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PATIENTS' DIRECT ACCESS TO THEIR ELECTRONIC MEDICAL RECORD USING THE INTERNET: A LITERATURE REVIEW

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Abstract: Patient-accessible medical record is an important element of evolution in the patient-physician relationship: patients want to become more active in their health care process. We want to highlight the results of studies that analyse the impact of patients having access to their electronic medical record using the Internet on patients, on physicians and on their relationship. The studies were identified using "Pub Med" and "Web of Knowledge". The search was limited to articles published between 2000 and October 2012. We focused on articles about patients accessing, through Internet, their electronic medical record that are created and filled in by physicians. 26 studies were selected and analysed. Quantitative data were obtained through questionnaires, analysis of the log-ins and analysis of the records, while qualitative data were obtained through interviews and focus groups. The specificity of our review refers

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to the electronic means through which patients access their electronic medical (and particularly Internet).

Keywords: *Electronic medical record, Patients access, Internet, physician-patient relationship, health knowledge, communication, autonomy*.

INTRODUCTION

Patient-accessible medical record is part of a wider movement of changes in the patient-physician relationship. Nowadays, patients want to become more active in their healthcare process: they want to be informed about their health status and participate in the decision-making process. The electronic medical record (EMR) is now widely used and Internet allows patients to access it when and how they want.

METHOD

The studies were identified using "Pub Med" and "Web of Knowledge". In "Pub Med", we used equations such as "Medical Records Systems, Computerized"[Mesh] AND "Physician-Patient Relations"[Mesh], "Medical Records Systems, Computerized"[Mesh] AND "Patient Access to Records"[Mesh], "Patient Participation"[Mesh] AND "Medical Records Systems, Computerized"[Mesh] and "Online Systems"[Mesh] AND "Medical Records"[Mesh]) AND "Patients"[Mesh]. In "Web of Knowledge", we used topic words such as "Medical Record","Patient" and "Access". The search was limited to articles published between 2000 and October 2012. The bibliographies of these articles were also checked for potentially eligible studies. We only included articles about patients accessing, through Internet, their EMR created and filled in by physicians.

The published literature on patient access to their medical records has already been reviewed in 2003 by Ross et al.[1] and in 2007 by Pereira et al.[2] and our specificity refers to the Internet through which patients access their EMR.

26 studies were selected and analysed.[3-23,28-32] Quantitative data were obtained through questionnaires[3-5,7-9,11-19,22,23,28,32] and analysis of the log-

ins[3,7,8,18,20,28,30] while qualitative data were obtained through interviews[3-6,10,11,16,17,19,21,23,29,30] and focus groups.[4,5,16,21,29]

RESULTS

Among the 26 studies analysed, some studies analyse expectations towards patients' access to their EMR online, from patients and/or healthcare professionals[9-15,17,21,22,23,32] and others give results of projects in which patients experienced access to their record. The majority of those studies analyse access by patients to their EMR via Internet and by themselves, with some exceptions.[5,28,30]

The topics analysed in this review (table 1) were inspired by other literature reviews[1,2] and adapted.

IMPACT ON THE PATIENTS

In order to study the impact of patients' access to their EMR online, we analyse different topics: 1) the patients' interest in reading their record, 2) the possibility to lead to a better knowledge and understanding of their health status, 3) the possibility to encourage patients to adopt a more active role in the management of their health, 4) the capacity of patients to understand their record or the risk to be confused by it, 5) the anxiety or the reassurance that patients can feel when accessing their record, 6) the concerns about security and confidentiality and 7) the control of the quality of data by the patients.

PATIENTS' INTEREST IN SEEING THEIR MEDICAL RECORD

Patients' interest is interpreted, in this paragraph, as feeling curious about something (and not as benefiting from it).

A preliminary element is the patients' knowledge to their right to access their medical record. The studies reveal that such knowledge is high: from ¾ of the patients[9,13] to all patients[10] are aware of their right.

