

Use of the internet by parents of paediatric outpatients

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Aims: (1) To establish how many parents of children seen in paediatric outpatient departments use the internet to find information about their child's medical condition. (2) To ascertain what information is sought and found, and what proportion of all parents had access to the internet at home or elsewhere.

Methods: Over a six week period in 2000, parents of children attending general paediatric outpatient clinics in the district general hospital in Bath and in the 10 associated community hospitals, were asked to complete a questionnaire survey.

Results: Of the 577 questionnaires distributed, 485 were returned, a response rate of 84%. A total of 332 (69%) families owned a computer and 248 (51%) had internet access; 107 (22%) had looked on the internet for information about the problem for which their child was being seen in clinic that day. Parents who knew their child's diagnosis were more likely to have used the internet than those who named their child's symptoms only. A health professional had suggested that parents seek information on the internet in 6% of cases. These parents were more likely to use the internet than parents to whom this had not been suggested (67% v 20%, $p < 0.001$). Eighty nine (84%) parents who had used the internet prior to this clinic appointment found it useful. Thirty six (34%) parents had discussed or were planning to discuss the information they had found with their doctors.

Conclusion: A significant proportion of parents have access to the internet and use it to find information about their child's medical condition. The parents who discuss what they find with the clinic doctor are in the minority. Doctors should be prepared to ask parents about their information needs and discuss use of the internet.

Many parents find written information on their child's condition beneficial but it is unclear how many use the internet to access this. Consumer surveys show that in some parts of the UK, access to the internet among the general population rose from 34% to 45% during 1999,¹ and in the year 2000, 25% of all homes were connected to the internet.² Government statistics for April 2002 show that 55% of the UK adult population have now used the internet, with the figure for adults aged 16–24 years being 89% and for those aged 25–44, 74%.³ Studies have shown that 40–68% of internet searches in the USA were to find medical information.^{4,5} Although much has been published about what information is available on the internet and how doctors can access it, there is little published information on patient use.

This study was designed to establish the extent of internet access and use among parents attending general paediatric outpatient clinics at a district general hospital.

METHODS

Over a six week period in 2000, all parents of children attending general paediatric outpatient clinics were asked to complete an anonymous questionnaire while waiting to be seen. Clinics where the authors were working were excluded.

A covering letter explained the purpose of the study and assured confidentiality. The majority of the responses were tick boxes, with a few questions on internet use allowing free text responses.

Questions were asked concerning previous use of the internet, ownership of a home computer, and internet access. Other questions related to whether a health professional had suggested searching the internet for information and whether the parent felt that doctors should suggest suitable internet sites. Parents were asked whether they had looked on the internet for information about the condition for which the child was attending clinic on that day. Only those who answered yes to this question were asked to complete the second part of the questionnaire.

Further questions addressed the types of information sought, whether the information was helpful, and if so, how. Parents were asked whether they would use the internet again and whether they had discussed or were planning to discuss their findings with the paediatrician.

Ethical approval for this study was obtained from the local research ethics committee. The results were analysed using the statistics package SPSS.

RESULTS

Where appropriate, the results were analysed using χ^2 ; $p < 0.05$ was considered to be statistically significant.

Of 577 questionnaires distributed, 485 were completed (a response rate of 84%).

Patient details

The ages of patients attending the clinics ranged from 4 weeks to 23 years, with a mean age of 6 years 4 months. Parents were asked with what condition their child had come to clinic. Where possible, conditions were then categorised as "acute disease", "chronic single system disease", "chronic multisystem disease", or "symptoms only" (see table 1); 75% of questionnaires included a classifiable problem.

Computer ownership and use of the internet

A total of 480 (99%) respondents had heard of the internet and 293 (61%) had used it; 332 (69%) owned a computer and 248 (75% of computer owners, 51% of total) had internet access at home. A total of 154 (32%) had used the internet for health information in the past; 422 (88%) thought doctors should suggest suitable internet sites to parents.

Use of the internet for the problem for which they attended clinic

A total of 107 (22%) of the sample had used the internet to find information about the problem for which they were being seen in clinic that day; 106 parents completed the second part

Table 1 Use of the internet and parental description of child's medical problem

	No. whose parents used internet	Total (%)
Multisystem chronic disease	17	30 (57)
Single system chronic disease	62	181 (34)
Acute disease	4	13 (31)
Symptoms only	12	140 (9)
Unclassifiable	12	121 (10)
Total	107	485

Table 2 Information looked for

	No. of parents (%)
More information on diagnosed condition	89 (84)
Medical treatments	66 (62)
Long term outcome	60 (57)
Alternative treatments	41 (39)
Possible diagnoses	40 (38)
Self help or patient support groups	40 (38)
Other families with a child with a similar problem	28 (26)
Other doctors or hospitals specialising in the condition	22 (21)
Other*	6 (6)
Total	392
(Total number of parents responding to question)	106)

*Information for schools (1), genetic or research updates (3), drug company information (1), general information (1).

of the questionnaire giving more details on the information sought. Those families who had looked on the internet on this occasion were more likely to have internet access at home than those who had not (78% *v* 45%, $\chi^2 = 14.5$, $p < 0.001$); 89 (84%) found the information useful, 14 (13%) were unsure, and three found it unhelpful; 103 (97%) said they would use the internet again for health information.

