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Why do People Want a Paper Copy of Their Electronic Patient Record?

Torunn Wibe[abc], Mirjam Ekstedt[a], Ragnhild Hellesø[c], Laura Slaughter[de]

[a] *Center for Shared Decision Making and Nursing Research, Oslo University Hospital, Oslo, Norway*
[b] *Teaching Nursing Home, Oslo, Norway*
[c] *Faculty of Medicine, Institute for Health and Society, Department of Nursing and Health Sciences, University of Oslo, Norway*
[d] *The Interventional Center, Oslo University Hospital, Oslo, Norway*
[e] *Department of Computer and Information Science, Norwegian University of Science and Technology (NTNU), Trondheim, Norway*

Abstract

Changes have recently been passed in the Norwegian legislation, allowing for more exchange of patient information between health personnel. These legal changes came as a result of a long and still ongoing debate concerning the potential conflict between confidentiality issues and patient safety as health care is getting more fragmented. At the same time, an increasing number of patients now make use of their legal right to access their patient record. In this paper, we shed light on some of the reasons why patients request a copy of their record. We report the preliminary results from an interview study in which seventeen patients who have asked for a copy of their patient record following a hospital stay have been interviewed. In our interview study, securing transmission of information between health care workers is one of the main reasons for requesting a copy of the record. We will discuss how this finding might contribute to the ongoing debate.

Keywords:

EPR, Medical record, Patient access to records, Patient information, Communication, Confidentiality, Patient safety, Empowerment, Interview study

Introduction

An increasing number of patients now make use of their legal right to access their patient record in Norway, as in other countries [1-3]. This legal right can be seen as part of a larger trend in health care during these past several years to strengthen patient autonomy. Making health personnel's assessments and decisions more transparent is expected to contribute to patient empowerment and reduce the power imbalance between patient and providers. It is claimed that in order for patients to be true partners in the health care encounter, they must have access to their own personal clinical health information [4-6]. In Norway, the legal term has changed from medical record to patient record, to emphasize these changes. But in Norway, as in other countries, like for instance Canada, there has been some unwillingness on the part of health personnel to give up "ownership" and embrace the new role as custodian of the patient record [5]. Norway is likewise facing a shift from paternalistic attitudes in health care to a more consumer based approach. In this process health personnel have tended to be more skeptical of the benefits patients might receive from reading their own records. Like in other countries, Norwegian health personnel have been worried that reading their own record may worry, confuse or embarrass patients [7].

Changes have also recently been passed in the Norwegian laws regulating health registers and the work of health personnel, allowing for more information exchange inside the hospitals, between hospitals, and between hospitals and primary care/community services. These legal changes came as a consequence of a long ongoing debate due to strict legal confidentiality regulations in Norway and an increasing fragmentation of the health care system that has made efficient transmission of information between health personnel more and more important [8;9]. The debate concerns the potential conflict between confidentiality issues and patient safety, a conflict that does not seem to be completely solved by the recent Norwegian law changes. A similar debate has been going on in other countries, e.g. in England in connection with the creation of a national database of health records [10]. We conducted an interview study to explore why patients request a copy of their record and their experiences in connection with receiving such a copy. In this paper we are reporting some preliminary results from this interview study that contributes to the debate mentioned above.

Materials and Methods

In this explorative study we conducted in-depth interviews with former patients who have asked for and received a copy of their patient record following their stay at two Norwegian hospitals. EPRs (electronic patient records) have been in use for some years in these hospitals, but patients who want to read their record receive a paper copy by mail from the central record archives. There is no electronic record access for patients.

Inclusion criteria

Men and women over 18 years old, who have requested and received a copy of their patient record at the hospital, speak/read fluent Norwegian, and have no known cognitive impairment were included in the study.

Participants

A convenience sample of the 17 first patients that volunteered for an interview - sixteen women and one man - between the ages of 28 and 67 were interviewed. They had different diagnoses (e.g. cancer and childbirth) and different lengths of hospital stay.

Procedures

The interviews took place either in the researcher's office or in the informant's home or work place depending on the patient's preferences 3-4 weeks after the informants had received the copy of their record in the mail. The interviews were tape recorded and then transcribed verbatim.

Analysis

The interviews were analyzed by qualitative content analysis [11]. The first author conducted the textual analysis by reading and re-reading sections of the interviews and identifying differences, similarities and patterns in the text. All interviews were divided into meaning units that were coded, condensed and abstracted. To address trustworthiness the co-authors who were experienced in the field and the method, checked and discussed analysis and interpretations to reach consensus. In the analysis of the manifest content of the interviews a main theme was constructed and grouped into sub-themes.

