

From Narratives to Numbers: Data Work and Patient-Generated Health Data in Consultations

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Abstract. This article presents preliminary findings on how the introduction of patient-generated health data (PGHD) triggers changes during patient-nurse consultations. This article builds on a two-year case study, examining the work practice at a cancer rehabilitation clinic at a Swedish Hospital using PGHD. The study focuses on how nurses' use data, gathered by patients with a mobile phone app, during consultations. The use of PGHD introduce a change in the translation work, the work of turning rich patient descriptions and transform them into data, during the consultation for documentation and clinical decision-making. This change affects precision, questions asked and the use of visualizations as well as the patient-nurse decision making.

Keywords. translation, data work, patient-generated health data, PGHD, cancer rehabilitation

Introduction

This article presents a few initial findings on how PGHD is used in clinical decision-making as part of consultations, i.e. face-to-face meetings between a patient and clinical staff. More specifically, what is demanded from nurses and patients to make use of the PGHD during consultations.

The documentation and compilation of information and data from different sources in clinical decision-making is central to the study of Health Informatics [1-4]. Making use of this data in practical work can be understood as translation work, where interpretation and reformulation of data into relevant and communicable information is critical [1]. Translation demands particular skills and effort from the participants. This work is at the core of our analysis. The translation process is both about reducing and re-contextualizing the information [2]. It is a process where rich patient descriptions are transformed into data, for documentation in ERPs, into repositories supporting collaboration between nurses, but also patients, as well as for secondary use, outside of the clinic. Additional, contextualizing information is added for clarity and interpretability in new context of use [3].

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The study was conducted at a cancer rehabilitation clinic, with a focus on the work of specialized oncology nurses and patients who suffer from treatment-induced survivorship diseases caused by chemotherapy, surgery, and radiotherapy. The patients' symptoms are defecation and urination urgency, fecal leakage, excessive discharge of gas or mucus. At the clinic, the patient is part of a rehabilitation process that includes a mobile app to collect PGHD, subsequent consultations with a nurse, and follow-up telephone calls.

This study shows that when the clinical data gathering become distributed, switching from primarily talk and patient narratives during consultations to also include patient generated data via mobile apps, the context of data production is altered. From the question-answer procedure within the consultation room into the patient's everyday life. Previous literature has not addressed this increasingly pressing issue since PGHD is a more recent phenomenon [5-7]. Consequently, the research question is: How is patient-generated data affecting data production and the patient-nurse consultation? The empirical setting examined is a cancer rehabilitation clinic in West Sweden, with the focus on the nurses' data work during consultations.

1. Method

The approach for this research is a case study that includes different supplementary forms of data, as suggested by Yin [8]. Over a two-year period we engaged with the clinical practice on a bi-weekly basis, and the use of data in the treatment process was studied using observations, interviews, and analysis of documentation. From this larger body of data we in this analysis investigate 20 full days of overt non-participant observation. We observed ten consultations. Additionally, we observed five telephone consultations. Four semi-structured interviews were conducted with the clinic's nurses, and seven interviews with patients. Two workshops were held with nurses and patients, where the focus was on data visualization in consultations.

2. Results

2.1. *The Consultation*

Two different types of consultations have been observed: face-to-face and follow-up telephone calls. The consultation starts with the question: "How is your situation at the moment?" Without the app, the consultation is a situation where the nurse asks questions, and the patient answers based on her memory recollection. To get the necessary information from the patient, the nurse asks a range of questions while also explaining what type of information is needed. Patients must in situ interpret the questions and provide answers based on their recollections days and weeks after the actual activity they are talking about. In most cases, there are memory biases in the patients' answers observable through hesitation and explicitly stating that they are not sure. These answers are extended and many minutes long, consisting of emotions, stories about everyday life with a mixed temporal structure, memories and recollections from the day before are intermingled with last weeks impressions. During consultations, important topics are defecation, urination frequency and urgency. Defecation consistency is relevant to both the diagnosis and treatment plan. To identify

consistency, the nurse shows the patient the Bristol Stool Scale (i.e., a scale used within healthcare to measure defecation consistency), and discusses the consistency in relation to the scale. The nurse asks additional questions concerning the average number of defecations during the last few days and asks about specifics of the feces, such as smell, oiliness, and mucus. Thus, the nurse asks about quantity and complex quality of defecations several days after the actual experience. Thus, the patient need to assess qualities they might never thought of, days after the specific experience.

