

Infrastructuring knowledge in practice: designing self-experiments for type 2 Diabetes care

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Abstract. Healthcare institutions increasingly delegate the self-management of their condition to patients and their extended network: consequently, there is an increasing production of patient health data outside healthcare settings, also thanks to the increasing number of digital technologies able to assist in the collecting, interpretation and use of health data. This shift on the “personal” dimension of data has placed emphasis on self-knowledge practices supported by personal informatics systems. In the last years, studies on digital technologies supporting lifestyle-related diseases are becoming interested in the so-called “personal experiments”, emphasizing self-interpretation of patient-generated health data through self-reflection. In this paper I will present some preliminary points concerning my PhD research project, in which I’m following the co-design and implementation of technology-supported personal experiments aiming to encourage type 2 diabetes patients to collect personal health data and increase their motivation and self-knowledge.

Introduction

In recent years in the healthcare sector there has been a growing emphasis on self-knowledge practices supported by personal informatics systems, shifting the attention on the “personal” dimension of health data (Gherardi et al. 2018). This is despite health care services sometimes obstruct rather than support self-care and learning (Cooper et al. 2003), because the ethics of individualism (i.e. blaming the individual patient), because the privileging of experts over lay people and because a one-way flow of information (Gravois Lee and Garvin 2003). The increasing production of patient health data outside healthcare settings is made easier by the growing number of digital technologies able to assist in the collecting, interpretation and use of health data (Piras 2016, 2018). In numerous clinical settings, patients are required to keep track of parameters for various purposes (e.g. management, diagnosis) and in some cases, the objective of the patient-provider encounter itself is the analysis of self-tracked data. This collection specifically denotes the monitoring of data that can only be collected by patients themselves, sometimes also referred to as ‘observation of daily living’ (Brennan & Casper, 2015). Recently, studies on personal informatics systems supporting lifestyle-related diseases are becoming interested in the so-called “personal experiments”, a

collection of data based on self-tracking but with a particular emphasis on self-interpretation of data through a structured self-reflection. In the next paragraphs I will present the background and motivation of my PhD project, aimed to investigate how personal experiments goes into the process of knowledge and management of type 2 Diabetes, affecting the daily care practices of patients and their relationship with providers.

From collection to reflection: self-experiments

The starting point of my PhD project has been to explore and try to give an order to literature about systems and methodologies that support the conduction of “self-experiments” aimed to collect health data for self-knowledge. These approaches has been explored especially by studies on Personal Informatics (PI), defined ‘those that help people to collect personally relevant information for the purpose of self-reflection and gaining self-knowledge’ (Li et al. 2010, 558). The advent of digital technologies has been vitally important in promoting the cause of PI. Mobile and wearable digital devices have facilitated the ever more detailed measurement and monitoring of the body and everyday life in real time and the analysis, presentation and sharing of these data (Lupton 2014). The conventional approach driving personal informatics systems in the field has been self-betterment through self-knowledge, potentially enabling the arising of self-discoveries, self-reflection, and triggering processes of behaviour change (Choe et al. 2014; Rapp et al. 2018). In recent years PI has been expanded to include the so-called “lifestyle related diseases,” including metabolic syndrome, obesity, cardiovascular disease and type 2 diabetes (Heymsfield & Wadden 2017; Arsenault & Després 2017; Van Ommen et al. 2018). This shifting has led to a growing interest in production of personal health data outside healthcare settings. From this perspective, PI can be employed as an intervention technique for behavior recording and producing a change in behaviour itself (Consolvo et al. 2006, Matthews & Doherty 2011; Rapp et al. 2018). Following this stream, some studies have been shifted the focus on self-experimentations or personal experiments (Daskalova et al. 2016; Karkar et al. 2015; Lee et al. 2017; Kocielniket al. 2018). The “experiment” can take place independently or in collaboration with health providers and usually requires three standardized phases: formulating a hypothesis (es. “does physical activity impact my glycemic index?”), testing the hypothesis (measuring glycemic index before and after doing physical activity) and examining the results of the study through reflection (Karkar et al. 2015; Lee et al. 2017). The hypothesis is testing using “paired testing” (Parkin et al. 2009; Greenwood 2015), a process that includes defining independent variables (e.g., causes, triggers) and the dependent variables they may affect (e.g., symptoms, health outcomes). Technology for self-experimentation can be included in this process: traditional self-tracking methods, such as food journals or fitness trackers, may be adopted to collect data and tests hypotheses. Patients can then use findings to target the most appropriate health behavior change to address their needs.

