Type One Diabetes and Instagram: an exploration of how people living with type one diabetes use Instagram as a resource

A THESIS

Presented to the University Honors Program

California State University, Long Beach

In Partial Fulfillment

of the Requirements for the

University Honors Program Certificate

Tian Walker

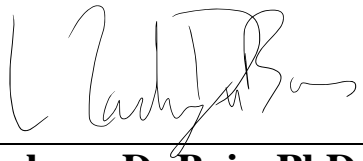
Summer 2018

I, THE UNDERSIGNED MEMBER OF THE COMMITTEE, HAVE APPROVED THIS THESIS

TYPE ONE DIABETES AND INSTAGRAM: AN EXPLORATION OF HOW PEOPLE LIVING WITH TYPE ONE DIABETES USE INSTAGRAM AS A RESOURCE

By

Tian Walker



Zachary DuBois, PhD. **Department of Anthropology**

California State University, Long Beach

Summer 2018

Abstract

TYPE ONE DIABETES AND INSTAGRAM: AN EXPLORATION OF HOW PEOPLE LIVING WITH TYPE ONE DIABETES USE INSTAGRAM AS A RESOURCE

By

Tian Walker

Summer 2018

Type one diabetes is a demanding disease that requires unrelenting vigilance and intensive care. The demands of caring for the disease are an immense burden on mental health. The social support offered and informational tips provided by the Instagram community of people with type one diabetes may be an impactful resource. Engaging with the Instagram community may decrease diabetes distress and diabetes burnout. Accounts from 10 Instagram users with accounts dedicated to type one diabetes were selected and analyzed using content analysis. Expected themes were found as well as emergent themes. Community support, diabetes gear, and treatment information were topics present among all 10 accounts. Findings corroborate with what is present in the literature regarding the benefits and utility of social media engagement among people with chronic illness. The unique platform provided by Instagram deserves further, more in depth exploration.

AKNOWLEDGEMENTS

I would like to thank my advisor Dr. Zachary DuBois for the countless hours of guidance throughout this process. Without his support this thesis would not have been possible.

I would like to thank the honors program for all of the support and inspiration they provided throughout my undergraduate career. I am deeply grateful for the opportunity to write this thesis. I would also like to thank my friends and family for their support throughout my undergraduate process. I would specifically like to thank my mom for her dedication to helping me overcome all obstacles and her unending support throughout my life.

I would like to dedicate this thesis to all of the people living with type one diabetes. I am truly inspired by how much tenacity, bravery, and strength the people in the type one community have and I hope that one day my work may contribute to lessening the burden of this agonizing disease.

TABLE OF CONTENTS

Introduction

Type one diabetes is a disease, an identity, and an experience. Often confused with type 2 diabetes, it is a unique autoimmune disease that requires 24-hour a day monitoring. It frequently causes near-death experiences even with the most vigilant monitoring and treatment. It is the intensity of the disease that leads to it becoming an identity and a unique life experience. Social networking sites have become a place where people go to find others who share similar diseases, identities, and experiences (Shaw & Johnson, 2011). Type one diabetes is a unique conjunction of all three. While social networking users commonly go to these platforms to either seek information or share and explore their identity (Ngai, Tao, & Moon, 2015), people with type one diabetes have been using the social networking site, Instagram, to do both.

Instagram offers a unique platform in which users can create public accounts through which they can spread awareness and education while simultaneously connecting with one another. It is unique because it allows all of the features of a blog while maintaining the structure of a social network with a profile page and the ability to send and receive personal messages. The ability to engage in comments beneath a post just like with a blog, opens the door to unmoderated discussion. The profile page and personal messaging ability removes the anonymity and fosters a personal connection between users.

It may be a tool to help buffer the immense mental health burden of living with such a demanding chronic disease as well as a mechanism to share experiences that are not yet documented in medical protocols, and access ideas and behaviors that are not yet FDA approved. Instagram is a global source of user-generated information that allows people to be informed regardless of their insurance and whether their doctor is up to date on current diabetes resources. This study aimed to assess how people living with type one diabetes use Instagram, and to

ascertain whether the sharing of information and experiences on Instagram might serve as a buffer to diabetes distress as well as a means of spreading important information that otherwise would not be readily available.

The Disease

Type one diabetes is an invisible disease that has no known cause or cure and is on the rise throughout the world (World Health Organization, 2014). It is an autoimmune condition in which t cells destroy the part of the pancreas that produces insulin. Insulin is a regulatory hormone that enables sugar in the blood to be transported into the cells, where it is used for energy. It is impossible for the brain and other organs to function without insulin (Gray, Meijer, & Barrett, 2014). Additionally, without insulin it is almost impossible to get energy from eating. Therefore, the absence of insulin in the body is a very serious problem (Atkinson, Eisenbarth, Davis, & Michels, 2014). The only solution available today is to exogenously administer insulin either through injections or an insulin pump.

The severity of type one diabetes is best understood through the impact that high and low blood sugar has on acute and long term well-being. A healthy person has blood sugar that fluctuates between 80mg/dl and 120mg/dl. The range that people living with type one diabetes aim for is around 70mg/dl to 180mg/dl. The experience of low blood sugar has a lot of variability between individuals but it is common for blood sugar levels below 70 mg/dl to result in severe shakiness and loss of coordination that has been linked to potential long term damage to cognitive function (Frier, 2011). Levels above 180 result in fatigue and grogginess and over the long term are known to cause cardiovascular damage, kidney damage, and nerve damage that can lead to blindness and foot amputation(Frier, 2011; Group, 2005; Nathan & DCCT/EDIC Research Group, 2014; Zhang, Krzentowski, Albert, & Lefebvre, 2001) The only way to remedy

low blood sugar is to eat food and the only way to remedy a high blood sugar is to take more insulin. There are times when extreme low blood sugar forces a person with type one diabetes to eat sugar as fast as possible. All food eventually becomes blood sugar, but sugar itself becomes sugar in the blood the fastest of all foods. It is common for the biological reaction to a low blood sugar to be so extreme, that a person feels the need to eat way more sugar than they actually need (J. C. Pickup & Sutton, 2008). This results in a high blood sugar that can only be corrected by taking more insulin. It often becomes a cyclical process resulting in a blood sugar graph that resembles a rollercoaster.

