

Computer-supported patient involvement in heart rehabilitation

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ABSTRACT. Two of the five Danish regions, covering close to half of the population, are in the process of implementing a new EHR system. One of its sub-systems is a patient portal. The work-in-progress reported here is an exploratory study and a first level of analysis concerned with why, how and with which effects patients start to orient themselves towards this subsystem, and the degree to which this has an effect on the clinicians' work. The overall approach is a multi-site ethnographic study involving 5 patients and 3 nurses responsible for a rehabilitation program for ischemic heart patients. Data are being collected through artifact and document analysis, and by interviews and observations in patients' homes and in nurses' offices over so far 6 months. The analysis is informed by medical phenomenology and by conceptual frameworks developed in earlier projects conducted by the author's research group. The preliminary findings include that patients and clinicians do see the potentials of the portal, but in order to harvest these potentials we recommend rethinking the functionality and the implementation strategy, including training of patients and clinical staff.

Introduction

It is becoming common to stimulate patients to get involved in their own treatment and care. This is also the case in the rehabilitation program for ischemic heart patients at a Danish hospital that is the focus of this study. The instruction that guides rehabilitation nurses prescribes: "The consultation is organized to meet the patient's needs and wishes" (Rehab, 2014). As we shall see below, the nurses take pride in doing so, because they know from experience that it helps in obtaining the purpose of the consultation. The nurse is trained to look for certain biological phenomenon indicated by lab results, to listening to the patient's own

account, and to the replies to her questions. The most important part of the job is to encourage patients to do their part in seeing to that problematic tests results get as close to clinically recommended boundaries as possible.

The degree to which patients are invited to – and is interested in – taking part in their own care may be described in terms like involvement, participation, and empowerment. It is outside the scope of this paper to go into a discussion of these concepts, but the order in which they appear above indicates a progression.

The Capital Region of Denmark and the Region Zealand joined forces in a call for tender and the subsequent procurement of a new EHR system. The winner was the American EPIC systems, which has widespread use in the US, e.g. at Kaiser Permanente, and which lately also has been implemented e.g. in UK, The Netherlands and now Denmark. Currently 4 of the regions 18 hospitals have started to use the system, called the Health Platform (HP). The main parts of the system are the usual modules for clinicians' notes, lab tests, ordering, and medication. The exploratory study reported here however, focus on one of the subsystems called My Health Platform (MHP). It is a portal meant for outpatients.

Patients, who e.g. take part in a rehabilitation program after hospitalization, are able to communicate with clinicians, access parts of the clinicians' notes, fill out and send questionnaires, access lab results, and receive reminders about news from the clinic. Parents are able to do the same on behalf of their children, and so is a relative to e.g. a frail person, who has given consent (MHP, 2017).

So what type of system is the Danish version of MHP? One sees that it shares some of the characteristics of the Markle Foundation's definition of a Personal Health Record: "An electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment" (Markle, 2003). So far however, information is managed by hospitals rather than by patients.

Careyva et al (2016) and Santana et al (2014) show that improved patient-physician communication may improve patient outcome. They report on integrating patient-reported outcome measures, which so far is not part of the system studied here. However, their results bear indications that given certain circumstances - that has to be researched further - even MHP's limited modes of involvement hold potentials for improved patient outcomes.

Otte-Trojel et al (2015) report on a study of the Kaiser version of MHP, which has evolved over 15 years and is used by clinicians, administrative staff and patients. Their study is based on interviews with "eighteen physician leaders and executives particularly knowledgeable about the portal to learn about how they believe the patient portal works and what organizational factors affect its workings." (ibid). Among their finding the following are especially interesting as to our study: 1) "...the portal's ability to ease access to services improves some patients' satisfaction as well as changes the way patients seek care". 2) "...the transparency and activation of information enable some patients to better manage

their care.” 3) “...care management may also be improved through augmented patient-physician interaction.” Further, they found these organizational factors of particular importance, which have affinity to this paper’s focus: 4) “...synergy with existing IT infrastructure and operations”, 5) “...inclusive decision making and knowledge sharing, and 6) “...emphasis on patient-centered design.” (ibid). Here we note that even though we share research interests with the Otte-Trojel study, our methodology differs in mainly two ways. We worked with nurses and patients rather than physician leaders and executives. Secondly, rather than being based solely on interviews, this study in addition builds on artifact and document analysis, and on observations in patients’ homes and in nurses’ offices.

