Building Continents of Knowledge in Oceans of Data: The Future of Co-Created eHealth
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Developing an eHealth Tool to Support Patient Empowerment at Home

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Abstract: In previous research we have learned that patients with chronic or complex diseases often experience difficulties when transitioning from hospital care to self-care in their home. We address these difficulties by developing an eHealth tool for patients – ePATH (electronic Patient Activation in Treatment at Home) – intended to empower each patient to manage their individual situation. We have employed a user-centered design process involving both patients and healthcare personnel to specify the content and functionality of ePATH. The system is deployed as a web application with secure login for patients. In this article, we describe the main content and functionality of the system that makes it possible for a patient to manage symptoms development in relation to treatment progression Interactive functionality, e.g., reminders and social support, is included to make the ePATH a useful and informative bridge between patients, next-of-kin and different caregivers. One lesson learned is that it is necessary to incorporate motivational components in the development of an eHealth tool to successfully overcome the “intention-behavior” gap. The self-determination theory of motivation can be used to ensure that important aspects are not missed.

Keywords: transitions in care; patient participation; personalized care; eHealth; user-centered design

Introduction

The global burden of non-communicable diseases (NCDs), including heart disease, stroke, cancer, diabetes and chronic lung disease, is rapidly increasing. In Sweden, 60-70% of people older than 75 years have three or more concurrent diagnoses in their medical records and have been hospitalized three or more times in the last 12 months [1]. Although patients with NCDs are frequent users of healthcare resources, they spend the majority of their time outside the hospital, managing their symptoms and complex medication regimens on their own. Management of care at home includes several tasks, such as handling medication, monitoring symptoms, and the physical, emotional and psychosocial consequences of having a NCD. It also includes the tasks of coordinating care and transferring information between specialized care and primary care [2]. Several studies including our own [3] have shown that patients are not adequately prepared to handle their self-management at home. There is evidence

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indicating that web-based interventions can improve self-management and patient empowerment [4]. However, to be effective, web solutions should include multifaceted components aimed at enhancing patients' capacity for self-care [5].

Drawing on our own and related research on care transitions and eHealth tools developed for more specific settings, we have developed a prototype eHealth tool that aims to empower patients when transitioning through their healthcare trajectories and managing their chronic conditions or postoperative symptoms at home. In future, we believe that the prototype may inform the specification of more generic design principles for patient self-care, supporting people with NCDs to navigate their care trajectory and perform their self-care activities at home. This paper reports on the lessons learned during the initial phases of the development process.

1. Methods

The multidisciplinary research team has applied a user-centered design process (based on the ISO standard of "Human-centered design for interactive systems") that involved patients with prostate cancer and healthcare personnel in iterative design cycles [6]. Sweden has a standardized care plan for prostate cancer and professionals' work processes are relatively well defined. Nevertheless, most patients experience distressing symptoms post-treatment (e.g. fatigue, urinary leakage, and erectile dysfunction) for which self-care activities are required during several months to reduce the risk of chronicity.

Initially, three group interviews with a multidisciplinary team of professionals at a county hospital in southern Sweden were performed to map prostate cancer patients' care trajectories through the healthcare system. This included identification of typical obstacles or common questions that patients raise during treatment and healthcare professionals' initial thoughts on how an eHealth tool could be used. Three semi-structured interviews with prostate cancer patients recruited through an urotherapist at the hospital were conducted. The patients were 68-76 years old, had received their prostate cancer diagnosis one to two years earlier, and had been treated with radical prostatectomy. The interviews were focused on experiences of their care trajectory from diagnosis and treatment trough transitioning from hospital to home; information they found missing or useful; and experiences of handling post-operative symptoms at home.

