

Paolo Rossi  
Grazia Sances  
Giuseppe Nappi

## ***www.cefalea.it: the first five years***

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P. Rossi (✉)  
Headache Clinic,  
INI Grottaferrata,  
Via S. Anna, snc, I-00046 Rome, Italy  
e-mail: paolo.rossi90@aliceposta.it  
Tel.: +39-06-94285243  
Fax: +39-06-94285243

P. Rossi • G. Sances • G. Nappi  
University Centre for Adaptive Disorders  
and Headache,  
IRCCS C. Mondino Institute of Neurology  
and University of Pavia,  
Pavia, Italy

G. Nappi  
Department of Clinical Neurology  
and Otorhinolaryngology,  
University of Rome “La Sapienza”,  
Rome, Italy

**Abstract** The Italian headache disorders website (*www.cefalea.it*) was launched in 1999 by the CIRNA foundation in partnership with AI.Ce, which is a lay association and member of the World Headache Alliance. In 2004, the website registered almost 130 000 hits (+200% on the 1999 figure). The most visited parts were the sections devoted to topical issues relating to headache, the list of headache specialists, the headache glossary and the support group. This article summarises the website's first five years of activity and highlights the Internet's potential to improve headache-related decision-making, behaviour and outcomes.

**Key words** Electronic messages • Headache • Healthcare • Internet • World Wide Web

### **Introduction: the online revolution of health systems**

Recent observational data show that the Internet's exciting penetration of our daily lives continues apace (in Italy reliable sources indicate that 16 000 000 people go online, almost 30% of the entire population) [1]. Technology apart, the Internet can, in essence, be viewed as a novel environment for communication; and as communication is the basis of all human activity, it is reasonable to predict

that the spread of the Internet will change every aspect of social existence [2].

When social scientists started, through the application of rigorous scientific methods, to analyse the socio-cultural impact of the Web, an unexpected fact came to light. Health care, of the various spheres of communication, is the one showing the most marked Internet-driven transformation (in terms of its cultural practices and structural organisation). Indeed, an “online revolution of health systems” is under way.

In 2000, 55% of US citizens with Internet access used it to obtain health care information and/or services (this figure rising to 62% in 2002) [3]. Most (92%) of these “health seekers” judged the information they obtained on the Web to be useful; 81% said they had learned something new and 70% said that the information they had accessed online had affected their decisions about treatments. Looking for health-related information/services online is the third most frequent use of the Internet after corresponding via e-mail and using search engines [3]. Interestingly, 10% of US citizens has taken part in online support groups [3].

To summarise, it seems clear that: (a) the Internet has rapidly become the preferred medium for searching for health information and has the potential to actively influence health-related behaviour, decision-making and outcomes; (b) a growing number of people search the Web not only for health services but also for psycho-educational therapies.

Is this use of the Internet as a health care tool just a fashionable and passing trend or does it herald a radical transformation of the health care system and of society?

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### The fascination of online medicine

Health care is, in essence, a sphere of information, an activity based on the transfer of knowledge to external “consumers”. From this perspective, the searching of the Web for information and/or services can be viewed as an attempt to fill a knowledge gap and can be analysed using the models traditionally applied to the study of human information-seeking behaviour. According to Choo [4], individuals in search of information engage in dynamic, interactive cycles of activity comprising three clear stages. The first is the *information need* stage, in which individuals recognise gaps in their knowledge. The second is the *information seeking* stage, where information needs become crystallised as questions or topics that guide the choosing of and interaction with information sources in an information search. The third stage, *information use*, involves the selection and processing of information to reach a new level of knowledge.

The information need stage determines the demand for health care information/services. In the last few years, this demand has been growing rapidly for at least three reasons: (a) there has been an increase in information sources, and thus a growing call for information; (b) medical practitioners, the traditional source of health care information, are failing to fulfil their role as primary imparters of knowledge because of a deep organisational crisis of the structure within which they work. On average, a general practitioner (GP) spends 7–10 minutes per

consultation, and a specialist 14 minutes. Most physicians tend to interrupt patients after less than half a minute and GPs often issue a prescription within 2–5 minutes of hearing the patient’s account of his or her symptoms. Clearly, then, many patients leave the physician’s office without getting answers to all their questions, and with gaps in their knowledge still waiting to be filled. (c) We are currently seeing a global transformation of the way health care is organised, with patients being encouraged to play a responsible and assertive role their own care [5, 6]. Patients are asked to collaborate actively in the health care process by changing their lifestyles and obtaining information that will enable them to participate in clinical decision-making and to improve their self-care. This emerging self-help movement, which promotes the value of lay knowledge and experience, has found, in the Internet, a natural space in which to grow and develop [7].

In the context of this high demand for health-related information, the intrinsic characteristics of the Web make it the preferred channel in the information-seeking stage. In fact, searching the Web for health information is convenient, user-friendly, cheap (US data revealed that the search for health information is a popular activity, with no major income effect), comfortable, anonymous and interactive. Finally, “health seekers” can obtain from the Web more information than they can get from other sources and can become aware, in real time, of the most recent results of scientific studies.