This exploratory study provides a first level of analysis of 3 research questions:

- RQ1: Do patients start to orient themselves towards MHP? How and why?
- RQ2: What do patients get out of using MHP?
- RQ3: Do patients’ use/non use have an effect on the nurses’ work?

Research setting and method

At the end of May 2016 the first two hospitals went live with the new EHR overnight across all departments. This exploratory study was conducted at a heart rehabilitation clinic at one of the hospitals. It started after 5 months of consultations and easy negotiations of terms in parallel with the implementation process. The clinic is responsible for rehabilitation of ischemic heart patients, who have recently been discharged after treatment for a blood clot. Every 6 weeks during a 3 months period patients are offered consultations with a nurse, who has specialized in rehabilitation, and to whom certain rights of prescription is delegated. Further, she coordinates with other involved personal at the hospital and in the municipality. That includes doctors, who see the patient for stratifying and up-titration purposes; lab-technicians, who draws blood before each session; physiotherapists, who conducts a so-called bike-test, and various other therapists and nurses in the municipality. The municipality is responsible for the last part of the rehabilitation program that includes a course on being a heart patient, on alcohol and smoking cessation, on heart diet, and an exercise program. The consultations with the nurse are scheduled for ½-1 hour covering orientation about the rehabilitation program, teaching about the heart, blood clots, and medication as well as patient initiated life style changes. The main part however, takes the form of counseling - emphatic listening to the patient’ concerns while zooming in on what might be relevant for this patient. Other issues dealt with include: Mental reactions, job and family situation.

Long before the introduction of the new system nurses were given an instruction for the rehabilitation program that stresses the importance of patient involvement, which MHP has the potential of enhancing. Politicians and hospital management found it important that HP from the very start should include even

minimal features for patient involvement. But so far that part of the system has not been given priority, neither as part of the clinicians' teaching program before the implementation of HP, nor in terms of actions to get patients involved. However, the patients included in this study were given a leaflet on MHP together with the participant information and consent material produced for the study.

Data collection

Data for this study has been collected through initial meetings with staff at the clinic and staff responsible for the implementation, artifact and document analysis, and recorded and transcribed interviews and observations in patients' homes and in nurses' offices. Initial interviews of 45-60 minutes were conducted in each patient's home, or at a place of their choosing. So far 5 patients and 3 nurses have been interviewed separately for 15 minutes before and after each consultation, which in addition have been observed (30-75 minutes). All in all some 40 hours of audio recordings are in the process of being analyzed.

Analytical frameworks

The following conceptual frameworks were guiding the analysis.

Toombs' medical phenomenology: Toombs explains how and why patients and clinicians fundamentally live different lives and therefore have *divergent concerns* when it comes to health and illness. She explains why and how patients experience illness as a unique, personal event that transforms their bodily awareness and disrupts their everyday practices, roles and relationships with others. Instead physicians understand disease as an entity in itself, a biological phenomenon that can be categorized as an instance of a known type, for instance as a particular case of ischemic heart disease, that may be treated according to scientifically tested procedures (Toombs, 1993). In Andersen et al (2014) we point to that this crucial difference is rarely acknowledged in the literature on eHealth nor in the design of it-systems launched to augment patient-clinician interaction.