All interviews were audio-recorded, transcribed verbatim and analyzed using qualitative content analysis [7]. Results from the analysis have fed into the iterative design work of specifying the eHealth tool. A patient journey map visualizing the patient's care trajectory, information needs, and touch points with different stakeholders was created to determine where an eHealth tool could provide most value to patients [8]. The development of the eHealth tool progressed from initial design mockups to low fidelity prototypes and finally a functional web application.

2. Lessons learned

The design process resulted in a functional prototype that captures patient needs and also emphasizes the need of integration with the care processes of healthcare providers.

A two-way communication tool for information exchange between patient and healthcare was developed.

2.1. *The four basic pillars – information needs*

Our input values in the beginning of the research project were that the eHealth tool should present information on 1) the patient's planned self-care activities, 2) medication management, 3) health and symptom tracking, and 4) contact information to caregivers. This information constitutes four basic pillars on which an eHealth tool can be developed. Our interviews with both personnel and patients, confirmed that this set of basic information is important to present to patients, as more knowledge about their condition and treatment may relieve patients from some anxiety about the future.

We learned that although information was provided, and patients were assigned a personal nurse coordinator, they were not always fully aware of what symptoms to expect after treatment and how they could work on ameliorating them. Therefore, once they were at home, patients often found it difficult to motivate themselves to actually perform the recommended self-care activities to reduce the post-operative symptoms.

2.2. *The fifth pillar – social support*

All patients mentioned the importance of having social support, from the time of diagnosis, through treatment and beyond. The patients also mentioned that their partners were as informed about the disease and treatment as the patients themselves and had been a great support during this difficult time. One patient described the importance of "peer patients", as he could relate to their experiences. He believed that a forum where he could share and "normalize" his experiences would have been beneficial even early in his cancer care trajectory. On the same note, one patient got a diary of his brother's prostate cancer experience, written by his brother's wife. The patient who read the diary, written in a factual style, often felt well prepared for his encounters, and he believed that the diary had helped him a lot.

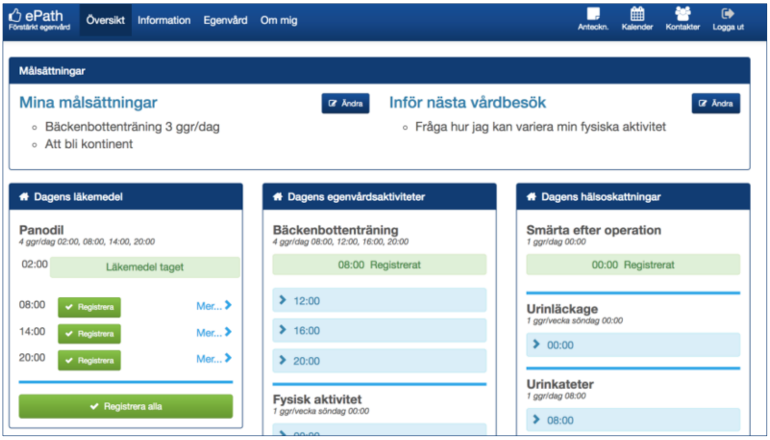
2.3. *A tool for interactivity and motivational support*

We experienced the power of using simple prototypes of the eHealth tool (sketches), to communicate early, conceptual ideas to personnel and patients. It was an eye-opener for personnel to be shown early design ideas, and they immediately started thinking about how it would impact their daily work. For example, how the use of an eHealth tool could support collaboration between different clinics (e.g. surgery and oncology) which would improve communication and handovers of patients during treatment. Patients, in turn, recognized the benefit of having diagnosis-specific information and healthcare contacts gathered in a single tool. One patient said that access to such a tool might have motivated him to sustain his postoperative training which might have prevented his chronic urinary incontinence.