Of the whole population, 27 (6%) said that a health professional had suggested they search the internet for information about their child's condition, of whom 18 (67%) had looked on this occasion, compared to 20% where no such suggestion had been made. This is statistically significant ($\chi^2 = 33.6$, $p < 0.001$).

Table 2 gives details about what information parents looked for. A series of choices were given with tick boxes. All parents ticked more than one box. Parents were asked an open question on how the information had been useful. Table 3 gives a summary of those responses. The responses of a few parents fell into more than one category.

Parents were asked whether they planned to or had discussed their findings with the clinic doctor. Of those who answered the question, 36 (34%) said yes, 50 (48%) no, and 19 (18%) said don't know. Those answering no, were asked why this was. Table 4 gives a summary of those responses.

DISCUSSION

Discussions in the literature on the use of the internet in paediatrics have focused on the benefit to doctors rather than parents.⁶ Little work has been published about patients using the internet. A small postal survey of adult gastroenterology outpatients⁷ found that although patients were not currently using the internet for medical information, two thirds felt that this would be an important source of information in the future. These patients felt that they might use the internet for information about their treatment and the best hospitals to provide it.

Table 3 How the information was useful

	No. of parents (%)
Further knowledge and understanding	54 (77)
Reassurance	8 (11)
Support for family	7 (10)
Research updates	5 (7)
Information for school	3 (4)
Information on prognosis	3 (4)
Information aimed at child	1 (1)
Total	81
(Total number of parents responding to question)	70)

Table 4 Why information was not discussed with doctor

	No. of parents (%)
Information already covered by doctor	12 (33)
Not relevant	10 (28)
No point/need	5 (14)
Discussed with another doctor	3 (8)
Doctor too busy	2 (6)
Doctor already knows information	2 (6)
Not sure of relevance	2 (6)
Information not helpful	1 (3)
Information not relevant to health	1 (3)
Total	38
(Total number of parents responding)	36)

Computer and internet ownership

Nearly 70% of parents in this study owned a computer and 51% had internet access at home. Figures for the general population show computer ownership in the UK in 1998 was 32%, rising to 39% a year later, with certain areas having levels more recently of 50%.⁸

Internet access was estimated to be in around a quarter of homes by mid-2000.² National figures for home internet use are difficult to compare with those from this study as they represent the whole adult age range, rather than parents of young children. We do know however, that almost 70% of adults who use the internet are aged 15–44.⁹ With internet access available widely in workplaces and schools as well as in public areas such as libraries, most of the population have access to the internet, although some may be unaware of this. The difference between our figures and those of national surveys may be due to several factors. It may reflect the fact that this area is slightly more affluent than the average or that families with young children have higher levels of ownership than the general population. However, since studies have also shown that the fastest rise in internet use recently has been among those with children and the less affluent,¹⁰ even if our figures are unrepresentative of the UK as a whole, other areas may have similar rates of usage in the future.

Internet use for the child's medical problem

This study shows that over one fifth of parents attending paediatric outpatient clinics at a district general hospital have looked for information about their child's condition on the internet. The most common reason for using the internet was to find information about the child's condition, its management, and outcome. Around a quarter looked for families in a similar situation to themselves, and a fifth were looking for specialist centres or doctors. Although we did not ask about this, some of these latter families may have been looking at ways of obtaining second opinions.

Selected comments from parents on how the information helped

"[We were] reassured about his condition ... [found] contact addresses for other sufferers ... [it] alleviated worry about any hidden information"

"[We] realised that although the condition seemed serious, it was actually very common in premature babies"

"[We were] better informed when talking to doctors"

"It gave us fuller information so we felt in a better position to ask more questions"

Selected comments from parents on why information was not discussed with doctor

"The information was regarded as supplementary and not an alternative ... I would not consider the internet as a sort of on-line consultant"

"[The doctor] ... won't be interested due to lack of time"

"The doctor already knows all there is to know about the condition"

"[The information was] not as detailed as that from the doctor"

Proportionally more parents whose children had a chronic multisystem disease used the internet than those who were only able to give one or more symptoms as a reason for attending clinic. This may be a reflection of information needs among the different groups, ease of searching for a named condition, or the length of time the child has had the condition.

Most parents who had used the internet, found it useful, the majority of these saying it provided additional knowledge and understanding about the child's condition. Although not specifically asked for, there were no spontaneous negative comments from parents about their experience. We are therefore unable to say whether there are any adverse effects from gaining information in this way. Questionnaires were only offered to families attending clinic. Non-attenders may be different with regard to access to and use of the internet.

