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Short report

How will e-health affect patient participation in the clinic? A review of e-health studies and the current evidence for changes in the relationship between medical professionals and patients

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ABSTRACT

In this report we discuss the consequences of e-health for patient–clinician encounters. On the basis of an analysis of the literature, we propose an analytical framework, composed of five different themes, regarding the impact of e-health on the relationship between patients and their health professionals. Internet health sites can: be or come to be a replacement for face-to-face consultations; supplement existing forms of care; create favorable circumstances for strengthening patient participation; disturb relations; and/or force or demand more intense patient participation. Though there is as yet insufficient empirical evidence supporting these effects, we believe that distinguishing the proposed themes will help to guide an in-depth discussion and further research. We conclude that in particular the redistribution of tasks and responsibilities to patients in their daily lives requires more attention in future research.

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Introduction

Taken collectively, health websites do not reflect a monolithic objective; there is a great diversity of features and formats, and they vary in terms of level of sophistication. In general, these sites have in common that they separate clinicians and patients in time and space; patient–doctor relations are thus lifted from their local contexts and recombined. This is expected to lead to a reconfiguration of ‘expertise’ and new medical pluralism, and to increasingly impact upon the relationship between patients and medical professionals. However, what the exact consequences of the Internet informed patient are for patient–clinician encounters remains under researched (Broom, 2005; Hardey, 2001; Murray et al., 2003).

As part of a study on e-health and chronically ill children in the Netherlands, we conducted a literature study on how the relationship between patients and medical professionals can be affected by Internet health websites, and what evidence current literature offers for these changes. Most often the (anticipated) change in the doctor–patient relationship is described as

a disturbance; though sometimes it is also seen as an improvement, with benefits derived from the promising features offered by the Internet. Aside from these two extremes, our review of the literature shows a much more complex process, with disadvantages for the relationship but also advantages; some well known, others more subtle, and most as yet hypothetical. These different changes in the relationship between medical professionals and patients, as raised in the literature, and the current evidence for these changes, are discussed in this report.

Methods

Search strategy, inclusion and exclusion criteria

This report is a short review article, summarizing multiple studies on Internet health. The key search terms were: Internet, e-health, and patient–physician relationship. Secondary search terms were: chronic illness, support groups, participation, disease management, and self management. The search was conducted between October 2008 and 31 May 2009, and was limited to studies in English and Dutch, published in the last fifteen years. Databases used were MedLine, PubMed, Elsevier Science, Picarta, and Google Scholar. We found a great diversity of articles, mostly providing material for debates, rather than offering empirical evidence. In line

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with the explorative nature of this body of knowledge, we decided to use a grounded approach for its analysis. This approach permitted the review to accommodate diverse types of articles, identify emergent themes, and establish intertextual connections.

All papers that addressed the issue of Internet/e-health in combination with patient–physician relationships were included. Articles addressing specific legal, technical, or administrative processes were excluded, since they often reflect local circumstances and were therefore considered less interesting in relation to our research question. Abstracts were assessed for relevance, and the full text of relevant works was gathered ($n = 68$). The search was augmented with follow-up references from article reference lists ($n = 18$) (see [online supplementary data](#)). The aim was to prioritize papers that appeared relevant in relation to our research question rather than particular study types or papers that met particular methodological standards.

Overall, articles on chronically ill people prevailed in our search, not because we used ‘chronic illness’ as a primary search term, but because for several reasons this group has a great potential to be affected by e-health. For instance, they form a large group of health consumers who are confronted daily with their disease, have conditions with a strong focus on self management, and have longstanding and intensive relationships with healthcare professionals. Those who suffer from chronic illnesses also account for the majority of worldwide medical costs; thus improving the management of chronic conditions holds great potential for cost savings. Our question regarding the effects of e-health for the patient–clinician relationship is therefore of particular relevance for this group.

Findings

Review of the papers highlighted five, partly overlapping, potential changes in the relationship between patients and medical professionals as a result of e-health. Internet health sites can:

- A. *Be(come) a replacement* for face-to-face consultations;
- B. *Supplement* existing relationships and forms of care;
- C. *Create favorable circumstances for improvements* or for strengthening patient participation;
- D. *Disturb* relations;
- E. *Force or demand* more intense and more frequent patient participation.

