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Medical Records Online for Patients and Effects on the Work Environment of Nurses

Åsa CAJANDER^{a;1}, Jonas MOLL^a, Sara ENGLUND^a and Anastasia HANSMAN^a ^aDepartment of Information Technology, Uppsala University, Uppsala, Sweden

Abstract. In 2012 Patients Accessible Electronic Health Records (PAEHR) was introduced in Region Uppsala, Sweden. When PAEHR was introduced heath care professionals were very concerned especially in relation to potential negative effects on their work environment. However, few studies exist that investigate in what way work environments have been affected, and no studies have focused on the nurses' working in primary care. Hence, the purpose of this study was to fill this gap through seven interviews with primary care nurses that were transcribed and thematically analysed. The study shows that the nurses' experiences an altered contact as patients accessing PAEHR came prepared to meetings with more informed questions. They also experienced that the service had increased their work load and that it creates uncertainty for nurses who do not know when to inform the patient about test results etc. Finally, some implications are discussed in relation to the patients' role in shared decision making.

Keywords. eHealth, electronic health records, work environment, nursing, patient participation

1. Introduction

E-health encompasses a variety of services that transform health care. One of these is the Swedish Patient Accessible Electronic Health Record (PAEHR) service Journalen, which was introduced in Region Uppsala in 2012. In the beginning of 2013 the decision was made to deploy the service nationally and thus enabling access for all Swedish citizens [1]. Through Journalen patients can for example fill in health declara-tion forms, track their referrals, renew prescriptions and read their medical records including test results online. One feature much discussed is the possibility for patients to read notes and test results that are unsigned, which means that they are not approved by a physician. The main reasons why Journalen was introduced was that patients would become more involved, and able to make more decisions regarding their own health care.

Previous research on expectations about the introduction of PAEHR services shows that the majority of health professionals believe that their workload would in-crease significantly and that the documentation method would change [2] [3]. There is a certain fear among doctors that PAEHR services can create anxiety among patients if they, for example, may have access to test results [2]. On the other hand, for example cancer patients have shown overall positive attitudes when it comes to introduction of PAEHR in Sweden [4]. Patients were pleased with the introduction of PAEHR services much due

¹Corresponding Author: Åsa Cajander, Uppsala University, Lägerhyddsvägen 2, SE-751 05 Uppsala, Sweden; E-mail: asa.cajander@it.uu.se.

to the increased accessibility to their own medical records and a better and more informed communication with health care providers [2]. An American study shows similar results [5]. According to that study, health professionals and patients both experience improved communication and more efficient meetings after implementation of the PAEHR services, since patients become more well-informed and can discuss their health problems at a higher level. A meta study based on over 150 studies on PAEHR services also came to similar conclusions regarding benefits for patients [6]. Furthermore, studies show that it is important for caregivers to be involved in the establishment of PAEHR services and that health professionals are more positive towards these services in counties where the service has not yet been introduced [7] [8]. It is also important to point out that even though the majority of the physicians, at least in the Swedish context, have shown concern when Journalen has been introduced [9], some have also been positive and actively encouraged patients to use Journalen [10].

Up until now, the vast majority of the studies performed related to PAEHRs in Sweden has focused on the physicians' and the patients' views and thus there is limited knowledge about nurses' perception of the PAEHR services and how they affect their work environment. This is problematic, since nurses are, as well as physicians, directly affected by the PAEHRs in their daily work through interacting with the actual content and through communication with patients and colleagues. The purpose of this study is therefore to investigate the nurses' perspective of the introduction of PAEHR services and how it affects their work environment.

2. Method

Data was collected through semi-structured interviews with seven female nurses of varying age and experience working in a primary care health centre in Region Uppsala. The interviews were conducted at the participants' work place and were 40 minutes long. Two of the authors participated in the interviews - one interviewed the nurses and the other took notes and recorded the interviews. The interviews focused on the use of eHealth services in genereal and Journalen's effects on the work and the communication with patients in particular. The data was first presented as a bachelor thesis work in Swedish [11], and later a second analysis was done focusing the results on the work environment only, and the report was rewritten into this paper.

Uppsala Region's primary care division and the head of the primary care centre approved of the study. The study followed the World Medical Association's "Declaration of Helsinki" and the recordings were erased as soon as they had been transcribed and in this paper the material is anonymized and the respective nurse is denoted "Nurse X". Thematic analysis was used to analyse the transcribed interviews. Coding was done by two of the involved researchers. The four themes found are presented in the results section. In the last iteration representative quotes were chosen as a means of illustrating the themes found.

3. Results

The results in this section are structured according to the four themes; altered contacts, increases workload, creates uncertainty and requires new knowledge.

Altered Contacts The introduction of the PAEHR service Journalen was perceived by the nurses to lead to altered contact with patients in several different ways. One example brought up was that patients who have read their medical record online come pre-pared with more informed questions. This often lead to more in-depth discussions that took time for the nurses. Another means by which contact was reported to be altered was that patients were more active in their own care and as a result had a better overview. Other effects mentioned during the interviews were that patients were more involved in their own care and experienced a greater transparency, which in turn could lead to a better cooperation between the patient and the health professionals: Patients feel more involved, they might understand more what happens and how the doctor thinks or how we think within healthcare and can cooperate more and better, yes (Nurse 3).

