



Short report

Lay people's experiences with reading their medical record

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ABSTRACT

An increasing number of patients now make use of their legal right to read their medical record. We report findings from a study in which we conducted qualitative interviews with 17 Norwegian adult patients about their experiences of requesting a copy of their medical record following a hospital stay. Interviews took place between May, 2008 and April 2009. The analytical process, guided by qualitative content analysis, identified two main themes; "keeping a sense of control" and "not feeling respected as a person". The informants' experiences with reading their own medical record were often connected to their experiences in direct communication with health care professionals during the hospital stay, revealing a delicate interaction between trust and power. The informants were hoping for a more mutual exchange of information and knowledge from which they could benefit in the management of their own health. We conclude that to meet patients' expectations of mutuality, health care professionals in hospitals need to be more conscious about their attitudes and communication skills as well as how they exercise their power to define the patient's situation. At the same time, there should be more focus on how structural changes in the organization of hospitals may have impaired the capacity of health care professionals to meet these expectations. In the future, greater attention should also be paid to information exchange to avoid placing unreasonable responsibility on the patient to compensate for deficits in the health care system.

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Introduction

Recent legislation in many countries has given patients the right to access their own medical records (Fisher, Fitton, Poirier, & Stables, 2007; Fowles, Kind, Craft, & et al, 2004; Ross & Lin, 2003). In Norway, where this study took place, patients' access to their records became a legal right in 2001. This legal right can be seen as part of a broader trend in health care, in which a higher level of education in the population and access to health information on the Internet are contributing to more multifaceted and less paternalistic patient-provider relationships (Boyer & Lutfey, 2010). Making health care professionals' assessments and decisions more transparent by giving patients access to read their medical records

is expected to reduce the power imbalance between patient and provider (Fisher et al., 2007; Ross & Lin, 2003).

Norway is a wealthy welfare state, characterized by high literacy rates, a well developed social safety net, and a collective orientation. Hospitals are mainly state owned, and public health care is tax-financed and free for all citizens. Both general practitioners (GPs) and hospitals have been using electronic patient record (EPR) systems for several years. However, due to strict legal confidentiality regulations in Norway, the electronic transmission of record documents between different hospitals and between hospitals and general practitioners has been limited.

Patients have unique subjective, experience-based knowledge about their own situation that could be seen as a crucial source of information for health care professionals. Somehow, the value of the non-medical aspects of this experience-based knowledge has historically been underrated by health care professionals (Barker, 2008). Changes in organization and financing of Norwegian hospitals in recent decades, resulting in shorter consultations and less provider continuity, might also contribute to health care professionals focusing less on cultivating personal relationships with their

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patients, and to less documentation of life-oriented perspectives in medical records (Potter & McKinlay, 2005; May, 2007).

Clinicians have initially been worried about the impact of patient access to records, fearing that mistakes and uncertainty would be exposed (Fisher et al., 2007). This might be interpreted as a concern about the erosion of medical authority and patients' trust in doctors (Mechanic, 2008). In a review article, Ross and Lin (2003) identified different and partly conflicting reasons for patients to make spontaneous requests to read their medical record, including a wish for more information, as well as dissatisfaction and/or perceived grounds for complaint. Few patients found the experience of reading their own record confusing or upsetting. However, patients commonly found it difficult to understand at least part of their records. In many studies, patients also found inaccuracies in their records. Despite some negative experiences reported in the reviewed studies, Ross and Lin (2003) conclude that patients are generally satisfied with the experience of reading their medical record.

In Norway, like many other countries, there are initiatives to develop a personal health record system (PHR), defined as an electronic application through which people can access, manage and share their health information (Tang, Ash, Bates, Overhage, & Sands, 2006). The best-known PHR development project in Norway aims at making parts of the hospital record available for patients online (www.minjournal.no).