Insulin is a very powerful medication. Despite the fact that it is needed to stay alive, a small excess of insulin in the body can cause immediate death. There is currently, no means of assessing or measuring how much insulin a person needs at a given time. Insulin needs in the body are constantly changing based on a myriad of factors including outside temperature, a person's diet, how much walking a person has done in a day, and the amount of stress they are experiencing. This makes treating type one diabetes a delicate process that demands a huge amount of involvement from the person living with the disease. The treatment for type one diabetes is unlike most biomedical treatment models in which a medication is given to treat an illness and the patient does not need to understand anything about their disease or why the medication works. Insulin stops people from dying from type one diabetes, but it does absolutely nothing to make type one diabetes go away. Additionally, because insulin is so dangerous and the need for it is in constant flux, people with type one diabetes must have an acute awareness of their disease and constantly monitor how every aspect of their life might affect the amount of insulin they need.

The only way to monitor how much insulin is needed at a given time is to constantly measure the amount of sugar in the blood. An excess of sugar in the blood means that more insulin is needed and too little sugar in the blood means that less insulin is needed. It is not always clear whether a high or low blood sugar reading is indicative of an event that changed insulin needs, an improper calculation of insulin to be paired with food that was consumed, or a shift in the body's physiological demands. Once blood sugar is too high or too low, the problem has already taken place and the person with type one diabetes has to try to play catch-up to solve the problem. It can take hours to get blood sugar levels back into a healthy, normal range, and the smallest of mistakes can send it spiraling out of range again within minutes. It is common for there to be so many incidents of out of range blood sugar in a given day that it is nearly impossible to isolate causes and effects. This means that rather than treating out of range blood sugars with a discrete insulin adjustment, people with diabetes are having to use trial and error to see what works. Endocrinologists provide patients with different starting points and mathematical equations to use when applying trial and error to fix out of range blood sugars. There are currently two ways that blood sugar can be monitored. The most accessible option is self-monitored blood glucose testing (SMBG). A machine called a glucometer is used to test the amount of sugar in a drop of blood. There are small lancing devices that allow a quick puncture of the finger that can then be squeezed to yield the proper-sized drop of blood. A special strip is inserted into the glucometer and then the blood is absorbed by the test strip. The machine provides a blood sugar reading in a matter of seconds. All of these machines have about a 20% variance rate which means that if you measure two drops of blood one after the other from the same finger it is common for the numbers to be more than 10 mg/dl apart. This can make it difficult to decide exactly how much insulin is needed.

The other option for monitoring blood sugar is called a constant glucose monitor. Constant glucose monitors are machines that allow for constant monitoring of blood sugar. In many ways they have revolutionized the ability to manage type one diabetes. A small sensor is inserted under the skin where it measures blood sugar via interstitial fluid. A machine called a transmitter is placed on top of the sensor. The transmitter sends blood sugar readings to a receiving device every 5 minutes. There are a variety of companies with different nuances in the technology, but one thing that they all have in common is that they allow people with type one diabetes to see trends in the directions of their blood sugar. Rather than simply a single-point reading from a finger prick they are able to see a chart with every blood sugar reading from the past 24 hours. Most of these machines have an arrow that appears next to the blood sugar reading that indicates whether blood sugars are stable, trending downward, or trending upward. This removes some of the guessing involved with making insulin dose decisions because it allows a person to see the direction that their blood sugar is headed, not just where it is at one given moment. Additionally, all of the data is saved and can be turned into graphs and charts that enable analysis of blood sugar patterns. It is possible to look at patterns in blood sugar over weeks and months in order to better ascertain which out of range blood sugars were caused by acute problems and which ones are indicative of the need for a longer term insulin adjustment. Despite the revolutionary nature of these machines, they are expensive to access and require that a person has a device attached to them at all times which poses obstacles around comfort and self-image.

Studies have shown that dosing information based on data from SMBG and CGM have basically the same results (Chico, Vidal-Ríos, Subirà, & Novials, 2003), but patients who use the data from the CGM in real time to make micro-adjustments to their insulin have better control of

their blood sugar (Deiss et al., 2006). Another study found that individuals who had more fine-tuned insulin rates had better health outcomes, and the CGM is what makes it possible to fine-tune insulin. Therefore, if a person has a CGM they are able to have better blood glucose control. Better blood glucose control is associated with a higher quality of life (Hoey et al., 2001).

It is important to understand how insulin is delivered and that different types of insulin work differently (Lepore et al., 2000). The current insulin delivery options are the use of multiple daily injections of insulin through needles or the use of a machine called an insulin pump that delivers insulin through a small catheter that remains attached to the body at all times. Multiple daily injections therapy requires that people with type one diabetes take 1-4 shots of long-acting insulin and 3 or more shots of fast-acting insulin every day. Long acting insulin lasts between 8 and 72 hours depending on the brand and so this treatment option does not allow for the same amount of flexibility as an insulin pump where fast-acting insulin is given constantly and can be adjusted at any time. The insulin pump allows for tighter blood sugar control because it enables doses of fast-acting insulin to be altered in real-time. However, using an insulin pump is considered to be more demanding than using injections and it is also costly (J. Pickup & Keen, 2002). Both therapy options keep people with type one diabetes alive and offer the potential of eliminating long-term damage but they require an intense amount of vigilance at all times. The demands of both treatment options reach far beyond what is addressed through the required, quarterly doctor visits. This is in large part because there is no way for someone with type one diabetes to achieve completely normal insulin use in the body because the current methods of taking insulin and the insulins themselves are not equivocal to what a healthy pancreas produces and does.

The American Diabetes Association gathered data from the type 1 diabetes exchange registry and they found that among the 16,061 participants ages 2-75, the average blood sugar level of all of the participants was 220 mg/dl. The blood sugar levels of someone who does not have type one diabetes typically does not go above 120mg/dl. An average blood sugar level of 220 mg/dl is causing permanent damage to blood vessels and organs that will manifest in things like blindness and kidney failure over the span of decades. The average blood sugar is slightly higher among teens and slightly lower among adults older than 65, but the average number is an accurate representation of all of the age groups in that they are all dangerously high. The lowest average blood sugar number of any group is 187 mg/dl, which is right at the cusp of levels known to result in long-term damage. It is important to note that blood sugar levels fluctuate a lot and so if the average blood sugar level is 220 it is likely that a person's blood sugar is hitting levels as high as 400 and as low as 40. The same study found that 68% of participants used an insulin pump and only 7% used a constant glucose monitor. The conclusion from the study was that barriers to current technological benefits need to be addressed and that new therapies for treating type 1 diabetes are needed (Miller et al., 2015).

