Patients reading their medical records: differences in experiences and attitudes between regular and inexperienced readers

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Introduction. *We report results of a study of how ordering and reading of printouts of medical records by regular and inexperienced readers relate to how the records are used, to the health information practices of patients, and to their expectations of the usefulness of new e-Health services and online access to medical records.*
Method. *The study is based on a combined postal- and Web-survey of a simple random sample of 1000 patients who ordered a paper copy of their medical records from the Uppsala county council (Sweden) with a final analysed sample of 354 returned questionnaires.*
Analysis. *The data were analysed using SPSS 21.0 using descriptive statistics, one-way analysis of variation (ANOVA) using Tamhane's T2 test, chi-squared tests and logistic regression analysis.*
Results. *The analysis shows that individuals who had ordered a copy of their medical records in the past perceive their usefulness in broader terms than first-timers. The regular readers are also most concerned about their health and the quality of care.*
Conclusions. *It seems that in addition to certain demographic factors, many of the variations in the data can be explained in terms of adaptive structuration theory. This is a result of a parallel structuration of patients, medical records and the paper-based and online technologies of access, and consequently how patients perceive records and the different methods of accessing and using them.*

Introduction

Digitalisation of health information has opened up new possibilities for patients to access their medical records. There is a relatively large number of studies on how different patient groups access their medical records online and their attitudes to the prospective introduction of new online e-health services (Ammenwerth, Schnell-Inderst and Hoerbst, 2012) and the use of online health information (Pálsdóttir, 2011; Ross, Todd, Moore, Beaty, Wittevrongel and Lin, 2005). In contrast, there is considerably less research on how patients utilise the opportunity to access paper copies of their medical records. Who are the current and potential users of these services and what are the impacts of these non-digital health information practices on patients' attitudes to the introduction of new online access services?

The aim of this paper is to analyse how ordering and reading of medical records by regular and inexperienced readers relate to their use and to patients' health information practices and expectations of new online access services. The analysis of the influence of being a regular or an inexperienced reader builds on the adaptive structuration theory of DeSanctis and Poole (1994). The study is based on a survey of a simple random sample of 1000 patients who ordered a paper copy of their medical records from a Swedish county council with a final analysed sample of (n=) 354 returned questionnaires.

In this study, the term *medical record* is used to denote a record a patient can access that consists of textual notes and information produced when a patient is in contact with health care services that relate to the patient's health or other personal matters. The records were only delivered on paper at the time of the

study. By the time of writing online access to an exact copy of the record held by health care providers had become available, as is required by Swedish legislation which stipulates open access to all personal data held by public institutions. Formally, it is at the health care provider's discretion to make a formal decision on the release of a medical record to a patient and it is possible to withhold parts of the record. In practice, in the studied county council, records have been withheld very seldom.

Literature review

The development of e-health services and patient access to medical records is motivated by diverse arguments such as empowerment, consumerism and technological utopianism, and the emphasis on individual responsibility in society (Mager, 2012; Ünver and Atzori, 2013; Robertson and Vatrapu, 2010). There is a relatively broad consensus that patients need to assume a more active role to take charge of their health and medical care (Huber and Gillaspy, 2011). Furthermore, giving patients an active role will reduce errors (Institute of Medicine, 2001), decrease health care budgets (Bernabeo and Holmboe, 2013; Carman *et al.*, 2013), and give patients better understanding of their conditions (Ferreira *et al.*, 2007), as well as improve the quality of care through the compliance of patients with their prescriptions (Detmer, Bloomrosen,Raymond and Tang, 2008; Sittig, 2002). Others argue that e-health services and giving access to medical records are a means to demedicalise healthcare and improve the mutual understanding of medical doctors and their patients (Evans, 2007).

Arguments against giving patients access to their medical records include that it leads to increased workload for healthcare professionals (Davies, 2012; Delbanco *et al.*, 2010), that patients may over-interpret documented symptoms and become depressed based on uncertain early diagnoses (Delbanco *et al.*, 2010), that it will negatively influence the patient–provider interaction (van der Vaart, Drossaert, Taal and van de Laar, 2013), and that it will lead to security problems, for instance, with patients with psychiatric illnesses (Brakoulias, 2013). In contrast to the often fairly positive attitudes of patients (as discussed below), the opinions of health care professionals tend to be more split and the same arguments are used both for and against allowing patients to access their medical records (e.g., Davies, 2012; Delbanco *et al.*, 2010). One reason for this is the difference in the legal status of medical records in different countries. Another reason is the nature of the medical record itself. In contrast to simplistic ideas of perceiving it merely as an objective total record of everything, as sometimes presented in the literature (e.g., Rector, Nowlan and Kay 1991), studies of the use of medical records have shown that they are political and constitutive artefacts that reside in a liminal space between patients, different branches of healthcare, individual professionals, legislation and other public and private institutions. Even if a patient sees accessing a medical record as a relatively uncomplicated matter, professionals who work with these artefacts on a daily basis are aware of the complexities of the records and record-keeping practices, differences in the contents of the individual parts of the record (Berg 1996; Berg and Bowker, 1997;) and the similarly complex premises and implications of allowing patients to access their records.

There is empirical evidence that active patients (i.e., patients who actively participate in their healthcare) have better experiences and health outcomes. Hibbard and Greene (2013) demonstrated that it is possible to activate patients and that less active patients are associated with higher health care costs (Hibbard *et al.*, 2013). Many of the proponents of patient activation see patient access to medical records as a significant precondition of an anticipated healthcare revolution (e.g., Ammenwerth *et al.*, 2012; Gaunt, 2009; Hoerbst *et al.*, 2010; Joubert *et al.*, 2007; Munir and Boaden, 2001; Sittig, 2002). It should, however, be noted that the evidence of the causal correlation between providing access to medical records and patient activation (Ross and Lin, 2003) or other positive outcomes is not conclusive (Ammenwerth *et al.*, 2012). The uncertainty of positive outcomes tends also to relate to other forms of sharing of personal health related information. Pitkethly *et al.* (2008) report positive outcomes of providing cancer patients with access to their records and summaries, but note that more evidence is needed. Farrelly, Brown, Flach, Barley, Laugharne and Henderson (2013) and Ko, Turner, Jones and Hill (2010) reviewed the outcomes of user-held medical records in psychiatric care with no conclusive evidence to support the impact of the approach. Boyle, Solberg and Fiore (2014) report a similar lack of evidence of the positive effects of access to electronic health records in smoking cessation support. Brown and Smith (2004) provide evidence of both positive and negative outcomes of providing women with their own case notes during pregnancy, but underline that their findings suggest a lack of evidence rather than a lack of benefits.

