SUPPORTING PEOPLE WITH DIABETES:
THE ROLES OF HEALTH LITERACY AND COMMUNICATION OF SUPPORT

by

GRACE ELLEN BRANNON

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Abstract

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Grace Brannon, MA

The University of Texas at Arlington, 2014

Supervising Professor: Charla Markham Shaw

In the U.S., the number of people with diabetes is estimated to surpass 330 million by 2030. Previous research has focused on the direct link between communication and a person's overall health. Strong patient-provider interaction, medical education through community events and outreach, and stable support systems within family and friends can improve a person's awareness which leads to an increased health literacy level and better well-being. The health literacy level of an individual has been shown to have a direct impact on a person's overall health. Social support and corresponding communication have also been shown as vital. This study used a mixed-methods survey to examine how diabetes health literacy levels impact the communication of support to a person with diabetes. The hypothesis was supported, showing a relationship between interaction with a person with diabetes and an increased diabetes health literacy level. This study is the first to examine how support is communicated to a person with diabetes while also examining the role of health literacy. Recommendations for future research based on the findings are offered in an effort to examine the importance of types of support and levels of diabetes health literacy.

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Chapter 1

Introduction

Many studies have been done, primarily in the last decade, which demonstrate a direct link between communication and a person's overall health (Mahmud, Olander, & Haglund, 2013). Studies have shown that strong patient-provider interaction (Ishikawa & Yano, 2011), medical education through community events and outreach (Riesch et al., 2013), and stable support systems within family and friends (Quinn et al., 2014) can improve a person's awareness and, through that, an increased health literacy level leading to better well-being. The health literacy level of an individual has been shown to have a direct impact on a person's overall health, as well as health experience (Eadie, 2014). Social support and corresponding communication have also been shown as important to those diagnosed with a particular illness (Kennedy, Kiecolt-Glaser, & Glaser, 1991; Hobfall & Stephens, 1990; McGrew, 2008). The different approaches (Albrecht, Burleson, & Goldsmith, 1994) and varying types of support (High & Steuber, 2014) have been studied extensively as well. While most studies focus on the person with a disease and how social support impacts that person, it is important to focus on those close to the person with the disease as they may be a source of support. The primary purpose of this study is to examine the role of diabetes health literacy and how support is communicated to people with diabetes by those close to them.

Diabetes

According to the Centers for Disease Control and Prevention (CDC, 2014), diabetes is a chronic disease affecting people of varying ages, races, and gender, and is currently the seventh leading cause of death in the United States of America. Diabetes is caused by resistance, either partially or completely, to insulin which aids in the breakdown of glucose. When the body doesn't make enough insulin, or doesn't make any at all, glucose (blood sugars) is built up and can cause serious complications. Common difficulties include eyesight failure and blindness, periodontal disease, nervous system disease, kidney failure, amputations, hypertension, increased risk of heart disease, as well as an increased susceptibility to illnesses and death. In fact, according to the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK, 2014), people with diabetes are more than twice as likely to have a stroke or heart disease as those without diabetes, and typically do not have the usual symptoms of a heart attack.

In 2005, approximately 14.6 million adults in the United States had been diagnosed with diabetes, with another 6 million undiagnosed (McGrew, 2008). As of 2011, the numbers have grown to 18.8 million diagnosed and approximately 7 million undiagnosed; this is 8.3% of the entire population of the United States (NIDDK, 2011). It was estimated in 2010 that only 215,000 of these diagnosed were children. The number of people with diabetes is estimated to surpass 330 million by 2030 (Wild, Roglic, Green, Sicree, & King, 2004). The primary forms of diabetes mellitus are type 1 (T1DM), type 2 (T2DM), and gestational diabetes.

T1DM is “an autoimmune disease that results when the body’s immune system destroys the beta cells in the pancreas that produce insulin” (McGrew, 2008, p. 10), and there are currently no known preventions for the disease. According to the CDC, only approximately 5% of all diagnosed cases of diabetes are type 1. Symptoms are usually mitigated by physical activity and healthy eating, as well as frequent blood glucose testing and monitoring and multiple shots of insulin or utilizing insulin pump therapy each day. Without the injections or pump therapy, T1DM would not be survivable. Because type 1 typically occurs in children, and was at one point nicknamed “juvenile-onset” diabetes, it is considered to be “one of the most common severe chronic diseases of childhood” (Bennett, Rewers & Knowler, 2003) as there are no known cures. Risk factors “may be autoimmune, genetic, or environmental” (NIDDK, 2011), but no specific reasons are currently known.

T2DM, which accounts for approximately 90-95% of all diagnosed cases of diabetes (CDC, 2014), occurs when the body either doesn’t produce enough insulin or the body becomes insulin-resistant. Physical activity, healthy eating, and a combination of oral medication and insulin shots are the rudimentary coping methods of T2DM, but blood glucose testing is generally required as well. In some cases, the diabetes symptoms lessen, or disappear entirely. While the majority of diagnosed cases are in adults, children are increasingly being diagnosed with type 2. A person may be more likely to contract T2DM if they are of an older age, obese, physically inactive, of particular race/ethnicity, have a family history of diabetes, and/or have a history of gestational diabetes. Lifestyle interventions of increased physical activity and weight loss have been shown to reduce development of type 2 diabetes by 58-71% over a three year period (NIDDK, 2011).

Gestational diabetes, developed solely by pregnant women, is carefully monitored with blood glucose testing and a specific diet plan. Usually, gestational diabetes disappears after the baby is born. All women have some level of insulin resistance during the later stages of pregnancy, but only if the pancreas does not produce enough insulin does a woman actually develop gestational diabetes (NIDDK, 2014).

In 2005, diabetes was the sixth leading cause of death in the United States, and is currently the seventh leading cause of death. However, the National Institute of Diabetes and Digestive and Kidney Diseases [NIDDK] noted that studies have shown that diabetes is underreported as a cause of death. The NIDDK also noted that the risk of death for a person with diabetes is approximately twice that of a person who does not have diabetes. For many people with diabetes, depression and stress go hand in hand with their diagnosis, as the disease is quite involved (Robertson, et al., 2013); men with diabetes are far more likely to be depressed than a man or women without diabetes, and women with diabetes are more likely to experience anxiety than a man or woman without diabetes.

Self-management of the chronic illness is the primary method of reducing negative symptoms in all types of diabetes. The management of diabetes is tied to self-efficacy, regardless of whether the self-efficacy refers to the person with diabetes and self-management or a parent/caretaker in the management of a young child's diabetes (Marchante, et al., 2014). The term "person with diabetes" originated from Rubin and Peyrot's (2001) study. Self-efficacy, a concept developed by Bandura (1995), is "the belief in one's capabilities to organize and execute the courses of action required to manage prospective situations" (p. 2), and as the "confidence to perform diabetes-specific self-management tasks within the constraints of one's daily life" in the world of diabetes (Robertson, Amspoker, Cully, Ross, & Naik, 2013, p. 189). Self-efficacy is important when studying diabetes, as the majority of the tasks for the care of one's diabetes are performed by the person diagnosed. The self-management tasks include taking prescribed medications (oral or insulin shots), maintaining a level of physical activity, having specific meal plans, extensively monitoring glucose, and regular doctor and specialist appointments. Generally, a diagnosed person with diabetes visits several doctors and specialists annually, including an endocrinologist (a specialist in diabetes care), an optometrist (specialist in eye care), and a dietitian (NIDDK, 2014). While it is generally impossible to achieve "normal" blood glucose rates after being diagnosed with diabetes (McGrew, 2008), by confidently self-managing the disease, diabetes is no longer a death sentence.