The Identity

New therapies for type one diabetes are needed because currently it is not possible for a doctor to prescribe the right amount of insulin and send a type one diabetic home to follow certain steps that will result in successful disease management. Instead, it is a constant guessing game. In the end only the person living with the disease can figure out how to make the therapy work for them. The disease becomes a part of type one diabetics' identity because of this personalized nature of the disease combined with the demand for vigilance that it places on a person (Balfe et al., 2013).

Medical sociologist, Mildred Blaxter writes about the ways that Western culture views disease as something apart from what is "normal". She talks about how Western culture's roots in Christianity result in the value that illness is in some ways the fault or responsibility of the person that has it (Blaxter, 1997, 2010). Research on type one diabetes specifically has shown that it can be seen as a weakness or something that makes a person "different" and by extension less desirable in the social world (DiMatteo, 2004a). This can cause an internalization of the identity in which people living with type one diabetes are embarrassed to take care of the disease in public (DiMatteo, 2004b). This leads to an array of issues including poor control of the disease and a lack of social support (Hains et al., 2006; Van Dam et al., 2017).

Type one diabetes studies have found that individuals' personality and their perception of whether or not the treatment can work, play a significant role in how well they manage the disease (L. Fisher et al., 2018; Skinner, Hampson, & Fife-Schaw, 2002). Studies have also found that depression and poor disease control go hand in hand (Hassan, Loar, Anderson, & Heptulla, 2006), and that active and engaged forms of coping are connected to better blood sugar control outcomes (E. B. Fisher, Thorpe, McEvoy DeVellis, & DeVellis, 2007; Snoek & Skinner, 2006). Quality of life as well as psychological, emotional, and behavioral factors have been documented as important elements in diabetes management (E. B. Fisher et al., 2007). Therefore, the nature of the identity that is formed around a diagnosis of type 1 diabetes can have a profound impact on an individual's capacity to manage the disease effectively.

Social stigma is a prevalent issue among people with diabetes (see Schabert, Browne, Mosely, & Speight, 2013 for review). Diabetes in general is stigmatized and people with type one diabetes have a unique experience of stigma (Browne, Ventura, Mosely, & Speight, 2014). Multiple studies have found that people who do not have type one diabetes do not think that it is

stigmatized, but people living with type one diabetes face perceived stigmatization as well as direct discrimination. (Browne et al., 2013.; Schabert et al., 2014). The negative social interactions that occur because of stigma and discrimination make it challenging to embrace the identity of being type one diabetic. The politically correct way to describe being a person who has type one diabetes is to say that you are "living with type one diabetes". This shift in language reflects efforts of type one diabetes support organizations aiming to create language around the disease that does not imply that the person is the disease.

As if the diagnosis of a chronic illness is not enough, the nature of type one diabetes lends itself to creating a feeling of failure every time blood sugar goes out of range (which happens a lot). This can often cause people living with type one diabetes to identify themselves as "bad diabetics" or failures. The process of attempting to figure out how much insulin is needed throughout the day can be overwhelming and discouraging. It is nearly impossible to emotionally handle persistent out of range blood sugar while exerting the maximum amount of effort. The support of friends, family, and the healthcare team are extremely impactful in helping someone manage the burden of treatment "failures" (Pendley et al., 2002). Out of range blood sugars often make a person feel extremely sick which makes pushing through mental health struggles more challenging. It is common for people living with type one diabetes to experience a period of total lack of motivation to continue trying to achieve blood glucose control in which they give up completely. This is called Diabetes Burnout. It often leads to a deadly condition called diabetic ketoacidosis that requires immediate hospitalization.

The Experience

Identity informs experience and vice versa so in reality they can't be pulled apart, but for

the sake of clarity ‘experience’ has been isolated to mean any explicit occurrence that takes place allowing a person to take a photograph of said occurrence and post it on Instagram.

The experience of diabetes burnout is commonly depicted on social media by posting photos of oneself in a hospital bed. The experience that generally leads to diabetes burnout is called diabetes distress. This term is defined as “the emotional burdens, anxieties, frustrations, stressors and worries that stem from managing a severe, complex condition like Type 1 diabetes” (Balfe et al., 2013). A scale has been developed for mental health purposes that can be used to measure how much diabetes distress a person is experiencing (Polonsky et al., 2005). All of the studies that have assessed diabetes distress and social support have come to the conclusion that peer to peer interactions with other people living with type one diabetes can lessen the negative impact that diabetes has on mental health (Balfe et al., 2013; Van Dam et al., 2017).

One way to access connections to other type one diabetics is through books. There are a number of useful books written by type one diabetics explaining how to successfully manage blood sugar levels by documenting their personal experiences and those of other people living with type one diabetes. “Think Like a Pancreas” gives insightful information about how to adjust insulin levels in relation to exercise, and how to assess the accuracy of the insulin to carb ratio used when eating (Scheiner, 2011). “Sugar Surfing” is a proposed way of life in which one watches blood sugar levels constantly and makes lots of small adjustments to insulin, exercise, and diet in order to maintain in-range blood sugar levels (Ponder & McMahon, 2015). “Brite Spots and Landmines” documents all of the “do’s and don’ts” of successful diabetes management including things like not blaming oneself for an out of range blood sugar number (Brown & Close, 2017).

Social media is an emerging way to connect with other people sharing the experience of a disease (Orizio, Schulz, Gasparotti, Caimi, & Gelatti, 2010). In the last 8 years, Instagram has become a platform in which people living with type one diabetes share management tips and disease experiences in real time without having to write a book, and with ability to interact in discussion. Facebook support groups have been a source of peer support for people with type one diabetes as well (Greene, Choudhry, Kilabuk, & Shrank, 2011), but the type one diabetes Instagram community has taken on a unique form.

