Digital Healthcare Empowering Europeans
R. Cornet et al. (Eds.)

doi:10.3233/978-1-61499-512-8-672

Experiences as input to eHealth design – a hip surgery patient journey case

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Abstract. The objective of the study is to describe the planned hip-surgery care process as experienced by patients and healthcare professionals, as well as a qualitative analysis of problems. Data was collected through 3 focus group meetings with patients and healthcare professionals. We present the results in form of a patient journey model, examples of problems as expressed by patients and examples of proposed eHealth services by both patients and care professionals. The results indicate that although the patient journey is similar for most patients, their experiences are highly individual and designing eHealth to improve the patient journey will require flexibility and adaptability to the individual's needs.

Keywords. Consumer health informatics, Patient journey mapping, eHealth

1. Introduction

eHealth is often suggested to have the potential to revolutionize the way health care and prevention is provided, shifting the balance of power and responsibility from healthcare professionals to patients and citizens [1][2]. Yet, many of the applications developed for patients are either designed from a healthcare providers' perspective, or completely detached from healthcare. A more balanced way for eHealth design taking account both patients' and healthcare professionals' experiences is sought for in this paper. To design eHealth that provides patients with an overview of their often fragmented care requires a deep understanding of their experiences. In service design [3], customer journey mapping is used to capture experiences of using a service, and this method has lately also been applied in healthcare to describe the patients' experiences [4]. The work presented in this study was performed within the Swedish research project "My Care Pathways" [5]. The project aims to create new mobile citizen e-services that allow patients to follow, own and manage their care process related information. The project is supported by VINNOVA Swedish Agency for Innovation Systems (2011-02536).

2. Methods

We applied a participatory design approach to the qualitative analysis of problems and needs, actively involving both patients and healthcare professionals in the process. All participants were recruited by convenience sampling via an orthopedic surgery unit in southern Sweden (Table 1).

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Table 1. An overview of participants

Focus group	No participants	Roles	Focus
FG1	4	Patient (n=1), Orthopedic surgent (n=1), nurses (n=2)	User stories, my patient journey
FG2	4	Patients (n=3), family (n=1)	Perceived need for e-services
FG3	3	Orthopedic surgent (n=1), nurses (n=2)	E-services from HCP perspective

Ethical approval was obtained from the regional ethical review board (2011/2093–31/5).

3. Results

The results are presented in the form of a patient journey model, important patient experiences and examples of proposed eHealth services. The model was presented to both patients and healthcare professionals to validate that we have indeed captured the stages that are important for the patients (fig. 1).

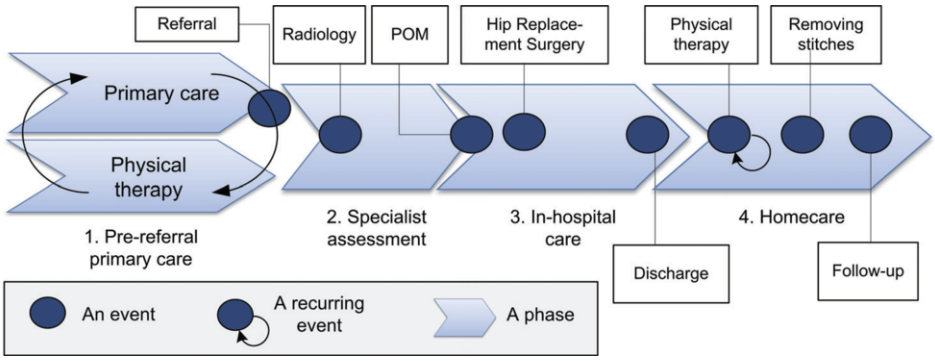

Figure 1. An overview of the hip surgery patient journey.

We distinguished 4 clearly separated phases that the patients go through which may incorporate several events; (1) *Pre-referral primary care* is a long, often uncertain process with increasing pain. An important event that all participants described was the decision to refer to specialist assessment and radiology. (2) The *specialist assessment* is much shorter, ranging from the referral to the orthopedic clinic for surgery to the decision whether or not the patient should receive surgery. (3) *In-hospital care* is structured and time-efficient; begining with a Pre-Surgery Meeting (POM in Swedish) after which the patient is admitted to the hospital, undergoes surgery and spends approximately 48 hours in recovery. (4) *Homecare* is the final phase to which the patient is discharged after surgery with instructions for post-operative self-care, medications, and physical activity/rehabilitation.

Table 2 shows examples of problems experienced by hip replacement patients related to phases.

Table 2. Examples of experienced problems

Phase	Problem	Description of the problem
1-2	Getting the referral	waiting and uncertainty dominated the time leading up to the actual referral to surgery, despite receiving physical therapy and attending education regarding

		arthritis. The participants felt it very much depended on the individual healthcare professional in primary care whether you got your referral to surgery or not, which was expressed as frustrating. Self-referral was an option taken by one of the participants
4	Medication at home	Information is provided both before surgery and before discharge home, and was unclear and since the information leaflets contained information for both knee- and hip surgery patients it was confusing. It was also difficult to reach the orthopedic clinic to have questions answered.
4	Physical activity after surgery	The patients were provided with exercises both on paper and as a DVD. This caused different issues for different patients; some overdid the exercising which caused pain, whereas others found it difficult to motivate themselves to do the activities.
4	Follow-up	is important to ensure that infections do not occur. Both patients and healthcare professionals expressed that it is difficult for patients to judge whether the dressing of the wound looks normal or not, and when to contact healthcare.

Based on the modeled process and the identified issues, we suggested a number of potential eHealth services, and some examples of these are presented in table 3.

Table 3. Examples of proposed eHealth services

Phase	Problem	Proposed eHealth service
1	Getting the referral	An eHealth service describing how and why ***self-referrals*** can be made was suggested. A description of the "normal" care process was also considered useful to reduce frustration while waiting.
4	Medication at home AND Physical activity after surgery	Participants suggested a ***self-care schedule*** including an overview of everything that is to be done on a daily basis after the surgery; including different types of medications as well as physical activities.
4	Follow-up	A service suggested by both patients and healthcare professionals was a ***secure but simple tool for communicating images (still or video)*** of the wound for follow-up purposes.

4. Discussion

We used the patient journey model to understand the patient experiences before, during and after a planned hip replacement. The results indicate that although the patient journey is to a large degree similar for different patients, their experiences are highly individual and dependent on their personal needs and interpretations of the process. Designing eHealth to improve the patient journey will therefore require flexibility and adaptability to the individual's needs.

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