2.4. *Conceptual design of the eHealth tool*

After several design iterations using low-fi prototypes that were discussed with healthcare personnel and patients, we have implemented our design ideas for the eHealth tool (electronic Patient Activation in Treatment at Home - ePATH) in a web application. Figure 1 illustrates the start page that the patient sees upon login to ePATH. It contains an overview of the patient's set goals and all the planned medications, activities, health and symptom tracking for the current day. Self-care activities, as well as health and symptoms can be registered using self-assessment questionnaires. All registrations can also be done directly from a mobile application (mPATH) that communicates with the web application. Selected data will be aggregated and illustrated as graphs (not shown), allowing the patient to see how their health progresses over time. The graphic overview may have an educational and motivational effect, as it helps the patient to detect patterns and understand relationships between his health status and self-care exercises over time.

The navigation panel allows the patient to navigate to different more detailed views presenting diagnosis specific information that has been selected based on the patient's individual needs, as well as information and guidance on self-care activities, medications, and health and symptom tracking. The patient also has a section to write their private diary and notes. Furthermore, ePATH contains contact information to the patient's healthcare contacts and clinics, and a messaging service for sending short text messages to dedicated healthcare contacts.



Mina målsättningar
- Bäckenbottenträning 3 ggr/dag
- Att bli kontinent

Inför nästa vårdbesök
- Fråga hur jag kan variera min fysiska aktivitet

Panodil
4 ggr/dag 02:00, 08:00, 14:00, 20:00
02:00 Läkemedel taget
08:00
14:00
20:00

Bäckenbottenträning
4 ggr/dag 08:00, 12:00, 16:00, 20:00
08:00 Registrerat
12:00
16:00
20:00

Fysisk aktivitet
1 ggr/vecka söndag 00:00

Smärta efter operation
1 ggr/dag 00:00
00:00 Registrerat

Urinläckage
1 ggr/vecka söndag 00:00
00:00

Urinkateter
1 ggr/dag 08:00
08:00

Figure 1. A section of the start page that is presented to the patient upon login to ePATH – shows an overview and allows patient to register planned activities of the current day.

4. Discussion

The main value of eHealth is to provide content and functionality that will drive patient empowerment to effective self-management. The pillars of ePATH can be analyzed on the basis of the self-determination theory, a general theory of motivation which posits that all persons have three basic psychological needs: autonomy, competence and relatedness [9]. Research has shown that the use of a pedometer, for example, can support patients' feeling of autonomy, competence and relatedness, and thereby motivate them to engage in physical activity [10]. Similarly, ePATH can support motivation by putting relevant care-related information in the hands of the patient, and remind the patient to take medication, perform self-care activities and to track symptoms and health. The patient can learn about the diagnosis and treatment and discuss symptoms development with healthcare personnel, or show their next-of-kin personal information and planned encounters. These features support both patient *autonomy* and *competence* [9]. Patients with complex and/or chronic diseases often receive support from several people: healthcare personnel, next-of-kin, and peer patients, which help to motivate them during treatment as well as in coping with chronic conditions. This social support – enabling patients to connect with others (e.g., next-of-kin, peer patients, healthcare personnel) – is essential to getting patients motivated in their own treatment. Through this, the *relatedness* aspect, the need to feel connected and cared of by others, can be supported.

From a healthcare point-of-view, ePATH makes it possible for personnel to get a better understanding of symptoms development related to medication adherence as well as other factors such as patients' self-care activities, based on patients' self-registered data. This could open up for new ways of collaboration through more frequent, flexible and needs-based contacts between healthcare personnel and patient, without the patient having to come to the hospital. Furthermore, ePATH could be a tool to bridge communication and information gaps in the continuity of care in a complex healthcare system, where multiple caregivers are involved in a single patient's care [11]. The tool can thus be passed as a baton between entities that may not have integrated medical records, where information must be transferred manually.

The main lesson learned is that it is necessary to incorporate motivational components in the development of an eHealth tool to successfully overcome the "intention-behavior" gap and form new and lasting self-management behavior. The basic psychological needs of autonomy, competence and relatedness included in the self-determination theory of motivation can be used as a guiding theory to ensure that important aspects are not missed.

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