Instagram, Social Media and Healthcare

Instagram was created in 2010. It originally required that a person have an account in order to view posts and it was only available on iOS. Now however, public posts can be viewed by anyone with an internet browser (Kamel Boulos et al., 2016). According to a review article on the applications of Instagram and WhatsApp for healthcare purposes, Instagram is primarily used for motivational/supportive and educational/informational purposes (Kamel Boulos et al., 2016). The review article concluded that Instagram has the potential to help create "virtual communities of enquiry and practice". That is exactly what has happened with the type one diabetes Instagram community.

A comprehensive study of social networking forums used to share disease experiences done in 2010 illustrates the fact that before Instagram occurred all of the online forums that existed to connect and share about disease experiences prior to Instagram were moderated and controlled by specific people. In the 2010 study, most of the forums were run by doctors or "specialists" of some sort. (Orizio et al., 2010). Numerous studies have been done to understand the best ways to use social media to promote healthy behaviors (Korda & Itani, 2013).

Numerous studies have been done to document the benefits and harms of the internet. Additionally, there are concerns that have been addressed in regards to conducting internet based research. Studies have found that online interactions are harmful if they result in harassment (Ybarra, Mitchell, Wolak, & Finkelhor, 2006), and if they simply serve as a forum for people who are suffering to reaffirm the negative aspects of their experiences (Takahashi et al., 2009). Research has also shown that there is an emerging issue around privacy due to assumed audiences when people are posting on public accounts like on Instagram (Keim-Malpass, Steeves, & Kennedy, 2014; Markham & Markham, 2005). Overall however, there is strong evidence among multiple studies, that social media in which users create content and share experiences has the potential to immensely benefit people suffering from chronic disease (Chung et al., 2017; Lorig et al., 2008; Moorhead et al., 2013; Shaw & Johnson, 2011). The benefits of social media specific to type one diabetes have been documented in one study that assessed Facebook support groups (Greene et al., 2011) and another that assessed the utility of engagement with Instagram (Yi-Frazier et al., 2015). Both studies found that there were strong benefits worthy of further exploration.

Methods

The methodological approach taken was a passive online ethnography (Keim-Malpass et al., 2014) following immersion in the community through personal engagement that preceded the study. There is an entire community of people with type one diabetes spreading awareness, sharing tips, and documenting their experiences on Instagram. In order to determine if a content analysis was feasible, roughly 3,000 Instagram posts from people who had created accounts solely for the purpose of documenting diabetes experiences were skimmed. It was determined that a content analysis was feasible and worthwhile. A preliminary list of themes was developed

based on observations from the personal engagement with Instagram that preceded the study. The themes were then methodically applied in a thematic content analysis (Bernard, 2011)using Dedoose mixed-methods software.

Photos and corresponding text from posts were coded together as they went together 98% of the time, and the exceptions were cases where a random photo was used as a place-marker in order to tell a story about diabetes.

The California State University of Long Beach institutional review board (IRB) was consulted, and it was determined that an IRB approval was not necessary because the accounts being analyzed are public and accessible to anyone. The accounts that were used in the analysis were selected through a search of three hashtags following selection methods from previous studies (Boepple & Thompson, 2016; Tiggemann & Zaccardo, 2018). The hashtags were identified and selected after the initial skim of 3,000 posts. The hashtags were #typeonestrong, #fiasp, and #typeonediabetessucks.

Selection Criteria

The accounts that created photos with these hashtags were selected for analysis if:

- they had at least 500 followers
- claimed to have type one diabetes in their account biography
- had followers with some version of t1d in their usernames
- English was the primary language used in the account
- the majority of their posts were related to type one diabetes and
- they belonged to an individual documenting their experiences with type one diabetes.

Accounts were excluded if:

- they were not an individual person
- the intention of their account was to sell something

- they had posts with diabetes related hashtags but no content in text or images relating to diabetes
- they were focused on a specific exercise or food program
- the account biography stated that they were a teenager/minor

Unlike previous health behavioral studies of Instagram (Boepple & Thompson, 2016; Tiggemann & Zaccardo, 2018), comments were deemed important, and they were included in analysis if they contained anything beyond a statement of supportive affirmation. It was determined that saturation was reached between 17 and 24 posts. Text content was capped at 11 pages copy and pasted into Microsoft Word due to time constraints and the goal to include as many accounts as possible. There were 6 emergent themes that were applied to posts in addition to the original 10 themes. Each individual post comprised of an excerpt to allow for post level content analysis.

Posts were omitted if they did not picture or mention diabetes in any way and were of inanimate objects. A photo of the person themselves doing something was included because the person has diabetes and thus a photo of them doing something may be intended as an image of a type one diabetic doing said activity. While the majority of comments were included, comments that were in languages other than English were not included.

Results

Sample Characteristics

A total of 220 excerpts from 10 Instagram accounts documenting experiences of type one diabetes were analyzed in this study. The majority (8 out of 10) presented as women and 2 presented as men. Diabetes duration ranged from 2 years to 20 years, though not all of the accounts revealed number of years spent living with type one diabetes. The accounts were held by individuals in the United States, United Kingdom, Germany, and Canada. The majority of the

accounts (9 out of 10) were those of people using a constant glucose monitor and 6 out of the ten were using an insulin pump. Among the 4 not using an insulin pump, 3 were using injections and one did not post about treatment method at all. The number of followers of the accounts ranged from 536 to 7,439. Accounts with more followers had more comments that were included in the analysis. Three of the accounts were found through the #fiasp hashtag, 6 from the #typeonestrong hashtag, and one from the #typeonediabetessucks hashtag.

Themes

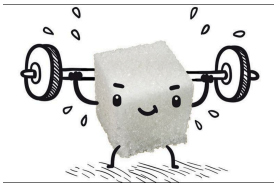
There were 18 major themes among the Instagram posts that were analyzed. Every Instagramer talked about diabetes gear, community support, and treatment information. All but one talked about the visibility of their type one diabetes to the outside world, a theme I called "Diabetes on Display". All but two of the ten Instagramers talked about ways to navigate the world as a type one diabetic. Humor appeared in the form of memes and sarcastic written posts. Insurance came up in the context of accessing diabetes devices and types of insulin. Only 3 people talked about their symptom experience from high or low blood sugar. There were three accounts that emphasized spreading awareness of diabetes issues both among people with type one diabetes and among people outside of the type one diabetes community. Frustrating encounters with ignorant people came up in three of the ten accounts. A full list of all of the themes and the number of times they were applied can be found in Table 1.

