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Living with Lung Cancer – Patients' Experiences as Input to eHealth Service Design

Maria Hägglund[a], Peter Bolin[a, b], Sabine Koch[a]

[a] *Health Informatics Centre, department of Learning Informatics, Management and Ethics, Karolinska Institutet, Stockholm, Sweden*
[b] *Stockholm County Council, Sweden*

Abstract

The objective of the study is to describe the lung cancer care process as experienced by patients, as well as to perform a qualitative analysis of problems they encounter throughout the patient journey. A user-centered design approach was used and data collected through two focus group meetings with patients. We present the results in the form of a patient journey model, descriptions of problems related to the journey as expressed by patients and proposed eHealth services discussed by patients in the focus groups. The results indicate that not only is the patient journey fragmented and different for each patient going through it depending upon their specific type of lung cancer and treatment options, but their experiences are also 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.

Keywords:
Consumer health informatics; Patient journey mapping; eHealth; Participatory design.

Introduction

Consumer health informatics [1] is a growing field of research, as more and more applications are developed for patients and citizens rather than for health care professionals. The term eHealth was introduced by Eysenbach in the year 2000 as "an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies" [2]. eHealth has 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 [3, 4]. Yet many applications developed for patients are either designed from a healthcare provider's perspective, e.g. applications to collect patient reported outcomes, or stand-alone health applications, e.g. mobile apps for activity tracking. A more balanced way for initiating eHealth service design taking patients' experiences of the patient journey into account is suggested in this study. To design eHealth services that provide patients with a holistic overview of their often fragmented care requires a deep understanding of their experiences of the patient journey. In service design [5], customer journey mapping is often used to capture the consumers' experiences of using a service, and this method has lately also been applied in healthcare to describe the patients' experiences [6, 7].

My Care Pathways

The work presented in this study was performed within the Swedish research project "My Care Pathways" [8]. 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 also aims to adapt and further develop the Swedish National platform for citizen e-services and provide an open software development kit (SDK) for developing new e-services [9].

In the initial stages of the project, three patient groups were involved in the e-service design: stroke patients [10], lung cancer patients and patients undergoing planned hip surgery. In this paper, we focus on the lung cancer patients. The objective of the study is to describe the process of being diagnosed with and treated for lung cancer as experienced by patients, as well as a qualitative analysis of problem areas in this care process. In this paper, we present the patient journey model, examples of problems as expressed by patients as well as examples of proposed eHealth services to address them.

Methods

We applied a user-centered design approach [11] to the analysis of problems and needs and actively involving patients in the process. An overview of the approach is shown in Figure 1.

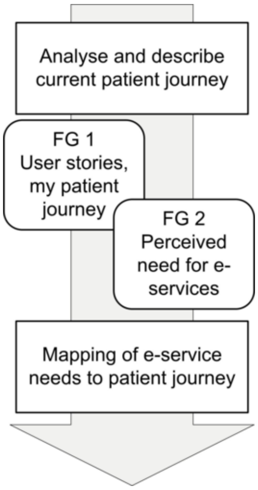

Figure 1 – Overview of the Needs Analysis Process

The first stage of the process was to do an initial analysis and description of the current patient journey. The initial patient journey model was based on literature and materials gathered from clinicians at the Karolinska hospital who are involved in different stages of the lung cancer diagnosis and treatment process. The model was then presented to the patients to validate that we had indeed captured the stages that are important for the patients.

Two focus group interviews were held to explore the problems and experiences of the patients and how these problems change throughout the patient journey. An overview of participants is given in Table 1. All participants were recruited by convenience sampling via the lung cancer patient organization Stödet (http://stödet.se) in Stockholm, Sweden.

Table 1- An overview of participants

Focus Group	Number of participants
FG 1	Patients (n = 4)
FG 2	Patients (n = 5)

All focus group meetings were facilitated by a moderator (first author of this paper, MH) and notes were taken by two researchers (PB, SK). Each focus group lasted 2-3 hours. The focus group meetings were audio recorded and transcribed. Content analysis [12] was used to identify categories and themes related to the patient experience. In addition, current paper-based information given to patients at different stages was gathered and studied.

The collected qualitative data was used to model a patient journey, referring to "the experiences and processes the patient goes through during the course of a disease and its treatment" [7]. The patient journey model aims to provide a common picture of the processes and the way the patients experience them.

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

Results

The results are presented in the form of a patient journey model, important patient experiences and proposed eHealth services.