Results

A main theme coming out of the analysis is that informants wanted to have a copy of their record due to *"a wish to have control"*. This main theme consisted of several sub-themes that will be presented inn full elsewhere. In this paper we are focusing on one specific subtheme that seems to be relevant to the debate on patient safety vs. confidentiality issues. We have called this sub-theme "*transmission of information*".

Transmission of information

Patients who volunteered to be interviewed explained that they wanted a copy of their record to secure the transmission of information between health personnel, inside the hospital, between different hospitals, between hospital and GP or specialist outside the hospital. The informants discussed at length during the interviews that the documentation of care was poorly communicated and largely unused by health personnel. Informants felt that a large number of different health personnel they met during a hospital stay and/or at the outpatient clinic did not have a full overview of their situation. The informants took it upon themselves to be fully updated on their record content to make sure that the health personnel did not forget or misunderstand anything. To have a copy of the record gave some of the informants a feeling of control in this situation. They could choose to show a copy to who ever in the health care team that they thought needed it or tell them to read for example the admission note for a certain piece of information that they knew was documented there.

Informants were also concerned that important information would not be transmitted between different hospitals where treatment took place, so they took on the role as "messenger" or "postman". One informant described it like this: "*I did have questions that I wanted an answer to when asking for a copy of my record, but first and foremost my purpose was to pass on the record information to this other hospital where the birth was going to take place, to get help to decide whether a caesarean or a normal birth would be best.*" Later in the interview this informant said: "*... I find it strange that there is no common patient register… If I move to another part of the country, then it's only me that can pass on relevant information in case of complications with the birth… And what if I'm not sufficiently aware of things – is this safe enough?*"

Likewise there were examples in the interviews of how informants felt they had to take responsibility for the transmission of information from the hospital to their GP or specialist outside the hospital and the judgment of what information that would be relevant and necessary for these doctors to receive.

Informants pointed out that one does not normally get a copy or even a receipt of the correspondence between health personnel, like referrals and discharge summaries, as one would do in many other situations in the role as a customer or a client. This lack of confirmation made some of the informants unsure if the letter or referral that health personnel said they would send was actually sent and how their case was explained in that document.

One informant described that she received the referral from her GP and got the responsibility to find a specialist herself to make an appointment. She felt quite troubled about this task, as she did not know any specialists, and just had to look it up in the telephone directory without knowing who would be the best to see. She also commented that they all had limited calling hours that she had to find out. Although she was interested in what the referral said, she would rather not see this information, when it implied making all these phone calls.

Discussion

From the findings in this study we get a picture of patients requesting a copy of their record as representatives for the modern patient, conscious about their civil rights and free will, but also aware of their duty to take responsibility [12]. The patients' experiences can be seen as statements of the fact that the problem in health care today is not lack of information, but bad communication [13]. Bad communication might potentially threaten patient safety and the use of ICT in health care could lead to better communication and more efficient flow of information. It is certainly in the patients' interest that health personnel have the necessary information when they need it. Through the experiences of our informants, we get the impression that the hospital routines for transmission of information might not be good enough. The patients are left with an unreasonably big responsibility, not only to transmit important information within the health care system, but also to decide who needs what information. In this way, the patient might be seen to be exploited as a customer to enforce cuts in public expenditure [12]. The investment in extra time and resources to improve continuity of care through better routines for information exchange is not a prioritized task within the system of financing that dominates Norwegian hospitals today. This illustrates how the role as the modern patient contains new opportunities for patients' empowerment, but at the same time expectations of self-responsibility that do not always seem reasonable [12] The informants in our study are surprised that transmission of information doesn't happen in a more smooth and automatic manner. Moreover, patients are often unsure if information is transmitted or not. They therefore take action to get the information transmitted, just to be on the safe side. This speaks for a more efficient transmission of information between health personnel and preferably electronic transmission. However, is a more liberal sharing of EPR content between hospitals and between hospitals and GPs the best way to go then?

Risk of information overflow

Patients feeling that they have to secure transmission of information between health personnel even inside the hospital, indicates that the EPR solutions that exists on the hospital level in Norway is not well enough organized to make it easy for health personnel to find relevant and necessary information. The EPRs are still to a great extent organized the same way as the paper records were. Consequently all the various information from a hospital stay will be spread out in many different folders and these are normally not easy to put together in one view.

