More Than Numbers: Designing Effective Diabetes Decision Support

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Abstract
Type 1 Diabetes is a serious condition that demands careful balancing of lifestyle and medication to avoid serious complications. Current mobile health approaches for diabetes management are usually either automated insulin delivery systems or logbooks that depend on manual data collection and reflection. Both have their shortcoming such as loss of engagement and autonomy in the former approach, or fatigue and cognitive stress in the latter. Based on my pilot research, my thesis considers the wider implications of an approach that: (1) reduces workload through minimizing manual logging; (2) automates knowledge extraction from collected data (3) communicates insight in the right way at the right time; (4) creates a feedback loop that encourages previously effective behaviors. This thesis contributes to the exploration and evaluation of new strategies for mobile personalized support through ubiquitous computing technologies, and the development of tools for improving the lives of those with chronic health conditions

Current Academic Situation
In August 2016, I completed the probation period at The Open University UK, with a written summary and oral defense of past and planned work. I now enter my principal research, which explores reducing the effort of

leveraging personal health data. This inquiry will be conducted in the UK and Germany, and will explore UI/UX associated with networked and mobile personal health systems. With my advisor, Blaine Price, we will be working with the NHS Research Ethics Committee and Milton Keynes General Hospital as well as with the Berlin diabetes community to further pursue this work.

Context and Motivation for Dissertation

A few years ago, I experienced significant health concerns and realized that I needed to better manage my Type 1 Diabetes (T1D), or risk serious consequences. I became interested in the potential benefits of newer digital technologies, and entered the PhD program in human computer interaction (HCI) at the Open University to contribute to this effort. My principal research focuses on the use of ubiquitous computing to assist in the management of T1D, a prevalent and serious chronic condition that necessitates the careful balancing of multiple lifestyle factors and the hormone insulin to avoid severe short and long-term complications. Mobile devices such as smartphones are promising platforms, and there are already over a thousand diabetes apps available. However, my early research suggests that 'logging' apps, the paradigm most often associated with daily care, often suffer from poor long-term adoption, and therefore could be improved.

Research Objectives/Goals/Questions

This thesis seeks to support more effective management of chronic health conditions by researching how automated decision support systems could assist with daily management. Such a system could be differentiated from the three principal existing paradigms: the 'artificial pancreas' that attempts to automate insulin dosages; repetitive manual recording as a tool of increasing engagement with personal data; and cognitively demanding reflection on collected data as a means of personal growth and positive habit formation. My earlier research has suggested the need to increase the perceived value of interventions while minimizing the work required [5], and to overcome the barriers users face in deriving actionable insights from collected data [6]. I therefore posit four key areas for designing a sustainable-use mobile diabetes system for assisting with daily care: (1) minimize manual logging to reduce workload and increase long-term adoption; (2) automate knowledge extraction from collected data to reduce bias and effort; (3) communicate the correct insight in the right way at the right time; (4) encourage previously effective behaviors. My research will investigate the potential for integration of these areas, as well as their psychosocial implications.

Background/Literature Review

The HCI community has long investigated the ways in which digital technologies can encourage healthier behaviors. UbiFit garden attempted to foster physical activity using a graphic garden metaphor on a mobile device [2], while Fish'n'Steps used social mechanisms, sharing step information as a motivator [8]. Intille et al. [4] proposed precisely timed reminders to support healthful behavior change. The Quantified Self (QS) movement has led to much interest in the role of personal data for life optimization. Li et al. [7] asserted that while manual data collection could support engagement, it also formed a major barrier to long-term use. However, Li et al. cautioned automation potentially reduced awareness, and that other means become necessary to keep users engaged. HCI techniques have frequently been applied to assist with

diabetes management, with many researchers developing digital tools to increase engagement with personal data. Mamykina et al. [9] has written extensively on the use of technology to support diabetes management through encouraging deliberate 'sensemaking'. Much HCI research in diabetes has primarily involved tools to enable collection and effortful reflection on personal data. The paradigm can be seen as an extension of earlier paper-based diary systems, with the addition of digital features such as social sharing, analytics, and data visualization. However, there is a lack of specific research on how best to communicate to end-users the complex, emotion-laden, multivariate data of the kind that PWD must process on a daily basis to maintain glycemic control. Furthermore, Harrison [3] noted that due to the mobile nature of smartphones, cognitive load is an essential factor to be considered in app usability, as users expect the platform to reduce mental stress. This view implies that an app that requires excessive cognitive effort faces a major barrier to adoption. Barr et al. [1] supported this theory, highlighting the ways in which smartphones have become an extension of the mind, and asserting the natural human tendency to seek to reduce cognitive load. This propensity towards conserving mental effort would seem to promote the need for intuitive rather than effortful experiences with mobile devices, implying a need for automated assistance in understanding complex data.