Only 6% of our sample had been advised to look on the internet by health professionals. However, 88% of parents felt that doctors should suggest internet site addresses. The views of particular clinicians may affect both use of the internet and the willingness of patients to discuss their findings with their doctor. However, the study did not ask clinicians whether they actively encouraged or discouraged parents to use the internet. Professional concern about the accuracy and reliability of information on the net is understandable, given the findings of some studies. A study looking at information gained by searching the internet for information on Ewing sarcoma, found that number of retrievals varied with spelling variations, some searches gave differing numbers of references with variation in capitalisation; some information was misleading, clearly erroneous, or out of date.¹¹ Other recent studies found incomplete and inaccurate information in a significant proportion of sites concerning a variety of medical conditions, and lack of referencing was a major shortcoming in some.¹²⁻¹⁵

Only 34% of the parents in our study discussed the information they found with the clinic doctor. In some cases there may be nothing gained by this discussion but in many

cases, it may have been helpful. Sadly, a small number felt that their child's doctor would be uninterested or too busy to discuss the information. Discussion of information found with the parent would enable the doctor to be aware of the information needs of the parents, correct any misconceptions, discuss differences in information found and suggest other sites if the parent had been unable to find adequate information. This requires doctors to be proactive in asking parents about searches made and to have a good working knowledge of reliable and useful sites.¹⁶

Parents in this study appeared to have a generally positive attitude towards the internet, with 88% of them feeling that doctors should suggest suitable sites to parents. In addition, increasing numbers of patients and families are likely to use the internet for health information in the future. Professionals will therefore need to keep up to date with the information available, and health care providers need to consider the provision of internet access in clinics and surgeries for those who do not have access elsewhere.



The questionnaire can be viewed on the ADC website [www.archdischild.com]

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Paediatric Outpatients and the Internet Study Questionnaire

1. How old is your child?years.....months
2. For what problem or condition is your child seeing the doctor today?
-

For each question, please tick the appropriate box.

3. How many times has your child been to this clinic before?
First appointment Once before More than once before
4. Have you heard of the internet?
Yes No Don't know
5. Have you ever used the internet?
Yes No Don't know
6. Do you have a home computer?
Yes No Don't know
7. If yes, do you have internet access? (If no, go to question 8)
Yes No Don't know
8. If no, do you have access to the internet somewhere else (for example, at friends, internet café, work) ? (Leave this question if you answered yes to question 6)
Yes No Don't know
9. Have you used the internet in the past for medical information?
Yes No Don't know
10. Do you think that doctors should suggest suitable internet sites where families could find relevant information about their child's problem?
Yes No Don't know
11. Has a health professional suggested that you look for information on your child's problem on the internet?
Yes No Don't know
12. Have you looked on the internet for information about the problem for which your child has come to clinic today?
Yes No Don't know

If you answered *no* to question 12, you do not need to fill in any more of this questionnaire. Thank you for completing it so far. Please place it in the box provided.

If you answered *yes* to question 12, please continue with the questionnaire.

13. Did you look on the internet before consulting a doctor about your child's problem?

Yes No Don't know

14. What information did you look for on the internet? **You can tick as many as you like.**

- Possible diagnoses
- Medical treatments available
- Alternative treatments available
- More information about a diagnosed condition
- Long term outcome of the condition
- Self help or patient support groups
- Other families whose children have similar problems
- Hospitals or doctors specialising in the condition
- Other (please give details below)

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15. Did you find information which was useful to you?

Yes No Don't know

16. Please tell us how the information has helped you and your child.

.....
.....

17. Would you use the internet again for health information?

Yes No Don't know

18. Have you, or do you plan to, discuss the information you found with the doctor you see in clinic?

Yes No Don't know

19. If no, why is that?

.....
.....

20. In the future we may wish to contact families who have used the internet to get more detail about the information they obtained. Would you be happy for us to contact you in this situation?

Yes No

If yes, please write your name, address and home telephone number below. This information will remain confidential.

If you have any other comments, please write them below.

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.....

.....
Thank you for completing the questionnaire. Please put it in the box provided.

Paediatric Outpatients and the Internet Study

Dear Parent or Guardian

Many families find written information about their child's medical condition very useful. Many people now have access to computers and are using them to obtain medical information which is available on the internet.

We would like to find out how many families whose children come to paediatric outpatients, are using the internet to gain information about their child's problems. We would also like to know how useful they find that information and how they use it.

Whether or not you have used the internet, we will be very grateful if you would complete the attached questionnaire. It should not take more than 5 minutes to complete. The questionnaire is anonymous and confidential.

When you have filled it in, please place it in the box provided before leaving clinic. We don't mind if you do not want to fill one in, but please put the unused questionnaire into the box when you leave clinic. If you have already completed one of these forms at an earlier clinic visit, you do not need to complete another, but please write that fact on the form and place in the box.

The results of the survey will be available from the study organisers listed below when the study is complete. Please note on your questionnaire, or on a separate piece of paper, if you would like to be sent a summary of the results.

Many thanks for your help.

Yours sincerely

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