Open Access Theses & Dissertations

2018-01-01

Seeking Health Information In The Diabetes Online Community (doc); The Role Of Health Literacy, Social Support And Community Interaction On Treatment Adherence

Allyson Hughes
University of Texas at El Paso, allyhughes10@gmail.com

Follow this and additional works at: https://digitalcommons.utep.edu/open_etd

Part of the Psychology Commons

SEEKING HEALTH INFORMATION IN THE DIABETES ONLINE COMMUNITY (DOC);

THE ROLE OF HEALTH LITERACY, SOCIAL SUPPORT AND COMMUNITY

INTERACTION ON TREATMENT ADHERENCE

ALLYSON SUE HUGHES, PH.D.

Doctoral Program in Psychology

APPROVED:

_____

Osvaldo F. Morera, Ph.D., Chair

_____

James Wood, Ph.D.

_____

Ashley S. Bangert, Ph.D.

_____

Katherine Serafine, Ph.D.

_____

Jessica Shenberger-Trujillo, Ph.D.

_____
Charles Ambler, Ph.D.
Dean of the Graduate School

DEDICATION

This dissertation is dedicated to my loved ones.

To my husband, Dan, who encouraged me to shine and pushed me up every single step of the way. At many points in this journey, I relied on you to carry me and for that, I will be forever grateful for your patience, kindness, support and love.

This dissertation would not be possible without the support of my family. Thank you, Mom and Dad for your strength and certainty that I can do anything that I set my mind to.

To Jenn, thank you for your infinite knowledge, your time and your humor. Thank you for pestering me to hurry up and finish already. I needed that more than you know.

Nazy Joon, my work wife and right hand. Thank you for taking this journey with me. You, Scott and the rest of your family motivated me and provided me with the energy to get this done. Merci, Heydarians.

To Dr. Katie Aguirre, thank you for your cut throat feedback and being such a great role model.

To Paris, my little sister. Thank you for believing in me and encouraging me to never give up.

SEEKING HEALTH INFORMATION IN THE DIABETES ONLINE COMMUNITY (DOC);

THE ROLE OF HEALTH LITERACY, SOCIAL SUPPORT AND COMMUNITY

ENGAGEMENT ON TREATMENT ADHERENCE

by

ALLYSON SUE HUGHES, PH.D.

DISSERTATION

Presented to the Faculty of the Graduate School of

The University of Texas at El Paso

in Partial Fulfillment

of the Requirements

for the Degree of

DOCTOR OF PHILOSOPHY

DEPARTMENT OF PSYCHOLOGY

THE UNIVERSITY OF TEXAS AT EL PASO

December 2018

ABSTRACT

Social support, being valued and cared for by others (Wills, 1991), is a critical construct for disease management and often includes providing advice and information to peers online. Approximately 83% of individuals with chronic disease search for health information online and there are more than 500,000 active social media users in the Diabetes Online Community (DOC) who have varying levels of disease management expertise. Due to the strenuous nature of Type 1 Diabetes (T1D), members of the DOC are continuously asking for and receiving anecdotal health information, yet very few studies have evaluated the impact of the DOC on treatment adherence and health outcomes. The main aim of this dissertation included developing the Attitudes Toward Seeking Health Information scale in a sample of individuals with T1D who are active in the DOC. The studies investigated the link between treatment adherence, technology, and peer support by developing and testing a scale to measure the information-seeking portion of this research problem. Using themes from preliminary data that investigated antecedents of seeking health information online (Hughes, Perez, & Morera, 2017), DOC stakeholders provided qualitative feedback on the measure in Study 1. In Study 2, the scale was revised based on feedback from individuals recruited from the DOC in Study 1 and was tested on DOC members. The scale was revised and validated. Study 2 participants provided feedback regarding the scale and multiple regression models assessed the link between treatment adherence, technology and peer support. The project highlights the connection between social support, online health information seeking, diabetes distress, and treatment adherence.

TABLE OF CONTENTS

LIST OF TABLES

APPENDICES

CHAPTER 1: INTRODUCTION

1.1 OVERVIEW

Seeking Health Information in the Online Community

Seeking health information online is a significant and emerging public health phenomenon. Approximately 72% of individuals with chronic disease sought health information online in the past year (Fox and Duggan, 2013). As health information is readily accessible online, there has been a shift in how individuals with chronic disease are acquiring health information. That is, individuals with a chronic disease are more likely to search online for health information than their peers without a chronic disease diagnosis (Fox and Duggan, 2013). Individuals with Type 1 Diabetes (T1D), an autoimmune disease that requires 24/7 medication and self-care, seek health information online from their peers and share anecdotal evidence and published articles (Hilliard et al., 2015). According to Funnell and Anderson (2000), it is widely regarded that 95% of diabetes management is self-care but the relationship between health literacy, online health information-seeking and treatment adherence in individuals with T1D remains undefined. Furthermore, the link between these constructs and health outcomes is not clear across existing studies.

Social support is the foundational construct that facilitates seeking health information online in a chronic disease community. In the right form and amount, social support can exert a positive effect on disease management. Support from family and friends promotes overall treatment adherence by encouraging both optimism and self-esteem, as well as lowering stress and reducing symptoms of depression (Shumaker & Hill, 1991; Wallston et al., 1983). Of note, social support is a widely-studied construct in chronic disease management but much of the diabetes-related social support literature focuses on the parent-child dynamics in adolescents with T1D or behavior change in adult individuals with Type 2 Diabetes (T2D). There are very

few studies examining social support provided in the Diabetes Online Community, known also as the DOC and composed of over 500,000 online members. This is troublesome due to the foundational nature of social support in treatment adherence. Social support is key for psychological adjustment (Shelley et al., 2011), health information seeking (Greene et al., 2010), maintaining mental health (Turner and Brown, 2010) and physical health (Uchino 2004, 2009) but very few studies have examined social support in adults with T1D. In addition, for individuals with T1D, this social support does not always occur in the traditional settings-- it is often experienced on social media platforms such as Facebook and Twitter (Oh, & Cho 2015).

There are existing antecedents and benefits of social media usage, including that as trust in social media increases, online self-disclosure increases (Lin, Zhang, Song, & Omori, 2016). Facebook usage was positively associated with emotional support, and both seeking health information online and emotional support were positively related to health self-efficacy in the general Facebook population (Oh et al., 2013). Previous literature has established the emotional benefits of social support in disease management but the physical benefits (i.e., objective health outcomes such as Hemoglobin A1c or T1D related health outcomes) have not been examined in the DOC (Shaffer-Hudkins, et al., 2014). The studies investigated if social media usage is related to patient outcomes and the underlying mechanisms that affect those objective health outcomes. An extensive section on social support is reviewed later in this document.

Other research has qualitatively examined how patients physically and psychosocially manage chronic conditions. In a study that interviewed bloggers with T1D and clinicians, participants described personal experiences of gaining, managing, and sharing health information. Participants used information-seeking to better understand their identities within and apart from their chronic disease community, their peers and their condition. Each person has

unique information needs and preferences, and existing online tools do not support these individual differences (O'Kane, et al., 2016). This need for tailored health information often leads T1Ds to seek information from their peers in a phenomenon known as peer-to-peer healthcare (Fox, 2013). Part of peer-to-peer healthcare dynamics includes social media disclosure where a patient must decide how much information they will be disclosing online in a very public space. There are many reasons for individuals with chronic disease to pursue social media discourse, including connecting with others who are experiencing the same medical diagnoses and seeking health information about others' health experiences (Greenwood, Perrin, & Duggan, 2016).

This study used the Social Provisions Scale (Cutrona & Russell, 1987) which follows the Social Provisions framework (Weiss, 1985), a model that focuses on the importance of the benefits of social relationships, such as guidance and opportunities for social integration. There are six types of social necessities available from the participant's social network: 1) *Reliable Alliance* (practical help), 2) *Guidance* (informational support), 3) *Attachment* (emotional support), 4) *Social Integration* (belonging to a group of similar peers), 5) *Reassurance of Worth* (esteem support) and finally, 6) *Opportunity for Nurturance* (providing support).

1.2 TYPE 1 DIABETES AND THE DIABETES ONLINE COMMUNITY

Health information is being exchanged continuously in the Diabetes Online Community (DOC; Hilliard et al., 2015). This online community thrives on social media sites such as Facebook and Twitter and provides largely anecdotal evidence (microblogging via tweets, Facebook posts, blogging and discussion boards) in medical decision-making events (Korda & Itani, 2013). Although using anecdotal evidence may be sufficient for individuals with high

health literacy and the ability to validate the information, individuals with low health literacy are at high risk of being susceptible to false information that may be life-threatening.

Currently, 29 million U.S. residents are living with diabetes. Within this group, over 1.23 million U.S. children and adults have T1D (American Diabetes Association (ADA), 2015) and this number is expected to increase three-fold by the year 2050 (Imperatore et al., 2012). The T1D diagnosis rate is equal across male and females (Soltesz et al., 2007). T1D is an intensive chronic condition that requires checking blood glucose levels multiple times a day, multiple insulin injections daily, and/or use of durable medical equipment that intravenously provides the patient with insulin (ADA, 2015). Successful T1D management requires multiple specialist appointments per year and regulatory/maintenance medication. Moreover, effective T1D management is not "one size fits all"; each patient's experience is different. For example, individual differences exist in insulin sensitivity and sensitivity towards environmental factors that may affect blood sugar (food, exercise, sleep and several other factors, Brown (2018)). Health practices that work extremely well for one patient may be detrimental for another patient.

In addition, T1D management is grounded in self-care and self-management that is often steered by a peer-to-peer network. Internet search engines and social media sites are an important part of critical decision-making processes for patients with T1D and their caregivers (Wiebe, Helgeson, & Berg, 2016; Niela-Vilen, Axelin, Salantera, Melender, 2014; Scullard, Peacock, Davies, 2010). The internet also serves as a way for T1D peers to connect. A recent panel composed of diabetes advocates described the need for online interaction amongst individuals with diabetes as an "essential parallel prescription for living well" (Sparling, Tenderich & Warshaw, 2015). Finding accurate information to aid in decision making (that most often occurs without a physician) frequently leads patients to anecdotal evidence provided by

other patients with diabetes (Greene et al., 2009; Lian & Nettleton, 2015). T1D advocates and clinicians predict that patients with diabetes spend thousands of hours on disease management outside of the doctor's office per year (Gabel, 2017).

1.3 SOCIAL SUPPORT ON SOCIAL MEDIA

Social support is defined as being valued and cared for by others (Wills, 1991). Providing social support delivers the same mental and physical benefits as receiving it (Taylor, 2011). Decades of research show a positive relationship between social support and better health outcomes in a variety of chronic conditions (DiMatteo, 2004). In addition, individuals who identify as "lurkers", those who engage in reading online community content but do not engage with peers, also retain social support benefits and maintain the same level of support as active members (Chung, 2014). In addition to the power of social support, online communities also provide a place for individuals to develop their identity and explore their relationship with their chronic disease (Kingod, et al., 2017). Part of identity development is interacting with peers in the online community. Types of questions that are asked in online communities usually fall in three distinct categories: facts (seeking truth and/or objective evidence), values (seeking the subjective evaluation of a topic or item), and policies (seeking a plan to solve a problem) (Kanthawala et al., 2016).

The theoretical basis of this project includes the Social Provisions Model (Weiss, 1985). Social Provisions are the benefits that individuals receive from their social relationships. The six types of Social Provisions are guidance, reliable alliance, reassurance of worth, attachment, social integration and opportunity for nurturance. Examples of types of Social Provisions occurring in the DOC include guidance (e.g., informational support). Members of the DOC provide empirical articles to members who post about engaging in exercise or reducing

carbohydrate consumption. Reliable alliance (e.g., practical help) may involve sending medical

equipment to Facebook friends who reside in areas affected by a natural disaster (observed

during the flooding caused by Hurricane Harvey; Hirsch, 2017). Reassurance of worth may be

reassuring a Facebook friend that they will overcome their pain caused by complications from

T1D. Attachment (e.g., emotional support) may be expressed as voicing concern over a post that

features an extremely high blood sugar reading. Members often aid in deciding the urgency of a

medical event or symptoms. Members will also follow-up with a member who has posted an

urgent blood sugar reading to make sure that their blood sugar returned to normal. Social

integration may be experienced as identifying with other members of the DOC. Lastly,

opportunity for nurturance may be expressed when providing assistance by mentoring new

members.

Even though previous studies have qualitatively investigated the potential empowering

effect of online peer-to-peer support, it is still not quantitatively evident how peer-to-peer

support through online communities supports individuals in daily life with chronic disease. In a

qualitative examination of the DOC, the DOC has been described as actively "mirroring the

outside world" (Arduser, 2011). Benefits of DOC membership include being able to share

information between users through quick responses and accessing multiple opinions and gaining

support from peers—social and/or emotional. A recent review provided evidence of the power

and effectiveness of offline peer support. Individuals who experienced peer support offline saw

improvements in blood glucose, blood pressure, cholesterol, body mass index, physical activity,

self-efficacy, depression and perceived social support (Dale, Williams, Bowyer, 2012). Due to

this ability to "mirror" within the DOC, it is expected that these same physical benefits will be

experienced when receiving offline or online support.

There are many ways to get involved in the DOC. Over 1,000 Facebook groups exist to provide support for individuals with T1D. As such, peer support is the foundation of the DOC and is ultimately expected in online health environments. Popular Facebook groups allow individuals to "vent", express themselves or "boast" (*Type 1 Diabetes*). Others promote strong emotional ties and promote in-person meetings (*Diabuddies Support Group*). Many groups are centered on specific physical activities and treatment suggestions (*Type 1 Diabetic Athletes*). Additional groups focus on providing support for individuals using durable medical equipment such as continuous glucose monitors (CGM; *Dexcom CGM Users*) and insulin pumps (*Medtronic MiniMed Insulin Pump'ers and CGMs'ers*). These groups largely exist for sharing information and social support during the struggles of a disease that presents many unique challenges. A member can post a question and receive an answer in seconds.

Information found online greatly varies and largely depends on the source. Online platforms where individuals seek health information often share many overlapping qualities but also differ greatly (Chen, 2012). Characteristics of these networks include: 1) flow of information, 2) tone, and 3) accuracy (Collins & Lewis, 2013). The DOC is not limited to traditional social media sites such as Facebook and Twitter. The DOC also exists in different venues such that there are online communities that meet both in person and online (College Diabetes Network; Tu Diabetes), blogs (Sixuntilme.com; Rains, Keating, 2011), videos (Diabetes Dominator; Diabetic Danica), podcasts (Diabetes Connections), and Twitter chats (weekly Twitter discussions with #DSMA). Social events often result from the groups mentioned above, for example Bolus and Barbells (a yearly exercise training event) and conferences that serve as meet and greets (Children With Diabetes Conference). Overall, people with diabetes are using the DOC in order to achieve the following: 1) peer support, 2) advocacy,

7

3) information to supplement medical care, 4) self-expression, 5) sharing and seeking information, 6) improvement of diabetes management, and 7) humor (Hilliard et al., 2015).

There are many benefits to being a member of the DOC (Hilliard et al., 2015) including, but not limited to, the following: 1) increased positive emotional experiences, 2) increased positive attitudes towards T1D, and 3) increased engagement in T1D management behaviors. There are many psychosocial benefits to participating in online support groups. Individuals with diabetes who participate in online support groups report increased patient empowerment (Van Uden-Kraan et al., 2008). Perceived social support may be related to amount of time spent in the DOC and amount of contributions one makes to the community. Indeed, in a previous study, diabetes bloggers perceived more social support the more that they blogged (Rains & Keating, 2011). Potential risks of participating in the DOC are those associated with internet use, in general (Hilliard et al., 2015). Established risks include: 1) access to misinformation, 2) threats to privacy, and 3) access to sponsored information. For example, many diabetes device companies sponsor popular bloggers, so information from these sources may be biased.

There are many ways to measure social support, and previous literature has focused on the perception of the availability of social support, the roles one plays in the support, the frequency of support, and the amount of people providing said support (van Dam, et al., 2005; Strom & Egede, 2012; Skinner, John & Hampson, 2000). This same research has focused on specific subgroups: adolescents with T1D, adolescents with T2D, caregivers of adolescents with T1D, and adults with T2D. Very little social support research focuses on adults with T1D or investigates online support received and provided by adults with T1D. This is a critical gap that needs to be filled.

1.4 HEALTH INFORMATION SEEKING

Often when faced with health decisions, patients must rely on their family members and friends for assistance and information, yet when specialized information is required, patients often seek information online (Heaney & Israel, 2008). Health information-seeking has long been documented as a key coping strategy and is characterized as a monitoring behavior that leads to problem-focused coping strategies (Glanz & Schwartz, 2008). Findings show more information-seeking leads to more self-care and more health promotion (Lambert and Loiselle, 2007). Additionally, sharing health information is positively associated with behavioral intentions to follow health recommendations (Crook et al., 2016). Health information-seeking is most often studied in three contexts: a hypothetical threatening health situation, behavior change, and prevention.

Norman (2011) recommended that to create and measure online health information-seeking behavior, researchers must create items that assess confidence in expressing oneself in online social interactions as well as one's ability to navigate information obtained through an internet database. He also suggested examining the constructs of confidence in information found online, participant self-efficacy, and digital literacy. Due to the social aspect of this online health behavior information-seeking, or, more specifically, reaching out to peers for health advice, we expect patient demographics to relate to social media and internet usage. Race, gender, age, socioeconomic status, and geographic location all have an influence on online information-seeking behavior (Morgan, Ferguson, & Trauth, 2015).

1.5 EXISTING MEASURES OF HEALTH INFORMATION SEEKING

There are four existing scales that have been used to measure information-seeking in the context of health. The first is the Krantz Health Opinion (Krantz, Baum and Wideman, 1980)

which is composed of two subscales. This measure requests participants to answer about their preferences for information and largely focuses on the decisions that are actively occurring in a hospital examination room. The first subscale is comprised of seven statements about preferences for information and nine additional statements comprise the second subscale regarding behavioral involvement. Some researchers have used this scale in a binary fashion (yes or no responses) while others have used the scale with Likert items (rating 1 to 7) and then summed the scores. The reliability for the item scores that make up these scales range from being poor to acceptable ($\alpha = .52 - .73$) (Christensen, Moran, Ehlers, 1999).

The second measure, the Miller Behavioral Style scale (Miller, 1987), is a widely used measure that assesses coping, specifically monitoring and blunting behaviors. This scale is based upon the theory that when faced with a threatening situation, individuals seek information in primarily two different ways. Individuals who employ monitoring behaviors are seeking information. The scale poses four hypothetical threatening situations followed by four monitoring and blunting options for participants to choose from for each provided scenario. This scale suffers from methodological and conceptual issues including poor internal consistency, poor quality of scenarios and poor face validity. Another methodological issue includes the items being treated as both binary and Likert. This scale has displayed poor to acceptable reliability ($\alpha = .39 - .73$) (Ridder, 1997).

The third measure is the Threatening Medical Situation (van Zuuren et al. 1996; Wakefield et al., 2007) that measures monitoring and blunting during a medical threat. Participants are exposed to four different vignettes. The four vignettes present a medical threat (e.g., headache, hypertension diagnosis, potential heart surgery and appendicitis). Each medical threat differs in symptom onset and amount of information that the participant is provided. As

with the previous measures, this scale used a 5-point Likert response option., There are issues involving the factor structure and the poor scale reliability (coefficient α = .58; Wakefield et al., 2007).

The fourth scale is the Autonomy Preference Index (Ende, Kasiz, Moskowitz, 1989; Bonfils, 2015) which aims to measure both patient autonomy and agency. The 14 Likert item scale has largely been used in samples of individuals with mental illness and has good reliability (coefficient α = .82 - .87; Simon et al., 2010) but suffers from inconsistent factorial structure and items that are not specific to health information seeking.

There are multiple methodological issues with each measure; namely, the hypothetical nature of these measures and their vignettes may lead to discrepancies between true health information-seeking and hypothetical health information-seeking (Garvin & Kim, 2000; Loiselle, 1995). These measures do not lend themselves to chronic conditions, as the measures require the participant to embrace a hypothetical medical condition and make their responses based upon these hypothetical conditions. Importantly, the majority of the scales demonstrate poor levels of reliability and poor ecological validity. Another validity issue to consider in the chronic disease population and, specifically, the T1D population is the difference between existing and/or long-term diagnoses and short-term/more recent diagnoses; current measures do not account for these important temporal differences. For these reasons, a new scale has been developed for this project that is specifically tailored to adults who have T1D.

1.6 ATTITUDES TOWARDS SEEKING HEALTH INFORMATION ONLINE SCALE

Previously, our laboratory has conceptualized the construct of interest (Attitudes Toward Seeking Health Information Online), identified and described behaviors that underlie the construct (seeking information from multiple sources, specific barriers that promote seeking

health information online, longevity of symptoms, and severity of symptoms) and developed the initial instrument (the Attitudes Toward Seeking Health Information Online scale) (Hughes, Perez, Morera, 2017). One hundred fifty-four participants contributed qualitative and quantitative data via Amazon Mechanical Turk (data collection was completed prior to the bot issues that Amazon Mechanical Turk is currently experiencing). This data was collected to further conceptualize the construct of seeking health information online and to understand how online information is evaluated (Diviani et al., 2015). The project also sought to understand the barriers in healthcare that lead to seeking health information online. The project used a Grounded Theory approach, useful for theory development and using qualitative data or mixed methods data (Strauss & Corbin, 1998), and followed a thorough qualitative coding framework (Braun and Clarke, 2006).

Two researchers with extensive coding experience identified participant responses using Nvivo (QSR, 2011). The qualitative coding followed a codebook developed precisely for this project (Hruschka et al., 2004). Next, codes were generated for each of the responses and once coding was completed, the researchers met to consolidate coding discrepancies. Next, the codes were sorted into themes which provide designated categories for the coded responses. One such response involved why the participant did not want to go to the doctor: "Because [Bc] I was embarrassed to talk to a doctor [dr] about it." This response became the code "embarrassed to talk to doctor". A pattern was detected amongst many of the codes and a theme was generated with this code and other relevant codes. This theme was "Embarrassed". All participants answered 11 qualitative prompts regarding antecedents to seeking health information online. Sixteen participants were excluded due to response brevity.

The majority of the sample used Google to seek their health information online. Regarding antecedents for finding information online, approximately a fourth of the participants describe the speed of the internet, "It's very fast to get information. It's quick and you can check multiple resources for help." Meanwhile, a fifth of the sample described the trustworthiness of specific online sources, "I only consider information from accredited, trusted sources, such as Mayo Clinic." Participants also mentioned reliability and accessibility of information online. Furthermore, over a third of the participants reported being motivated to go online to seek health information due to the severity and longevity of their symptoms.

Participants also described the need to seek out health information online to find out more about their symptoms, "I searched the internet for my symptoms after visiting another country." Barriers to seeking the information offline include finances and copays experienced at the doctor's office, "The deductible gets higher and higher." Lastly, participants also reported having difficulty with health insurance, "I don't have health insurance and can't afford to go to the doctor if what I am experiencing is something that I can deal with myself."

One third of the sample reported that information found online is very trustworthy. Obtaining matching medical advice from multiple sites, specifically WebMD and/or the Mayo Clinic, was a method used by participants to check for validity. Of particular interest to the current project, severity and longevity of the negative health symptoms, was linked to willingness to seek health information online. Participants reported using information found on Google as a decision-making tool to decide whether or not they needed to go to the doctor. The results highlight how online information is being used to make important decisions that may impact health in the long-term.

