be entirely safe.

Five critical incidents described negative impacts of client use of the Internet. One patient selectively used the information, ceasing to take the recommended medication for a condition which had been previously well-managed, while a parent, having obtained Internet information, projected the parent's own anxiety about the child's illness onto the child in question. The third example concerned an adult who had contracted a rare degenerative disorder. The clinician believed that the patient, having searched the Internet, had uncovered clinical information that caused concern. The consequence was that the patient constructed an impenetrable carapace around himself. The fifth critical incident concerned the parents of a young man with schizophrenia who became:

rather over-involved, always on the phone, always clutching at straws. . . . They spoke to me about fish oil supplements . . . which they said had been used in Canada to improve the prognosis for people with schizophrenia.

**Table 8.** The influence of client use of the Internet on consultation

| Type of influence on consultation | Use had been<br>by patients only | Use had been<br>by carers only | Users had been<br>a mixture |
|-----------------------------------|----------------------------------|--------------------------------|-----------------------------|
| Longer consultation               | 8 (33%)                          | 3 (10%)                        | 38 (30%)                    |
| Client displays knowledge         | 9 (26%)                          | 7 (23%)                        | 41 (32%)                    |
| Client seeks verification         | 14 (41%)                         | 15 (50%)                       | 69 (54%)                    |
| Greater partnership               | 12 (35%)                         | 9 (30%)                        | 39 (30%)                    |
| Totals                            | 34                               | 30                             | 128                         |

Respondents could select more than one option, % is of responses under each column.

As a consequence, the son was living almost entirely on sardines. In the cases of severe disorders, family members were just as likely as patients to catch hold of a diagnosis or a treatment that suited their own paradigm within the context of a prognosis.

### *Consultation Style*

The degree of influence that client Internet searches had on consultations varied, but was perceived to be greater where the Internet user was a carer, probably more frequently in child psychiatry cases. The greatest influence on consultation style across all the three categories of client Internet users (patients only, carers only, or both) was a need for clients to verify Internet-derived information (Table 8). Some psychiatrists interpreted this as clients desiring to demonstrate their knowledge of the condition and its treatment. One consultant described how

Sometimes people sound more knowledgeable than they are as a result of accessing this information so I have to tactfully check the information they give me and ensure that they really understand.

This consultant deliberately did not ask a patient or carer whether they were using the Internet at first, although she was aware that the patient was probably waiting for her to ask. Clinicians who have little personal experience of Internet use may disappoint an articulate proactive patient. And patients wishing to debate issues may be disappointed by constraints on consultation time, as well as with the clinician's desire to proceed with treatment.

In situations where it was not clear how much control patients desired to have over their treatment, the level of Internet use could provide an indication. Overall 30% of responding consultants believed there to be a greater partnership with clients as a result of client Internet use. The sharing of responsibility for treatment was welcomed by over 65% of responding psychiatrists (see Table 9), although over 70% were concerned about the accuracy of clinical information on the Internet. A consequence of increased client knowledge of psychiatric conditions, diagnosis and treatments was the possibility, or even likelihood, that they may have had more information on rarer conditions than the clinician, a

**Table 9.** Psychiatrists' perspectives on changes in relationships arising from client use of the Internet

| Psychiatrists' feelings over client use of the Internet | Use had been by patients only | Use had been by carers only | Users had been a mixture |
|---------------------------------------------------------|-------------------------------|-----------------------------|--------------------------|
| Welcome shared control                                  | 22 (65%)                      | 20 (67%)                    | 116 (67%)                |
| Concern over accuracy                                   | 26 (76%)                      | 22 (73%)                    | 140 (81%)                |
| Threat to own authority                                 | 3 (9%)                        | 2 (7%)                      | 33 (19%)                 |
| Changed relationship                                    | 3 (9%)                        | 1 (3%)                      | 10 (6%)                  |
| Trust undermined                                        | 13 (38%)                      | 6 (20%)                     | 71 (41%)                 |
| Totals                                                  | 34                            | 30                          | 173                      |

Respondents could select more than one option, % is of responses under each column.

situation interpreted by some psychiatrists as a threat to their authority. Others perceived this as positive:

On rare conditions they may have information I don't.

Challenge from patient questioning is thought-provoking and can keep the psychiatrist abreast of other influences on patient compliance.

The patients ask questions which are relevant, often already have(ing) background information which saves time.

For certain conditions (e.g. dementia) the use of Internet searching could reduce the emotional impact of the diagnosis 'as they are already aware of its features and progression'. A number of respondents referred to a greater sense of partnership or collaboration:

I am happy to share decision-making with informed patients in a collaborative way rather than looking for patients to be compliant.

It changes the power imbalance, reducing the impression that doctors are all knowledgeable.

Psychiatrists' perspectives on the negative effects of client Internet use on consultation style can be grouped into three categories: the quality of information obtained, changed patient/carers expectations, and changed clinician patient/carers relationships. Concern was expressed that if patients or carers believed unproven claims made on the Internet they might not agree with the treatment recommended by the consultant. Some carers were reported as insisting on a change of treatment subsequent to an Internet search. A frequently made observation concerned the volume of information: 'trying to separate the good from the bad' and the difficulty of helping the patient 'learn the skill of evaluating evidence'. One clinician pointed out that 'access to information is only problematic if they [clients] are then denied the opportunity to verify or clarify it with clinicians'. Some psychiatrists were concerned when the patient, informed by the Internet, disagreed with their professional judgement. One consultant admitted to feeling 'some loss of authority I suppose; I don't have time to update myself always'.

