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Access to health information: going from professional to public practices

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Abstract— Health information has encountered deep changes these last years under the influence of Information and Communication Technologies (ICT). Medical information that is controlled, produced and distributed by specialists (public and scientific institutions for example), has seen the rise of public information, partly produced by non-specialists. These evolutions have consequences on the access to this information, that has been enlarged and transformed, evolving from essentially professional uses for which the boundaries are clearly defined, to public uses in which personal discourses and specialized information are merged. This article raises two complementary facets of access to health information. Firstly, we present the professional practices, and those of patients whom participate in health forums.

Index Terms— health information, informational practices, discussion forums, health doctors, patients.

I. INTRODUCTION

Health information has evolved during the last years under the influence of ICT. Romeyer [15] underlined the coexistence of two types of information in the medical sector: in one hand, medical information, traditionally produced by specialists and meeting the criteria and mechanisms of scientific information, and in the other hand, a new category of information destined to the general public, and distributed on the internet. In this context, the question of the ways to access this information is raised both from the point of the concerned users, as well as the evolution of the strategies that are put to work.

We studied tow kinds of users on health information: health doctors, who needed to access medical information whether for daily professional practice or to respond to training obligations; and patients whom are increasingly seek and produced information that is related to their illness.

In the first part of this paper, we are going to focus on professional uses of medical information; the second part will be dedicated to the patient's practices on health forum.

II. ACCESS TO SPECIALISED INFORMATION: THE PROFESSIONALS' PRACTICES

A. Informational practices by hospital doctors

To apprehend the expectations and uses of hospital doctors, we studied the informational practices of doctors at the Grenoble hospital [1]. This study took place as part of an European project (Noesis) for which the objective was to build a platform in order to help during daily medical practices. The tools put at hand for this project are part of a wider panel of devices allowing to access information. Their adoption by doctors presupposes a certain level of expertise in the use of new technologies and the existence of informational practices that are favourable for electronic resources. Thus the intentions of this research were to determine in their entirety the informational practices of the doctors, to understand their informational behaviour in relation to the "needs" sensed in the professional activity, to identify the factors or satisfaction and to underline their eventual expectations in relation with the informational electronic device.

To reach these objectives, we carried out interviews with sixteen doctors in order to determine the practices and needs of doctors from the Grenoble University Hospital Center, relating to the scientific and technical information and more particularly in the context of general use of the internet.

The indicative grid used to interview the doctors was shared into four parts:

- General questions about identity, specialized medical field, status
- Technological aspects: uses of computer, of internet (context, frequency...)
- Informational practices: kind of information sources (traditional like library or online), information research, selection criteria, validation circuits ...
- Continuous training activity: kinds of activities, frequency...

First, we framed a set of hypotheses:

- As doctors are a professional population, one would think that they have requests or expectations related to their job or their speciality.
- In addition, some hospital doctors can also practice as a university professor; thus one could expect that their practices and needs may not only be related to their more or less immediate clinical activity, but also

to the objectives of research and a scientific career, such as the necessity to frequently update very specialised knowledge and regularly public is English. The resort to online scientific information should thus also be more important for practitioners that are involved in research activities and a university career.

- Finally, any doctor finds himself implicated in a continuous training activity, either as a trainer or as a trainee. One can thus imagine that the preparation for classes as well as other training interventions reinforce the place given to information research in the professional activity.

The analysis of the results allows us to underline a few strong characteristics related to the informational behaviour of the population we interviewed although it cannot be considered representative of all the medical staff. We noticed a regular use of the computer, both in professional and private contexts. The diversity of tasks realised with the computer and the oldness of this use allow us to conclude that there is a good integration of information technology tools in daily practice as well as in the professional culture. Thus the general context is relatively favourable for the use of new technologies that could anchor themselves inside of older ones. Nevertheless this does not lead to the acceptance of any new technology, as we will see further on.

The informational practices are also favourable for the use of computer technologies. Practically all of the subjects give privilege to electronic information sources at the expense of more traditional resource centres (such as libraries). In all the cases, the “traditional sources” are used when online research isn’t satisfying or when computer means are down. This orientation towards electronic sources exploits an abundant informational offer that most of the subjects consider satisfying. Consequently, factors of dissatisfaction are more so related to information access procedures, to the break-up of sources, and thus to the time lost spent researching the information needed, to the unavailability of certain sources (although clearly identified) because of lack of subscriptions, or even, in some cases in which subjects work according to “watch” logics, to the overabundance of information generated to the massive distribution of information.

