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Rivista della Società italiana di antropologia medica / 19-20, ottobre 2005, pp. 71-78

# 1.3 *The leading edge of the situation: the patient perspective in a health technology assessment*

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## *Patient Perspective on Electronic Patient Record*

An obstetric doctor: «This electronic patient record has a fantastic way of removing ones attention from what it is all about... that is the woman. I have been diversed from the cause. Earlier I listened with an open mind. Now it happens that a woman leaves the consultation without me noticing that she was upset...she left crying...but I didn't notice...».

Woman at the maternity ward: «The doctors and nurses are well informed – they are updated, more so than before the electronic patient record. In the consultation you have a dialogue concerning what to write in the record...it makes me feel important and co-responsible».

This is apparently enough not the exact same experience they are referring to, but they refer to the same frame of experience. What I found was that doctors and midwifes were far more concerned about the drawbacks of the medical record than were the women. The doctors experienced that the medical record was a very problematic new technology affecting the contact between patient and professional to a disturbingly high degree. Where as most woman were very positive and tended to suppress the less positive aspects in favour of the overall good experiences.

So what I am asking myself is; does looking at "the patient perspective version" actually blur what is really going on and is this really "for the good of the patients"? Do the patients realize what they are not getting? And would we in fact be doing the patients a disservice if we let their voices be decisive in this kind of research. Is this in fact another good example of how important participant observation is when trying to convey interaction and put into perspective respectively the doctors and the women's experience? Finally can this be done on a limited budget working interdisciplinary with economists and medical doctors? Especially the last question is a large challenge. In Denmark the task of integrating the anthropological perspective in interdisciplinary research is still some what like introducing an alien in a world where everyone else seems to agree on different research traditions. And the reality is that it is very seldom possible. So as anthropologists we have to make the best of the little "space" we do get.

My paper, "Patient Perspective on Electronic Patient Record" is part of a Health Technology Assessment of the Electronic Patient Record in Frederiksborg County in Denmark. What I would like to achieve with this paper is partly to present some results – a little piece of applied anthropology. Some results which hopefully will illuminate and eventually help better conditions for pregnant women and women giving birth within the Danish health sector. And partly to debate if I can conduct anthropology when I work within the setting and under the premises of the Health Technology Assessment framework and the timeframe constituted by the economy.

## *HTA of the Electronic Patient Record*

It is widely believed that introducing the electronic patient record into hospitals can benefit health care in a number of ways. There has however, been very few studies documenting this assumption, justifying investments in such systems. To address this subject we conducted a study based on the principles of HTA of a new electronic medical record within an obstetric department in two hospitals in Frederiksborg County in Denmark.

The researchers on this HTA was an interdisciplinary team consisting of medical doctor and specialist in health care informatics, Peter Wied, health economist, Anne Hvenegaard, and me as social anthropologist. I was at the time of the survey employed at DSI the Danish Institute of Health Services Research as a researcher and am now employed at the Institute of Anthropology at the University of Copenhagen. The HTA was financed by CEMTV (Center for Health Technology Assessments in Denmark, Frederiksborg County and DSI - Danish Institute for Health Services Research.

## *What Is a Health Technology Assessment?*

A Health Technology Assessment is build over 4 individual analysis – one of respectively the technology, the organization, the economy and the patient perspective followed by a synthesis. A synthesis which is the real challenge as this is to be one joint presentation of results from research very often belonging to very different theories of science.

Personally I believe this framework to be constructive and productive if the researchers with the very different scientific approached relate to one another and have a running dialogue in order to influence the formulating of the synthesis. This however, is very often not the case. Traditionally this framework is used within the medical world by researchers with a medical and an economic background. When the researchers finally arrive at the "patient" part this has for a large part been surpassed. The larger HTA's however, financed by the CEMTV in Denmark have started to use researchers from the social sciences and so has DSI where I worked. It was very evident, however that the invitation to dialogue has to come from the researcher representing the social sciences – our scientific worldview apparently enables us to encompass other worldviews more often than visa versa.

## *Where and Why?*

Frederiksborg County is one of 14 Danish counties numbering a total of 350.000 citizens. At the time of the study there were two hospitals in the county with obstetric service. Both departments were under the same management and were included in the study.

