

Parents and the Internet

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Abstract

BACKGROUND

THE INFORMATION GAP

The increasing emphasis on ambulatory care in Paediatrics over the past few years has meant that children are increasingly being discharged following short stays in hospital¹. Sending a child home in the early stages of recovery has many implications for the parents of the convalescing patient. Although community nursing services are well developed in some regions², the greatest burden of care will almost always fall on the parents. Research has shown that this responsibility may often feel overwhelming³. One of the reasons underlying this is a lack of information regarding the child's illness and expected recovery. Parental ignorance of how they should be caring for the child, the signs that should cause alarm, the long-term implications of a disease and a fear of the unknown may all be translated into anxiety. This anxiety leads to increased use of health services which would not have been required if information was more freely available. MacDonald⁴ found that over half the mothers of children who had been admitted to hospital sought professional help after discharge and that these carers could not recall information given to them in hospital.

In order to try and address this information gap, hospital workers have the job of educating parents whilst they are in the hospital. This is a difficult task. Not only are hospital stays shortening but learning of new information in the hospital setting is limited⁵. Parents are under considerable stress during their stay and the information supplied is often forgotten. There is little published work on parental information needs on discharge but what there is, emphasises the need for both verbal and written information sources to aid effectiveness of what is provided⁶.

'Parent Information' leaflets can be an extremely valuable resource when well produced. They can inform the parents of the important information they need about a condition and augment this with illustrations. They can also address

commonly asked questions. They can be browsed at leisure and referred to later, allowing reflection and consolidation of information. Research shows that providing leaflets to patients does improve their knowledge of the subject and could lead to change in behaviour⁷. However, the information can be of variable quality and is usually generalised in nature. The reality of 'Parent Information' is often single photocopied sheets. These may be difficult to read through multiple copying and may be years out of date. The need to constantly update medical information makes it difficult to justify resources for comprehensive and high quality presentation, if an expensive reprint is required annually. Such work is repeated at many hospitals and can lack quality assurance. Keeping stocks of up to date leaflets is costly in terms of both time and space⁸. The information is also given out at a time of great anxiety and the move from hospital back to the home is an excellent opportunity to misplace a loose piece of paper. Another drawback, in the eyes of parents, is that the hospital represents only one source of information. There is increasing awareness, especially in areas such as vaccination, that there is more than one side to health issues. The hospital may not be considered as the definitive authority to provide information on a disease. This becomes of great concern to the health professional when unreliable sources of information are used instead.

THE POTENTIAL OF THE INTERNET

The access to information for parents, as well as health professionals, has been revolutionised by the Internet. Since its inception in 1991, the World Wide Web has grown exponentially. Recent estimates suggest that there are 33 million regular web users in the United Kingdom⁹, which represents almost 56% of the population. This figure is continuing to rise as the Internet becomes more accessible through digital television and mobile devices. These people have access to almost limitless information. There were 800 million pages on the World Wide Web in June 1999 and this

was growing at the rate of 20 million pages a month¹⁰.

Obtaining healthcare information is one of the most common uses of the Internet. Surveys suggest that up to 52% of all adults in the United States have accessed online health related information¹¹ and this figure is bound to rise as the number of consumer health care sites increases. It is impossible to say how many health related websites exist at any one time, but the number certainly runs to hundreds of thousands. Unfortunately, this information explosion has made the finding of quality, evidence-based matter extremely difficult. Healthcare information on the Internet, with respect to common childhood ailments, has been found to be unreliable¹². Studies by Impicciatore et al have investigated the quality of available information with regard to managing childhood fever¹³ and cough¹². In 1997 they found few sites provided accurate information and some provided potentially dangerous advice, although they did find some improvement in a systematic re-evaluation 4 years later¹⁴. They noted that it was extremely difficult for the layperson to differentiate the reliable and unreliable sites. The concern that patients cannot discriminate genuine insight from deliberate invention has been well documented¹⁵. Research into the habits of lay consumers searching for health information on the Internet have shown that the credibility of a website is appraised more on the basis of a professional site design than the authors qualifications¹⁶. Furthermore, when a website's medical credibility was systematically assessed by doctors, there was little correlation between the credibility and the accuracy of information provided¹⁷.