1.7 THE ROLE OF EHEALTH LITERACY

Many factors affect the perception of acquired information (both online and in person). The most recent findings support and extend the relationship between health literacy and health outcomes by examining eHealth literacy (comfort with seeking and evaluating online health information). Low health literacy is negatively related to the ability to evaluate online health information and overall trust in online health information (Diviani et al., 2015). Individuals with greater eHealth literacy are young and educated active consumers who seek information from multiple online sources. These individuals are capable of using more advanced search strategies, and judging information more effectively, which leads to better health outcomes (Neter & Brainin 2012; Oh & Cho, 2015). In a review of the literature involving diabetes self-management in patients with low health literacy, health literacy was associated with self-efficacy, knowledge and social support (Fransen, Von Wagner and Essink, 2011).

1.8 TREATMENT ADHERENCE

Treatment adherence, the act of following the prescribed methods, schedule, and medical intake that the health practitioner prescribed or suggested, is a major concern for researchers, practitioners, and patients with T1D. There are many barriers to treatment adherence. A high level of knowledge, literacy and numeracy (the ability to apply numerical concepts to everyday situations) are required to adhere to treatment, especially for T1D management which has rapidly changed in the last three decades. T1D self-management often includes durable medical equipment (e.g., insulin pump therapy, continuous glucose monitoring) that requires knowledge of the device, a certain level of literacy to manage the device requirements, and numeracy to make treatment decisions (Gonder-Frederick, Shepard, Grabman, Ritterband (2016). Individuals who are not fluent in medication literacy may experience more difficulty making treatment

decisions (Raynor, 2008). Treatment for T1D is heterogeneous in nature, such that insulins may work differently for individuals with specific diets or those who experience high levels of activity in their daily life (The most common measurement of T1D treatment adherence is the Hemoglobin A1c (ADA, 2015). This value provides an estimate of the patient's average blood glucose over the past 10 to 12 weeks. Recent research has shown that patient reported Hemoglobin A1c values are 92% accurate (Schneider et al., 2012). Much research has been conducted to examine the determinants of treatment adherence. One such construct is social support which has systematically been shown to increase chronic disease treatment adherence (Umberson & Montez, 2010).

Earlier research suggested social support may buffer stress and allow an individual to engage in more adaptive sick-role behaviors such as taking positive action toward treatment adherence for their chronic condition (Wallston et al., 1983). In addition, social support has been shown to affect not only short-term treatment adherence but also long-term treatment adherence (Smith et al., 1994; Uchino et al., 2012). Conversely, if an individual is not seeking information about their health then they can be considered avoidant or blunting (Case et al., 2005) which allows individuals to not violate their already established knowledge or beliefs. An extensive body of literature exists to further explore this robust relationship between social support and treatment adherence, yet not much is known about the mechanisms by which social support sustains and/or improves treatment adherence.

1.9 DIABETES DISTRESS

It is well established in the literature that having a chronic disease means an increased risk of experiencing disease related emotional distress (Nicolucci et al., 2013). Patient reported outcomes usually encompass two domains: the physical and the mental and are used to assess

"success" in patients with T1D. One example is diabetes distress which stems from the emotional stress of handling the self-management of diabetes (Fisher et al., 2014; Dennick, Sturt, & Speight, 2017). Examples of the burden of diabetes include the time-consuming nature of management and how expensive diabetes medication are (American Academy of Certified Endocrinologists, 2016). A major mental health burden for individuals with T1D is diabetes distress, where symptoms comprise emotional distress related to diabetes includes depressive symptoms and anxiety surrounding the different aspects of the management of the disease (Polonsky et al., 2005; Fisher et al., 2008; Fisher et al., 2012).

Women with T1D reported higher levels of Diabetes Distress (Fisher et al., 2015). In addition, age and number of complications are positively related to Diabetes Distress. Of note, high levels of Diabetes Distress are related to low levels of disease management and glycemic control in individuals with T2D (Fisher, Glasgow, & Stryker, 2010). In individuals with T1D, low Diabetes Distress is related to better glycemic control and improved quality of life (Fisher et al., 2015). This dissertation project used the Diabetes Distress Scale for Adults with T1D (DDS-T1D; Fisher et al., 2015). The DDS-T1D measure is a reliable ($\alpha = .91$) and heavily validated 28 Likert item measure that assesses distress that a participant has experienced in the last 30 days. The Likert items are from 1 (no distress) to 6 (serious distress). The subscales of Diabetes Distress are: *Powerlessness* (example item: "feeling that no matter how hard I try with my diabetes, it will never be good enough"), *Negative Social Perceptions* (example item: "I have to hide my diabetes from other people"), *Physician Distress* (example item: "feeling that I don't get help I really need from my diabetes doctor"), *Friend/Family Distress* (example item: "my family and friends make a bigger deal out of diabetes than they should"), *Hypoglycemia Distress* (example item: "I can't ever be safe from the possibility of a serious hypoglycemic

16

event"), *Management Distress* (example item: "I don't give my diabetes as much attention as I probably should"), and *Eating Distress* (example item: "thoughts about food and eating control my life").

Our approach to examining how individuals with T1D are using online health information included two studies. The studies examined the relationship between eHealth literacy, seeking health information online, social support, and treatment adherence in individuals with Type 1 Diabetes.

1.10 GAPS IN THE KNOWLEDGE BASE

The current project sought to clarify several existing gaps in the literature in a two-study design. There currently exists a gap regarding the influence of the DOC on self-management behaviors and treatment adherence. To resolve this widely-recognized problem, we proposed to identify the relevant relationships between health information-seeking online and treatment adherence to allow identification of the underlying relationship. The literature lacks research which demonstrates the magnitude of the relationship between eHealth literacy, social support, seeking health information online, Diabetes Distress and treatment adherence. Reviews of physical effects of social media usage, and more specifically, social media health information-seeking via social support are currently missing from the literature. The current project sought to gain more information about the following research question: What impact does online community involvement have on health outcomes in the chronic disease community?

1.11 THE NECESSITY TO BUILD A SCALE

Much of the T1D social science literature contains research where data was obtained from untailored questionnaires, not meant for usage in the T1D community. For this study, a measure was tested and refined to assess attitudes toward seeking health information online by the T1D

community which will contribute to understanding not only about the health decisions of this community, but also the health implications of these decisions that are made outside of the clinic. This scale is founded not only in the theoretical underpinnings of seeking health information online but is also based on preliminary data. In order to establish the validity of this measure, this questionnaire was tested and based in the opinion of adults with T1D who are active DOC members. This scale is necessary because existing measures of information seeking often suffer from poor reliability and construct validity. This dissertation aimed to develop and validate a scale based in inductive and deductive approaches and these unique perspectives will likely add to the literature and aim to encourage researchers to assess the DOC in deeper and more meaningful ways.

1.12 THE PRESENT STUDY

The major goal of this dissertation was to develop a valid and reliable scale to measure information seeking in adults with T1D. The secondary goal of this dissertation was to assess how information seeking relates to health outcomes of adults with T1D. Findings from this study will contribute to the knowledge base of the healthcare of adults with T1D. Participants were forthcoming about the items of the scale as they are part of a very active and communicative population. Findings from this first study informed revisions of the initial scale. When the items were assessed, they were revised in order to create a valid and reliable measure. The *long-term research goals* of this work are to develop a better understanding of the relationship between information seeking and long-term health outcomes in the T1D community.

To better understand the correlations between DOC membership and health and develop and validate a reliable scale of online health information seeking, the following research

questions were answered by the qualitative data collected in study 1. The hypotheses were

assessed based on data collected in study 2.

1.13 RESEARCH QUESTIONS AND HYPOTHESES

Qualitative research question 1: What are individuals with T1D's perceptions of how the

DOC assists members with their physical and mental health?

Q*ualitative research question 2*: How do individuals with T1D make a treatment decision

in the DOC?

Qualitative research question 3: What elements of the DOC do individuals with T1D

find to be most useful?

Hypothesis 1: Participants with higher scores on the Attitudes Toward Seeking Health

Information Online will report more positive health outcomes (higher treatment adherence, lower

Hemoglobin A1c, and less diabetes related complications).

Hypothesis 2: Participants with lower scores on a measure of Diabetes Distress will

report more positive health outcomes (higher treatment adherence, lower Hemoglobin A1c, and

less diabetes related complications).

Hypothesis 3: Participants with higher scores on a measure of Social provisions will have

more positive health outcomes (higher treatment adherence, lower Hemoglobin A1c, and less

diabetes related complications).

CHAPTER 2: METHODS

METHODS

  Mixed Methods Framework. This study employed the mixed methods scale development methodology of the Onwuegbuzie et al., (2010) approach to develop a valid and reliable scale (see Table 1). Mixed methods includes the benefits of both qualitative and quantitative methods, such that quantitative and qualitative data complements each other (Johnson, Onwuegbuzie, & Turner, 2007; Teddlie & Tashakkori, 2003). Quantitative analyses employ descriptive and inferential statistics, whereas qualitative analyses produce expressive data that provide descriptive details to examine the study's research objectives. There is much diversity in how qualitative data is collected in general (i.e., structured or semi-structured interviews, focus groups, and other forms) (Creswell, 2013). This study's qualitative data was collected solely online.

  Collecting both quantitative and qualitative data during the same study does not guarantee a mixed methods design. Instead, mixed methods relies on data integration (combining qualitative and quantitative data), including triangulation and the mixed methods matrix (O'Cathain, Murphy, & Nicholl, 2010; Bryman, 2006). Study 1 of this project quantified qualitative data using the matrix method by comparing scores on questionnaires with participant qualitative data. The research team created and used summary statements from each participant to help with the more abstract portion of the analyses. Summary statements were constructed in order to provide a brief appraisal that described the participant's responses, general codes and an overall gist of the available qualitative information.

  The current project employed a thorough thematic analysis framework for analyzing the qualitative data (Braun & Clarke, 2006). *Phase 1* involved the researcher and their research team immersing in the full dataset by reading and making initial comments about ideas regarding the

data. *Phase 2* encompassed generating initial codes (unique codes that categorize participant quotes) and organizing the most basic elements into meaningful blocks (codes). This is where the story of the qualitative data was first detected. During this phase, the coders detected all possible patterns (themes or patterns found among the categorized codes). Next, *Phase 3* involved searching for themes and determining a broader, more general portion of the analysis. Both coders completed separate analyses and then met to compare their analyses. The overall goal was to identify potential themes and code and assign all data to specific potential theme. In *Phase 4*, coders reviewed the themes via a roundtable discussion. This activity further refined the themes in order to have more precision and better contextual fit. At this point validity was assessed based on triangulating the existing theory, which means using multiple types of data to better answer the study's research questions with mixed methods data. During *Phase 5,* coders defined and named themes, wrote detailed analysis and example quotes for mixed methods analyses. Lastly, *Phase 6* included the final analysis of the qualitative data which involved reconciling the general (summary statement analyses) and more specific (thematic) analyses.

Data was then integrated using a mixed methods matrix. Each row represented one participant and contained data from both the questionnaires and qualitative prompts. The columns delineated each piece of data. This allowed the research team to not only assess the data case by case but also detect patterns across all cases in a qualitative cross-case analysis (Tashakkori & Teddlie, 1998). Thematic analysis was used to identify, analyze and report patterns and themes that occurred in qualitative data. The preliminary data for this project was largely data-driven (inductive). Conversely, the data for this project was deductive (theoretical) as a means of confirming previous responses and generalizing findings.

Research Assistant Training

In order to promote validity and reliability of the findings, two research assistant (RA) were trained to code the quantitative data collected during studies 1 and 2. The training was similar to a journal club setting and the RA met with the principal investigator several times to practice coding. The research team discussed the benefits and limitations of mixed methods in the online setting and discussed assigned readings, YouTube videos and podcasts regarding the culture of T1D in adults.

2.1 PARTICIPANTS

Participants were recruited from the DOC via Facebook ads, tweets, peer to peer referrals and email listservs. Participant eligibility required the following: 1) being 18 years of age or older, 2) being a member of the DOC and 3) having been diagnosed with T1D by a doctor. Recruitment began March 2018 and ended July 2018. Participants had the opportunity to refer other members of the DOC to the study. Study 1's sample included 95 DOC stakeholders. Study 2's sample included 166 DOC members. Prior to data collection, these studies underwent review by the Institutional Review Board at the University of Texas at El Paso. To protect participant privacy, only the author and the trained research assistants had access to the data. Data were de-identified and stored in a password protected computer.

2.2 MEASURES

Demographic questions **(Appendix A).** The demographics questionnaire asked participants to self-report their age, gender, marital status, ethnicity, and education level. Items also included questions regarding their experience with diabetes including diabetes duration and mode of insulin delivery (insulin pump, multiple daily injections, inhalable insulin, and other options). Health outcomes (comorbidities and complications) were also collected (Appendix B).

eHealth Literacy **(eHEALS, Norman and Skinner, 2006; Appendix C)*.*** The eHealth Literacy measure assessed participants' perceived ability to read online health information, use computers to seek health information online, search for health information online, interpret online health information, and use said information. The measure has also been tested in samples composed of individuals with chronic disease and been found to be both valid and reliable (Paige et al., 2016). The questionnaire assesses eHealth literacy in internet users via ten Likert items. It is a 1 factor questionnaire with acceptable model fit (Comparative Fit Index/Tucker Lewis Index (CFI/TLI > 0.90)). Previous research shows that test score reliability of this measure is exceptional ($\alpha = .94$). An example item reads: "How useful do you feel the Internet is in helping you in making decisions about your health?"

Social Provisions Scale **(Cutrona & Russell, 1987; Appendix D).** The Social Provisions Scale (SPS) has 24 Likert items encompassing six types of social necessities available from the participant's social network. The six types of social necessities encompass: 1) *Reliable Alliance* (practical help), 2) *Guidance* (informational support), 3) *Attachment* (emotional support), 4) *Social Integration* (belonging to a group of similar peers), 5) *Reassurance of Worth* (esteem support), and finally, 6) *Opportunity for Nurturance* (providing support). Each type of social provision is a subscale of the SPS with four items per subscale. The SPS is widely used and shows good test score reliability ($\alpha = .92$) while test score reliability of the various subscales range from .65 to .76 (Cutrona & Russell, 1987; Gottlieb & Bergen, 2010). The six subscale scores were used for this project. The SPS is based on the model of Social Provisions (Weiss, 1974), a model that focuses on the importance of the benefits of social relationships, such as guidance, from their non–assistance-related functions, such as opportunities for social integration.

***Feedback Questions* (Appendix E).** Participants provided responses based on each item's clarity, aesthetics, relevancy, tone and length of time needed to respond and cultural competence*.*

***Qualitative Questions for Stakeholders* (Appendix F).** Stakeholders were provided with additional qualitative questions in order to better understand their role in the DOC.

***Treatment Adherence* (ARMS-D, Mayberry et al., 2013; Appendix G).** This study used a version of the Adherence to Refills and Medications Scale (ARMS; Kripalani, Risser, Gatti, Jacobson, 2009) which was originally constructed to measure adherence in individuals with coronary heart disease. The scale was then tailored and tested for individuals with Diabetes (ARMS-D, Mayberry et al., 2013). An example item includes: "How often do you….forget to take your diabetes medicine(s)? This scale in total has been found to be reliable (α = .86). The predictive validity of this scale with the key marker of diabetes treatment (Hemoglobin A1c) was confirmed. The construct validity was also confirmed with other commonly used diabetes treatment adherence scales and biological variables. The final way that this project assessed treatment adherence is through the self-report biological adherence marker of Hemoglobin A1c.

Diabetes Distress* (Polonsky, 2005; Appendix G)*. The Diabetes Distress Scale (DDS-T1D; Polonsky et al., 2005; Fisher et al., 2008; Fisher et al., 2012) is a reliable (α = .91) and well validated 28 Likert item measure that assesses diabetes-related distress that a participant has experienced in the last 30 days. The Likert items range from 1 (no distress) to 6 (serious distress). The subscales, which are sources of Diabetes Distress, are: *Powerlessness*, *Negative Social Perceptions*, *Physician Distress, Friend/Family Distress*, *Hypoglycemia Distress*, *Management Distress*, and *Eating Distress*. This score has excellent internal reliability (α = .95).The subscale reliability in previous studies has ranged between .76 and .88.

***Attitudes Toward Seeking Online Health Information Scale (*Appendix I*).** Study 1's scale had 15 items. After study 1, items were edited and an additional 4 items were generated. Study 2's version of the scale was comprised of nineteen items.

2.3 PROCEDURES

Participants accessed the Qualtrics survey link via Facebook ads, tweets, peer to peer referrals or email listservs. The informed consent was signed on Qualtrics and then participants proceeded to immediately start the set of demographics questions, qualitative prompts and surveys. Three equally spaced attention checks existed throughout the surveys. Sample attention checks included true false questions such as: "The Earth is round". Participants who answered any of the attention checks wrong were not included in the data analyses. In addition, participant IP addresses and emails were compared within and across studies to determine whether participants had taken the study twice. Once the survey was completed then participants were presented with this closing statement: "Thank you for your valuable feedback and participation. For your participation you will receive a link to the free download of Daniele Hargenrader's book: *Unleash your Inner Diabetes Dominator* and $10 Starbucks gift card." On average, participants completed Study 1 in 25 minutes and participants completed Study 2 in 43 minutes.

Mixed Methods Framework

This study followed the Onwuegbuzie et al., (2010) conceptual framework of developing quantitative scales via mixed methods. The 10 phases are described in more detail below.

Phases 1 - 3

Phase 1 of this 10-step methodology is to conceptualize the construct of interest (seeking online health information); the second phase is to identify and describe behaviors that underlie

the construct and the third phase is to develop the initial instrument. The first three phases have already been completed, as they were the basis of the author's first year project. This project aimed to complete the remaining phases of the 10-phase framework.

Phase 4

This project began with phase four: assessing the initial instrument. Part of the testing during this phase assessed each item's suitability (clarity, aesthetics, relevancy, tone, length of time needed for a response, and, above all, cultural competence). The framework raises the importance of the literature review when developing a scale. For this reason, there was a dual methodology to the development of the questionnaire's items such that parts of the developed question were theoretically driven (based on previous literature) while other items were data driven (from this preliminary data) (see appendix I). Three fourths of the items were based on theoretical considerations and previous literature while ¼ of the items were developed based on the results of the preliminary data. Onwuegbuzie et al., (2010) encourages this phase to focus on content validity areas such as face validity and item validity.

A key suggestion from the authors of this framework is the importance of stakeholders who can improve the items due to their expertise in the field of interest. For this reason, stakeholders provided feedback and the instrument was revised based upon this feedback. Stakeholders were identified in multiple ways. The first method was to identify leaders in the community who are actively advocating for the T1D community (both offline and online). The second way was to identify the more general population of DOC members who may not have leadership roles. Study 1 gained stakeholder feedback on clarity, esthetics, relevancy, tone, length of time needed for a response, and cultural competence.

Phase 5

The fifth phase is to validate the revised instrument quantitatively. After collecting stakeholder feedback, the instrument was revised and then the instrument was tested in Study 2. This phase's goal was to assess the content-related validity, and construct-related validity (convergent validity) of the scale. Qualitative coding for this project was a multistep process and a codebook was completed by the research team and included expected codes and themes in order to promote interrater reliability (Hruschka et al., 2004).

Phase 6

In Phase 6 of the current project, the Confirmatory Factor Analysis (CFA) was conducted on the data collected in Phase 5. A sufficiently powered CFA was conducted on data collected in Study 2. The qualitative data collected along with the quantitative scale from Phase 5 was analyzed. The qualitative data collected in Study 1 was analyzed using thematic analysis.

Phases 7, 8, 9

In Phase 6, a factor analysis was conducted with the data from Study 2. The quantizing qualitative data portion of Phases 7, 8 and 9 of the Onwuegbuzie et al., (2010) framework were not conducted due to the nature of the existing study 1 and study 2 data and underlying statistical assumptions. Study 1 was a very large sample and quantizing the themes and then conducting an EFA would have introduced bias. For more information on phases 7, 8 and 9 please refer to Onwuegbuzie et al., (2010).

Phase 10

The findings from these analyses were compared, and convergent findings and discrepancies between the different phases of data analysis were identified. Phase 10 included synthesizing the results and discussing their meaning and implications. Results from studies 1

and 2 were compared and their implications are included in the discussion section of this document.

Data Collection – Data collection included two types of data: 1) quantitative (surveys) and 2) qualitative (qualitative prompt responses and item feedback). Participants received both surveys and qualitative prompts. Participants in both studies provided feedback on the items in the Attitudes Toward Online Health Information Seeking scale as a means of measuring validity by comparing participant feedback to the item statements. Data was collected on Qualtrics and ads were distributed across the DOC in both studies 1 and 2. Two research assistants were trained to code both the qualitative and quantitative data. Validity was assessed in both studies and reliability was assessed in study 2. The first study assessed factors driving health information seeking in individuals recruited from the online T1D community. Participants were recruited from Facebook, the Diabetes Hands Foundation, the Juvenile Diabetes Research Foundation and various email listservs. Those who participated in study 1 were not allowed to participate in Study 2.

Study 1: Revise the instrument and seek stakeholder feedback. A sample was collected from experts in the field, key informants, and stakeholders. Participants provided feedback on items via qualitative prompts. Before data collection in study 2, the instrument was edited based on the feedback received during study 1 (see appendix J for updated scale). In study 1, participants completed the demographics form and the Attitudes Towards Seeking Health Information Online Scale, provided qualitative feedback on the Attitudes Towards Seeking Health Information Online Scale, and answered qualitative questions regarding the nature of the social support that they receive in the DOC. Study 1's data provided support to refine the design of the instrument by revising the instrument based upon participant feedback.

Study 2: Test the initial instrument. Testing occurred with individuals recruited from the DOC. Participants assessed each item for clarity, esthetics, relevancy, tone, length of time needed to respond, and cultural competence. One hundred seventy-five participants were recruited from Facebook, Twitter, peer to peer referral and various email listservs. Although only 145 participants were needed per the power analysis (see power analysis in table 2; (Preacher & Coffman, 2006), additional participants were collected due to the possibility of participants not following instructions or trolling. Key constructs were measured in two different forms so that the scores could be matched to check for content and construct validity by receiving feedback regarding each item from participants. This assessed each item for clarity, esthetics, relevancy, tone, length of time needed to respond, and cultural competence. In study 2, participants completed the surveys in this order: a demographics form, a health questionnaire, the Attitudes towards Seeking Health Information Online Scale, qualitative feedback on the Attitudes towards Seeking Health Information Online Scale, the Social Provisions scale, the Diabetes Distress scale, and the Treatment Adherence (ARMS-D) scale.

Validity was assessed with correlational indices (see table 3 for more information). Structural validity was assessed via confirmatory factor analysis. Psychometric indices were used to assess the items and qualitative indices were used to assess the responses. Correlations and reliability were also assessed.

2.4 DATA ANALYSIS

Study 1. Obtained stakeholder feedback. The first study gathered opinions on the scale once it had been edited based on the quantitative and qualitative results of the preliminary data. Key stakeholders (individuals with research background, influential members of the DOC, and general members) provided feedback on the Attitudes Toward Seeking Health Information

Online Questionnaire. The key to finding stakeholders is that they provide a voice in the position of key informants and still represent the samples of DOC members as a whole. Importantly, these individuals are active members of the DOC and often speak collectively for this community. They are representatives that serve as key online personalities and influencers in the DOC. Ninety-five stakeholders took part in this phase, following stakeholder sample size considerations (Marshall, Cardon, Poddar, & Fontenot, 2013). Participants completed an almost entirely qualitative questionnaire to assess the clarity, esthetics, relevancy, tone, length of time needed to respond, and cultural competence of the scale (phase four of Onwuegbuzie and colleagues' (2010) framework).