Literature Review

Health Literacy

According to Nutbeam (2000), who was quoted by the World Health Organization (WHO), health literacy is defined as “the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health” (p. 263). According to Nielsen-Bohlman, Panzer, and Kindig, (2004), health literacy is defined as ““the degree to which individuals have the ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (p. 2). Health literacy goes beyond understanding what the disease is or how to schedule a doctor’s appointment. It infers that someone who is health literate is capable of making decisions. Access to information, and the ability to utilize this information, is paramount to a high level of health literacy. The Institute of Medicine (IoM) has defined health literacy as “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” (Baker, 2006). Nutbeam (2009) developed a model of health literacy that focuses on three particular components: functional literacy, interactive health literacy, and critical health literacy. Each of the three components of health literacy have corresponding goals; functional health literacy -- to understand health risks; interactive health literacy – to gain knowledge, motivation and self-confidence; and critical health literacy -- to empower oneself (Eadie, 2014).

Previous studies outline how important health literacy is to both health/research communities and to the patient (Fransen, von Wagner & Essink-Bot, 2012; Riesch et al., 2013). The concept of health literacy is very closely tied with communication. According to Oldfield (2005), there are four skill sets that are associated with health literacy:

reading, comprehension, numeracy, and communication. Of the four, communication is the most important: “reading, writing, speaking, and listening encompass *communication skills,* which are valuable and necessary tools to understand information” (Eadie, 2014, p. 11). Without effective communication of information between patient and caretaker, or patient and friend, or any number of other scenarios, health literacy would decline.

The communication between a health care provider and patient is particularly important to those with a chronic illness, such as diabetes. According to Gutierrez (2013), “research has shown that shared decision making between providers and patients can improve patient outcomes, particularly among patients with chronic diseases” (p. 83). When the “collaborative communication exchange” (p. 83) is limited or impeded by factors such as low health literacy, the patient suffers.

According to Vosbergen, Peek, Mulder-Wiggers, Kemps, Kraaijenhagen, Jaspers, and Lacroix (2014), one of the most pressing problems of a chronic illness, be it diabetes or another, is that those diagnosed must “adapt their lives to the limitations imposed by their illness, make changes to their lifestyle behavior, and follow a medication regimen” (p. 631). These extensive changes can only be accomplished by increased knowledge and intensive self-management (Coffman, Norton & Beene, 2012; Robertson, Amspoker, Cully, Ross, & Naik, 2013) and are tied to health literacy because of this. Coffman, Norton, and Beene (2012) noted that health care use can be predicted by adequate health literacy levels, which “presumably leads to better diabetes management and improved diabetes control” (p. 8).

Many tools have been developed in recent years to assess health literacy. Typically, people are considered as either high in health literacy or low, but the National Assessment for Adult Literacy (NAAL) divides people into four categories: below basic, basic, intermediate, and proficient (Kutner, Greenberg, Jin, & Paulsen, 2006). The most commonly utilized tools to screen people and divide them into the levels are the Rapid Estimate of Adult Literacy in Medicine [REALM] and the Test of Functional Health Literacy [TOFHLA]. Others, predominantly the National Assessment of Adult Literacy survey [NAAL], the Health Literacy Management Scale [HeLMS], and the Health Literacy Questionnaire [HLQ] provide a focused look at the varying dimensions of health literacy and the relationships between health literacy and differing social factors (Sørensen, et al., 2013). While the Diabetes Knowledge Test, developed by the Michigan Diabetes Research Training Center (1998), does not test for overall health literacy, it is a short multiple-choice test that assesses a person's knowledge of the chronic illness. Finally, the Diabetes Social Support Questionnaire (La Greca & Bearman, 1995; 2002) focuses on the diabetes-specific support measures offered by family and friends and how the person with diabetes is affected. Because the support message is based on the knowledge someone supporting a person with diabetes has, it is important to identify the health information sources used.

Health Information Sources

Zhang (2014) stated, "Information sources are containers or carriers of information" and can take on many different forms. Since the first step of information seeking is often selecting a source (Zhang, 2014), the source you choose will have an effect on the type of information found, along with the quality and accuracy of the information. Since health information can be found from many different sources, including interpersonal and media, it is plausible to assume that a person typically selects a source with which they are most comfortable. This preference is usually attributed to certain demographic factors, including age and income (Case, Johnson, Andrews, Allard, & Kelly, 2004) and ethnicity (Cline & Haynes, 2001).

Because there are many different ways a person can obtain health information, it is possible that information given by different sources will conflict. This was shown to be especially true for those who visit specialists while also visiting their primary care doctors (Carpenter, Elstad, Blalock, & DeVellis, 2014). Since people diagnosed with diabetes are considered high-risk for many complications, they are typically required to visit several specialists every year. This increase of sources providing information gives the possibility of a higher rate of conflicting information.

A national study conducted on health information sources related to preventative health behaviors found that the primary types of health information sources, excluding medical professionals, were divided into two categories. The first, mass media, was comprised of print, television, and Internet sources. The second, interpersonal and social network, was comprised of Internet, family/friends, and organizational community sources (for example, hospital informational events) (Redmond, Baer, Clark, Lipsitz, & Hicks, 2010). The inclusion of Internet as a part of an interpersonal network is relatively new. Before Web 2.0's introduction, and the possibility of synchronous communication with those who are considered close, the Internet would only have been considered mass media.

Internet Sources

The Pew Research Internet Project (2014) surveyed over three thousand people in September 2012 and estimated that 72% of all Internet users looked for health information online in the past year. They found that for technical health-related questions, a patient was more likely to seek out a professional source, but when a patient had questions related to coping techniques or quick relief, he/she would seek assistance from a non-professional source. The survey also estimated that while 70% of adults in the United States received information, care, or support from health care professionals, 60%

of adults sought information and/or support from friends and family. More than 75%of the people searching for health information started with a search engine (Google, Yahoo!, Bing), while 13% started with a specialized website like WebMD. A combined 3% stated they started research at general informational sites (Wikipedia) or social networking sites (Facebook). This has been a fairly new change, as the Internet is a relatively recent addition to our everyday lives. According to Lee, Hoti, Hughes, and Emmerton (2014), it is “unrealistic, in terms of the health professional’s time and ability… to expect consumers to rely entirely on written and verbal information provided by their regular practitioner(s)” (p. 1).

In a survey taken solely by college students, it was found that “most social media platforms were used as information sources” (Kim, Sin, & Tsui, 2014, p. 175), and that age was a factor in the increased use of social media platforms as well as usage of wiki sites as information sources. While the specific information sought varied dependent upon the different social media platforms, “media-sharing and social Q&A sites were used mainly for finding solutions” (p. 176). The study did not specifically look at health information and related sources, however a large part of the reasoning behind selecting the Internet as a primary source is that of anonymity, particularly when researching information on “delicate” (Zhang, 2014, p. 912) topics like “sexually transmitted diseases, pregnancy, [and] weight loss” (p. 912). While some social stigma surrounding these topics has seemed to disappear to a degree, many people would rather remain anonymous than seek information from an interpersonal source.

Hu and Sundar (2010) found that “online health seekers are quite satisfied with the Internet as a health information source” (p. 106). Machiko, Miyako, and Ichiro (2013) noted that the Internet is “frequently used to acquire health-related information” (p. 41) and that patients can, and may, use the information acquired from the Internet to learn how to care for themselves. The researchers then tied the use of the Internet for health-related information to the three levels of Nutbeam’s (2009) model of health literacy. The levels of health literacy, which were theorized by Nutbeam (2009), are similar to Bloom’s (1956) cognitive processes. Functional health literacy, similar to Bloom’s level of knowledge, is achieved from “reading and [the] exchange of information on the web,” communicative health literacy, akin to Bloom’s level of application, is achieved through “gathering information and applying the information to self-care” and critical health literacy, like Bloom’s level of analysis, is achieved through “critically analyzing the information” (p. 41). Through their study, they found that a patient’s communication with his/her physician was positively related to the understanding of the illness of diabetes and increased self-efficacy related to self-management of diabetes with findings related to the communicative and critical levels as most significant. The researchers also found that the communication between patients and their physicians was associated with a stronger sense of self-efficacy and health literacy than when a patient used the Internet to find information.

