THE FAKEBETES CHALLENGE:  
A Pilot Study of the Patient as Educator in Diabetes Care

Michelle Litchman, PhD, FNP-BC  
University of Utah

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ABSTRACT

Objective: Healthcare providers do not typically fully understand what it is like to live with a chronic condition. One strategy to help healthcare providers better understand the day-to-day challenges of living with diabetes is to practice being a patient. The purpose of this study was to understand the experiences of healthcare providers and patient educators who participated in the Fakebetes Challenge, a high-fidelity simulation of living with diabetes that utilized patients who were living with diabetes as teachers.

Research Design and Methods: In this descriptive qualitative pilot study, blogs written by participants following their participation in the Fakebetes Challenge were examined using content analysis.

Results: The Fakebetes Challenge was beneficial to both healthcare provider learners and patient experts who served as educators. Three themes were identified: 1) enjoyment from the teaching-learning process of having Fakebetes; 2) healthcare providers’ ability to relate, understand, and empathize; and 3) Fakebetes Challenge concerns and frustrations expressed by Fakebetes Teaching Associates.

Conclusion: The Fakebetes Challenge as a pedagogical approach is promising in educating healthcare providers about the day-to-day challenges of living with diabetes and should be replicated with a larger sample. Patients with personal experience and expertise in diabetes can supplement healthcare provider education and support patient-centered care.
INTRODUCTION

Over twenty million Americans have diabetes, and the incidence continues to rise [1]. Individuals who have adequate knowledge and skills to manage their diabetes have better glycemic control [2, 3]; therefore, healthcare providers have a responsibility to adequately educate their patients with diabetes in an effort to support patient care and optimal outcomes. Despite extensive training, healthcare providers do not always fully understand the day-to-day challenges experienced by individuals with diabetes.

One strategy that may help healthcare providers better understand the challenges of living with diabetes is to practice being a patient using high-fidelity simulation. High-fidelity simulation is an environment where healthcare providers can experience living with diabetes by practicing the management of day-to-day diabetes care. The purpose of this study was to understand the experiences of healthcare providers and patient educators who participated in a high-fidelity simulation of living with diabetes called the Fakebetes Challenge. In this study, individuals living with diabetes were placed in the role of a Fakebetes Teaching Associate, and healthcare providers were placed in the role of a patient with diabetes. The Fakebetes Teaching Associates were paired with the healthcare providers in an effort to provide the healthcare providers with realistic examples of day-to-day glucose variation and an enhanced assessment of the physiologic and psychosocial aspects of living with diabetes.

Simulation has been used for teaching purposes for decades. There have been a variety of approaches to simulation to provide education on diabetes management; however, few simulated experiences allow the learner to fully understand the day-to-day challenges of living with diabetes. Pharmacy students have participated in a 1-week simulation experience as if they had diabetes, checking glucose levels, taking saline injections, and logging diet and exercise [4, 5]. In another simulation, pharmacy students engaged in a 6-week patient/provider interaction simulation. While results of diabetes simulations are positive with regards to improving empathy [6, 7], self-efficacy [6], confidence in teaching diabetes self-management skills [4, 5], and diabetes attitudes [5], none incorporated advanced critical thinking skills related to day-to-day challenges (unexpected hypo- or hyperglycemia, changes in glucose related to illness, stress, or exercise, etc.). Utilizing the expertise of real patients may benefit healthcare providers with regards to attaining complex skills and knowledge [8], and supporting patient-centered learning [9], and supporting patient-centered learning [10]. While there are anecdotal reports of healthcare providers learning from patients, little is known about organized learning in which patients are the educators and healthcare providers are the learners.