Alignment of concerns: In Andersen et al (2014) we further suggest that "when designing eHealth systems to support collaboration between patients and clinicians it is particularly important to identify and align the concerns that are *meaningful* to patients and in turn which can be made (clinically) actionable and organizationally feasible to clinicians." And here I want to add that for patients to play an active part in their own rehabilitation process, data need to be *actionable* and *organizationally feasible* to them too.

Clinical accountability: Emanuel and Emanuel (1996) define accountability as being "about individuals who are responsible for a set of activities and for explaining or answering for their actions." They distinguish between three models

of accountability in healthcare: Professional, political, and economical accountability. The *professional* model consists of two primary loci of accountability: Physicians to their professional colleagues and organizations and to their individual patients. Traditionally professional accountability has focused on competence and legal and ethical conduct. The *political* accountability refers to the decision-making process within an organization, and the fundamental locus of accountability is the relation of providers to some version of a governing board (here e.g. the local instructions for the hearth clinic's rehabilitation nurses). *Economical* accountability has to do with consideration for adequate use of resources.

Results

In this section we use the analytical frameworks briefly presented above to show emerging relations among clinicians' and patients' practices; infrastructures like clinical guidelines and IT-systems; and the potential and achieved outcomes of rehabilitation consultations. We do that based on quotes from the observed consultations and the research interviews.

Alcohol consumption and the triglyceride count

A good example of what Toombs calls divergent concerns and how they may slowly become aligned is illustrated by quotes from a patient's two consecutive rehab consultations with a nurse (with an interval of two months) and the accompanying interviews with me before and after each consultation.

The patient, P1, is reluctant to change behavior, although he says to both of us that he is currently drinking too much.

The below quotes further show how the nurse demonstrates her professional accountability, as she keeps explaining and motivating the patient to change behavior. They also show how a certain scientifically tested procedure – cutting down on alcohol consumption through monitoring the level of triglyceride – becomes meaningful, actionable and feasible for the patient. And finally, the development of the conversation shows that the new system has potential for helping patients becoming more active in their own care processes.

At first P1 wonders why the clinicians consider him a patient. In fact he has not had a blood cloth, but was hospitalized due to ongoing chest pain. He is invited to the rehabilitation program to prevent his situation getting worse. During the first interview in his home he says:

P1: "I'm impressed that they consider me a patient – I don't do that myself"

And at the start of the first consultation he asks the nurse N1:

P1: "Am I a patient?"

Later on N1 asks P1 (in a tone indicating that this might be a delicate issue)

N1: "Is it right when the notes have that you drink 42 units a week?"

P1: “Yes, and that’s about twice as much as it should be ... currently it is a habit that I drink a bottle of wine each night.”

The nurse tells him that actually this is triple the amount recommended, and she then asks if he has done that for many years, and if he plans to continue doing that. He replies:

P1: “It depends on the situation, e.g. when we travel, my wife and I share a bottle for the dinner.”

When the nurse asks if he needs a bottle each night, he explains:

P1: “For instance last night I was home late and drank only two glasses of wine before I went to bed.”

Later in the conversation the nurse explains that alcohol makes the triglyceride count raise, and that his triglyceride count is almost double as high as it should be. In the interview after the consultation one of my standard questions is “What did you get out of the consultation?” Then P1 replies:

P1: “Of course I’ll embrace the offers about diet and exercises.”

But he does not mention alcohol. Later on he acknowledges that

P1: “I’m not 100% healthy.”

He explains that normally he looks up all kind of issues on Google, but that his hesitation to see

P1: “... myself as a patient has caused me not to check even my new type of medicine. ...But I need to realize the situation as it is.”

Then to my question if he got any tasks from the nurse that he intend to take on, he does not get back to the issue of alcohol. It seems that he is hesitant to let the heart incident disrupts this everyday practice.

However, in the following consultation N1 reminds him that the only blood count that is too high is his triglyceride. In the subsequent interview with me he explains that this is due to his alcohol consumption. Then when I repeated the question from the last interview - if he was given any tasks that he wants to take on – the he replies:

P1: “Yes, I’ll drastically reduce my consumption of alcohol.”