Smith (2011) found that younger adults (18-29) with both higher educations and incomes were more likely than any other population to trust the Internet when searching for health-related information, and that “even as trust in physicians remained steady and trust in the Internet decreased, the use of the Internet as a first stop for respondents seeking information rose over time” (p.200). Smith also cited a 2010 Pew Internet Project report examining adults diagnosed with chronic diseases, stating that 86% of adults ask a health professional, 68% ask a friend or family member, 57% use the Internet, 54% use books or other printed reference material, 33% contact their insurance provider, and 5% use another source. The report did not differentiate between health and non-health professional Internet sources or health and non-health professional books or printed references materials.

Source Credibility

Of course, depending upon the type of health information requested, the chosen sources could vary. One characteristic of information sources is source credibility. Bates, Romina, Ahmed, and Hopson (2006) defined source credibility as being trustworthy, truthful, readable, and complete. Rieh (2009) describes credibility as "people's assessment of whether information is trustworthy based on their own expertise and knowledge" (p. 1338). Hu and Sundar (2010) noted that perceived source expertise and perceived source homophily were also important. Source homophily describes the similarities between the sender and receiver, creating a stronger sense of identification within the communication process. They further commented that the Internet uses “both layperson and professional sources” (p. 113), and the weight given to utilize the health information acquired depend, at times, on the type of source.

It is not surprising when a study shows that among those with a chronic illness like diabetes there are several ways to acquire health information from various sources. Longo, Schubert, Wright, LeMaster, Williams and Clore (2010) found that, within their nine focus groups conducted, the primary ways of obtaining health information came from different sources depending on the person and the need. They noted that “this diversity reflects the nature of diabetes, which touches all aspects of daily living, including relationships with family and friends, medications, cooking and portion control, exercise, and food shopping” (p. 335). Because there are several reasons why one might look for health information, including needs for support or information, it is important to examine the diversity of reasons why a person with diabetes, or a person supporting a person with diabetes, might choose a source for health-related information.

Diabetes and Health Literacy

According to Coffman, Norton, and Beene (2012), the lower the health literacy level of an individual with diabetes, the lower the knowledge the person has on diabetes. Nilsson, Johahsson, and Sundquist (1998) found that a person with diabetes who was less educated on his/her illness had 40% higher mortality when compared to a person with diabetes with more education on the illness. Increased knowledge of the disease would affect both her diabetes health literacy and overall health literacy positively. Without having adequate information, one cannot dose medicine (oral or injection) correctly, compose meal plans, or exercise plans. A healthy, livable lifestyle is out of the question for people with diabetes without certain fundamental knowledge of the illness. Increased complications (Schillinger et al., 2003) and a lack of blood glucose control (Schillinger et al., 2002) are also negative effects of having low diabetes health literacy. Coffman, Norton, and Beene (2012) noted that health care use can be predicted by adequate health literacy levels, which "presumably leads to better diabetes management and improved diabetes control" (p. 8).

Given the research focused on health literacy and diabetes health literacy, which indicates that having a higher diabetes health literacy level positively impacts diabetes management, it makes sense that a person who is close to a person with diabetes would have a higher diabetes health literacy level when compared to a person who is not close to a person with diabetes. The lack of research focusing on the importance of someone supporting a person with diabetes is cause for examination. The following hypothesis is proposed.

H1 – Those who have a close friend or family member diagnosed with diabetes will have a higher diabetes health literacy level than those without a close friend or family member diagnosed with diabetes.

Supportive Communication

Social support is an integral part of communication between humans. Previous studies show a positive link, both directly and indirectly, between supportive acts and a person's health (Kennedy, Kiecolt-Glaser, & Glaser, 1991; Hobfall & Stephens, 1990), increased life expectancy, quicker recovery from illnesses, alleviated distress, (Albrecht, Burleson, & Goldsmith, 1994), and positively influenced self-perception, which includes "feelings of control, self-efficacy, esteem, relational closeness, and life satisfaction" (High & Steuber, 2014, p. 157). Particularly, friends and family have an important and useful role in combating stressful experiences for those close to them (Felmlee, 2001). Medical resources, such as a doctor, a nurse, or a support group, also provide a form of social support (Cacciatore, Schnebly, & Froen, 2009).

Of course, as cultures differ, the values and processes involved in social support differ as well. Previously, Albrecht, Burleson, and Goldsmith (1994) studied social support as a part of the American culture, noting that there have been few studies examining other culture's social support networks. Feng (2014) examined the roles of advice (informational support) and emotional support in two different cultures: American and Chinese. Feng differentiated the two cultures by noting the American culture as individualistic and the Chinese culture as collectivistic. The research found that "people across cultures have similar emotional needs when coping with stressful situations" (p. 925) but also found that "demographic factors such as nationality affect support processes by influencing underlying psychological states such as beliefs and value orientations" (p. 926) which differ from culture to culture. The present study will focus solely on the society of the United States.

Over the last several decades, the concept of social support has changed from "the individual's perception of acceptance and caring" (p. 420) to add in the concept of communication and related “notions” (p. 421) including feedback, the actual interpersonal transactions, the relationship between the sender and receiver, and the utilization of the message. While a basic understanding of communication is that of a sender sending a message to a receiver (Ruxton & Schaefer, 2011), Albrecht, Burleson, and Goldsmith (1994) further defined communication as “a transactional, symbolic process of mutual influence embedded within relationships and social networks” (p. 421). The working definition of supportive communication, based upon Albrecht and Adelman’s study in 1987, is “verbal and nonverbal behavior that influences how providers and recipients view themselves, their situations, the other, and their relationship” (p. 421). This is later refined by Burleson and MacGeorge (2002) as “verbal and nonverbal behavior produced with the intention of providing assistance to others perceived as needing that aid” (p. 374), which clarifies the intention and perceptions related to the aid given itself or the actual act of support. According to Lakey, Drew, and Sirl (1999), the perceptions of the aid received is what makes social support measurable.

The three approaches to the study of social support outlined by Albrecht, Burleson, and Goldsmith (1994) consist of social network approaches, perceptual approaches, and interaction approaches. The first, social network approaches, focus primarily on the communication networks that exist, usually reported by the individual as having a particular tie to another person. The second, perceptual approaches, focus on the feeling or sense of support, which, while subjective, focuses on “how supportive ties affect people’s lives” (p. 423). The third approach, interaction, will be the one examined in the present study, and looks at the communication processes used when support is requested by the person with diabetes. In addition to the approaches to studying social support, there are multiple dimensions of social support structure, many types of support, and several functions of support.

Lee, Arozullah, and Cho (2004) stated that “positive resources and support in individuals’ social networks can improve their ability to acquire and understand medical information and to negotiate the health care system” (p. 1314). Two dimensions of social support exist. Structural social support is defined by how actively involved a person is in her community or how active she is within her social networks, as well as how she keeps in contact with others. Functional social support will be the focus of this particular study, and includes “communication and transaction activities that serve a variety of emotional, informational, and tangible needs, all of which link to notions of information, uncertainty reduction, and personal control” (p. 1315).

The types of support, adapted from Xu and Burleson (2001) by High and Steuber (2014), include informational, emotional, esteem, network, and tangible. Informational support generally provides information about the problem, with a focus on “factual information or advice about a problem” (p. 161) while emotional support provides both sympathy and empathy. Emotional support also focuses on expressing love or care for the person being supported, as well as when the person needing support is encouraged to “express their feelings” (p. 161). Esteem support focuses on increasing one’s self-perception or self-worth, and network support “involves expanding people’s social resources” (p. 161), typically done in common social settings and through various activities. Finally, tangible support is the provision of tangible aid, usually goods, money, or physical help. Of the five, Cutrona and Suhr (1992) found informational and emotional to be the most sought after forms of support, particularly by family members or romantic partners when in a time of stress. Burleson (2003) stated that emotional support was conceptualized as having “expressions of care, concern, affection, and interest, especially during times of stress or upset” (p. 552), and also noted that the relational factor of how close a person is to another greatly affects the level of emotional support that is received. According to Cutrona and Suhr (1992), informational and emotional support are the most wanted types of support.

