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Patient Empowerment Meets Concerns for Patients - a Study of Patient Accessible Electronic Health Records in Sweden

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Background
As part of a EU project, the Swedish county Uppsala launched a patient portal, Journalen in 2012 [1]. Patients can now access their Electronic Health Records (EHR) online, which is aimed to increase patient empowerment. The medical professionals reacted strongly on patients accessing the medical records. Main concerns were related to quality of care, the effect on their work environment, providing bad news through the eHealth service, and also the wellbeing of patients. While the opportunities of implementing these e-health services seem promising, the concerns of the medical professionals have to be understood and addressed, as well as the actual use of the system by patients. This presentation integrates results from two interview studies with physicians and patients related to patients accessing their medical records online [2,3].

Methods
The presented results are synthesis of the interviews studies with 12 physicians [2] and 30 patients [3], which took place about 6-12 months after the launch of the portal. The synthesis presented in this paper focus on Technological Frames [4] of physicians and patients including the attitudes and experiences in relation to possible 1) anxiety creation, 2) increased of workload, and 3) the general value of patients reading medical records.

Results
Anxiety creation due to receiving bad news. Many physicians believe that breaking bad news to patients during a patient encounter is vital as this would give them the possibility to also explain treatments and answer questions. Somewhat unexpectedly, some patients preferred receiving bad news through Journalen instead of waiting for the physicians. The patients argue that waiting times causes more anxiety. The choice of not accessing is also important, as there are patients who do not want to receive bad news before a patient encounter.

Workload increases. Many physicians are worried about the workload of doctors, as reading the medical record online may result in increased number of phone calls because of anxious patients. However, many patients did not tend to take any additional contacts to ask questions. Some of the patients even believe that access to their medical records reduces the number of contacts with healthcare.

Usefulness of accessing online. Many physicians are concerned that online access will have a negative impact on the patient such as increased anxiety and misconceptions as they lack understanding of medical terms. Unlike the doctors' perspective, many patients argue that they do not have major difficulties in understanding the contents. They also argue that Journalen was central to their coping with their decease.

Conclusion
From this study it is clear that the Technological Frames of physicians differ from those of patients, and that they have different attitudes and experiences towards the system. The intention from the politicians was that the system would contribute to Patient Empowerment, but that framing of the technology differs from the physicians’
view, as they are concerned of the consequences. More research is needed on the framing of the technology and how that has been changed after the launch of the system.


Keywords: eHealth and intersectoral documentation, health telematics, telemedicine, Digital healthcare strategies, Health information and process management, Hospital information systems, computerized medical record systems, Research IT infrastructures and EHR data reuse, Human factors

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