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Worlds Apart - Doctors' Technological Frames and Online Medical Records

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Abstract. The ability of individuals to access and use their online medical records serves as one of the cornerstones of national efforts to increase patient empowerment and improve health outcomes. However, the launch of online medical records in Uppsala County, Sweden, has been criticized by the medical profession and the local doctors' union. The aim of this paper is therefore to present the results from an exploratory study where interviews with two oncologists are analysed and discussed based on the theory of Technological Frames and Patient Empowerment. The results indicate that medical doctors have different assumptions and perspectives that affect their use of technology and how they view patient empowerment in everyday clinical work.

1 Introduction

The digitalization of health records enables the use of medical documentation in a different way than its original purpose. What started as a working tool for healthcare professionals to document and communicate patient-related information, can now also be used as a communication tool between the healthcare provider and the patient, since the latter can also access the medical record now. Other uses of the medical records are quality assurance, research and legitimizing the work done. Personalized patient information has potential benefits, e.g. increased sense of empowerment, improved patient satisfaction, improvements in patients' knowledge and understanding of their condition ([4], p. 83). Patient empowerment refers to a process with the purpose of educating people to be able to think critically and autonomously, where the outcome should be an enhanced sense of self-efficacy in the educated person [2]. In 2012 several eHealth services were deployed in Uppsala County, Sweden, including a service that enables citizens over 18 years of age to access their medical records online. The deployment was preceded by several challenges [5] and especially the online medical records were criticized by the medical profession and the local doctors' union [6]. The medical professionals criticized that having patients accessing their medical records would endanger the effectiveness and value of the records, because these are viewed primarily as working tools ([5], [8]). Additionally the professionals viewed patients' access more as a means to control and monitor the professionals rather than a service to the patients [5]. Interestingly, patients already had the right to access their medical records before by requesting a paper copy sent by mail, but this has been considered "less interfering to the professionals' autonomy" [6]. However, not all professionals have been negative regarding patients' access, since some also considered it "valuable assistance as errors and mistakes are discovered and corrected" [6].

In this exploratory study, we analyse and discuss interviews with two oncologists from the theory of Technological Frames [7], which are composed of the assumptions and values that users have of technology. In the paper we have a special focus on the perspective of patient empowerment and the work environment of medical doctors, which to our knowledge has not been done before. The paper first presents the notion of Technological Frames and patient empowerment. This is followed by a description of the method. We then present the results from the analysis of the interviews from the perspective of Technological Frames and patient empowerment. This is followed by a discussion of the results in relation to other research and some implications for the introduction of eHealth systems. The purpose of the study is to spark a discussion and to receive feedback on these preliminary results.

2 Online Medical Records in Uppsala County Council

Introducing online medical records in Uppsala County Council in 2012 was the result of a process with different projects, law changes and pilot studies that started fifteen years earlier. One of the main reasons for launching online medical records in Uppsala County Council was to increase patient empowerment and to contribute to patientcentred care (for a full description of the development of the system in relation to laws and technical norms, see [5]). Medical records are available to patients through a national e-service called "My Healthcare Contacts". Patients access the service using an e-ID or alternative secure login options. When the system was launched in 2012, unsigned test results and medical records, i.e. information not yet approved by medical staff, were invisible to the patients. As soon as they were approved, patients could see them in their online record. This was the status of the system when the data collection for this paper was made. However, in March 2013 this was changed and now patients can see test results and text in the online medical records as soon as they are entered into the system. However, the patient can see that these test results have not been verified by medical staff by a text in the system that says: *"This information is not signed, which means that it can be changed or deleted"*.

3 Theoretical Underpinnings

In this section we present the theory of Technological Frames [7], which is followed by a presentation of the concept of patient empowerment. The medical doctors' underlying assumptions and expectations are a part of their Technological Frame presented below. In the context of online medical records for patients, the underlying assumptions about patient empowerment are of special interest, since one of the goals when introducing the system was to improve patient empowerment.