It has been known for several decades that a large majority, up to ninety per cent, of patients tend to respond positively to the introduction of access to medical records (Ball, Smith and Bakalar 2007; Michael and Bordley, 1982) and that patients expect to access their records if the information is easily accessible on the Internet (Ekendahl, 2011). In a study of online access to personal health records by Woods *et al.* (2013)

patients had predominantly positive experiences. In an earlier study, Fowles *et al.* (2004) found that thirty-six per cent of respondents (survey n=4500, response rate eighty-one per cent) stated that they were very interested in reading their medical records. Interest correlated with active health information seeking, subscribing to a health newsletter, and using a health resource book in the month prior to responding to the survey. Interested respondents were also likely to be very concerned about errors in care and lacked trust in their clinicians. Health status, use of health care services, education, or income did not explain the level of interest. The most common reason for patients to want to consult their medical record was to see what their clinician had written about them. Fowles *et al.* (2004) also found that clinical characteristics were inferior to the frequency of the use of health care services as an explanatory factor of patients' interest in reading their medical record. Gender was related to interest as the authors expected whereas education and income were not. Munir and Boaden (2001) concluded that even if the majority of the respondents in their study in the UK were in favour of being given access to records, it turned out that a majority would not be interested in reading their record and that a majority of those who would, wanted to consult their records on paper. The findings of Ross *et al.* (2005) confirm this trend and underline the fact that some patients are strongly against accessing medical records online. Even if patient age tends to correlate with lower interest in consulting online health information sources (Manafò and Wong, 2012; Pálsdóttir, 2005), it is not related to their interest in reading medical records.

Patients with poor health (Bhavnani, Fisher, Winfield and Seed, 2011), chronic illness, frequent users of health care, and individuals caring for close relatives have the greatest interest in medical records (Ball *et al.*, 2007, see also Østerlund, Dosa and Arnott Smith 2010; Guy, Ratzki-Leewing and Gwadry-Sridha, 2012). It is worth noting that concurrent studies show that interest in seeing medical records does not necessarily correlate with actual behaviour. It is common that only a small minority of patients have ordered a copy of their journals (e.g., Delbanco *et al.*, 2010; Michael and Bordley, 1982; Munir and Boaden, 2001; Ross and Lin, 2003).

Patients are often worried about the confidentiality of the records (Ball *et al.*, 2007; Delbanco *et al.*, 2012) even if only a minority tend to be aware of specific incidents where this has been breached (Ball *et al.*, 2007). A related concern is that a patient can violate privacy by disclosing their own personal information to others (e.g., family members and health care professionals) (Chaytor, Brown and Wareham, 2006).

In contrast to the large body of literature on the anticipated impact of giving patients direct access to their medical records, there is only a relatively small number of empirical studies on this topic. One example is a study by Woods *et al.* (2013), reporting positive responses from patients and indications of empowerment even if their findings are not conclusive on the actual clinical impact of medical record access. Other studies provide contradictory evidence of both increase (e.g., Palen, Ross and Powers, 2012) and decrease in the number of visits to and time spent with physicians by patients who have accessed their medical record (e.g., Ålander, Eklund and Joustra-Enquist, 2004; Delbanco *et al.*, 2012; Pagliari, Shand and Fisher, 2012). Self-reported benefits experienced by patients include positive impacts on following advice on medication and lifestyle (Bhavnani *et al.*, 2011) and improved health (Nazi, Hogan, McInnes, Woods and Graham, 2013). In a Norwegian study, patients described reading their medical records as a means to gain a more complete understanding of their condition and to take responsibility for the flow of correct information by verifying the accuracy of the record. Some informants in the same study described experiences of feeling underestimated and misjudged by health care professionals (Wibe, Hellesø, Slaughter and Ekstedt, 2011), which are findings that also have emerged in other studies (Merrill and Grasley, 2008; Pellisé and Sell, 2009: Robinson and Thomson, 2001). Fischer, Bhavnani and Winfield (2009) show that access can help to prepare patients for appointments, compensate for communication problems during appointments, provide patients with a comprehensive view of their health, and create a feeling of being more engaged with their personal health care.

Even if some trends can be observed in studies relating to patient use and expectations of medical records, earlier research points to extensive complexity in how patients seek and use health information (Marton and Choo, 2012). Pálsdóttir (2005) has studied the Icelandic population and their health information behaviour extensively and her research shows considerable differences between active, moderately active, moderately passive, and passive health information seekers. Medical records are one source of information that is frequently complemented with others.

A challenge of synthesising earlier research is that in general, studies are not always directly comparable with each other. This is because the definition of the term *medical records*, and the opportunities patients have to access their records, and the level of interest in doing so tends to differ from one country and health care system to another. Access to medical records is often provided alongside other services, or the medical

record or parts of it are provided as a part of a broader (electronic) health record (e.g., Häyrinen, Saranto and Nykänen, 2008). In addition, it is possible that individual and collective views presented in studies can be heavily influenced by local context and situation, and factors such as discussions about the sharing or not sharing of medical records and positive and negative prior experiences. Therefore, it is not surprising that reactions vary especially among healthcare professionals that use and produce the records. Even if the lack of conclusive findings is problematic, from the point of view of the present study which focuses on patient attitudes, the significant aspect is that there are certain recurring patterns, including the generally positive patient attitudes in the pre-implementation phase of medical record access systems, the contradiction between anticipated and actual use, the influence of chronic illnesses and the dichotomy of broad interest and lack of interest in health information.