And then he mentions that he will start using HMP for monitoring the level of triglyceride as he changes his drinking habits.

In a supplementary telephone interview a month after P1’s last consultation he explains that in fact he does use MHP to monitor the triglyceride count. Finding a piece of paper where he keeps track of the readings, he says:

P1: “It is decreasing, which is fine. But of course, I don’t know if that is because of the medication or me changing my diet.”

Missing functionality and unhelpful modes of interaction

Both patients and nurses request other types of data and modes of interacting with the system. The patients find that there are limitations that need to be dealt with in

order for them to find the information meaningful, actionable and feasible. Instead, patients, with a few exceptions, are generally even impressed by the clinicians' willingness and ability to keep them informed while they were hospitalized, and also by the ways in which the rehabilitation nurses provide information. But they wonder why MHP does not do the same, and when it does give access to e.g. lab test results or parts of the clinicians' notes, the content and the format is often neither meaningful, actionable nor feasible. Further, they often find the modes of interaction cumbersome.

A patient, P4, was very impressed by the type and form (oral, text and drawings) of the information she received from the clinicians before, during and after her treatment at the hospital. When she was sent home she read about MHP in the material she was given by the nurse, who recruited her for this study. So she accessed MHP, but did not find it very helpful:

P4: "I did find the lab test results and parts of the physicians notes. But I want to read all of the doctors' notes. And as to the blood tests, they were not well arranged. It would have been easier to see them all in one picture. Instead, I had to click on each test to see the value. Also, I missed to see the normal values. I can't recall what they are."

Another patient, P2, sees himself as "an info-freak" as he often looks up all sorts of information on the net. He wonders why the system does not contain information about what the rehabilitation program is all about. Further, P2 says:

P2: "I would like to see the X-rays to compare my X-rays with what I find on the net. How bad was my situation? And what is the amount of fluid in my lungs?"

Patient P4 also wonders why a lot of information about the disease and the treatment is not available through MHP:

P4: "For instance why is there not information about known side effects of the medicine they prescribe. I looked up the side effects of beta blockers on the net. But why is not in MHP? Or a link? Likewise with the leaflets I received today on diet and physical training."

These, and other issues raised by the patients, may be rather mundane things to fix. However, they carry evidence that MHP is not based on a proper understanding of patients' concerns, and this does not increase the patients' motivation to take advantage of the potentials of the system.

Education and training

MHP was not given much attention during the implementation. The clinicians went through an education and training program on HP before "go-live". It focused primarily on the technical parts of the system intended for their use, instead how to integrate the system into their work practices, and how these might have to be changed in order to obtain the intended effects was left to the clinicians to figure out. MHP was mentioned, but clinicians were not instructed how to use that part of the system, and patients only learn about the system when they are invited for consultation or when e.g. new lab results are ready. So it should not come as a surprise that MHP's potentials for augmenting patient-clinician interaction is still to be harvested.

In an interview with P2 before a consultation I learned that he had used the system to fill out a questionnaire that the system prompted him to answer. Asking the nurse after the consultation if that was helpful to her, she replies:

N1: "How should I be able to see that? Interesting, the system has him as inactive... I checked just before you arrived. Hmm, now his status is active, do you know if he used the system this morning? ... I wonder which questionnaire that is? I haven't received it, and I haven't send him one. ... I might be able to look it up, but then I have to learn how - it was not part of the training we received."

The patients involved in this study were given brief descriptions about MHP when they were recruited, and some of my interview questions mention the system, but without directly promoting it or providing a tutorial. The nurses sometimes suggested to patients that they might start using MHP, if they think that the patient is ready for that.

N1: "Have you used My Health Platform to look at the physicians notes?"

P1: "Yes, but I couldn't figure it out. But I did try to look for the blood tests this morning, but they were not there yet."

