PATIENT GENERATED DATA AND AFFORDANCES:

CONVERSATION CUES IN CLINICAL DECISION MAKING

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Abstract

An increasing number of systems support the use of patient-generated data in patient-provider collaboration. However, there is yet limited understanding of how patient-generated data impact the way health personnel work with data in clinical decision-making processes, and whether patient-generated data might be able to support clinical processes, for instance by providing evidence for diagnoses, treatment monitoring, or recovery. In this paper, we explore the use of patient-generated data in clinical decisions in two case studies. In the first case an App is used by patients in cancer rehabilitation to track their pain levels, frequency of specific events, and symptoms. Rather than requiring patients to remember past events at the time of the visit, patients can use the App to register events as they happen. In the second case an App is used in conjunction with a set of digital medical devices to track a defined set of parameters in remote care for patients with chronic conditions. Both Apps are designed with the aim to improve data accuracy and ensure data quality. Our findings show that beside gaining data quality and accuracy, patient generated data work as conversational cues in the context of the interaction between patients and health personnel. This finding is relevant as it shows that patient generated data need to be treated not just as facts but as cues or as an affordance for patient-provider dialogue. Based on this understanding, we identify three design implications for Apps for patient-generated data to support patient-provider dialogue.

Keywords: Patient-generated data, App, Affordance.
1 INTRODUCTION

Several initiatives in many countries are addressing the problem of chronic conditions by experimenting with different ways to provide prevention and early detection of exacerbations (Lupton and Maslen 2016). The aim of these initiatives is to reduce the burden of chronic disease on patients and enable them to improve their quality of life. In this paper, we focus on the use of patient-generated data in chronic care as one of the tools to achieve these goals. Patient-generated data are data that are directly produced by patients, often outside of traditional healthcare settings, in contrast with health data that are produced by health personnel, at the hospital. Traditionally, the patient’s experience related to symptoms, goals of care, and overall quality of life has been captured during visits and through conversations between patients and health providers, who then interpret and document the data. Recently however, is recognized that incorporating the patient direct experience and voice is critical for ensuring good care.

In this paper, we want to draw attention to the use of patient-generated data that is mandated to patients as part of a treatment. The literature on patient-generated data considers mainly the use of personal apps and digital measuring devices that are autonomously bought and used by patients (Fallah and Yasini 2017; Cabitza and Locoro 2016). This literature tends to see the use of patient generated data as a challenge to established clinical knowledge and practices traditionally driven by health personnel generated data. However more and more these apps and devices are designed for, and given to, patients to use by the clinics, and are designed to fit in with existing care practices and related information processes. Thus, it is important to understand how patient-generated data are actually used in treatment processes in clinical decision, and how they affect healthcare practices.

In this view, patient-generated data can be seen as a type of the so-called Patient Reported Outcomes (PRO). PRO data can be of different types on a continuum from precise, narrowly defined data points collected using curated and validated instruments, to patients’ answers to more basic screening questions such as “Do you feel weak?” These are data reported by patients and can be both descriptive, exploratory, or diagnostic (Cella 1997). The literature points to several challenges in the clinical use of patient-generated data. First, data are relevant to clinicians for different reasons and purposes, and clinicians of different specialties tend to look for different types of information (Huba and Zhang 2012). Second, patient motivation in generating data needs to be considered. Research has shown how the key to high-quality patient-generated data is to have immediate and actionable data so that patients experience the importance of the data for their own care as well as for research purposes (Howie et al. 2014).

However, there is yet limited understanding of how this flow of data from patients impact on the way health personnel work with data in clinical decision-making processes, and whether patient-generated data might be able to support clinical processes, for instance by providing evidence for diagnoses, treatment monitoring, or recovery. In this paper we address the following research question: what is the role of patient-generated data in clinical decisions? We make use of the concept of affordance (which we present in section 2), and which directs our attention to how patient-generated data become structuring devices and provide cues in clinical conversations. Our findings show that beside feeding into data analysis processes, patient-generated data afford new dynamics in the conversation between health personnel and patients. Based on our findings, we identify three design implications for systems or Apps which support patient-provider collaboration around patient-generated data.