The electronic patient record was implemented in the year 2000 and after implementation and more than one year of experience with the new system both leaders and staff of the obstetric department agreed that much had been gained. There were however, still a number of uncertainties of the consequences of the EMR and it's exact benefits or drawbacks. Moreover it was perceived, that implementation had been costly, but it was not known how many resources had actually been put into the project altogether.

In choosing the analytical pathway we wished to use a systematic interdisciplinary method that would make it possible to illuminate the electronic patient record – in relationship to several perspectives and relate these perspectives to one another.

The focus of my paper is the analysis of the expectations and experiences of the woman over the entire course of maternity and birth. That is from the patient perspective – what are the benefits and drawbacks of the electronic patient record and under what conditions are they perceived?

## *How Was Data Generated?*

Datageneration for the analysis of the technology, the organization and the patient perspective are based on a methodological triangulation. The health economic analysis is a cost-consequence analysis.

Data was generated by:

- observational studies in the wards as well as in the delivery rooms
- questionnaires aimed at both patients and staff
- single qualitative interviews with patients, leaders and selected staff members
- focus group interviews with staff members mixed and in separate occupational groups
- project account data and data extracts from the EMR and other IT systems – which was not used in this particular analysis.

The data pool provided the empirical basis for my analysis focusing on interaction between patient, caregivers and technology.

The data also provided the empirical basis for the organizational and the technological analysis as well and it supported the analysis of the economy. This, I believe was one of the main reasons why we succeeded fairly well in doing a cross disciplinary analysis – we generated most of the data together and had a running dialogue while analyzing it for each part of the HTA.

Observational studies were used to perspectify the interviews and the questionnaires as they are eminent for showing the interaction and relationship between people, and the schisma that can arise between what people say the are doing and what they actually are doing.

## *Experience, Relationships and Wishes*

My paper focus on the women‘s experiences over the entire course of pregnancy, labor, and the post-natal period what are the benefits and drawbacks of the electronic medical record and under what conditions are they perceived? I selected three core themes in order to evolve this focus.

- Does the use of EPR influence the relationship between patient and caregivers and if so in which way?
- Does the use of EPR influence the patients perception of quality of care and if so in which way?
- Does the EPR support the patients wishes and needs and if so in which way?

## *Being Someone*

«One is involved in a dialogue relating to ones own history when the caregivers are writing in the EPR – that feels good», remark from a new mother.

«I felt a bit insecure when the midwife turned away from me during delivery to write in the EPR», a woman expressed after giving birth.

«It is good if we involve the women in the dialogue when writing in the EPR – it makes them more responsible», a caregiver said after a consultation.

«We loose the contact with the socially weak women – they are the loosers», a caregiver said with concern after having experienced a consultation where he overlooked a womans signs of distress while he was using the EPR.

Being involved and feeling co-responsible and updated, are apparently key parameters for feeling confident and safe.

On the drawback side we have the woman feeling left out and alone when the midwife turns away. We also have the caregivers, especially doctors, expressing deep worry concerning the socially weak women – they fear that they (the doctors) are not able to pay attention to the signs and expressions when being absorbed with dataentering in the EPR. This also turned out to be the case during several of my observations. Following one of these the doctor commented «yes, and there she was crying when she left...the young pregnant women, and I hadn't even noticed...»

The women's level of satisfaction reflects the caregivers ability to involve her in a dialog concerning the information being "put into" and "produced" by the EPR. It was experienced as very positive by most women that they themselves were able to keep track of what was being written on the screen and at the same time being able to participate in a dialogue with the caretakers about what was being written.

## *On the Leading Edge of the Situation*

Most women thought that EPR was a useful instrument for the caregivers and this especially came into expression through a perceived improvement of the communication procedures and information flow.

The women experienced that the caregivers were on the "leading edge of the situation" and therefore capable of "putting pieces of information on top of each other" – in other words they knew what had happened or had been said and, what was to happen next. On the other hand the women experienced an information failure or breakdown in the cases where the midwife consultations had no EPR – which was the case in a couple of satellite consultations in the county.