Theoretical Framework

This study was guided by the Transformative Learning Theory [11]. The Transformative Learning Theory posits that individuals can change their points of view through critical reflection. Transformation and reflection can take place when an individual is able to do the following:

1. elaborate on the current point of view
2. establish new points of view
3. transform the point of view
4. transform their habits through a deeper understanding of their own biases [12]

Healthcare providers are expected to be autonomous and responsible thinkers, and oftentimes have inherent assumptions about individuals with diabetes and management strategies. Specifically, healthcare providers do not typically understand the day-to-day challenges experienced by those living with diabetes. The Fakebetes Challenge provided healthcare providers an opportunity to self-reflect on the day-to-day challenges of diabetes management, further developing the foundational knowledge of what it must be like to live with diabetes. For example, this self-reflection supported mastery of task-oriented and critical thinking activities related to daily diabetes care, as well as understanding how living with diabetes may impact psychosocial health. Furthermore, self-reflection allowed healthcare providers to critically evaluate their point of view of successful diabetes management from the patient and provider levels, supporting the ability to adapt and collaboratively problem solve with patients.
RESEARCH DESIGN AND METHOD

Participants

This qualitative descriptive study was conducted by examining healthcare providers and Fakebetes Teaching Associates blogs following their participation in the Fakebetes Challenge. A convenience sample of nurses and dietitians were recruited from Salt Lake City, UT. Healthcare provider participants were eligible for the study if they were 18 years or older, could read/write English, and were currently providing care for individuals with diabetes. Recruitment advertisements for Fakebetes Teaching Associates were posted to diabetes social media sites. Fakebetes Teaching Associate participants were eligible for the study if they were 18 years or older, could read/write English, and had lived with insulin-dependent diabetes for at least 5 years, and were living in the United States. All participants volunteered to participate in the Fakebetes Challenge knowing there would be no additional compensation.

Procedure

Healthcare provider participants were supplied with a glucometer, syringes or insulin pump supplies, and randomly matched with a Fakebetes Teaching Associate. Working in pairs, healthcare provider participants and the Fakebetes Teaching Associates communicated diabetes-related information via text throughout the Fakebetes Challenge. Since patients do not get to choose their diabetes diagnosis date, Fakebetes Teaching Associates notified the healthcare provider when they were diagnosed with Fakebetes, thus initiating the Fakebetes Challenge. Throughout the Fakebetes Challenge, healthcare provider participants were expected to 1) test his/her blood sugar using a glucometer at least four times per day and when additional testing was needed as determined by glucose levels or symptoms provided by the Fakebetes Teaching Associate; 2) count and log carbohydrate intake, calculate and log insulin doses, and administer the appropriate dose of fake insulin (saline) using a syringe or insulin pump; 3) notify the Fakebetes Teaching Associate of glucose levels, planned activity levels, carbohydrate intake, and other factors that may affect glucose levels; and 4) respond to the Fakebetes Teaching Associate when provided with glucose levels or symptoms that should prompt glucose testing or ingestion of rapid glucose.

Fakebetes Teaching Associates were expected to provide healthcare provider participants with glucose levels or symptoms throughout the day based on likely scenarios (e.g. hypoglycemia following increased activity levels, or hyperglycemia following an insulin pump site occlusion). Given that diabetes can be unpredictable, there was no restriction on the frequency or time of day when the Fakebetes Teaching Associate could communicate a glucose level or symptom to the healthcare provider. Finally, Fakebetes Teaching Associates were expected to provide advice about what they may have done to manage Fakebetes in various scenarios (e.g., adjust insulin for “sneaky” carbohydrates found in sushi or avoid certain foods altogether due to the effect it may have on blood sugar).

Data Analysis

Following the Fakebetes Challenge, participants were asked to write a reflection about their experience and post it to an online blog. These blogs were qualitatively examined using content analysis [13]. The data was analyzed line by line using an open-code approach in order to develop a codebook consisting of categories and subcategories. The categories and subcategories were then systematically organized to develop a taxonomy that informed the themes [14]. Member checking was employed to validate results [15].

