



Health information technologies for patients with diabetes



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ABSTRACT

Patients with chronic illnesses, such as diabetes, need daily care and follow-up beyond occasional visits to healthcare providers. Research has shown that overcoming a multifaceted illness, such as diabetes, requires patients to be engaged in the monitoring and management of their own health. Health information technology (HIT) has been shown to empower chronically-ill patients to take charge of their healthcare, and alleviate their daily frustrations while they strive to lead a normal life. In this paper, we surveyed 31 patients with diabetes to identify the major frustrations they experience daily, examine the role of HIT in their current treatment, and identify gaps in their current care and education that, if addressed, could improve their quality of life. Themes identified in our survey results include a lack of interaction with healthcare providers, difficulties in scheduling appointments, a lack of timely communication with healthcare providers, and challenges in managing the complex care of diabetes. The contributions of this paper include a detailed set of recommendations on how HIT can be utilized to help chronically-ill patients live a better life despite their illnesses, with a particular emphasis on diabetes care and management.

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1. Introduction

Diabetes is a metabolic disease that causes individuals to have high blood glucose levels because their body does not produce enough insulin or because their body does not respond to the insulin that they produce. This disease currently affects nearly ten percent of Americans [1]. If the current trend ensues, it is expected that 1 in 3 Americans will have diabetes by 2050 [1]. Type 1 diabetes often begins suddenly in young people and is not related to obesity. Rather, it is caused by an autoimmune response that destroys the body's ability to produce insulin. Type 2 diabetes, on the other hand, is an insulin-resistant disease that is often linked to obesity, family history, impaired glucose metabolism, and/or physical inactivity. Once thought to be an adult-onset illness that rarely strikes individuals under the age of 40, Type 2 diabetes is

now a growing problem among children and young adults [2]. Type 3c diabetes, also known as exocrine pancreatic insufficiency, occurs when a patient has characteristics of Type 1 diabetes but it is discovered later in life. Type 3c diabetes is relatively rare, accounting for only 0.5–1.5% of all people with diabetes [3]. Unlike Type 2 diabetes that is related to insulin resistance, both Type 1 and Type 3c diabetes occur when the islet cells are destroyed by the immune system. There is no known cure for diabetes, but the disease can be controlled through health management that includes keeping blood glucose levels as close to normal as possible with diet, exercise, and medications, possibly including insulin injections [2].

For many years, patients with Type 1 diabetes were only able to manage their disease with insulin injections that they were required to take 4–6 times per day to keep blood glucose levels under control. While this method of managing the disease is still used by some people and has been mostly effective, it relies heavily on the patient's memory. Often times, when patients forget whether they have already received their insulin injection, too little or too much insulin would be injected. If patients had taken an insulin injection and had forgotten about it, additional insulin from

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another injection would cause their blood glucose level to drop too low, resulting in sweating, dizziness, headaches, and fatigue. Conversely, forgetting to take the insulin injection would cause the patients' blood glucose levels to become dangerously high. Prior studies [4,5] have shown that health information technology (HIT) can effectively decrease these memory lapses, and can help improve the overall health of people with diabetes at a much lower cost. The insulin pump, in particular, is an HIT innovation that automatically administers insulin in a patient's blood stream; however only basal insulin is administered in this manner. Patients must still count the number of carbohydrates they consume and input the amount of insulin needed to cover the intake. Additionally, if blood glucose is elevated, the insulin pump should be calibrated to provide enough insulin so as to effectively lower the elevated blood glucose level. A Continuous Glucose Monitor is another tool that can be utilized with the insulin pump to assist with keeping glucose levels within the prescribed control range. Like the insulin pump, however, the glucose monitor has a plastic cannula that remains under the skin, possibly increasing the dangers of having an additional break in the integument. Additionally, the Continuous Glucose Monitor is not covered by many insurance companies creating yet another cost barrier [6]. In sum, there are various HIT products that can effectively improve the health and safety of patients with diabetes, but they often cause additional frustrations for patients.

In this paper, we conduct a survey of patients with Type 1, Type 2, and Type 3c diabetes, to gauge how, from their own point of view, HIT can help them conquer their respective diseases and improve their lives. The information gathered during this study allowed us to make recommendations about how to best utilize HIT to alleviate the struggles of patients with diabetes. Because of the complexity of managing diabetes it would be ambitious to claim that HIT can resolve all of the patients' frustrations; nevertheless, our findings show that many of these frustrations emanate from the patients' difficulties in closely managing their health, which can be greatly improved with the help of HIT.

