
Be Informed Be Involved: Enhancing the Patient Experience of Oncology Patients

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Abstract

We present ongoing research to design a patient individual information system that supports cancer patients in making informed decisions on their treatments and in planning their daily routine of fighting the illness. We discuss different stakeholders, their roles and some ways to present the information on mobile devices.

Author Keywords

Patient experience, empowerment, healthcare app

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

Introduction

Patients having a severe illness such as cancer often are emotionally distressed from fear and worries. One reason mentioned when talking to these patients is a lack of information, an uncertainty about their current condition, the next treatment steps, or the treatment schedule. Some only vaguely understand the explanations from the medical staff but are required to make informed decisions on possible treatment options. To take a more active role in their treatment, patients often want a deeper insight into the disease and treatment details.

Nowadays it is not difficult to get medical information (e.g. from the internet) but rather understanding and evaluating them. To decide, what applies to one self, what is relevant, is difficult if not impossible without support and guidance.

The aim of our research is to provide patients with patient individual data and information they can access and understand themselves. While we choose mobile devices as a platform to present this information, the goal is accessibility and appropriate representation, which could also be reached differently. In the end, informing and empowering the patients should lead to a better experience while fighting a serious illness. One further assumption is that it will also enrich and cultivate the patient-clinician-relationship, as the clinician and the hospital take part in this process.

Stakeholders

Although treatment options are diverse, cancer treatment is well defined in terms of treatment plans once a specific option has been chosen. This is one of the reasons we focus on this group of patients and use these plans as guidance.

Besides patients, relatives, medical staff, and hospital management are additional stakeholders with interests in this communication process.

Patients

Patients differ widely in their information needs. Trust in the skills and expertise of the attending physician plays an important role here. There are patients that totally trust their well-being to the doctors and have no interest in further information [1].

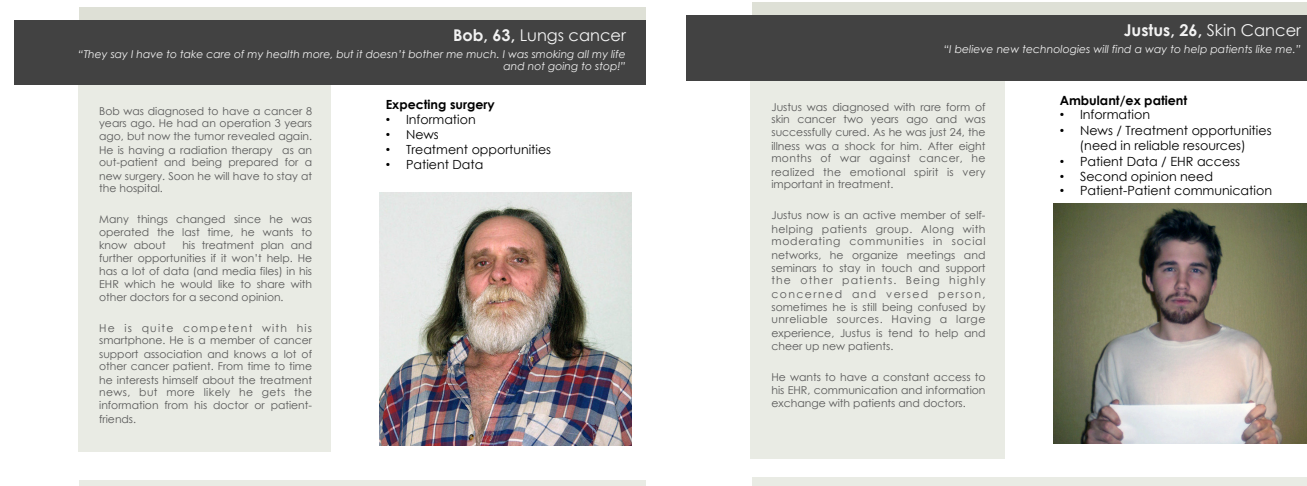


Figure 1. Two of five personas we created after interviewing patients (images are fictitious and do not show real patients)

And there are patients who generally mistrust information from medical staff and prefer other sources. Naturally, most patients are somewhere in between (see Fig. 1).

In our research we often hear that patients want their doctors to spend more time explaining treatments, medications, progress, schedule, etc. or that personnel should pay more attention. Generally, patients complain about frequent changes in the schedule of examinations or treatments. Patients not staying at the hospital feel the greatest impact on their daily live by this.

Also, some treatments are very tiring, such as radiation or chemotherapy, especially after cancer reoccurrences. Information and motivation will help those patients to continue with the treatments.

Relatives

Family and friends want to be informed about the treatment. Especially if children or older parents are the patients, the family plays a very active role and often becomes an equal contact for the clinicians. Families can be big with many members interested in details about the current status and treatment progress.

Medical Staff

Task and involvement of the medical staff in the treatment are diverse. From the attending physician to nurses, laboratories, and even the receptionists that schedule appointments, all participate in the provision and reception of information.