3.1 Technological Frames

Orlikowski and Gash's theory on Technological Frames [7] is relevant to our study as it elucidates how different user groups interpret information technology (IT) differently and how these interpretations guide them to make sense and take action. These frames are social in nature, and have implications for technology development, implementation and use. Technological Frames constitute the "cognitions and values of users and designers" and "the underlying assumptions, expectations, and knowledge that people have about technology" [7]. In our study, the professionals working in healthcare have one interpretation of IT based on for example their purpose, context, knowledge base, power and previous experience of similar systems, which constitutes their technological frame. Orlikowski and Gash also propose the notion of congruence and incongruence in Technological Frames, where congruent frames are related to each other through their structure and content, whereas incongruent Technological Frames have important differences in expectations, assumptions or knowledge about some key aspects of technology which make these frames incompatible.

3.2 Patient Empowerment

Patient empowerment describes a situation where the patient's role is changing from a patronized patient to a patient that is informed, autonomous and engaged in his or her own care [1]. The concept of empowerment is highly ambiguous and may be interpreted in many ways. Empowerment according to Shalom (2007) “involves a sense of control and self-efficacy, as well as an active position within the healthcare system” ([9], p.168), where one of the main sources for empowerment is information. Shalom also argues that there are different levels of patient empowerment [9]. On the basic level, the patient learns to ask questions relevant to his/her health condition. On an advanced level, the patient will become a partner in the decision-making process. Anderson and Funnell (2010) view empowerment as both a process and an outcome [2]. According to them, empowerment is a *process* when the purpose of an educational intervention is to increase one's ability to think critically and act autonomously. Empowerment is an *outcome* when an enhanced sense of self-efficacy occurs as a result of the process. They elaborate further that the empowerment approach involves that patients are facilitated and supported to reflect on their experience of living with a specific illness [2]. An important aspect of patient empowerment is also self-determination, which refers to the “philosophical view of humans having the right and ability to choose by and for themselves” [3]. At the same time, the empowerment-oriented approach also views patients as “being responsible for their choices and the consequences of their choices” [3]. This also includes determining which decisions they want to make themselves and when to ask healthcare professionals what to do [3]. While patients are in control of their daily self-management decisions and therefore responsible for the decisions they make, including the consequences, healthcare professionals are responsible for supporting patients to make informed self-management decisions [2]. However, Anderson and Funnell (2010) talk about healthcare professionals being socialized to a set of responsibilities and expectations, which might contradict the empowerment approach, but since it is deeply embedded in the professional identity, they might not even be aware of it [2]. As part of the empowerment process, not only the patients but also the professionals change, because they might have to “unlearn being in control” [3].

4 Method

This workshop paper presents the experiences of two oncology doctors when it comes to the launch of online medical records in Uppsala County Council, Sweden. These two oncologists were interviewed as part of a large interview study focusing on the medical professionals’ perceptions and experiences of online medical records and other eHealth services. The interviews were conducted in the summer of 2013, which is about six months after the eHealth services for patients were launched. For the purpose of this workshop paper, these interviews have been re-examined from the perspective of Technological Frames and patient empowerment. We chose to further examine the Oncologist interviews in this workshop paper, since, at the time of the launch of the eHealth services, Oncology was considered by many in the media as the most troublesome area of medicine from an ethical perspective. The two interviews were semi-structured and an interview template was used. The interviews were carried out on site and lasted for about one hour. One researcher conducted the interviews, and they were transcribed verbatim, but sometimes they have been slightly rephrased in this paper in order to be more readable. Moreover, we present the interviewees as women in this paper to make them anonymous. In the data analysis the following categories were used as a part of the thematic analysis [10], some of which were predefined and some emerged from the analysis of the data: What is their perspective and view of patient empowerment in connection to the launched eHealth services? What do they think about patients reading online medical records and test results? Have they changed their way of writing in the medical records? How does the eHealth Service online medical record affect the work environment? The interviews were read through and analysed separately by the three authors of the paper, and then we discussed and analysed them together. The writing of this workshop paper was also a part of the analysis (as presented by for example [11]).

5 Results

In this section we present findings related to the theme of Technological Frames and patient empowerment.