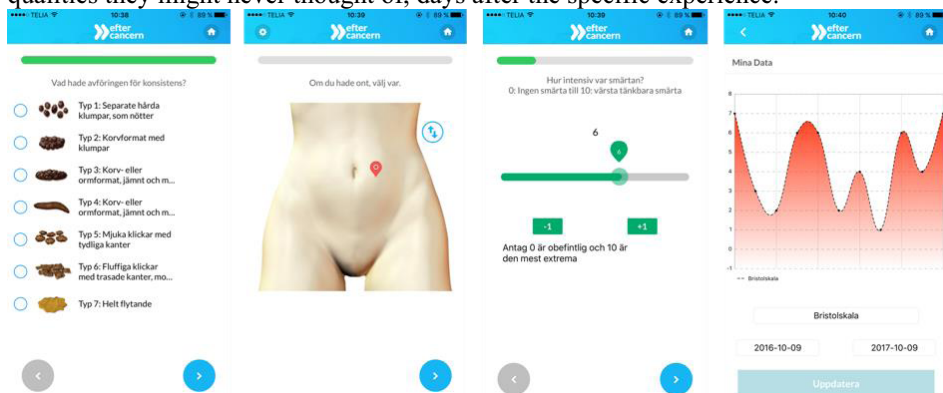


Figure 1. From the app

The patients are informed about the app and can install it on their own device (iPhone/Android). Both the patient and the nurse have access to the patient's data.

Patients who use the app report each time they visit the toilet, when they have pain, or when they take their medication. Thus, when app-data is part of the consultation, the data they use is typically gathered during a two-week period before the consultation. The data is then gathered in connection to the activity it is recording, making it possible for nurses and patients to recreate a more detailed trail of past activities regarding toilet visits. With app-data present it takes different work to elicit or extract information, for instance, about defecations. The data is presented in diagrams, depending on the type of data. A patient expressed how she used the visualizations to check her data to understand how the last couple of days had been. While looking at the visualizations she realized it had really been a hard period, with a lot of defecations. Something she had not reflected upon, prior to looking at the data. She didn't see the big picture while running back and forth to the toilet all the time (Based on patient interview). With PGHD present, the nurse's question tactics move from open questions based on the patient's recollections to more precise questions with a focus on validating data. The first question is usually: "Can you describe how your week has been?" While the data visualizations provide a foundation, the nurse must still lead the consultation and re-contextualize parts of the data. During interviews the nurse state that they have to ask fewer questions and listen more to the patient's re-contextualization of the data. Thus, the data is a way for both parties to participate in the analysis; they focus the discussion on descriptions of the visualized data with the purpose of adding enough information so the nurse can validate premade classifications made by the patient in the app. With PGHD, the patient narrative is based on data, not only memory recollection. It is no longer the nurse who extracts data from the patient narrative. Instead, it is the patient who re-contextualizes the data in order for the nurse to validate it.

3. Discussion: Data re-contextualization

By introducing a new data gathering tool, as well as new visualizations, the data work becomes distributed from the clinic and into the patient's everyday life [9]. This transition affects precision, questions and visualizations as well as the translation process between the patient and the nurse.

With PGHD, part of the translation process is delegated to the patient and the app. The app structures the data collection and de-contextualizes the information. During the consultation, the patient again re-contextualizes the data in order to make it work in the clinical decision-making and the nurse, again re-contextualize it into notes that fit the format of the electronic patient record. In the following text, we will elaborate on this process [1, 10].

3.1. Precision, Questions and Visualizations

When working without app data in the consultation, nurses must extract the relevant data from the patients' narratives. However, with the app, data is collected closer to the actual activity (e.g., defecation or urination), resulting in more reliable data, which is requiring fewer questions from the nurse to interpret. This has three implications.

The consultation has the potential to become more targeted on the actual problem. The patients' symptoms are no longer only represented by patient narratives; instead, the patient takes an active role [9] by repeatedly answering the questions in the app, and is thus educated regarding which information is important during the consultations. The patients' answers about their activities are reported, reduced, and de-contextualized when using the data. Previously, the nurse performed the reduction, from narrative to numbers, while taking notes during and after the consultation.

Questions are about validation rather than information. Visualized patient-generated health data augments the information. The nurses questions based on the app visualization serve to validate the data. This validation is done together in the consultation. The conversation revolves around the nurse asking about the reported data, both as a way of confirming the data and as a way of connecting with the patient. When using the mobile app as part of the consultation, there is a move in precision and focus. For the nurse, *the patient's narrative becomes more reliable when it rests on relevant, precise data*. They no longer need to make the patient talk about last week and the related toilet habits and from that narrative sherry pic relevant data points. With the app data, *the nurse's question tactics change from extracting information to re-contextualization and validation of the visualized data* [1, 11, 12].

Visualizations are not neutral. Data have always been important in consultations but while narratives used to be the carrier of the patient conditions, digital representations in the form of visualizations are becoming more common. Data, or rather visualizations are becoming the patient proxy. It is central to have awareness of the following: Behind each visualization are questions, answers in the form of data and algorithms and graphics performing the visualization. Visualizations are not neutral, each step in the sequence requires careful considering regarding the potential of new biases. By using the app, the patient assesses the activity (toilet visit), enters the data and makes judgement based on the data. Thus, the patient makes assessments as well as judgements without involving the nurse at the time of registration. While this move responsibility from the nurse to the patient, the patient narrative might become limited and only based on the questions in the app. Questions formulated by healthcare rather

than the patient herself. Hence, while the work to gather data and make judgement is moved from the nurse to the patient, it is still, or maybe even more so, the healthcare who defines what data should be collected. While we see that translation work is delegated to the patient and technology and become more collaborative, it is not clear if it empowers the patient or just burdens them with more work.

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