

Evolving relations between the practices of nurses and patients and a new patient portal

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Abstract. The paper offers preliminary reflections on a patient portal that is part of a global digital infrastructure – an EHR - currently being implemented at 18 hospitals in two of the five Danish regions covering more than half of the population. We focus on the evolving relations between the technology and the practices of nurses and patients in a rehabilitation program after a blood clot, with a specific interest in how the rehabilitation infrastructure promotes clinical governance and patient empowerment. Our analytical lens is that of patient empowerment, understood broadly as the patient's capacity for and experience of self-care within the infrastructure. This, we contend, may be seen as a specific and increasingly important aspect of clinical governance.

Introduction

Infrastructures in healthcare have traditionally served the double purpose of 1) supporting clinicians in their daily practices and 2) being the basis for the practices of managers and researchers through primary or secondary use of data generated in the former practices.

This secondary use of data supports governance in the health sector. In recent years clinical governance has grown in importance due to the rapid changes in the economic, legal and technological developments around healthcare organisations. The fundamental assumptions behind clinical governance originate from the field of corporate governance, with an explicit interest in securing cost-effectiveness, efficiency, quality and safety in healthcare services, but there are also differences in their focus as clinical governance is associated more closely with the ward,

unit, department, health centre and clinic (Braithwaite & Travaglia, 2008). Bodolica and Spraggon (2014) states that clinical governance is a top-down approach to develop and improve the system of healthcare delivery. It can be defined as macro-level governance and refers to the creation of “appropriate infrastructures for integrated clinical governance initiative aiming at elimination medical failures, minimizing costs, and boosting the efficacy of service delivery” (Bodolica and Spraggon, 2014, p. 187). However, Bodolica and Spraggon claim the need for including micro-level processes in order to enhance the effectiveness of the macro-level initiatives. Micro-level are the processes “...related to different tools monitoring the relationship between the medical staff and the consumer of care...” and are labelled as “relational governance” (ibid, p. 192, 194). The micro-level therefore includes the work done by patients in relation to the clinician, but also in relation to the technological infrastructure as such. Citizens, patients and relatives are to an increasing degree included as new types of users and stakeholders of such infrastructural arrangements for the purpose of improved patient experience and outcome, or for “out-sourcing” to them what for a long time has been tasks and responsibilities of clinicians.

Patients’ infrastructuring work may be described using the vocabulary of self-tracking. In the self-tracking literature, new forms of patient-driven monitoring of health issues through the use of IT have been celebrated for empowering the patient in the medical system (Hansen, 2012; Swan, 2009). Indeed, having access to one’s medical trajectory is seen to enable ‘self-care’ and engaging the self-monitoring individual in para-clinical practices (Greenfield, 2016). This has the potential to destabilise the institutional arrangements and expert regimes in the medical sector. But the idea of self-care also potentially shifts the responsibility for the patient’s health, diagnosis and treatment from the medical professionals and the system to the individual patient (Lupton, 2013; Wang et al., 2014). This shift, in turn, ties in with questions about governance and governmentality. Subsuming the individual patient to the logic of self-care, patient treatment costs are allegedly lowered, thereby ensuring a more efficient and lean health care system.

In this paper, we present a case study of Danish heart patients’ experience and practice of using MY HEALTH PLATFORM (MHP) as part of their medical treatment and rehabilitation for e.g. communication and self-tracking purposes. Our overall research questions include: In what ways do patients feel empowered and experience MHP as involving a shift in responsibility towards self-care? What are the possibilities and pitfalls for patient empowerment that may be taken into account in the future development of the infrastructure?

MHP is part of a larger infrastructural arrangement, THE HEALTH PLATFORM, the main parts of which are the usual EHR modules for clinicians’ notes, lab tests, ordering, and medication. We see it as a *glocal* digital infrastructure as it is developed for *global* usage, and as it has to be adapted to the

local technical and organizational infrastructures in each of the healthcare provider organizations that buy it. It is intended to serve local, clinical interests while simultaneously enabling regional integration and management of the health care system in The Capital Region of Denmark and Region Zealand.

In turn THE HEALTH PLATFORM is part of yet a larger infrastructural arrangement including e.g. clinical databases, nationwide registers and sundhed.dk. The latter “is the official portal for the public Danish Healthcare Services and enables citizens and healthcare professionals to find information and communicate. The portal facilitates patient-centred digital services that provide access to and information about the Danish healthcare services.” (sundhed.dk, 2017). Hence, there is some overlap between sundhed.dk and MHP.

Part of the political vision for MHP is to digitally include and engage patients in their own treatment and care processes. From a governance perspective, the digital infrastructure is seen as a way of enhancing patient involvement and participation. It is envisioned to facilitate *patient empowerment* through access to parts of the clinicians’ notes and tests results, communication with clinicians, managing appointments at the local hospital etc. It is not designed and marketed as a tool for patients’ self-management or self-tracking, but it allows for some of the same kinds of information processing and communication that is typically implied in such health care apps and services.

Yet, vision and practice often fail to connect, as witnessed by decades of scholarship into the potentials and actual realizations of IT across domains. We analyse the experienced potentials and barriers as gleaned from current uses of MHP from the patient’s viewpoint at this very early stage in the implementation of this glocal digital infrastructure in Danish healthcare practice.

