How to Design Persuasive Health Technologies for Adolescents with Chronic Illness?

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Abstract  
In this workshop, we will share our experience of working with individuals with asthma and diabetes as well as their caregivers. In our work we have focused on understanding how to improve both the physiological and psychological aspect of disease outcomes. The goal is to discuss the role that persuasive health technologies can have in improving the adherence and self-monitoring of adolescents battling these diseases.

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Introduction  
Chronic diseases such as diabetes and asthma are defined by the World Health Organization as "diseases of long duration and generally slow progression." Management of these diseases requires constant
monitoring and medication regimens that can be particularly difficult for children to follow [1]. On a physiological level, diabetes patients need to monitor their blood sugar to potentially adjust their treatment plans and asthma patients are recommended to keep track of their peak flow measures. On a psychological level, patients with a chronic illness should all be aware of their recent symptoms and to reflect on their behaviors that influence their disease progression. This requires a lot of discipline on a day-to-day basis, so parents of children with chronic illness are often advised to help their children with these tasks. However, as children mature, their parents are encouraged to let them take greater responsibility for the management of their disease. This transition of care normally occurs when they become adolescents, and this leads to serious control issues.

Technologies for Self-Monitoring
Self-monitoring is a big part of chronic care management and is shown to be an effective method for health behavior change [7]. This is the case for both asthma and diabetes. Technologies exist that automatically collect and visualize the physiological measure of interest (whether blood glucose or peak flow). The idea is that viewing the history of their outcome measure should allow the patients to spot issues and reflect on their self-care behaviors.

On a psychological level, recent studies investigated the use of ubiquitous computing technologies to help patients monitor their recent symptoms [7]. Using the MAHI system allowed diabetes participants to achieve more of their self-management goals. After using the system these patients were found to have adapted an internal locus of control. However, this research was conducted with adults. Thus, the question still remains whether the same self-monitoring methodology can be effectively applied to adolescents who may have a vague sense of responsibility and inadequate knowledge of self-management.

Adherence Issues for Adolescents
Adolescents with chronic illness have more regimen adherence issues than adults. In a study of adherence to self-management of diabetes, patients aged 10-20 were found to have the worst level of control and adherence to their treatment plans when compared to patients younger than 10 years old or older than 20 years old [8]. The researchers sited both physiological and psychological reasons for these results. These included: changes in insulin resistance, reaction to the hormone changes of puberty, recklessness, error, simple fatigue in daily management. The psychological issues may also be related to the fact that it is the first time that this population has to take responsibility for managing their chronic illness. An article mentioned another psychological cause may be that adolescents usually feel that they are invulnerable to the long-term complications of their chronic illness [3]. With the dramatic mental and physical change at this time of their life, it is very challenging for adolescents to keep their chronic illness under control.

Result from our interviews with diabetes health care providers indicate that the only effective way to get adolescent patients to adhere to their treatment plans is to get their parents involved, someone who can hold them accountable for their self-management behaviors. This concurs with results from previous studies that showed premature withdrawal of parental involvement in the adolescent’s diabetes self-management can
cause poor diabetes control [10]. However, we have taken the approach that we do not only have to count on parents to monitor children’s ongoing care. We allowed another stakeholder, the healthcare providers, to loosely monitor the pediatric asthma patients remotely with non-individualized messages. We did this by using an SMS system to query patients about their asthma symptoms.

**Individualized Feedback to Support Self-Monitoring**

In building technology to motivate individuals to self-monitor, the question arises as to the necessity of supporting individualized feedback. The literature indicates that systems with or without individualized feedback can both be effective.

Diabetes remote monitoring systems that encourage self-monitoring behaviors of the patients have showed promising results. One study had diabetologists provide personal feedback via SMS on the mobile phone to help adolescents manage their disease based on the self-monitoring data they sent over [9]. A similar positive finding was reported using another system that sends individually-targeted messages about diabetes care automatically to adolescent diabetes patients with motivational messages provided by a diabetes care team [2].

Having personalized feedback is effective to motivate the adolescent patients better manage their chronic illness. However, the cost of having a real person remotely supporting the patients is still high. The good news is that providing no personalized feedback has been found to lead to positive outcomes as well with better self-monitoring.

We designed a system that sends predefined SMS text messages daily to ask them about their recent symptoms, medication, and general knowledge about asthma [11]. This effectively helps the patients self-monitor their chronic diseases. When a patient responds to a question with a simple Yes/No (Y/N) text message, the answer is immediately sent to a clinical system that alerts the patient’s doctor about the response. The patient never received any individualized response via our system but we nevertheless had a high overall 87% response rate during the 4 month study period. The study group that received daily messages showed significantly improved pulmonary function. These exciting results have led us to apply this methodology to adolescent diabetes patients to see if it can also lead to improved physiological outcomes.

**Towards Self-Motivated Self-Monitoring**

Our earlier work showed that using non-individualized messages with minimal remote support from the doctor's office can help the patients improve their health outcome. The patients are partially motivated by the health care providers that inspect their self-monitoring behaviors. The question is can we push it even further by completely removing this remote person holding the patients responsible for their self-management tasks and moving towards self-motivated self-monitoring? In this case, the role of persuasive technologies could be to motivate proper self-monitoring behaviors of adolescent patients and in turn alleviate the impact of the transition to independent self-management of their chronic illness.

Research found that teens like to text and enjoy using online social networking tools [5, 6]. Therefore, can we use these tools to aid adolescents in their daily
monitoring? For example, can an online community of adolescents with chronic illness leverage their shared experience with the disease so that the social interaction serves to motivate the self-monitoring behavior of the individual?

A final consideration is that earlier studies showed that people with different personality types can have dramatic differences in what persuasive techniques will work for them [4]. For adolescents that are actively trying to change their personality to fit into their social life, this can pose a particularly challenging issue.

In summary, what we want to bring to the discussion table is 1) sharing our experience in working with individuals with asthma and diabetes as well as their caregivers; and 2) discussing what types of novel persuasive technologies could be designed to help adolescent patients better monitor their chronic illness and achieve better regimen adherence and control.

References