A key-concept of personal experiments is that of “self-reflection”: patient is involved in both collection and reflection on the data at the end of the experiment. (Baumer 2015; Li et al. 2010; Greenwood 2016). Clinicians have a significant role in the final reflection: they can encourage the person’s problem-solving skills by asking questions (e.g.: “Review the comments you made during the week. What can you learn from these notes?”, or “What changes can you make next week? What would you like to learn?”) helping them to reflect on their week. According to literature, reflecting on their data patients can increase their self-knowledge and formulate realistic behavior change goals (Lee et al. 2015; Kocielnik et al. 2018). However, as for the reflection phase, a gap exists in understanding how the reflection process can be supported through technology (Slovak et al. 2017; Baumer 2015; Fleck and Fitzpatrick 2010; Baumer et al. 2014). Indeed, one first means of facilitating reflection in behavior change and personal informatics relies on visualizations of self-tracking data, assuming that reflection will occur naturally when data is presented (Kocielnik et al.2018). One second means is based on conversational systems that delivers a structured reflection prompts on 3 levels based on learning theory: Noticing, Understanding, and Future Actions (Fleck and Fitzpatrick 2010; Moon 2013). A third means could be to integrate a motivational interviewing approach that can help patients identify their strengths and challenges and what changes they can implement in an action plan (Greenwood 2015).

As illustrated in the previous paragraphs, although the emphasis of personal-experiments on the importance of self-experience, literature describes the process as strictly standardized and methodologically rigorous. Analysis on self-knowledge are limited to the “reflection” phase, conceived as a well-defined moment that follows a structured script. These approaches are especially focused on the development of persuasive systems and on the evaluation of behavioral and clinical outputs, but seeks to overshadow the broad processes and infrastructures through which, during the use of a technology, knowledge practices take place.

The case study: infrastructuring self-experiments for type 2 diabetes

My PhD research project is flanking a clinical trial conducted in north Italy and aimed at quantifying the effectiveness and the acceptability of a self-tracking/remote-monitoring platform for type 1 and 2 diabetes patients. The system includes a web interface for the doctor (medical dashboard) and a mobile interface for the patient (app). The web-based dashboard accessible by doctors was endowed with a system of rule-based alarms designed to send an alert to clinicians and/or patients in the presence of certain data or combinations of data, and permits to the doctor to activate or not activate the functions of the app, depending on patient’s needs. The app for the patient is prescribed by the doctor and supports the management of diabetes, partly through virtual coaching, and partly sharing data with the doctor. The virtual coaching intervention is preceded by a self-care profiling phase and a patient's lifestyles analysis. The main features of the app are

patient’s diary, on-demand educational modules, microlearnig activities, a virtual coach intervention to support lifestyle goals defined with clinician, a chat with other patients and a chat with clinicians. It is also expected the design and implementation of a digital support for the execution of personal experiments. The idea is that clinician could prescribe the experiment from his/her dashboard, “personal experiment” feature would support patients during the data collection -sending reminders and motivational messages- and at the end of the experiment provider would encourage patient’s reflection on their data asking them focused questions. The more long-term goal of the implementation of this feature is to design and implement a chatbot-based conversation that would permit to patients to reflect independently on their data. The whole implementation process is shown in the figure below, that includes also a preliminary phase during which personal experiments will be conducted using a paper diary, according to a co-design approach. And that’s where my doctoral project came in.

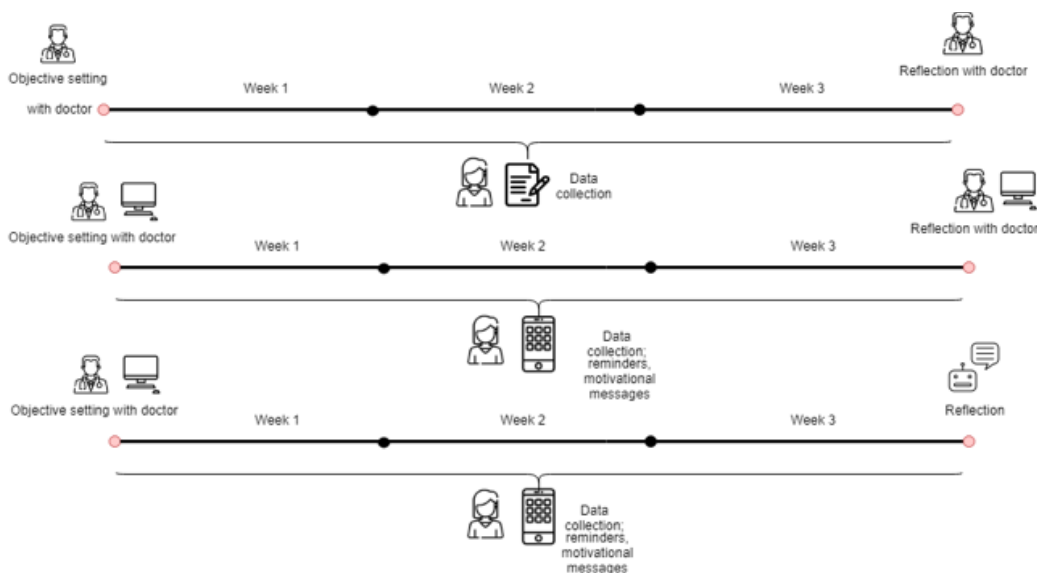


Figure 1. Implementation process

Type 2 Diabetes

The case study introduced in this paper is therefore part of this larger infrastructural arrangement and will explore type 2 diabetic patients’ experience and practice of personal experiments as part of their medical treatment. Indeed, type 2 diabetes (T2D) seems to be an interesting setting to explore digitally-supported personal experiments. T2D is a “genotype-environment interaction disease”, where the diabetic phenotype is expressed as a result of accumulated environmental pressures (wrong diet, too little physical exercise, disrupted sleep, and too much stress) in concert with genes that render individuals susceptible to the disease (Van Ommen et al. 2018). The chances of getting T2D increase with age and often occurs in