Given the focus of previous research on the diabetes health literacy level of a person with diabetes, this study has instead chosen to focus on a person close to a person with diabetes and the supporter's diabetes health literacy level. This is because research has shown that the support from a friend or family member directly impacts the person with diabetes and can impact how the person with diabetes manages her disease. An increased level of the supporter's diabetes health literacy should indicate a better knowledge of the illness and, thus, better support. While a scale will not be utilized for this study to directly measure closeness, it will be operationalized by the frequency of interaction between the person with diabetes and the person supporting a person with diabetes. The potential of someone's diabetes health literacy level may impact the type of support given, as well as the ability to effectively communicate the type of support. This, combined with the types of support, leads to the first research question of the study.

RQ1 – Does the diabetes health literacy level of someone close to a person with diabetes affect the type of health-related supportive message communicated by that person to a person with diabetes?

According to Knapp and Miller (1994) different communicative acts lend themselves to varying levels of support. For example, the act of giving information solely to provide information that is needed is in itself supportive. In these particular cases, "communicative acts do not `convey' support; rather, they are acts of support" (p. 426). Other types of communication may be used when emotional support is needed or wanted, which conveys the feeling of support.

Lee, et al. (2004) noted that "positive resources and support in one's social networks might buffer and alleviate the adverse health consequences of low health literacy" (p. 1316) and that alternatives to current intervention programs to increase health literacy would be more beneficial to the patients by drawing on social support if family members were to be educated along with the patient. So, it would not be a stretch to assume a friend or family member would be able to provide more functional social support to the patient if he/she has a solid foundation of accurate, correct information and a basic level of health literacy. McGrew (2008) agreed, stating that "supportive processes are conceptualized as activities with functional, tangible intentions such as providing assistance, giving advice or reducing emotional distress" (p. 41).

Given the research focusing on health information sources and the research on the types of support, two research questions related to types of support and health information sources are asked. Research has indicated an increase in the usage of the Internet as a health informational source, and has indicated that a person who utilizes accurate information from credible sources is more likely to provide social support to a person with diabetes. The first, RQ2a, focuses on health professional information sources.

RQ2a – What types of support messages are used by those who employ health professional information sources?

The second, RQ2b, focuses on non-health professional sources.

RQ2b – What types of support messages are used by those who employ non-health professional information sources?

Diabetes and Social Support

In diabetes-specific contexts, a psychosocial resource "has consistent associations with better physical and mental health, throughout a range of populations" (Baek, Tanenbaum, & Gonzalez, 2014, p. 146). Distress related to diabetes complications, as well as depression, are considered a "diabetes-related burden" by

Baek, Tanenbaum, and Gonzalez (2014). While not utilizing High and Steuber's five types of support, Baek, Tanenbaum and Gonzalez (2014) cite several studies that show that increased social support of a patient with diabetes lessens their emotional distress and is typically tied with better adjustment in different areas of life (Bukberg, Penman, & Holland, 1984; Hann, Oxman, Ahles, Furstenberg, & Stake, 1995; Serovich, Kimberly, Mosack, & Lewis, 2001; Trunzo & Pinto, 2003). Since supportive behaviors from family have been significantly related to lower diabetes distress (Karlsen, Oftedal, & Bru, 2011), it is important to further examine the roles of a supportive person in the life of a person with diabetes.

Another example of the need for social support, particularly in a person with diabetes, is when examining mental illnesses. Eating disorders, which are classified as a mental illness, are altogether too common in adolescents. While up to 24 million people in the United States of all ages and genders suffer from an eating disorder (The Renfrew Center Foundation for Eating Disorders, 2003), 86% of people surveyed reported onset of eating disorder by the age of 20 years (National Association of Anorexia Nervosa and Associated Disorders, 2000). When an adolescent with diabetes has an eating disorder, however, complications quickly arise, especially in type 1 patients. An article by Davidson (2014) identified one such disorder as diabulimia, where a person with diabetes purposely does not give his/herself adequate insulin so they can lose weight. Like in all eating disorders, it is important to have a sense of support or "warm and trusting relationships" (Kaap-Deeder, Vansteenkiste, Soenens, Verstuyf, Boone, & Smets, 2014) in order to rehabilitate effectively. Davidson (2014) stressed that it was "important to support the individual in a multidisciplinary context" (p. 47).

According to a study conducted by de Vries, van der Heijden, van 't Riet, Baan, Kostense, Rijken, Rutten, and Nijpels (2014), social support via peers is a form of motivation, as well as a stress-reliever. Another study, by Malik and Koot (2012) noted that peer support through friends provided an “alternative to the authoritative and supervisory style” (p. 238) of a parent’s support. Using the DSSQ – Friends version of the survey developed by La Greca (1995; 2002), they also found that a person with diabetes felt more independent when describing interactions with her friends compared to her parents or other supervisory figures. One difference was that a person with diabetes’ friends reminded her of medication rather than telling, and the friends talked about the illness compared to how the parents talked at the person with diabetes. Karlsen and Bru (2014) also noted that “documented positive relationships between social support and diabetes-related health” (p. 440) are becoming much more prevalent and significant as empirical research is conducted. In fact, they proposed that a person with diabetes must have support in order to “maintain and sustain self-management activities in order to live well” with diabetes (p. 440.) While familial support towards a person with diabetes is considered “vital” (p. 441), professional support is a deciding factor as well (Thorne & Paterson, 2001).

Every person’s diabetes can be different from the next, and not only because of the type. Indicators of hyperglycemic or hypoglycemic events can differ from person to person, making it difficult for the person with diabetes to learn to care for herself after the initial diagnosis. Further, this complicates personal interactions with those who may be unfamiliar with a particular type of diabetes or certain reactions. Perhaps an individual knows a person with diabetes in elementary school, and is involved enough in his life to know his signs of hyperglycemia and hypoglycemia. However, the individual has another friend with diabetes. The second person with diabetes could very well be experiencing those same hyperglycemic and hypoglycemic symptoms as the first person with diabetes and have lessened or even nonexistent symptoms, making it difficult for the individual to support her physically. Because physical support is not the only type, however, it is beneficial to uncover other methods of support. It is also important to examine how the messages relating to social support are processed.

Elaboration Likelihood Model

The Elaboration Likelihood Model, formulated by Petty and Cacioppo (1986), has provided a theoretical framework for prior health literacy research (Ahn, Park, & Haley, 2014) and will be a theory guiding this study. While central processing is supposed to be the primary method of absorbing information to retain for long periods of time, many patients often use peripheral processing centered in external cues based on heuristic evaluation, which often include the source's attractiveness or the quantity of information presented (Weber, Westcott-Baker, & Anderson, 2013), thus possibly having an effect on patients' levels of health literacy. For example, a patient could focus only on the physical attributes of his/her physician (an external cue) rather than listening intently to the content being communicated. While the patient may be able to retain part of the information, the distracted nature of the patient could affect both how well he/she recalls the information and how long he/she is able to recall the information. The message, or informational content, is typically centrally processed (Miniard, Dickson, & Lord, 1988). Interestingly, the source's credibility has been evaluated as being both a central cue (Miniard, Dickson & Lord, 1988) and a peripheral cue (Li, 2014).

Central processing is characterized by a "great deal of mental effort weighing and evaluating the information" (Chmielewski, 2012, p. 35) before making a particular decision or taking an action. Only through careful evaluation (Perloff, 2003) of the messages or arguments will a message be processed. Based on Petty and Cacioppo's model, Chmielewski (2012) noted that "central route processing occurs when an individual has both the motivation and ability to think about the message and the issues involved"(p. 35) and thus makes a decision. Petty and Cacioppo (1979) defined motivation as how much one wanted to process a message, while ability is defined as if the person can actually analyze the message critically (Chmielewski, 2012). Ability is tied to health literacy, particular as it is quite beneficial for a person to have certain capabilities, which could include reading prescription labels, scheduling doctor appointments, traveling to the doctor appointments, taking prescribed medication, etc. Without having the abilities to do the above, it is likely that the person would not have a high health literacy level.

