Patient Accessible EHR is Controversial:
Lack of Knowledge and Diverse Perceptions Among Professions

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ABSTRACT

In Sweden, a national eHealth service providing Patient Accessible Electronic Health Records is now being widely deployed, with 400 000 users in January 2016. Although the Patient Data Act states that patients have a right to take part of their health records, the introduction has been controversial. Results from a pre-deployment questionnaire to record-keeping care professions in a healthcare region indicate that perceptions and knowledge differ not only between the professions but, more importantly, that knowledge about current eHealth development and action plans needs to increase as implementation will affect their work processes. Staff perceptions and knowledge are considered being some of the most important issues to handle during the implementation of eHealth services aiming to provide healthcare information and communication tools for patients and relatives. To cover the gaps, specific training is needed, and all record-keeping professionals need to be more involved in the implementation of such eHealth services.

KEYWORDS

INTRODUCTION

The number of eHealth services for patients and relatives is rapidly increasing as many countries are launching such services as a means to manage an ageing population, to increase efficiency in healthcare, and to empower patients. One of these services is the patients' online access to their own EHR (Delbanco, Walker, Darer, Elmore & Feldman 2010). Patient accessible electronic health records (PAEHRs) enable patients to access and sometimes also manage personal health information that is made available to them by their healthcare providers. It is thought that the shared management nature of medical record access improves patient outcomes and patient satisfaction (Jilka, Callahan, Sevdalis, Mayer, & Darzi, 2015). However, direct access to a health record of a patient is not seen as entirely positive. In the current debate, a discrepancy is noted between legislation, policies and decision ambitions versus the care professionals' preferences and knowledge regarding the issue.

In the case of the Swedish eHealth service "Journalen", a national study points out that healthcare professionals did not favor the reform (Scandurra, Jansson, Forsberg-Fransson & Ålander, 2015). They expressed concerns in relation to their work environment (e.g. anticipation of increased workload), that patients would mostly be worried by reading their health records and that such service would be of little value for the patient (Grünloh, Cajander & Myreteg, 2016, Scandurra et al., 2015). Consequently, the adoption of these services by healthcare professionals have often not been as successful as anticipated by politicians and vendors (de Luisignan et al., 2013) and to date, services aiming to provide healthcare information and communication tools for patients and relatives do not always provide the expected effect (Erlingsdottir & Lindholm, 2014).

Patients, on the other side, want to communicate and interact more with their healthcare provider, which can be facilitated and streamlined by information technology (Pagliari, Shand & Fischer, 2012). Patients also often strive to manage their own health and illnesses and want to find ways to get copies of their electronic health records (EHRs); to share with their physicians, load into apps, submit to researchers, link to their genomic data, or have it on hand just in case (Mandl & Kohane, 2016).

Aware of the discrepancy of ideas and the controversy during the development in the Swedish pilot county (Lyttkens, 2015) this paper aims to investigate knowledge and perceptions among different healthcare professions in a region that not yet has deployed the service. The outcome of this study may also support practice in targeting activities to the staff in order to facilitate the implementation and acceptance of the service.

Research Rationale

Physicians have traditionally regarded the health record as a tool for themselves and other healthcare professionals (Grühnloh et al., 2016), while patient representatives have argued that patients should own their own information (Docteur & Coulter 2012). Docteur and Coulter (2012) reported that patients had a difficulty in getting access to their own health records, due to records not being available electronically, and that healthcare providers could be slow and reluctant in responding to patient requests for disclosure of record copies (Docteur & Coulter, 2012, p. 74).

This handling is opposite towards the Swedish legislation: Patients have the right to take part of their health records, dating back more than 60 years, and information shall be submitted as soon as possible Moreover, health records should be written in the Swedish language and clearly designed so they are understandable to patients (Patient Data Act, 2008). Another study examined the approach of physicians to documentation (Allvin & Kvist, 2011). One-third of 139 physicians responded to the survey. All but one respondent replied that they wrote the documentation "to a very large extent" to their colleagues. Regarding writing to the patient, the same amount of physicians replied "to a very low extent" as "to a very high extent." The article concluded e.g. that physicians rarely or never adapt record documentation to the patient (Allvin & Kvist, 2011).

The controversy of PAEHRs has been discussed from different research perspectives, sometimes based on organizational theory. Being a multidisciplinary arena and a complex "professional organization", other players have difficulties to control the clinical professionals (Hallin & Siverbo, 2003, p. 187). This is partly due to the fact that appreciation of the colleagues is more fundamental to the professional than to get an acceptance by management (Thylefors, 2007, p. 53-54). When the eHealth services are to be implemented in the healthcare context, organizational theory by e.g. Mintzberg (1992) and Söderström (2005) regarding clarification on how multi-cultural professional organizations work, could provide guidance in how the implementation should be performed. To gain knowledge of further implementation, preferences and knowledge of healthcare professionals in this pre-deployment study are discussed in the light of these concepts.

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