Increases Workload Although the interviewees expressed a positive experience of Journalen, generally, the introduction of the PAEHR service was perceived to create an increased workload. One common problem brought up was that it sometimes generates duplication of work. One example of this is that the patients read their records online and then both call and email with questions they may have. The most common quest-ions were related to test results, where the slightest deviation from the reference value could create anxiety in the patient. The following quote illustrates the problem with increased workload. When they have read their medical records, they often send us a question via "My care contacts" when they have logged in... Sometimes it can be too much! Sometimes they both contact us via "My care contacts" and then call... (Nurse 4).

Creates Uncertainty The introduction of Journalen was also perceived to create uncertainty for the patients, because they have the opportunity to read notes in their medical record that can sometimes reveal serious diagnoses. Many nurses experienced this as very stressful and were concerned about this change. To recieve access to these notes the patient must actively enable that possibility. Activation of that feature is everyone's own responsibility since it is only people of age 18 or above who have access to PAEHR. One nurse said: If you go in as the patient and read your medical record, then maybe you have to take responsibility and be prepared to learn things you can not get answers to,... you see it in black and white ... (Nurse 7). According to interviewees, Journalen also create uncertainty for those who work in health care as it may be unclear when and how the patient should be informed about information in the medical record. Information and statements of a more serious nature should not be possible to access before the doctor has had time to inform the patient, according to the nurses: I think it would be good if news of a more difficult character was signed before it is displayed [in Journalen], as a health professional one must have a fair chance to get time to report it [to the patient]. (Nurse 4). The introduction of Journalen and the increased transparency was also seen to make it even more important to document respectfully and health professionals should be able to discuss the written words with the patients. An incorrect documentation can make the patient feel offended or misunderstood if caregivers e.g. miss or exclude anything that the patient experiences as relevant. The following quote illustrates this. What is written in the medical record, you should be able to stand for. One should not be afraid to write about that the patient was angry when he or she left. One should not write everything, but what is relevant in a respectful way. (Nurse 5).

Requires New Knowledge Informing the patient about the different possibilities of Journalen was, however, considered to be a challenge due to the lack of knowledge. One nurse said the following, about the lack of knowledge: It can be a very good co-operation between health professionals and patient if you have the knowledge yourself. The patient then also gets a central role in their treatment ... We have not gotten the information quite

yet and patients maybe even less. (Nurse 2). Furthermore, Journalen may be able to reduce the workload for the medical professionals in the future when patients have learned to use system: It might become better further on... When you get into it and find smarter ways of working with and using the service ... (Nurse 1).

4. Discussion

The results from the interviews with nurses is in line with earlier research on PAEHRs conducted with physicians and it is an interesting result that the nurses have the same experiences of the effects of Journalen as the physicians even though they have quite a different role in health care.

Two possibilities, which were brought up by several of the nurses, was that PAEHRs led to improvements in the contact with patients and that patients could take more active part in their own care. According to the interviewees, the more active participation in discussions was manifested by the patients being more up-to-date before visits and asking more informed questions, which in turn led to higher and more equal level discussions where patients can play an active part. This aspect is generally appreciated in today's care and also in line with earlier research in Sweden [2] and abroad [6]. This is important, since support for good communication, which Journalen was perceived to provide, is key to shared decision making and an overall understanding of one's own health [12].

Apart from possibilities, a few challenges were also brought up by the nurses; insecurities, for both patients and care professionals, and increased workload. The nurses brought up that patients' have difficulties in understanding medical terms [3] [13], and hence contact health care professionals for clarification. The possibility of patients becoming anxious when reading about new and unsigned notes, diagnoses and/or test results (also acknowledged by e.g. [2]) was also mentioned in several interviews and this was of concern for nurses. Thus, one can conclude that both physicians and nurses see this as a potential problem. Some nurses highlighted the fact that the patients themselves needed to activate a function if they wanted to read unsigned data and that the patients had a responsibility in this respect.

An overall comment from the nurses was that there was a need for more knowledge and to educate medical professionals, and to some extent even patients, in eHealth services. This result is interesting to relate to findings from Scandurra et al. [8], e.g. stating that medical professionals who work in county councils where Journalen is introduced are more positive towards the system than those who work in county councils which have not yet introduced the service. This has at least two implications for the present study. Firstly, Journalen was introduced in Uppsala county council already 2012 and hence the results from this study may not apply to county councils which have not introduced the system or those which has just started to use it - this applies especially to the positive aspects brought up during the interviews. Second, since several nurses mentioned a need for more education on the utilization of eHealth services, it is reasonable to believe that the benefits could be even higher and that the existing problems can be targeted in better ways in the future. Interestingly enough a study with physicians as late as 2016 acknowledged the same need for education and training [7]. If medical professionals receive more training in how to use eHealth services like Journalen and how to discuss the content and the possibilities with patients, an even greater potential can be unlocked.

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