Chmielweski's (2012) study on political involvement and the Elaboration Likelihood Model was based on the premise that defined involvement as a "person's participation in various activities that reflect cognitive and behavioral participation in the election" (p. 36). Likewise, involvement in the present study would be based upon the person's participation in various activities of support that reflects cognitive and behavioral participation in the person with diabetes' life. Because of this, involvement in a topic would be considered a central cue. The closer someone is with a person diagnosed with diabetes, the more likely she would be involved in that person's life and, perhaps, the more likely she would be to process information related to that as a central cue. Not showing support would be an example of lack of involvement.

According to Mittler, Martsolf, Telenko, and Scanlon (2013), engagement is another term used to show involvement, but implies a sense of further accomplishment and, thus, further elaboration. They defined engagement as more than the participation linked to involvement, specifically notating the "the individual's capacity and commitment to taking an active role in his/her own health and health care" (p. 44) as well as "perceived as being more emotionally invested and dedicated to taking charge of their health" (p. 44). They stated the term "patient activation" was "synonymous" (p. 45) with the term “engagement” and noted that a person’s knowledge and feelings towards their role in their personal health care, among others, dramatically affected the level of engagement. Because engagement and involvement are important aspects of how a person processes information, it is important to examine them as a part of the Elaboration Likelihood Model.

Because a person with a higher diabetes health literacy level would be more knowledgeable of the disease, the more likely it is that he or she processes centrally, as information content is typically processed centrally. Further, a health-related message, especially if relevant to a person who is close to a person with diabetes, would be more likely to be processed centrally because of the person who is close to the person with diabetes’ involvement in his/her life. A higher diabetes health literacy level should be indicative of more centrally processed health-related messages.

The Elaboration Likelihood Model indicates that if a person close to a person with diabetes can understand something, he/she is more likely to elaborate, so he/she would be more likely to offer a type of supportive communication. This study will focus on the usage of the Elaboration Likelihood Model on those close to a person with diabetes, rather than the prior research utilizing the Elaboration Likelihood Model in health communication focused on the person diagnosed with diabetes.

Given the previous research focused on the Elaboration Likelihood Model and health literacy, and previous research linking both health literacy and diabetes health literacy and social support, research needs to focus on the communication between the person sending the supportive message and the person with diabetes. In particular, research needs to focus on how supporters communicate knowledge and support to people with diabetes in their lives.

As a restatement of the hypothesis and each of the research questions, all are listed below.

Hypothesis and Research Questions

H1: Those who have a close friend or family member diagnosed with diabetes will have a higher diabetes health literacy level than those without a close friend or family member diagnosed with diabetes.

RQ1 – Does the diabetes health literacy level of someone close to a person with diabetes affect the type of health-related supportive message communicated by that person to a person with diabetes?

RQ2a – What types of support messages are used by those who employ health professional information sources?

RQ2b – What types of support messages are used by those who employ non-health professional information sources?

Chapter 2

Methods

After obtaining IRB approval, a purposive sample consisting of 212 students at a large southern university was utilized. Participants were required to be over eighteen years of age, but were not required to have a close friend or family member who was diagnosed with diabetes. Incentives included a drawing for a debit gift card and extra credit. Recruitment began after receiving approval from the university's Institutional Review Board for human subjects research. The study was announced through face-to-face and electronic forms of communication in classrooms of the Department of Communication. Participating professors announced the opportunity to take part in the research study in their courses, and then the researcher posted a link to the university's e-learning site that allowed students to sign-up for a specific date and time slot in a reserved computer lab on campus.

Participants

The final sample consisted of 212 participants. While 213 individuals completed the survey, one of the survey responses was discarded when the participant entered a year of birth that indicated that the participant was under eighteen years of age. The majority of participants, 134, were female (63.2%), and 78 participants were male (36.8%). Ages ranged from 18 years old to 56 years old, with the average participant being 23 years old. Six participants did not enter a numerical value for their age, but signed an informed consent form that stated they were at least eighteen years of age. The majority of participants self-identified as Caucasian (26.4%) or Hispanic (26.4%) and were followed in frequency by African-Americans (24.5%), Asians (14.6%), and Other (7.9%). Most of the participants reported their highest level of education as some college (54.7%), while others reported an associate's degree (28.8%) or a bachelor's degree

(7.5%). Only a slightly larger percentage (9%) reported high school as their highest level of education.

Of the 212 participants, 95 (44.8%) indicated that they were close to someone with diabetes and with whom they interacted with on a regular basis (at least once a week). Table A.1 shows the following: of the 95 individuals, 42 (44.2%) indicated that the person with diabetes was their parent, 25 (26.3%) stated the person was a grandparent, 25 (26.3%) identified the person as a friend, and 3 (3.2%) selected significant other. Two other choices, sibling and spouse, were also present, but were not selected by any participant.

Procedures

After reading and signing an informed consent form, participants completed a questionnaire via a link sent to them through the SignUpGenius.com site or directly to their email addresses. The questionnaire was hosted through Google Forms. Demographic information that was collected included age, ethnicity, gender, and highest education level.

While participation was not limited to those who were close to a person with diabetes, the survey was structured using skip-logic so participants who did not have anyone close to them diagnosed with diabetes completed a shorter survey. The participants who were close to someone diagnosed with diabetes and interacted with the person with diabetes often were asked several questions about the person with diabetes.

The survey questions were both quantitative and qualitative. The quantitative questions included questions adapted from the Diabetes Social Support Questionnaire [DSSQ] developed by LaGreca and Bearman (1995; 2002), the Diabetes Knowledge Test developed by the Michigan Diabetes Research Training Center (1998), the Diabetes Numeracy Test developed by Huizinga, M. M., Elasy, T.A., Wallston, K. A., Cavanaugh, K., Davis, D., Gregory, R. P., Fuchs, L. S., Malone, R., Cherrington, A., DeWalt, D. A., Buse, J., Pignone, M., & Rothman, R. L. (2008), and the survey developed by McGrew (2008) which focused on how a person with diabetes would “reason about their long-term diabetes future” (p. 68) with communication-related behaviors (fear of disclosure, willingness to talk about diabetes topics, and diabetes-related social support).

Participants who indicated that they knew someone with whom they interacted on a regular basis (at least once a week) that had been diagnosed with diabetes were given several open-ended questions as a part of their survey. Because of this requirement, the sample of open-ended participants decreased from 212 to 95 (44.8%). The questions were selected to be open-ended so as not to lead the respondents to any particular answer.

The qualitative questions were open-ended questions from a study conducted by Pizur-Barnekow, K., Darragh, A., & Johnston, M. (2011), and each respondent was asked questions related to health information sources and social support. For example, each respondent was asked to describe the general ways they provided support to a person with diabetes. Each respondent was also asked to specifically narrate a time that he/she communicated with a person who had diabetes and provided support. The respondent was instructed to record as much as possibly, as accurately as possible, and to provide detailed context of the event. The two open-ended questions relating to social support were analyzed using High and Steuber’s (2014) five types of support: informational, emotional, esteem, network, and tangible. Because not all participants were expected to have a close friend or family member diagnosed with diabetes, the same survey with skip-logic contingency questions was given to those who did not have a close friend or family member diagnosed with diabetes; this data functioned as a means of comparison.

Quantitative Survey Questions

All 212 participants completed the Diabetes Knowledge Test, developed by the University of Michigan, prior to answering the demographic questions. Participants completed the questionnaire online through Google Forms, which made all responses downloadable in a Microsoft Excel format. Data from each of the closed-ended questions were then transferred to a SPSS file for data analysis. The questions taken from the Diabetes Knowledge Test provided the data to effectively analyze H1 and RQ1.