2 THEORY

The concept of affordances originates from ecological psychologist James J. Gibson. He defined affordances as all “action possibilities” or capabilities latent in the environment, independent of the individual’s ability to recognize them, but always related to the actors and therefore dependent on their capabilities (Gibson, 1986). For instance, technologies have material properties, but those material properties afford different possibilities for action based on the contexts in which they are used. Thus, in this view, the material properties of a digital technology - its physical appearance, its graphical user interface and its content - does not determine its use.

In Information System, affordance has been used as a lens for theorizing the relationship between technology, users, actions and goals. The affordance lens is particularly useful for understanding those mechanisms that arise from the relation between technology and users because it explicitly involves both at the same
time, while still holding them distinct (Bygstad, Munkvold & Volkoff, 2016). For instance, Marcus and Silver (2008) emphasize that affordances arise when a person interprets a technology through his or her goals for action and defines affordances as "the possibilities for goal oriented action afforded to specific user groups by technical objects" (p. 622). Accordingly, affordances work as emergent cues between the goal of actors, material properties and the situation at hand. When actors actualize cues as they use a technology, specific results take place. In most situations there are numerous possible affordances for a user to act upon but only a few are actualized. In this article we focus on the actualized affordance of patient-generated data in clinical situations and its role in the dialog between nurses and patients. By using the theory of affordances and by identifying how they work as cues in specific practices, our aim is to suggest directions for future designs of systems.

3 RESEARCH METHODOLOGY

3.1 Study design

This paper is based on two case studies based on an interpretive approach (Walsham 1993) and qualitative data. In both cases data were collected through interviews, ethnographic observations and document analysis (Silverman 2016; Wolcott 2005). Both cases are about patients’ use of an app for generating data that are then used in clinical decision making. The two settings considered were selected as one is within a specialized care - a specialized hospital clinic for cancer rehabilitation - and the second is in primary care – a municipal care center for homecare of patients with chronic conditions. In both studies, the patients are asked to generate data while at home. Both apps enable patients to access their record of data, and graphical representations of data over time. The case settings, context, and data collection methods are described in the following two sections.

3.2 Case 1: Cancer rehabilitation

In Case 1, the research reported is based on a case study on the use of an app for patients in cancer rehabilitation. The case study is conducted in the context of a design project started in 2015 and still ongoing. Data were collected via interviews and non-participants observations of the work practices of the nurses at the clinic, and of project workshops. The main data come from 20 nonparticipant observation days at the clinic, four semi-structured interviews with the clinic’s nurses, and seven individual interviews with patients. In addition, developers have been interviewed throughout the development process.

The clinic receives patients, mostly women, who have been treated for cancer in the pelvic cavity and who suffers from chronic survivorship diseases, that is, diseases that are consequences of the cancer treatment including radiation, chemotherapy and surgery. Some patients have just finished their cancer treatment, and others have been cancer free for over 10 years. The clinic treats around 200 patients per year, and the average patient has contact with the clinic from six months up to two years. The chronic survivorship diseases relate to intestinal health, faecal leakage, urinary incontinence and impaired sexual function. The problems are, among other things, related to anal sphincter dysfunction, gut-wall inflammation, excessive mucus discharge, excessive gas discharge and blood discharge. This means that patients cannot wait to go to the toilet and are dealing with constipation or loose stools. There is a range of solutions for these symptoms, including diapers (for leakage), Imodium (for urgency and diarrhea), Inolaxol (for constipation, urgency and easier passing of stools), antibiotics (for bacterial overgrowth from the colon to the small bowel), and Dimor and muscular exercises (for gas and urgency). A large survivor group also struggle with sexual problems, either as the main complication or in addition to other complications.
Patients visit the clinic regularly for consultations. The nurses at the clinic prepare for consultations by examining the answers of the patient to the Clinical Trial Form (CTF) and information from the electronic patient records (EPR). A few weeks before the consultation the patient receives a CTF. This is a paper-based survey of 182 questions about demographic data, fecal leakage, urinary leakage as well as sexually related problems (Dunberger & Bergmark 2012; Dunberger et al. 2013). Before the face-to-face consultation the nurse analyses the survey by reading it while taking notes. The nurses take notes on a plain paper where they gather the notes from the different sources, first from the EPR and then from the survey. During the consultation they add further notes and after the consultation these notes are used for documenting the visit in the medical record. Patient have also the option of using an app for patient-generated data.