Theoretical framework

Theorisation of the differences between those patients who ordered a copy of their medical record for the first time and those who had ordered it once or multiple times before is based on the *adaptive structuration theory* of DeSanctis and Poole (1994). Adaptive structuration theory examines the role of technologies in socio-technical change from two vantage points. It scrutinises the types of structures that are provided by technologies, and the structures that emerge as people interact with them. Adaptive structuration theory was formulated as a critique of earlier technology-centric theorising (DeSanctis and Poole, 1994). Desanctis and Poole positioned adaptive structuration theory in their original publication as a theory of the influence of advanced technologies in organisational change, but since its introduction the theory has been used in a wide range of contexts of technology adaptation and change (e.g., Jones and Karsten, 2008; Kane and Fichman, 2009; Karahanna, Straub and Chervany, 1999) including healthcare (e.g., Goh *et al.*, 2011). Even though adaptive structuration theory was formulated in the context of group decision support systems and much adaptive structuration theory oriented research has focused on relatively small groups, DeSanctis and Poole (1994) are explicit that their approach is applicable to other advanced technologies and settings as well.

In this study, adaptive structuration theory helps to explicate the patterns of how survey respondents conceptualise the usefulness and their use of the paper copies of their medical record (an analogue technology) and the potential usefulness of online access and related e-health services (a digital technology). Adaptive structuration theory is used as a theoretical lens for describing and understanding the dynamics of the social and the technological rather than a method of analysis (cf. DeSanctis and Poole, 1994). In this study the *advanced information technology* is the medical record in all its complexity as discussed by Berg and Bowker (1997). In comparison to small groups (usually professionals) in many earlier adaptive structuration theory oriented studies, in this study the informants are patients, and more specifically those patients who choose to read their medical records. It is apparent that with a less homogeneous group, the group is a weaker source of structure, but as sociologically and anthropologically oriented studies of doctor-patient interactions have shown, the notions of styles of interaction (e.g., Strauss, 1985), knowledge and experience of structures (common with chronically ill individuals, e.g., Fox, 2005), and observable albeit emergent and mediated agreements on preferred activities occur even in such a weak constellation as a generic group of patients. Similarly, a loose group may use an advanced information technology either faithfully or unfaithfully to the *spirit* (i.e., a premisory values and goals related general intent underlying the structures of the technology, DeSanctis and Poole, 1994) and structural feature design of a technology (DeSanctis and Poole, 1994) and display certain *attitudes* (DeSanctis and Poole, 1994) in terms of relaxed use (comfort), respect (perceived value) and willingness to master an advanced information technology (challenge) (DeSanctis and Poole, 1994).

In contrast to studies of small groups, the relevance of adaptive structuration theory for this study is less in its focus on the dynamics of close-knit communities, but on how it describes the interplay of technologies and different levels of social structures from groups to the environment through appropriations (notion borrowed from Ollman, 1971). This aspect distinguishes adaptive structuration theory from related approaches based on Giddensian theory of structuration (Giddens, 1984) such as the theoretical work of Orlikowski on the duality of technology (Orlikowski, 1992), frequently used in information research. DeSanctis and Poole describe appropriations as the "immediate visible actions that evidence deeper structuration processes" (1994, p. 128). They can be faithful or unfaithful to the spirit of the technology depending on how they appropriate the features of technologies for various purposes. Another difference between adaptive structuration theory and other strands of structuration is in how it interprets Giddens' notion of memory traces (1984). DeSanctis and Poole (DeSanctis and Poole, 1994; Poole, 2009) also argue that structures can be embodied in information technologies, a view which is not shared by all structuration theorists.

Methods

The aim of the study was to find out how and for what purposes patients order and use their medical records, and their perceptions of the opportunity to access their records online. Contextual data was gathered on self-perceived health, health information behaviour and demography.

The data were gathered using a combined postal and Web survey sent to a simple random sample of 1000 patients that ordered a paper copy of their medical record from a Swedish county council between June and August 2012. The final analysed sample was (n=) 354 returned questionnaires (response rate 35.4%). An invitation to participate in the study and a survey form was mailed to respondents in the same envelope as the copy of their medical record. Respondents were also offered the opportunity to fill in the survey online. All responses were completely anonymous. No identifying personal data was collected.

The survey instrument consisted of thirty-nine questions of which nine (with fifty-five statements) were on a five point Likert scale. The questionnaire was constructed on the basis of earlier questionnaires (Ekendahl, 2011; Fowles *et al.*, 2004) and complemented with additional questions developed by the researchers on the basis of their expertise and the specific aim of the study. The questions and statements are listed in Table 1.

The data were analysed using SPSS 21.0 using descriptive statistics, one-way analysis of variance using Tamhane's T2 test. Even if Likert-like scale data do not adhere to the requirements of t-test analysis (including Tamhane's T2) to have a normal probability distribution, it has been shown that the t-test generally has equal explanatory power, for instance, with the Mann-Whitney-Wilcoxon test (de Winter and Dodou, 2010) if the data are normally distributed. The normal distribution of the data was tested by using Shapiro-Wilk and Kolmogorov-Smirnov tests. Tamhane's T2 test, a conservative t-test based test was chosen for analysis of variance, because the data were normally distributed, but did not have an equal variance according to Levene's test.

Chi-squared tests (appropriate for testing the relations of categorical data) and logistic regression (appropriate for binary i.e., yes/no data) were used to analyse the relationships between the groups of first-timers (group A), second-timers (B) and regular readers (C), and ten categorical and binary socio-demographic variables described in the following section. The final sample consisted of (n=) 354 returned valid surveys. Some of the respondents decided to leave some questions about socio-demographic background unanswered. Seventy-four per cent (253/343) of the respondents were female and twenty-six per cent (90/343) were male. Eighty-nine per cent (309/349) were born in Sweden. Thirty-seven per cent (131/350) were employed and twenty-seven per cent (96/350) were pensioners. Eighty-three per cent (283/342) had secondary or upper secondary level education. Three per cent (10/342) had no formal education. Sixty-six per cent (219/334) used the Internet at least one hour every day and nine per cent (31/334) were non-users. Ninety-two per cent had Internet access at home. Forty-one per cent (140/346) of respondents worked or had worked in, or in close contact to, health care, and fifty-one per cent (176/347) had friends and/or relatives that worked or had worked in, or in close contact to, heath care.