The identity of the person with diabetes was selected from a list of six options, including parent, sibling, spouse, significant other, grandparent, or friend. Age of the person with diabetes was determined by a list of seven age ranges. To avoid any possible interactions involving minors, the youngest age group began with 18 years old. Because “parents have primary responsibility over a young child’s diabetes” (Marchate, Pulgaron, Daigre, Patiño-Fernandez, Sanchez, Sanders, & Delamater, 2014, p. 111) they do not provide the same types of support that two adults would provide each other. Also, while a parent maintains primary control over their child’s diabetes, as the child grows into adolescence, sharing the responsibility of and relating to diabetes becomes a priority for both the parent and the child (Hanna, Dashiff, Stump & Weaver, 2012). Because these perceptions change as children grow into adolescents, and then into adults, the research focused on those 18 years old and older. The age groups were separated into 10 year groupings after age 18.

The type of diabetes of the person with diabetes was selected from a list of four options: Type 1, Type 2, gestational, and a fourth option for those unsure. The Type 1 option had a parenthetical description following, including the common nickname of “juvenile-onset diabetes.” Similarly, the Type 2 option had a parenthetical description following, including “adult-onset” nickname. Gestational did not have any further description. The treatment closest to how the interaction participants' diabetes was managed was selected from a list of six options: insulin, 1-2 times a day; insulin, 3+ times a day; insulin pump; tablets (oral medication); diet with or without exercise; and a final option for those unsure. The treatment options, adapted from McGrew (2008) are displayed on the American Diabetes Association's medication web page (2014). The participants were also asked how often they and the person with diabetes interacted, which was selected from a list of seven options: daily; 1 time a week; 2 times a week; 3 times a week; 4 times a week; 5 times a week; 6 times a week. Finally, the participants were asked to choose the medium by which they interacted most often with the person with diabetes: face to face; telephone (phone calls); text messaging; email; social media; other.

Those who answered the above questions were also required to answer eight open-ended questions in relation to the person with diabetes they thought of specifically at the beginning of the survey. A series of close-ended and open-ended questions followed based on the eighth open- ended question followed.

Qualitative Survey Questions

The first open-ended question asked each participant to describe what he/she knew about the person with diabetes' illness. This question was designed to allow the participants to describe as much as possible about diabetes without prompts that could inhibit their responses. It also allowed the participants freedom to include other pieces of information about the person with diabetes that might not have been obtained otherwise.

The second open-ended question, which is connected to RQ2a and RQ2b, asked the participants where they acquired their information on diabetes, and added "(please be specific)" in order to gain depth in responses. Because health information sources take on a variety of forms (Zhang, 2014), as well as the Internet's increased usage as a health informational source (Machiko, Miyako, & Ichiro, 2013), it is important for the participants to think of the sources on their own without any stimuli that could influence an honest answer.

The third open-ended question expanded upon the previous one, focusing on the reason(s) behind using the sources named in the second question. Source credibility, source expertise, and source homophily have been three of the primary reasons why a person chooses a particular source for information (Rieh, 2009; Hu & Sundar, 2010). Providing the participant with the ability to explicate why he/she chose a particular source, rather than selecting from the three primary reasons above, gives the participant the opportunity to examine why a particular source is used over others and to explain. Further, this allows the participant to use the type of informational source as an example in the response.

The fourth open-ended question queried participants to describe the ways they supported the person with diabetes. By allowing each participant to elaborate on how he/she actually supports the person with diabetes in his/her own words, the response can then be categorized into one of the five types of support (High & Steuber, 2014). This question was analyzed in correspondence with the eighth open-ended question to determine what types of social support each respondent reported providing to the person with diabetes. This question corresponded with RQ1, RQ2a and RQ2b.

The fifth open-ended question inquired about the skills or knowledge required to support a person with diabetes. Because diabetes is a broad illness, the skills or knowledge required to support a person with diabetes could be quite broad. While there are five different types of support outlined by High and Steuber (2014), there are many different elements that can make up each specific type. By allowing the participant to respond to an open-ended question rather than choosing from a drop down list or having a multiple choice question, this allowed for greater depth to the specific skills and/or knowledge required to support a person with diabetes.

The sixth open-ended question asked what things made supporting a person with diabetes easier, while the seventh asked what things made supporting a person with diabetes more difficult. The questions were selected to find similarities and differences in participants' perceptions of supporting a person with diabetes.

The eighth open-ended question was the starting point for three close-ended questions. The participants were instructed to describe a specific interaction with the person with diabetes and how they (the participant) provided support. They were further told to record as much as possible, as accurately as possible, the context of the situation (what happened before the conversation, what led up to the conversation, the setting, etc.), as well as describe what was said and what happened. Following this question were a series of three questions that participants answered on a closed scale of 1 to 10, where 1 represented "no change at all‟ and 10 represented "extreme change." The questions asked the participants how the above interaction impacted their knowledge of diabetes, impacted their feelings about diabetes, and further impacted how they could support the person with diabetes. The subsequent open-ended question asked the participants if they thought there were any other things that they could have done to be supportive and to describe them.

Data Analysis

Quantitative

In order to test the hypothesis and answer RQ1, the National Assessment of Adult Literacy's [NAAL] four classifications of the levels of health literacy (Kutner, Greenberg, Jin, & Paulsen, 2006) were used as a basis for defining four levels of diabetes health literacy. The NAAL scores are broken into four sections and the proficiency level then assigned to the participant. A NAAL score of 0-184 would have a below basic rating, a score of 185-226 a basic rating, a score of 226-309 an intermediate rating, and a score of 310-500 a rating of proficient. The Diabetes Knowledge Test of 23 questions was converted to the NAAL 500 point scale in order to achieve the levels. A score of 0-8 on the Diabetes Knowledge Test would have the below basic rating, a score of 9-11 the basic rating, a score of 12-14 the intermediate rating, and a score of 15-23 the proficient rating. New scores were based on the percentages corresponding to NAAL's 500-point assessment.

Original answers on the Diabetes Knowledge Test were reordered in SPSS so that an index could be created. The survey was given in multiple choice format, with the correct answer to each question selected. For example, the answer to the first question may have been "A," but the answer to the second question could be "C," and so forth. In order to create the index, the final set of data was reordered so that the correct answer was "A" for each question. Following reorganization, new variables were created, where all answers "A" (correct answers) were set to equal "1" and all other (incorrect) answers were set to equal "0." After creating twenty-three new variables, the first seven were added to create an index, the second eight created a second index, and the remaining variables a third index. Finally, the three indexes were added together to compile the final score of the Diabetes Knowledge Test across all participants. An independent-samples t-test tested the hypothesis.

To examine the data corresponding to RQ1, the data accumulated from the two open-ended questions, #4 and #8, were integrated into SPSS and coded numerically. Only the 95 respondents who had answered "yes" to the first question, asking if they interacted with a person who had diabetes on a regular basis, were given the set of open-ended questions.

In order to answer RQ1 and to test the hypothesis, the National Assessment of Adult Literacy's four classifications of the levels of health literacy (Kutner, Greenberg, Jin, & Paulsen, 2006) are scored on a scale of 500 points. The scores are then broken into four sections, and the proficiency level then assigned to the participant. A score of 0-184 would have a below basic rating, a score of 185-226 a basic rating, a score of 226-309 an intermediate rating, and a score of 310-500 a rating of proficient. The Diabetes Knowledge Test of 23 questions was converted to the 500 point scale in order to achieve the levels. A score of 0-8 on the Diabetes Knowledge Test would have the below basic rating, a score of 9-11 the basic rating, a score of 12-14 the intermediate rating, and a score of 15-23 the proficient rating.

Then original answers of the Diabetes Knowledge Test were reordered in SPSS so that an index could be created. The survey was given in multiple choice format, with the correct answer to each question selected. For example, the answer to the first question may have been "A," but the answer to the second question could be "C," and so forth. In order to create the index, the final set of data was reordered so that the correct answer was "A" for each question. Following reorganization, new variables were created, where all answers "A" (correct answers) were set to equal "1" and all other (incorrect) answers were set to equal "0." After creating twenty-three new variables, the first seven were added to create an index, the second eight created a second index, and the remaining variables a third index. Finally, the three indexes were added together to compile the final score of the Diabetes Knowledge Test across all participants.