Patients' interest in seeing their medical record is generally very high: from 79%[9] to 95% of patients wanted to be able to review their medical records.[15] This can be explained by the benefits they predict from such

Table 1. Topics and number of articles related to each of them

Topics	N° articles	References in the bibliography
Patients' interest		
• knowledge of the right	3	9,10,13
• Interest in seeing record	5	5,9,10,13,15
• Interest in seeing electronic record	4	9,10,13,17
• Interest in using Internet	10	3,5,7-10,12,15,23,32
• characteristics of patients interested	7	4,9,15,17,20,28,32
• Nature of the data	12	3,4,5,8,9,11,16-18,20,21,30
• Frequency of access	5	7-9,17,29
Better knowledge and understanding	12	3-6,8-10,13,15,23,28,29
More active role	6	3,4,9,28,29,31
Understanding or confusion	11	3-5,13,15,16,18,21,23,28,31
Anxiety or reassurance	9	4,6,7,15,16,18,19,23,29
Concern about confidentiality/ security	9	4,5,7,10,11,13,16,17,28
Correcting errors: quality of data	10	4,5,10,11,13-16,23,28
Physicians' opinion on patients' interest	7	3,4,7,12,14,15,22
Effects on workload	6	4,11,14,15,16,23
Physician-patient communication	4	3,12,14,18
Physician-patient relationship	8	3,4,10,11,21,28,31,32

access: "*understand their health better, make easier to plan consultations, easier to talk to their doctors, aid making decisions about their own healthcare*",[13] "*be more active in their own healthcare, see what the physician said about them*",[9] "*improve understanding of medical conditions, improve understanding of doctors' instructions, be reassuring, increase trust in doctors, increase patient satisfaction, identify errors in the medical record*".[15] Some patients explained why they were not interested in seeing their medical record: "*no need, never occurred to me, not*

aware I could, no time, or never interested",[10] "*confidence in their general practitioner, concerns about confidentiality, lack of interest, resistance to change, fear of the content and visual impairment*".[5]

Patients are divided about the electronic or paper format they would like for their medical record.[9,10,13,17]

The proportion of patients interested in reviewing their record using the Internet varies from unanimity (the four patients concerned)[3] a majority of them,[5,7,8,23] about half of them[9,10,15] to a fourth of them.[12] Patients who are not in favour of Internet are generally motivated by security and privacy concerns, particularly those without previous experience using the Internet.[15,32]

Studies show that interest in reading EMR through Internet is not linked to socio-economic situation,[9,15,17] is not clearly influenced by clinical factors (in only one study, the patients in poorer health used records access more than those reporting good health[28] while in others that interest was not a function of health status or healthcare use),[9,20,32] is not significantly linked to patients' age [9,13,15,20] or gender.[3,7,15,32]

Patients are more interested in accessing personal information than general information;[8] they often want to access more information than those already available;[11,16,21] the nature of the information that patients are interested in to read differ between patients.[3,4,5,9,17,18,20,30]

Patient who have looked at their medical record in the past remain interested in reading it.[9]

Physicians' opinions about patient-accessible medical record are not unanimous. Physicians are generally suspicious and worried about such access. They anticipate problems (such as increased worry or finding test results confusing).[4,15,23] However, some physicians anticipate benefits for patients: increased knowledge and understanding of their health, ability to monitor their health at their own pace, easier decision making about their health, increased sense of control, improved understanding of their instructions and increased trust in doctors.[4,12,14,15,23] After experiencing access by the patients to their medical record, physicians' doubts disappear; predicted benefits for patients are confirmed[3,4] and physicians endorse the general concept of giving patient access to their medical records.[4,7]

DOES DIRECT AND ONLINE ACCESS BY THE PATIENTS TO THEIR MEDICAL RECORD LEAD TO A BETTER KNOWLEDGE AND UNDERSTANDING OF THEIR HEALTH STATUS?

Patients predict to have a better knowledge and a better understanding of their health thanks to access to their EMR.[10,13,15]

This is perceived in the reality.[3,4,5] The possibility *"to keep track of the progress of their illness and treatments"* is really appreciated by the patients.[4,6] They *"felt that they understood better what had previously been discussed at appointments"*.[28] *"Patients could refresh memories, understand why things have been said and improve their knowledge"*.[29]

DOES DIRECT AND ONLINE ACCESS ENCOURAGE PATIENTS TO ADOPT A MORE ACTIVE ROLE?

Patients assume that direct access to their medical record will help them to be more active in their health care[9] and to increase their *"sense of control"*.[15]

When experiencing such access, patients feel more like *"a partner"*,[29,31] *"more involved in their health care process"*[3,4,28], *"increased ownership of their healthcare"*,[3] improvement in *"their ability to coordinate their care"*.[4] In one study, patients feel that accessing their record even *"improved their health care"*.[3] In another, patients feel that *"seeing information in the record confirmed the need to make lifestyle changes"*[29] illustrating the *"potential effect of prolonged record access on improving or reinforcing health behaviour and potentially changing health status over time"*.[28]

DO PATIENTS UNDERSTAND THE CONTENT OF THEIR RECORD OR ARE THEY CONFUSED BY IT?