      Study 2. The second study tested the questionnaire. Multiple confirmatory factor analyses (CFA) was conducted using M*plus* 7.11 (Muthén & Muthén, 1998-2018). Robust maximum likelihood estimation was used in this model. This step of the analyses used absolute fit indices (obtained from the fit of covariance matrices and the robust maximum likelihood estimation) (Ullman & Bentler, 2012). These indices do not use an alternative model to make comparisons. The absolute fit indices used in this project include $\chi 2$ and Standardized Root Mean Square Residual (SRMR). Relative fit indices (computed by conducting model comparison using a null model) were also used in this project. The relative fit indices included the Tucker-Lewis Index (TLI). Noncentrality-based indices were conducted using a model comparison technique that seeks to compare the model results to the alternative hypothesis (Root Mean Square Error of Approximation (RMSEA), Comparative Fit Index (CFI).

      Following factor analysis and model fit comparison guidelines (Hu and Bentler, 1999), CFA results were then compared to assess for model fit utilizing: SRMR < .09 in combination with either TLI or CFI < .96, or RMSEA > .06. Of note, the Type I and Type II error rates are

lowest for sample sizes of 250 or greater (Hu & Bentler, 1999). Items were also assessed

qualitatively when participants provided feedback on each item (see appendix B).

A power analysis was conducted for study 2. Sample size estimates were computed

using RMSEA. Once RMSEA was computed, then it was used to determine the noncentrality

parameters (the foundation for some types of power calculations) (MacCallum, Browne, & Cai,

2006). These statistics were computed using quantpsy.org (Preacher & Coffman, 2006). A test of

close fit using values of RMSEA (for null and alternative hypotheses) was computed to

determine the sample size needed to detect a difference in fit of the null and alternative models

and determine the model with an optimal number of factors (MacCallum, Browne, & Cai, 2006).

The results were $N = 145$, *number of items* = 15 and the model's degrees of freedom equaled 87.

A sample size of 145 is necessary to obtain power $= .80$, $\alpha = .05$, RMSEA null $= .05$, and

RMSEA alternative $= .08$. Next, item loadings, inter-item correlations and reliability were

carefully assessed (McDonald, 1999).

I also conducted hierarchical regression models using SPSS (IBM, 2017) to test the

proposed hypotheses. The hierarchical regression models were variations of the following

regression model: Step 1 always included the following covariates: Diabetes duration, eHealth

Literacy, socioeconomic status (SES), and education (Kuske et al., 2017). The second step

included a variation of: Attitudes Toward Seeking Health Information Seeking subscales,

Diabetes Distress subscales and Social Provisions subscales. Dependent variables included:

Treatment Adherence, Health Outcomes (number of diabetes related complications) and

Hemoglobin A1c. Correlations were also calculated.

There was very minimal missing data in this dataset. For the reported variables used in

analyses, SES had 7.8% missing data, Hemoglobin A1c had 1.8% missing and number of

Facebook groups a member of had 1.8% missing. Data was assessed using Little's test (using a chi square test to assess whether the variables were missing at random; Little, 1988) Upon conducting the test, assessing the context of these variables and determining the distribution of the data, it was determined that the data was missing at random. These missing data were addressed using SPSS to impute the missing values using Markov chain Monte Carlo multiple imputation with 20 imputed datasets. Multiple imputation replaces the missing data value with a set of potential values.

This study addressed phases 5 and 6 of Onwuegbuzie and colleagues' (2010) ICDV process as the scale was revised based on feedback from Study 2. Data from Study 2 was quantitatively analyzed with a CFA. Crossover analyses were completed in various ways but for the purposes of this dissertation project, the crossover analyses were conducted using the previously mentioned mixed methods matrix. Lastly, the final scale was evaluated and overall conclusions and generalizations were completed.

CHAPTER 3: RESULTS

3.1 STUDY 1 – PARTICIPANT CHARACTERISTICS

One hundred DOC stakeholders participated in Study 1. Four participants were excluded due to age restrictions. Additionally, the data indicated that a participant completed the survey twice. Of the 95 participants included in this sample, 91.6% identified as female with an average age of 26.8 years (SD = 7.176 years). The majority of sample participants (95.8%) were located in the United States. Approximately 78.9% of participants were white/Caucasian, 2.1% African-American, 9.5% Mexican-American, and 3.2% were other Hispanic or other Latinx. The average household income was $66,283 (SD = $56,148, mode = $50,000). Regarding education, participants reported the highest level of education that they had obtained: 35.8% completed a Bachelor's degree, 14.7% completed a graduate degree, 12.6% had completed an associate's degree and 23.2% of the sample reported that they had received a high school diploma. More than half of the participants (70.5%) reported being diagnosed with T1D before the age of 18.

Participants also provided information about their history with diabetes and their usage of durable medical equipment. More than half of the participants (62.1%) reported using an insulin pump. Participants reported a mean Hemoglobin A1c of 7.17% (SD = 1.5%). Of note, over half of the participants (51%) reported having a Hemoglobin A1C of 7.0% or over, which translates to having an average blood sugar of 154 mg/dL. Of importance, a target Hemoglobin A1c for individuals who have been diagnosed with T1D is below 6.5%. The Diabetes Control and Complications Trial found that a Hemoglobin A1c below 7% was efficacious, and it showed a marked reduction in diabetes-related complications for individuals with a Hemoglobin A1c below 7% (Miller, 2014).

Fifty-five users reported using a continuous glucose monitor (CGM). These CGM users reported achieving blood sugar targets 68.85% (SD =19.676%) of the time. Participants reported

33

testing their blood sugar on average 4.51 (SD = 2.54) times per day. Nearly all participants (91.7%) reported having an active Facebook account and 98.9% reported searching for health information on their cell phone. All participants reported searching for health information online and 85.4% reported searching for health information using applications on their phones. Participants reported being a member of 3.29 (SD = 4.347) Facebook groups.

Health Demographics

Participants also reported comparisons of their health with others and their satisfaction with their own health. When asked to rate their own health in comparison to others, ("Compared to other people your own age, how would you rate your physical health?"), 44.8% of participants reported their health as "average", 29.2% reported "better than average" and 19.8% reported "worse than average". In addition, participants were also asked how satisfied they were with their current well-being ("How satisfied are you with your present health?"), to which 55.2% of participants stated that they were "somewhat satisfied" while 17.7% stated that they were "not very satisfied". Participants reported that health problems "sometimes" stand in their way (36.5%).

Overall, this sample of participants was very active; 88.5% of the sample reported participating in a regular form of exercise (e.g., climbing stairs, walking, or other forms of exercise). Sixty-four percent of participants take additional medications beyond insulin. Participants also reported on their T1D comorbidities: Anxiety 34.4%, Celiac disease 6.3%, Depression 33.3%, Eating Disorder 18.8%, Gastroparesis 5.2%, Grave's disease 3.1%, Hashimoto's 11.5%, and Renal disease 1%.

Mental health is a current priority in the Diabetes clinician community and, most recently, the American Diabetes Association (ADA) and American Psychological Association

(APA) collaborated to create a training session for mental health professionals to become certified to provide care for the mental health of patients living with diabetes. At this point in time, we do not know how many individuals with T1D are experiencing Diabetes Distress, depression, anxiety, and eating disorders. For additional health demographics and general health concerns, refer to table 4.

Participants described their experience in the DOC. They also described their leadership roles, which included assisting support groups, fostering nonprofits, and serving on national leadership committees. Sixteen participants (16.8%) reported having at least one leadership position in the DOC during the time of the survey.

Stakeholder Assessment of Seeking Health Information Online Scale

Study 1's coding categories included 756 quotes, and 36 themes. Participants completed a detailed assessment of the Attitudes Toward Seeking Online Health Information scale in Study 1. More than half of the participants (56.6%) reported completing the scale in 15 minutes or less. Seventy-seven percent of the participants believed the questions were written by someone who had an accurate idea of Type 1 Diabetes. Regarding additional comments about the questionnaire, participants reported support for the items and endorsed the cultural competency of the scale with statements such as: [ID 195]: "asked relevant questions for someone with T1D", and [ID 149]: "Asking how the diabetes community has helped with physical and mental health. Those are 2 significant aspects that are affected by this condition". Several participants endorsed Instagram as part of the DOC because they sought social support for T1D management on Instagram. Instagram had not been previously included in the survey materials but due to these comments, the demographics section for Study 2 and scale items for the Attitudes Toward

Seeking Health Information Online scale included Instagram as an example of social media in the DOC.

Based upon detailed feedback provided by participants, the Attitudes Toward Seeking Health Information Online scale was edited for Study 2 (see Appendix J for the edited scale). Specific participant requests encompassed a need to improve clarity and change "treatment decisions" to "advice". Many participants stated the importance and major impact of the DOC in how they make decisions about which medical devices they will be using. Much of the conversation in the DOC involves medical device usage, tips and tricks, navigating insurance and medical claims advice and overall conversations on accessibility. Breaking news about medical devices is often shared widely in the DOC such that when FDA approval is given to a new diabetes device, DOC members will find out from social media-based news outlets and other DOC members before they find out from their doctor. Of importance, participants stated that they began using specific types of durable medical equipment due to endorsements from DOC members.

Participants were instructed to rate the following statement: "How Clear is the Language of These Questions?" Overall, the questions were rated as "clear" and "very clear" (37% of the participants reported that the language of the questions was "clear" and 47% reported that the items were "very clear"). Participants were also instructed to rate the following statement: "How Natural do these Questions Sound?" Forty-five percent of the participants reported that the questions were "natural" and 38% of participants reported that the questions were "very natural". Participants were also instructed to address the following question: "How would you describe the tone of the questions?" Fifty-nine participants described the items from the Attitudes Towards Seeking Health Information Online scale as "Academic" ($n = 12$), "Appropriate" ($n = 2$), "Clear"

($n = 6$), "Clinical" ($n = 3$), "Conversational" ($n = 1$), "Curious" ($n = 1$), "Diabetes Friendly" ($n = 1$), "Easy and open" ($n = 5$), "General" ($n = 2$), "Good" ($n = 11$), "Informational" ($n = 6$), "Neutral" ($n = 3$), "Normal" ($n = 2$), "Objective" ($n = 1$), "Positive" ($n = 2$), and "Professional" ($n = 2$).

Participants also reported seeking existing advice in order to answer any health questions they may have. Members of the DOC may endorse the answer to the question or state how this piece of information has impacted them. This dynamic challenges how online health information seeking was originally conceptualized for this set of studies. The initial conceptualization did not account for existing information but instead focused on sharing new information. Lastly, participants encouraged more tailored questions for T1D and the DOC.

Participants requested more open-ended survey questions and more studies about various aspects of information seeking in the DOC. Participants in this community are very forthcoming in what they need and want to see in research. Overall, participants stated that the questions seemed relevant to T1D and DOC usage. They reported gathering information first in preparation for making a decision about whether or not to go to the doctor. Participants reported that the DOC provided them with information on how to use their medical devices, including information about how to address treatment management for sick days, emergencies situations, and exercising.

An interesting phenomenon within these data (and generalized to this community) is that some DOC members indicated that they provide advice to others but they do not request it. Key quotes included: [ID 189]: "I wouldn't make a treatment decision online with someone who I do not know as that could result in poor treatment. I have made suggestions once in a while or advised how I would treat myself in that situation." and [ID 173]: "A woman had asked about

using her libre [CGM] to make decisions on the insulin, she was new to it and was hesitant about how to treat. I gave her several personal examples and showed successes and failures. Others did the same thing. She decided to try small changes and let her doctor know which I also advised". Another key quote: [ID 108]:

"I have a family in CO who has a son about the same age as my son who was having a hard time reach out to me direct, and I was able to help them get some things set while their son had the flu. It was a really good feeling and we have been friends for some time now. As for me, I haven't had to ask for help on anything in a long time since I have done most of it on my own for so long."

This dynamic has important implications for the way that individuals with chronic disease seek health information. Specifically, existing information seeking theories do not take into account the role of information brokering that occurs in the online community. Furthermore, there is a difference between the types of information (by topic) that are being sought and how (actively asking advice versus passively seeking advice) they are being sought.

Participants had a wide range of experience and weekly commitment giving medical advice in the DOC. An example of this range was that some participants stated that they spent 0 minutes weekly providing advice in the DOC but others stated that they spent 6 to 7 hours giving advice in the DOC per week. Of note, one participant indicated: [ID 103] "Not much. While I appreciate anecdotal advice but I prefer medical information to come from my endocrinologist. I rarely SEEK out medical advice...that doesn't prevent it from being offered to me though...." Several participants stated that they were recipients of unsolicited health advice in the DOC. Another identified: [ID 109]: "whatever time I don't spend looking, I am helping." Another

38

participant stated, [ID 179]: "Currently, I am not seeking advice, at least not 100% of the time. Sometimes I'm just reading and stumble upon advice that I find useful."

3.2 STUDY 1 – THEMATIC ANALYSES

Participants were very forthcoming in what they wished to improve in their T1D management (see Table 5). Participants reported that they wished to "Avoid blood sugar excursions ($n = 33$). This includes the wish to improve their overall health by limiting the amount of out of range blood sugars that they experience. Blood sugar excursions are generally viewed as readings below 70 mg/dL and above 180 mg/dL. One participant stated: [ID 146] "I wish I could improve how much I spike after meals". This expression of frustration is to be expected, as T1D is characterized by the disruption of normal blood sugars. Diabetes self-management involves a constant cycle of medication and measured food intake and treatment of hyperglycemia may lead to episodes of hypoglycemia.

The next theme was "Improving Nutrition", including counting carbohydrates and improving overall food quality ($n = 16$). One participant stated: (ID 172): "I would like to have better control in food management. I need to work on eating healthier rather than the stuff I eat currently. For example, I eat sugary cereal for breakfast and kind of eat whatever I want". Importantly, participants also demanded improvement in the diabetes related devices (insulin pumps, CGMs and blood glucose monitors). One participant stated a need for [ID 160]: "An easier way to check BG [blood glucose]/ have all systems communicate with each other (meter, pump, logbook, etc.)."

Varying Levels of Assistance in the DOC

The second qualitative question assessed how participants perceived that the DOC assists them (see Table 6). The majority of participants stated that the DOC assists them ($n = 63$).

39

Assistance in this instance means that the DOC supports and helps other DOC members with a wide variety of issues. Particularly, a participant indicated that the DOC is: [ID 109] "[…]Great resource for crowdsourcing, learning about others experiences, and just meeting others in a similar boat as me, even if they live around the world." Another participant indicated: [ID 171]: "Yes. Being a part of it encouraged me to seek out a CGM and go back on a pump, giving me 1 year of the best a1cs since my diagnosis." Participants also reported the common theme of multiple types of support in the DOC including emotional support, encouragement to get a CGM, informational support and inspiration: [ID 140]" YES! There are so many things I've learned from my online friends that I didn't even learn from my doctor."

Of note, 2 participants stated that they do not receive assistance from the DOC. One participant stated that topics such as eating disorders are not discussed often in the DOC: [ID 102]: "Few talk about eating disorders (diabulimia) and far too many people post CGM graphs or talk about blood sugars which is extremely triggering to me." Others stated how members of the DOC only sometimes assist other members of the DOC ($n = 10$): [ID 112]: "[…] Instagram can be a big help but it can also be confusing because what works for one does not work for all." These statements begin to illustrate how the DOC differs person to person even, and group to group ($n = 1$) and that it may actually be difficult to find help for some people ($n = 1$). Other participants stated that they are not "active" members of the DOC ($n = 14$). Although recruitment consisted entirely within the DOC, some participants did not consider themselves members of the DOC ($n = 13$). Participants also elaborated on the support and motivation that they are experiencing in the DOC and reported receiving multiple types of support in the DOC ($n = 19$): [ID 140] "YES! There are so many things I've learned from my online friends that I didn't

even learn from my doctor." Others also endorse gaining *Emotional Support* (*n* =1), and *Informational support* (*n* = 11).

Usefulness of the DOC

The next set of themes reflected what participants felt as the most useful part of the DOC (see table 7). Three main themes encompassing social support and types of support were present in this dataset. The first theme was sense of community (n = 48), where members reported experiencing an overall feeling of belonging to something "bigger" in the DOC. One example of this is: [ID 177]: "Reading other people's stories whom I can relate with. No judgement and everyone understands each other." Of note, the DOC is an online community, so it is expected that themes like sense of community would be expressed. Individuals in the community often express the benefits. Overall, these examples and themes provide powerful support that the DOC has a beneficial impact on the amount of social support that individuals with T1D are experiencing. In turn, this social support involves supplemental advice about medical care which promotes not only physical health but also mental health.

The second theme was *social interaction and support* (*n* = 30). This theme was defined as DOC members interacting with other members and receiving social support during these interactions. In general, participants are part of the DOC because they are benefitting from it and many seek the positive components and ignore the negative ones. A participant also reported searching for individuals with specific demographics in the DOC that they cannot experience in their everyday in vivo environment. One participant stated that she uses the DOC to [ID 174]: "Connect with other women". Much like other participants, this participant expresses that she is seeking something that she cannot find in her everyday life. The third theme was *informational support* (*n* = 29), incorporating exchanging advice, suggestions related to diabetes management

41

and overall information. Participants stated: [ID 112]: "Learning about new technologies and insulin."

At the core of this research, is the need to further understand how individuals with T1D are gaining health information in the DOC and the impact that this has on their health and health outcomes (see table 8 for more information). Several participants did not consider themselves members of the DOC but then described behavior that constituted participating in the DOC. An example statement from an individual who does not endorse that they are an active member of the community includes: [ID 102]: "I don't post questions about diabetes. The few I've asked questions about unrelated health issues, I rarely get responses." This user reported frequently using Twitter instead of Facebook and this is where she experiences her sense of community. Other participants endorsed that they had an overall positive experience in the DOC defined by quality feedback, helpfulness, and encouragement (n = 60). One participant stated: [ID 115]: "I have gotten really great feedback and advice from fellow T1Ds. People have been extremely helpful."

Pros and Cons of Membership in the DOC

Participants were also asked to describe the pros of being a member of the DOC (see table 9). Themes included informational support where members gain *information and advice from other members of the DOC* (*n* = 25). The types of information being shared in the DOC are varied. Participants expressed sharing information regarding nutrition and exercise. One participant stated: [ID 119]: "I also enjoy learning of low carb recipes that people post." Not surprisingly, participants stated that they felt a "*sense of community*" within the DOC (*n* = 52), stating [ID 108]: "We are all going through this together, so that is the best part." Participants

42

also describes cons of being a member of the DOC (see table 10). Themes included *comparing self to others (n = 10)* and *misinformation (n = 6)*.

Physical Impact of the DOC

Overall participants stated that the DOC had a *positive impact on their physical health* (n = 64), stating improvements in self-care, exercise behaviors, improved nutrition, and access to healthcare and medication. Quotes included: [ID 109] "It's improved. I've learned a few tidbits to apply to daily life, especially about alternative snacking habits and insulin dosing strategies." Another participant stated that the DOC helped them adjust to a new lifestyle change: [ID 120]: "Definitely! I used to dance a lot years after being diagnosed and I had a hard time adjusting to the lows for a long time. After I retired from dancing, I had to pretty much adjust my entire lifestyle in regards to eating and working out. Being able to see what others do in regards to their diet and preventing highs and lows before, during and after workouts has been amazing." Lastly, a participant described a dire time that would have had severe physical implications had they not reached out to the DOC, [ID 155]: "At one point I had no insulin and as soon as I asked for help someone from the group quickly got in contact with me and sent me some right away." See table 11 for more information.

From these quotes, a deeper understanding of the nature of the impact of the DOC on each member can be determined. Members report saving money, becoming physically and mentally healthier, finding their "people" and developing a sense of community within the DOC. Overarching themes included that the DOC is a resource for information and social support. Participants commented on developing their sense of understanding of both themselves and T1D. In addition, the DOC provides meaningful interactions for those who may be feeling isolated and do not have the resources to access health information or acquire medical products on their own.

The Impact of High Expenses on PWD

High expenses are a common occurrence in the Diabetes community. Insulin (required by all individuals with T1D) is extremely expensive. Several participants commented that they experienced difficulty when acquiring their medicine and medical equipment due to the exorbitant price (n = 6). Recent news has portrayed individuals with T1D rationing their insulin because they cannot afford it. This rationing has resulted in the death of many adults with T1D and the DOC has provided a platform for these news stories.

Mental Impact of the DOC

Participants were also asked to report how the DOC has impacted their mental health. Participants reported receiving encouragement, feeling less alone, having an improved mental health status, feeling a sense of community, and normalizing the diabetes experience. The majority of participants endorsed that the DOC had a *positive impact on their mental health* (n = 61). One participant stated: [ID 162]: "Yes. Helps with not feeling isolated". Of note, participants also stated the *negative mental health impact* that the DOC can impart. Precisely, [ID 189]: "Probably slightly negatively just in that I feel I'm not doing as well as others". Participants stated that being part of the DOC caused them to experience anxiety about T1D and that involvement in the DOC promoted negative behaviors including triggering the participant after they compared themselves to other DOC members. An example of this negative behavior occurs when a member of the DOC shares a picture of what their blood sugars have been in the last 24 hours. If they post a picture of in range blood sugars then that may produce anxiety in DOC members who are not experiencing in range blood sugars. This interaction (although passive and innocuous in nature) may produce not only anxiety but also feelings of guilt, isolation and distress. See table 12 for more information.

Participants were also asked to describe one time when they interacted with another DOC member to make a treatment decision. Twenty-eight participants reported that they *do not seek this kind of information in the DOC*. Several participants reported *seeking out advice about dosing insulin* ($n = 11$). Overall, participants largely discussed looking for advice regarding durable medical equipment ($n = 16$). Overall, there were varied responses to this prompt with very few overlapping topics such that some participants were seeking advice about: *insulin dosing while exercis*ing ($n = 9$), *Allergic Reactions* ($n = 1$), *Blood Glucose Advice* ($n = 3$), *Diabulimia Treatment* ($n = 1$), *Blood Sugar Meter Advice* ($n = 1$), *Nutrition* ($n = 2$), and *Sick Days* ($n = 1$). Others described consulting not only their healthcare professional but also the online community (*doctor and DOC* ($n = 1$)) and *giving advice* ($n = 5$). Of note, one participant described seeking help from the DOC when they were in the middle of a medical emergency in a foreign country ($n = 1$). See table 13 for more information. These responses show that information sought in the DOC is diverse and seeking health information in the DOC is not for everyone but those who do seek the health information benefit greatly and that the DOC is capable of providing important, tailored information and assistance.

3.3 STUDY 1 – SUMMARY STATEMENT ANALYSES

Data from Study 1 were integrated using a mixed methods matrix. Each row represented one participant and contained data from the demographics, health information and qualitative prompts. These analyses are viewed as exploratory and general thematic analyses were conducted to identify, analyze and report patterns and themes that occurred in qualitative data. The preliminary data for this project was largely data-driven (inductive).

Summary statements were written in order to conduct a broad comparison of patterns across participants by clustering specific patterns (namely demographics variables). Some

participants stated specific requests (exercising with insulin, understanding more about using new types of insulin, and gaining knowledge on different types of medical devices). Examples include seeking information about exercising: [ID 188]: "I was struggling with getting low blood sugar while working out and someone suggested doing a temp basal of 50% an hour before working out. It actually worked to prevent lows and now I do that every time I work out." Other participants sought information about overnight blood sugars [ID 175]: "I would always go high at night and someone advised that maybe I should eat something little before bed and it did help!"

Generally, participants in Study 1 described specific types of groups that they belong to on Facebook. These groups were varied, but the most popular groups included ones where members focus on nutrition and exercise such that members encourage and assist others with exercising and insulin dosing, groups where members follow specific types of diets. Other groups provide focused informational support and/or emotional support for individuals using insulin pumps and CGMs. Lastly, there are also groups that strongly encourage in-person meetups among its online members. Importantly, despite the differences in information that participants are seeking, all are still able to find benefits in membership in the DOC.