The app is introduced to patients by the nurse during the consultation. The patient is asked to use the app and generate data for at least two weeks. Two weeks of data are considered enough for the patient and nurse to get an overview of the patient’s problems. By using the app, the patient reports various activities directly such as pain, defecation, urination or intake of medications. For pain and defecation patients are asked to provide a qualitative assessment of their experience (not just reporting frequency). When the patient takes contact with the care provider, by phone, video consultation or physical meeting, both the nurse and the patient have access to similar visualisations of the same reported data. Commonly, the patient calls the nurse and they talk about the his/her conditions over a ca. fifteen minutes phone call. During these calls both the patient and nurse refer to the visualisations in the app.

3.3 Case 2: Remote care for chronic patients

In Case 2, the research reported is based on a case study on the use of an App for patients in remote care. The study started in January 2017 and ended in April 2018. Data were collected via interviews and observations. A total of 23 interviews and 27 hours of observation were conducted. This paper builds mainly on data from the observation of the work practices of the nurses at the remote monitoring center as they attended to patients. Detailed notes were taken at each session and subsequently transcribed. We payed attention to how the nurses made sense of the measurements received in the system, how they wrote messages to patients, how they in general interacted with patients based on the received data. Often the nurses explained out loud their reasoning while they were working, and we could ask follow up questions in situ.

The App (MyProAct) is used by patients on a tablet and it is linked to a system (ProAct) nurses use in a health center at the company premises. The center follows ca 150 patients in a municipality in the South of
Norway. Figure 2 illustrates how the remote care service is set up. The ProAct runs on a cloud platform and collects data from measurements taken with a set of personal digital devices used by patients in their homes and connected to the ProAct app installed on the tablet (i.e. iPad given to patients). ProAct is thus accessed by the patient via the ProAct app on tablet, and by the nurses via a web view on their computers in the center. For instance, patient with COPD affiliated with the center are equipped with the following personal digital devices: a spirometer which measures the volume of air inspired and expired by the lungs (FEV 1 and PEF), values which decrease when the conditions become worse; a pulsometer which measures the pulse (frequency of heart beats per minute) and the oxygen saturation, while oxygen saturation decreases with worsening conditions, the pulse increases; a thermometer which measures body temperature and increases at early signs of infections; and a scale which measures body weight and a decrease in body weight is a sign of disease development. The scale is given only to those patients for whom weight is a risk factor. The nurses in the center coordinate with the municipal services but do not have access to their electronic patient record system used in municipal health including GPs.

ProAct organizes information in a record for each patient. Each record contains a number of tabs showing the patient profile, measurements from each device, graphical visualization of the measurements, personal set up of the devices, messages between nurses and patients, and a personalized questionnaire. For instance, for COPD patients the questionnaire covers a standard set of themes about COPD symptoms (e.g. cough, shortness of breath, fever, excess mucus) and activities that are important to follow (e.g. physical exercise, regular eating and sleeping). Patients are assigned to the center by a nurse coordinator from the municipal care services. When patients are enrolled in the service, they receive a home visit from one of the nurses who deliver the devices and explains how they should be used. After this visit, patient are remotely guided into using the devices, and they are expected to take measurements (e.g. temperature) at specific times (for instance every morning and every evening), attend to the directions given by the nurses and answer the personalized questions in the App.