N1: "... The system was down this morning - that might be the reason. If for instance you get in doubt of for how long you shall take the medicine, and how much, or if the note I gave you gets lost, then you can look up my note in the system."

(Inter) organizational issues

N3 finds the platform helpful in smoothing cross-sector communication since her notes on a patient are made available in the general practitioner's system as a basis for the subsequent monitoring of the patient. But there are still some issues to be taken care of:

N3: "It is much easier than before when we used email for such purposes. Inter-disciplinary communication has become easier, like referrals. However, we are not always sure who gets them. E.g. when a physician refers a patient to heart rehabilitation, it doesn't always go to the right clinic. The responsible nurse at the right clinic might not see it. It might end up at another hospital. We are working hard on getting it right, but it is very difficult."

Physicians are not always aware of the responsibilities of the different rehabilitation clinics,

N3: "...the system doesn't make it easier for them."

Reflecting on the templates offered by the system for her notes, she tells:

N3: "I'm not sure if it is faster than making them from scratch as I used to. But since our last interview where you asked if I used the templates, I actually started using them. But they irritate me as I have to delete something, but then again other issues are transferred automatically from other sub-systems like the blood pressure. But something is still not validated properly."

The templates may help nurses to be professional accountable as a template works as a reminder of all the issues she needs to cover and the different type of data she needs to type in.

Inter organizational issues are also important to patients, who often see clinicians at different parts of the hospital as well as at different hospitals.

Further, they see their GP and meet clinicians and other staff from the municipality, and they are concerned about coordination among these, and they are not always sure about who is responsible for what.

P4: "MHP should involve my GP and the specialists too."

It actually does, but she is not informed about that, and P1 touch upon the same issue when he asks me:

P1: "My GP and the department at the hospital, do they know about each other?"

And he asks the nurse:

P1: You give me medication to lower the cholesterol, and my GP for lowering my blood pressure ... and something to lower my pulse. It is related, and it should be coordinated.

N1: Yes, unfortunately we don't monitor you blood pressure, that has to be checked too often for us to do that, so it is taken care of by your GP."

Other patients have asked for MHP to contain information about the overall rehabilitation plan, including who is responsible for what and when.

Conclusion and further work

The preliminary analyses may be summed up as answers to the research questions.

RQ1: Do patients start to orient themselves towards MHP? How and why?

The study indicates that the patients tried out MHP more than once. Some times when prompted by e.g. an alert via the system for their next consultation. Other times they are motivated by a specific concern. Some looked for general information like side effects of medication or an overview of the various rehabilitation services provided by the hospital and the municipality. Others looked for information specific to their health like their own rehabilitation plan, blood tests and X-rays.

RQ2: What do patients get out of using MHP?

Patients appreciate that MHP offers information, but they do not always find the type of information they look for, or in a format that to them is meaningful, actionable and feasible. They find that MHP seems not to be designed based on a proper understanding of their needs and concerns. They all see that MHP holds such potentials, but it requires rethinking the functionality and the implementation strategy, including training of patients and medical staff. Some patients find motivations to change lifestyle by monitoring medical parameters, when they learn about their relations.

RQ3: Does patients' use/non use have an effect on the nurses' work?

This is too early to say, but again the study indicates that it would require revisiting the functionality and the implementation strategy, including training of patients and medical staff. Ideas that came up during the interviews include the possibility to store and refer patients to information specific to the clinic, and features that would support a patient and a nurse in settings goals and monitor how the patient fare in meeting the agreed upon goals.

In conclusion, this study supports that clinicians and patients also have divergent concerns (Toombs, 1993), as well as our own proposal that when designing support for their collaboration it is important to identify and align their concerns. Further studies will dig deeper into an understanding of the practices of patients and clinicians, and how these practices may be enhanced by developing further the potentials of MHP and by remedying some of its negative consequences.

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