3.4 Study 2 – PARTICIPANT CHARACTERISTICS

One hundred seventy-five DOC members participated in Study 2. Two participants were removed due to being statistical outliers with respect to their income (i.e., their high income levels were determined to be outliers by calculating the interquartile range). Three participants were excluded due to validation issues. Three participants were removed due to being younger than 18 years of age. One participant did not endorse a statement regarding being diagnosed with T1D so they were also removed. Respondent data was also checked for potentially

problematic responses, systematic responses and outliers. Of the 166 participants included in this sample, 89.8% identified as female with an average age of 34.33 years (SD = 11.249 years). 89.8% of sample participants were located in the United States. Approximately 86.1% of participants were white/Caucasian, 1.8% African-American, 3.6% Mexican-American, and 3.0% Hispanic or Latino. The average household income was $85,425.28 (SD = $59,146.68, median = $74,500).

Regarding education, participants reported the highest level of education that they had obtained: 2.4% completed less than a high school diploma, 1.8% completed a GED, 16.3% obtained a high school diploma, 16.9% completed technical training, 12.7% completed an associate's degree, 24.7% completed a bachelor's degree, 3% completed some graduate level training and 22.3% completed a graduate degree. More than half of the participants (64.5%) reported being diagnosed with T1D before the age of 18. Participants also provided information about their history with T1D, related illnesses and their usage of durable medical equipment. The average Hemoglobin A1c was 7.3% (SD = 1.36%) and more than half of the participants (53%) reported using an insulin pump. Of note, (42.8%) reported having a Hemoglobin A1C of 7.0% or over, which translates to having an average blood sugar of 154 mg/dL. This average Hemoglobin A1c is to be expected in a sample of individuals with T1D.

One-hundred-twenty-one participants reported using a CGM. These CGM users reported being "in range" (meaning "normal" blood sugar readings) 63.5% (SD =20.7%) of the time. Participants were asked about their social media usage and what websites they frequent. Specifically, 98.2% reported having an active Facebook account and 54.2% reported having an active Twitter account. Additionally, 77.1% reported having an active Instagram account and 98.2% reported searching for health information online. Participants reported being a member of

4.18 (SD = 2.76) Facebook groups. Within this sample, 84.9% of participants reported searching for health information using applications on their phones and 96.4% reported using their phone to search for health information.

Health Demographics

Participants also reported health demographics. When asked to rate their own health in comparison to others, ("Compared to other people your own age, how would you rate your physical health?"), 44.6% of participants reported their health as "average", 16.3% reported "better than average" and 31.9% reported "worse than average". In addition, participants were also asked how satisfied they were with their current well-being ("How satisfied are you with your present health?"), to which 39.2% of participants stated that they were "somewhat satisfied" while 35.5% stated that they were "not very satisfied". Participants reported that health problems "sometimes" stood in their way (39.8%).

Overall, this sample of participants was very active, such that 77.7% of the sample reported participating in a regular form of exercise (e.g., climbing stairs, walking, or other forms of exercise). Of note, 81.9% take additional medications beyond insulin. Participants also reported on their T1D comorbidities: Anxiety 26.5%, Celiac 4.8%, Depression 33.3%, Eating Disorder 14.3%, Eye disease 8.3%, Gastroparesis 6.6%, Graves 3.6%, Hashimoto's 7.2%, and Renal disease 1.8%. Additional health demographics and general health concerns are shown in table 14.

DOC Member Assessment of Seeking Health Information Online Scale

Participants completed a detailed assessment of the Attitudes Toward Seeking Online Health Information scale in Study 2. Many participants (92.3%) reported completing the scale in fifteen minutes or less. Eighty-eight percent of the participants believed the questions were

written by someone who had an accurate idea of T1D. Participants did not suggest removing any questions but they did express that they did not feel comfortable with listing their income (several participants did not provide that information). Specific participant requests encompassed a need to improve clarity and trade out language about "treatment decisions" for language about "advice".

Changes in the scale included: item 1: "I frequently use the internet to answer my health questions Diabetes Online Community" became "I frequently use the internet to gain health advice in the Diabetes Online Community." Item 7: "I trust the health information that I find on internet search engines Diabetes Online Community" became "I trust the health information that my friends on social media (Facebook, Twitter, Instagram, discussion forums) provide in the Diabetes Online Community". Item 14: "I do not post items on Twitter or Facebook regarding health behaviors Diabetes Online Community" became "I do not post health related items on social media (Facebook, Twitter, Instagram and/or discussion forums) in the Diabetes Online Community."

Additional items were also added. The first item that was added was: "I prefer to get advice about medical devices (insulin pumps and CGMs) from the Diabetes Online Community instead of my doctor." The second item that was added was: "I feel comfortable providing advice to others in the Diabetes Online Community". The third item added was: "I do not post health related items on social media (Facebook, Twitter, Instagram and/or discussion forums) in the Diabetes Online Community." The last addition was: "I find myself giving advice more than receiving advice in the Diabetes Online Community."

Participants were also instructed to rate the following statement: "How Clear is the Language of These Questions?" Overall, the Attitudes Toward Seeking Online items were rated

as "clear" and "very clear" (49.4% of the participants reported that the language of the questions was "clear" and 39.3% reported that the items were "very clear"). Of note, this was an 8.7% increase in clarity ratings in comparison to study 1. Participants were also instructed to rate the following statement: "How Natural do these Questions Sound?" Forty-two percent of the participants reported that the questions were "natural" and 24.7% of participants reported that the questions were "very natural". Of note, the natural ratings decreased by 17.3% between studies 1 and 2.

Participants were also instructed to describe the tone of the scale. Participants described the items from the Attitudes Towards Seeking Health Information Online scale as: "Clinical" (n = 7), "Natural" (n = 2), "General" (n = 8), "Practical" (n = 1), Straightforward" (n = 27), "Concise" (n = 8), "Positive" (n = 6), "Neutral" (n = 32) "Serious" (n = 2), "Acceptable" (n = 1), "Subtle" (n = 2), "Engaging" (n = 1), "Inquisitive" (n = 2), "Weird" (n =1), "Fair" (n = 1), "Professional" (n = 16), "Boring" (n = 1), "Inquisitive" (n = 10), "Curious" (n = 3), "Very bleak" (n = 1), "Very appropriate" (n = 1), "Simple but informative" (n = 4), "Easy to understand" (n = 3),"Confusing" (n = 2), "Repetitive" (n = 1), "Friendly" (n = 1). One hundred forty-four participants described the tone of the overall scale. From this feedback, it is clear that the feedback was mostly positive (96%). Participants did indicate that the scale was somewhat confusing because "they all sound like the same question so I had to go back a few times to make sure I knew what was being asked". This may mean that the question redundancy needs to be reduced in order to make questions clearer and more precise.

Participants provided many detailed responses to questions that should be added and overall general comments. Study 2 participants commended the cultural competency and relevancy and had question suggestions: [ID 110] "The questions reflect an understanding of

what t1s typically do in the online space. One question I would have liked to see, or at least something I'd add, is that my decision to follow advice in the DOC often depends on how well I feel I "know" the person giving the advice. (Ie, is he/she active in DOC, have I interacted with him/her in DOC, etc)". One participant commented that the questions were too neutral: [ID 116]: "They appear canned, as in not things that a long term T1 would generally know/be able to describe in detail. It sounds generic. Perfectly neutral." One participant stated it needed to be more personable and "less robotic sounding!" while another said the wording "caught them off guard". Overall, these comments are in the minority but must be addressed in future usage of this scale.

Participants were also asked to address the cultural competency of the Attitudes Toward Seeking Health Information Online scale: [ID 129]: "Each question was something someone living with type 1 diabetes could answer or relate to." One participant who has participated in other research studies for individuals with T1D stated: [ID 137]: "This is one of the first surveys that includes all methods of diabetes management." Another participant identified how the items correctly reflected what individuals with T1D experience [ID 179]: "They understood the DOC is able to help through the disease, especially to avoid an appointment with the endo since those are hard to get sometimes." Another participant further complimented the cultural competency of the measure: [ID 265]: "It feels like the person asking these questions understands what a person with type 1 diabetes would be searching for on social media."

Participants were asked which questions would you remove from the Attitudes Toward Seeking Health Information Online scale. The majority of participants did not have a suggestion for removal (98%) but instead used the space for suggestions for other parts of the survey protocol. One participant stated that the scale should be specific to which types of health advice a

51

participant is seeking. Question suggestions included, ""Does your decision to follow a fellow DOC member's advice reflect how well you know him/her?" and "How reliable the information you receive in online diabetic community is?"

Participants also suggested adding items about information integrity and assessing whether attitudes towards diabetes have changed because of the health information obtained in the DOC. Regarding the general battery, participants felt that more diabetes related demographics should have been collected (types of insulin used, Diabetes ketoacidosis (DKA) experience, more information about diabetes related complications, more questions about doctor's visits, sleep patterns, and more details on activity levels). Other participants made suggestions specifically related to seeking health information in the DOC: types of health information being sought in DOC, how many times hospitalized with a diabetes related complication, information about diagnosis, what information do you not seek in the online community, and what type of information a member is comfortable with providing and receiving online, and assessing for age differences.

Measure feedback was not the only information provided. Importantly, one participant explained how they get information from multiple sources and rely heavily on sources outside of their doctor's office: [ID 150]: "Yes because so often diabetics don't get important info from their doctors. We have to get it from fellow diabetics that have experienced the same things." They emphasized the necessity to find information outside of the clinic such that it is not a choice but instead a requirement.

In addition, participants also had feedback on the methodology of the project and issues with item comprehension such that one participant stated the need for open ended questions rather than a questionnaire: [ID 155]: "The questions are not easily able to answer. Diabetics

need open ended questions as to get a better handle on what we can answer. Every one of us are different in every aspect of life that you can imagine. There are 2 types of diabetes but each and every person has a different way to handle theirs. No 2 people with diabetes will experience the same thing in one day." This participant identifies the need to further test and further simplify the items. One such participant said, ID [208] "It seems to me that the person who wrote the questions understands that people with diabetes question their healthcare providers judgement MORE than they would question peers with their same disease. Another participant stated that "Being a diabetic gives a person more knowledge and experiences than a medical degree. So checking with other diabetics is becoming common place".

Participants stated that the questions were easy to answer and were worded in such a way that a person with diabetes would word them. Another stated: [ID 265] "It feels like the person asking these questions understands what a person with type 1 diabetes would be searching for on social media." Another participant commented: [ID 266] "The questions applied to a chronic illness where doctors don't have all the answers but then the online community doesn't either. The questions addressed the struggle type 1s have in receiving and also giving information." Another participant made a statement about the cultural competency of this study: [ID 267] "Seems to have an understanding of topics relevant to the disease and how the online community can play a role in today's patient health care and health education." Regarding cultural competency: participants stated that the survey used patient endorsed terminology and that questions seemed to indicate this person had knowledgeable of T1D, largely due to the level of detail. Regarding cultural competency, participants stated: [ID 271]: "They understand the amount of info given and received through the DOC".

3.5 STUDY 2 – CONFIRMATORY FACTOR ANALYSES

Three CFAs were conducted and compared: A three-factor model with all 19 items (as was initially proposed), a three-factor model with 16 items (items were previously removed due to correlated residuals and item loadings) and a two-factor model with 16 items. Modification indices and standardized residuals were examined to assess how well the model explains the covariances between items. The wording of items was also examined to assess which items should be indicated as correlated in the model. A confirmatory factor analysis (CFA) was conducted using M*plus* Version 7.11 (Muthén & Muthén, 1998-2018). Robust maximum likelihood estimation was used. Model fit and factor analysis guidelines were followed (Hu and Bentler, 1999), CFAs were conducted and their results were compared to assess for model fit utilizing: Root Mean Square Error of Approximation (RMSEA) < .06, CFI > .95, and Standardized Root Mean Squared Residual (SRMR) < .09), and Akaike (AIC; when comparing two models it is usually best to choose the model with the smaller AIC).

Reliability of Quantitative Scales

The reliability of the project's quantitative scales were assessed using coefficient α. Every scale exhibited good to excellent reliability, *eHealth Literacy* (Norman and Skinner, 2006), α = .897. The *Social Provisions Scale* (Cutrona & Russell, 1987) has excellent overall reliability, α = .936, yet the *Social Provisions* subscales also had a mix between excellent and fair reliability: *Attachment*: α = .845, *Social Integration*: α = .796, *Reassurance of Worth*: α = .687, *Reliable Alliance*: α = .828, *Guidance*: α = .854, and *Opportunity for Nurturance*: α = .802. The *Treatment Adherence (*Mayberry et al., 2013) scale had excellent reliability α = .889. The overall *Diabetes Distress* scale (Fisher et al., 2005) also had excellent reliability, α = .937. The Diabetes Distress subscales exhibited good reliability: *Powerlessness:* α = .820, *Management*

Distress: α = .760, *Hypoglycemia Distress*: α = .860, *Negative Social Perceptions*: α = .841, *Eating Distress*: α = .766, *Physician Distress*: α = .883, and *Friend/Family Distress:* α = .860. Lastly, the *Attitude Toward Seeking Online Health Information Scale had excellent reliability,* α = .839. The reliability coefficients were computed and examined for factors one and two. Reliability was fair for factor one (α = .789), and fair for factor two (α = .746).

The 3-factor model with 19 items

In the 19 item, hypothesized 3-factor model, the first hypothesized factor was: *Truth in Online Health Information*, the second hypothesized factor was: *Self-efficacy in Evaluating Online Health Information* and the third hypothesized factor was: *Health Information and Health Advice on Social Media*. Regarding the 3-factor fit, it was predicted that items 1-7 would load on Factor 1, items 8-14 would load on Factor 2 and items 15-19 would load on Factor 3. The first CFA was conducted with the full 19 items and it was determined that Item 2 (*I am critical of the health information that I find in the Diabetes Online Community*) did not load on factor 1 or factor 2. For this reason, Item 2 was deleted. Next, Items 15 (*I share health articles on my social media account (s) in the Diabetes Online Community*), 16 (*I do not post health related items on social media (Facebook, Twitter, Instagram and/or discussion forums) in the Diabetes Online Community*) and 17 (*I prefer to read the health information that I find on social media websites but not engage in online conversation about the health information in the Diabetes Online Community*) all loaded on Factor 2. Items 3 (*I review multiple internet sources in the Diabetes Online Community before making a health decision for myself*) and 9 (*It is difficult for me to find health information online in the Diabetes Online Community*) also loaded on Factor 2. The rest of the items in the Attitudes Toward Seeking Health Information scale loaded on Factor 1.

Next, correlated residuals were assessed to determine if unique item variances were correlated with each other. Of note, Items 12 (*I prefer to get advice about medical devices (insulin pumps and CGMs) from the Diabetes Online Community instead of my doctor)* and 14 (*I would prefer to search the internet for health information in the Diabetes Online Community instead of going to a doctor's appointment*) had correlated residuals and a decision was made to eliminate item 14 due to the similarity of these items. Next, items 18 (*I feel comfortable providing advice to others in the Diabetes Online Community*) and 19 (*I find myself giving advice more than receiving advice in the Diabetes Online Community.*) also had correlated residuals. Due to the interrelatedness of the concepts of items 12 and 14, the item with the more direct wording was retained, item 14 was deleted and item 12 was retained in the model. Due to the correlated residuals of items 18 and 19, the items were assessed conceptually and determined to be related in nature and item 19 was deleted. Regarding model fit, the following indices presented a poor model fit: $\chi2(149, N = 166) = 359.323$, RMSEA = .092, 90% CI [.080, .104], CFI = .753, AIC = 10467.554 and SRMR = .091. Of note, there was a high correlation between Factors 1 and 2 ($r = .923$), but not between Factors 1 and 3 ($r = .345$) or Factors 2 and 3 ($r = .487$). Table 15 shows the item loadings, standard errors and z scores.

The 3-factor model with 16 items

The second CFA was conducted with 16 items (after removing items 2, 14 and 19 as described in the previous CFA's results). Of note, the correlations between factors were: (Factor 1, Factor 2) = .942, (Factor 1, Factor 3) = .364, and (Factor 2, Factor 3) = .492. The high correlation between Factors 1 and 2 persisted across both the 3-factor CFAs and violated discriminant validity. For this reason, Factor 3 was removed from the list of items for the second

CFA analysis and the next CFA was a 2-factor model. Items 15, 16, and 17 and 18 were moved to Factor 2 for the third CFA.

Regarding model fit, the following indices presented a good model fit: Satorra-Bentler $\chi2(101) = 271.026$, RMSEA = .101, 90% CI [.086, .115], CFI = .748, AIC = 8667.727 and SRMR = .086. Of note, there was a high correlation between Factors 1 and 2 ($r = .997$), but not between Factors 1 and 3 ($r = .618$) or Factors 2 and 3 ($r = .591$). See table 16 for item loadings, standard errors and z scores.

The 2-factor model with 16 items

After item deletion, 16 items remained (after removing items 2, 14 and 19). Due to the high correlation between Factors 1 and 2 in the previous CFAs, Factor 1 is composed of items 1-6 and 8-13 and Factor 2 is composed of items 15-18. The 2-factor CFA model produced a very similar fit with the second CFA (the 3-factor model with 16 items). Regarding model fit, the following indices presented a good model fit: $\chi^2(103, N = 166) = 163.672$, RMSEA = .060, 90% [.042, .076], CFI = .906, AIC = 8631.384 and SRMR = .072. Of note, although the AIC is indeed lower for the second CFA, this model has been determined to be a better fit due to the indices and the correlations between factors 1 and 2 ($r = .401$). For more information see table 17.

Correlations among Key Variables

Bivariate correlations were conducted to assess significant relationships between key constructs in this project. Correlations between eHealth literacy, Attitudes Toward Seeking Health Information Online subscales, Social Provisions subscales, Diabetes Distress subscales, and Treatment Adherence are presented in Table 3. Factor 1 (Trusting and Evaluating Online Health Information in the DOC) of the Attitudes Towards Seeking Health Information Online scale was associated with Diabetes Distress-Powerlessness ($r = .198$, $p = .011$), Diabetes

Distress-Hypoglycemia Distress ($r = .153$, $p = .049$), Diabetes Distress-Physician Distress ($r = .204$, $p = .008$), Social Provisions-Attachment ($r = .183$, $p = .018$), Social Provisions-Social Integration ($r = .260$, $p = .001$), Social Provisions-Reassurance of Worth ($r = .251$, $p = .001$), Social Provisions-Reliable Alliance ($r = .273$, $p < .001$), Social Provisions-Guidance ($r = .341$, $p < .001$), Social Provisions-Opportunity for Nurturance ($r = .172$, $p < .001$), and eHealth literacy ($r = .413$, $p < .001$).

Factor 2 (Engaging with Online Health Information in the DOC) of the Attitudes Towards Seeking Health Information Online scale was associated with Diabetes Distress-Management Distress ($r = .169$, $p = .029$), Diabetes Distress-Hypoglycemia Distress ($r = .158$, $p = .042$), Diabetes Distress-Friend/Family Distress ($r = .219$, $p = .005$), Social Provisions-Attachment ($r = .269$, $p < .001$), Social Provisions-Social Integration ($r = .276$, $p < .001$), Social Provisions-Reassurance of Worth ($r = .353$, $p < .001$), Social Provisions-Reliable Alliance ($r = .264$, $p < .001$), Social Provisions-Guidance ($r = .314$, $p < .001$), Social Provisions-Opportunity for Nurturance ($r = .324$, $p < .001$), and eHealth literacy ($r = .197$, $p = .011$).

Age was associated with Engaging with Online Health Information in the DOC of the Attitudes Towards Seeking Health Information Online scale ($r = -0.156$, $p = .044$) as was Hemoglobin A1c level ($r = -.358$, $p < .001$). Younger participants scored higher on Factor 2 of the Attitudes Toward Seeking Health Information Online scale and had high Hemoglobin A1c levels. Number of Facebook groups that a participant is a member of was associated with Trusting and Evaluating Online Health Information of the Attitudes Towards Seeking Health Information Scale ($r = .161$, $p = .039$), Factor 2 of the Attitudes Towards Seeking Health Information Scale ($r = .229$, $p = .003$), Hemoglobin A1c ($r = -.192$, $p = .013$), Social Provisions-Attachment ($r = .230$, $p = .003$), Social Provisions-Reassurance of Worth ($r = .176$, $p = .023$),

Social Provisions-Reliable Alliance ($r = .289$, $p = .015$), Social Provisions-Guidance ($r = .201$, $p = .009$), Social Provisions-Opportunity for Nurturance ($r = .251$, $p = .001$), and Diabetes Distress-Friend/Family Distress ($r = .218$, $p = .005$).

3.6 REGRESSION ANALYSES

Hierarchical regression models were conducted using SPSS to test the proposed hypotheses. Of importance, estimates for income, education and Hemoglobin A1c were pooled across the multiply imputed data sets. Education was dummy coded and the reference condition was "high school diploma".

Hypothesis 1: Participants with higher scores on the Attitudes Toward Seeking Health Information Online will report more positive health outcomes (higher treatment adherence, lower A1c, and less diabetes related complications).

Hypothesis 1 was partially supported with a dependent variable of ARMS-D. The first step was not statistically significant, accounting for 4.3% of the variance explained ($p = .067$). The covariate eHealth literacy was significant ($\beta = -2.822$, $p = .009$). In the second step, the model was significant, accounting for an additional 42.1% of the variance explained ($p < .001$). Both factors of the Attitudes Toward Seeking Online Health Information (Trusting and Evaluating Online Health Information in the DOC, $\beta = .181$, $p = .795$) and (Engaging with Online Health Information in the DOC, $\beta = .350$, $p = .630$) were not significant. Factor 2 (Management Distress) of the Diabetes Distress scale was significant ($\beta = 2.196$, $p < .001$) but the remaining Diabetes Distress subscales were not significant, suggesting a lack of a relationship between Treatment Adherence and the varying types of Diabetes Distress. For

regression results please see table 18. Of note, each regression model was assessed for potential moderating effects. None of the models had statistically significant moderation effects.

Hypothesis 1 was partially supported with a dependent variable of Hemoglobin A1c. The first step was significant accounting for 7.9% of the variance explained ($p = .004$). In the second step, the model was significant, accounting for an additional 32.9% of the variance explained ($p < .001$). Both factors of the Attitudes Toward Seeking Online Health Information (Trusting and Evaluating Online Health Information), $\beta = -.046$, $p = .746$) and (Engaging with Online Health Information in the DOC, $\beta = -.095$, $p = .405$) were not significant and did accounted for minimal variance in this model. Factor 2 (Management Distress) of the Diabetes Distress scale was significant ($\beta = .742$, $p < .001$) but the remaining Diabetes Distress subscales were not significant. For further information please see table 19.

Hypothesis 1 was not supported with a dependent variable of number of diabetes related Complications. Poisson regression was used to test this model. Only one covariate, duration of T1D, was found statistically significant, $\beta = .012$, $p = 0.043$. The Diabetes Distress subscales were not significant, suggesting lack of a relationship between experiencing worry regarding diabetes and the number of diabetes related Complications. None of the independent variables were found to be statistically significant. For further information please see table 20.

Hypothesis 2: Participants with lower scores on a measure of Diabetes Distress will report more positive health outcomes (higher treatment adherence, lower Hemoglobin A1c, and less diabetes related complications).

Hypothesis 2 was partially supported with a dependent variable of ARMS-D. The first step was not statistically significant ($p = .067$) and none of the covariates were statistically significant. In the second step, the model was significant, accounting for an additional 16.9% of

the variance explained (p = .005). The second factor of the Attitudes Toward Seeking Health Information Online scale (Engaging with Online Health Information in the DOC) was statistically significant (β = 1.507, p = .025). Only the third Social Provisions subscale (Reassurance of Worth) of the Social Provisions subscales was statistically significant (β = -.925, p = .007). For further information please see table 21.