4 RESULTS

We present our results in two parts. We first describe what it takes for patient to be data producers, and then we describe how the data are used in the clinical setting for decision making. Each section is organized in two subsections one for each case.

4.1 Patients as data producers

Case 1. In case1, patients generate data in three ways. The app records data on defecation frequency and quality, on location of pain, and on the use of medications. Defecation quality is registered by using a standard scale (the Bristol scale) as illustrated in figure 1. Patients are asked to self-assess and register their assessment on the scale. For registering the location of pain, the screen shows an illustration of the mid
body part. This information is important to understand the health condition of the patient and the quality of life. Before the use of the app, the patient was asked during the clinical consultation to remember these data. With the app, the patient enters data closer in time to the actual experience, data-gathering is triggered by the occurrence of the event the patient is asked to collect data about. The data is thus produced in everyday situations, and not as a result of questions asked during the consultation.

As one patient stated in an interview: “I have used the [visualizations] to check my data. I have looked at all the visualizations, but I have had most use of the Bristol scale. I have used it to see how it has really been. It can be hard to see when you are all up in it, to remember how yesterday was. I have had a hard period, and it has been a lot [of defecations], and it has been difficult. But it has been nice to actually be able to see how it really has been. It is so hard to remember when you are running back and forth to the toilet all the time.”

Case 2. In case 2, patient generate data in two ways. They take measurements with the digital devices, and they respond to the questionnaire. Both measurements and answers are performed daily, and sometimes more than once per day. The devices send the measured value to the App, and consequently, the nurse at the center receives a message in the system that a new measurement has been taken. Patients are given ca two weeks to learn to use the devices correctly. During these first two weeks, they are asked to take measurements very often, in order to become familiar with how the devices work, how they should be positioned and handled. In addition, patients need to learn when to take measurements, and the nurses have the task to support patients in learning these skills. For instance, a nurse describes the following episode: “I remember a patient who called about her blood sugar level, and she said “I don’t understand why my blood sugar level is high now in the morning” and I asked what did you do? And she replied “you know, I was on my way out to shop, and then I remembered that I did not take the measurements, and I was stressed”. So she was stressed and went back home. “But do you know that when you get adrenaline it releases sugar, it is a natural reaction, and the blood sugar increases?”.

The following two weeks are dedicated to setting the acceptable value range for each device. During these two weeks the patient takes measurements with the devices, and receives feedbacks for instance if his/her use of the device is correct, and the measured value. They are expected to be active in the production of personal health data, to frequently take measurements with their devices, and to share their thoughts and reflection in form of digital text on how they experience symptoms and changes of their health condition. Patients need to learn to master their devices, to position them appropriately, and obtain correct measurements.

4.2 How data are used in the clinical setting

Case 1. The App used in case 1 was designed with the aim to support decision making at the clinic and for the patient. The data generated through the mobile app can be visualized in the app and in the information portal, protected by a secure login (i.e., the backend). The nurse and patient can access the same data and the same visualizations; however, the visualizations are slightly simpler in the mobile app due to screen space.

The patients still come to the clinic for periodical controls. However, with the use of the app the content of the consultations has changed. During the face-to-face (sometime takes place via video) consultation, the patient and the nurse access the mobile app data and assess the information at the same time. The first question asked by the nurse to the patient is usually the following: “Can you describe how your week has been?” The data visualizations of the app provide a foundation for the consultation with larger and more accurate dataset. The nurse drives the conversation by asking questions to the patient. However, as Figure 3 shows, the visualizations in the backend are more detailed than those in the mobile app, and when the nurse and the patient meet during a consultation and discuss the data seen in the visualizations, the data becomes the point of departure for the conversation. In this way, the data generated by the patient provides a way for both parties to participate in the analysis. The patient needs only to answer the questions with brief descriptions that add enough information for the nurse to validate premade classifications.
Patients are not expected to be able to remember to measure all the time. One reason is that they need to bring their phone to the toilet, which does not always happen. Other times they are too sick to be bothered to record data in the app. However, the nurses know how to interpret the data and its quality. One nurse explained the following: “When looking at data points from seven days, you can see a span from two to eight times...The more data you have, it’s less likely to be random, it’s less likely that it’s affected by chance.” Another nurse said: “Exactly. This could be a good day that you just happened to measure.”