Table 1

		# accounts with theme present n(%)	# of times theme applied
Themes	**Sub-themes**		
Diabetes gear		10 (100%)	86
Community support		10 (100%)	66
Treatment information		10 (100%)	59
	Dealing with blood sugar	6 (60%)	36
	Blood sugar management tips	8 (80%)	23
Diabetes on display		9 (90%)	40
Navigating the world as a t1d		8 (80%)	32
Sharing resources		7 (70%)	24
Admitting defeat		7 (70%)	11
Exercise		6 (60%)	24
Humor		6 (60%)	9
Food		5 (50%)	23
Blood sugar success		5 (50%)	9
Insurance		5 (50%)	7
Diagnosis story/diaversary		4 (40%)	8
A1c		4 (40%)	6
Social support		4 (40%)	5
Spreading awareness		3 (30%)	7
Frustrating ignorance		3 (30%)	5
BG symptom experiences		3 (30%)	5

Community Support

Community support was one of the most prominent themes among all of the accounts. It was defined as “strength found in connections with other type ones”. A term that was used to describe fellow diabetics was “diabuddies”. There were three main contexts in which community support was apparent: posts in which people talk about difficult experiences and others respond by sharing similar stories, posts and comments sharing information about insulin and diabetes products and how they work, and posts explicitly stating how important and valuable the type one diabetes Instagram community is. This post exemplifies the third context:



"let's be honest. Sometimes as a diabetic you just want to ignore everything that affects your diabetes and also make "vacation" of all the blood glucose measurements, catheter changes, calculations and insulin injections. 💑 but do we have a choice? No! we don't have. Especially in these moments Im grateful for this great community here & the support of family and friends which motivates me to continue and not give up. 💪
Many thanks to all Diabuddies out there who also show that diabetes isn't always beautiful and wonderful and there are times when BG's aren't what we want them to be. 🙌Your posts spray motivation and energy here. 💕
Thanks a lot for this!
wish you a beautiful Sunday!💕
Over and out! 💁
#typeonestrong #diabuddies #community#motivation #healthymind
#diabetes #diabetestype1#type1diabetes #typeonestrong#type1diabetic #type1warrior#diabetesawareness #diabeetus #t1dlife#t1dlookslikeme #t1d #t1dfamily#motivation #healthydiabetic #community#diabadass #diabuddies #thankful" –Instagrammer two

Diabetes on Display

The demands of type one diabetes lead to performing treatments in public as well as wearing mechanical devices that are often visible. Instagramers in the study often post images of themselves out in the world doing things that display their diabetes: sometimes it is taking an injection and others it is going to the beach with an insulin pump and CGM in plain sight. The term "diabetics in the wild" was used to describe the experience of seeing other strangers out in the world wearing diabetes gear. Instagramers and commenters shared funny stories about interactions where people asked them weird questions about their insulin pumps. Commenters relayed that seeing posts on Instagram of diabetes gear being worn in plain sight inspired them to do the same.

Diabetes Gear

Diabetes gear was a prominent topic. It was mentioned at least once by all of the Instagramers. Diabetes gear included any machine used to help treat diabetes such as constant glucose

monitors, insulin pumps, and glucometers. Insulin pens were not considered diabetes gear. This was among the emergent themes. In addition to talking about diabetes gear in the context of its visibility to the outside world, it also came up in the context of its utility, the frustration it caused when it didn't work properly, and general tips on where to put sites based on utility. Many posts were about being frustrated with diabetes gear when the blood sugar readings on the glucometer and the constant glucose monitor did not match. There were also multiple posts about insulin pumps breaking down leading to a forced return to the use of multiple daily injections.

Treatment Information

Medical information was relayed through the sharing of personal experiences. None of the accounts explicitly posted medical advice. There were posts where commenters were learning about new insulins, constant glucose monitors, and products that help medical devices stay attached. There were also posts that were reminders in which the people posting would remind readers the importance of something like drinking ample water. In fact, there were multiple posts about drinking enough water in which the person posting informed readers that proper hydration is required in order to receive accurate CGM readings. Blood sugar treatment information was shared by the telling of how individuals navigated specific challenging situations. It was apparent in many comment sections that the information being shared was novel to readers/commenters. There were two main categories of treatment information: insulin and CGM information and dealing with unexpected situations. For example, Mimi* posted about a new type of insulin:

"I GOT FIASP!!! Fiasp is sort of a new insulin - it is Novolog (which I was on from 2009 until this January) combined with the vitamin B3 which essentially speeds up the insulin. Novolog and Humalog (the insulin that I have been on since January due to insurance reasons) begin working 15-20 minutes after injection which often leads to those high blood sugar mountains - not great for my body in the long run. Fiasp starts working 2-5 minutes after injection, in other words, this speedy insulin is a GAME CHANGER in Type One Diabetes management. Fiasp has been in the works for a while but it finally got approved by the FDA for use in the end of September. My doctor waited to prescribe it to me after he and I had both heard how it was working for others. I've read so many posts giving Fiasp great reviews that I knew I wanted to try it." – Mimi, Omnipod Pump user, 1,317 followers

Sharing Resources

The Instagramers shared information about how to access diabetes-specific products. They shared a lot of information about navigating insurance, and they also talked about new insulins and technologies on the market. A couple of them had received trial periods with new technology, and they tracked their trial experience on their Instagram accounts. Many posts talking about types of insulin that are relatively new to the market (like the quote above) received comments asking about what they were and how they worked. The same was true of devices like constant glucose monitors. There are different regulations in different countries and so sometimes some of the technologies that people are posting about have not yet made their way to the countries where readers/commenters are located. There are also a number of products that help devices stay in place. An image with a device that had tape that looked like it was coming off would receive a comment giving the name of a product that helps enhance the stickiness of the tape. Additionally, there are many small companies creating diabetes-specific everyday objects like t-shirts and hats. Some posts would talk about items from a particular place and tag the company in the post allowing readers to click on the name and be linked directly to the page where they can purchase similar products.