Hypothesis 2 was partially supported with a dependent variable of Hemoglobin A1c. The first step was statistically significant accounting for 7.9% of the variance explained ($p < .001$). Two covariates were found to be statistically significant, Diabetes Duration (β = -.021, p = .024) and eHealth literacy (β = -.637, p = .007). No other variables were significant predictors and minimal variance was accounted for. In the second step, the model was not statistically significant, accounting for an additional 12.2% of the variance explained (p = .489). None of the Social Provisions subscales were statistically significant. For further information please see table 22.

Hypothesis 2 was partially supported with the dependent variable of diabetes related Complications. Poisson regression was used due to Complications being a count variable. None of the covariates were statistically significant. Two subscales were statistically significant in this model, Engaging with Online Health Information in the DOC was statistically significant (β = .123, *p* = 0.048) and Reassurance of Worth-Social Provisions (β = -0.072, *p* = 0.023). For further information please see table 23.

Hypothesis 3: Participants with higher scores on a measure of Social provisions will have more positive health outcomes (higher treatment adherence, lower Hemoglobin A1c, and less diabetes related complications).

Hypothesis 3 was partially supported with a dependent variable of ARMS-D. The first step was not statistically significant, accounting for 4.3% of the variance explained ($p = .067$). The covariate eHealth Literacy was significant ($\beta = -2.822$, $p = .009$). In the second step, the model was significant, accounting for an additional 43.5% of the variance explained ($p < .001$). None of the Social Provisions subscales were statistically significant. Similar to previous regression models, only Management Distress was statistically significant ($\beta = 2.774$, $p < .001$). For further information please see table 24.

Hypothesis 3 was partially supported with a dependent variable of Hemoglobin A1c. The first step was statistically significant accounting for 7.9% of the variance explained ($p = .004$). The covariate eHealth Literacy was significant ($\beta = -.602$, $p = .003$). In the second step, the model was significant, accounting for an additional 36% of the variance explained ($p = .001$). One of the Social Provisions subscales, Guidance, was statistically significant, ($\beta = .116$, $p = .034$). The second Diabetes Distress subscale (Management Distress) was also statistically significant ($\beta = .752$, $p < 0.001$). For further information please see table 25.

Hypothesis 3 was partially supported with a dependent variable of Complications. Similarly to the previous regressions models with diabetes related Complications as a dependent variable, Diabetes Duration was a statistically significant covariate, ($\beta = 0.011$, $p = 0.035$). Minimal variance was accounted for in this model and the other variables in this model were not found to be statistically significant. For further information please see table 26.

Convergent validity was also assessed in this survey between eHealth Literacy, the Social Provisions subscales, the Diabetes Distress subscales and the developed Attitudes Toward Seeking Health Information Subscales. Every scale and subscale was related to Trusting and Evaluating Online Health Information except for Negative Social Perceptions, Eating Distress

and Friend/Family Distress. Every scale and subscale was related to Engaging with Online

Health Information in the DOC except for Powerlessness, Negative Social Perceptions, Eating

Distress and Physician Distress. Please see table 27 for more information on these relationships.

This phase further assessed face validity convergent validity. Items were written to ensure face

validity and convergent validity was assessed by evaluating correlations between scales and

subscales that were expected to be related.

CHAPTER 4: DISCUSSION

4.1 SEEKING HEALTH INFORMATION IN THE DIABETES ONLINE COMMUNITY

The present set of studies examined seeking health information online in the DOC, a prominent diabetes focused health community where peers provides multiple types of social support and broker information. The present set of studies sought to establish a valid and reliable measure of Attitudes Toward Seeking Health Information Online in the T1D community. The creation and development of this scale was necessary due to the needs of the T1D community who seek much of their health care information online from peers. The unique DOC member perspectives gained in study 1 allowed for the generation of items based not only on literature but also on the patient perspective, examining patient focused research questions in a meaningful and impactful manner.

This study also quantitatively assessed the relationship across key variables. Of interest, Factor 1 of the Attitudes Toward Seeking Health Information Online scale (Trusting and Evaluating Online Health Information) was positively related to multiple types of Diabetes Distress (Powerlessness, Hypoglycemia Distress, Physician Distress). These findings are a unique contribution to the T1D literature because they provide support that with more feelings of Powerlessness, more Hypoglycemia Distress, and more Physician-related Distress, individuals with T1D are trusting online health information more and feeling more competent in their ability to evaluate that information. In addition, Trusting and Evaluating Online Health Information was also found to be positively related to several types of Social Provisions (Attachment, Social Integration, Reassurance of Worth, Reliable Alliance, Guidance, and Opportunity for Nurturance). These relationships were expected, because informational support is a type of social support.

Factor 2 of the Attitudes Towards Seeking Health Information Online scale (Engaging with Online Health Information in the DOC) was related to Diabetes Distress-Management Distress, Diabetes Distress-Hypoglycemia Distress, Diabetes Distress-Friend/Family Distress, Social Provisions-Attachment, Social Provisions-Social Integration, Social Provisions-Reassurance of Worth, Social Provisions-Reliable Alliance, Social Provisions-Guidance, Social Provisions-Opportunity for Nurturance, and eHealth literacy. These findings are a unique contribution to the T1D literature because they provide support that with more feelings of distress towards managing T1D, more hypoglycemia related distress, and more distress caused by friends and family, individuals are engaging more with online health information in the DOC.

Engaging with Online Health Information in the DOC was also found to be positively related to several types of Social Provisions (Attachment, Social Integration, Reassurance of Worth, Reliable Alliance, Guidance, and Opportunity for Nurturance). Lastly, and as expected, both Factors 1 and 2 were positively related to eHealth literacy. These Factor 1 and Factor 2 findings highlight the importance of new lines of research, providing evidence for these relationships and further determining how they impact other areas of disease management.

Demographic variables were also found to be related to the newly created scale such that age was related with Factor 2 (Engagement with Online Health Information) of the Attitudes Toward Seeking Health Information Online scale and Hemoglobin A1c level such that younger participants scored higher on Factor 2 of the Attitudes Towards Seeking Health Information Online scale and had high Hemoglobin A1c levels. Interestingly, the number of Facebook groups that a participant is a member of was associated with Factor 1 of the Attitudes Toward Seeking Health Information Scale, Factor 2 of the Attitudes Towards Seeking Health Information Scale, Hemoglobin A1c level, Social Provisions-Attachment, Social Provisions-Reassurance of

Worth, Social Provisions-Reliable Alliance, Social Provisions-Guidance, Social Provisions-Opportunity for Nurturance, and Diabetes Distress-Friend/Family Distress. These relationships may be explained by Facebook group membership serving as a proxy for DOC interaction, but future research should seek to further examine these relationships to elucidate the underlying mechanisms.

4.2 SUPPORT FOR RESEARCH QUESTIONS

Support for the qualitative research questions are as follows: The first qualitative research question was: *What are PWD's perceptions of how the DOC assists them with their physical and mental health*? Participants expressed varying levels of assistance and support found in the DOC. Participants stated that the DOC does assist with a wide variety of issues (including information gathering, with medical devices, acquiring social support and connecting others. Participants also reported seeking different types of social support in the DOC including emotional support, encouragement to get a CGM, informational support and inspiration. Of note, the majority of participants stated that the DOC had a positive impact on their physical health, stating improvements in self-care, exercise behaviors, nutrition, and access to healthcare and medication. Participants were also asked to report how the DOC has impacted their mental health. Participants reported receiving encouragement, feeling less alone, having an improved mental health status, feeling a sense of community, and normalizing the diabetes experience. Participants endorsed that the DOC had a positive impact on their mental health. Importantly, a handful of participants reported experiencing anxiety due to the DOC which appears to be connected to the behavior of comparing oneself to other members of the DOC.

The second qualitative research question was: W*hat characterizes an individual with T1D's experiences interacting with DOC members to make a treatment decision?* The majority

of participants described one time when they interacted with another DOC member to make a treatment decision but 28 participants reported that they do not seek this kind of information in the DOC. Many participants sought advice about medication dosing and using insulin pumps and CGMs. There were very few overlapping topics which garnered further support for the complexity of the needs in the DOC and the difficulty of T1D disease management. Participants sought information on exercising, treating a high blood sugar, and treating a low blood sugar. Several participants reported not seeking information online but instead providing information online. These diverse responses show that seeking health information in the DOC is not for everyone but those who do seek the health information benefit greatly. The DOC is capable of providing important, tailored information and assistance.

The third qualitative research question was: *What elements of the DOC do T1D patients find to be most useful?* Participants were very expressive in what was the most useful part of the DOC such as informational support where DOC members are exchanging advice about disease management. Participants also expressed the importance of social interaction and support where DOC members are interacting with other members and receiving social support during these interactions. The final main theme was the sense of community experienced by members of the DOC. Participants express feeling part of a larger grouping where they do not feel judged and they related to other members while reaping benefits of said membership. Overall, these examples and themes provide powerful support that the DOC has a beneficial impact on the amount of social support that individuals with T1D are experiencing. At the core of this research, is the need to further understand how individuals with T1D are gaining health information in the DOC and the impact that this has on their health and health outcomes. Other

participants endorsed that they had an overall positive experience in the DOC defined by quality feedback, helpfulness, and encouragement.

Scale development

Participants provided quantitative and qualitative feedback in both studies. Expectedly, study 2 participants rated the second iteration of the Attitudes Toward Seeking Health Information Online questionnaire as clearer than the first iteration. Unexpectedly, study 2 participants also rated the second iteration as less natural than the first iteration. This may be due to the clinical and neutral tone that participants reported of the second iteration of the scale. For example, 3 participants reported the first iteration as neutral but 32 participants reported the second iteration as neutral. Future research should focus on this wording while still maintaining the current level of cultural competence.

Regarding how information seeking is occurring in the DOC, participants also reported following advice that already existed in social media such that they are not generating a new post to find an answer to their question. Instead, they are seeking existing posts where their same health question has already been answered. Most social media sites have a search mechanism that makes this fast and easy to accomplish. Importantly, members of the DOC also reported on the phenomenon of endorsing existing answers which impacts the trustworthiness of the information. This dynamic greatly challenges how online health information seeking was originally conceptualized for this set of studies and how it is presently studied in the literature (using the existing scales with vignettes based on hypothetical situations). This project provides a view of the "real world" perspective T1D management outside of the health clinic.

The project also sought to clarify how members of the DOC seek health information and what they perceive to be the benefits of being a member. Prior research has suggested evidence

of benefits of membership include emotional support and informational support (Green et al., 2011). Previous research has also suggested anecdotal evidence of benefits of membership include increased positive emotional experiences, increased positive attitudes towards T1D, and increased engagement in T1D management behaviors (Hilliard et al., 2015). A third study that echoes this information focused on the Nightscout phenomenon (do it yourself coding involving CGM usage driven by parents of adolescents with T1D) (White et al., 2018) where members of the Nightscout online community report spreading awareness, sharing technical assistance, providing support and donation. They also reported high trust in peers versus health care professionals and 40% reported using health information they found online for decision making.

Although these benefits exist and DOC membership was listed as a suggestion for individuals with both T1D and T2D on the CDC's T1D basics website (CDC, 2018), participation in the DOC is not without its faults and participants were forthcoming about their negative experiences in the online community, stating that they have experienced bullying, "us vs. them" mentality and misinformation. Despite many established psychosocial benefits to participating in online support groups and also physical benefits to the information being brokered in the online community, this community (and precisely, particular subgroups) may not be for everyone.

This project has qualitatively and quantitatively further established and validated these social support findings. However, study 1 participants stated their sense of community and types of social support that they find in the DOC and added several types of social support (assessed qualitatively in study 1 and quantitatively in study 2) to that list that have not been previously mentioned in the literature (Reassurance of Worth, Reliable Alliance and Guidance). Participants also explained the benefits of the DOC by listing specific examples related to their health and

mental health such that overall, there are many psychosocial and physical benefits to participating in online support groups.

Support for quantitative hypotheses

In the present study, it was predicted that high scores on Attitudes that exist Towards Seeking Health Information Online and the *lower* the levels of Diabetes Distress would predict *higher* levels of Treatment Adherence. There was support for Hypothesis 1 such that when controlling for eHealth Literacy, Management Distress (experiencing distress related to self-managing T1D) predicted Treatment Adherence (ARMS-D). There was support for Hypothesis 1 such that when controlling for eHealth Literacy and education, Management Distress predicted Hemoglobin A1c.

Hypothesis 2 was partially supported with a dependent variable of ARMS-D such that Engaging with Online Health Information in the DOC and Reassurance of Worth were statistically significant predictors. This may be due to Factor 2 (Engagement with Online Health Information) being related to several subscales of the Social Provisions scale. Hypothesis 2 was partially supported with a dependent variable of Hemoglobin A1c. Similarly, to hypotheses 1 and 2, hypothesis 3 found that eHealth Literacy, Education level, higher levels of Management Distress and Hypoglycemia Distress were significant predictors of higher Hemoglobin A1c. Each of the Diabetes Distress subscales have previously been found to predict Hemoglobin A1c levels so these findings replicate findings in the existing literature (Fisher et al., 2015).

Hypothesis 3 was partially supported with a dependent variable of Hemoglobin A1c. When controlling for eHealth Literacy and Education, Management Distress and Hypoglycemia Distress were statistically significant. Hypothesis 3 was partially supported with a dependent variable of ARMS-D. When controlling for eHealth Literacy and Education, Management

Distress was statistically significant. There was little evidence supporting the relationship between online information seeking, social support, diabetes distress and health outcomes.

Confirmatory Factor Analyses (CFA) Discussion

Three CFA models were tested and compared and after collapsing three factors into two and removing three items due to correlated residuals, a good fitting scale prevailed. This two-factor, 16 item scale, had good modification indices and small standardized residuals (Hu and Bentler, 1999). The majority of the project's scales had excellent reliability but a few scales had $\alpha < .80$ including: Social Provisions-Social Integration, Social Provisions-Reassurance of Worth, Diabetes Distress-Management Distress, Diabetes Distress-Eating Distress, and Attitudes Towards Seeking Health Information Online (Factor One), and fair for Attitudes Towards Seeking Health Information Online factor two. Future research should aim to increase the reliability of both factors of the Attitudes Towards Seeking Health Information Online scale.

Attitudes Towards Seeking Online Heath Information in the DOC

The primary purpose of the current study was to develop and test the Attitudes Towards Seeking Health Information Online scale and secondary goals were to investigate the PWD's perceptions of how the DOC assists with physical and mental health, PWD's experiences interacting with DOC members to make decisions about their medical care and what is perceived to be the most useful component of the DOC. This project provided much support for both the positive and negative impact of online interaction centered on health. This research contributed to understanding the challenges of chronic disease populations as they occur outside of the doctor's office and assessed how health information seeking relates to health outcomes of adults with T1D.

The goal of this study was to create a validated and reliable measure to assess attitudes regarding seeking health information online in individuals with T1D. The project sought to clarify several existing gaps in the literature in a two-study design where relevant relationships were identified between health information-seeking online and treatment adherence. This project further demonstrated the magnitude of the relationship between eHealth literacy, Social Provisions, Seeking Health Information Online, Diabetes Distress and Treatment Adherence. This project also provided information on the physical effects of social media usage (gained from qualitative prompts), and more specifically, social media health information-seeking via social support. Findings from this study will contribute to the knowledge base of the healthcare of adults with T1D. Participants were forthcoming about the items of the scale as they are a very active and communicative population.

The current study largely found that Attitudes Towards Seeking Health Information Online are related to Diabetes Distress and Social Provisions but are not largely not predictive of T1D related health outcomes: Hemoglobin A1c, T1D related complications and Treatment Adherence. Both the significant and null findings better explain the nature of self-management of a chronic disease and information seeking, in general. Additional research is necessary to further examine this phenomenon and better understand the role that these variables play on Treatment Adherence and biological health outcomes for individuals with T1D.

From these findings we have found support for the four key types of social support qualitatively: *emotional support* (e.g., providing caring endearments when needed), *informational support* (e.g., providing advice about how much insulin to dose during exercise), *instrumental support* (e.g., providing insulin pump training to individuals who do not have the local training resources), and *appraisal support* (e.g., members make other feel normal and

72

remind them that they can achieve their goals despite T1D). In addition, we have found support for social provisions qualitatively: *guidance* (e.g., advice about treatment decisions), *reliable alliance* (e.g., guarantees that others will be there in a stressful situation such as being without insulin or when an insulin pump breaks), *reassurance of worth* (e.g., recognition of one's competence found during times struggling with blood sugar readings that are out of range), *attachment* (e.g., emotional closeness with group members and group as a whole), *social integration* (e.g., a sense of belonging to a group of social media acquaintances), and *opportunity for nurturance* (e.g., providing assistance to others such as when). From these findings we can better understand increased positive emotional experiences, increased positive attitudes towards T1D, and increased engagement in T1D management behaviors found in study 1.

4.3 FUTURE DIRECTIONS

The current study examined Online Health Information Seeking in the DOC. Future research should be conducted based on an edited scale of the Attitudes Toward Seeking Health Information scale. Participant feedback for future research was varied and insightful. Future research should examine the platform each participant is using: [ID 227] "Further exploration of the ways in which people in the diabetes communities on different platforms seek information may illuminate different modes of information use online. For example, those who exclusively engage with the communities on Twitter (such as myself) may be more willing to honestly engage in the community because of the anonymity Twitter allows its users. Conversely, those on Facebook may be more performative in their use of the online communities for support and information because of their clear, preexisting relationships outside of the online sphere." Future research should also assess the different groups using the DOC (across age groups and varying levels of internet interactivity). Specifically, the samples included within this study did not

73

include many older adults. Therefore, it is important to capture these individuals within future work.

There are many benefits to DOC membership where physicians and healthcare professionals should consider promoting DOC membership to their patients. Although these benefits exist, membership in the DOC is not without potential risks and members are very aware of them. Several participants discussed what they identify as the cons of membership, including the triggering effects of the DOC. The food discussions occurring naturally in the DOC can be triggering for individuals who are suffering from an eating disorder and T1D. Many members stated feelings of needing to compare themselves to others in the DOC, which often led to guilt. Other participants also discussed how they have observed other DOC members being judgmental in nature or even bullying other members.

Overall, DOC members were extremely warm and positive about their DOC membership and the impact that it is has had on their diabetes management. T1D is not "one size fits all" and DOC members are capable of providing tailored information to those who seek it. Additional research should seek to examine information seeking regarding nutrition information (recipes, carbohydrate counting and gathering information on specific diets). Many participants stated that they sought nutritional information but did not provide detail as to what type of information. For this reason and due to the nature of type 1 diabetes, it would be very beneficial to know more about this relationship.

Future studies that seek to assess scales using patient feedback should aim to develop feedback measures that provide meaningful information. Studies aiming to assess social media usage in any population should determine the most accurate time assessment. For example, specific phones can provide how many minutes and hours are spent on each social media app

each day but if specifically seeking how much time the participant spends in specific diabetes groups, then a measure of that does not yet exist and patient estimates may be inaccurate. Future research in this area should also seek to collect data from minority populations.

Future research should include the study of covariates and other moderators that are associated with information seeking such as coping mechanisms, the different types of information that are located offline (HCP, medical team, family, friends, and traditional media), comprehensive health history and self-efficacy. This study yielded important information regarding the relationships between Online Information Seeking, Social Provisions, Diabetes Distress and Treatment Adherence. Specifically, project provided very strong support for these relationships qualitatively but did not provide very strong support for these relationships quantitatively. Another sample should be collected regarding the 16 item scale to confirm the findings from study 2. Lastly, similar research considering and incorporating the thousands of individuals who are caregivers for adolescents with T1D would be extremely beneficial. There are hundreds of Facebook groups specifically for caregivers (parents of children with T1D).

4.4 LIMITATIONS

Due to limitation of online qualitative data collection, some qualitative responses were very brief while others were not answered at all. Future studies should screen for seeking advice versus providing advice as many participants stated that they did not seek advice but instead offered it. Both samples for this project were cross-sectional and used convenience sampling. Both samples were recruited from the DOC which introduces the possibility of sampling bias. Importantly, these results should not be generalized to other types of diabetes because each type of diabetes differs greatly. As to be expected, both samples were mostly Caucasian, well-educated and female. This is to be expected as this is an accurate depiction of the current DOC

population. Of note, this is not an accurate depiction of the general population of individuals with T1D. This mostly female second sample prevented gender differences from being assessed in the quantitative data. Finally, this study was limited to adult DOC users, and findings should not be generalized to individuals with other types of diabetes. The developed scale was created for the T1D community but could be edited to for other chronic disease groups and health conditions groups who seek health information online, examples may include mental health issues, infertility, and others.

4.5 CONCLUSIONS

In conclusion, this project's findings provide support for the relationships between Attitudes Toward Seeking Health Information Online, Social Provisions, Diabetes Distress, and T1D related health outcomes and behaviors. This dissertation identified new lines of research that need to be conducted. This project adds to the information seeking knowledge base by characterizing how individuals with T1D are using social media in place of going to the doctor. These findings should aim to be replicated in other chronic disease groups including (depression, mental health, eating disorders and comorbidities of T1D). With a better understanding of the roles of online social support and seeking health information online on treatment adherence, this project serves as the first of several series of studies to improve usage of the DOC and facilitate constructions of interventions that encourage or discourage specific aspects of each behavior.

REFERENCES

American Academy of Certified Endocrinologists. (2016). The burden of Type 1 Diabetes.

> Retrieved from: http://outpatient.aace.com/type1-diabetes/the-burden-of-type-1-diabetes.

American Diabetes Association (2015). Statistics About Diabetes. ADA, 2015. Retrieved from:

> http://www.diabetes.org/diabetes-basics/statistics/?referrer=https://www.google.com/

Arduser, L. (2011). Warp and weft: Weaving the discussion threads of an online community.

> *Journal of Technical Writing and Communication*, *41*(1), 5-31.

Bonfils, K. A., Adams, E.L., Mueser, K.T., Wright-Berryman, J. L., & Salyers, M.P. (2015).

> Factor structure of the autonomy preference index in people with severe mental illness.

> *Psychiatry Research, 228* (5), 526-530.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in*

> *Psychology*, *3*, 77–101.

Brown, A. (2018). 42 Factors That Affect Blood Glucose?! A Surprising Update. Retrieved

> from: https://diatribe.org/42factors

Case, D. O., Andrews, J. E., Johnson, J. D., & Allard, S. L. (2005). Avoiding versus seeking: the

> relationship of information seeking to avoidance, blunting, coping, dissonance, and

> related concepts. *Journal of the Medical Library Association*, *93*(3), 353-362.

Chen, A.T. (2012). Exploring online support spaces: Using cluster analysis to examine breast

> cancer, diabetes and fibromyalgia support groups. *Patient Educ Couns*, *87*, 250-257.

Chung, J. E. (2014). Social networking in online support groups for health: how online social

> networking benefits patients. *Journal of Health Communication*, *19*(6), 639-659.

Christensen A.J., Moran P.J., Ehlers S.E. (1999). Prediction of future dialysis regimen

> adherence: A longitudinal test of the patient by treatment interactive model. Poster

> presented at the annual meeting of the Society of Behavioral Medicine. San Diego, CA.

Collins, S. E., & Lewis, D. M. (2013). Social media made easy: Guiding patients to

    credible online health information and engagement resources. *Clinical Diabetes*, *31*(3),

    137-141.

Crook, B., Stephens, K. K., Pastorek, A. E., Mackert, M., & Donovan, E. E. (2016). Sharing

    health information and influencing behavioral intentions: The role of health literacy,

    information overload, and the Internet in the diffusion of healthy heart information.

    Health Communication, *31*(1), 60-71.

Cutrona, C. E., & Russell, D. W. (1987). The provisions of social relationships and adaptation to

    stress. *Advances in Personal Relationships*, *1*(1), 37-67.

Dale, J.R., Williams, S.M., & Bowyer, V. (2012). What is the effect of peer support on diabetes

    outcomes in adults? A systematic review. *Diabetic Med*, *29*, 1361-1377.