The Patient Journey Model

We distinguish between phases and events in the patient journey model (Figure 2). A phase is extended over time and may incorporate several events. An event is a specific interaction between patient and healthcare, where information is created, shared or communicated. Patient journey models often only include phases, but to use the patient journey as a basis for design of eHealth services, it is important to also map these events, typically called touch points in customer journey maps [5].

We identified 5 distinct phases that the lung cancer patients go through: (1) pre-diagnosis care (primary and/or acute), (2) diagnostic examinations, (3) treatment, and finally (4) rehabilitation (when the patient is in remission), or (5) palliative care.

The *pre-diagnosis care (primary and/or acute)* phase can be a long and often uncertain process. Patients sometimes seek care on several occasions before the suspicion of lung cancer is actually raised, and a high proportion of patients who are finally diagnosed present with advanced disease [13, 14]. The first contact is often with a primary care physician, and if the suspicion of lung cancer is raised in primary care, referrals are sent for further assessments. However, it is not uncommon that patients seek acute care after having been misdiagnosed and treated with antibiotics in primary care and the referral to specialist care is sent from the acute care department [14]. An important event that all participants in this study described was when the decision was made to refer to diagnostic examinations.

The second phase, *diagnostic examinations and specialist assessment*, can be fragmented since many different clinics are involved in the examinations, which may include laboratory tests, chest X-ray, computer tomography (CT scan, CAT scan), positron emission tomography (PET scan), sputum cytology, fine-needle aspiration biopsy of the lung, bronchoscopy and many more. This phase is often perceived as time consuming and frustrating by the patients, as they are anxiously awaiting the results of the examinations. The phase is often coordinated from a pulmonary clinic, and begins when the patient is referred there for diagnosis and staging. After lung cancer has been diagnosed, the phase continues with further examinations to determine the type of lung cancer (non-small cell and small cell lung cancer) and staging, i.e. to determine how far the

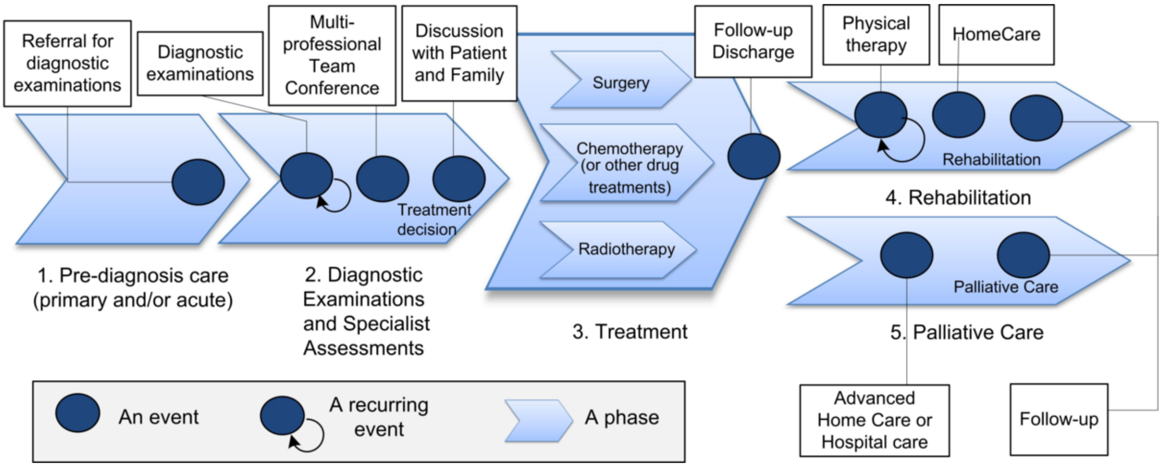

Figure 2 – The Lung Cancer Patient Journey Model

cancer has spread. The phase ends with a multi-professional conference where clinicians with different specialities meet to discuss the diagnosis and treatment options. The preferred option is then discussed with the patient and family members before treatment begins.

The *treatment* phase depends very much on the choice of treatment, but usually consists of surgery, radiotherapy, chemotherapy, or a combination of these. Different specialist clinics are responsible for different treatments, thorax for surgery, oncology for radiotherapy and chemotherapy, and pulmonary clinic for palliative and post-surgery care. Patient experiences varied depending on the type of treatment they had received. Patients who received care at different clinics expressed frustration at the poor communication between clinics and lack of coordination of activities. One participant who fell ill with breast cancer while undergoing treatment for her lung cancer described the lack of coordination:

"But I think the communication between the Radiology clinic and Thorax is poor. It feels like I have to… this spring when I was receiving treatment that would last until summer, I asked if it could clash with the medication I was getting from the Radiology clinic. […] The chemotherapy is a drug given for breast cancer too so they could 'take each other out' and it turned out no one told me to stop taking this medicine I was taking everyday. And they clashed. I got pretty ill."