A. Replacement for face-to-face consultations

Internet health sites can be(come) a replacement for consultations in which the patient and the professional meet each other physically. Current examples in the Netherlands include mainly e-therapy for mental health care and for addiction, but there are also some examples in the general healthcare system, for example a home program for coronary care which allows patients to make their own heart movie at home and transmit the data directly to their specialist.

The extent to which Internet health sites actually lead to a replacement of face-to-face consultations, however, is still unknown. Baker, Wagner, Singer, and Bundorf (2003) found that ninety-four percent of their informants said that Internet use had no effect on the number of physician visits they made, and ninety-three percent said it had no effect on the number of telephone contacts. Sillence, Briggs, Harris, and Fishwick (2007) found that women faced with decisions concerning the menopause were influenced by online information and advice, though this did not alter their desire to communicate directly with physicians. Indeed, the physician was still viewed as the single most important source of advice on health

issues. On the other hand, the study of Linssen (2006) shows that some people, feeling that they do not want to infringe upon the often full agenda of their doctor by asking questions, will first search the Internet. This suggests that a replacement is made in terms of the first port-of-call, and that the Internet is combined with, rather than substituted for, other sources of help.

Constraints for the replacement of face-to-face interactions are practical and juridical. Practical constraints include, among others, the fact that basic diagnostic skills such as observation and palpation simply cannot be performed on the Internet, and that existing treatment programs cannot easily be translated into an e-version. This translation demands an extension of partners, learning new cultures of communication, new skills, time, money, and further research about the utility and effects (Atkinson & Gold, 2002; May, Finch, Mair, & Mort, 2005). This constraint might disappear in the future given the many pilot projects being carried out at the moment concerned with developing observational tools and providing means for monitoring patients at a distance. A noted juridical constraint is that the Dutch Association for Medical Specialists proscribes against advising patients specifically without having a treatment relationship in which the patient is known (Van Meersbergen, 2007).

B. Supplement to existing relations

As Neuhauser and Kreps (2003) have summarized, social influence theory suggests that there are two requirements for communication to be persuasive. The first requirement is that it must involve a transaction between the sender and receiver – ‘a spiral of changing feelings and beliefs’. This participatory process is thought to be necessary in order to ‘internalize the message’ to affect change. The second requirement is that the recipient drives the communication; the communication should be dependent on the participation of the receiver, not the sender. Therefore, interactivity – something the Internet has in surplus compared with classic health promotion methods – may be the attribute of communication with the greatest implications for effective health promotion (cf. Cline & Hayes, 2001; Kreijns, Kirschner, & Jochems, 2003). Another reason why health promotion over the Internet might be more effective is the possibility to personalize or tailor messages, and the possibility to reach people at home, in real time, where they live their lives and their knowledge has to be practiced (Lustria, Cortese, Noar, & Glueckauf, 2009).

Another supplementary feature of e-health is the improvement of transparency, and the possibility to organize forms of dialog which are otherwise not easy to arrange within the traditional confines of the healthcare system. E-health is faster, and you do not have to wait for an appointment but can ask questions whenever it suits you or is considered necessary. This is expected and hoped to be a solution for the time constraints that often mark consultations in the face-to-face healthcare system, and will reduce costs (Bashshur, Reardon, & Shannon, 2000; Oudshoorn, 2008).

Lastly, e-health offers opportunities for a new business model based on value creation, by which ‘value’ can be defined by multiple people, including healthcare providers and patients (Gray, Klein, Noyce, Sesselberg, & Cantrill, 2005). For patients, health sites offer the opportunity to compare and check obtained information, and to find information of a different kind, such as from peers or that which is more focused on day-to-day life.

C. Creating favorable circumstances for improvements or strengthening patient participation

The Internet seems to stimulate patient participation in the clinical setting in three ways, by: 1) acting as a mitigating mechanism, 2) offering a safe training ground for patients, and 3) causing a lever effect.

1) *Mitigating mechanism.* Information technologies can empower patients by providing a mechanism for interaction with physicians, offering information that supports choices, presenting a decentralized decision structure, and stimulating self disclosure (Gerber & Eiser, 2001; Sillence et al., 2007). In particular, the anonymity of the Internet is expected to contribute to the latter. Several studies have found that people are more willing and feel more comfortable sharing sensitive information or asking sensitive questions on the Internet (Berger, Wagner, & Baker, 2005; Cline & Hayes, 2001; Hardey, 2001). This self-disclosure can be of great importance for the development of empathy, relations, and friendships (Bonniface & Green, 2007; Gray et al., 2005; Tjora, Tran, & Faxvaag, 2005).