RESULTS

Participants included nurses (n=3, one male and two females), dietitians (n=2, both female), and Fakebetes Teaching Associates (n=5, all female). Sex was identified by the use of pronouns in the blogs. At the time of this study, the participating healthcare providers were providing diabetes specialty care to patients as certified diabetes educators (n=3), or worked in an outpatient facility that provided diabetes care but did not specialize in diabetes care (n=2). The common criteria for the Fakebetes Teaching Associates included living with type 1 diabetes for over 15 years and using an insulin pump to manage their diabetes. Since this study examined blogs, demographic information was not collected. Blogs averaged 708 words (range 432-1165 words) and included an average of 2 pictures, most of which were screen shots of text message communication between the healthcare provider and Fakebetes Teaching Associate participants.
The results of the study provided insight about the experiences of healthcare providers and Fakebetes Teaching Associates following their participation in the Fakebetes Challenge. The analysis revealed the following themes, which are discussed in further detail in the subsequent paragraphs:

1. Enjoyment from the Teaching-Learning Process of Having Fakebetes

2. Ability to Relate, Understand, and Empathize

3. Fakebetes Challenge Concerns and Frustrations

1. Enjoyment from the Teaching-Learning Process of Having Fakebetes

Healthcare providers found the Fakebetes Challenge to be beneficial with regards to learning about the day-to-day challenges of living with diabetes. Healthcare providers decided to participate in the Fakebetes Challenge because they wanted to understand diabetes on a deeper level in order to better help the patients they treat. Participants were open to learning from Fakebetes Teaching Associates and appreciated the opportunity to gain tacit knowledge related to diabetes management.

Fakebetes Teaching Associates decided to participate because they were intrigued with the concept of supporting healthcare provider education with regards to day-to-day diabetes management and found their participation to be worthwhile and fun. Some Fakebetes Teaching Associates would throw “curve balls” or learning opportunities which required healthcare providers to make decisions to treat a glucose in real-time, but also consider trends throughout a day or two to determine if changes were necessary. One example included having a healthcare provider experience a hypoglycemia episode after several meals in a row, and over time, the healthcare provider realized an adjustment to the insulin to carbohydrate ratio was necessary. Other Fakebetes Teaching Associates were happy to share tips, tricks, and “life hacks” that they hoped the healthcare provider would be able to use to educate patients in the future. Overall, Fakebetes Teaching Associates enjoyed the process. One participant stated, “It was a really interesting and obviously rewarding experience helping [healthcare providers] learn more about the nitty-gritty of diabetes management and how it’s not always so easy to remember to do everything and do it right.”

The “diagnosis” of Fakebetes provided healthcare providers with opportunities to critically think about how to manage fluctuating blood sugars while meeting the demands of their everyday life. Healthcare providers had to trouble-shoot each scenario in real-time, identifying the factors that could not be changed, those that could be changed, then deciding how they wanted to respond, and how that decision would affect them later in the day. Textbook knowledge without the lived experience left some healthcare providers feeling vulnerable for the first few days, however, by the end of the challenge healthcare providers were becoming more comfortable with the critical thinking necessary to manage diabetes. Healthcare providers gained new perspectives from this learning experience. One healthcare provider stated, “Those of us who do not have diabetes, but work with people with diabetes, take for granted just what is involved in the day to day care of diabetes if we don’t try to immerse ourselves in it.”

Two healthcare providers related their experience to being a new mother, needing to plan ahead in order to be prepared for a variety of scenarios. Comparing the Fakebetes Challenge to motherhood, one healthcare provider stated, “One could read a parenting book, but it’s not the same as experiencing it firsthand. Other parents just get it, because they have lived it.” Having the hands-on diabetes learning experience provided an educational opportunity that had not been available elsewhere.

2. Ability to Relate, Understand, and Empathize

Healthcare providers did not anticipate the amount of time, preparation, and planning that went into the management of diabetes. There were several factors that had not been fully considered, including making sure there was enough battery/charge in the technology devices that supported diabetes management, being patient when waiting for blood sugar to respond after manipulating insulin or ingesting glucose, and being consistent and accurate with carbohydrate counting. Healthcare providers also noted that they did not always follow the advice they would give to their own patients. For example, some healthcare providers altered behaviors to avoid injections, or they completely forgot to check pre-meal blood sugars or “insulin” doses for a snack on the go.

The psychosocial components of having Fakebetes hit home for the healthcare providers. Participants realized firsthand what it would be like to check a glucose level or
take “insulin” while in public; how to make the best of social situations, such as attending a pool party while wearing an insulin pump that wasn’t waterproof; the challenges that being outside of your normal routine (e.g., vacation) can bring; or how hypoglycemia can wake you in the middle of the night or make you late for a meeting. One healthcare provider internalized what could have happened if her Fakebetes had actually been diabetes.