Due to economical reasons medical staff may not spend as much time as required with the patient. While

treatments are generally well explained in the beginning, less time is spent in the ongoing process. Since staff would be required to provide information to the information system that is not yet available in the HIS, it should be directly beneficial for them as well. One aspect mentioned in this regard is that the patient client may "recall" a doctor-patient conversation, hence could be used by the patient to inform family members.

Hospital Management

Attracting patients by providing and advertising a patient individual information system may prove beneficial [2]. Also such a system could offer opportunities for further information from the hospital to the patient to build a better relationship.

Patient information requirements

What kind of information is most requested by the patients?

Individual patient data

Patients want to be informed about their condition. Therefore, all data that is collected during their stay in the hospital or in ambulant treatment should be accessible. Also, a comparison of data taken at different time points and a progression over a period of time should be provided.

General disease information

Details of their illness and possible treatment options: There is a gap of information between patients and doctors: Patients are usually not familiar with medical expressions and are often afraid to ask, and doctors do not always have time to explain everything in detail and sometimes are unable to empathize with the patient.

Treatment plan

Upcoming treatments: when will it start, how long will it last, and most of all what is going to happen. Although there are usually no fixed dates beforehand, an overview of the sequence of upcoming processes is of interest, along with detailed information about the treatment process and medication.

Also, if a diagnosis is not yet clear (e.g. a tumor is confirmed but has to be further examined), it might be interesting for a patient to learn about the criteria which affect further treatments.

Treatment schedule

While issues like repeated changes of schedule are due to workflows that cannot be changed easily, medical staff could provide this information to the patient so they can plan their private time during the hospital stay, or are being notified when they are at home.

Patient diary

There is already some research about patient diaries. As it might not be suitable to always contact a doctor directly, it could be helpful for patients to write a kind of diary or "status report" about their current condition, e.g. degree of pain, side effects after taking medicine, or just an overall description of the patients feeling.

Using mobile devices to enhance the user experience

The patient may access the information using a mobile device such as a smartphone or tablet. The information can be interactively explored and is graphics-oriented to foster understanding.

Besides the patient client, there will be also a dedicated client for the medical staff. There still are a lot of questions on this side, which we are currently investigating, e.g.: How could such a system support the medical staff in enhancing the communication with patients?

Information representation

How can the relevant information be presented to the patient in an appropriate way?

General disease information and individual patient data

To inform patients about their illness and discuss treatments, it is necessary to explain the disease in more detail. For most common types of cancer we provide patient individual surgery plans with risk analysis targeted at surgeons (see Fig. 2). These 3D models are perfectly suited to also give a patient more insight into what's going to happen and what the possible risks are.

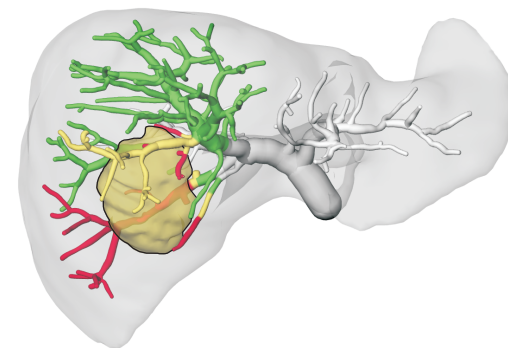


Figure 2: Patient individual model of a liver cancer with the vascular structure that could be at risk during surgery.

Treatment plan and schedule

As the treatment often lasts over a longer period of time, we choose a timeline-based approach to visualize the treatment process. In Fig. 3, a change in treatment plan based on a certain criteria is indicated. More than one possible option is presented to inform the patient in advance.

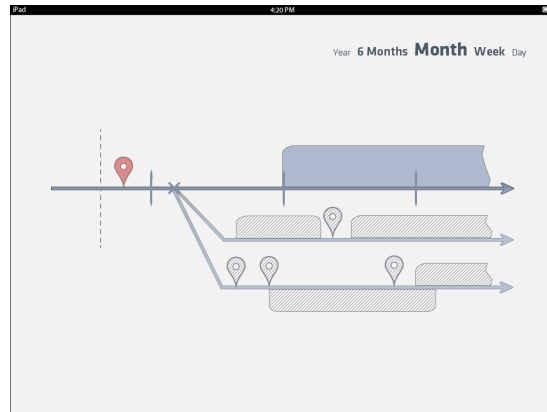


Figure 3: Timeline based visualization of different treatment plans. The plan may change based on certain criteria.

Information provision

The main questions here are: How can the required information be provided, and can it be done without additional efforts on the clinician-side? Who is involved in providing these information? How are these information currently communicated to patients? What must be changed in order to implement such a system?

Conclusions

A patient individual information system that patients may access themselves may support a more active role of patients in their treatment possibly having a positive impact on the patient experience and their health [3].

References

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