To quantitatively answer RQ1, a crosstabs was then completed on each of the five sets of social support data (informational, emotional, esteem, network, tangible) and the four classifications of health literacy of the National Assessment of Adult Literacy (Kutner, Greenberg, Jin, & Paulsen, 2006), as shown in Table A.2. The types of social support were investigated as five separate categories, and observed from within, and compared between the categories. Frequencies of each level of health literacy, developed by the National Assessment of Adult Literacy, were then run in comparison with the five types of support. These were compared between groups of levels of health literacy.

To answer RQ2a and RQ2b, data were collected from the second open-ended question, which asked the participants who had previously stated they were close to a person with diabetes to identify where they obtained information on diabetes. The responses were coded into seven categories. These responses were then recoded numerically into SPSS into three different categories: health professional, non-health professional, and do not use sources. Open-ended questions #4 and #8 provided the data to test for the types of social support messages. A crosstabs test analyzed the relation between the types of social support messages and those who use either health professional or non-health professional sources.

Qualitative

The open-ended questions related to social support were analyzed by multiple coders using High and Steuber's (2014) five types of support: informational, emotional, esteem, network, and tangible. Each of the types of support were identified by Xu and Burleson (2001) originally, but have been reworked to include varying contexts of human communication. Because social support involves a "network of people" (High & Steuber, 2014, p. 160), it is important to look at the types of support through the eyes of the people supporting a person with diabetes, rather than the person with diabetes alone. The unit of analysis for each of the open-ended questions was each participant's individual response related to the type of support the participant gives to a person with diabetes The process of thematic analysis was utilized. This approach, influenced by grounded theory (Glaser

& Strauss, 1967; Strauss & Corbin, 1990; Strauss & Corbin, 1998), led to preliminary themes and the identification of categories as the data was analyzed. Grounded theory (Glaser & Strauss, 1967) was developed from the idea that the theory should originate from the data collected, rather than the theory being the ground level. Strauss and Corbin (1998) discussed the inductive mindset of the theory, specifically through three styles of coding: open, axial, and selective.

The open coding process identifies the concepts, which are essential to the grouping of categories. While concepts were roughly labeled in the initial categorization process, they were relabeled frequently throughout the stages of coding. This is because the emerging concepts are constantly compared (Strauss & Corbin, 1998) and the process of constant comparison is one of evolution. The ability to identify “variations in the patterns” found in the data (Strauss & Corbin, 1998, p. 67) is a focal point of the comparison process, and allows researchers to examine the dimensional processes of the pattern itself that may not be immediately visible.

Axial coding focuses on “relating categories to their subcategories” (Strauss & Corbin, 1998, p. 123) by asking questions such as “where,” “who,” “why” and “how” of the data in search of relationships. In this stage of coding, categories, which are more abstract than concepts, begin to be utilized. A category is shaped around concepts with similarities, which sometimes creates subcategories. First, the words used by respondents are reviewed. The conceptualization, or the researcher’s “translation and definition” (Strauss & Corbin, 1998) follows. By asking questions of the data, particularly “why” and “how,” and answering these questions, an analyst is able to combine the structure and process necessary to “capture the dynamic and evolving nature of events” (Strauss & Corbin, 1998, p.127).

Lastly, selective coding facilitates the integration of data collected to become core categories which may later be refined in developing theory. Another look at the data aids the researcher in filling in the categories that may not be as developed as necessary. The concept of variability is especially important to draw attention to here, as not every case fits into a distinct category. While every aspect of data may not be completely covered, the overarching core categories should be evident and fully supported by the data.

Analyses of the qualitative data used thematic analysis, in which categories emerged from revisiting the data. The research bias was minimized with certain procedures. First, the data was analyzed by multiple coders. Preliminary categories emerged. Multiple readings of the data were completed, resulting in the renaming of various categories, and the fit of units of analysis into other categories. Before beginning initial categorization, each set of data was carefully read multiple times. After thorough reflection, responses were sorted into a set of preliminary categories based on explicit responses. For example, in responses to the question asking participant to describe the ways that he or she supported a person with diabetes, answers that included phrases such as “Cooking her healthy foods” would be placed into the category of tangible support. After reviewing the preliminary categories, new categories were created, while others were combined into broader categories. After a last review, the core categories were finalized.

To qualitatively answer RQ1, the data from open-ended questions #4 and #8 were analyzed using grounded theory. The types of social support were initially investigated as five separate categories: informational, emotional, esteem, network, and tangible. A sixth category, those who do not provide support, was also added in the process. Each individual response was analyzed to identify the occurrence of each category. Since some responses contained more than one category of social support, each response was classified using each category found within.

To answer RQ2a and RQ2b, the data from the second open-ended question was analyzed through grounded theory. This question asked participants to identify the diabetes health information sources used. The responses were categorized into seven specific categories which were later collapsed to be health professional and non-health professional sources. A third category of those who do not use information was also used to coordinate the quantitative data. The original categories are as follows: health professional sources (e.g., a doctor or nurse); online health professional sources (e.g., medical website like WebMD); printed health professional sources (e.g., a hospital brochure on diabetes); personal sources (e.g., a friend or family member with diabetes); the Internet (a non-health professional source); academic courses; and those who do not seek health information.

Chapter 3

Results

Characteristics of Those Who Support a Person With Diabetes

Participants were recruited from communication courses that were held on campus by their professors. Those participants who indicated they were close to someone with diabetes and interacted with that person on a regular basis (at least once a week), were asked to identify the person with diabetes' age. Table A.3 shows the breakdown of PWD (person with diabetes) age ranges. The most common age range of a person with diabetes was 48-58 (39.6%), followed in frequency by 58-68 (15.6%), 18-28 (14.6%), 68-78 (13.5%), 38-48 (8.3%), 78+ (7.3%), and finally 28-38 (1%). According to the CDC (2011), over half of people in the United States diagnosed with diabetes are age 65 years or older, but the age group of 45-64 has long been the group projected with the highest increase in diagnoses. Table A.4 identifies the gender categories, and Table A.5 the ethnic categories. Finally, Table A.6 illustrates the participants' levels of education. In identifying the type of diabetes, 48 participants (50%) identified the person with diabetes as having type 2 (also called adult-onset diabetes), 37 (38.5%) stated they did not know, 9 (9.4%) indicated type 1 (also called juvenile-onset diabetes), and 2 (2.1%) selected gestational. The CDC (2011) states that people with type 2 diabetes account for "90-95% of all diagnosed cases of diabetes." Because of the age ranges of the person with diabetes selected by the participants, it is quite likely that the majority of the participants' selections of "I don't know" would actually be persons with type 2 diabetes. The participants were then asked to identify the person with diabetes' treatment: insulin 1-2 times a day; insulin 3+ times a day; insulin pump; tablets/oral medication; diet with or without exercise; do not know. Responses were as follows: tablets/oral medication, n = 27 (28.1%); insulin 1-2 times a day, n = 22 (22.9%); do not know, n = 16 (16.7%); insulin

3+ times a day, n = 14 (14.6%); diet with or without exercise, n = 13 (13.5%); insulin pump, n = 4 (4.2%). Because the majority of persons with type 2 diabetes treat their illness by tablets/oral medication followed by occasional insulin injects (CDC, 2011), the sample is fairly representative of the national averages.

Participants also indicated how often they interacted with the person with diabetes on a weekly basis: daily, n = 32 (33.3%); one time a week, n = 22 (22.9%); two times a week, n = 15 (15.6%); three times a week, n = 10 (10.4%); four times a week, n = 8 (8.3%); six times a week, n = 5 (5.2%); five times a week, n = 4 (4.2%). The most common medium of communication was face to face, n = 63 (65.6%), followed by telephone calls, n = 23 (24%); text messaging, n = 7 (7.3%); social media, n = 2 (2.1%); and other, n = 1 (1%). Email was another option for responses, but was not selected.