Davison, K. P., Pennebaker, J. W., & Dickerson, S. S. (2000). Who talks? The social psychology

    of illness support groups. *American Psychologist*, *55*, 205–217.

Dennick, K., Sturt, J., & Speight, J. (2017). What is diabetes distress and how can we measure it?

    A narrative review and conceptual model. *Journal of Diabetes and its Complications*,

    31(5), 898-911.

Dexcom CGM Users (n.d.). In Facebook Group. Retrieved March 1, 2018, from

    https://www.facebook.com/groups/268385496689037/

Diabuddies Support Group (n.d.). In Facebook Group. Retrieved March 1, 2018, from

    https://www.facebook.com/groups/1494231364145019/DiMatteo, M.R., 2004. Social

support and patient adherence to medical treatment: a meta-analysis. *Health Psychology*. *23*,

207-218.

Diviani, N., van den Putte, B., Giani, S., & van Weert, J. C. (2015). Low Health Literacy and

      Evaluation of Online Health Information: A Systematic Review of the literature. *Journal*

      of Medical Internet research, *17*(5), e112.

Ende J., Kazis L., Ash A., & Moskowitz M.A. (1989). Measuring patients' desire for autonomy:

      decision making and information-seeking preferences among medical patients. *Journal of*

      General Internal Medicine, *4*,23–30.

Fisher, L., Glasgow, R.E., Mullan, J.T., Skaff, M.M., & Polonsky, W.H. (2008). Development of

      a brief diabetes distress screening instrument. *The Annals of Family Medicine*, *6*(3), 246-

      252.

Fisher, L., Glasgow, R.E., & Stryker, L.A. (2010). The relationship between diabetes distress and

      clinical depression among patients with T2D. *Diabetes Care*. 33, 1034–1036.

Fisher, L., Hessler, D., Polonsky, W., & Mullan, J. (2012). When is diabetes distress clinically

      meaningful? Establishing cutpoints for the Diabetes Distress Scale. *Diabetes Care*,

      35(2), 259-264.

Fox, S., & Duggan M. (2013, November 26). The Diagnosis Difference. Retrieved from:

      http://www.pewinternet.org/2013/11/26/thediagnosis-difference/

Fox, S. (2011). The social life of health information 2011. Washington, DC: *Pew Internet &*

      American Life Project.

Fox, S. (2013). After Dr. Google: peer-to-peer health care. *Pediatrics*, *131*(4), 224-225.

Fransen, M. P., von Wagner, C., & Essink-Bot, M. L. (2012). Diabetes self-management in

      patients with low health literacy: ordering findings from literature in a health literacy

      framework. *Patient Education and Counseling*, *88*(1), 44-53.

Funnell, M. M., & Anderson, R. M. (2000). The problem with compliance in diabetes. *JAMA*.

284(13), 1709-1709.

Gonder-Frederick, L. A., Shepard, J. A., Grabman, J. H., & Ritterband, L. M. (2016).

Psychology, technology, and diabetes management. *American Psychologist*, *71*(7), 577.

Greene, A. (2009). What healthcare professionals can do: A view from young people with

diabetes. *Pediatric Diabetes, 10*(13), 50-57.

Greene, J.A., Coudhry, N.K., Kilabuk, E., & Shrank, W.H. (2010). Online social networking by

patients with diabetes: A qualitative evaluation of communication with Facebook. *J Gen

Intern Med*, *26*, 287-292.

Greenwood, S., Perrin, A., & Duggan, M. (2016). Social media update 2016: Facebook usage

and engagement is on the rise, while adoption of other platforms holds steady. *Pew

Research Center*.

Gabel, H. (2017, May 2). An open letter to the National Diabetes Institute of Diabetes and

Digestive Kidney Disease (NIDDK) [Blog post]. Retrieved from:

https://thechronicscholar.com/2017/05/02/an-open-letter-to-the-national-institute-of-

diabetes-and-digestive-and-kidney-disease-niddk/

Garvin, B. J., & Kim, C-J. (2000). Measurement of preference for information in U.S. and

Korean cardiac catheterization patients. Research in Nursing and Health, 23, 310-318.

Heaney, C. A., & Israel, B. A. (2008). Social networks and social support. *Health Behavior and

Health Education: Theory, Research, and Practice*, *4*, 189-210.

Hilliard, M.E., Sparling, K., Hitchcock, J., Oser, T., & Hood, K. (2015). The emerging diabetes

online community. *Current Diabetes Reviews*, *11*(4), 261-272.

Hirsch, J.S. (2017, September 4). When Hurricane Harvey Arrived, They Kept the Diabetes

    Community Afloat. Retrieved from URL: https://diatribe.org/when-hurricane-harvey-

    arrived-they-kept-diabetes-community-afloat

Hruschka, D. J., Schwartz, D., John, D. C. S., Picone-Decaro, E., Jenkins, R. A., & Carey, J. W.

    (2004). Reliability in coding open-ended data: Lessons learned from HIV behavioral

    research. *Field Methods*, *16*, 307–331.

Hu, L. T., & Bentler, P. M. (1999). Cutoff criteria for fit indexes in covariance structure analysis:

    Conventional criteria versus new alternatives. *Structural Equation Modeling: a*

    Multidisciplinary Journal, *6*(1), 1-55.

Hughes, A.S., Perez, G.M., & Morera, O., F. (2017). WebMDon't: Creating a scale to measure

    online health information seeking behavior. Poster presented at the 38th Annual Meeting

    and Scientific Sessions of the Society of Behavioral Medicine, San Diego, California.

Imperatore, G., Boyle, J.P., Thompson, T.J., Case, D., Dabelea, D, & Hamman R.F. (2012).

    Projections of type 1 and T2D burden in the U.S. population aged <20 years

    through 2050: dynamic modeling of incidence, mortality, and population growth.

    Diabetes Care. *35*, 15-20.

Kanthawala, S., Vermeesch, A., Given, B., & Huh, J. (2016). Answers to health questions:

    internet search results versus online health community responses. *Journal of medical*

    Internet research, *18*(4), e95.

Kingod, N., Cleal, B., Wahlberg, A., & Husted, G. R. (2017). Online peer-to-peer communities

    in the daily lives of people with chronic illness: a qualitative systematic review.

    Qualitative Health Research, *27*(1), 89-99.

Kontos, E., Blake, K. D., Chou, W. Y. S., & Prestin, A. (2014). Predictors of eHealth usage: insights on the digital divide from the Health Information National Trends Survey 2012. *Journal of Medical Internet Research*, *16*(7), e172.

Krantz, D. S., Baum, A., & Wideman, M. V. (1980). Assessment of Preferences for self-treatment and information in health care. *Journal of Personality and Social Psychology*, *39*(5), 977-990.

Kripalani, S., Risser, J., Gatti, M. E., & Jacobson, T. A. (2009). Development and evaluation of the Adherence to Refills and Medications Scale (ARMS) among low-literacy patients with chronic disease. *Value in Health*, *12*(1), 118-123.

Fisher, L., Gonzalez, J., & Polonsky, W. (2014). The confusing tale of depression and distress in patients with diabetes: A call for greater clarity and precision. *Diabetic Medicine*, *31* (7), 764-772.

Lambert, S. D., & Loiselle, C. G. (2007). Health information—seeking behavior. *Qualitative Health Research, 17*(8), 1006-1019.

Lian, O. S., & Nettleton, S. (2015). "United We Stand" Framing Myalgic Encephalomyelitis in a Virtual Symbolic Community. *Qualitative Health Research*, *25*(10), 1383-1394.

Lin, W. Y., Zhang, X., Song, H., & Omori, K. (2016). Health information seeking in the Web 2.0 age: Trust in social media, uncertainty reduction, and self-disclosure. *Computers in Human Behavior*, *56*, 289-294.

Little, R. J. (1988). A test of missing completely at random for multivariate data with missing values. *Journal of the American statistical Association*, *83*(404), 1198-1202.

Loiselle, C. G. (1995). Self-evaluation and health information seeking: A study of self-

    assessment and self-protection. Unpublished doctoral dissertation, University of

    Wisconsin, Madison.

Lu, Y., Zhang, P., Liu, J., Li, J., & Deng, S. (2013). Health-related hot topic detection in online

    communities   using text clustering. *PLoS One*, *8*, e56221.

MacCallum, R. C., Browne, M. W., & Cai, L. (2006). Testing differences between nested

    covariance structure models: Power analysis and null hypotheses. *Psychological*

    Methods, *11*(1), 19.

Marshall, B., Cardon, P., Poddar, A., & Fontenot, R. (2013). Does sample size matter in

    qualitative research?: A review of qualitative interviews in IS research. *Journal of*

    Computer Information Systems, *54*(1), 11-22.

Mayberry, L. S., Gonzalez, J. S., Wallston, K. A., Kripalani, S., & Osborn, C. Y. (2013). The

    ARMS-D out performs the SDSCA, but both are reliable, valid, and predict glycemic

    control. *Diabetes Research and Clinical Practice*, *102*(2), 96-104.

McDonald, R.P. (1999). Test theory: a unified treatment. Lawrence Erlbaum Associates.

Medtronic MiniMed Insulin Pump'ers and CGMs'ers (n.d.). In Facebook Group. Retrieved

    March 1, 2018, from https://www.facebook.com/groups/442016569217015/

Miles M., Huberman, A. (1994). *Qualitative data analysis: an expanded sourcebook*. Sage.

Miller, S. M. (1987). Monitoring and blunting: validation of a questionnaire to assess styles of

    information seeking under threat. *Journal of Personality and Social Psychology*, *52*(2),

    345-353.

Morgan, A. J., Ferguson, Y. M., & Trauth, E. M. (2015). Consumer Demographics and Internet

    Based Health Information Search in the United States: The Intersectionality of Gender,

Race, and Class. *International Journal of E-Health and Medical Communications*, *6*(1), 58-72.

Muthén, L. K., & Muthén, B. (2004). M*plus*: The comprehensive modeling program for applied researchers, Version 3. Muthen & Muthen, Los Angeles, CA.

Neter, E., & Brainin, E. (2012). eHealth literacy: extending the digital divide to the realm of health information. *Journal of Medical Internet Research*, *14*(1), e19.

Nicolucci, A., Kovacs Burns, K., Holt, R. I., Comaschi, M., Hermanns, N., Ishii, H., & Tarkun, I. (2013). Diabetes Attitudes, Wishes and Needs second study (DAWN2): Cross-national benchmarking of diabetes☐related psychosocial outcomes for people with diabetes. *Diabetic Medicine*, *30*(7), 767-777.

Niela-Vilen, H., Axelin, A., Salantera, S., & Melender, H. (2014). Internet-based peer support for parents: A systematic integrative review. *Int J Nurs Stud*, *51*, 1524-1537.

Norman, C. (2011). eHealth literacy 2.0: problems and opportunities with an evolving concept. *Journal of Medical Internet Research*, *13*(4), e125.

Norman, C. D., & Skinner, H. A. (2006). eHEALS: the eHealth literacy scale. *Journal of Medical Internet Research*, 8(4), e27.

NVivo 10 [software program]. Version 10. QSR International; 2012.

O'Cathain, A., Murphy, E., Nicholl, J. (2008). Multidisciplinary, interdisciplinary or dysfunctional? Team working in mixed methods research. *Qual Health Res,* (*18*), 1574-1585.

O'Kane, A. A., Park, S. Y., Mentis, H., Blandford, A., & Chen, Y. (2016). Turning to Peers: Integrating Understanding of the Self, the Condition, and Others' Experiences in Making

Sense of Complex Chronic Conditions. *Computer Supported Cooperative Work*, *25*(6), 477-501.

Oh, H. J., Lauckner, C., Boehmer, J., Fewins-Bliss, R., & Li, K. (2013). Facebooking for health: An examination into the solicitation and effects of health-related social support on social networking sites. *Computers in Human Behavior*, *29*(5), 2072-2080.

Oh, Y. S., & Cho, Y. (2015). Examining the Relationships Between Resources and Online Health Information Seeking Among Patients With Chronic Diseases and Healthy People. *Social Work in Health Care*, *54*(2), 83-100.

Onwuegbuzie, A. J., Bustamante, R. M., & Nelson, J. A. (2010). Mixed research as a tool for developing quantitative instruments. *Journal of Mixed Methods Research*, *4*(1), 56-78.

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), 626-631.

Preacher, K. J., & Coffman, D. L. (2006). Computing power and minimum sample size for RMSEA [Computer software]. Available from http://quantpsy.org/.

Rains, S.A., & Keating, D.M. (2011). The social dimension of blogging about health: Health blogging, social support, and well-being. *Communication Monographs, 78*, 511-534.

Raynor, D. T. (2008, May). Medication literacy is a 2-way street. In *Mayo Clinic Proceedings* (Vol. 83, No. 5, pp. 520-522). Elsevier.

Ridder, D. D. (1997). What is wrong with coping assessment? A review of conceptual and methodological issues. *Psychology and Health*, *12*(3), 417-431.

Schneider, A. L., Pankow, J. S., Heiss, G., & Selvin, E. (2012). Validity and reliability of self-reported diabetes in the atherosclerosis risk in communities study. American journal of epidemiology, 176(8), 738-743.

Scullard, P., Peacock, C., & Davies, P. (2010). Googling children's health: Reliability of medical advice on the internet. *Arch Dis Child, 95*, 580-582.

Shaffer-Hudkins, E., Johnson, N., Melton, S., & Wingert, A. (2014). Social media use among individuals with diabetes. *International Journal of Communication and Health*, *4*, 38-43.

Shelley, T. (2011). Affiliation and Stress. The Oxford handbook of stress, health, and coping. *Oxford University Press*.

Shumaker, S. A., & Hill, D. R. (1991). Gender differences in social support and physical health. *Health psychology*, *10*(2), 102-111.

Simon, D., Kriston, L., Loh, A., Spies, C., Scheibler, F., Wills, C., & Härter, M. (2010). Confirmatory factor analysis and recommendations for improvement of the Autonomy□Preference□Index (API). *Health Expectations*, *13*(3), 234-243.

Skinner, T. C., John, M., & Hampson, S. E. (2000). Social support and personal models of diabetes as predictors of self-care and well-being: a longitudinal study of adolescents with diabetes. *Journal of Pediatric Psychology*, *25*(4), 257-267.

Smith, C. E., Fernengel, K., Holcroft, C., Gerald, K., & Marien, L. (1994). Meta-analysis of the associations between social support and health outcomes. *Annals of Behavioral Medicine*, *16*(4), 352-362.

Soltesz, G., Patterson, C. C., Dahlquist, G., & EURODIAB Study Group. (2007). Worldwide childhood type 1 diabetes incidence–what can we learn from epidemiology?. *Pediatric diabetes*, *8*, 6-14.

Sparling, K., Tenderich, A., ,& Warshaw, H. (2015, November 2). Community as Part of the

    Prescription: Social Media in Diabetes Care. Retrieved from:

    http://www.ajmc.com/journals/evidence-based-diabetes-management/2015/november-

    2015/community-as-part-of-the-prescription-social-media-in-diabetes-care?p=3

IBM Corp. Released 2017. IBM SPSS Statistics for Windows, Version 25.0. Armonk, NY: IBM

    Corp.

Strauss, A., & Corbin, J. (1998). Basics of qualitative research techniques. *Sage Publications*.

Strom, J. L., & Egede, L. E. (2012). The impact of social support on outcomes in adult patients

    with T2D: a systematic review. *Current Diabetes Reports*, *12*(6), 769-781.

Sylvestre, V. (2016). Type 1 Diabetes: Between Ability and Disability. Knots: *An*

    Undergraduate Journal of Disability Studies, *2*, 16-25.

Tashakkori, A., & Teddlie, C. (1998). Applied social research methods series, Mixed

    methodology: Combining qualitative and quantitative approaches. Thousand Oaks, CA:

    Sage Publications.

Teddlie, C., & Tashakkori, A. (2009). Foundations of mixed methods research: Integrating

    quantitative and qualitative approaches in the social and behavioral sciences. Sage.

Tennant, B., Stellefson, M., Dodd, V., Chaney, B., Chaney, D., Paige, S., & Alber, J. (2015).

    eHealth Literacy and Web 2.0 Health Information Seeking Behaviors Among Baby

    Boomers and Older Adults. *Journal of Medical Internet Research*, *17*(3), e70.

Tierney, S., Deaton, C., Webb, K., Jones, A., Dodd, M., McKenna, D., & Rowe, R. (2008).

    Isolation, motivation and balance: living with type 1 or cystic fibrosis-related diabetes.

    Journal of Clinical Nursing, *17*(7b), 235-243.

Turner, R. J., & Brown, R. L. (2010). Social support and mental health. Handbook for the Study of Mental Health: Social Contexts, Theories, and Systems, 2nd ed., *Cambridge University Press*. 200-212.

Type 1 Diabetes (n.d.). In Facebook Group. Retrieved March 1, 2018, from https://www.facebook.com/T1Diabetes/

Type 1 Diabetic Athletes (n.d.). In Facebook Group. Retrieved March 1, 2018, from https://www.facebook.com/groups/Type1DiabeticAthletes/

Uchino, B. N. (2004). Social support and physical health: Understanding the health consequences of relationships. *Yale University Press*.

Uchino, B. N. (2009). Understanding the links between social support and physical health: A life-span perspective with emphasis on the separability of perceived and received support. *Perspectives on Psychological Science, 4*(3), 236-255.

Ullman, J. B., & Bentler, P. M. (2012). Structural equation modeling. *Handbook of Psychology, Second Edition, 2*.

Umberson, D., & Karas Montez, J. (2010). Social relationships and health: A flashpoint for health policy. *Journal of Health and Social Behavior, 51*(1), 54-66.

Van Dam, H. A., van der Horst, F. G., Knoops, L., Ryckman, R. M., Crebolder, H. F., & van den Borne, B. H. (2005). Social support in diabetes: a systematic review of controlled intervention studies. *Patient Education and Counseling, 59*(1), 1-12.

Van Uden-Kraan, C.F., Drossaert, C.H.C., Taal, E., Seydel, E.R., & van de Laar, M.A.F.J.. (2008). Self-reported differences in empowerment between lurkers and posters in online patient support groups. *Journal of Medical Internet Research, 10*, e18.

Van Zuuren, F. J. , de Groot, K. I., Mulder, N. L., & Muris, P. (1996). Coping with medical

    threat: An evaluation of the Threatening Medical Situations Inventory (TMSI).

    Personality and Individual Differences, *21*, 21-31.

Wakefield, C. E., Homewood, J., Mahmut, M., Taylor, A., & Meiser, B. (2007). Usefulness of

    the Threatening Medical Situations Inventory in individuals considering genetic testing

    for cancer risk. *Patient Education and Counseling*, *69*(1), 29-38.

Wallston, B. S., Alagna, S. W., DeVellis, B. M., & DeVellis, R. F. (1983). Social support and

    physical health. *Health Psychology*, *2*(4), 367-391.

Wendler M. C. (2001). Triangulation using a meta-matrix. *J Adv Nurs* (35) 521-525.

White, K., Gebremariam, A., Lewis, D., Nordgren, W., Wedding, J., Pasek, J., & Lee, J. M.

    (2018). Motivations for Participation in an Online Social Media Community for

    Diabetes. *Journal of diabetes science and technology*, *12*(3), 712-718.

Wiebe, D. J., Helgeson, V., & Berg, C. A. (2016). The social context of managing diabetes

    across the life span. *American Psychologist*, *71*(7), 526.

Wills, T. A. (1991). Social support and interpersonal relationships. In M. S. Clark (Ed.), Review

    of Personality and Social Psychology, Vol. 12. *Prosocial behavior*. Thousand Oaks, CA:

    Sage Publications.

TABLES

Table 1: Onwuegbuzie et al. (2010) instrument development and construct validation framework for scale development using mixed methodology

Phase	Description	Study	Details
1	An in-depth, multidisciplinary review of literature to establish theoretical framework. In this phase, constructs of interest are defined.	Preliminary data	Borrows from psychology, sociology, and rehabilitation counseling literature.
2	Open coding, and constructing themes from literature and conversations with informants.	Preliminary data	
3	The scale is written.	Preliminary Data	The instrument will be developed from preliminary data responses and the literature review.
4	Each item is assessed for "clarity, aesthetics, relevancy, tone," time taken to answer the item, and "cultural competence" of the item (i.e., is it phrased in a way that is considerate of the culture of the participants?)	Studies 1 & 2	A larger list of potential items will be assessed and the number of items reduced.
5	Data are collected on a sample large enough to provide adequate power for an EFA.	Study 2	Participants will complete the scale developed in Studies 1 and 2, provide supplementary ratings, and summarize each scale item in their own words.

6	In Phase 6, the EFA is conducted on the data collected in Phase 5.	Study 2	A sufficiently powered EFA will be conducted on data collected in Study 2.
7	The qualitative data collected along with the quantitative scale from Phase 5 is analyzed.	Studies 1 & 2	The qualitative data collected in Study 2 will be analyzed using thematic analysis.
8	The qualitative data from Phase 5 is quantized and a factor analysis is conducted with these quantized data to examine underlying factor structures	Study 1	Data from thematic analyses will be quantized and entered into an EFA to determine the factor structure of the data from qualitative responses.
9	The factors generated from the EFA calculated with the quantized qualitative themes will be correlated with factors generated from the EFA calculated with the revised quantitative scale itself. The factors generated from the EFA calculated with the quantized qualitative themes will be correlated with factors generated from the EFA calculated with the quantitative scale itself.	Studies 1 & 2	The factors that emerge from the EFA conducted on quantized themes will be correlated with the factors generated from the factor analysis conducted on the data from the scale being developed.
10	The findings from all the different types of analyses are compared, and convergent findings and discrepancies between the different phases of data	Discussion	Results from Studies 1 and 2 will be compared and their implications will be discussed.

analysis are identified and discussed.

Phase 10 includes synthesizing the

results and discussing their meaning and

implications.

Note. Exploratory factor analysis (EFA) is used to determine the underlying structure of scales. This was not necessary for this project.

Table 2

Calculation for degrees of freedom and subsequent calculation of estimated sample sizes

P = # of items	K = # of factors	[P(p + 1)/2] -	{[(k(k + 1)/2) - k]	+ m(λ)	+ m(ψ)}	= df	*N
10	**2**	55	1	10	10	34	285
15	**3**	120	3	15	15	87	145
20	**4**	210	6	20	20	164	96

Note. Calculations of degrees of freedom (df) are shown above. Minimum number of items per factor m = 5, number of factor loadings for each item λ = k, item unique variances and ψ = k. Df, RMSEA null = .05, RMSEA alternative = .08, desired power = .80, and α = .05 were plugged into the sample size estimator utility from quantpsy.org (Preacher & Coffman, 2006) to calculate estimated sample size (*N).