combination with other symptoms and diseases such as overweight and cardiovascular diseases. T2D is quite mute and can remain unnoticed for several years without the diabetic experiencing the disease very concretely. Such as other chronic conditions, T2D need long-term approach to care, which imply a higher synergy and service integration outside of the institutional boundaries of hospitals. To be a type 2 diabetic thus entails that you learn to be diabetic, and that you must continue to be so for the rest of your life (Maunsbach 1999). Since it is mostly treated through a combination of medication and lifestyle changes, such as dieting and physical exercise, it must include the patient's active participation in both the treatment and the preventive actions against further development of the disease. Hence, patient empowerment is central to the diabetic condition in order to enable diabetics to participate actively and rationally in their treatment (Danholt et al. 2004). Studies explored the effectiveness of mHealth interventions in modifying type 2 diabetes patients lifestyles, especially those related to dietary behaviors and physical activity, by facilitating diabetes self-management processes outside the clinical setting (Cotter et al. 2013; Holts, Loring).

Personal experiments as sociotechnical infrastructure

Although contextual informations and personal knowledge provided by patients and caregivers are relevant, their contribution is often underestimated as an integral part of a work of articulation of care that remains invisible or underestimated (Unruh e Pratt 2008; Piras e Zanutto 2010; Gherardi et al. 2018). Therefore, my intention is to consider personal experiments as organizational arrangements and knowledge forms that are to be weaved into existing healthcare structures. On that basis, P.E. are sociotechnical infrastructures of care permeating the daily lives of patients and health professional and that may have implications for what it means to be a patient (and a health professional) and what constitutes care in practice (Langstrup 2013). In order to analyze P.E. from this point of view, I draw on perspectives from Science and Technology Studies and in particular on processes through which the diabetic patient learns to manage his/her illness (Mol, 2000; Mol e Law, 2004; Bruni e Rizzi, 2013; Miele, Piras 2016). The studies of Annemarie Mol, in particular, show how diabetes management is a situated and emerging activity that involves first of all the patient's body, technologies and therapies, leading the individual to develop their knowledge about the disease. Health data tracking has a situated meaning, and specific sense of clinical self-tracking must be considered in the context of the organisational practices of which it is part (Gherardi, 2010; Oudshoorn, 2012). The same self-tracking activities may be performed to delegate an active role to patients, to monitor their compliance, to educate newly diagnosed patients or to delegate most of the care to patients themselves. From this perspective, technologies allow patients to redefine their identity, renegotiate the power relationship with health professionals and become experts in their illness (Ballegaard et al. 2008). This is because management tools "do much more than passively record an act" (Mol 2000, 9), becoming an essential part of the process that leads the patient to become autonomous from the doctor and, at the same time, orienting him to assimilate part of the medical role,

internalizing the practices and changing their gaze on data and measurements (Miele, Piras 2016). Observed through these lenses, P.E. are part of a context in which care practices are complex activities learned over time through continuous trials and errors, carefully studying your body and its reactions to various attempts to treat it and bring it to a state of well-being.

Conclusions and next steps

Starting from these considerations, my main research interest is to investigate how personal experiments fit into the daily care practices of persons with type 2 Diabetes, affecting the processes of knowledge and management of their illness.

Starting from this research interest, I am facing the following points of analysis:

- *The learning processes triggered by personal experiments*, observing the forms of appropriation and knowledge of personal experiments as sociotechnical infrastructures that involve the patient's body, objects, technologies, contexts and relations.
- *The ways in which in which personal experiments, and in particular the final reflection on personal data, affect the motivation* of persons with type 2 diabetes to maintain a correct lifestyle and, in the long term, affect their behavioral change.
- *The ways in which personal experiments fits in the doctor-patient relationship*, observing how technology becomes part of the doctor-patient relationship and affects existent educational and motivational practices.

Before starting the empirical study, I am planning to do two focus groups with clinicians and with diabetic patients, and a co-design workshop with diabetic patients to gather reactions to the self-experimentation process, to explore how self-experimentation fits with participant priorities and to design a first paper instrument.

During the empirical study, in order to explore educational and motivational efficacy of personal experiments, I am planning to do motivational interviews and questionnaires on self-efficacy and health literacy. In order to explore learning processes triggered by personal experiments, I set out to do semi-structured interviews with patients with diabetes after personal experiments.

In order to explore personal experiments inside the doctor-patient relationship, I propose to do semi-structured interviews with doctors before personal experiments and ethnographic observations of clinical encounters before and after the carrying out of personal experiments.

At the end of the empirical study, during which personal experiments will be conducted through a paper diary, the results will be delivered to the developers of the app, in order to implement a more efficient and user-centered instrument.

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