The rest of the paper is organized as follows. We first present findings from a systematic literature review on how HIT has been used to help patients with diabetes. We then discuss how we collected the survey data and present demographics and other characteristics of the surveyed patients. In the following sections, we consecutively present our findings, a set of recommendations and tools to better manage diabetes, and critical barriers to the successful adoption and implementation of these recommendations. We finally conclude by discussing the contributions and some limitations of the study, and by setting possible avenues for future research.

2. Background

A systematic review of the literature was conducted using the CINAHL database and the search terms "diabetes" AND "information technology" with limiters of being available in full text, published after January 1, 2005 and available in the English language. This returned 32 results. After reviewing those results, 21 were identified as not relevant to the topic studied because they either examine a different disease or are aimed at providers instead of patients. This left 11 articles for review. In examining the literature, several themes were identified, including challenges in diabetes management, difficulties with and between healthcare providers, difficulty in scheduling appointments, and a lack of interaction with healthcare providers. In reviewing each of these articles we did notice that although many focused on patient research they were not patient-focused; that is they did not discuss with the patient how HIT worked for them personally.

One theme that was identified in 6 articles is that of the personal challenges with managing the complexity of diabetes [7–12]. Lairson et al. [7] recognized that the complexity of the study, necessitated by the complexity of the disease, decreased the ability of patients to adhere to their treatment plans. Morrin et al. [10] investigated in their study whether or not the use of an EHR system improved patients' ability to manage their healthcare. The authors found that, as a freestanding use of technology, EHR systems do not improve diabetes care. Halkoaho et al. [8] found that the utilization of new technology in diabetes management might increase the complexity of disease management for those with limited technological skills. Kanstrup et al. [9] and Schiotz et al. [11] conversely identified that patients and their families were able to use various technologies to decrease and better manage the complexity of diabetes care. Jaen [12] examined the use of HIT from the healthcare providers' standpoint and discussed methods for addressing the complex treatment needed to manage diabetes. In sum, prior research has been ambivalent as to the benefits of HIT to patients with diabetes, and has acknowledged the increased cost and education necessary to implement HIT. None of the work we reviewed denied that HIT could be beneficial; yet most noted that the complexity of diabetes care management, in general, increases difficulty.

Issues regarding communication with healthcare providers constituted another commonly identified theme in 5 articles [7,8,13–15]. Nobel [13] found that patients' ability to communicate information electronically to case managers increased their ability for education. Lairson et al. [7] and Adaji et al. [15] found that improving communication between providers and patients was challenging although most patients and physicians found the ability to communicate via email helpful. Dorr et al. [14] implemented a managed communication program for case managers and patients and found that increased communication improved glycemic control. Halkoaho et al. [8] reported similar results when using an electronic method for tracking and communicating with patients, although the target subjects were nurses. In sum, most prior research identified the importance of communication between patients and their healthcare providers, but it only captured the healthcare provider's point of view. For a technological communication strategy to work, it would need to meet the needs and abilities of both the patient and the healthcare provider.

Endocrinologists are in high demand and often scheduling an appointment with them is difficult. Frequently, appointments need to be booked months in advance with limited ability to reschedule [16]. This theme was identified in 4 of our reviewed articles [7,11,14,16]. Prior research (e.g., Lairson et al. [7], Dorr et al. [14], and Schiotz et al. [11]) explained the benefits of giving different members of the healthcare team (e.g. nurses, case managers, and other physicians) permission to view each other's online calendars and make appointments. Hunt et al. [16] identified that patients should have the ability to set their own appointments and that by doing so they were more likely to be involved in their care.

We also noticed that the interaction between the healthcare team and their patients using some form of information technology (IT) impacted patient care. This theme was identified in 3 articles [11,13,15]. Adaji et al. [15] noted that IT has the ability to increase the quantity and quality of the interactions that patients have with their healthcare providers. Nobel [13] and Schiotz et al. [11] observed that the use of various types of IT by the healthcare provider would allow for more time for patient–provider interactions as well as for a better quality of care. With such complex management of diabetes, interaction with and support from healthcare providers are critical to patients' willingness and ability to self-manage their diabetes.

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