

Tell-Tale data: the value of self-tracked data for healthcare professionals

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Tell-Tale Data: The Value of Self- Tracked Data for Healthcare Professionals

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Abstract

In current research on the use of self-tracked data, complete and reliable data are often assumed as conditional for effective use. We argue that this is not only unrealistic, but also not required, for many potential benefits of sharing self-tracking data with healthcare professionals. In this paper, we discuss the value of a large historical account of day-to-day health and lifestyle data as a source of information for healthcare professionals. We see an important role for data as a tool in supporting communication and joint sense- and decision-making between client and healthcare professional.

Author Keywords

Self-tracking; patient-generated data; personal health records; healthcare professional; doctor-patient relationship; personalized health.

ACM Classification Keywords

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

Introduction

More and more people are keeping track of parameters related to their health [4]. The decision to start

tracking may stem from diverse motives, including having specific health-related questions, but also a general curiosity about what the data would show, or an interest in the capabilities of the tracking technology [14]. When health issues are developing, it is likely that at some point a healthcare professional will be consulted, e.g., a lifestyle coach, a general practitioner or a medical specialist. This results in a situation where a healthcare professional may examine self-tracked data (referred to in this domain as 'patient-generated data') of her client [18], as an additional source of information to more traditional diagnostic techniques like anamnesis and physical examination.

In most cases, data gathering begins only *after* a need or desire for tracking is signaled. It would, however, be extremely valuable to already have data *before* a problem arises, to provide a historical perspective and context, as well as an immediate starting point for analysis. For example, when a client develops sleeping problems, it would be helpful to examine her historical data to understand the problem and try to find possible solutions, rather than having to 'wait' for data to be gathered.

In this paper we sketch ways in which sharing a historical account of day-to-day self-tracked data can be beneficial and add value to the quality of healthcare. We discuss potential issues with the quality, reliability and interpretability of a 'lifetime of data', but argue that these shortcomings do not undermine the value of the data as a facilitator in an effective dialog between client and healthcare professional.

Potential Issues with Self-Tracked Data for Healthcare Professionals

Self-tracked data provide information about the client that is more ecologically valid, longitudinal, and fine-grained than data obtained through more traditional means of diagnosis. However, such data may not always be of sufficient quality for healthcare professional to draw reliable conclusions based on them.

First, the data are likely to be incomplete [3]. Especially in cases of very long-term collection of data (years, or even decades), gaps in the data are likely to emerge for a variety of reasons, including technical failure of sensors, or, especially if data are initially collected more or less for fun, user 'sloppiness'. These gaps in the data are unlikely to be random: when nothing was tracked, does that mean that the client did not experience anything worth noting? Were they especially busy, feeling especially well or not well? The answers to these questions are not trivial.

Data may also be incomplete in another sense: entire parameters may not have been tracked that would be needed to reliably interpret the data and draw useful inferences about the health question at hand. Since the question was unknown or irrelevant at time of data collection, the data were not collected for this specific purpose, and the tracked parameters may not suit, or be sufficient, to answer the questions that have emerged. Moreover, even when relevant variables are tracked, it is frequently hard, if not impossible, to determine cause and effect based on historical and incomplete data [6]. If one identifies, for example, a relation between frequent media use and sleep

disturbance, the causality relationship may go in either direction.

In addition, the reliability of the data that are present may be limited. Again, limitations in the robustness of sensor technology play a role, but subjective measures may be especially difficult to interpret. For example, when pain is tracked on a 5-point scale, what do the 1 and the 5 mean? The phenomenological nature of the parameter being tracked leaves the meaning of the numbers entirely up to the user's interpretation. Besides the experience varying from person to person, the experience of symptoms also may vary over time, so that what felt like a "3" a year ago may, for the same client, seem only a "1" a year later. This kind of 'baseline drift' makes interpretation and comparison of data over the long term especially complex.

Potential Value of Self-Tracked Data for Healthcare Professionals

Self-tracked data is rarely a stand-alone source of information. For the client, data about herself is by definition enriched with memories, and for a healthcare professional self-tracked data is often supplement to – rather than substitute for – a person-to-person interaction with the client. This implies that the aforementioned issues regarding to completeness and reliability of the data might not necessarily invalidate the use of long-term self-tracked data in a healthcare context.

Many studies have shown the benefits of good communication between client and healthcare professional, including a good interpersonal relationship, exchanging information and shared decision making [13,15]. Self-tracking data can serve

as a valuable tool in the communication between client and healthcare professional [1,11]. For example, data can serve an effective conversation starter. Just simply pointing to any subset of data (or the conspicuous absence of data) can trigger a response from the client that provides a better understanding of their daily life and experiences (cf. [8]). For example, the client might have been less active last Tuesday, because she visited an ill family member, which is a significant source of stress in her life currently. In other words, for the healthcare professional a number might just represent a step count, but for the client, there is a rich landscape of context, emotions and memories hidden behind that number.

This approach is in line with the concept of "lived informatics" [14], where self-tracking, especially on the long-term, is strongly related to people's subjective experiences instead of their objective behaviors. Also, Elsdon et al. [2] argue that the purpose of long-term self-tracking is mainly about creating an account of meaningful digital possessions, to serve for example as an external memory. Odom et al. [12] even go a step further, exploring the value of self-tracking data as digital inheritance. The general lesson here is that the value of self-tracking to a client is often related to what the data *means* to them, instead of the data itself. Not only for clients, also for healthcare professionals there is a value of self-tracking data in this regard, for example serving as trigger and facilitator of collaborative reflection and shared understanding [10,11,17].

In our own recent study [9,16], we also found evidence for the value of self-tracking 'beyond' the data, i.e. on the level of meta-data. For example, the simple fact

that a variable is chosen to be tracked, and the way it is tracked, can be informative in and of itself to the healthcare professional. When parents shared data of their newborns with healthcare professionals, the description of tracked parameters helped the healthcare professional to understand issues parents worried about or thought to be important. When parents shared data labelled as 'the ease of putting my baby to sleep', this reveals much more information than just 'sleep'. Also the opportunity to annotate the data provided a rich understanding of the client's subjective experience and context beyond the data points.

So, when clients share their data with their healthcare professional, they share much more than solely the data. By sharing their data, they focus the attention on the things that are important to them, they reveal their subjective experiences, their beliefs about what is good and healthy, their goals, and their perceived barriers.

The Illusion of a Need for Complete and Reliable Data

Currently, substantial efforts are made to understand the abandonment of devices [e.g.,4,5], implying that more and better data results in a greater usefulness of the data. Given the complexities of long-term tracking, the ambition of fully complete, reliable and 'high-quality' data might be an unrealistic one. More importantly, it may be an unnecessary and even misguided ambition. As we have argued, complete and reliable data are not required to leverage the value of sharing historical self-tracked data as tool in effective communication (cf. [2]). Gaps and irregularities in the data are, paradoxically, profitable triggers for healthcare professionals to use in their dialog with the client, giving them access to the rich context of

memories and experiences of the client. Observing what the client is inclined to track, whether it is 'for fun', or driven by a general curiosity or a specific worry about her own life, can be a valuable source of information and a starting point for effective communication, and shared sense- and decision-making between client and healthcare professional [11].

Our work underlines the value of participatory design and socially constructive approaches to self-tracking [7]. To move from raw data to personally and clinically meaningful information, self-tracked data need to be re-contextualized and interpreted through the lens of a personal narrative. In our view, this 'tell-tale data', even when incomplete, offers significant opportunities for a fruitful data-supported dialog between healthcare professional and their self-tracking clients.

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