
Benefits and Costs of Patient Generated Data, From the Clinician's and Patient's Perspective

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Abstract

In the relation between patient and clinician, communication is a central aspect. In this short paper, we conceptualize patient-generated data (PGD) as a means of communication. We present a case study in which we explore the experiences of clinicians and patients with PGD. We identify and discuss some real-world trade-offs in using PGD both effectively and meaningfully in clinical practice. Our key finding is that data collection and sharing is about a lot more than the data itself, and that a process of collective meaning making is required to focus on clinically relevant information, and to ground the communication in a sufficiently shared understanding of the subjective experiences associated with objective data points.

Author Keywords

Patient-generated data; Personal health records; Patient-physician relationship; Health care professional; Data science; Data visualization; Quantified Self

ACM Classification Keywords

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

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Figure 1: Toolkit for parents

Introduction

In a clinical relationship, interpersonal trust and effective communication are key contributors to positive health outcomes [3]. Patient-generated data (PGD), obtained through, for example, wearable sensor technology or health apps, can provide valuable information to clinicians about a patients' actual health behaviors over time and in-context, in addition to patients' self-reported behaviors and experiences during standard medical consultations [2]. When clinicians have access to PGD this is likely to change the communication process, and to affect the relation between patients and clinicians. Our short paper will present a case study that focuses on PGD as a means of communication. Looking at both costs and benefits of introducing PGD in a clinical relationship, our case study highlights some of the real-world trade-offs that both clinicians and patients are dealing with in the process of determining, collecting, recording, processing and discussing data.

Case

In the context of parents with newborn children (0-6 months old) with feeding issues, we investigated the value of home collected data for clinicians (varying from nurses in preventative care to pediatricians). A custom developed and adaptive toolkit was deployed (see Figure 1), to enable parents to track and share relevant data in relation to their baby. The toolkit consisted of several data trackers, including a push button, a rotary knob, an on/off switch, an audio tracker, a video module and a text module. Parents could decide for themselves what to track and which labels they would assign to the trackers (e.g., the rotary knob was used by one participant for 'ease of putting my baby to sleep', varying from 'fell asleep

immediately' to 'hard'). During the study, clinicians could also make suggestions on what to track, and how to specify the behavior (e.g., "please track crying, but not the whining that you can solve by feeding or soothing, only the screaming crying"). Via a screen in the toolkit the parents could see their own data, delete incorrect data points, and make comments to data points. Moreover, a chat feature enabled parents to ask questions to and share comments and insights with their clinician or the research team. The data was shared with the clinicians via a dashboard (see Figure 2). The clinicians inspected the data at least once a week, during a visit of the research team, over a period of 5 weeks. During this visit, we interviewed the clinicians on their experience with the data, their interpretation, the added value of the data for their decision-making process, their suggestions for adaptation of the data collection and data visualization in the dashboard. They were asked to respond to messages of the families, if there were any. After every single interview, the research team processed the suggested adaptations in the toolkit and the data visuals.

We involved 7 clinicians, where 3 were actively involved by following 1 or 2 families from their own practice, and 4 clinicians were involved during 2 soundboard meetings where they reflected on the findings. In total, 5 families participated in the study. The multidisciplinary research and design team (8 people) consisted of researchers from various fields, including industrial design, data visualization, human-computer interaction and psychology. This project was sponsored by and situated at Philips Design, and based on the philosophy of "data-enabled design" [1].



Figure 2: Dashboard for clinicians

The shared data, the messages between clinicians and parents, 34 one-hour interviews (22 with clinicians, 12 with parents) and 2 soundboard meetings provided a broad view on the clinician's perspective on PGD. Based on this, we discuss two tradeoffs between costs and benefits of PGD.

Comprehensiveness of data versus information overload

The parents in our study felt motivated to track and share data with their clinician. Many of them reported an urge to provide proof how (serious) the situation was, e.g., by recording how often their baby cried or vomited, or by making videos of the problem behavior of their baby. This was motivated by a frustration that their babies often did not show the relevant behavior during a consultation meeting with the clinician. The burden of data collection was offset by the benefits of sharing a complete picture with the clinician.