Research setting and method

In this paper, we focus on rehabilitation as it is practiced at one clinic at the first hospital to implement and adapt the new system. Patients, who have been recently discharged after being treated for a blood clot, are offered consultations with a rehabilitation nurse. Every 6 weeks during a 3 months period a patient sees the nurse for ½ to 1 hour. An overall guide for the rehabilitation sessions stresses the importance of patient involvement throughout and beyond the rehabilitation period.

This preliminary study involved 5 patients and 3 nurses over a period of 9 months. Data was gathered through artifact and document analysis, and recorded and transcribed interviews and observations in patients’ homes and in nurses’ offices before, during and after these consultations.

We approach the data through our main analytical concept, patient empowerment, which is a broad term for the processes, structures and relationships that can strengthen a patient’s agency and improve quality of life

(e.g. Piper, 2010). However, if empowerment is both a process and an outcome we mainly focus our analysis on the process, meaning the ways in which patients are engaged in the infrastructural arrangement around rehabilitation. Specifically, we study the consultation between the nurse and the patient and the patients' information practices in-between the consultations, asking: 1) What *information* is sought for and exchanged in the situation, 2) how it is *communicated*, and 3) to what extent does it equip the patient to *act* in terms of self-care and self-management through MHP throughout the rehabilitation process, see e.g. Jensen (2010).

Preliminary findings

In the following, we briefly present our preliminary findings on how the platform is actually used as an infrastructure for information, communication and action by the rehabilitation patients, in order to elicit its potentials and pitfalls for enabling self-care and thus, empowerment and governance of the patient.

Information

The nurse mainly lets the patient decide the themes for the consultation. However, she sees to that the patient get an orientation about the rehabilitation program, learns about the heart, blood cloth, and what might be done about it. Furthermore, she asks for information that she has to type into The Health Platform, for her own use and for other involved personnel at the hospital and in the municipality that may take over when she is done with the patient.

The main part however, takes the form of counseling - emphatic listening to the patient' concerns while zooming in on what might be relevant for this patient. Issues dealt with include: Mental reactions, job and family situation, medication and helpful changes in lifestyle. Also the nurses taking part in this study make sure that the patient is informed about MHP, and how that may be used.

Yet, while the rehabilitation meeting covers a variety of aspects and aims to provide clarity about the patient's treatment, progress, feelings and further activities, there may be gaps between the experience of clarity *in* and *after* the meeting. As one patient notes on the experience of leaving a rehabilitation meeting: "...you think you have thought things through, but then this insecurity comes" The same patient envisions MHP as a possible relief of this insecurity: "It would be great if I could look up my treatment plan. In the clinicians notes I can read what they consider my treatment plan, but it needs to be presented differently for me to understand."

The preliminary results indicate that patients have certain expectations about being informed by the hospital, doctors or nurses on issues of relevance regarding

their illness and/or treatment. Especially they request that information regarding their treatment e.g. treatment plans or overviews of medication, are *pushed* in their direction through the MHP. The patients express an interest in accessing information about their physical state e.g. some patients would like access to x-ray pictures, while all the patients looked up results from blood samples or other clinical tests. But they are also aware that this information is disseminated to the patient as the end-user, and that it often requires medical knowledge to interpret.

Communication

Our data suggest that MHP plays a very marginal role in the infrastructuring of the process of rehabilitation, at least for the patients. Although this is likely a result of the research taking place in the platform's early implementation phase, where this part of the system has not been given much attention from management and implementers, it is somewhat surprising. The rehabilitation process implies very episodic, though systematic, contact between the patient and the health care system/the clinician (once, every six weeks), and MHP has the potential to compensate for the low frequency of ongoing monitoring by facilitating mediated, asynchronous contact at times of the day suitable for the patient and clinician in the form of registration of symptoms and wellbeing, progress, consultation about medication etc.

While the patients value the conversations with the nurse, these meetings are fixed in time and space. A patient expresses that he would like the infrastructure to support a more 'ongoing' communication, e.g., the opportunity to pose questions on-line to nurses or doctors about diagnoses or medical treatment when they occur in the patient's daily rehabilitation work. While the nurses do inform patients about this feature in MHP, few patients make use of it so far.

Action

Patients may request various information as well as show interest in different ways of communicating about their rehabilitation. Yet, it does not necessarily mean that they to a greater extent want to be actively engaged and given responsibility for their own treatment. We found that the "drive" for empowerment through self-care is contradicted by most patients being comfortable by leaving decision making and management of their disease to the health care professionals, as also noted in Piper (2010, p. 174).

However, an important part of the rehabilitation program is that nurses make patients aware of the actions they need to do themselves e.g. in relation to diet, exercise, alcohol, and smoking. Some patients are starting to see the system as an

enabler for monitoring the effects of such self-care activities. E.g. monitoring the relations between diet changes and results from blood tests.

Discussion

So far patients have limited knowledge about the system's information and communicative options. It may not in its present form support answers to their questions and reduce their insecurity about their illness and its treatment. Therefore it does not offer them a real point of departure for actively engaging themselves in the rehabilitation process.

In terms of governance, the infrastructure thus appears mainly directed towards the clinicians – enabling, supporting but also monitoring their work practices.

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