The nurses have noticed that patient generated data and their visualization has affected the way they work during the consultation. For instance, they have noticed that patients become more competent and learn how to interpret their own data. One nurse said the following: “Yes, it’s us that have to interpret the numbers and tell [the patient] how it is. But on the other hand, if you get it visually in front of you, it can be easier to see and understand it yourself.” They continued: “And then I think that if you have gone through it one time, and they continue logging the data, they can read the data themselves. It’s a training process. Then in the long run I think they can handle it because we have gone through [the data] together.” Thus, the questions and answers during the consultation cover also issues of data interpretation in relation to the symptoms patients experience. When patients learn how to interpret the data, they also learn how to interpret their own symptoms. One patient said: “I definitely think it has been helpful. It has been good to see. Then I don’t have to keep track. It is so hard to remember. I have had headaches lately, and I checked the app and thought: hmm, yes, yeah, this is actually true. It’s not so strange that I have been feeling like this. I have to take fluid substitute now. It has really been bad.”

Case 2. In case 2, the conversations between nurses and patients take place mainly via text messages in ProAct and MyProAct. Less often they also talk on the phone. Nurses work to motivate and encourage patients to be active and participate in the communication, and to make them understand the added value they get by taking an active role. Nurses encourage patient to consider the interaction via ProAct as a continuous conversation where they share their experience of the chronic disease. For patients, it is not just a matter of receiving information or a feedback from a health service but to create a lasting relation based on trust and ‘real’ relations with people. This is reflected in the way nurses approach and write to patients. A nurse explains: “we try to help them to interpret their symptoms, to interpret how their symptoms are, and we try every time we are in contact to give a bit of knowledge, we never say something without ‘why’, because it is about understanding your own disease, and it is not the case that because people have had a disease for long they have knowledge about it.”

Thus, the data from the measurement taken feed into this conversation. For instance, if the nurse receives an alarm for a value that is out of the set acceptable range, she will look at the answers to the questions and additional data to understand the meaning of that value. For example, the notes from the observation describe this activity: “the nurse looks at (a patient) blood pressure value which is high and out of the
acceptable range. I ask what she is looking at and she explains that she is looking at the mean value. She looks at the graph. The graph is where she spends most of the time beside the messages. The nurse explains that if the patient has high blood pressure the goal is to get it down, and she says that “we have to try having a dialogue” with the patient. Then she writes the message to the patient describing what she has seen in the graph, she says “we speak a language that they understand, we describe how their week has been and we try to calm them”. The nurse analyses the red value in relation to the mean values the patient had over time. In this case the alert signals that the patient needs to be calmed down and guided to lower the blood pressure.

Figure 4 – The nurse view on patient-generated data in case 2.

5 CROSS-ANALYSIS OF THE TWO CASES

In both cases an app is used by patients to generate data while they are at home or outside of the traditional clinical settings. These data are in both cases then transmitted to a nurse and used as a base for follow up actions. The purpose of the app is different in the two cases. While in the case of cancer rehabilitation it is a way to record data as close to the events as possible, in the case of remote chronic care digital devices are used to take measurements, while the app supports the nurse-patient communication. Despite these differences, in both cases patient generated data feed into one of the central practices in nursing work, which is question asking. The data in the app work in both cases by focusing the conversation on the most critical issues, and enabling a conversation (via messages, video or face to face) that is experienced by both patients and nurses as meaningful. Thus, patient generated data function as cues which frames and guides the conversation. The ability to ask relevant questions is a prerequisite to understand more accurately the patient health condition and overall situation, and how to help him/her.

