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The Internet and the therapeutic education of patients: A systematic review of the literature

Internet et éducation thérapeutique des patients : revue systématique de la littérature

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Abstract

Objectives. – To evaluate from a review of the literature the interest of using the Internet as a tool for the therapeutic education of patients.
Method. – A systematic review of Pubmed was carried out using the key words: the Internet, or World Wide Web and patient education, or patient preference, or self-care. The search was restricted to articles in English published between 1990 and 2009. References to the selected articles were also analyzed. Only randomized controlled studies were retained.
Results. – Thirty-nine articles concerning 20 different diseases met the inclusion criteria and were analyzed. Different types of programs were proposed: informative, interactive, cognitive-behavioral and programs concerning self-management of the disease and the treatment. These different approaches were sometimes compared. The use of quality Internet sites made it possible to induce beneficial changes in lifestyle habits, and to diminish subjective and/or objective symptom severity in chronic invalidating diseases when used as a complement to traditional management. By using the Internet, patients were also able to improve decision-making skills to a degree that was at least as good as that obtained using traditional paper documents.
Conclusion. – The Internet is an effective complementary tool that can contribute to improving therapeutic education. Nonetheless, healthcare professionals should work with patients to create quality sites that correspond more closely to their expectations. It is also essential for learned societies such as the SOFMER to invest in therapeutic education on the Internet to make quality therapeutic education modules based on factual medical data and complying with good practices available on line.

Keywords: Internet; Patient education; Quality; Education tool; Cognitive-behavioral programs

Résumé

Objectif. – Évaluer à partir d'une revue de la littérature l'intérêt du recours à Internet comme outil d'éducation thérapeutique des patients.
Méthode. – Une revue systématique a été effectuée sur Pubmed avec les mots clés « Internet » ou *World Wide Web* et *patient education* ou *patient preference* ou *self-care*, limitée aux articles en langue anglaise publiés entre 1990 et 2009. Les références des articles retenus ont également été analysées. Seules les études contrôlées randomisées ont été retenues.
Résultats. – L'analyse a été effectuée sur 39 articles répondant aux critères d'inclusion, concernant 20 pathologies différentes. Différents types de programmes sont proposés : informatifs, interactifs, cognitivo-comportementaux, programme d'aide à l'autogestion de la maladie et du traitement. Ces différentes approches sont parfois comparées entre elles. L'utilisation de sites Internet de qualité a montré la possibilité d'induire des changements positifs dans les habitudes de vie ; ainsi qu'un intérêt pour diminuer la symptomatologie subjective et/ou objective de pathologies chroniques invalidantes, en complément à une prise en charge traditionnelle. L'utilisation d'Internet permet également d'améliorer la capacité d'aide à la décision des patients de façon supérieure ou égale aux supports papier traditionnels.
Conclusion. – Internet est un outil complémentaire pouvant contribuer à améliorer efficacement les démarches d'éducation thérapeutique**.** Il semble néanmoins nécessaire que les professionnels de santé collaborent avec des patients pour créer des sites de qualité, répondant mieux à leurs

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attentes. Il est également primordial que les sociétés savantes comme la SOFMER s'investissent dans l'éducation thérapeutique sur Internet afin de mettre en ligne des modules d'éducation thérapeutique de qualité, s'appuyant sur les données de la médecine factuelle, et en conformité avec les bonnes pratiques.

Mots clés : Internet ; Éducation thérapeutique ; Qualité

1. English version

1.1. Introduction

The neologism 'cyberchondriac' has been employed to describe the growing proportion of internauts who seek medical information [55,63]. In 2006, the number of internauts in the United States was estimated at 136 million (+ 16% compared with 2005; that is to say 77% of the adult population). Among these, 80% declared that they had already looked for information about health and went on line for this reason five times a month on average. They reported that they almost always found answers to their questions, and 76% of them believed that the information was reliable.

As early as 1999, a study of patients with cancer showed that the majority preferred to obtain information from an Internet site that had been created in the context of a program to fight cancer, even though they had little experience of using the Internet [32].

However, the explosion in the number of health-related sites available on the Internet makes it difficult to standardize information, and there are huge variations in the quality of the different sites. This raises the problem of the reliability of such sites as a tool for therapeutic education. Indeed, the quality of the sites depends on a variety of factors such as the involvement of healthcare professionals, the underlying commercial motivations or the influence of pressure groups. The two principal limits concern on the one hand, the absence of a consensus with regard to the information provided, given that in most cases it comes from the work of a single team, and on the other hand, the ability of the non-medical public to understand such information has rarely been tested.

Several studies have sought to evaluate the quality of medical information on the Web [19,31,36], and these have led to a certain consensus on criteria to determine quality [65].

Moreover, healthcare professionals have carried out studies to evaluate the quality of English language sites concerning specific diseases in the fields of pediatrics, Ear, Nose and Throat (ENT), gastroenterology, diseases of the locomotor system, cancerology, the management of pain, urology, psychiatry, nutrition, vascular surgery and the treatment of chronic lesions. Most of these studies concluded that the quality of the medical information available to the general public is usually poor.

Going beyond these studies, Bader et al. also showed that patients preferred multimedia documents, even though, in his study, scores in a knowledge test did not show that patients who had had information sessions on the Internet had higher levels of knowledge [1]. These data therefore suggest that though multimedia can be used to inform patients, the effect of these on knowledge acquisition is difficult to evaluate. A recent study that aimed to evaluate satisfaction with Internet sites dealing with low back pain by patients during a semi–directed qualitative evaluation in ecological conditions showed that the quality of the information did not always meet the expectations of the patients [24,25].

Whereas providing information consists in the delivery of knowledge and advice, education is a more complex process that aims to improve a patient's autonomy and sense of personal responsibility. The education of patients is incorporated into the healthcare process, and includes a series of activities that involve providing information and teaching in order to help patients understand their disease and the treatments, to take an active part in their care, to take responsibility for the state of their health and to foster a return to normal activities. The use of the Internet as an educational tool is therefore controversial not only because of the wide variations in the quality of information available, but also because it is impossible to evaluate the educational process even when patients consult quality sites.

1.2. Objective

To evaluate, thanks to a systematic review of the literature, the interest of using the Internet as a tool for the therapeutic education of patients.

1.3. Method

A systematic review of the literature in the Pubmed database was carried out using the key words 'The Internet' or 'World Wide Web' and 'patient education' or 'patient preference' or 'self-care', restricted to articles in English and French and published between 1990 and 2009.

Only high quality randomized controlled studies were considered (randomization procedures and type of intervention clearly described). Articles were selected by reading abstracts. A second selection was carried out by reading the abstract of the references in the articles selected in the first step.

1.4. Results

1.4.1. Review of the literature

This review found 72 randomized controlled studies. After exclusion of articles outside the scope of the study and/or not written in English and in French and/or of poor quality, 39 articles remained for the analysis.