These considerations indicate a regular and reflective practice (that one may qualify as “solid”) of online information research, accompanied by a very good global knowledge of electronic sources, whether for subjects with a university “status” or for hospital practitioners. Should that be identified as a particular expression of the professional culture and the job’s context? Is it a specificity related to our sample? The question remains unanswered.

We noted an important resemblance between informational practices observed at the University Hospital Centre and those currently associated to the scientists [6] [9] [17] [18]. Amongst the most important similarities: the preference given to online

resources, the central place awarded to a scientific article in comparison to other forms of publications (such as books), the current use of English whether for reading or writing articles (and the underlying domination of Anglophone information sources), the regular participation to colloquiums, the knowledge of scientific information validation circuits (evaluation by experts, reading committees, etc.) and their exploitation in effective research to select and validate the information, etc.

In parallel, we have also noted the distinctive elements that contribute to individualising the behaviour of the doctors we interviewed. Although other scientific categories easily adopt “innovative” behaviours, and thus act as genuine actors of innovation (for example with the use of open archives, or “pre-print” bases, that constitute diversified publication circuits, thus accepting more open information validation circuits...), doctors seem to be shyer and prefer to follow circuits that are already recognized (with strong credit given to professional medical internet sites, and reluctance towards revues that are online only, giving importance to the paper format...).

B. Practices and uses of information by expert doctors

As a complement to the Noesis project, a study was carried out amongst liberal specialised doctors in order to underline their informational culture and study their information practices [9]. Whatever the sector of activity, doctors must revise their scientific and medical knowledge and thus regularly resort to professional or scientific information related to their speciality.

The criteria observed for this study are the following: the effort of continuous training, the reasons that induce information research, the training given via scientific and professional information, the conditions of access, and the resources that are effectively used. We used in this study a grid adapted from the Noesis research for interviewing expert doctors.

Results firstly show that the sixteen doctors that were interviewed for this research are familiar with information and communication technologies as they all have computer equipment as well as an internet connexion both at home and at work.

The results also show that nearly all of the doctors participate all year around to teachings, meetings and/ or seminars. In average, a doctor goes to at least twenty of them a year, as a trainee (rarely as a trainer, on the contrary to hospital doctors). In addition, these specialists also attend two to five scientific colloquiums a year.

Many reasons are raised for information research: clinical activity, research, teaching, knowledge updating, answers to colleagues or patients... Nevertheless, the clinical activities predominantly encourage information research. The needs in information materialise via different forms: bibliography, very precise information (in order to choose the treatment, or for rare pathologies...), and punctual information requests. These last two cases are generally related to a daily clinical activity

even if the doctor doesn't necessarily have the time to research information.

Amongst used resources, the personal library occupies a main position (books of reference, professional reviews, speciality reviews, pharmaceutical laboratory documents, training and congress documents), mainly on paper. Discussions between colleagues are also mentioned, as well as libraries and the use of online resources that tends to be generalising.

Training to research information, when it used to exist, seems very limited and old. Interviews inform us that the training is often informal. City doctors consider themselves very inefficient, and it shows in their practices. In reaction to the difficulties they encounter (the necessary time needed to research efficient information, an incomplete knowledge of the resources at hand, the absence of any real training related to information research), these specialists are cautious with the data found on the internet.

Both studies presented in this article share characteristics amongst which the need to access medical information that has been validated, or the need for continuous training. Nevertheless, University Hospital Centre doctors seem better trained to look up information, and that has influence on their informational practices.

The development of medical information on the internet implies that doctors, whatever their sector of activity, and having for a long time exclusively used scientific medical information, renown in a research context, are maybe going to focus interest on health information too, that is more general, sometimes less reliable. They may integrate it into their professional practices and take into account the evolutions of their patients' information practices.