Navigating the World as a T1D

Posts about navigating life in general outside of the medical/blood sugar-focused context were prominent as well: questions and answers about how to navigate security at airports was a common topic. Instagramers also talked about how to deal with hot weather, how to navigate being a parent, and what they do when they need insulin while they are driving. There are all kinds of circumstances that put the Instagramers in awkward situations and they had creative, efficient solutions that they shared.

Individual Narratives

Each of the ten accounts had a slightly different style. All of the accounts had bleed through from their personal lives in addition to type one diabetes-specific posts. There were 24 posts that had a diabetes related hashtag but an absence of diabetes in the image and corresponding text. This illustrated that individuals were displaying a connection to diabetes even when it wasn't explicitly related to the subject of the post. A couple of the accounts had very distinct styles. The account of Jenny* for example, had alternating posts of black and white words and color photographs creating a very unique appearance. Jared* was a professional cyclist and the majority of his photos included his bicycle. Sarah* primarily posted pictures of herself with her insulin pump prominently visible. There are no rules and no moderators on this forum, yet there is a distinct culture in which Instagramers build their identities as people navigating life with type one diabetes. Cindy* posted about attending a conference for diabetes bloggers put on by a diabetes medical supply company. This demonstrated that the online diabetes community leads to meaningful in-person encounters that then become part of the stories shared with online community.

Discussion

Disease is thought to be "bad". In our culture of Christian origins there is a subtle implication that illness is our fault (Blaxter, 1997). With type one diabetes, every out of range blood sugar reading can be equivocated to receiving an f on a very important assignment. The Instagram community of type one diabetics allows type ones to see that they are not alone in suffering from the disease despite their best efforts. Seeing people that are doing well with management can provide hope and motivation, and seeing people suffering worse but

persevering can be inspiring as well. There are physical and mental benefits to engagement with the Instagram community for people living with type one diabetes.

Margaret Lock and Vinh-Kim Nguyen theorize that biomedicine has three technologies of the self: accounting, confessional, and pharmacological. The accounting and confessional selves are able to be expressed through Instagram. The accounting self exists in the context of the linear accounting of symptom of illness experience. The confessional self exists in the sharing of deep feelings that often remain unconscious without explicit effort made to express them. Lock and Nguyen tie the expression of personal experiences and feeling on social media to Freud's theory of the architecture of self and the subsequent psychotherapy methods of guiding individuals to reflect on their innermost feelings and use language to describe these deep parts of themselves. In this lights, the accounts analyzed in this study allowed the Instagramers to reinforce their relationship with biomedicine by following a linear account of illness experience, and delve into their innermost feelings in a psychotherapeutic manner. The extent to which type one diabetes Instagram posts are interwoven with biomedicine is worth further exploration. An integration of the treatment tips, as well as successful tricks to navigating life with type one diabetes needs to happen quickly. Studies are currently being done to figure out how to integrate information from user-driven content on social networks into the biomedical treatment model (Korda & Itani, 2013).

Limitations

It is surprising that there weren't more posts about blood sugar success as there is a phenomenon of type one diabetics in the online community posting whenever they capture a blood sugar level of 100mg/dl and calling it "catching a unicorn". The fact that none of the posts speak to this illustrates that 220 posts from 10 people did not encompass 100% saturation of all themes. A

more exhaustive study would be needed to accomplish full saturation. Additionally, this study was done as a passive analysis and therefore it was not possible to gain any information outside of what existed in the posts that were analyzed.

Conclusion

Instagram provides an open forum where people living with type one diabetes can share experiences with one another, document their disease experiences in real time, and increase global awareness of this extremely demanding and misrepresented disease. It also creates a community environment that fosters accountability which increases incentives to partake in taxing self-care regimens/treatment plans. While there are serious concerns about ethics around online research as well as the potential negative impacts of online harassment, there are potential benefits that need to be explored in future studies. Type one diabetes is such an intense disease that it would be nearly impossible to fabricate an Instagram account documenting daily experiences of the disease. The people posting on this online community are not trying to remain anonymous. Many of them are proud to be the face of type one diabetes. For this reason, connections made on Instagram can easily be followed up with in person meet-ups removing the concern of potential disengagement with the physical world. Efforts need to be made to provide the peer support and access to information that Instagram has made possible in other mediums as well. It would be particularly beneficial to people with type one diabetes who have not been exposed to social media (e.g., older adults) for the resources offered by Instagram to be available through their doctor's office. Further research is needed to determine what form that would take and how to carry it out. The Instagram type one diabetes community is allowing social connections, peer support, and information exchange at an unprecedented rate.

References

Balfe, M., Doyle, F., Smith, D., Sreenan, S., Brugha, R., Hevey, D., & Conroy, R. (2013). What's distressing about having type 1 diabetes? A qualitative study of young adults' perspectives. *BMC Endocrine Disorders*, *13*(1), 25. https://doi.org/10.1186/1472-6823-13-25

Bernard, H. R. (Harvey R. (2011). *Research methods in anthropology : qualitative and quantitative approaches*.AltaMira Press, United Kingdom

Blaxter, M. (1997). Whose fault is it? People's own conceptions of the reasons for health inequalities. *Social Science & Medicine*, *44*(6), 747–756. https://doi.org/10.1016/S0277-9536(96)00192-X

Blaxter, M. (2010). *Health*. Polity Press, Cambridge.