Table 3. Correlational Indices

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19
1. Diabetes Duration	--																		
2. eHealth Literacy	-.130	--																	
3. Hemoglobin A1C	-.152	.210**	--																
4. Income	-.068	.043	-.043	--															
5. Complications	.127	-.016	.097	-.029	--														
6. Social1	.084	.188*	.026	.113	.035	--													
7. Social2	.101	.355**	-.082	.013	-.014	.603**	--												
8. Social3	.078	.340**	-.091	-.003	-.085	.659**	.698**	--											
9. Social4	.035	.260**	.041	-.041	.013	.669**	.569**	.559**	--										
10. Social5	.126	.255**	-.082	.009	.032	.786**	.728**	.749**	.752**	--									
11. Social6	.110	.175*	.011	.071	.001	.735**	.459**	.613**	.566**	.639**	--								
12. Distress1	-.167*	.046	.183*	-.128	.270**	.169*	-.081	-.204*	-.057	-.135	-.117	--							
13. Distress2	-.153*	-.072	.505**	-.029	.244**	-.089	-.117	-.219*	.021	-.112	.008	.575**	--						
14. Distress3	.015	.027	.086	-.055	.211**	.039	.033	-.028	.064	.032	.048	.564**	.434**	--					
15. Distress4	-.285**	.053	.201**	-.016	.240**	.064	-.030	-.188*	.034	-.038	.013	.579**	.510**	.428**	--				
16. Distress5	-.149	-.015	.246**	.046	.197*	-.123	-.054	-.163*	-.054	-.131	-.079	.676**	.575**	.414**	.472**	--			
17. Distress6	-.095	.043	.225**	-.037	.217**	-.046	-.037	-.134	.066	-.064	-.038	.558**	.620**	.470**	.451**	.576**	--		
18. Distress7	.084	.098	.014	.130	.034	.848**	.435**	.528**	.571**	.686**	.741**	-.166*	-.037	-.016	.067	-.096	-.034	--	
19. Factor 1	-.064	.413**	-.096	.055	-.010	.183*	.260**	.251**	.273**	.341**	.172*	.198*	.062	.153*	-.008	.122	.204**	.123	--
20. Factor 2	.078	.197*	-.016	.116	.136	.269**	.276**	.353**	.264**	.314**	.324**	0.051	.169*	.158*	.011	.052	.076	.219**	.356**

Note. * = p < .05, ** = p < .001

94

Table 4 - Study 1 Health Demographics and General Health Concerns

General Health Concerns in Study 1	Percentage of occurrence in Study 1
Chronic migraine headaches	14.6
Meningitis	8.1
Epilepsy	4.2
Heart attack or bypass surgery	4.2
Multiple sclerosis	4.2
Parkinson's	6.3
Rheumatoid arthritis	14.6
Osteoarthritis	9.4
Stroke	6.3
Alzheimer's or Dementia	5.3
Other cognitive disorder	7.3

Table 5. Qualitative Responses - "If there was one aspect of your diabetes management that you could improve, what would it be?"

Themes	Definition	Quotes	Counts
Avoiding Blood Sugar Excursions	Improving overall health by limiting amount of out of range blood sugars	(ID 115): "Trying to keep a steady blood sugar line. I'm always either on my way up or down, can't seem to find a way to keep it steady."	33
Avoiding High Blood Sugars			17
CGM Management			1
Less BG Excursions During Exercise			5
More Time in Range			1
Overall Improvement in BG Excursions			5
CGM Device Improvement and Accessibility	Improving specific CGM devices and their accessibility	(ID 105): "Accuracy of cgm"	5
Acquire CGM			1
Device Improvement			2
CGM Device Improvement and Accessibility			2
Improving Blood Sugars During Exercise	Improving blood sugars during physical activity	(ID 148): "Numbers while exercising"	3
High Expenses	Improving cost of Essential Diabetes Supplies	(ID 138): "The Overall Cost" 6	
Improving the Cost of Diabetes Management			6
Improving Mental Health	Improving Mental Health	(ID 139): "Stress and anxiety and how it affects my blood sugars"	4
Improving Nutrition	Improving Food Intake	(ID 172): "I would like to have better control in food management. I need to work on eating healthier rather than the stuff i eat currently. For example, I eat sugary cereal for breakfast and kind of eat whatever i want"	16
Carbohydrate counting			1
Nutrition Fluency			2
Improving Treatment Adherence			
Carrying Diabetes Supplies	Employing Necessary Tasks and Tools	[ID 120]: "Remembering to take insulin before every meal when I am busy at work and on the go when eating. There are many of times when I take it after due to a time crunch and I find myself having to counteract or bolusing for a high when I would have been in range if I would have taken a few extra minutes for myself and diabetes."	8
Precision in Timing of Dosing and Amount of Dose			1
Remembering to Take Insulin			5
Using CGM more			1
Other			1
Miscellaneous	Miscellaneous		**7**
Health Insurance			1
Improvement in Doctor			2
Medicine Accessibility			1
More Education			1
More Support			1
Medicine and Device Improvement	Improving specific Medicine and Devices	[ID 160]: An easier way to check BG/ have all systems communicate with each other (meter, pump, logbook, etc).	14
Grand Total			96

Table 6. Qualitative Responses - "Do you feel that the Diabetes Online Community assists you?"

Themes	Definition	Quotes	Counts
DOC Assists	Members of the DOC assists other members of the DOC	Yes! Great resource for crowdsourcing, learning about others experiences, and just meeting others in a similar boat as me, even if they live around the world.	64
DOC is Generally Helpful			53
Sense of Community			10
Uses DOC to Help Others			1
DOC Does Not Assist	Participants stated that they do not get assisted by other members of the DOC or the DOC as a whole	[ID 102]: Few talk about eating disorders (diabulimia) and far too many people post CGM graphs or talk about blood sugars which is extremely triggering to me.	2
DOC Sometimes Assists	Members of the DOC sometimes assist other members of the DOC	[ID 112]: Sometimes. Instagram can be a big help but it can also be confusing because what works for one does not work for all.	1
Depends on Group Membership			1
Not Active Part of DOC	Participants stated that they were not an active member of the DOC	[ID 168]: "Not really"	14
Hard to Find Help			1
Not in DOC			13
Support and Motivation	Participants reported receiving multiple types of support in the DOC	[ID 140]" YES! There are so many things I've learned from my online friends that I didn't even learn from my doctor.	19
Emotional Support			1
Encouraged to Use CGM			2
Informational Support			13
Informational support Better than Doctor			1
Inspiration and Support from Other Women with T1D			1
Grand Total			111

Table 7. Qualitative Responses -"What do you find to be the most useful parts of the Diabetes Online Community?"

Themes	Definition	Quote	Counts
Informational Support	Advice, suggestions, and information	[ID 115]: "It's a support system. People share what works for them which gives me options to try as well."	29
Social Interaction/Support	Members interact with other members and receive social support during those interactions	[ID 174]: "Connect with other women"	30
Sense of community	Members experienced an overall feeling of belong to something bigger in the DOC.	[ID 177]: "Reading other people's stories whom I can relate with. No judgement and everyone understands each other."	48
Grand Total			107

Table 8. Qualitative Responses –"Please describe your experience with posting health questions on social media websites."

Themes	Definition	Quote	Count
Not an active participant in DOC	Participant stated that they are not an active member in the DOC	[ID 102]: I don't post questions about diabetes. The few times I've asked questions about unrelated health issues, I rarely get responses.	54
Does Not Post			12
Level of Engagement Varies			15
Not An Active Participant			27
Other	Miscellaneous responses		2
Sarcasm Regarding Responses			1
Navigating pregnancy			1
Overall positive experience	Members report willingness to help and encouraging experiences in the DOC	[ID 115]: I have gotten really great feedback and advice from fellow T1Ds. People have been extremely helpful.	60
Quality feedback			8
DOC is superior to Doctor			1
Device Advice			2
Easy			2
Fast			9
Online Information Must be Sorted			9
Helpful			8
Positive Experience			14
Posts Within Groups			1
General Support			3
Variety of Responses			3
Grand Total			116

Table 9. Qualitative Responses – "Describe what you view as pros of being a member of the Diabetes Online Community."

Themes	Definition	Quotes	Counts
Advocacy	Members of the DOC take part in advocacy (insulin accessibility)	[ID 131]: "rallying against the horrors of big pharma trying to kill us all by pricing medical supplies WAY too high"	6
Informational support	Members gain information and advice from other members of the DOC	[ID 119]: "I also enjoy learning of low carb recipes that people post."	25
Other	Miscellaneous responses		4
Appreciation			1
Free			1
Great			1
Quick and Constant			1
Sense of Community	Members experienced an overall feeling of belong to something bigger in the DOC.	[ID 108]: "We are all going through this together, so that is the best part."	52
Building Friendships			10
Sense of Community			42
Support Provided in the DOC	Members states that they receive general and varied types of support	[ID 120]: "huge support group"	12
Connecting with Others			3
Emotional Support			2
Experiences Love and support			1
Support Promotes Feelings of Normalcy			6
Grand Total			**99**

Table 10. Qualitative Responses – "Describe what you view as cons of being a member of the Diabetes Online Community."

Themes	Definition	Quote	Count
Comparing Self to Others	Members stated that seeing in target blood sugars was very negative	ID 115: "constantly seeing others having great blood sugars can sometimes be hard because it sometimes makes me unmotivated since I keep trying and sometimes it doesn't work"	10
Judgmental DOC Members	There are judgmental DOC members who bully other members	[ID 122]: "Sometimes people are mean if your practices don't align with theirs."	18
Misinformation	Members sometimes experience false information that may be detrimental to their health	[ID 161]: "there is a lot of incorrect information"	6
Other	Miscellaneous Responses		10
Abundance of Unnecessary Post			1
Device Availability			1
Diabetes Burnout			1
Guilt			1
Not In Person			1
Not For Impressionable People			1
People Take Advantage (Free Supplies)			1
Some Members Shouldn't Post			1
Too Much T1D Involvement			1
Wasting Time with Unimportant Posts			1
Grand Total			44

Table 11. Qualitative Responses - "How has the Diabetes Online Community impacted your physical health?"

Themes	Definition	Quote	Count
No impact	Participants stated that the DOC did not have an impact on their physical health	[ID 118]: "It hasn't"	14
Positive Impact	Participants stated that the DOC has a positive impact on their physical health	[ID 109]: It's improved. I've learned a few tidbits to apply to daily life, especially about alternative snacking habits and insulin dosing strategies.	64
Better self-care			4
Health Lifestyle improvement			2
Improved exercise behaviors and physical health			15
Improved mental health			2
Informational support			14
Lower a1c and improved T1D behaviors			14
More nutrition			2
Motivating			9
Received insulin from group members			1
Saved money			1
Started device because of reviews	Participants reported that DOC support encouraged them to start their medical devices	[ID 166]: "I've gotten a new insulin pump because of seeing and hearing about other people's experiences"	12
Initiated usage of CGM and insulin pump			2
Initiated CGM because of other's reviews			3
Initiated pump			4
Strives to be healthier like others			1
Stronger and more aware of capabilities			1
Wants to post good numbers to IG motivated them			1
Grand Total			90

Table 12. Qualitative Responses -"How has the Diabetes Online Community impacted your mental health? "Question 8: "How has the Diabetes Online Community impacted your mental health?"

Themes	Definition	Quote	Count
Negative Impact	Participants stated that the DOC had a negative impact on their mental health	[ID 189]: "Probably slightly negatively just in that I feel I'm not doing as well as others"	5
Enhance anxiety about T1D			1
Promotes Comparing Self to Others			3
Triggering			1
No impact	Participants stated that the DOC had a negative impact on their mental health	[ID 163]: "It hasn't impacted my mental health."	5
Positive Impact	Participants stated that the DOC had a positive impact on their mental health	[ID 162]: "Yes. Helps with not feeling isolated"	61
Encouragement			7
Feels Less Alone			15
Improved			17
Normalizes the Diabetes Experience			
Sense of community			22
Grand Total			71

Table 13. Qualitative Responses -"Please describe one time when you interacted with another Diabetes Online Community member to make a treatment decision."
Themes

Themes	Definition	Quote	Counts
Advice About Insulin Dosing	DOC members sought advice about specifics of insulin dosing (when to dose, how much to dose, etc.)	[ID 107] "Hyperglycemic and correction doses not having any apparent effect, a DOC member advised me to try an IM injection for better absorption, and it worked!"	11
Allergic Reactions	DOC member sought advice about treating and prevention allergic reactions.	[ID 145] "I have regularly interacted with other members of this community to seek treatment decisions regarding allergic reactions to adhesives and to find out what products work for other people who may have had a similar issue."	1
Blood Glucose Advice	Members seek advice about blood glucose	[ID 175] "I would always go high at night and someone advised that maybe I should eat something little before bed and it did help!"	3
Consults Both Doctor and DOC	Participant stated that the they consult both their doctor and the DOC for health information	[ID 114] "I take tips but i also consult with my doctor first"	1
Diabulimia Treatment	DOC member sought information about treatment for Diabulimia (an eating disorder involving restriction of insulin and binging and/or purging food).	[ID 102] "I had worked with We Are Diabetes in the past and discussed diabulimia treatment."	1
Doesn't Seek Information in the DOC	Participants stated that they do not seek health information in the DOC.	[ID 119] "I have not reached out to anyone."	29
Durable Medical Advice	Participants sought miscellaneous advice regarding CGMs and insulin pumps	[ID 121] "When I asked questions on an Instagram post about CGMs. I then decided to try out Dexcom."	16
Exercise and Insulin	Members requested advice and tips about using insulin dosing and activity (before, during and after exercise activity)	[ID 137] "A tip was once given to me about treating lows after the gym and I followed these tips and it really worked"	9
Gives Advice	Participants described situations where they had provided advice to other DOC members	[ID 182] "was complaining of post meal BG spikes and they werent sure why. I recommended pre-bolusing at least 15 minutes before they eat to try to avoid he spike".	5
Gives Advice But Doesn't Ask for Advice	Gives Advice but does not ask for advice from the DOC	[ID 188] "I wouldn't make a treatment decision online with someone who I do not know as could result in poor treatment. I have made suggestions once and a while or advised of how I would treat myself in that situation"	1
Meter Advice	Participant asked other DOC members for advice about which meter to choose	[ID 183] "I asked for meter advice and got helpful tips on which one they use"	1
Nutrition	Participants requested nutrition advice	[ID 143] "I have asked another Type 1 Diabetic about supplemental use and	2

		about gluten free foods, but never to treat."	
Sick Days	Participant requested advice on how to dose medication while experiencing a sickness	[ID 184] "Deciding what to do when sick based on suggestions from other T1ds"	2
Sought Advice about Insulin Injections	Participants sought information about new types of insulin or how to dose specific types of insulin	[ID 190] "I've spoken to several people about why they switched to tresiba, and why they love it so much. Unfortunately it's not approved to go in a pump at this time, and I'm not willing to go back on shots"	2
Sought Advice in Emergency	Participant was desperately seeking advice during an emergency.	[ID 185] "I was about to come home from Australia and my pump went down. I reached out to someone from a group who I knew could help me figure out dosing for the emergency long acting insulin I had with me."	1
Grand Total			85

Table 14 - Study 2 Health Demographics and General Health Concerns

General Health Concerns in Study 2	Percentage of occurrence in Study 2
Chronic migraine headaches	30.1
Meningitis	6
Epilepsy	3.6
Heart attack or bypass surgery	4.2
Multiple sclerosis	1.2
Parkinson's	1.2
Rheumatoid arthritis	13.9
Osteoarthritis	3
Stroke	2.4
Alzheimer's or Dementia	1.2
Other cognitive disorder	1.8

Table 15. Factor loadings for the 3-factor model with 19 items

Item #	Item	F	Λ	S.E.	z-score
1	I frequently use the internet to gain health advice in the Diabetes Online Community.	1	0.506	.086	5.880
2	I am critical of the health information that I find in the Diabetes Online Community. *(Reverse Coded)*	1	-0.007	.097	-.077
3	I review multiple internet sources in the Diabetes Online Community before making a health decision for myself.	1	0.246	0.102	2.423
4	I do not follow the health information that I find on social media in the Diabetes Online Community. *(Reverse Coded)*	1	0.493	0.092	5.360
5	I trust the health information that I find in the Diabetes Online Community.	1	0.700	0.069	10.215
6	I feel comfortable receiving health advice in the Diabetes Online Community.	1	0.910	0.027	34.119
7	I trust the health information that my friends on social media (Facebook, Twitter, Instagram, discussion forums) provide in the Diabetes Online Community.	1	0.799	0.045	17.892
8	I feel confident in my knowledge of the available online health resources in the Diabetes Online Community.	2	0.671	0.064	10.510
9	It is difficult for me to find health information online in the Diabetes Online Community. *(Reverse Coded)*	2	0.318	0.108	2.941
10	I feel confident in my ability to find accurate health information in the Diabetes Online Community.	2	0.486	0.116	4.198
11	When I am confronted with a health problem, I can usually find several solutions via advice in the Diabetes Online Community.	2	0.682	0.067	10.218
12	I prefer to get advice about medical devices (insulin pumps and CGMs) from the Diabetes Online Community instead of my doctor.	2	0.371	0.078	4.776
13	Item 6: When trying to understand my symptoms, my first resource is social media in the Diabetes Online Community.	2	0.534	0.064	8.392
14	I would prefer to search the internet for health information in the Diabetes Online Community instead of going to a doctor's appointment.	2	0.403	0.073	5.533
15	I share health articles on my social media account (s) in the Diabetes Online Community.	3	0.735	0.058	12.750
16	I do not post health related items on social media (Facebook, Twitter, Instagram and/or discussion forums) in the Diabetes Online Community. *(Reverse Coded)*	3	0.747	0.070	10.606
17	I prefer to read the health information that I find on social media websites but not engage in online conversation about the health information in the Diabetes Online Community. *(Reverse Coded)*	3	0.572	0.065	8.810
18	I feel comfortable providing advice to others in the Diabetes Online Community.	3	0.574	0.095	6.061
19	I find myself giving advice more than receiving advice in the Diabetes Online Community.	3	0.351	0.099	3.561

Note. F – the factor, 1, 2 or 3, that the respective item loads on. λ – factor loadings. S.E. – standard error associated with the given loading.

Table 16. Factor loadings for the 3-factor model with 16 items

Item #	Item	F	λ	S.E.	z-score
1	I frequently use the internet to gain health advice in the Diabetes Online Community.	1	.502	0.086	5.813
3	I review multiple internet sources in the Diabetes Online Community before making a health decision for myself.	1	.243	.101	2.415
4	I do not follow the health information that I find on social media in the Diabetes Online Community. *(Reverse Coded)*	1	0.488	.091	5.343
5	I trust the health information that I find in the Diabetes Online Community.	1	.700	0.069	10.176
6	I feel comfortable receiving health advice in the Diabetes Online Community.	1	.914	0.026	35.492
7	I trust the health information that my friends on social media (Facebook, Twitter, Instagram, discussion forums) provide in the Diabetes Online Community.	1	.799	0.044	18.097
8	I feel confident in my knowledge of the available online health resources in the Diabetes Online Community.	2	0.680	0.065	10.472
9	It is difficult for me to find health information online in the Diabetes Online Community. *(Reverse Coded)*	2	0.326	0.105	3.100
10	I feel confident in my ability to find accurate health information in the Diabetes Online Community.	2	0.494	0.114	4.331
11	When I am confronted with a health problem, I can usually find several solutions via advice in the Diabetes Online Community.	2	0.674	0.072	9.322
12	I prefer to get advice about medical devices (insulin pumps and CGMs) from the Diabetes Online Community instead of my doctor.	2	0.344	0.078	4.393
13	Item 6: When trying to understand my symptoms, my first resource is social media in the Diabetes Online Community.	2	0.512	0.063	8.140
15	I share health articles on my social media account (s) in the Diabetes Online Community.	3	0.735	0.056	13.063
16	I do not post health related items on social media (Facebook, Twitter, Instagram and/or discussion forums) in the Diabetes Online Community. *(Reverse Coded)*	3	0.773	0.059	13.049
17	I prefer to read the health information that I find on social media websites but not engage in online conversation about the health information in the Diabetes Online Community. *(Reverse Coded)*	3	0.583	0.065	9.001
18	I feel comfortable providing advice to others in the Diabetes Online Community.	3	0.515	0.080	6.406

Note. F – the factor, 1, 2 or 3, that the respective item loads on. λ – factor loadings. S.E. –

standard error associated with the given loading.

Table 17. Factor loadings for the 2-factor model with 16 items

Item #	Item	F	Λ	S.E.	z-score
1	I frequently use the internet to gain health advice in the Diabetes Online Community.	1	.519	0.083	6.246
3	I review multiple internet sources in the Diabetes Online Community before making a health decision for myself.	1	.254	0.099	2.559
4	I do not follow the health information that I find on social media in the Diabetes Online Community. *(Reverse Coded)*	1	.486	0.092	5.302
5	I trust the health information that I find in the Diabetes Online Community.	1	.698	.067	10.442
6	I feel comfortable receiving health advice in the Diabetes Online Community.	1	.899	0.025	35.648
7	I trust the health information that my friends on social media (Facebook, Twitter, Instagram, discussion forums) provide in the Diabetes Online Community.	1	0.792	0.045	17.484
8	I feel confident in my knowledge of the available online health resources in the Diabetes Online Community.	1	.659	0.063	10.508
9	It is difficult for me to find health information online in the Diabetes Online Community. *(Reverse Coded)*	1	.303	0.101	2.984
10	I feel confident in my ability to find accurate health information in the Diabetes Online Community.	1	.490	0.106	4.622
11	When I am confronted with a health problem, I can usually find several solutions via advice in the Diabetes Online Community.	1	.649	0.072	9.039
12	I prefer to get advice about medical devices (insulin pumps and CGMs) from the Diabetes Online Community instead of my doctor.	1	.347	0.074	4.668
13	Item 6: When trying to understand my symptoms, my first resource is social media in the Diabetes Online Community.	1	0.497	0.064	7.751
15	I share health articles on my social media account (s) in the Diabetes Online Community.	2	.732	0.056	13.056
16	I do not post health related items on social media (Facebook, Twitter, Instagram and/or discussion forums) in the Diabetes Online Community. *(Reverse Coded)*	2	.782	0.060	13.127
17	I prefer to read the health information that I find on social media websites but not engage in online conversation about the health information in the Diabetes Online Community. *(Reverse Coded)*	2	0.580	0.065	8.933
18	I feel comfortable providing advice to others in the Diabetes Online Community.	2	.509	0.081	6.277

Note. F – the factor, 1, 2 or 3, that the respective item loads on. λ – factor loadings. S.E. – standard error associated with the given loading.