III. GENERAL PUBLIC INFORMATION: THE PATIENTS' PRACTICES

A. Patients and health information

Patients and their family increasingly ask to be better informed whether about their illness, the potential treatments, and more widely access conditions to care. The reasons for which they ask to be informed are various, and in parallel they have access to a multiplicity of sources, notably through the medical internet [10] that provides them with a set of contents, from general public health information, widely distributed on the network, to specialised resources that were reserved to health professionals until then, and are now available on the internet for free [16].

Renahy [14] quotes different investigations that show that thirty to fifty per cent¹ of internet users use the internet to research information that is related to health; amongst them, over seventy per cent use search engines, twenty-seven per cent directly contact specialised internet sites, and thirty per

¹ Thirty per cent according to INSEE and fifty per cent according to an investigation carried out by INSERM.

cent resort to discussion forums as a source of information. Thus information research is sometimes related to a medical consultation, and in that case, it sometimes precedes it. A large amount of health information research that is done on the internet has no direct link to the consultation of a health professional [4].

B. The analysis of interventions in health forum

In this context, we took interest in health related discussion forums and lead a study from with the Gresec [5], that consisted in analysing the interactional dynamics and the type of content exchanged inside a medical forum. We chose to take interest in *Doctissimo*, the most consulted French health forum.

Firstly, one must consider that discussion forums include characteristics that have an influence on the users' practices.

The available content on forums structures itself automatically as the messages appear: the users decide, contingent to their interventions, of the themes that are raised and the way they are raised in the train of the discussion. The users, who are all at once consumers as well as information producers, determine by themselves the content that is conveyed as well as its organisation. And as any device available on the internet, forums are open twenty four hours a day. Thus they allow asynchronous exchanges in an anonymous context.

Last but not least, anybody can consult messages, research in the forum archives, without producing any content himself and without being involved in the discussion.

Although the participants' aim inside the forum is to obtain medical information and/or general public health information, a hypothesis would be that they enter those forums for other reasons too because the medical information does exist and is available elsewhere (databases, public institution internet sites, patients' organisation sites, medical press...).

To answer this hypothesis, two methodological approaches were used. Firstly, the interventions on the forum were analysed according to their informational content. Each message was characterised according to a set of labels: we considered that each component matches as unity that could be a "question" (Q) or an "answer" (A). Then, the Q and A were characterised according to the kind of content conveyed: a testimonial (T), scientific information (SI), practical information (PI), advice (Ad) or interjection (I).²

	Question	Answer
Testimonial	QT	AT

² For more precision concerning the methodology, the reader will refer to the original publication that presents this work: CLAVIER V., MANES-GALLO M-C., MOUNIER E., PAGANELLI C., ROMEYER H., STAI A. (2010) Dynamiques interactionnelles et rapports à l'information dans les forums de discussion médicale. In *Le Web relationnel : mutation de la communication?* (sous la dir. de Florence Millerand, Serge Proulx et Julien Rueff), Presses Universitaires du Québec, 374p.

Scientific information	QIS	AIS
Practical Information	QPI	AIP
Advice	QA	AA
Interjection	QI	AI

Table 1: Possible Information contents.

We consider that “questions” are messages that seek information from other participants. These questions are not necessarily expressed in an interrogative mode. The “answers” are then interventions that represent an informational contribution for the participants.

The “testimonials” are interventions that are characterised by a strong reference to the life and individual experience of the participant. The “scientific information” category characterises messages for which the content is considered objective and for which its validity is not built on individual experience. “Practical information” includes references to external sources (links towards websites, public organisations...); “advice” is in reference to a procedure, a way of doing; and the “interpellation” label is associated to unities for which the function is mainly “phatic” (requesting an answer...).

Secondly, we analysed the vocabulary specialised in the participants’ interventions.

The results of this study that were largely published in [5] confirm that the patients participate in the forum with informational motivations as well as emotional reasons [13].

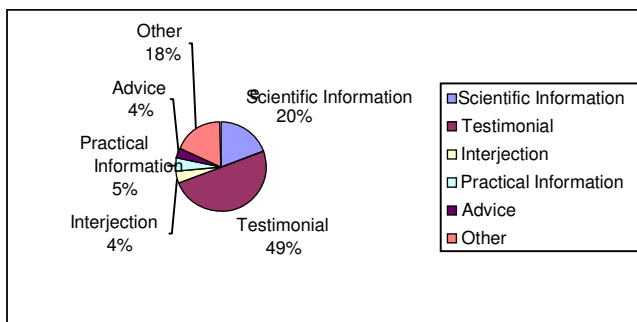


Figure 1: Distribution of information types

Thus, “scientific information” exchanges can be found in the forum as well as “testimonials”. Although the last category is what is most represented, the patients intervene on the forum to talk about their experience and share it, to consult the testimonials of other individuals that have met the same events and thus find information that is centred on the individual himself as well as his experience.