Patient Empowerment in Connection to the launched eHealth service

Oncologist A does not seem to consider patients’ access to information (such as test results) as a way to increase patient empowerment. She believes that it is the doctor’s responsibility to deal with test results. She emphasizes: *“They only get worried by reading, and they usually only focus on the medical details. They should live their lives as usual and come to the medical appointments without worrying. /.../ we try to do the best for all patients, /.../ it is we who take responsibility for complications and everything. Therefore they should try to enjoy life and not sit in front of the computer and check test results /.../. They're supposed to do other things, not to look for information online about which options they have.”* When asked about the possible opportunities when patients are reading their medical records, Oncologist A acknowledges that patients could prepare and read about alternative treatments. At the same time she is afraid that those well-read patients will be more demanding when they visit their doctor. Moreover, Oncologist A is worried about the future of her profession as a medical doctor when patients are able to access test results: *"Why do you need a doctor if patients themselves can look at the test results before they are signed /.../"* Oncologist B believes that empowering patients is important and she therefore encourages her patients to read their online medical records and other information on the Internet related to the patient's illness. Oncologist B also argues that patients today are more informed about their illness because of easy access to information. This has transformed the patient into an active collaborator in the patient meeting, where he/she asks questions relevant to his/her health condition, and where he/she takes part in the decision-making process: *"Based on the results we discuss what we should do or not do and together we discuss which treatments are appropriate /.../"* Oncologist B also believes reading their online medical record can help patients take responsibility of their own care and outcomes, which is important for achieving patient empowerment.

Perspective on Patients Reading Medical Records and Test Results

Oncologist A has an overall negative opinion about patients reading their online medical records: *"Well, I am negative to this system, even though it has its advantages, but at the end of the day I am negative."* Oncologist A has chosen not to sign the test results, because this will prevent patients from seeing this information. She feels upset knowing that patients will be able to access unsigned test results in the future without first consulting a doctor. She explains: *"Patients being able to see test results before consulting the doctor, it's a catastrophe!"* Oncologist B emphasizes that although she encourages patients to access their medical records, she also tells them that the access can have consequences, such as not being able to contact the physician immediately after reading the medical record. Oncologist B emphasizes: *"And then I tell them that they should access it, but that they also need to face the consequences of having to wait until their next planned patient visit to discuss the results. And I believe that this suits some patients, but many patients also say that 'I don't dare to read my medical record'. /.../ And I believe, even just read the notes about the disease contributes to improved engagements. So I am positive to this if it doesn't result in problems or harm for the patients, for example that they get notified at strange times when they cannot contact anyone. But when the patient is aware of this, then I don't see any problems with it. I mean you must take responsibility for your actions and if you want to log in and look for the test results at a certain time, then you have to take* *responsibility for it even if it's in the middle of the night.*" Oncologist B also believes that test results should be made available to the patient immediately without any delays (i.e. waiting for the doctors to sign them). Moreover, she considers the test results to be the most important information that patients want to have access to and therefore it should be made available immediately.

Changing the Way of Writing in the Medical Records

After the launch of online medical records, Oncologist A has become very careful about what to document in the medical records. She is especially careful when it comes to writing about progression, and she does not write anything in the medical records before she has informed the patient. Oncologist B argues that the online access to medical records has not had any major impact on documentation. However, she argues that she sometimes takes the opportunity to write a comment into the medical record to the patient, as she states: *"It is possible that I change a little bit my way of writing in the medical record, you can sneak in some messages to the patient such as quit smoking or something like that."*

Online Medical Records Affecting the Work Environment

Oncologist A has experienced that patients ask more detailed questions about their treatment, and specifically about different blood samples, after accessing their online medical records. She believes that access to the test results has a negative impact on the patient meeting as patients have a tendency to focus on the results of single samples, without understanding the full picture of the disease. She argues: *"It is just one test that the patient happens to see, and that test does not say anything about the health condition at large nor does it give a full picture"*. Oncologist A also believes that access to test results will contribute to increased phone calls with expectations to get quick answers regarding how the results affect the treatment. Furthermore, Oncologist A is worried about how patients accessing non-signed test results will affect her work environment. She claims that she will be more stressed knowing that the patients are reading the test results. She also feels that patients want to supervise and control doctors by reading their online medical record. According to her, this has negative implications on the work environment: *"We speak the truth so, it feels that the patients want to supervise us all the time, but we try to do our best, we do not work against patients"*. Oncologist B does not believe that the online medical record has had a major impact on the working environment. She argues that the concerns healthcare practitioners had regarding patients' access to test results seem to have been unfounded, as the latter has not been proven to have any adverse effect. For example, the number of phone calls to the clinic has not increased. The physician emphasizes: *"Access to the online medical record can generate some phone calls but it could also take away some phone calls so therefore I do not think there will or has been an increased burden on the clinic, something that many of my colleagues have been worried about."*

6 Discussion and Conclusion

From the analysis of the interviews with Oncologist A and B we can see that they have incongruent Technological Frames, where their assumptions and views held about the function and role of the system are clearly different.