Table 18. Hypothesis 1- ARMS-D

Variables	β	Std. Error	*t*	*p*
Step 1				
Income	-.00000279	0	0.299	.765
Diabetes Duration	-.031	.049	-.631	.529
eHealth Literacy	-2.822	1.062	-2.658	.009
Step 2				
Attitudes Factor 1	.181	.695	.260	.795
Attitudes Factor 2	.350	.555	.630	.530
Distress 1	1.124	.599	1.877	.062
Distress 2	2.916	.575	5.069	<.001
Distress 3	.129	.384	.366	.738
Distress 4	.574	.456	1.258	.210
Distress 5	-.575	.477	-1.205	.230
Distress 6	-.009	.500	-.018	.985
Distress 7	1	.656	1.525	.129

Table 19. Hypothesis 1- A1C

Variables	β	Std. Error	*t*	*p*
Step 1				
Income	-.0001052	0	-.606	.546
Diabetes Duration	-.022	.009	-2.435	.016
eHealth Literacy	-.602	.198	-3.045	.003
Step 2				
Attitudes Factor 1	-.046	.142	-.324	.746
Attitudes Factor 2	-.095	.113	-.836	.405
Distress 1	-.095	.122	-.775	.439
Distress 2	.742	.117	6.319	<.001
Distress 3	-.073	.078	-.938	.350
Distress 4	-.048	.093	-.511	.610
Distress 5	.041	.098	.421	.674
Distress 6	-.072	.102	-.706	.481
Distress 7	.136	.134	1.019	.310

Table 20. Hypothesis 1 – Complications

Variables	β	Std. Error	t	p
Step 1				
Income	.002	.032	.071	.943
Diabetes Duration	.012	.005	2.519	.012
Education 1	.604	.669	.903	.367
Education 3	.751	.600	1.253	.210
Education 4	.730	.597	1.223	.221
Education 5	.859	.612	1.405	.160
Education 6	.560	.601	.933	.351
Education 7	.819	.644	1.272	.204
Education 8	.498	.604	.826	.409
eHealth Literacy	.002	.011	.214	.831
Step 2				
Attitudes Factor 1	-.096	.082	-1.169	.242
Attitudes Factor 2	.100	.064	1.567	.117
Distress 1	.097	.070	1.379	.168
Distress 2	.004	.064	.056	.956
Distress 3	-.041	.041	-.987	.324
Distress 4	.034	.050	.680	.497
Distress 5	.010	.052	.185	.853
Distress 6	.034	.054	.626	.532
Distress 7	.062	.080	.779	.436

Table 21. Hypothesis 2- ARMS-D

Variables	β	Std. Error	*t*	*p*
Step 1				
Income	-.0002790	0	-.299	.765
Diabetes Duration	-.031	.049	-.631	.529
eHealth Literacy	-2.822	1.062	-2.658	.009
Step 2				
Attitudes Factor 1	.533	.817	.652	.515
Attitudes Factor 2	1.507	.664	2.269	.025
Social 1	-.018	.253	-.072	.943
Social 2	-.231	.338	-.682	.496
Social 3	-.926	.340	-2.723	.007
Social 4	.595	.350	1.700	.091
Social 5	-.016	.319	-.050	.960
Social 6	.401	.237	1.690	.093

Table 22. Hypothesis 2- A1C

Variables	β	Std. Error	t	p
Step 1				
Income	-.0001052	0	-.606	.546
Diabetes Duration	-.022	.009	-2.435	.016
eHealth Literacy	-.602	.198	-3.045	.003
Step 2				
Attitudes Factor 1	-.007	.159	-.042	.966
Attitudes Factor 2	.075	.130	.578	.564
Social 1	.062	.049	1.257	.211
Social 2	.021	.066	.320	.750
Social 3	-.029	.066	-.433	.666
Social 4	.113	.068	1.660	.099
Social 5	-.111	.062	-1.787	.076
Social 6	.012	.046	.251	.802

Table 23. Hypothesis 2 – Complications

Variables	β	Std. error	t	p
Step 1				
Income	-.010	.032	-.305	.760
Education 1	.637	.670	.951	.342
Education 3	.714	.598	1.194	.233
Education 4	.773	.594	1.3	.193
Education 5	.964	.604	1.598	.110
Education 6	.586	.594	.986	.324
Education 7	.672	.637	1.055	.291
Education 8	.455	.597	.762	.446
Diabetes Duration	.007	.005	1.575	.115
eHealth Literacy	.005	.012	.419	.675
Step 2				
Factor 1	-0.070	.080	-.877	.380
Factor 2	.123	.062	1.977	.048
Social 1	.023	.027	.836	.403
Social 2	.034	.034	1.006	.314
Social 3	-.072	.032	-2.272	.023
Social 4	-.062	.035	-1.752	.08
Social 5	.023	.030	.765	.444
Social 6	0.012	.024	.486	.627

Table 24. Hypothesis 3 – ARMS-D

Variables	β	Std. Error	*t*	*p*
Step 1				
Income	-.0002790	0	-.299	.765
Diabetes Duration	-.031	.049	-.631	.529
eHealth Literacy	-2.822	1.062	-2.658	.009
Step 2				
Social 1	-.132	.267	-.493	.623
Social 2	-.351	.289	-1.214	.227
Social 3	-.093	.301	-.309	.758
Social 4	.384	.299	1.285	.201
Social 5	.040	.264	.151	.880
Social 6	.142	.214	.662	.509
Distress 1	1.131	.591	1.913	.058
Distress 2	2.774	.575	4.824	<.001
Distress 3	.193	.388	.497	.620
Distress 4	.538	.464	1.161	.247
Distress 5	-.499	.481	-1.038	.301
Distress 6	-.055	.497	-.110	.913
Distress 7	1.029	1.283	.802	.424

Table 25. Hypothesis 3 – A1C

Variables	β	Std. error	t	p
Step 1				
Income	-.000052	0	-.606	.546
Diabetes Duration	-.022	.009	-2.435	.016
eHealth Literacy	-.602	.198	-3.045	.003
Step 2				
Social 1	.116	.054	2.146	.034
Social 2	0	.058	-.006	.995
Social 3	.054	.061	.889	.376
Social 4	.060	.060	.991	.323
Social 5	-.093	.053	-1.736	.085
Social 6	-.029	.043	-.680	.498
Distress 1	-.066	.119	-.550	.583
Distress 2	.752	.116	6.476	<.001
Distress 3	-.106	.078	-1.357	.177
Distress 4	-.402	.094	-.448	.655
Distress 5	.042	.097	.428	.669
Distress 6	-.089	.100	-.886	.377
Distress 7	-.204	.259	-.786	.433

Table 26. Hypothesis 3 – Complications

Variables	β	Std. error	t	p	
Step 1					
Income	-.005	.033	-.164	.870	
Education 1	.506	.681	.743	.458	
Education 3	.630	.605	1.041	.298	
Education 4	.677	.602	1.126	.260	
Education 5	.837	.614	1.362	.173	
Education 6	.505	.602	.838	.402	
Education 7	.780	.651	1.199	.231	
Education 8	.425	.608	.699	.485	
Diabetes Duration	.011	.005	.351	.035	
eHealth Literacy	.004	.012	2.109	.726	
Step 2					
Social 1	-.036	.034	.481	.630	
Social 2	-.058	.035	.761	.447	
Social 3	-.036	.035	-1.026	.305	
Social 4	-.058	.036	-1.642	.101	
Social 5	.015	.030	.495	.620	
Social 6	0	.025	.001	.999	
Distress 1	.066	.069	.954	.340	
Distress 2	.045	.065	.698	.485	
Distress 3	-.024	.042	-.582	.560	
Distress 4	.021	.052	.400	.689	
Distress 5	.020	.053	.373	.709	
Distress 6	.013	.054	.240	.810	
Distress 7	.096	.159	.604	.546	

Table 27. Convergent validity amongst scales and subscales

	Factor 1	Factor 2
eHealth Literacy	.413**	.197*
Social Provisions-Attachment	.183*	.269**
Social Provisions-Social Integration	.260**	.276**
Social Provisions-Reassurance of Worth	.251**	.353**
Social Provisions-Reliable Alliance	.273**	.264**
Social Provisions-Guidance	.341**	.314**
Social Provisions-Opportunity for Nurturance	.172*	.324**
Diabetes Distress-Powerlessness	.198*	.051
Diabetes Distress-Management Distress	.062	.169*
Diabetes Distress-Hypoglycemia Distress	.153*	.158*
Diabetes Distress-Negative Social Perceptions	-.008	.011
Diabetes Distress-Eating Distress	.122	.052
Diabetes Distress-Physician Distress	.204**	.076
Diabetes Distress-Friend/Family Distress	.123	.219**

Note. * indicate those correlations significant at the .05 level. ** indicate correlations

significant at the .001 level.

APPENDIX A

DEMOGRAPHICS

Age (in years) _____

Gender _____

Occupation _____

) Highest level of education:

_____ Less than a high school education

_____ High school diploma

_____ GED Diploma

_____ Some technical training

_____ Associates Degree

_____ Bachelors' Degree

_____ Graduate level training

_____ Graduate Degree

4) I am:

_____ Single (never married)

_____ Married

_____ Divorced

_____ Widow/Widower

_____ Separated

_____ Living with someone

5) Please indicate the ethnic group(s) to which you belong:

_____Mexican American

_____Other Hispanic/Latin ethnic group (list which one?)

_____White

_____African American

____Asian American

____Native American

____Other (please fill in)

_____

6) Do you currently have an active Facebook account?

____Yes

____No

7) Do you currently have an active Twitter account?

____Yes

____No

8) Do you search for health information on your cellphone?

___Yes

___No

10) Do you use health information apps on your phone?

___Yes

___No

1) What form of Insulin Delivery do you use (please select all that you use)?
   a. Syringe
   b. Insulin pump
   c. Insulin pump and syringe
   d. Inhalable insulin

12) How often do you test your blood sugar per day?

13) How often do you see your health care provider for your diabetes needs?

14) How many Diabetes Facebook groups are you part of?

15) What was your last Hemoglobin A1c? Date of last A1c.

16) If you use a Continuous Glucose Monitor (CGM), then
please provide the amount of time you spend in range
(directions will be provided).

Qualitative Questions (presented immediately after demographics)

1) If there was one aspect of your diabetes management that you could improve, what would it be?
2) Do you feel that the Diabetes Online Community assists you?
3) How much time do you spend in the Diabetes Online Community per week?
4) Of this time, how much of this is time spent *seeking* advice about health information?
5) Of this time, how much of this time is spent *giving* advice about health information?
6) What do you find to be the most useful parts of the Diabetes Online Community?
7) Which Diabetes Online Community T1D Facebook groups are you part of?
8) Which group is your favorite and why?
9) Please describe your experience with posting health questions on social media websites.
10) Describe what you view as pros and cons of being a member of the Diabetes Online Community.
11) How has the Diabetes Online Community impacted your physical health?
12) How has the Diabetes Online Community impacted your mental health?
13) Please describe one time when you interacted with another Diabetes Online Community member to make a treatment decision.

EXCERPTS FROM THE ADAPTED HEALTH AND ACTIVITIES QUESTIONNAIRE

2) Compared to other people your own age, how would you rate your physical health?

1 = much worse
2 = worse than average
3 = average
4 = Better than average
5 = Much better than average

3) How satisfied are you with your present health?

1 = Not at all satisfied
2 = Not very satisfied
3 = Neither satisfied nor dissatisfied
4 = Somewhat satisfied
5 = Extremely satisfied

4) How often do health problems stand in the way of your doing the things you want to do?

1 = Never
2 = Seldom
3 = Sometimes
4 = Often
5 = Extremely Satisfied

5) Do you participate in any regular form of exercise or activity (e.g., climbing stairs, walking, other forms of exercise)?

1 = Yes
2 = No

If YES, please list the activities below and the approximate number of hours per week spent engaging in each activity.

6) Do you take any other medication (prescription or nonprescription) on a regular basis (at least once a week)?

1 = Yes – Please answer question 7
2 = No – Skip to question 8

7) List all prescription and nonprescription medications you use at least once a week.

8) Please check which of the following conditions you have now or have had in the past.

Condition	In your lifetime	Now
Chronic migraine headaches		
Type 1 Diabetes		
Encephalitis of Meningitis		
Epilepsy		
Heart attack or bypass surgery		
Multiple sclerosis		
Parkinson's disease		
Rheumatoid arthritis or other autoimmune disorders		
Osteoarthritis		
Stroke		
Alzheimer's disease		
Dementia or other memory disorder		
Other significant illnesses or medical diagnoses (please list)		

9) Have you ever experienced the following comorbidities?

Condition	In your lifetime	Now
Hashimoto's		
Graves		
Celiac Disease		
Gastroparesis		
Renal Disease		
Eating Disorder		
Depression		
Anxiety		
Other significant illnesses or medical diagnoses (please list)		

10) Please list any diabetes complications that you are currently experiencing or have experienced in the past.

10) How many SURGERIES have you had in the LAST FIVE YEARS?

11) How many times have you been HOSPITALIZED in the LAST FIVE YEARS?

EHEALTH LITERACY SCALE

I would like to ask you for your opinion and about your experience using the Internet for health information. For each statement, tell me which response best reflects your opinion and experience right now. Items 1-2 have response possibilities of: 1= Not useful at all. 2 = not useful. 3= unsure. 4 = useful. 5 = very useful. Items 3-10 have response possibilities of: 1= strongly disagree, 2 – disagree, 3= undecided, 4= agree, 5= strongly agree.

1. How **useful** do you feel the Internet is in helping you in making decisions about your health?

2. How **important** is it for you to be able to access health resources on the Internet?

3. I know **what** health resources are available on the Internet

4. I know **where** to find helpful health resources on the Internet

5. I know **how** to find helpful health resources on the Internet

6. I know **how to use** the Internet to answer my questions about health

7. I know how to use **the health information** I find on the Internet to help me

8. I have the skills I need to **evaluate** the health resources I find on the Internet

9. I can tell **high quality** health resources from **low quality** health resources on the Internet

10. I feel **confident** in using information from the Internet to make health decisions

APPENDIX D

SOCIAL PROVISIONS SCALE

Next, I'm going to ask you about your relationship with other people in the DOC. Please answer with how much each statement describes your situation by using these responses. For example, if you feel a statement is VERY TRUE you would say Strongly Agree. If you feel a (4 item) statement CLEARLY does not describe your relationships, you would answer Strongly Disagree.

1. There are people I know will help me if I really need it.

2. I do not have close relationships with other people.

3. There is no one I can turn to in times of stress.

4. There are people who call on me to help them.

5. There are people who like the same social activities I do.

6. Other people do not think I am good at what I do.

7. I feel responsible for taking care of someone else.

8. I am with a group of people who think the same way I do about things.

9. I do not think that other people respect what I do.

10. If something went wrong, no one would help me.

11. I have close relationships that make me feel good.

12. I have someone to talk to about decisions in my life.

13. There are people who value my skills and abilities.

14. There is no one who has the same interests and concerns as me.

15. There is no one who needs me to take care of them.

16. I have a trustworthy person to turn to if I have problems.

17. I feel a strong emotional tie with at least one other person.

18. There is no one I can count on for help if I really need it.

19. There is no one I feel comfortable talking about problems with.

20. There are people who admire my talents and abilities.

21. I do not have a feeling of closeness with anyone.

22. There is no one who likes to do the things I do.

23. There are people I can count on in an emergency.

24. No one needs me to take care of them.

FEEDBACK QUESTIONNAIRE

Your feedback is valuable in improving this survey. This survey will be used in future studies with people in the diabetes online community. Please take some time to reflect on each question and give your feedback by answering the prompts following each question.

- How clear is the language of this question? (scale of 1=very unclear to 7 = very clear)
- How natural does this question sound? (scale of 1=vary unnatural to 7 = very natural)
- How relevant is this question? (scale of 1=very relevant to 7 = very relevant)
- How would you describe the tone of this question? (open-ended)
- Approximately how much time did it take you to answer this question? (open-ended)
- Do you get the feeling that the person who wrote this question has an accurate idea of the experience of individuals with type 1 diabetes? [Check yes or no]. Please explain why or why not. (open-ended)

Note. This last question is meant to measure cultural competence.

STUDY 1 STAKEHOLDER QUESTIONNAIRE

- How are you involved with the online type 1 diabetes community?
- Please describe your leadership roles within the type 1 diabetes online community?

Your feedback is valuable in improving this survey. This survey will be used in future studies with people in the diabetes online community. Please take some time to reflect on each question and give your feedback by answering the prompts following each question.

- How clear is the language of this question? (scale of 1=very unclear to 7=very clear)
- How natural does this question sound? (scale of 1=vary unnatural to 7=very natural)
- How relevant is this question? (scale of 1=very relevant to 7=very relevant)
- How would you describe the tone of this question? (open-ended)
- Approximately how much time did it take you to answer this question? (open-ended)
- (Cultural competence) Do you get the feeling that the person who wrote this question has an accurate idea of the experience of individuals with type 1 diabetes? Please explain why or why not. (open-ended)
- What further comments do you have?

TREATMENT ADHERENCE SCALE – ADHERENCE TO REFILLS AND MEDICATIONS SCALE – DIABETES (ARMS-D) (MAYBERRY ET AL., 2014)

In the last six months, how often have you.... Never = 1, Seldom = 2, Sometimes = 3, Often = 4, Always = 5.

 1. forget to take your diabetes medicine(s)?

2. decide not to take your diabetes medicine(s)?

3. forget to get your diabetes prescription(s) filled?

4. run out of your diabetes medicine(s)?

5. skip a dose of diabetes medicine(s) before you go to the doctor?

6. miss taking your diabetes medicine(s) when you feel better?

7. miss taking your diabetes medicine(s) when you feel sick?

8. miss taking your diabetes medicine(s) when you are careless?

9. forget to take your diabetes medicine(s) when you are supposed to take it more than once a day?

10. put off refilling your diabetes medicine(s) because they cost too much money?

11. plan ahead and refill your medicine(s) before they run out? *(reverse scored)*

APPENDIX H

DIABETES DISTRESS (T1-DDS)

Instructions

Living with type 1 diabetes can be tough. Listed below are a variety of distressing things that many people with type 1 diabetes experience. Thinking back over the past month, please indicate the degree to which each of the following may have been a problem for you by selecting the appropriate number. For example, if you feel that a particular item was not a problem for you over the past month, you would select "1". If it was very tough for you over the past month, you might select e "6". "1" = Not a problem, "2" = A slight problem, "3" = A moderate problem, "4"= A somewhat serious problem, "5" = A serious problem, and "6" A very serious problem.

1) Feeling that I am not as skilled at managing diabetes as I should be.
2) Feeling that I don't eat as carefully as I probably should.
3) Feeling that I don't notice the warning signs of hypoglycemia as well as I used to.
4) Feeling that people treat me differently when they find out I have diabetes.
5) Feeling discouraged when I see high blood glucose numbers that I can't explain.
6) Feeling that my family and friends make a bigger deal out of diabetes than they should.
7) Feeling that I can't tell my diabetes doctor what is really on my mind.
8) Feeling that I am not taking as much insulin as I should.
9) Feeling that there is too much diabetes equipment and stuff I must always have with me.
10) Feeling like I have to hide my diabetes from other people.
11) Feeling that my friends and family worry more about hypoglycemia than I want them to.
12) Feeling that I don't check my blood glucose level as often as I probably should.
13) Feeling worried that I will develop serious long-term complications, no matter how hard I try.
14) Feeling that I don't get help I really need from my diabetes doctor about managing diabetes.
15) Feeling frightened that I could have a serious hypoglycemic event when I'm asleep.
16) Feeling that thoughts about food and eating control my life.
17) Feeling that my friends or family treat me as if I were more fragile or sicker than I really am.
18) Feeling that my diabetes doctor doesn't really understand what it's like to have diabetes.
19) Feeling concerned that diabetes may make me less attractive to employers.
20) Feeling that my friends or family act like "diabetes police" (bother me too much).
21) Feeling that I've got to be perfect with my diabetes management.
22) Feeling frightened that I could have a serious hypoglycemic event while driving.
23) Feeling that my eating is out of control.
24) Feeling that people will think less of me if they knew I had diabetes.
25) Feeling that no matter how hard I try with my diabetes, it will never be good enough.
26) Feeling that my diabetes doctor doesn't know enough about diabetes and diabetes care.
27) Feeling that I can't ever be safe from the possibility of a serious hypoglycemic event.
28) Feeling that I don't give my diabetes as much attention as I probably should.

APPENDIX I

ATTITUDES REGARDING SEEKING HEALTH INFORMATION ONLINE SCALE

(STUDY 1)

The statements below concern various aspects of online health information seeking behavior. Please select a number for each statement to indicate the extent to which you agree or disagree with that statement. 1 = Disagree Strongly, 2 = Disagree a Little, 3 = Somewhat Agree, 4 = Neutral, 5 = Agree a Little, 6 = Somewhat Agree, 7 = Agree Strongly.

Factor 1: Digital Health Usage
Item 1: I frequently use the internet to answer my health questions Diabetes Online Community.
Item 2: I am critical of the health information that I find on the internet Diabetes Online Community. *(reverse coded)*
Item 3: I review multiple internet sources before making a health decision for myself Diabetes Online Community.
Item 4: I do not follow the health information that I find on social media Diabetes Online Community. *(reverse coded)*
Item 5: I trust the health information that I find on internet search engines Diabetes Online Community.

Factor 2: Self-Efficacy in evaluating Digital Health information
Item 1: I feel confident in my knowledge of the available online health resources Diabetes Online Community.
Item 2: It is difficult for me to find health information online Diabetes Online Community. *(reverse coded)*
Item 3: I feel confident in my ability to find accurate health information online Diabetes Online Community.
Item 4: When I am confronted with a health problem, I can usually find several solutions via internet search engines Diabetes Online Community.
Item 5: I trust the health information that my Facebook friends provide Diabetes Online Community.

Factor 3: Health Information on Social Media

Item 1: I share health articles on my social media site(s) Diabetes Online Community.
Item 2: I do not post items on Twitter or Facebook regarding health behaviors Diabetes Online Community. *(reverse coded)*
Item 3: I prefer to read the information that I find social media websites but do not engage in online conversation about the information Diabetes Online Community.
Diabetes Online Community. Item 5: I would prefer to search the internet for health information instead of going to a doctor's appointment Diabetes Online Community.

ATTITUDES REGARDING SEEKING HEALTH INFORMATION ONLINE SCALE

(STUDY 2)

The statements below concern various aspects of online health information seeking behavior. Please select a number for each statement to indicate the extent to which you agree or disagree with that statement. 1 = Strongly disagree, 2 = Disagree, 3 = Somewhat Disagree, 4 = Neutral, 5 = Somewhat agree, 6 = Agree, 7 = Strongly agree.

Proposed theme: <u>Truth in the information</u>

Item 1: I frequently use the internet to gain health advice in the Diabetes Online Community.

Item 2: I am critical of the health information that I find in the Diabetes Online Community. *(reverse coded)*

Item 3: I review multiple internet sources in the Diabetes Online Community before making a health decision for myself.

Item 4: I do not follow the health information that I find on social media in the Diabetes Online Community. *(reverse coded)*

Item 5: I trust the health information that I find in the Diabetes Online Community.

Item 6: I feel comfortable receiving health advice in the Diabetes Online Community.

Item 7: I trust the health information that my friends on social media (Facebook, Twitter, Instagram, discussion forums) provide in the Diabetes Online Community.

Proposed theme: <u>Self-Efficacy in evaluating Digital Health information</u>

Item 1: I feel confident in my knowledge of the available online health resources in the Diabetes Online Community.

Item 2: It is difficult for me to find health information online in the Diabetes Online Community. *(reverse coded)*

Item 3: I feel confident in my ability to find accurate health information in the Diabetes Online Community.

Item 4: When I am confronted with a health problem, I can usually find several solutions via advice in the Diabetes Online Community.

Item 5: I prefer to get advice about medical devices (insulin pumps and CGMs) from the Diabetes Online Community instead of my doctor.

Item 6: When trying to understand my symptoms, my first resource is social media in the Diabetes Online Community.

Item 7: I would prefer to search the internet for health information in the Diabetes Online Community instead of going to a doctor's appointment.

Proposed theme: <u>Health Information and Health Advice on Social Media</u>

Item 1: I share health articles on my social media account (s) in the Diabetes Online Community.

Item 2: I do not post health related items on social media (Facebook, Twitter, Instagram and/or discussion forums) in the Diabetes Online Community. *(reverse coded)*

Item 3: I prefer to read the health information that I find on social media websites but not engage in online conversation about the health information in the Diabetes Online Community. *(reverse coded)*

Item 4: I feel comfortable providing advice to others in the Diabetes Online Community.

Item 5: I find myself giving advice more than receiving advice in the Diabetes Online Community.

Allyson S. Hughes
Health Psychology

Allyson Sue Hughes was born in Lima, Ohio. She worked at UTEP with Dr. Ashley Bangert as a grant funded research assistant during undergrad and graduated with her Bachelor's of Science in Psychology in August 2012. She graduated with a Master's of Arts in Clinical Psychology at UTEP.

Dr. Hughes was the recipient of a UTEP Graduate School Dodson Research Grant. She worked with Dr. Osvaldo Morera as a grant funded research assistant on the BUILDing SCHOLARS grant from Summer 2015 to Spring 2018. She has conducted over 30 poster and panel presentations for conferences held by the National Hispanic Science Network, the Society of Behavioral Medicine (SBM), the American Psychological Association (APA) and the Society for Prevention Research (SPR).

Dr. Hughes was awarded a presidential citation from the American Psychological Association in 2016. She was also awarded the National Award of Excellence in Research by a Student by the National Hispanic Science Network in 2016.

Dr. Hughes's dissertation, "Seeking Health Information in the Diabetes Online Community (DOC); the Role of Health Literacy, Social Support and Community Interaction on Treatment Adherence" was supervised by Dr. Osvaldo Morera. She is currently a Research Scientist at the T1D Exchange, a nonprofit that aims to improve and inform type 1 diabetes product development with a patient centered perspective.

Contact Information: ahughes@t1dexchange.org