Professionals are concerned by the fact that patients may not understand the content of their record, interpret the data incorrectly and be confused.[15,23] Patients' expectations are variable: some think that they will understand the content of their medical record[13] while others anticipate finding data confusing and recognize their own potential for error in interpreting their records but are still interested in accessing their record online.[4,15]

Patients' experience is rather positive: in different studies, the majority of patients find their record easy to understand.[3,4,5,13,16] Different systems are put into place to help patients understand their record: organisation of a meeting about what a medical record is and how to view records,[31] development of a glossary of frequently used terms and references of relevant websites,[5] hyperlinks to explanation of tests,[18] precision in the consent document[7] Some patients suggest that access to EMR should be accompanied with educational materials[23] "*personalized to the specific needs, wishes, comprehension capabilities, and experiences of each individual patient*".[21]

DOES DIRECT AND ONLINE ACCESS MAKE PATIENTS ANXIOUS OR REASSURED?

Physicians often anticipate that direct access will make patients worry more,[15,23] overreact or panic[7,16] while patients do not predict such reaction.[16]

Patients' experience varies: in a study involving patients undergoing in vitro fertilization, there is "*no adverse psychological effects such as increased levels of anxiety or depression.*".[19] Many studies even report that patients are reassured by being able to review their record.[4,6,7] The reassurance comes from different elements: being able to look up their results and confirm for themselves that everything is ok,[4] having the possibility to review their record for accuracy and completeness,[4] knowing that "*doctors were communicating fully and nothing was hidden*",[29] being "watched" by physicians.[6] Another study shows that many patients are concerned by receiving abnormal results or bad news.[5] In one study, some information is manually released to patients by the physician after seeing it first.[18]

DOES DIRECT AND ONLINE ACCESS LEAD TO CONCERNS ABOUT CONFIDENTIALITY AND SECURITY?

The use of Internet to access EMR leads to new risks of unauthorized access and breaches of confidentiality. The majority of the patients are not concerned or only a little concerned by such risks.[5,10,16] When they are, they refer to "*the potential commercial use and exploitation of their data*",[5] the possibility for their data to "*be made available to employers*

or government agencies without their permission".[4] Another study indicates that the greatest amount of concern was among racial and ethnic minorities and individuals with lower amounts of education.[17]

When experiencing such access, the majority of users is not worried about unauthorized people having access to their electronic record.[11,28]

DOES DIRECT ACCESS LEAD TO BETTER QUALITY OF THE DATA?

Patients and physicians predict improvement of the quality of the data:[10,13,14,15,23] "*patients can act as quality controllers*".[11]

This feeling is confirmed: in some studies, one third of the patients find errors in their records (medical events or procedures not recorded, inaccurate information about medical history, allergies and health conditions).[5,13,28]

IMPACT ON THE PHYSICIANS

An important concern of physicians about patients accessing their medical record is its impact on their workload: they fear that patients will contact them more frequently.[4,11,14,15] The staff members of a study thought that it could initially increase the number of questions they receive but ultimately thought this could decrease the workload.[23]

The studies show that access by patients to their record does not affect physicians' workload.[4] There is "*no extra calls from patients who had not understood the information.*"[11] Some physicians even believe that EMR "*and Web messaging could be a time-saver for both patients and providers.*"[16]

IMPACT ON THE PATIENT-PHYSICIAN RELATIONSHIP

Evaluating the impact of patients' access to their record on patient-physician relationship is a difficult task because there are no clear criteria that can easily determine the quality of the communication or the relationship.

Both physicians and patients expect their communication skills to improve.[12,14,15] Experiencing patients access to their record confirms im-

provement of the communication during consultations: by "*an enhanced level of discussion about the patient's problems and issues such as complications*"[3] and more relevant questions[29] by a better understanding of the information given by the physician,[8] by a feeling that doctor understood them,[10] by saving "*time during appointments*",[28] by providing "*clarity and reassurance, and compensating for what some patients sometimes perceived as poor or rushed communication*",[29] globally by having "*a positive outcome*".[4]