2) *Safe training ground.* Health sites not only offer information from different stakeholders but also a training ground where they can share knowledge through collaborative learning and problem solving, and discuss and practice different values, norms, and identities (Fox, Ward, & O'Rourke, 2005; Kreijns, Kirschner, & Jochems, 2003). Being better informed may help patients to work with health professionals and so facilitate and enrich their consultations. However, while it is tempting to romanticize the effects of the Internet and the empowering nature of information, as Broom cautions, 'the question if Internet reduces feelings of powerlessness [...] still remains' (Broom, 2005:337).

3) *Lever effect.* Medical professionals can become convinced of the importance of working together with patients by the very existence of healthcare Internet sites. Or as Hulst (2008) puts it, these sites can function as a lever, stimulating changing processes and discourses such as 'patient centered care'.

When a new medium emerges which breaks down old ways of communicating, institutions may undergo profound changes, especially if already under pressure to change. Today, few institutions are under such pressure to change as healthcare. Radin (2006) explains that the Internet is a natural promoter of this change in three ways: 1) it is a massive expert database, 2) it is a global broker, a means for individuals anywhere with special concerns to find each other, and 3) it is a global collective memory, allowing people to contribute, store, and annotate comments.

D. Disturbing relations

Cline and Hayes (2001) conclude that many providers are threatened by their loss of power and fear damage to physician–patient communication due to the Internet. Providers may be stressed by added responsibilities for information seeking and clarification, and become frustrated and resistant due to time costs in correcting inaccuracies (Hart, Henwood, & Wyatt, 2004; Nettleton, Burrows, & O'Malley, 2005). O'Neill (2002, in Nettleton et al., 2005: 975) argues that as people have access to more information and 'supposed sources proliferate', people become increasingly uncertain, confused, and less sure of who to trust for guidance, advice, and support.

Murray et al. (2007) report that their data do not support concerns that health information on the Internet currently results in increased requests for inappropriate care: only eight percent of their sample presented information from the Internet to their physician. Linssen (2006) also reports that people show reservations in taking Internet information to the consultation room; the found information is often translated into a question, rather than starting with 'I read on the Internet that...'. Thirteen percent of the respondents of Fox and Rainie (2002) had 'got the cold shoulder' when presenting Internet material to their doctor.

These three studies above show that patients are well aware of the fact that their Internet use might disturb the relationship with their clinician. This might lead to reservations about sharing the

found information, but also to increased feelings of frustration, insecurity, confusion, and fear (Broom, 2005; Diaz et al., 2002).

Fear of increased consumer access to alternative knowledge on the side of medical professionals has contributed to the labeling of Internet usage as an activity that represents dissatisfaction with conventional medicine, though this contradicts the findings of Broom (2005) and Hardey (2001). Hardey (2001) reports examples of how patients critically confront each other when they take up therapies that are not scientifically proven, and how they advise fellow sufferers to consult biomedically educated professionals. Broom (2005) concludes that for the majority of the men he interviewed, accessing support and information online did not increase their negativity or skepticism toward biomedical treatment.

Much of the debate in medical journals has been framed in terms of the reliability and quality of Internet health material (Fox et al., 2005; Ziebland, 2004). This can be seen as a means of ensuring users are not exposed to the 'risks' of pluralistic health knowledge. But seen from another perspective, the use of terms such as 'quality' (or 'evidence based') may be regarded as an attempt to maintain boundaries around medical knowledge. It is clear, according to Broom (2005), that for some medical specialists, Internet informed patients challenge their power within the medical encounter, resulting in the employment of strategies to reinforce paternalistic dynamics and alienate patients who use the Internet. These strategies implicitly or explicitly discredit the ability of patients to become informed via the Internet, and present serious barriers to shared decision-making and acceptance of the importance of information seeking. This is what Broom (2005) has described as a 'backlash', and may present a considerable barrier to reaping the benefits of the Internet as a resource.

Within this scope it is important to realize that an increasing number of doctors are involved in the development and maintenance of Internet sites. Indeed, as Hardey (2001) concludes, the content of many health-focused sites is primarily authored by health professionals. This probably also explains the findings of Nettleton et al. (2005) and Fox et al. (2005) that lay use of the Internet regarding health increasingly aligns itself with the dominant biomedical conception of what is considered good information and necessary treatment.