Clinicians valued having a complete overview of the baby's behavior and the opportunity to see the problem situations at home via videos. On the other hand, they were also critical. Having such detailed and complete information is rarely required. For them, their information needs start by taking the question of the patient as starting point. Just by understanding and clarifying the question, often suitable advice can be given and the problem can be solved without extra data. Moreover, they emphasized that when you start looking at data, always some issues will come up, which will not necessarily be experienced as a problem by the patient. On top of that, it is often ambiguous what is right or wrong based on data only, the advice highly depends on the experiences, questions, and context of the patient.

Some parents in our study acknowledged potential information overload for the clinician, but they still strived for completeness, afraid that key aspects would be overlooked. A mother reported: "I might be doing something completely wrong, which I'm not aware of, and I want to give my clinician the opportunity to respond to that." The tension between parents trying to be complete and clinicians to keep focused, shows that it is not trivial to give preference to either patient-initiated or clinician-initiated data collection.

Value of objective versus subjective data

The word 'data', is associated with objective and quantifiable facts, like event frequencies, measurable quantities, and other physical units. In our case, shared data have shown to be broader than that. It also included subjective data, i.e., experiences that are implicitly or explicitly reported, e.g., via text or video messages. For example, a mother writing a comment with a vomiting data point stating her baby vomited "at least 5 milliliter!", also contains a (subjective) judgment of the mother that that is a lot of milk.

The value of objective data is clear to both clinicians and parents. For example, by tracking feeds of their baby, parents discovered that they didn't feed 8 times per 24 hours as expected, but only 7 times because of longer intervals during the night. This was important to know, to adapt the amount of milk needed per feed.

However, objective measures are not always practically feasible or relevant. For example, in the case of a baby's crying, an audio tracker can track crying sound, but clinicians explained that a baby can be clearly uncomfortable and still be (relatively) quiet. Therefore, it can be more valid to have parents track their baby's

crying (or discomfort) manually. However, this is in essence a subjective assessment, where one parent may have a lower threshold for pressing the cry-button than another. This is not necessarily a problem, in fact, it can even be an advantage. Many clinicians in our study reported that, in order to fully leverage the objective data, the connection to the experience of the parents (subjective data) is required. For example, some clinicians proposed to parents to indicate whether it was a good or bad day, to fully interpret the data, communicate effectively to the parents, and to generate a suitable advice. In this way, through a process of collective labelling and meaning making, clinicians and parents arrive at a shared understanding of the data.

It is tempting, especially for engineers, to assume that objective data is the most valuable information, and that automated tracking is the best method to collect this data, as it appears to limit human biases in judgement. However, while acknowledging the added value of objective data, our study illustrates the value of subjective data, manual tracking, and collective meaning making. The source of this information can be very broad, varying from the patient's choice of trackers, formulation of labels, textual annotations with data points, or self-reports via video or text.

Conclusion

Patient-generated data (PGD) have the potential to be a valuable addition to clinical practice, by generating a continuous flow of health-related data that can give insight into the temporal dynamics and contextual contingencies of factors influencing individual health. In our case study, we enabled parents of newborn children with feeding issues to determine the sources of data to

be collected, to semantically label these sources, and to share these data with their clinicians. By extensively exploring the experiences of clinicians with PGD, we found that adding PGD to the interaction between patient and clinician, introduces various trade-offs in communication benefits and costs. Our main finding is that data collection and sharing is about a lot more than the data itself, and that a process of collective meaning making is required to focus on clinically relevant information, and to ground the communication in a sufficiently shared understanding of the subjective experiences associated with objective data points.

Background of the workshop participant

The first author will visit the workshop. She has a background in psychology and mathematics. Her interest is in exploiting the strengths of technology and the strengths of humans in the domain of health coaching.

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