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Patient opinion – EHR assessment from the users perspective

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Abstract

Electronic Health Records (EHR) are becoming an integrated part of modern health care. The introduction of EHR in healthcare has been evaluated by many actors and from many perspectives. However, there is hardly any study exploring the opinion of the ultimate users of the system, the patients. This study aims to provide information about patient values and communication that will be useful in the design of a more patient friendly health system. We have asked patients in three different hospitals about their opinions about EHR, using semi structured individual interviews and focus groups. The patients are open to the use of EHR, but they have some concerns: they want their privacy to be respected, and the systems to be safe from the intrusion from outsiders. These results underline the general societal tendencies of citizen accepting the use of new technology, but being very keen to protect their privacy.

Keywords:

Electronic health record, patient satisfaction, privacy, technology assessment.

Introduction

This work is part of the research the EHR observatory conducts about the implementation and the development of EHR in Denmark.

The aims of the EHR Observatory are:

- Survey and analyse the development of EHR systems in the Danish healthcare sector
- Support the development of a common frame of reference for EHR-systems
- Establish networks, knowledge exchange and dialog between the various EHR-development projects, local decision makers in the hospitals and the central health authorities.
- Initiate transfer of strategic EHR-experience from the other Nordic countries.
- Disseminate results of the activities above to all groups in the Danish health care sector.

The results of the activities in the EHR-observatory are published in annual reports [1- 4], and in conference papers [5 - 9].

Expectations

There are many expectations about the advantages EHR will bring to the health care. The use of EHR will prevent errors, provide a more effective health system, and give a better service, as it would allow the health provider to have easier access to the information. Once the data has been entered into the system it will be available continuously in multiple locations, so there is no need to ask the patients the same questions repeatedly. The ease in access to information makes a difference in the way information is used. It is the idea that this will save time and makes the patient feel more confident [9].

Challenges

There are some challenges about the use of EHR, too. On the one hand, ethical issues about the use of EHR need to be explored [10], e.g. concerns about privacy [11]. On the other hand, some physicians are concerned about the negative effect that the use of EHR may have in their relation with the patient [12]. While there have been many expectations about the use of EHR as a tool to increase clinical effectiveness and cost containment, the impact on human issues and patient opinions remain relatively unexplored. However, what do we know if the systems are acceptable to the patients? In order to develop effective and robust systems, an evaluation of the systems by the patients would be useful and relevant. [12].

Literature review

We searched literature in two main areas:

Patient satisfaction:

A search in MEDLINE with keywords "patient satisfaction" and "electronic patient records" revealed 13 titles. The criterion of relevance was whether patients had actively been involved, which excluded 11 titles. Of the two remaining relevant articles, Mair and Whiten [14], review the existing literature about patient satisfaction with telemedicine, and show that my of them had methodological problems, in for example choosing and wording the questions to be asked. In another study, physicians and patients have indeed shown a positive attitude towards the use of ICT in the general practice [10]. We found no similar studies about the use of EHR in a hospital setting.

In Denmark there has been several countrywide studies on general patient satisfaction. They all apply a quantitative approach. They have not been published internationally. An exception to

the quantitative work is the work of Baumgarten [13]. She used anthropological methods to reveal patients opinion about the hospital, and the areas that patients considered important. This study reveals opinions and point of view that otherwise seldom have been named, giving the patients time and possibility to set their own agenda. This study has been very inspiring for us, and helped to make us aware of a similar study was needed regarding the patients opinion about EHR.

Patient empowerment:

The literature about empowerment of patients is increasing. The patients wish to be empowered and more active in their own health, but physicians do not feel confident about this development, as they wish to retain control of the treatment [15]. Patient empowerment literature is concerned about patients as active subjects in their treatment [16], and opinion from health professionals about how to empower patients by the use of ICT [17].

Medline was searched using the terms "patient empowerment" and "electronic records", and 26 titles were browsed for inclusion. The relevance criterion was whether the patients had been actively involved in the study. No new study of relevance was found. The closes we could get were a study where primary care physicians were asked about their patients using the Internet. [18]. As above, we found no relevant study for the secondary sector.

It is found relevant to explore whether the expected patient related effects of EHR really happen, and how the patients perceive this. This study investigates the patient's opinion on the use of EHR.

Methods

In order to describe the patients' opinion, a number of patients were asked about their experiences with EHR, using open individual and group interviews. That way, the patients have the time and the opportunity to explain their opinions and rationale.

It is accepted that qualitative methods are a way to access areas such as beliefs and values. On the other hand, qualitative research is a prerequisite and a complement to quantitative research in new areas of research [19]. Is about how people behave and what they mean when they describe their experiences, attitudes and behaviours.

This study applies three different methods to collect the data: traditional individual interviews, focus groups and observations. This procedure enables an overall view of the processes and the ward routines: the observations enriched the interview guide, and the information from the interviews sharpened out attention to certain details of the functioning of the wards. That way, the different methods complement and enrich each other.

Interviews

Qualitative interview is a method suitable to uncover personal experiences and opinions. The subject set the agenda, and uncover the factors that are most important to the patient, and why [20]. We expect the interviews to give a description of the understanding of the situation, and the behaviour of the different actors.

Informants with different ages, backgrounds and a balanced gender representation were included in the study.

Focus groups

A focus group is a group interview about a theme. In this study focus groups investigated the provider and the patients reaction to the interviews already performed.

Focus group can be defined as a semi-structured interview with 6-10 participants where a moderator seeks to start a process that will conduct to a multicoloured clarification of a focused issue [21]. Distinguishing features of the focus groups are interaction between the participants in the groups, rather that between the interviewer and the persons, and secondly, the focussing on a certain issue. Focus groups are especially relevant in exploring how people communicate [22].