Analysis

Table 1 (Appendix) presents an overview of the descriptive statistics of questions and statements on a five point Likert-like scale. chi-squared tests between the groups (A, B and C) and the following categorical variables showed no relation:

- how respondents had found out how to order a copy of their medical record
- how they ordered the copy of their record
- what was their principal reason (Q3-11, see Table 1) for ordering a copy of their record
- how long they thought it was acceptable to have to wait for information to appear in an online medical record
- whether respondents will be able to read all information at once online
- what was their education

A one-way analysis of variance of the questions with Tamhane's T2 post hoc test based on the statement '*I have ordered a copy of my medical records before*' with alternatives '*Never*' (Group A: 197/345, 57%), '*Once*' (Group B: 68/345, 20%) and '*Multiple times*' (Group C: 80/345, 23%) revealed significant variation between the groups at the significance < 0.05 level (Tables 2,3 and 4). Members in group A will be referred to as first-time readers, members in group B as second-time readers and those in group C as regular readers.

Table 2 (Appendix) shows significant differences in how respondents in groups A, B and C perceive the relevance of reading their medical records and how they interpret the information. Group C differs from the other two groups in their generally higher levels of interest and broader view of the relevance of their records.

The group-wise variation of patients' views on the future possibilities of accessing their own medical records and other e-health services online is described in Appendix Table 3 . In comparison to the current use of medical records (Appendix Table 2), the preferences within the three groups are more diverse.

Table 4 (Appendix) describes the variation between the groups based on health, health behaviour and socio-economic aspects. Group C stood out from the two other groups in that respondents were more frequent users of health care services and were more worried about their health than respondents in the other two groups.

A combined analysis of the three groups (Tables 2, 3 and 4) shows that group C of regular readers used medical services more than the two other groups (mean 2.88, diff. A-C 0.95 sig. < 0.00, A-B .32 non-significant). They were more inclined to order their medical record to get an overview of their medical history (mean 4.52, diff. C-A 0.770, C-B 0.694), to verify details in the record (mean 4.26, diff. C-A 0.864, B-C 0.931), and to follow up what was said during a visit (mean 3.83, diff. C-A 1.127, C-B 1.018) than the two other groups. Regular readers perceived the ability to read their medical records as a necessary premise for active participation in their own health care (mean 4.37, diff. C-A 0.855, C-B 0.682) and were less inclined to ask their family and friends if they did not understand their medical record than the two other groups (mean 2.48, diff. A-C 0.725, A-B 0.917).

In comparison to first-time readers, regular readers were also more likely to distrust health care providers (mean 2.64, diff. C-A 0.732), take the opportunity to check who has been using their medical records (mean 4.47, diff. C-A 0.360), to block access to the records in an online service (mean 4.06, diff. C-A 0.535), and to use the journal to verify whether they had received proper care (mean 2.93, diff. C-A 0.880). They were also more likely to use their record as documentation of their health care for their personal records (mean 4.27, diff. C-A 0.555) and to believe that reading their own record improves their health care (mean 4.05, diff. C-A 0.660), communication with health care professionals (mean 4.35, diff C-A 0.662) and their own inclination to take care of their health (mean 3.74, diff. C-A 0.591) than those who had never ordered a copy of their medical record before. In contrast, the regular readers were less inclined to turn to their family and friends if they did not understand their medical record (mean 2.48, diff. A-C 0.725, B-C 0.917) and less willing to read potentially serious or alarming hypotheses or test results before being in contact with professionals than the first-time readers (mean 1.67, diff. A-C 2.71).

Patients who had ordered a copy of their medical record once before (group B) had the most positive attitude towards the possibility of reading their medical records online (mean 4.37). The difference was significant (p < 0.05) in comparison to group C (diff. 0.581) and non-significant (diff. 0.294) in comparison to group A. Respondents in group B were also using computers more on a daily basis than members of the other two groups (mean 2.97, diff. B-C .402 sig. < 0.05, A-C .134). Patients who had ordered a copy of their medical record before considered that they were likely to use such a service more often than first-time readers. The difference was significant between groups A and B (diff. 0.394). Group B were also least inclined to resort to talking to health care professionals instead of reading their medical records. The difference between groups A and B was significant (diff. 0.462). Group B were also least interested in communicating results of tests they could take at home using an online service (mean 3.33). The difference between groups B and C was significant (0.591).

Part of the differences between the three groups can be explained or related to various demographic and health status related factors (Table 4). Members of group A considered that their health was significantly better than those in group C (mean 3.93, diff. A-C 0.912). Members of group A were also less worried about their health (mean 2.42, diff. A-C 0.750), they used less health care services and visited fewer doctors (mean 3.21, diff. A-C 3.236, A-B 2.967) as compared with those in groups B and C. Logistic regression analysis of binary background variables showed that members of groups B and C were also somewhat more likely to have read medical literature (Wald 6.147 sig. < 0.02, Exp(B) 1.473), to be members of a patient association, to be older (significant diff. A-C 6.103), female (Wald 8.687, sig < 0.01, Exp(B) 0.606), and have worked in or in contact with health care (Wald 7.618, sig. < 0.01, Exp(B) 1.444) than those in group A.

Discussion

The analysis shows differences between groups A, B and C in how they use and perceive the usefulness of their medical records. It is necessary to note that the definition of medical record used in this study (including the survey) does not necessarily correspond with how the term is used in other scholarly sources, or texts consulted by the patients. It does not strictly speaking comply with the formal Swedish definition of a medical record, which consists of textual notes and all patient related incoming, outgoing and internal documents including electrocardiograms, videofilms and photographs. The definition is also different from the way the terms medical, patient and health records are used in other countries and how access to this information is regulated. At the same time, however, it is conceivable that the colloquial understanding of medical records as information kept by health care providers on their patients is reasonably universal and as such a viable basis for discussing the findings and how they relate to previous national and international research.

Use and usefulness of medical records

The findings show a diverse range of motivations for reading medical records and a variety of anticipated and actual impacts of the possibility of accessing medical records online. In general, the respondents' interest in online access is similar (i.e., high) to the earlier international findings in the literature (e.g., Ball *et al.*, 2007; Ekendahl, 2011; Fowles *et al.*, 2004). In this study, nine out of the sixteen statements on the perceived usefulness of new services had average scores of over four (out of five), and fifteen out of sixteen had 3.49 or higher. Ball *et al.* (2007) refer to multiple US surveys in which over fifty per cent of patients have indicated their interest in consulting or using their health records. Ekendahl (2011) refers to a Swedish interview and survey study in which eighty-seven per cent of respondents indicated that they would read their medical records online if there was an opportunity to do so. In a study by Fowles *et al.* (2004) seventy-nine per cent of respondents were either very or somewhat interested in reading their medical records. Similar to these earlier surveys, this study does not provide unambiguous evidence of the interest and actual propensity to read medical records online. Similar to the study by Fowles *et al.* (2004), the interest in reading (and actual reading) was higher among women. Some earlier studies have shown that only a small minority of patients have ordered a copy of their medical record (e.g., Michael and Bordley, 1982; Ross and Lin, 2003). In the Swedish county where this research was conducted, approximately 11000 patients (of 300000), 3.6%, have ordered a copy of their medical record annually (Leif Lyttkens, personal communication, August 15, 2013), which corresponds rather well with the literature. In the county where this survey was conducted, nine months after the introduction of a Web-based access system in August 2013 approximately six per cent of registered patients had consulted their medical record online (Benny Eklund, personal communication, November 16, 2013).