Clients could 'seem more challenging, which feels threatening'. One consultant acknowledged feeling that she was 'being examined by the patients'. Some psychiatrists drew attention to the way in which the Internet influenced their own motivation to keep up-to-date in order to be able to respond to 'increased questioning . . . unexpected questions on rare conditions'. It was recognised that knowledge—whoever possessed it—influenced the power balance, one consultant commenting on the 'patient using information to threaten or test me', adding that 'this could be a valuable learning experience'. Another suggested that information 'could be a weapon to bash me with'. These comments highlight the tension between threat and opportunity when encountering the empowered patient. The indication is that, if nothing else, the Internet increases the complexity of knowledge–power relationships during consultation.

### **Conclusions and Policy Implications**

Half the respondents to the survey reported that they had encountered no patient/carer use of the Internet. This figure probably over-represents non-Internet use amongst clients since the results indicate that psychiatrists who were neither Internet users nor IT-skilled were less likely to discern Internet usage among clients. This should come as no surprise, but the implications could be important. The inference could be drawn that significantly more patients/carers are using the Internet to obtain clinical information than is apparent to consultants. The hidden potential influence on the consultant/client partnership for treatment (concordance) is considerable.

While survey respondents were not asked to state their specialty, many did, the indication being that clinicians in child and adolescent psychiatry perceived greater client Internet use than specialists in adult psychiatry. The indication is that there may be many adult clients whose use of the Internet goes undetected by the clinician. The data suggest that patients are not always willing to reveal their Internet exploration of therapy alternatives, unless the clinician first indicates a willingness to discuss them. This is undoubtedly a situation which pre-dates Internet technologies, but one which is growing in importance through the enabling effects of these technologies. Such a situation might contribute to higher levels of anxiety amongst the clients of less proactive psychiatrists.

In the past, the psychiatrist could act as a barrier or filter to information. This situation has been changed by the relative ease with which electronic media can be searched, media that can unite as well as disinform. The Internet removes barriers of time and space so that people with rare conditions can meet regularly in real time and virtual space, as can those whose sense of isolation hinders the making of contact through more conventional support networks. Clients in these circumstances might benefit from encouragement and assistance in the use of the Internet. Information search on the Internet can have a therapeutic role by enabling greater patient/carer engagement with diagnoses and treatment. The balance of power may shift as the client feels more in control of the condition and its treatment, in partnership with the clinician. Use of the Internet may, however, impede treatment where the client disputes and rejects clinical advice. Current thinking on professional relationships between clinicians and patients/carers favours forms of partnership in which the patient/carer plays an active role in weighing-up risks and taking decisions, as well as achieving concordance with treatment. The implication is that this style of relationship is preferred by most

patients, although it is acknowledged that the clinician–patient partnership model may find more favour with younger clinicians. However, it is believed that the more serious a patient's condition, the more likely he/she is to prefer power to reside with the clinician. There are indications that use of the Internet alters client preference for either a partnership or an authority relationship with a clinician, and that with the confidence gained from Internet use, he/she may be more prepared to articulate this preference.

The psychiatry profession appears to be following patients and carers' use of Internet technology rather than leading, although there are some notable exceptions. Several psychiatrists indicated that they were not computer literate. It must be questioned whether this is acceptable, or how long it can remain so. Some psychiatrists appear defensive, questioning patient motives and having a concern for whether the Internet has become a basis for testing or challenging their professional competence. Psychiatrists face a dilemma. On the one hand, they wish patients to have a role in their treatment/recovery, but wonder where the boundaries lie? Some psychiatrists encouraged debate on the issues—'information therapy'—while others were concerned that patients' hopes might be unduly raised. The concern is that psychiatrists do not seem fully to have acknowledged the powerful force for change in the dynamics of consultation which patient/carer use of the Internet presents. Not only is there a need for the psychiatry profession (and other specialties in secondary, as well as primary, care) to address the issue of Internet healthcare information and patient/carer access to it, clients, too, will need to consider the responsibility that comes with a greater sharing in clinical decision-making. There is a role here for continuing professional development to facilitate greater professional confidence and skill in ICT. And there is a need for initial medical training, and the training for College membership, seriously to address the issue of information obtained by patients from the Internet, as well as to consider how Internet usage by clients affects consultation content and style. The informed client will have a responsibility to develop not only ICT skills but also skills in weighing-up evidence (including an understanding of probability) and the evaluation of risk in different treatments.

In the past, networks within healthcare have been relatively circumscribed in terms of access and content, but such controls do not exist on the Internet. The author of the note in the *British Medical Journal* who wrote 'you have got to know what you've got before you can look it up' underestimates patient and carer preparedness to devote time to searching for information on a suspected condition.<sup>40</sup> Respondents in this study encountered patients who correctly self-diagnosed, as well as those who did not. While Australian general practitioners considered the potential for Internet guidelines on psychotic illness and attention deficit disorder as 'extremely' or 'very' useful,<sup>41</sup> British consultant psychiatrists are currently more circumspect about the potential benefits for patients and carers as well as for their profession. While the desire of some clinicians to control health information on the Internet is understandable, it is unrealistic. Royal Colleges will need to consider how to communicate effectively with clients in accessible language on websites. The less profession-endorsed information available, the more the vacuum will be filled by alternatives. Cassell *et al.* suggest that the Internet, with its characteristic for persuasive communication, may combine the positive attributes of both interpersonal and mass communication.<sup>42</sup> If this is the case, Internet-based communication will need to be addressed as a matter of urgency by the Royal Colleges and the Department of Health.

## Notes and References

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