The women's experiences and perceptions thus indicate that the quality of care can be supported by an adequate use of the EPR – provided that information can flow freely and unhindered between all involved caregivers. The information flow – thus – is the precondition for feeling that the quality of care is good.

### *Quality Confidence in the Caregivers*

The women's evaluation of the quality of care was primarily related to their experience of service in the ward and the degree to which they experienced that the caregivers were being supported by the EPR. The women agreed that what really meant something was when they felt that the caregivers were "on top of the situation" that is knew what had been done, what had happened and what was to happen. This meant that the women had confidence in the caregivers and this equals good quality. It was however difficult for the women to determine and relate to the professional definition of quality of the care and treatment. However, the women's experiences and perceptions indicate that the quality of care can be supported by an adequate use of the EPR – provided that information can flow freely and unhindered between the involved caretakers.

### *Supporting Wishes and Needs*

By large the women expressed that the EPR altogether supported their wishes and needs. Well-informed and forward looking doctors, nurses and midwifes were perceived as the precondition for a well-planned pathway for the women (patient).

The fact that the EPR also gave room for a very intentional and direct involvement and thereby created a sense of co-responsibility for the course of care and treatment supported this positive experience furthermore.

Drawbacks were experienced by both patients and caregivers primarily concerning lack of attention in given situations and a tendency towards the technology "favoring" the women whom themselves were able to "build bridges". This meaning that socially weak women might be even more lost if the caretakers are not especially aware of this pitfall.

It seems that

- The practical skill with which the caregivers use Epr is decisive for the degree to which the women are satisfied
- The womens satisfaction is reflected directly by caregivers ability to involve her in a dialogue relating to the information "being put into the Epr" which again is interdependent with the caregivers practical skill
- The womens experiences indicate that the quality of care is perceived as being related to and supported by the use of Epr. The precondition being that information can flow unhindered between all parties involved in the care taking of the women
- Well informed caregivers are perceived by the women as the precondition for a well organized patient pathway

Caregivers thus have to be very aware of the pitfall called "absorbing themselves in technology" instead of "being there, being attentive and actively going into a dialogue with the women". A difficult but necessary lesson in communication!

Finally Epr systems should only be implemented if all parties involved in the patient pathway have access to it – otherwise lacking information is perceived as quality flaw producing uncertain and unsatisfied women.

The synthesis of the four Hta elements (which is a must in a Health Technology Assessment) shows an apparent lack of in depth understanding of the patient perspective contrasting the caregivers perspective – the synthesis does not grasp the great concern expressed by the caregivers and not perceived by the woman themselves – especially not the woman in question – the socially weak woman. The synthesis presents the overall positive patient perspective – and this is what will be put forward to the political decision makers. The synthesis has not captured the "in between conclusions" which could have been supported by more observational studies – which there in this interdisciplinary study was neither money nor understanding for. And with the objectives of an Hta and working with hardcore scientists it was not possible to argue that it was exactly the relationship between the different perspectives that conveyed the essence of the problem. I still wonder if the the patientperspective analysis in this Hta in fact will be of a disadvantage for the patients if the "lost womens voises" are not brought into the synthesis and I wonder if this is possible when working within the framework of four different theories of science according to the Hta framework?

The synthesis was framed as follows: the HTA of all four perspectives showed that EPR indeed held many advantages. However, some of these were only potential. To reap the full benefit further organisational changes matching the new possibilities with an EPR were needed. Patients were generally content and felt confident with the use of computers. A better service and treatment was perceived when the EPR was well implemented and the caregivers had learned the skill of communication and involvement while working with EPR. Implementation as well as the daily use of the system was rather costly especially in terms of staff time needed and loss of productivity.

This is what is presented for the political decision makers and this is what they will act upon...

I believe however, that the results support the ongoing work within the health sector concerning the uncovering of patient wishes, needs and concerns. A weighty amount of patient satisfaction surveys have yet to convey what patient satisfaction really is. I believe my results actually express core elements concerning patient interests. The fact that this does not come clearly through in the present HTA synthesis I can live with if I believe the results point towards a better understanding of patient needs in general within the Danish health sector. And this I do.

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