Both patients and physicians expect improvement in their relationship.[3,10] This is confirmed: experiencing such access reinforces patients' "*trust and confidence in GPs*",[10,28,29] patients are "*showing a better understanding for the complex and time consuming health care processes*",[11] "*the physician-patient with IBD relationship evolves from one of passive dependency and expectation to one of interdependency, mutual appreciation, mutual support and shared problem solving.*"[21] However, in a study, physicians do not observe any change in the relationship but do not think that "*patients should be denied access.*"[4] For some patients, record access improves observance: in a study, a majority of the participants "*thought that the record access helped them understand why they needed to take the medications*".[28]

DISCUSSION

A number of limitations need to be considered in evaluating the validity of this review: papers were reviewed by just one researcher; all the studies included in this review were not randomized trials; the sample size of participants was not always large and the samples of participants were sometimes very specific. The results of the studies analysing patients' direct access to their EMR have then to be taken with precaution but can be summarized in two steps: prior to such access, physicians have a lot of concerns while patients seem to be interested in it. After experienced it, physicians seem more nuanced and agree with patients on the positive impacts on patients (better knowledge of their health status and more active role, getting better care thanks to accurate information in the record), on the communication and the relationship with their patients (enhanced confidence in GPs, more effective use of the time during consultation, better understanding of what had been said during consultations), and on the absence of strong undesirable effects (no increased

workload). It also seems that record access has an impact on patients' health: some patients changed their medicine taking or wanted to make lifestyle changes.

Internet simplifies patients' direct access to EMR: if patients have access to the Internet, they can access their EMR whenever and from wherever they want and benefit from it at any moment; they are not confronted to barriers to access their record, except maybe for the privacy concerns: published literature shows that patients who are not in favour of Internet (particularly those without previous experience using the internet) are generally motivated by security and privacy concerns and that such concern seem to vanish when people actually use Internet to access their record. This leads to the question of the education to the use of the Internet.

Internet facilitates positive effects of such access, as described above, but it also raises questions even more accurately, about temporality and patients' rights on their record.

First, Internet allowing patients to access their record at any moment leads to the question of "when new results should be available for patients?": in *"real-time, after physician approval or after a specified time delay"*?[23,27] When information is not given in real-time, this is sometimes justified by the risks of misunderstanding or anxiety by patients. This is why patients need tools (such as technical tools or human help) to assist them understand, manage adequately and benefit from accessing their record.[23,24,27] The electronic format allows medical records to be "tailored" to each patient: technical tools such as dictionary, glossary and link to websites with useful resources can be helpful. Physicians can also help patients dealing with their record: they can adapt to each patient and act differently in function of the patient's needs. Patients' access to their EMR via Internet does not replace "traditional" relationship: physicians and patients have different ways to interact and patients' access to their record is a new element of such relationship.

Secondly, what are patients' rights on their record? When accessing their data, patients can have a certain feeling of control or of ownership of their data (by being aware of what is written in their record, being able to see who accessed their record, and checking the accuracy of their record). Patients' right to decide when they access their record is part of/ contributes to the feeling of ownership, of control. This leads to the question of other rights of patients towards their record: are they allowed to add, correct or delete data from their record? A lot of studies reveal that some patients are interested in adding information in their re-

cord.[3,4,5,10,13,17] Having this right *"provides a better insight in your situation"*[27] and helps to develop a stronger sense of ownership of data[24] and of illness.[21] The quality of the information seems however to be "in danger" if the patient can modify his record as he wants. A balance has to be found between patients' rights on their data/record and the necessity of quality data.

To ensure that patients benefit from accessing their EMR through Internet, some conditions need to be fulfilled: security and confidentiality have to be guaranteed because patients will not use a system if they do not trust it. This is particularly important in this matter because health data are very sensitive/personal; actors of the healthcare system have to be interested in such access, otherwise it is a loss of time, energy and money; patients have to be able to understand and manage such access from a technical point of view (tools must be available) and from an emotional point of view (physicians must accompany patients if the patients want such help). We have to be aware that all patients do not have a computer and an Internet connexion. A gap (called "numerical and cognitive fracture") can appear between patients who own such material and know how to use it and others who do not. As any technological development, one have to be aware that such risk exists and that things have to be done to avoid or limit it (such as information campaign, financial help,...)

As far as the Internet is concerned, using the Internet is now part of the daily life for a lot of people: for one patient, accessing the medical record online *"just seems a natural extension to what he is doing anyway": "I shop online, I communicate online, I educate myself online, and I control my finances online. It's only right that I look after myself online"*.[31] Will this feeling become a common feeling among the population?

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