I had a low of 61 occur around the same time I would have left to pick my son up from preschool. Then it dropped to 48. In the world of Fakebetes, I “treated” it on my way, but in real life, I may not have made it there in 30 minutes, or ever…as a single mom, that is not cool.

Healthcare providers gained perspective and a new understanding of the day-to-day challenges faced by individuals with diabetes. By viewing diabetes through the lens of a patient, healthcare providers felt compelled to be more engaged with their own patients who have diabetes in an empathetic way. One participant stated, “Having done this challenge, I will be much more in tune with my patient’s needs.” Findings relate to Transformative Learning Theory (Table 1).

3. Fakebetes Challenge Concerns and Frustrations

Fakebetes Teaching Associates noted a sense of surprise with regards to how much they thought about their own diabetes during the Fakebetes Challenge. Several reflected on how they can sometimes be hard on themselves in moments of dysglycemia, but also mentioned that they were proud of their diabetes management overall. Even though participants enjoyed their experience with the Fakebetes Challenge, the constant communication between the healthcare provider and Fakebetes Teaching Associate was overwhelming at times as they were managing their own diabetes. One participant noted:

*Within 4 hours of starting the challenge, I texted my mom saying how exhausted I was with narrating all the stuff I do regarding diabetes every day. There are so many things that I do subconsciously that are just part of my “normal life” until I stop and think about it.*

While there was much to be gained from the Fakebetes Challenge, Fakebetes Teaching Associates noted there were areas in which the Fakebetes Challenge could not simulate. These areas included: 1) feelings of guilt or even fear over fluctuating glucose levels; 2) the stress over having to go in for fasting labs; 3) the financial distress as a result of costly prescriptions or technology devices; 4) frustration with pharmacies over not having refills ready or with insurance companies when prior authorizations were necessary; and 5) the physical symptoms of hypo- or hyperglycemia. Despite some of the limitations of the Fakebetes Challenge, Fakebetes Teaching Associates appreciated being able to participate and function in an educator capacity, respected the healthcare provider participants for wanting to gain a deeper understanding of what it is like to live with diabetes, and acknowledged the Fakebetes Challenge being as the closest simulation of living with diabetes that currently existed.

### Table 1. Fakebetes Challenge Results as it Relates to Transformative Learning Theory [12].

<table>
<thead>
<tr>
<th>Transformative Learning Theory Components</th>
<th>Fakebetes Challenge Results</th>
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<tbody>
<tr>
<td>Ability to elaborate on the current point of view</td>
<td>Healthcare providers participated in diabetes maintenance tasks (e.g. counting carbohydrates and testing blood glucose levels) and critical thinking through the case scenarios developed by the Fakebetes Teaching Associates.</td>
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<tr>
<td>Establish new points of view</td>
<td>Healthcare providers realized how living with diabetes would impact their own lives.</td>
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<tr>
<td>Transform the point of view</td>
<td>Healthcare providers appreciated the difficulties in managing diabetes, and in some instances, could not follow the advice they gave patients.</td>
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<tr>
<td>Transform our own habits through a deeper understanding of our own biases</td>
<td>Healthcare providers could relate to patients, had a deeper understanding of what it would be like to live with diabetes, and developed empathy towards their own patients.</td>
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CONCLUSIONS

This study explored the experiences of healthcare providers and patient educators who participated in the Fakebetes Challenge. The results indicate that the Fakebetes Challenge was a novel, well-accepted, and beneficial pedagogical approach to educating healthcare providers about diabetes management while at the same time improving empathy. This innovative approach contributes to our understanding of utilizing patients as educators in a high-fidelity simulation.