It seems that Oncologist A has a Technological Frame that focuses on the professional's perspective and their work environment. She does not mention patients in her reasoning. Oncologist B, however, has a clearer focus on the patient's perspective and patient empowerment. These two Technological Frames are incongruent when it comes to the assumption about the role of the system, where Oncologist A has the perspective that the role of the system is that of a healthcare communication tool. From Erlingsdottir (2014) we can learn that this perspective of Oncologist A seems to be the most common one at this point in time, as most doctors strongly feel that the role of medical records is to support the communication between healthcare providers [6]. Oncologist B has a Technological Frame where the system can also be used to communicate with patients and empower them.

It is noticeable that the Technological Frame connected to patient empowerment is different between the two doctors as well. Oncologist A does not seem to consider patient empowerment issues or that technology can facilitate patient engagement. She believes that the patients should focus on living their lives, trust their doctors and not read their medical records or other information online. Oncologist B sees the access to the online medical records as a way for patients to get information about risks related to their illness and as a way for them to take responsibility for their own care and outcomes, which is important for achieving patient empowerment. This concurs with Anderson and Funnell, who state that for example diabetes patients control and are responsible for 98% of their care, which conflicts with the socialization of healthcare professionals to take responsibility for the care and outcomes [2]. Oncologist B describes that she sneaks in comments in the medical records to affect the patient's decisions. This reflects a basic assumption that the medical doctor knows what is best for the patient, and it is not based on the view of a patient as an equal partner. This would be in line with the initial view of patient empowerment, i.e. that the underlying purpose is to increase patient compliance or adherence [2]. However, according to Anderson and Funnell "Empowerment is the antithesis of compliance" and their intention with regard to patient education was to "increase the learner's freedom/autonomy (i.e. one's capacity to make informed decisions) rather than increase the learner's conformity / compliance (i.e., one's willingness to follow the instructions of those in authority)" [2]. It is noticeable from Oncologist A that online medical records are perceived as a threat to her professional role. In the interview it is clear that she is afraid that her job will become obsolete if patients have access to their test results. However, Anderson and Funnell (2010) emphasized the following with regard to diabetes patients: there is a need for two kinds of expertise (in their case: diabetes expertise by healthcare professionals and the equally important expertise of patients) and therefore collaboration is necessary [2].

Oncologist B is very aware of the stressful work environment of medical doctors, but she still thinks that it is a good idea that the patients read their medical records. She is aware that the work environment of the medical doctors would be very stressful if patients contacted the healthcare as soon as they have accessed their test result. Therefore, she expects patients to wait until their next visit to ask about specific test results. However, she does not think that the online medical record has had any negative impact on the work environment of doctors.

The results of our analysis support the view that the Technological Frame has implications for the use of a system. This can be seen when Oncologist A chose to *not* sign the results in order to prevent the patient from seeing them. In her view, patients should not bother reading their records. By choosing not to sign the test results, she puts her perspective on what is good for the patient into practice. This example also shows that how healthcare practitioners perceive technology affects how and whether they will try to make the patient an active and engaged collaborator. While Oncologist A uses the system to prevent her patients from accessing the test results, oncologist B is in favour of using technology as a way of increasing patient knowledge about their own health.

It is clear from this exploratory study on Technological Frames and patient empowerment that medical doctors have different assumptions and perspectives that affect their use of technology. These Technological Frames should be considered and discussed when implementing online medical records worldwide, especially when implementing eHealth services that aim to make the patient an active and central collaborator. Moreover, patient empowerment in relation to different eHealth services should also be discussed. If healthcare practitioners do not understand (1) how eHealth services such as online medical records can be used to increase patient empowerment, and (2) how they themselves can support patient empowerment, the objective of the system will fail. Moreover, further research is needed on Technological Frames and their impact on the use and adoption of eHealth services.

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