Yet, once the treatment finally began, many patients felt relief, *"… it had been 3-4 months, I think, when they put the needle in my arm [for chemotherapy], and then I felt; now I will get better, now I have received help!"*

Not all patients undergo curative treatments, many lung cancer patients are diagnosed at a late stage and suffer from co-morbidities such as COPD (chronic obstructive pulmonary disease) or heart disease, so that curative treatments are deemed unwise and it is decided to go directly to palliative care instead. The treatments described above may still be used, to relieve symptoms, but not with a curative purpose. If treatments have been performed with a curative aim, the patient hopefully goes into remission and moves on to the rehabilitation phase, but if the treatments are not effective, a *palliative* phase begins with focus on pain management and quality of life.

Rehabilitation was an important topic for our participants, as it was not available to all patients automatically. Depending on which clinic the patient was treated at (oncology, thorax or pulmonary) rehabilitation was more or less available despite patients suffering from similar symptoms. This was expressed as frustrating and a sign of inequity.

The Patients' Experiences

Describing the process in terms of phases and events is important, but designers of eHealth services also need guidance when patients experience problems. Table 2 shows problems experienced by lung cancer patients related to the phases.

Table 2 – Patient Experienced Problems

Phase	Problem	Description
1	Unnecessary delays before diagnosis	Several of the participants expressed that it took too long for primary care to acknowledge their condition. One participant had to visit the emergency department and was then recommended to contact the pulmonary clinic directly. Participants felt that they had to fight to get to get the right care and that it depended on the individual healthcare professional they met.
2-3	Poor communication with health care	Participants expressed frustration at reaching the clinics at the hospital. Especially when receiving care at different clinics, finding contact information and reaching the right person was challenging. Different clinics at the same hospital also had different approaches to communicating with patients making it more difficult to manage.
2-3	Poor coordination	As both diagnostic and treatment activities are distributed on many different clinics, patients suffered from poor coordination when e.g. appointments were scheduled two days in a row rather than after each other on the same day. The patients also lacked information about who (which department/clinic) is responsible for which part of their treatment.
2-3	Understanding of procedures	Some of the procedures are major and the patients are naturally worried and concerned beforehand. An issue that was brought up in the focus groups was that patient information was often not up to date, or was provided in what they interpreted as "homemade" brochures. This did not improve the patients trust and confidence in health care.
4-5	Patient follow-up	The patients receive different types of patient surveys. They are often repetitive and far too long. As a patient you do not have the strength to answer the surveys all the time.
All	Poor support for multi-morbidity	Many lung cancer patients also suffer from other conditions, yet health care is not adapted to this. Frustration was expressed at having to repeat information and act as the coordinator between different clinics and clinicians.
All	Learning to manage one's care	Several participants expressed that it took time for them to understand where and how to find information and to manage their care. If the patient participated in a study, then they received more information, more continuity and more visits.
All	Lack of channels for giving feedback	At the same time, the patients lacked a channel for giving their feedback, either immediately after a meeting or long-term. Instead, the patient organization receives this information, without being able to pass it forward.
All	Understanding of rights to choose	The patients lacked information about what opportunities they have to e.g. choose doctor and treatments, second opinion. Trusting your physician was expressed as crucial, and several participants had asked to see another physician after a bad experience. However, this option was not something everyone was aware of, and it took some time for the participants to realize how important this was.

Examples of Proposed eHealth Services

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

One participant expressed an overall need for eHealth services in the following way:

"... I can't demand to have total control over the entire process, but I should at least have as much control so that I can trust health care and focus my energy on getting well".

It was important for the participants to have information and insight into the care processes, but they stressed that the responsibility needed to remain with health care – eHealth services should not be a means for health care to leave the responsibility for coordination and communciation to the patients.