The characteristics of the groups of first time readers, second-time readers and regular readers also have similarities with the findings reported in the literature. The three groups share characteristics with the corresponding active and passive clusters of Icelandic health information seekers described by Pálsdóttir (2005). Regular readers show greater interest in and are more active seekers of health related information than members of the other two groups. Members of group A reported a better level of than members of the other two groups. They were also less worried about their health and required health care services less frequently, which is similar to the findings of Bhavnani *et al.* (2011) and Ball *et al.* (2007). Similarly to earlier findings (Ball *et al.*, 2007; Delbanco *et al.*, 2012), some of the respondents (mean 3.06, variance 2.106) were worried about the security of future online services even if the mean is not extremely high (min 1, max 5).

The factors that patients considered to be important when they ordered a copy of their medical records correspond largely with patient responses gathered in earlier studies. Questions three, four, seven and eleven (Q3, Q4, Q7, Q11 in Table 1) indicate various degrees of empowerment and taking of responsibility described in the literature (e.g., Wibe *et al.*, 2011; Woods *et al.*, 2013). Similar to earlier studies, the findings indicate that reading medical records can help to prepare patients for visits, compensate for communication problems during visits and provide patients with a comprehensive view of their health and a feeling of being more engaged in their personal health care (Fisher *et al.*, 2009).

The most popular reasons for reading medical records across the entire sample are related to receiving an overview of one's medical history and earlier care, or to verify some details thereof. These stood out particularly in group C, and also partly in group B alongside several other factors that are frequently discussed as indicators of patient empowerment (Pagliari *et al.*, 2007; Ünver and Atzori, 2013). In groups B and C, patients are especially inclined to believe that their information interactions are a premise for their active participation in their own health care and the possibility to access medical records has a direct influence to the quality of the care they receive. This finding corresponds with the empowerment thesis i.e.,

that (in some of the groups) patients are willing to take a more active role in their health care and this empowerment leads to measurable benefits (e.g., Detmer *et al.*, 2008; Evans, 2007; Ferreira *et al.*, 2007; Huber and Gillaspy, 2011). The preference of some patients to remain passive and rely on the expertise of health care professionals in this study is similar to the findings of Henwood *et al.* (2003). The diversity of motivations (willingness to participate in health care versus mistrust) can provide some explanation as to why the causal correlations between patient activation and health outcomes have not been conclusive (e.g., Ammenwerth *et al.*, 2012; Ross and Lin, 2003). If the motivation to participate is primarily related to an interest in surveying the medical record data rather than to concerns about personal health, patient activation needs to be causally correlated with positive health outcomes.

Even if it is apparent that further research is needed to corroborate these findings, the differences between groups A, B and C provide evidence that medical records have distinct informational roles for first time readers, second time readers and regular readers. As expected, the findings also show that individuals who have ordered a copy of their medical records previously perceive their usefulness in broader terms than first time readers. They are also more concerned for their health and the quality of their care, probably because they are more likely to have chronic illnesses and to be frequent users of medical services. It is interesting, however, that the second time readers are the group with the most positive attitudes towards online access to medical records, even higher than regular readers. Considering that members of group B are generally younger than members of group C, it may be assumed that acceptance of online access is going to increase with time, as technology use becomes more ubiquitous among older people.

Adaptive structuration of medical records

Even if several demographic and health related factors explain some of the differences between the three groups, it seems that the role of medical records for patients change when they have ordered a copy of their medical record first once and later multiple times. This process can be explained in terms of the adaptive structuration theory of DeSanctis and Poole (1994). This theory is based on Giddens' structuration theory and posits that technologies trigger adaptive structurational processes which, over time, can lead to changes in the rules and resources that organisations use in social interaction (DeSanctis and Poole, 1994). In its original context the theory refers to *advanced information technologies*, but the theory itself does not make assumptions that would decrease its validity in the context of other types of technologies.

It is possible to identify three parallel adaptive structuration processes of two distinct technologies in the survey data. The progression of becoming a regular reader of printed medical records is a process of structuration of the paper-based technology (the structural features of ordering a medical record, reading and using it, the level of sophistication of the technology and the comprehensiveness of the record) and its users (the styles and knowledge of and interaction with the paper-based record and agreement on appropriation). Regular readers were less inclined to prefer online access than the members of the other two groups, because they have developed a knowledge and style of interacting with the legacy technology and have become embedded in the practices and the technology itself. First time readers are more open to new services, because the process of structuration of the system of paper based medical records and their activities has only just begun. At the same time, they show, understandably, little interest in many e-health services they do not believe they need (see Q33 and Q56 in Table 1). They have not engaged in the formation of such social structures that would have tied them to the legacy system.

In addition to the two parallel structuration processes of the paper-based and proposed online systems of consulting medical records, the seemingly anomalous preferences of second time readers may be seen as an indication of the existence of a third parallel process. Group B tends to score higher in most of the questions regarding the use of medical records than first time readers. Group B are, however, more positive about the idea of online access than first-time readers. This can be interpreted to indicate that they are more inclined to see the benefits of accessing medical records, but as they have not yet become attached to the paper-based system, they are open to other potentially useful alternatives. As adaptive structuration theory suggests, structuration does not happen in isolation, but is influenced by the presence of a broad range of social interactions and technologies. These include other technologies (within and outside health care including the Internet, and medical literature as a quasi-technology) and social structures from a frequent interaction with health care (respondents in the regular readers group used more health care services and were more worried about their health), membership of patient associations (group C), and family and friends (difference between groups A and C).

