



Children, Parents and the Management of Chronic Illness in the Information Age

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RESEARCH FINDINGS

KEY FINDINGS

Is the everyday management of health and illness being altered by the availability of information on the Internet? Do parents whose children live with eczema, asthma and diabetes use the Internet to get information and support for these conditions? Why do people turn to the Internet for health information? How do they evaluate it and decide whether it is reliable or not? Does the information they source alter decisions about everyday health care? Do people who are better off make more effective use of the Internet for health than those who are relatively worse off?

- Many people are using the Internet for information about health and illness but they do not do this in isolation from other sources of health information derived from friends, family, magazines, books, newspapers and other media
- The way in which people use the Internet to seek information tends to be contingent upon their specific health care needs, or those of their family and friends
- People do not always tell their doctors that they have sourced information from the Internet but they do feel better prepared to ask the right questions of them
- Information from the Internet may be used to clarify, confirm or check information that they have received from their doctors, however health care professionals are still seen as the most authoritative and reliable source of information
- For some parents and children the Internet can be an important source of additional information and support which can facilitate their management of conditions such as eczema, asthma and diabetes. Others however, felt they knew all they needed to know and had excellent support from health professionals
- Some children with chronic conditions find that information sourced from the Internet made them feel more knowledgeable about their illness
- Most often the consequences of accessing information from the Internet for the management of chronic illness are not dramatic and medical regimens were rarely altered as a result, but people can feel reassured, not least by the fact that the information is easily available if they need it
- Most people feel confident that they are 'sensible' in their use of the Internet and feel that they are able to discriminate between reliable and unreliable information. However many express concerns that 'other people' may be misinformed by information that they find on the Internet

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Why do people use the Internet for health information?

Despite anxieties expressed in some sections of the medical literature and the media that people are being misinformed or duped by the mass of information that is now available on the Internet, the findings of this project suggest that use of e-health resources appears to be cautious and considered. Furthermore it is contingent upon people's particular health and health care needs, and meshes with their use of other sources of both informal and formal health care. It may be used to facilitate the assessment of symptoms; to clarify advice given by health professionals, and to help patients in their rehearsal of questions before going to see the doctor. It may also be used as a 'last resort' by people who feel that they have not been given sufficient information. Thus the use of the Internet is integrated into mundane and everyday decisions taken in relation to assessing symptoms, preparing for consultations and trying to make sense of interactions with health professionals. Perceptions that clinicians are not always able to provide sufficient information are not matched by any lack of trust in doctors nor in a loss of faith in biomedicine. However, where people felt they had insufficient help and support further information may be sought. For example, some parents of children with diabetes felt that the clinical aspects of their care was excellent but they sought out and indeed sometime secured advice and support pertaining to the social aspects of living with the condition from the Internet.

The embodied and embedded nature of e-health resources

Our findings led us to question claims that we are experiencing information overload, that information is 'disembedded', and that there are dangers that people will be misinformed. On the contrary, Internet use is more contextually specific, it is often

contingent upon a perceived need for health information and so the circumstances of use tend to be both embedded and embodied. Internet use is embedded in people's approach to seeking help, advice and information more generally and the internet is routinely placed alongside other (re)sources. In this respect it constitutes an extension of the 'information work' which forms part of the everyday management of health and illness and the social processes associated with illness and help-seeking behaviour. People draw upon a range of resources such as relatives, books, magazines, and friends, and it appears that Internet use is becoming thoroughly enmeshed with these processes.

Internet use is also embodied in that it is contingent upon specific 'bodily' needs. Information, knowledge and explanations may result in people feeling more reassured about illness, prognosis, treatments and so on, and as such can profoundly impact upon both the emotional and pragmatic aspects of the illness experience, making people feel more in control and so more confident in their responses to symptoms.

Accessing information on the Internet thus needs to be understood in the broader context of people's lives. The consequences of this are not dramatic, but we do get a sense that the information gained is substantially contributing to the informal health work that is routinely carried out by people caring for themselves and others. However, this does not replace the need for medical care, and there was an overwhelming sense in our sample that people do, and indeed want to, trust and rely on health professionals. Even in those instances where people sought information on the Internet as a result of 'poor care' and/or 'inadequate information' they did not articulate a lack of trust in doctors nor express any loss of faith in biomedicine.

How do people make use of e-health?