Table 3 – Proposed eHealth Services

Problem	Proposed eHealth service
Overview of the diagnostic procedures	An e-service showing the **progress of the different diagnostic examinations** made was requested. The participants did not want to receive the results online, but wanted an expected time frame and did not want to have to wait for an appointment once the results were ready. *"So, it had taken time, but then I was supposed to wait 3 weeks for a doctor's appointment so I could find out what it was when they were done. Then I lost it completely..."*
Poor coordination	Participants suggested that health care should be working more with logistics to get the processes right. An **overview of the "normal" care process** would be useful to both patients and professionals. If it could also show the patient's current position and who is responsible for different parts of the process it would be even more useful.
Understanding the procedures	Available information beforehand is necessary to decrease anxiety. The information should be updated and easy to understand to make patients feel confident. Online information sites in various designs were recommended.
Patient follow-up	**Online patient surveys** which could make the answers available during the whole care process were requested.
Lack of channels for giving feedback	**e-services for giving immediate feedback** to healthcare were deemed useful by the participants, but they also wanted a way to communicate feedback later on when you have more perspective on the care process. Channels for making formal complaints are available, but the participants lacked an easy **means for communicating feedback and improvement suggestions**.
Poor communication with health care	**Improved services to communicate with health care** were requested. Individual patients have different preferences for synchronous and asynchronous communication, and alternatives should be available. However, overview and responsibility was again stressed – who do I contact about this specific issue?
Learning to manage one's care	Many participants expressed that it took them time to learn how to navigate through health care, where to find information and how to ensure you get the care you need. If this process could be faster it would be helpful, and support from other patients in combination with other **guiding or e-learning eHealth services** could be useful.
Understanding of rights to choose	e-services **clarifying patients' rights** both in terms of choosing a health care professional you trust, and when it comes to requesting second opinions, choosing treatment etc. Most participants expressed that they trusted the judgments made by health care professionals, especially during the multi-professional conference – but at the same time they had all experiences of questioning individual professionals' judgment and requesting to meet new physicians in the future.

The proposed eHealth services in Table 3 are not an exclusive list, but rather suggestions made by participants in the focus groups. Anyone reading about the problems may come up with their own ideas for eHealth services that could improve the situations for people living with lung cancer. This is one of the strengths of using patient journey mapping and patient experiences as a basis for design.

Discussion

We used the patient journey model to understand the processes a patient goes through before, during and after lung cancer treatment and the problems they experience during this journey. Gaining this insight is important input to proposing new eHealth services for lung cancer patients.

A limitation of this study is the low number of participants involved in the focus groups. Still, even this limited case study points to important insights into the patients' experiences, and important ideas for eHealth services were produced. These results will be used together with an in-depth content analysis of the patients' information and communication needs to further understand the content and functionalities eHealth needs to provide to support lung cancer patients throughout their patient journey.

All participants were recruited locally, and had received their care within the same county council. This limits the transferability of the results in terms of the patients' experiences and some of the proposed eHealth services. Yet, as a designer of eHealth services one may recognize similar problems from other contexts where these results can be applied. The important, transferable, result of this study is however the method of using patients' experiences as a basis for proposing new eHealth services to improve health care from a patient perspective. The approach can be applied locally in any context to explore patients' experiences and propose solutions to identified problems.

The lung cancer patient journey in Stockholm, Sweden, is fragmented and different for each patient going through it depending on their specific type of lung cancer and treatment options. In addition, their experiences are also highly individual and dependent on their personal needs and interpretations of the process. Designing eHealth to improve the patient journey therefore requires flexibility and adaptability to the individual's needs.

It is also important to acknowledge that health care is a socio-technical system [15, 16], and not all the problems identified in this study can be solved through new eHealth services. Therefore, it is crucial to involve healthcare professionals and other stakeholders within the healthcare organization to address the problems from more organizational and work process perspectives too. In addition, when designing and implementing new eHealth services to support patients throughout the patient journey, it is imperative to consider what impact these will have of the surrounding organization and how do thenew tools for communication between patients and professionals affect the daily work.

Conclusion

Patient journey models and qualitative analysis of patients' experiences are powerful tools that can be used to improve health care from a patient perspective. In this study we show how such tools can be used as input to the design of eHealth services, but by creating a patient journey model and describing patients' experiences of going through this journey, we also create opportunities for reaching a common understanding of issues and problems experienced by patients, thereby facilitating improvement work and in the long run increased patient satisfaction.

The results indicate that not only is the patient journey fragmented and different for each patient going through it depending on their specific type of lung cancer and treatment options, but their experiences are also 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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Address for correspondence

Maria Hägglund, maria.hagglund@ki.se