The interlocking of scientific information and testimonials inside the messages shows that the participants also bring neutral information about the treatments (the medical care...)

through their story, sometimes referring to their doctor’s speech to support their own words.

Here the individual appears to be both the carrier of objective knowledge (that he can hand out in the shape of advice, “scientific information” or “practices”), but also and even more so of a life experience that makes this knowledge more accessible, more human in the eyes of other participants.

It is thus the blending of informational and emotional components that constitute a certain interest for the participants in the forum: very often the individual attests, calls to testimonials, contributes with medical information, asks for advice, gives it or looks for it all at the same time.

Finally, the forum is characterized by the multitude of participants with different statuses, taking on different positions according to the messages (asking or giving information or advice) on different levels (emotional, informational).

On the contrary to traditional information distribution circuits, forums don’t have a validation procedure for the information they offer. Of course a moderator sometimes intervenes to correct false information. But in the strict frame of forums, it seems that participants aren’t attached to information that has been confirmed by experts. It is the life experience of the individual and not the scientific expertise that is a token of credibility and that makes the information relevant.

IV. CONCLUSION

The studies that we carried out until now underlined a set of questions that are interesting to answer from the point of view of information sciences. We suggest three leads for reflexion:

Forums are places in which there are exchanges and knowledge sharing. The testimonials are essential and constitute an important share of the interventions. The information built in forums is thus given a particular status: the individual is both the carrier of knowledge and the filter of this knowledge thanks to his own experience. This raises the question of the legitimacy of information that hasn’t been scientifically validated, but that has been given sense by the uses that surround it. Health forums are, just like blogs or social networks, tools of the Web 2.0, and they participate in the reconsideration of traditional authorities, the authority given to information isn’t transcendently provided, but rather influent or even popular [8].

A study was done in the United States about health blogs [11] that takes interest in the judgements made by patients on the information provided by these blogs. It appears that on one hand these patients interrogate the cognitive authority of health professionals, and on the other hand that the emotional authority of the bloggers plays a role in the informational judgement of the readers.

It is not the individual's expertise that conveys legitimacy to information, but the experience, thus operating a shift in the notion of informational authority to that of emotional authority.

It appears that a big number of internet sites include forums or sections related to health, even if it isn't their first function. Thus it seems that it is a subject that must absolutely be taken over, whatever the competences of the writers, and whatever the content of the concerned sections (food, dietetic...). We can observe the reproduction on the internet of a tendency that is present in other contexts, in particular in newspapers. This raises questions relating to the evolution of editorial choices on these internet sites, to their consequences on the image of these sites, and their audience, as well as to the notion of trust that is awarded to these testimonials, independently from the labelling that is done by some internet sites.

The uses of health information evolve. The resort to this kind of information by non specialists (and notably patients) is increasingly growing and may lead to various consequences.

The evolution of patients' informational practices can have an influence on the professional practices of doctors. Have the doctors considered in their medical practices the overabundance of information their patients have access to, or are they planning on doing so?

According to a study carried out by Cegala [3] there is no influence between the information research that is done by the patients and the communication that happens between the doctors and these same patients. Although Iversen (2008) referred to by [2], notes that according to a majority of patients, information research encourages them to ask questions during consultations. In addition, these patients inform their doctors of their research as they consider that they may be interested in what can be found on the internet.

The evolution of these practices can also influence the documentary organisation of the resources that are accessible to patients. Thus, the specialised information sources, until now made available to specialists and now used by patients, should they include these general public uses, for example by offering devices that allow to research with non-specialised vocabulary, or by structuring the sources in order to blend professional information and popularized information?

We must now go into these leads for reflexion in depth, in the aim to have a more complete view of informational practices in medical field and of their evolution according to information technologies. Some investigations onto forums [12] or in PhD contexts continues in this objective.

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