Boepple, L., & Thompson, J. K. (2016). A content analytic comparison of fitspiration and thinspiration websites. *International Journal of Eating Disorders*, *49*(1), 98–101. https://doi.org/10.1002/eat.22403

Brown, A., & Close, K. L. (n.d.). *Bright spots & landmines : the diabetes guide I wish someone had handed me*. R

Browne, J. L., Ventura, A., Mosely, K., & Speight, J. (n.d.). *"I"m not a druggie, I'm just a diabetic': a qualitative study of stigma from the perspective of adults with type 1 diabetes*. Retrieved from http://bmjopen.bmj.com/

Chico, A., Vidal-Ríos, P., Subirà, M., & Novials, A. (2003). The continuous glucose monitoring system is useful for detecting unrecognized hypoglycemias in patients with type 1 and type 2 diabetes but is not better than frequent capillary glucose measurements for improving metabolic control. *Diabetes Care*, *26*(4), 1153–7. https://doi.org/10.2337/DIACARE.26.4.1153

Chung, C.-F., Agapie, E., Schroeder, J., Mishra, S., Fogarty, J., & Munson, S. A. (2017). When Personal Tracking Becomes Social. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17* (pp. 1674–1687). https://doi.org/10.1145/3025453.3025747

Deiss, D., Bolinder, J., Riveline, J.-P., Battelino, T., Bosi, E., Tubiana-Rufi, N., … Phillip, M. (2006). Improved glycemic control in poorly controlled patients with type 1 diabetes using real-time continuous glucose monitoring. *Diabetes Care*, *29*(12), 2730–2. https://doi.org/10.2337/dc06-1134

DiMatteo, M. R. (2004a). Social Support and Patient Adherence to Medical Treatment: A Meta-Analysis. *Health Psychology*, *23*(2), 207–218. https://doi.org/10.1037/0278-6133.23.2.207

DiMatteo, M. R. (2004b). Social Support and Patient Adherence to Medical Treatment: A Meta-Analysis. *Health Psychology*, *23*(2), 207–218. https://doi.org/10.1037/0278-6133.23.2.207

Fisher, E. B., Thorpe, C. T., McEvoy DeVellis, B., & DeVellis, R. F. (2007). Healthy Coping, Negative Emotions, and Diabetes Management. *The Diabetes Educator*, *33*(6), 1080–1103. https://doi.org/10.1177/0145721707309808

Fisher, L., Hessler, D., Polonsky, W., Strycker, L., Guzman, S., Bowyer, V., … Masharani, U. (2018). Emotion regulation contributes to the development of diabetes distress among adults with type 1 diabetes. *Patient Education and Counseling*, *101*(1), 124–131. https://doi.org/10.1016/J.PEC.2017.06.036

Frier, B. M. (2011). Cognitive functioning in type 1 diabetes: the Diabetes Control and Complications Trial (DCCT) revisited. *Diabetologia*, *54*(2), 233–236.

https://doi.org/10.1007/s00125-010-1983-6
Gallen, I. (2012). Type 1 Diabetes: Clinical Management of the Athlete. *Clinical Chemistry*, *367*(9911), 194. https://doi.org/10.1016/S0140-6736(13)60591-7.Type
Gray, S. M., Meijer, R. I., & Barrett, E. J. (2014). Insulin Regulates Brain Function, but How Does It Get There? *Diabetes*, *63*, 3992–3997. https://doi.org/10.2337/db14-0340
Greene, J. A., Choudhry, N. K., Kilabuk, E., & Shrank, W. H. (2011). Online social networking by patients with diabetes: a qualitative evaluation of communication with Facebook. *Journal of General Internal Medicine*, *26*(3), 287–92. https://doi.org/10.1007/s11606-010-1526-3
Group, T. D. C. and C. T. of D. I. and C. (DCCT/EDIC) S. R. (2005). Intensive Diabetes Treatment and Cardiovascular Disease in Patients with Type 1 Diabetes. *New England Journal of Medicine*, *353*(25), 2643–2653. https://doi.org/10.1056/NEJMoa052187
Hains, A. A., Berlin, K. S., Hobart Davies, W., Smothers, M. K., Sato, A. F., & Alemzadeh, R. (2006). Attributions of Adolescents with Type 1 Diabetes Related to Performing Diabetes Care around Friends and Peers: The Moderating Role of Friend Support. *Journal of Pediatric Psychology*, *32*(5), 561–570. https://doi.org/10.1093/jpepsy/jsl040
Hassan, K., Loar, R., Anderson, B. J., & Heptulla, R. A. (2006). The role of socioeconomic status, depression, quality of life, and glycemic control in type 1 diabetes mellitus. *The Journal of Pediatrics*, *149*(4), 526–531. https://doi.org/10.1016/J.JPEDS.2006.05.039
Hoey, H., Aanstoot, H. J., Chiarelli, F., Daneman, D., Danne, T., Dorchy, H., … Aman, J. (2001). Good metabolic control is associated with better quality of life in 2,101 adolescents with type 1 diabetes. *Diabetes Care*, *24*(11), 1923–8. https://doi.org/10.2337/DIACARE.24.11.1923
Kamel Boulos, M., Giustini, D., Wheeler, S., Kamel Boulos, M. N., Giustini, D. M., & Wheeler, S. (2016). Instagram and WhatsApp in Health and Healthcare: An Overview. *Future Internet*, *8*(3), 37. https://doi.org/10.3390/fi8030037
Keim-Malpass, J., Steeves, R. H., & Kennedy, C. (2014). Internet ethnography: A review of methodological considerations for studying online illness blogs. *International Journal of Nursing Studies*, *51*(12), 1686–1692. https://doi.org/10.1016/J.IJNURSTU.2014.06.003
Korda, H., & Itani, Z. (2013). Harnessing Social Media for Health Promotion and Behavior Change, *14*(1), 15–23. https://doi.org/10.1177/1524839911405850
Lepore, M., Pampanelli, S., Fanelli, C., Porcellati, F., Bartocci, L., Di Vincenzo, A., … Bolli, G. B. (2000). Pharmacokinetics and pharmacodynamics of subcutaneous injection of long-acting human insulin analog glargine, NPH insulin, and ultralente human insulin and continuous subcutaneous infusion of insulin lispro. *Diabetes*, *49*(12), 2142–8. https://doi.org/10.2337/DIABETES.49.12.2142
Lorig, K. R., Ritter, P. L., Dost, A., Plant, K., Laurent, D. D., & Mcneil, I. (2008). The expert patients programme online, a 1-year study of an Internet-based self-management programme for people with long-term conditions. *Chronic Illness*, *4*, 247–256. https://doi.org/10.1177/1742395308098886
Markham, A. N., & Markham, A. N. (2005). The methods, politics, and ethics of representation in online ethnography. *THE SAGE HANDBOOK OF QUALITATIVE RESEARCH, SAGE, THOUSAND OAKS, CA*, 793--820. Retrieved from http://citeseerx.ist.psu.edu/viewdoc/summary?doi=10.1.1.508.444
Miller, K. M., Foster, N. C., Beck, R. W., Bergenstal, R. M., DuBose, S. N., DiMeglio, L. A., … T1D Exchange Clinic Network. (2015). Current state of type 1 diabetes treatment in the