Adaptive structuration theory also provides a framework to discuss the question of structures that are created by the three technologies and how they have been and are being appropriated. With emerging

technologies (online access to medical records) and projected expectations of how digital services should function it is apparent that some of the structures are imagined rather than actual. Even if it might be less obvious, the same also applies to the paper-based system. Patients interact with the system, but (with exceptions) cannot be expected to have an insight into the complexities of how information is produced, made available and used by other stakeholder groups.

In terms of adaptive structuration theory, medical records can be described as comprehensive (as they are supposed to contain all recorded information, with certain exceptions), but at the same time restrictive (from a patient perspective the record itself is given) and open (the use, scanning or copying, and sharing of the text on social media sites is not restricted by the system). The spirit of the system is based on a highly hierarchical configuration where patients have a right to access their own medical records, professionals have practical control over its contents, and the health care administration has the authority to make it available. Similarly, patients can be seen as groups with particular preferences for the styles of interacting with the three systems (by reading or interacting), different levels of knowledge and experience of their use and usefulness, perceptions of how others think that paper-based and online medical records and digital services should be used and appropriated for use.

Within this framework the greater significance of the control function of medical records (see Q45, Q46 in Table 1) in groups B and C could be related to how patients gradually realise and appropriate the medical record as a potential instrument of power and control. Similarly, the variation in the willingness to provide information could be seen as a sign of how a certain unspecific altruism in group A turns to scepticism in group B as to whether this would be an interesting alternative, and to realisation of the benefits of information exchange in group C. Considering the fact that members of group C are less confident about their health and more frequent users of health care services than members of the other groups, it seems likely that the process is also influenced by increasing experience of monitoring one's own health.

The diversification of the use of medical records may be seen as an example of "visible actions that evidence deeper structuration processes" (DeSanctis and Poole, 1994, p.128). In group C, respondents were more inclined to perceive the reading of medical records as a necessary premise for active participation in their care, and were less inclined to turn to their family and friends as a source of information if they could not understand the contents of their record. Their perceptions of the usefulness of the records were also more diverse than in group A. They were more interested in using it to check who had read their medical record, block access to it, and verify whether they had received proper care. They were also more inclined to keep a copy of the medical record as documentation and to believe that reading medical records improves their healthcare, communication with healthcare professionals, as well as improving their own propensity to take better care of their health. These uses may be seen as faithful or unfaithful depending on who is allowed to define the appropriate and inappropriate use of medical records. Because of the complexity of medical records discussed, for instance, by Berg and Bowker (1997), the spirit of medical records (as a technology) can be seen as a matter of perspective. From a professional point of view, it is not uncommon to perceive medical records as the property of health care staff (e.g., van der Vaart *et al.*, 2012) rather than as official documents about individual citizens that patients are allowed to consult. Advocates of patient empowerment would undoubtedly argue that all uses that indicate higher levels of taking responsibility on the part of the patient (cf. Detmer *et al.*, 2008; Ferreira *et al.*, 2007; Huber and Gillaspy, 2011; Sittig, 2002) would be faithful to the technology of medical record access whereas those who perceive the release of medical records problematic would see such uses as unfaithful (cf. Brakoulias, 2013; Davies, 2012; Delbanco *et al.*, 2010; van der Vaart *et al.*, 2012). Even if it might be tempting to see the indications of an ongoing structuration process as an argument that unconditional patient access to medical records is an unproblematic question, this interpretation fails to take into account the complexity of medical records and how they are used by stakeholders other than patients themselves. For instance, in contrast to the rather inconclusive evidence of the potential benefits of enabling patients with certain psychiatric conditions to access their medical information, Brakoulias (2013) raises a relevant question of psychiatric patients who have the potential to cause harm to their carers and whether the patients should have access to their notes or not.

The parallel structuration of medical records and their users and the paper-based and proposed online technologies can be argued to have two major implications for the development of related e-health services in the future. As observed multiple times before, legacy systems and their usefulness have an influence on the adaptation, perceived usefulness and acceptance of new systems (e.g., Venkatesh and Davis, 2000). In contrast, deep levels of structuration with legacy systems may imply unwillingness to perceive new complementary systems as useful whereas a lack of structuration may imply that patients might not have the necessary experience to see the benefits of the proposed systems. In addition to the interplay of old and

new systems, this study provides evidence that while the structuration of technical and socio-technical systems functions coincide temporally, it is a question of two parallel processes of adaptive structuration.

It is apparent that this analysis has certain limitations. The data were collected from a relatively small geographic area in Sweden and represent the views of only 354 individuals. At the same time, however, the analysis provides a range of insights into how the informants perceive medical records and prospective e-health systems. The quantitative approach does not provide an opportunity for drawing in-depth conclusions about the premises and implications of the analysed patterns. The analysis does, however, open several potential lines of inquiry that could increase our understanding of the medical record as a technology and an information artefact, how it is appropriated by different groups of patients and what differences exist between different methods of providing access to the records.

Conclusions

People choose to access their medical records for a broad variety of reasons. This study shows that there are significant differences between the groups of patients who ordered a copy of their medical record for the first time and those who had ordered it once or multiple times before. The anticipated impacts of the opportunity to access medical records online also vary between these groups.

We argue that in addition to individual demographic and behavioural factors, some of the observed variations in the data can be explained in terms of the adaptive structuration theory as a result of a parallel structuration of patients, medical records and the paper-based and online technologies of access. This study shows that individuals who have ordered a copy of their medical records previously perceive their usefulness in broader terms than first time readers. Regular readers are most concerned about their health and quality of care. Even though it could be expected that the group that has ordered a copy of their medical records multiple times would benefit most from online access to their records, the analysis shows that the group of second time readers had the most positive attitude towards such a service. From this perspective, it would seem relevant to be attentive to the wants and needs of patients in the middle of the structuration process i.e., those who have experience of how the legacy access to medical records works, but with whom the level of appropriation does not indicate a full commitment to the old system. They can be expected to have an idea of what they might need and want, but are unlikely to see the paper-based system as the only possible option. The number of interactions with legacy systems could function as a possibly proxy for estimating the level of structuration.