To expand the electronic access to this record to other hospitals and the primary care as well might therefore turn into a new example of bad communication and information overflow. There is reason to believe that exchanging knowledge about the patient, as it is done in referrals and discharge summaries, is more efficient than sharing all the record content (giving electronic access to the whole record). This view is supported by other studies [14-16] and is also emphasized in a report from the Norwegian Centre for Electronic Patient Record [17]. The writing and reading of summaries calls for reflection on the patient's situation by the health care workers, in a way that sharing of information does not equally contribute to [17]. There is a certain risk that less effort will be put in the discharge summaries if other hospitals and the GP have full access to the hospital's EPR. This could in fact increase the time health personnel spend looking for relevant information, which is not in the patients' best interest [17].

Related work is going on in Norway to develop a "core record" (in Norwegian, "kjernejournal") similar to what already is in use in Scotland under the name of Emergency Care Record. In our view, this would be of much more help in most clinical situations than hospitals opening the whole record and sharing all information with each other. At the same time this would hopefully reduce the patients' burden to secure the transmission of essential information between health personnel.

The right information at the right time

Some patients in our study had experienced that it took so long (several weeks and even months) to get a copy of the record that when they received it, they no longer really needed it. This was certainly not an empowering experience and did not leave the patient with a sense of control. In Norway there is some pilot work going on to develop electronic access for patients to provider held electronic records. So far there has been focus on electronic access to the discharge summary after a hospital stay and the possibility to communicate with health personnel by secure e-mail (e.g. www.minjournal.no). The experiences of the informants in the current study, that it sometimes took unreasonably long time to receive a paper copy of the record, should be an argument to put more resources into the further development of electronic access for patients to provider-held records, such as EPRs in hospitals. Given the increasing number of patients requesting paper copies of their EPRs, the development of electronic access for patients to the EPR, from the patients' point of view, is long overdue. Access to the EPR is a fundamental patient right and this development should therefore not be delayed. As stated by Wiljer et al. (2008) health care organizations should create a culture of custodianship, rather than ownership, of patient data. This shift could be alleviated by creating models of shared control between health care professionals, patients and the public [6].

From a patient autonomy and empowerment view, a requirement for sharing the patient record between healthcare institutions (hospital-hospital and hospital-GP) should be that patients get electronic access to their own record as well. Similar to what was found by Whiddett et al. (2006) in a New Zealand study, most of the patients interviewed in our study did not know to what degree their information was shared between health personnel in the hospital [18]. In our view, they should not be ignorant about the information that is exchanged between health personnel and a log should be easily accessible to the patient listing who reads their record, where, and when. Patients should have the right to know when and for what purpose their data is used [19] as well as the ability to control the flow of their clinical data and also to delegate access to the data. In addition, the patients seem to be in the best position to discover documentation errors in a situation where so many different health personnel are involved in their care. This is also pointed out by others [1-3;20;21]. When patients in our study discovered information in the record that was not correct or information that they would not like everyone to see, the lack of an effective system both to shield and correct record information bothered them terribly. Lastly, judged by these patient experiences it would not only be extremely timesaving for the archives if electronic access for patients was the norm and that a paper copy of the record was only sent out on request, but it would be an important step towards real patient empowerment and autonomy.

Limitations

First of all, these are preliminary results based on analysis of the manifest content of the interviews. A limitation of our work is that the sample is self-selecting. Patients who have a story to tell about bad experiences with health personnel or the hospital as an organization might be more likely to volunteer for an interview than patients who don't have these kinds of experiences. One should therefore be careful to generalize these findings as typical for patients' experiences on this area. Other studies have found that women are much more likely than men to be interested to read their record [2]. Even if the low number of men recruited to the study may reflect the number of men requesting to read their record in Norway the unequal participation of genders is a limitation of the study.

Conclusion

From the experiences shared by patients in this interview study, we conclude that there is a need for improvement in the organization of content as well as flexible views in the patient record system. Improvements can also be made in the system for electronic transmission of referrals and discharge summaries, so that patients can be sure of what is communicated and do not have to bring a copy to be on the safe side. Ongoing work to develop a "core record" should consider findings presented here.

Better discharge summaries and a "core record" might in many cases cover the patient's need for written information too. A requirement for providing broader electronic access to records as the legal changes now allow would in our view be that patients have access to the same information as health personnel to avoid diffusion of documentation errors without anyone noticing it. This is in accordance with the conclusions of Powell et al. [10]. Better organization of the record content is needed to be able to limit health personnel's access to what is relevant and necessary information about a patient to avoid information overflow and to shield information that is not in the patient's best interest that everybody see. Thus we support the view of Wiljer et al. (2008) that providing electronic access to EPRs is a vital next step in promoting active involvement of patients in their care and improving the health system on a profound scale [6].

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Address for correspondence

torunn.wibe@rr-research.no