To inform this development, a deeper insight into patients' experiences of reading their own medical record is important. To our knowledge, few recent studies have used in-depth interviews to address the reasons why people request their hospital records after a hospital stay and what significance they attach to what they read. The aim of this study is therefore to investigate laypersons' experiences of reading their medical record.

Methods

Participants

Participants were recruited from April 2008 to March 2009 from two large Norwegian university hospitals, which admit patients from both urban and rural areas. Men and women over 18 years old who had requested a paper copy of their electronic patient record (EPR) after a hospital stay were invited to participate in the study. Relatively few hospital patients make such a request. The patients who requested a copy of their record at the time of the study represent less than 1% of the patients admitted to the hospitals where the study took place during the same period. Of 108 patients who were invited to participate, 17 (16 women and 1 man) volunteered for an interview. The sample size of 17 participants was judged large enough to provide a variety of experiences in reading medical records and to allow sufficient depth in the analysis.

Participants were aged between 28 and 67 years (mean age 49, median 48). They had been admitted to hospital for various reasons: childbirth ($n = 6$), multiple chronic diseases ($n = 3$), cancer ($n = 2$), elective gynecological/urological day surgery ($n = 2$), acute eye conditions ($n = 2$), acute hematological conditions ($n = 1$), and acute neurological conditions ($n = 1$). According to their own statement eight (47%) had asked for a copy of their record after acute admissions. Their education level was relatively high: university ($n = 6$), college ($n = 5$), high school ($n = 5$), and primary school ($n = 1$). In comparison, of the 91 non-respondents, 79 were women (87%), the age range was 20–78, and the mean/median age was 42/38; 69 non-respondents (76%) had education beyond high school and the admission also varied between acute and planned (32% with acute admission, based on the patients' own statement), and various diagnoses.

Procedures

The hospital archive personnel sent written information about the study and an invitation to participate together with the requested copy of the medical record to persons who met the inclusion criteria. Narrative interviews were conducted by the first author. The interviews, which lasted between 25 and 60 min, were recorded with a digital voice recorder and transcribed verbatim. The study was approved by the Norwegian Regional Research Ethics Committee and recommended by the Privacy Ombudsman for each of the hospitals involved.

Analysis

The analytical process was guided by qualitative content analysis (Graneheim & Lundman, 2004). Through a continuous process of comparing codes for similarities, differences, and patterns in the text, the codes were sorted into preliminary categories: one concerning the motivation for participants to request their record and the second describing thoughts and feelings that emerged when they read their record. Next, these categories were examined for underlying meanings, that is, threads of meaning recurring through the entire condensed text, in the different categories. These threads of meaning were formulated as themes and sub-themes.

During the process of analysis, the focus alternated between the whole and parts of the interview text to confirm the interpretations made at a higher level of abstraction. Themes and labels were discussed between the first and last author and in seminars within the research group until consensus was reached.

Findings

The experiences of reading one's own medical record after a hospital stay are presented as two main themes and five sub-themes. The main themes are labeled: "Keeping a sense of control" and "Not feeling respected as a person".

Keeping a sense of control

This theme describes the informants' experiences of co-responsibility for their own health and of not fully trusting that their interests would be taken care of in an appropriate manner by health care professionals. Three sub-themes were related to this theme: "Acquiring more knowledge", "Taking responsibility for information flow" and "Examining the accuracy of the record".

Acquiring more knowledge

The informants described reading their medical records as a means to obtain a more complete version of their illness story, mainly by supplementing their own experiences with the biomedical description of what they have been going through. A common experience was that their knowledge of this specific part of their life was fragmented or inadequate. They wanted to acquire more knowledge about their health history in general or the course of events during one particular hospital stay, and about complications that had occurred. One informant described it this way:

It wasn't as though I was wondering what had happened or... No, it was more to have an overview of, both a bit of the medical and what happened when, because it's always difficult to remember later on.

The reading of the medical record included a desire to compare the informants' own experiences of what had happened during the hospital stay with what was documented in the record. Reading the record was also a way for informants to look for information that

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