Lastly, it is important to realize that medical professionals are not trained in the usage of Internet communication (Hart et al., 2004; McMullan, 2006). Professionals not only need to cope with the amount of information available and with emancipated patients; those working on the Internet also need to learn how to create 'intimacy at a distance' (Oudshoorn, 2008).

E. Force or demand increased patient participation

As stated above, the Internet does not provide means for diagnostic devices such as palpation and observation. This means that when and if medical professionals do not actually see the patient, they run the risk of missing crucial information in order to produce the right diagnosis. This literal absence of healthcare providers implies that patients have to use the technologies of inspection and enumeration themselves. It shifts (the burden of) responsibilities and agency onto patients (May et al., 2005; Oudshoorn, 2008). Neuhauser and Kreps (2003) vividly describe a – for that time – visionary example: Enrique, a man with diabetes, enrolls in an intensive e-health program for his condition, resulting in an improvement of his diabetes management by eighty percent. This highly participatory situation, however, means that the amount of 'sick work' Enrique must engage in has increased significantly; moreover, it cannot be postponed or limited to hospital meetings, but rather penetrates deeply into his private home sphere and daily life.

More indirectly, the Internet might force more patient participation by providing the means to be a well-informed patient, or, as we saw above, to become a capable conversation partner or expert patient, and through the possibility of gathering information without 'unnecessarily' disturbing a busy doctor (Linssen, 2006; Ziebland, 2004). It is exactly this provision that might grow into an obligation or create the feeling of one.

Hulst's lever effect not only stimulates changing processes such as 'patient centeredness', but also discourses like 'personal responsibility' and 'the well-informed patient is a good patient'. Indeed, health sites offer new modes of management control to solve problems around the distribution of healthcare, not only by redistributing tasks but also by constructing new resourceful, responsible, and active patients, who exercise 'self care' and connect with healthcare resources purposefully and rationally (May et al., 2005). Hart et al. (2004) refer to this as the 'Internet's symbolic power'; they found a strong sense among patients (but also among practitioners) that they should use the Internet and that they were missing out in a profound way if they did not.

Discussion

Given that this literature is relatively new and quite diverse, the current study focused exclusively on ideas about the effects of healthcare sites on the relationship between professionals and patients. Analysis of the literature has made clear that e-health is thought to have diverse and potentially contradictory effects on the patient–professional relationship in healthcare, with most attention on the extremes: the possibility to disturb or to enhance. Our analysis shows that the relationship between e-health and the patient–provider relationship could be much more complex.

In answer to the polarized responses of commentators who see the Internet either as a disturber or an improver of doctor–patient relationships, we provide an analytical framework consisting of five themes. Internet health sites can: be(come) a replacement for face-to-face consultations; supplement existing forms of care; create favorable circumstances for strengthening patient participation; disturb relations; and/or force or demand more intense patient participation.

Limitations

Our results must be considered a first attempt to systematically identify themes regarding the impact of e-health on the relationship between patients and healthcare professionals. It is acknowledged that 'cyberspace' is fundamentally embedded within specific social, cultural, and material contexts (Anderson, Rainey, & Eysenbach, 2003; Baur, 2000; Orgad, 2006); however, our analysis did not allow us to take these contexts, and the many changes that have taken place over the course of the last fifteen years, into account. Further research is required to study the precise nature of the impact of e-health on the patient–physician relationship, and to investigate the kinds of physician–patient relationships that are likely to emerge via the Internet in the current and future environment of medical practice; a practice characterized by constant demands to reduce costs and to produce measurable outcomes.

When pondering the risks of the Internet, the discussion centers on the quality of information. We think that more attention should be paid to the redistribution of tasks and responsibility to patients. Bringing treatments into the homes of patients can have many advantages and be very convenient, but the inconveniences, disadvantages, and added 'sick work' patients must do should also be considered, especially in times when discussion of costs and medical effectiveness prevails.

We hope that our analytical framework will provide a useful starting point for further and much needed empirical research, and

enable a more nuanced and critical debate on the complex effects of e-health on the patient–professional relationship in healthcare.

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Appendix. Supplementary data

Supplementary data associated with this article can be found, in the online version, at doi:10.1016/j.socscimed.2010.10.701.

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