Observations

The third tool implies the use of observations. The purpose of the observation is to reveal the details in the situation, to get as complete a picture as possible. On the one side we will follow the daily routines of the health personnel (at least one for each profession), and experience how EHR is used in the daily routines. On the other side we will follow a patient quotidian routines. Those results will be analyzed in conjunction with the results of the interviews.

Observational method involves systematic, detailed observation of behaviour and talk [23]. It may overcome the difference between what people say and what people do Observations may uncover reactions of the actors are unaware of and may help the actors to reflect about the reason for their behaviour.

The three different approached can be functional as a method-triangulation i.e. the focus groups will verify the results of the interviews, and the results of the interviews can review the results of the observations.

Procedures

12 patients aged 17 to 72 years, were interviewed in three specialties in three hospitals. 3 Children and their parents were included from Hvidovre Hospital, 4 patients from an orthopaedic surgery unit in Kolding Hospital and 5 patients at an internal medicine unit at the Funen Hospital in Svendborg.

The EHR situation and the procedure for the interviews at the three locations differed slightly

1. Funen Hospital in Svendborg

At the Funen Hospital, the EHR system has been developed and used in daily practice for the past ten years. Today the EHR system has approximately 600 clinical users.

All clinical staff read and writes in the record on a daily basis to search information and document actions and observations. The EHR is therefore an essential tool for the clinical staff. [24]

Observations

A full observation day was set up to get a preliminary overview of the daily routines. The next couple of weeks observations were combined with interviews.

In the observation period different nurses, physicians, and patients in various wards were observed, in order to study a diversity of situations and communication.

Interviews

In this location we interviewed both patients and health personnel, to uncover views from both sides. As the groups will have to interact later in the project, care will be taken to ensure that both groups should be treated on an equal basis, which will help the deliberative process.

A group of 5 patients, 3 females and 2 males were interviewed. From the staff two physicians and three nurses were interviewed. Thereafter a group interview was made with all the individuals. The interviews lasted between 20 and 30 minutes.

We were asking for voluntaries among the patients, and then choosing our subjects in cooperation with the hospital. The interviews took place immediately afterwards, in order to pick the patients while they were admitted. However, in reality the choice was limited by the patient's health, and the treatment they were given. The group of patients interviewed turned out to be somewhat older that we expected, 2 males and 3 females, between 50 and 70. The interviewed patients that were sent home after treatment, agreed to come to the hospital for the group interview.

As for the health personnel, we wanted to interview persons familiar with EHR systems, from different professions and different ages. We suggest that the hospital asked for voluntaries, so that we could choose our subjects. It turned out that we were dependent of choosing persons who would be on duty and who could be substituted when we held the group interview. The hospital management was helpful in assisting us to find two physicians, a male and a female, belonging to two different age groups. Three nurses were chosen, with different ages and experience: two of them had worked quite a long time with the system; one of them was new to it. No male nurse was available for us to interview.

Focus group

We made a focus group with the patients and the health personnel in order to test and enrich the point of view of the patients when confronted with another opinion. All the informants (patients and health staff) met and discussed EHR. We used the funnel method, starting with broad questions, and focusing more on the subjects and finally asking concrete questions about concrete statements.

This procedure showed to be very demanding on the patients and as the results from the individual interviews were similar in the other hospitals, we chose to perform only individual interviews.

2. Hvidovre Hospital

The paediatric ward of the Hvidovre Hospital was among the first in Denmark to use EHR. They have used EHR in the reception ward since 1997. The interned children wards are using EHR since 2002. The entire unit is expected to use EHR from the start of 2004. The unit has 50 beds and a turnover of 17000 patients a year. As a very innovative feature, the parents are able to read their children's record from their home computer via an encrypted connection to the hospital.

Observations

We followed the daily life of the ward during a day.

Interviews

We interviewed three patients: a couple with a new born child, that had been hospitalised for some days, and a mother with a 9 year old child, also hospitalised for some days.

3) Kolding Hospital

At the Kolding hospital, the surgery ward has been using EHR since 2001. The surgery ward has 46 beds, and a turnaround of approximately 2300 patients a year. All information functions are administered with EHR.

Observations

The daily activity of the ward, consultations in the ward round and the ambulatory care routines were observed during a day.

Interviews

We interviewed 4 patients, 2 male and 2 females. Patients with only mobility problems, but with a good general health condition were chosen in collaboration with the hospital.

Results

Overall the patients were positive about the use of EHR in the hospitals. The patients had some concerns, though, principally about following issues:

Physicians questions: While older patients did not mind the physicians asking repeatedly the same questions, the younger patients would prefer the doctors not to repeat their questions and be adequately prepared before talking with them.

Privacy: The patients expect that their privacy is respected and that the hospital respect the rules of informed consent.

Safety: The patients expect the system to be safe against hackers. Concerns for technical breakdown were mentioned as well.

Portability: The patients expected the information in the EHR to be accessible (previous informed consent) to their family doctor and other hospitals.

Access to own record: Some patients wanted the information to be available for themselves. Interestingly, the reason given for that was that those patients had found errors in their journals previously.

Discussion and conclusion

It seems that the patients readily accept the use of EHR in the secondary sector. The major concern is the issue of the data security, and confidentiality, and a desire of the patient information to be portable. These findings reproduce to a considerable degree the results of a citizen panel that was asked to evaluate EHR technology development in Denmark [11]

We found however some differences depending of the age of the patients, the older patients tending to trust the system more and to be less demanding. This is consistent with other studies [13].

The results of this study indicate that:

- The patients accept the use of EHR.

- Privacy and security issues should be given priority in the development of future EHR system.
- The portability of data is very important for patients. Common standards should be implemented.

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