Problem Statement/Research Question

Type 1 diabetes and other chronic health conditions negatively impact quality of life, are financially costly, and increasingly prevalent. Digital devices such as blood glucose meters, insulin pumps, and continual glucose monitors have successfully been adopted into daily self-care routines, but are currently limited in ability to offer personalized advice. Existing diabetes management apps depend on collecting diverse personal data, which is then displayed within charts, tables, and graphs. However, the value of such systems is limited by the user's ability to continuously maintain data collection, successfully derive insights from these assets, and convert insights into action. This process places significant barriers to long-term adoption and practical utility. While telemedicine or networked experts can offer valuable advice, the total number of individuals with chronic health conditions, and their requirements place limits as to the economic scalability of such models. Therefore, I propose researching the design of a practical and autonomous system for assisting in diabetes self-management. Such a system must meet diverse user requirements such as: privacy and security, low workload, ease of use, trustworthiness, emotional sensitivity, and adaptability to individual lifestyles. As such systems do not currently exist and are difficult to pass through regulatory standards, there is currently limited knowledge as to how such systems would fit into the complex ecosystems of personal health care.

Research Question:
What are the primary concerns and necessary components of an automated system that is capable of providing appropriate information derived from contextually relevant data to assist in T1 diabetes management from a patient-centered perspective?

Research Approach and Methods

This thesis will apply diverse methods in order to investigate user needs, and to evaluate potential solutions. The first stage of my research employed a

survey and semi-structured interview to investigate long-term use of diabetes apps, as well as to probe the user experience associated with these systems. This was followed by an interaction study exploring existing diabetes apps as tools for understanding data. The next stage will use a combination of consumer devices for acquiring data; semi-structured interviews to better understand user experience and privacy concerns with wearable health support systems; statistical analysis to derive meaningful correlations from collected data; and established HCI techniques such as prototyping and participatory design to explore means of communicating relevant information with glanceable watch interfaces.

Results to Date

The initial pilot study [5] suggested that there remain substantial barriers to the long-term adoption of diabetes smartphone apps due to such factors as poor perceived value in relation to work required, negative emotional impact, lack of sufficient positive effects, and doctor resistance. While these apps continued to be used periodically by a minority of users, and were for certain situations seen as useful tools, they were only being used daily in 2/26 cases. Considering the continual demands of diabetes management, and that the great majority of participants were using non-diabetes apps on a daily basis, this suggests the potential for improvements in diabetes app design. The following study [6] suggested that while diabetes logging apps are useful for broad overviews of collected data, they do not adequately support the understanding of the subtle correlations in multivariate data that are essential for making better decisions. Many participants expressed a desire for clearly stated, immediately applicable insights rather than tools for past reflection.

Dissertation Status and Next Steps

Last spring, I completed the probationary phase of PhD studies in HCI at The Open University, in the UK. The assessment included delivery of a viable research question, literature review, research proposal, preliminary work, work plan, and mini viva examination. My expected completion date is set for Fall 2018. I will now enter into my next stages of gathering diabetes lifestyle relevant data for analysis, and research on how connected systems could better integrate and support health management practices.

Current and Expected Contributions

The primary contributions so far have been in helping to understand why existing diabetes logging apps are not adequately meeting user needs, and the ways in which reflection based app paradigms can be ill-suited to mobile platforms. Future work will contribute to the development of personalized mobile health support systems. Key areas of exploration include: (1) psycho-social implications of wearable connected tracking systems; (2) privacy and security concerns of systems which track and process lifestyle and medical data; (2) the role of automation in adoption; (3) the viability and acceptance of automated lifestyle suggestions; (4) methods of communicating health insights in an intuitive, emotionally sensitive, and actionable manner.

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