Empathy can be taught. In the context of patient care, Hojat and colleagues [16] define empathy as a cognitive attribute that involves understanding, and being able to communicate their understanding, of patient concerns and perspectives with intention to help by alleviating pain and suffering. Learning about diabetes from the lens of the patient allowed healthcare providers to feel vulnerable. This vulnerability provided healthcare providers an opportunity to relate, become more understanding, and ultimately achieve empathy towards their patients with diabetes. Research indicates healthcare providers who have empathy for their patients with diabetes build stronger relationships with their patients [17], and have better clinical outcomes [18, 19]. In this study, healthcare provider participants planned to be more engaged with their patients who have diabetes. The Fakebetes Challenge should be considered for healthcare providers and healthcare provider students who plan to care for individuals with diabetes to better understand and empathize with the day-to-day challenges that can be experienced by those with diabetes. Participation in a pedagogical activity such as the Fakebetes Challenge has the potential to improve patient outcomes and satisfaction.

Expert patients are valuable resources that should be utilized to educate healthcare providers and promote patient-centered care. In this study, healthcare providers were not threatened by receiving education from expert patients. In fact, healthcare providers enjoyed the process of being able to gain insight from the patient. While there has been a recent push to engage patients in the research process [20] and quality improvement [21, 22], patient participation in health sciences education is limited. This study included a novel approach to educating healthcare providers by harnessing the expertise of patients with diabetes. In this role reversal, patients were the educators and healthcare providers were the learners in understanding the day-to-day challenges of diabetes. Collaborating with patients in the education of healthcare providers, such as the patient-led Fakebetes Challenge curriculum, should be taken into consideration as a pedagogic approach to supplement continuing education in diabetes management.

Curriculum additions to the Fakebetes Challenge should be considered. In this study, Fakebetes Teaching Associates noted that the Fakebetes Challenge was not able to replicate some of the day-to-day challenges experienced by those with diabetes. For example, the Fakebetes Challenge could not simulate the physical symptoms or fully address the emotional concerns (e.g. fear, guilt, everyday ups and downs) associated with crisis management, or the financial strain [23] of not being able to afford lifesaving medications and equipment. Further, experiencing diabetes can involve uncertainty, isolation, stigma, and identity questions [24] which would be difficult, and ethically impossible, to simulate. However, there are areas in which the Fakebetes Challenge could be augmented to improve and more accurately reflect the experiences of someone living with diabetes, such as incorporating a visit to a Fakebetes pharmacy, a call from a Fakebetes insurance company about coverage, or to a Fakebetes healthcare provider about a prescription refill or concern about blood glucose levels. Further, given that individuals with diabetes often times live with multiple chronic conditions, incorporating additional diagnoses (e.g. hypothyroidism, hypertension, hyperlipidemia) should be considered to provide a more well-rounded simulation of living with diabetes. Finally, careful thought and consideration should be given to the Fakebetes Teaching Associates as to not overwhelm them as an educator given their necessary efforts to manage their own diabetes.

LIMITATIONS

There was a small sample of healthcare providers and Fakebetes Teaching Associates in this pilot study. While findings were positive, the study should be replicated with a larger and more diverse sample (both healthcare providers and Fakebetes Teaching Associate participants) to enhance reach and impact. Fakebetes Teaching Associates all had type 1 diabetes, the means to manage their diabetes with an insulin pump, and enough health literacy to be engaged in the diabetes online community. A Fakebetes Teaching Associate with type 2 diabetes, health disparities, disability, complications, low health literacy, or difficulty accessing tools to perform self-care behaviors may have resulted in different learning opportunities for the healthcare providers. Further, since participants volunteered to participate, results may have selection bias through interest in the project.
Blogs analyzed in this study were relatively short; therefore, focus groups or one-on-one interviews may elicit a richer understanding of the participants’ experience. While it is impossible to fully simulate the experience of living with diabetes, the Fakebetes Challenge and results from this pilot study provides healthcare providers a deeper understanding of the social and economic inequality of those living with diabetes. It is difficult to ascertain the impact of the Fakebetes Challenge in this study. Future research should include pre and post Fakebetes Challenge measures to determine how participation in the Fakebetes Challenge impacts healthcare provider practice, and longitudinal analysis to examine how the intervention may affect patient outcomes.

CONFLICT OF INTEREST DISCLOSURES

The author has completed and submitted the ICMJE Form for Disclosure of Potential Conflicts of Interest. Dr. Litchman reports other from Dexcom, Inc. during her time as a clinical site PI for an RCT between August-December 2015. No other disclosures were reported.

REFERENCES