U.S.: updated data from the T1D Exchange clinic registry. *Diabetes Care*, *38*(6), 971–8. https://doi.org/10.2337/dc15-0078

Moorhead, S. A., Hazlett, D. E., Harrison, L., Carroll, J. K., Irwin, A., & Hoving, C. (2013). A new dimension of health care: systematic review of the uses, benefits, and limitations of social media for health communication. *Journal of Medical Internet Research*, *15*(4), e85. https://doi.org/10.2196/jmir.1933

Nathan, D. M., & DCCT/EDIC Research Group, for the D. R. (2014). The diabetes control and complications trial/epidemiology of diabetes interventions and complications study at 30 years: overview. *Diabetes Care*, *37*(1), 9–16. https://doi.org/10.2337/dc13-2112

Ngai, E. W. T., Tao, S. S. C., & Moon, K. K. L. (2015). Social media research: Theories, constructs, and conceptual frameworks. *International Journal of Information Management*, *35*(1), 33–44. https://doi.org/10.1016/J.IJINFOMGT.2014.09.004

Orizio, G., Schulz, P., Gasparotti, C., Caimi, L., & Gelatti, U. (2010). The World of e-Patients: A Content Analysis of Online Social Networks Focusing on Diseases. *Telemedicine and E-Health*, *16*(10), 1060–1066. https://doi.org/10.1089/tmj.2010.0085

Pendley, J. S., Kasmen, L. J., Miller, D. L., Donze, J., Swenson, C., & Reeves, G. (2002). Peer and Family Support in Children and Adolescents With Type 1 Diabetes. *Journal of Pediatric Psychology*, *27*(5), 429–438. https://doi.org/10.1093/jpepsy/27.5.429

Pickup, J. C., & Sutton, A. J. (2008). Severe hypoglycaemia and glycaemic control in Type1 diabetes: meta-analysis of multiple daily insulin injections compared with continuous subcutaneous insulin infusion. *Diabetic Medicine*, *25*(7), 765–774. https://doi.org/10.1111/j.1464-5491.2008.02486.x

Pickup, J., & Keen, H. (2002). Continuous subcutaneous insulin infusion at 25 years: evidence base for the expanding use of insulin pump therapy in type 1 diabetes. *Diabetes Care*, *25*(3), 593–8. https://doi.org/10.2337/DIACARE.25.3.593

Polonsky, W. H., Fisher, L., Earles, J., Dudl, R. J., Lees, J., Mullan, J., & Jackson, R. A. (2005). Assessing psychosocial distress in diabetes: development of the diabetes distress scale. *Diabetes Care*, *28*(3), 626–31. https://doi.org/10.2337/DIACARE.28.3.626

Ponder, S. W., & McMahon, K. L. (n.d.). *Sugar surfing : how to manage type 1 diabetes in a modern world*.

Schabert, J., Browne, J. L., Mosely, K., & Speight, J. (n.d.). Social Stigma in Diabetes A Framework to Understand a Growing Problem for an Increasing Epidemic. https://doi.org/10.1007/s40271-012-0001-0

Scheiner, G. (2011). *Think like a pancreas : a practical guide to managing diabetes with insulin*. Da Capo Lifelong.

Shaw, R. J., & Johnson, C. M. (2011). Health Information Seeking and Social Media Use on the Internet among People with Diabetes. *Online Journal of Public Health Informatics*, *3*(1). https://doi.org/10.5210/ojphi.v3i1.3561

Skinner, T. C., Hampson, S. E., & Fife-Schaw, C. (n.d.). Personality, Personal Model Beliefs, and Self-Care in Adolescents and Young Adults With Type 1 Diabetes. *Health Psychology*, *21*(1), 61–70. Retrieved from http://epubs.surrey.ac.uk/23664/2/Skinner, Hampson and Fife-Schaw (2002) author copy.pdf

Snoek, F. J., & Skinner, T. C. (2006). Psychological aspects of diabetes management. *Medicine*, *34*(2), 61–62. https://doi.org/10.1383/MEDC.2006.34.2.61

Takahashi, Y., Uchida, C., Miyaki, K., Sakai, M., Shimbo, T., & Nakayama, T. (2009). Potential benefits and harms of a peer support social network service on the internet for people with

depressive tendencies: qualitative content analysis and social network analysis. *Journal of Medical Internet Research*, *11*(3), e29. https://doi.org/10.2196/jmir.1142

Tiggemann, M., & Zaccardo, M. (2018). "Strong is the new skinny": A content analysis of #fitspiration images on Instagram. *Journal of Health Psychology*, *23*(8), 1003–1011. https://doi.org/10.1177/1359105316639436

Van Dam, H. A., Van Der Horst, F. G., Knoops, L., Ryckman, R. M., Crebolder, H. F. J. M., & Van Den Borne, B. H. W. (2017). Social support in diabetes: A systematic review of controlled intervention studies. *Patient Education and Counseling*. https://doi.org/10.1016/j.pec.2004.11.001

World Health Organization. (2016). Global Report on Diabetes. *Isbn*, *978*, 88. https://doi.org/ISBN 978 92 4 156525 7

Ybarra, M. L., Mitchell, K. J., Wolak, J., & Finkelhor, D. (2006). Examining characteristics and associated distress related to Internet harassment: findings from the Second Youth Internet Safety Survey. *Pediatrics*, *118*(4), e1169-77. https://doi.org/10.1542/peds.2006-0815

Yi-Frazier, J. P., Cochrane, K., Mitrovich, C., Pascual, M., Buscaino, E., Eaton, L., … Malik, F. (2015). Using Instagram as a Modified Application of Photovoice for Storytelling and Sharing in Adolescents With Type 1 Diabetes. *Qualitative Health Research*, *25*(10), 1372–1382. https://doi.org/10.1177/1049732315583282

Zhang, L., Krzentowski, G., Albert, A., & Lefebvre, P. J. (2001). Risk of developing retinopathy in Diabetes Control and Complications Trial type 1 diabetic patients with good or poor metabolic control. *Diabetes Care*, *24*(7), 1275–9. https://doi.org/10.2337/DIACARE.24.7.1275