In order to gain some analytic understanding of the manner in which the households in our study engaged with the Internet in relation to health we developed a typology based upon different forms of use. First, in terms of what we might call variations in the relationship with the Internet - there are those people who feel 'at home' with the technology and use it regularly, we refer to these as domesticated users. Other participants, however, saw it as a valuable resource, albeit one to be used episodically. Others again, see the internet as more problematic and they might be typified as more reluctant users as they have more difficulty in coming to terms with a technology which feels unfamiliar. The second dimension relates to variability in what we might call reflexive engagement to the material accessed via the Internet. At one extreme, users might seek out information and then act upon it; for example they might try new treatments, or use information strategically in consultations with health professionals, and in this respect they are, what we term, instrumentally reflexive. Another type of use might appear to be more passive, in that there are no consequences for observable social action, but there are still consequences at a more emotional level people may feel better informed about a condition and/or feel reassured (or not) this is what we might term an affective reflexivity. Using these two dimensions allows us to begin to differentiate between six what we term different Health eTypes. This typology represents an analytic tool through which we can consider the different 'positions' that individuals may variably occupy. It conveys types of use rather than types of user.

Sensible use of the Internet

When it comes to talking about their use of the Internet, 'users' do describe themselves as being sensible and cautious in their approach. Study participants spoke about

the potential dangers on the Internet but invariably saw this as a problem for 'other people'. 'Other people' it was thought might be misinformed, misled or duped by potentially dangerous information which they were aware would be placed on the Internet by unscrupulous or simply foolish people. When describing their own use of the Internet participants described a range of strategies they used to ensure that they only made use of sound information and advice.

Reappraising the digital divide

Our appreciation of the everyday realities of internet use may prove useful for thinking about aspects of reflexivity and related debates on the 'digital divide'. Binary distinctions between reflexivity winners/losers and information rich/poor are often used to contrast between the capacity of socially and economically advantaged groups to gain from technology, and the incapacity of the socially excluded to benefit in the same way. In our sample things were far more complex. We found that reflexive use of the Internet is not exclusive to the socially and economically advantaged, and it does not simply serve as a proxy for structural dis/advantage. We are not suggesting that access to the Internet can alter the structural patterning of health and illness, nor that the technology is necessarily always empowering. Our conclusions are far more circumscribed. All we are suggesting is that use of the Internet meshes with other health and welfare resources which people draw upon in their routine management of health and illness. However, the social distribution and the nature of this use do not follow any simple pattern. This means that any reading of the 'digital divide' that is based upon a simple association between socio-structural location, reflexivity and differential ability to gain material purchase from information for health in the information age is misjudged.

Although access to the Internet will not necessarily fundamentally alter the social epidemiology of health and illness in the manner suggested by some advocates of policies aimed at constructing expert citizens. It may contribute to a more profound change at the level of social epistemology in that the proliferation of ICTs will influence the means by which medical knowledge and information are generated and sustained. The Internet may well be contributing to the construction of a new 'medical cosmology' one we might label e-scaped medicine, but it may well have to exist in a world in which patterns of structural inequality remain impervious to its effects.

About the Project

This 18 month long project was funded by the ERSC Innovative Health Technologies Programme and is one of a number of projects that aimed to explore the consequences that the growing use of e-health might have for health, illness and health care.

This project set out to examine concerns which have been raised about the formation of the so-called 'digital divide'. In particular we wanted to explore the assumption that, *ceteris paribus*, the 'information rich' will achieve better outcomes than will the 'information poor'. The rationale being that as the technology becomes ubiquitous it becomes less and less viable to restrict debates about the digital divide to discussions about who does and who does not have access to the internet. A more nuanced account of how different people access, evaluate and sometimes act upon information is deemed necessary not least in relation to health and the management of chronic illness. One of the prime motivations for the project was the realisation that until recently we did not

actually know very much about how people respond to or interpret the mass of digitally mediated information that now confronts them. Knowledge about this in relation to e-health is important not least because it has long been known that 'information work' of various sorts forms a very important aspect of the everyday self management of chronic illness. Our concern therefore was to explore if, and if so how, this information work has been transformed by the internet.

The main aim of the research was to explore if, and if so how, parents and children access, assess and make use of e-health resources, and to examine whether such resources facilitated the management of their chronic illnesses. The major objectives were to describe the nature and extent of e-health resources that are available for three chronic diseases - eczema, asthma and diabetes - and to interview parents and children to ascertain their experiences of using on-line health information. A number of methods were employed. These included: secondary analysis of existing statistical data; an 'audit' of the e-based resources available for our three illustrative chronic illnesses; a screening survey of parents with children who had been diagnosed with at least one of the three conditions in three contrasting localities; and qualitative interviews with parents and children. Sixty nine interviews were conducted with parents and 16 with children; 85 interviews in total.

The analysis of the data revealed that participants access, assess and make use of e-health resources in a variety of ways. From our analysis we were able to construct a typology of what we called 'Health e-Types'. People's approach to the internet is highly variable and is best understood in terms of different 'types of use' rather than different 'types of user'. It appears to be highly contingent upon their own health needs, or very often the health needs of their relatives and friends.

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