It is obvious that this finding does not negate the relevance of listening to the needs and wants of regular readers who may be thought to have deeper insights into medical records as an informational technology. It can, however, complement their views, which may be expected to be focused on the problems and affordances of the legacy system and to a lesser extent on the opportunities of developing new solutions. It is obvious that the experience or the phase of structuration is not the only variable that needs to be taken into account (others could plausibly be the type of condition of the patient, motivations for reading medical records and demographic factors that correlate with reading) when developing new systems, but it seems to be one that has been largely omitted in the earlier literature.

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Appendix 1

	Question	n	Mean	Standard deviation	Variance
Content of the medical record					
Q1	I understood most of the content of the medical record.	338	4.30	0.879	0.773
Q2	I understood the parts of the medical record that I was interested in.	297	4.43	0.807	0.651
Reasons for ordering a copy of my medical record					

Q3	General interest	267	3.22	1.673	2.799
Q4	To get an overview of my health/condition	290	3.94	1.512	2.287
Q5	To check/verify some details	277	3.59	1.623	2.634
Q6	Because I was unsure whether I received correct treatment	266	2.33	1.582	2.503
Q7	To follow up on what was said during my last visit	270	2.99	1.647	2.714
Q8	To provide information for another health care provider.	270	2.01	1.553	2.413
Q9	I need the information to apply for insurance	262	1.43	1.055	1.112
Q10	To get information for contact with the Swedish Social Insurance Agency	256	1.40	0.953	0.908
Q11	To involve my family members in my care.	257	1.66	1.202	1.445
What would you do if you did not understand something in the record text?					
Q12	Ask health care staff using the telephone.	290	3.18	1.554	2.415
Q13	Ask health care staff during my next visit.	289	3.74	1.440	2.073
Q14	Ask a person with knowledge of health care. e.g., using a 24/7 telephone counselling service.	268	2.61	1.476	2.179
Q15	Contact the health care professionals I usually contact using online channels (e.g., by secure email)	262	2.15	1.337	1.787
Q16	Ask a family member or a friend	267	3.09	1.509	2.278
Q17	Ask a health care professional I know personally. either in my family or among my friends.	270	3.44	1.499	2.247
Q18	Seek information by myself e.g., on the Internet.	279	3.92	1.374	1.889
Q19	Use social media such as a discussion forum or Facebook to get help.	263	1.54	0.915	0.837
Q20	Ask someone to help me to translate the record from Swedish to my own language.	254	1.27	0.755	0.570
What it means to you to be able to read you own medical record					
Q21	It improves communication between me and health care professionals	294	3.90	1.228	1.509
Q22	It leads to improvement in the care I receive.	285	3.60	1.273	1.621
Q23	I will be able to understand my health/condition better.	301	4.02	1.185	1.403
Q24	I will take better care of my health.	282	3.33	1.277	1.631
Q25	It is necessary for me to actively participate in my health care.	288	3.76	1.291	1.667
Q26	I will keep the medical record for my own records.	283	3.90	1.336	1.785
Q27	I am distrustful of health care.	268	2.15	1.366	1.865
General questions about an online access service to personal medical records					
Q28	It is a very good idea to be able to read medical records online (similarly to how I can manage my bank accounts online).	337	4.10	1.253	1.571
Q29	I am generally worried of the security of the service.	311	3.06	1.451	2.106
Q30	I am worried that the medical records are not managed securely enough in health care information systems if they can be read online.	311	3.18	1.422	2.023
Q31	I am worried that the service will be too difficult to use.	301	2.23	1.259	1.584
Q32	I am not so interested in my medical record that I would read it online.	292	2.17	1.298	1.684
Q33	I do not want to read my medical record online. only personally discuss with health care professionals.	296	2.15	1.376	1.892
It would be useful to have access to the following information services based on the information found in your medical record:					
Q34	Letters of referral (content and how they are processed by heath care providers)	313	4.36	1.041	1.083
Q35	List of all my medications	315	4.34	1.113	1.238
Q36	Overview of my vaccinations	311	4.53	0.946	0.895
Q37	Test results directly after tests have been conducted	324	4.46	1.030	1.060
Q38	Overview of all contact with health care together with the ability to read the entire medical record	314	4.39	1.024	1.049

Q39	Ability to manage and order medical certificates	310	4.27	1.113	1.239
Q40	Ability to report errors in my medical record.	312	4.11	1.191	1.418
Q41	Ability to write my own comments in the text of the record.	303	3.49	1.393	1.939
Q42	Ability to provide information about my own health (e.g., to submit a health declaration [obligatory in Sweden] before each visit).	306	4.00	1.168	1.364
Q43	Ability to provide information e.g., by reporting self-test results taken at home.	303	3.62	1.334	1.779
Q44	Ability to contact health care professionals online and to ask questions about the content of my medical record.	310	4.02	1.253	1.569
Q45	Ability to block parts of my medical record from being accessed by other health care staff (who did not write them).	308	3.69	1.360	1.850
Q46	Ability to see which health care units and categories of staff have read and written in my medical record.	313	4.23	1.186	1.407
Q47	Ability to manage services for my children (e.g., letters of referral. vaccinations and medication lists).	296	3.97	1.312	1.721
Q48	Ability to manage services for elderly family members (e.g., letters of referral. vaccinations and medication lists).	294	3.94	1.312	1.720
Q49	Ability to manage services for other people (e.g., letters of referral. vaccinations and medication lists).	289	2.99	1.537	2.361
Questions about health					
Q50	My health is very good.	315	3.66	1.307	1.709
Q51	I am very worried about my health.	296	2.63	1.399	1.957
Q52	I often think about my health.	292	3.51	1.203	1.447
Health information behaviour					
Q53	I like to communicate with medical doctors using email.	324	3.22	1.651	2.724
Q54	The Internet is a very important source of health information for me.	320	3.55	1.461	2.136
Q55	I use a lot of social media services for health information matters (e.g.. discussion forums. Facebook. Twitter).	313	1.61	1.084	1.175

Table 1: Descriptive statistics of questions on 5-point Likert-like scale.