Even in the information use stage, the Internet offers many advantages over other media. Indeed, in the virtual reality of the Web, “health seekers” can find a wide supply of health services and personalised treatment options to help them solve their problems.

On the basis of these considerations we can assert that the Internet has enormous potential as a health care tool. The Internet can be regarded as *the* health medium of the future mainly because it is a cultural phenomenon that reflects the current transformation of society. In modern society, social interaction is no longer taking place in the traditional spheres: social contact is becoming divorced from physical space and people are increasingly connecting on the basis of their interests, needs, strategies, values and beliefs. In the modern era, the network has become the primary form of organised interaction and knowledge transfer, and the Internet is its material infrastructure. In the words of Castells, modern society is “individualism organized in a network” [2]. This re-organisation of human society is resulting in a transformation of knowledge sharing. Health systems have gradually turned into patient-oriented networks, in which the patient is not only an external consumer, but also a member of a network community, playing an active role as a source of knowledge and as a health care operator.

**www.cefalea.it (the Italian headache disorders website)**

The website *www.cefalea.it* was launched in 1999 by the CIRNA foundation (a non-profit organisation devoted to promoting research and providing information on headache and adaptive disorders) in partnership with the patients' group AL.Ce (a lay organisation that is also a member of World Headache Alliance) [8].

The website's underlying philosophy is the belief that the Internet has the potential to bring about a cul-

tural change, founded on the network as an organisational model.

Table 1 summarises the current structure of the website. The most striking, unexpected development seen in these first five years has been the spontaneous transformation of the "open comments" section into a permanent, unstructured virtual community, where an increasing number of consumers share experiences and knowledge, ask questions, provide emotional support and self-help suggestions for headache sufferers, or simply tell their own stories.

**Table 1** Site content and monthly number of contacts per section

Section	Short description	Number of contacts per month
Italian headache network	A list of recommended headache specialists, clinics and centres, including a description of the health support they offer	1000
Al.Ce group	Information about Al.Ce: aims and activities	217
Cefalee Today	An e-magazine designed to circulate news about headache management. Patient contributions are welcome	
Confinia cephalalgica	A peer-reviewed journal dealing with headache and adaptive disorders containing comments, contributions and ideas from authors belonging to different medical and non-medical fields	218
Regular features	High-quality information written by headache experts on selected topics frequently raised by headache patients	
a) In-depth analysis		a) 1500
b) Headache drugs		b) 1170
c) Headache and food		c) 1000
d) Headache and hormones		d) 1450
e) Headache glossary		e) 1133
f) Cluster Club Italia		
g) Editorials		
h) Press review		
i) Others		
E-mail service (ask the expert)	An "ask the expert" e-mail service	
a) For patients		a) 245 contacts per year
b) For professionals		b) 69 contacts per year
Comments	A free space where website visitors may leave their comments, directed at the authors (unpublished), or at everyone (published in full on the website). The latter has spontaneously become a very crowded virtual community of our consumers	400
Health on the Net Foundation (HON) seal of approval	Information about the HON code of conduct for medical and health websites	
Events	An up-to-date list of events organised by the website owners and authors	
News	What is new on the website	
University Centre for Adaptive Disorders and Headaches (UCADH)	Information about UCADH aims, organisation and activities	
Links	A list of links to websites owned by professional and lay organisations active in headache care	

With regard to the language, the authors are very careful to avoid impenetrable scientific jargon or obscure terminology that might create confusion, as well as abstract messages that have little to do with the users' real concerns.

In 2004, the website registered almost 130 000 hits (+200% on the figure for 1999). The website currently receives 240–700 hits per day. The most popular sections are (Table 1): the information sections devoted to topical issues in headache, the list of headache specialists, the headache glossary, and the support group.

Through the "ask the expert" section the authors receive an average of 300 e-mails a year. Analysis of the content of these e-mail messages revealed that the most frequent reasons for communicating with a headache expert were: (a) to seek advice/opinion about symptoms (40%), (b) to seek advice/opinion about specific conditions (30%), (c) to seek information about services (10%); (d) to seek information or advice about treatments and procedures (7%); and (e) to seek information about a condition or an interpretation of information already obtained (7%).

Our first five years running this website has led us to several conclusions:

1. There is a widespread and unmet need for medical information, advice and services that the Internet may help to satisfy (quantitative and qualitative analysis of the website hits).
2. The Internet is a reliable source of recommendations for patients needing to decide who to contact for headache advice (in the period 2001–2005, 23% of the patients seen at the INI Headache Clinic had decided to consult this clinic after visiting the website; 85% stated that they had also decided to get a medical opinion independently from their GP).
3. The Internet has the potential to affect headache-related decision-making, behaviour and outcomes (data obtained from a 6-month follow-up e-mail sent to patients who had previously visited the website).
4. The Internet has the potential to change the physician's way of assisting headache patients (anecdotal reports and experiences of headache experts involved in the website project).
5. Headache patients may represent an extraordinary source of knowledge for other health care "consumers" and professionals (qualitative analysis of the website virtual community). The electronic peer-to-peer virtual community may represent a valuable source of additional support (self-help and socio-educational) for headache sufferers (follow-up data regarding patients participating in support group).

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