6 DISCUSSION

Apps and the use of mobile technologies has the potential to dramatically change patient diagnosis treatment, education, and follow-up. The use of apps supports patients in becoming more engaged in their care. For instance, mobile apps for chronic disease management have assisted patients to improve their control of a number of chronic conditions, such as asthma, chronic obstructive pulmonary disease, and diabetes, and to address sleeping problems, hearing issues, and fall risk (Mosa et al. 2012; Ozdalga et al. 2012; Demiris et al. 2008). In this paper, we have described how the use of apps and patient-generated data affect the conversation between health personnel and patients. Patient generated data are usually seen as a difficult to integrate in clinical decision making, either because they are perceived as requiring extra work on the part of health personnel, or because they are reputed of not enough quality. However, our study shows that patient generated data can play an important role in how they take part and shape the encounter between patients and e.g. nurses.
In this article, we focus on the role of patient generated data. Our findings show that beside being used for clinical decision making, data was used as a foundation for asking questions and making patients contextualize the data from graphs and visualizations. Thus, in both our cases the data act as cues that guide and structure the conversation between the two parties. The patient, who generated the data, acts as the storyteller and is the one who builds a narrative around the data points reported in the app. The nurse is the “question asker”, the interpreter and the discussant who asks for clarifications, background information and other additional information to add clarity to the available data. Thus, data is not primarily used as mere evidence or as representing truth of what actually happened or of the patient condition. Instead it is used as cues for questions and conversations when the data and patient experience is re-told as part of the patient-nurse dialogue. In this view, the app and the accompanied data through shared visualizations affords cueing, which triggers conversation with the goal to contextualize and enrich the patient generated data in order to be used for clinical decision making.

If the goal, from a healthcare efficiency point of, is to gather the right data to set a diagnosis or to calibrate medications, then just patient generated data would be enough. On the other hand, if the goal is to increase patients’ engagement in their disease management, then gathering the right and high qualitative data is not enough. According to the affordance lens, we need to align the goals of the involved actors by designing technologies that make it possible for them to actualize the affordance. One approach is to design technologies that enable interaction around patient-generated data, and as our analysis show, more specifically, to design technologies that afford conversational cueing. We understand the affordance of conversational cueing as an artefacts ability to support asking and responding to questions based on patient-generated data. Based on this collaborative data-question-response cycle, we suggest three design implications for systems with the aim to support patient-provider collaboration around patient-generated data:

- The system needs to enable storytelling in addition to decision-making by supporting the generation of data that is relevant to all involved parties, and by increasing the involved actors’ motivation to devote time to data gathering;
- The system needs to provide shared, distributed and meaningful visualizations of data to support interpretation and common ground for each actor;
- The system needs to enable collaborative conversations based on a question-centric perspective in order for the involved parties to produce a narrative useful for both self-management and clinical decision-making.

A system that supports these design implications should, according to this study offer the possibility for goal-directed action, thus, the affordance of conversational cueing. However, each practice is unique. The affordance of conversational cueing is based on a mutual interest of learning from the data, a mutual interest of doing and supporting self-management. Thus, a limitation from this study is that both our cases are about chronic diseases where patients are required to self-manage and handle everyday life on their own. Therefore, some of the motivating factors exists a priori in both these cases.

7 CONCLUSION

An increasing number of systems support the use of patient-generated data in patient-provider collaboration. In this paper, we explored the use of patient-generated data in clinical decisions in two case studies. Our findings show that beside gaining data quality and accuracy, patient generated data work as conversational cues in the context of the interaction between patients and health personnel. This finding is relevant as it shows that patient generated data need to be treated not just as facts but as cues or an affordance for patient-provider dialogue. Based on this understanding, we identify three design implications for systems supporting patient-generated data for patient-provider dialogue: (1) enable story telling; (2) provide shared, distributed and meaningful visualizations of data; (3) enable collaborative conversations based on a question-centric perspective. By designing for the affordance of conversational cues and by aiming for these implications the designers address the problems of data relevancy and actionable data reported by Huba and Zhang (2012) and Howie et al. (2014).
References


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