Dependent variable	Groups		Mean difference (I-J)	Significance
Content of the medical record				
Q4 To get an overview of my health or condition	A	B	-0.076	0.987
		C	-0.770*	0.000
	B	A	0.076	0.987
		C	-0.694*	0.028
	C	A	**0.770***	0.000
		B	**0.694***	0.028
Q5 To check or verify some details	A	B	0.067	0.993
		C	-0.864*	0.000
	B	A	-0.067	0.993
		C	-0.931*	0.006
	C	A	**0.864***	0.000
		B	**0.931***	0.006
Q6 Because I was unsure whether I received correct treatment	A	B	-0.339	0.487
		C	-0.880*	0.002
	B	A	0.339	0.487
		C	-0.541	0.255
	C	A	**0.880***	0.002
		B	0.541	0.255
Q7 To follow up on what was said during my last visit	A	B	-0.110	0.971
		C	-1.127*	0.000
	B	A	0.110	0.971
		C	-1.018*	0.003

		C	A	**1.127***	0.000
			B	**1.018***	0.003

What would you do if you did not understand something in the record text?

Q16	Ask a family member or a friend	A	B	-0.192	0.789
			C	**0.725***	0.009
		B	A	0.192	0.789
			C	**0.917***	0.005
		C	A	-0.725*	0.009
			B	-0.917*	0.005

What it means to you to be able to read your own medical record

Q21	It improves communication between me and health care professionals	A	B	-0.294	0.393
			C	-0.662*	0.000
		B	A	0.294	0.393
			C	-0.368	0.281
		C	A	**0.662***	0.000
			B	0.368	0.281
Q22	It leads to improvement in the care I receive.	A	B	-0.230	0.585
			C	-0.660*	0.001
		B	A	0.230	0.585
			C	-0.430	0.177
		C	A	**0.660***	0.001
			B	0.430	0.177
Q24	I will take better care of my health.	A	B	-0.093	0.960
			C	-0.591*	0.003
		B	A	0.093	0.960
			C	-0.497	0.106
		C	A	**0.591***	0.003
			B	0.497	0.106
Q25	It is necessary for me to actively participate in my health care.	A	B	-0.173	0.813
			C	-0.855*	0.000
		B	A	0.173	0.813
			C	-0.682*	0.008
		C	A	**0.855***	0.000
			B	**0.682***	0.008
Q26	I will keep the medical record for my own records.	A	B	-0.365	0.200
			C	-0.555*	0.014
		B	A	0.365	0.200
			C	-0.190	0.796
		C	A	**0.555***	0.014
			B	0.190	0.796
Q27	I am distrustful of health care.	A	B	-0.293	0.469
			C	-0.732*	0.003
		B	A	0.293	0.469
			C	-0.439	0.309
		C	A	**0.732***	0.003
			B	0.439	0.309

Table 2: Medical use and preferences. Analysis of variance between groups A (never ordered a copy of medical record before), B (had ordered once) and C (had ordered multiple times).

	Dependent variable	Groups		Mean difference (I -J)	Significance
	General questions about an online access service to personal medical records				
Q28	It is a very good idea to be able to read medical records online (similarly to how I can manage my bank accounts online).	A	B	-0.294	0.145
			C	0.287	0.385
		B	A	0.294	0.145
			C	**0.581***	0.022
		C	A	-0.287	0.385
			B	-0.581*	0.022
Q33	I do not want to read my medical record online, only personally discuss with health care professionals.	A	B	**0.462***	0.042
			C	0.055	0.992
		B	A	-0.462*	0.042
			C	-0.406	0.265
		C	A	-0.055	0.992

	Dependent variable	Groups		Mean difference (I-J)	Significance
			B	0.406	0.265
It would be useful to have access to the following information services based on the information found in your medical record:					
Q43	Ability to provide information e.g., by reporting self-test results taken at home.	A	B	0.267	0.442
			C	-0.324	0.230
		B	A	-0.267	0.442
			C	-0.591*	0.031
		C	A	0.324	0.230
			B	**0.591***	0.031
Q45	Ability to block parts of my medical record from other healthcare staff (who did not write them).	A	B	-0.281	0.401
			C	-0.535*	0.010
		B	A	0.281	0.401
			C	-0.254	0.578
		C	A	**0.535***	0.010
			B	0.254	0.578
Q46	Ability to see which health care units and categories of staff have read and written in my medical record.	A	B	-0.234	0.475
			C	-0.360*	0.045
		B	A	0.234	0.475
			C	-0.127	0.881
		C	A	0.360*	0.045
			B	0.127	0.881
Questions about an online access service to personal medical records					
Q56	How often do you think you would use such a service?	A	B	-0.394*	0.008
			C	-0.153	0.696
		B	A	**0.394***	0.008
			C	0.240	0.418
		C	A	0.153	0.696
			B	-0.240	0.418

Table 3: Online access to medical records and e-health services. Analysis of variance between groups A (never ordered a copy of medical record before), B (had ordered once) and C (had ordered multiple times).

	Dependent variable	Groups		Mean difference (I-J)	Significance
Questions about health					
Q51	I am very worried about my health.	A	B	0.387	0.109
			C	**0.912***	0.000
		B	A	-0.387	0.109
			C	0.525	0.076
		C	A	-0.912*	0.000
			B	-0.525	0.076
Q52	I often think about my health.	A	B	-0.207	0.680
			C	-0.750*	0.001
		B	A	0.207	0.680
			C	-0.542	0.072
		C	A	**0.750***	0.001
			B	0.542	0.072
Health behaviour					
Q57	Number of health care professionals consulted during the last twelve months	A	B	-0.268	0.868
			C	-3.236*	0.008
		B	A	0.268	0.868
			C	-2.967*	0.020
		C	A	**3.236***	0.008
Q58	I visit health care approximately: 1=Several times in month, 2=monthly, 3=quarterly, 4=twice a year, 5=yearly, 6=less than yearly	A	B	**0.518***	0.020
			C	**0.950***	0.000
		B	A	-0.518*	0.020
			C	0.432	0.137
		C	A	-0.950*	0.000
			B	-0.432	0.137
General questions					
Q59	Year of birth	A	B	1.265	0.939
			C	**6.103***	0.014
		B	A	-1.265	0.939
			C	4.838	0.215

		C	A	-6.103*	0.014
			B	-4.838	0.215
Q60	How much time do you spend using computers each day: 1=not at all, 2= less than one hour, 3=between one and three hours, 4=more than three hours	A	B	-0.134	0.650
			C	0.268	0.107
		B	A	0.134	0.650
			C	**0.402***	0.031
		C	A	-0.268	0.107
			B	-0.402*	0.031

Table 4: Health, health behaviour and socio-economic characteristics.

5 4 Last updated: 20 February, 2016