No standards exist at present to truly assure the quality of web-based information. Many have tried to create checklists for patients¹⁸ in order to identify sites most likely to provide high quality clinical information. Some organisations, such as the Health on the Net Foundation, will endorse sites that fulfil a certain number of criteria. However, of 98 rating instruments for the quality of health information identified in one study, none had been formally tested for reliability and validity¹⁹. At present, healthcare professionals, or the peer reviewed information packets they provide, still remain the most reliable source of patient information¹².

The Internet has great potential to fill the information gap that produces so much anxiety in parents looking after a sick child. A survey of 1000 health care consumers found 57% thought it likely that the Internet will help reduce or eliminate frustrations associated with visiting the doctor²⁰.

Forgetting to ask all the questions they had wanted to during a consultation, was a problem raised by 60% of the sample.

Providing electronic information to parents when they leave hospital, overcomes many of the shortcomings of the printed information presently provided. Larger quantities of information can be provided with no extra cost and this can be easily updated. Multimedia such as video and audio can be used to clarify difficult points. Linking to other sites allows parents to take their curiosity further and also feel that the information is coming from a variety of unrelated sources.

This method allows the linked sites to be reviewed by the disseminating physician to ensure their quality and avoids the parental search strategies that Impeccatore found could throw up so much misleading and contradictory advice.

Despite the potential benefits, this form of parent information on discharge does not appear to be available from UK hospital sources at present. Innovative forms of contact between patient and doctor by electronic means appear to have been well received²¹ and significantly improved family satisfaction with inpatient care²².

There has been no literature published on the value of providing a specific web-based information resource for a particular group of parents with observational data as to if and how they utilise it. Once provided with the extra resource, such a population could then be compared to suitable controls. This method could be used to investigate if access to this extra information affects the anxiety they feel regarding their child's illness, their satisfaction with their child's care and their confidence in dealing with the recurrence of the illness.

The difficulties faced by a parent searching for information on the Internet could be exemplified by febrile convulsions. This is a common condition that almost has a benign outcome but is extremely distressing to a witnessing parent.

An Internet search using the word 'fit' on the Google search engine retrieved 8,360,000 web pages, the top 3 all being in German. A more specific search for 'febrile convulsion' retrieved almost 2,500²⁴. Studies of consumer habits have shown that only the first few items provided by a search engine are investigated further. This greatly limits the usefulness of this method¹⁶.

Effective searching by parents is further hampered by differing uses of terminology (fit, seizure and convulsion) in

different countries. This huge amount of information plus inconsistencies of terminology make the need for guidance for the parent even greater. There is great potential for hospitals to be acting as the guide through this information minefield in order to allay parent's fears and thus decrease their likelihood of unnecessary re-presentation.

CONCLUSION

The Internet has revolutionised the world of informatics. Few areas have been more dramatically affected than medicine. The potential for improving the flow of information between professionals and patients is huge. However, if this potential is not harnessed then a great opportunity would be lost. Obtaining high quality health related information is a minefield for both patient and doctor. It is also known that patients will tend to seek out health information using commercial search engines rather than visiting sites they know will provide them with reliable information¹⁷. This opens parents up to a plethora of dubious sources. What parents need is an easy portal to high quality, peer reviewed and easy to understand information. With 61% of women with children in the UK now online¹⁸, this need is greater than ever.

Guidance for finding high quality information is coming not from doctors but from the lay press and commercially motivated publishers¹⁹. This situation is unlikely to improve if doctors do not make more use of the Internet's power in their communications with patients. Research has shown that doctors are not as keen to bring the Internet into their practice as their colleagues in the world of commerce²⁰.

The ideal of a comprehensive, doctor led, peer reviewed and evidence-based online resource for British parents would be a huge asset to our health service. However, for hospitals to provide such information would be both costly and time consuming. This effort needs to be justified by firm evidence of its value.

As more people search the web to find out about their children's illnesses, the greater the need will become for high quality, reliable information. This information gap provides a considerable challenge for those charged with responsibility for children's health.

Conflict of interest: None

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