Participants' Knowledge of Diabetes

Before the respondents were asked any questions regarding social support or diabetes health literacy, they were instructed to describe what they knew about the person with diabetes' illness. This provided information to the researcher that helped identify a qualitative form of diabetes health literacy. Of the 95 responses related to the question asking participants what they knew about the person with diabetes' illness, 19 were unusable (20%). An example of this category would be a response stating simple sentence like, "Dad told me when I was 10 years old." A total of 122 categories within the 76 usable responses were identified. The seven core categories that emerged were insulin, diet, sweets, blood glucose, diabetes as a serious illness, exercise, and runs in the family. These emerged because of the key words in the responses.

The core category with the largest number of occurrences was insulin, n = 33 (27%). Only a third, n = 11, appeared as a category alone, while the other two-thirds of responses, n = 22, appeared with more than one category. Some participants were quite clear in what they knew about diabetes, “What I know about my grandmother's diabetes is that she has to use insulin 2-3 times a day.” Others were vague but were able to identify something that was clearly related to insulin. For example, one participant stated, “She has to inject herself every couple hours and before every meal.” While the participant did not clearly state “insulin injection,” it is clear that that was the purpose of the shot.

The category following in frequency was diet, n = 27 (22.1%). While some participants detailed specific diet changes because of diabetes, “I don't know much about the disease itself, I just noticed my parents try not to drink sodas, using so much oil and salts in their food, and they cut the carbs as much possible,” others blamed the diagnosis on diet-related instances, such as “He obtained it through years of eating out.” The majority of the responses falling into this category also were multi-category responses.

The category of sweets received 18 responses, (14.8%). Participants predominantly focused on either sugar being limited for a person with diabetes or describing why a person with diabetes might need sugar. One person stated that “If person eat a lot of sweet, it appears disease [sic].” Another detailed a response as to why a person with diabetes might need sugar. “I know that if my grandma does not eat for a long period of time, she will begin to feel light headed and need to sit down and eat something sweet to feel better.” This focus on sweets was also found mostly in multi-category responses.

The category of blood glucose also received 18 responses, (14.8%). Interestingly, not one participant correctly identified the common term of “blood sugars” as “blood glucose.” According to the American Diabetes Association (2014), while “blood sugar” is used as a parenthetical description in one instance, the correct term is “blood glucose,” which is regularly used throughout the website. Participants used terms such as “sugar levels” or “blood sugars” throughout their responses. For example, one participant explained, “The type of diabetes my father has is type 2 diabetes, which means he's producing too much sugar. He has to check his sugar level on a daily basis to make sure it's not too high and maybe at times, not too low.” This participant showed knowledge of diabetes by describing the reasons for checking blood glucose, but identified it differently than the American Diabetes Association.

The category of a serious illness received 17 responses, (13.9%). This category focused primarily on participants who responded with phrases like “It’s inconvenient” and “He is limited in what he can do…” This is not unlike many other illnesses, in particular chronic illnesses.

The category of exercise received 5 responses (4.1%). Every occurrence of this particular category appeared only in multi-category responses. One response detailed a reference to exercise and to insulin. “Type 1 is insulin dependent. Type 2 is non-insulin dependent. Type 1 usually takes pills and can sometimes get it under control by exercising and losing weight.” While taking pills, exercising, and losing weight can indeed help control a form of diabetes, it is type 2, rather than type 1 diabetes (American Diabetes Association, 2014).

The final core category, runs in family, had 4 (3.3%) responses. In all cases, the respondent identified that “Diabetes runs in my family” or that “I think it is inherited diabetes.”

A large portion of responses contained multiple categories, n = 33 (34.7%). The combination of insulin and diet appeared the most often, n = 6 (18.2%). One person stated, “That she has to have insulin every time before she eats. Also, that she has to eat healthy.” Another commented, “My grandmother and grandfather both have diabetes and are required to take insulin at least 3 times a day. They are constantly checking their blood pressure and watching what they eat." It is interesting to note the reference to blood pressure in the last response. Typically, a person with diabetes checks his/her blood glucose, which could be what the participant is referring to, but, because blood pressure is also important and could be measured for reasons not relating to diabetes, it is unclear if the participant is mistaken or if he/she truly is referencing blood pressure.

The combination of both insulin and sweets and the combination of insulin and blood glucose both received 3 responses each (9.1%; 9.1%). An example of a participant response of the combination of insulin and sweets is "All I know is that she has diabetes, and she takes insulin 1-2 times a day. She is also not allowed to eat sweets." Another respondent spoke on insulin and blood glucose. "I know that if his blood sugar is low, he has to inject himself with insulin." This particular comment is intriguing, as a person with diabetes, if experiencing a hypoglycemic event (low blood glucose, or low blood sugar as the participant calls it), requires immediate administration of glucose to survive rather than a dose of insulin. A dose of insulin would, in fact, lower blood glucose levels even further, potentially causing injuries, coma, or death.

Other two-category combinations included the following: diabetes as a serious illness and insulin, n = 2 (6.1%); diet and exercise, n = 2 (6.1%); diet and sweets, n = 2 (6.1%); sweets and blood glucose, n = 2 (6.1%); diabetes as a serious illness and diet, n = 1 (3%); insulin and exercise, n = 1 (3%); diet and blood glucose, n = 1 (3%).

Almost a third of multi-category responses contained three or four combinations of categories, n = 10 (30.3%). These combinations included the following: diabetes as a serious illness, insulin, and blood glucose, n = 2 (20%); diabetes as a serious illness, diet, and sweets, n = 1 (10%); insulin, diet, and exercise, n = 1 (10%); insulin, diet, and sweets, n = 1 (10%); insulin, diet, and blood glucose, n = 1 (10%); insulin, sweets, and blood glucose, n = 1 (10%); diet, exercise, and sweets, n = 1 (10%); diabetes as a serious illness, insulin, diet and sweets, n = 1 (10%); diabetes as a serious illness, diet, sweets and blood glucose, n = 1 (10%).

In summary, participants were asked to describe what they knew about diabetes. The majority of the participants focused on insulin, as evidenced by both the single-category and multiple-category responses, followed by diet, sweets, blood glucose (which was referred to as “blood sugar” or “sugar levels” by the participants), diabetes as a serious illness, exercise, and runs in the family.

Diabetes Health Literacy Level

To test the hypothesis stating those who have a close friend or family member diagnosed with diabetes will have a higher diabetes health literacy level than those without a close friend or family member diagnosed with diabetes, an index was created and the data analyzed through SPSS. Table A.7 is based upon the National Assessment of Adult Literacy’s four classifications of the levels of health literacy (Kutner, Greenberg, Jin, & Paulsen, 2006). The original scale (500 points) is converted to a 0-23 scale to correlate with the scoring of the Diabetes Knowledge Test responses. A score of 0-8 on the Diabetes Knowledge Test represents a below basic rating, a score of 9-11 the basic rating, a score of 12-14 the intermediate rating, and a score of 15-23 the proficient rating. No participants scored below a 4 on the index, and no participants scored above a 20. The median score was a 10, and the average was 11.03. The number of participants in each range are as follows: basic, n = 75 (35.4%); intermediate, n = 66 (31.1%); below basic, n = 47 (22.2%); proficient (11.3%).

An independent-samples t-test was then conducted on the data set, testing the relation between those who have a close friend or family member diagnosed with diabetes and his/her diabetes health literacy level, compared to a person not close with a person with diabetes and his/her diabetes health literacy level. The t value was shown to equal 2.804. Significance was strong, equaling 0.006, showing that those who have a close friend or family member diagnosed with diabetes will have a higher diabetes health literacy level than those without a close friend or family members diagnosed with diabetes. The hypothesis is thus supported, as shown in Table 4.8.

Health Literacy and Support Messages

RQ1 focuses on the diabetes health literacy level of a person close to a person with diabetes, and how that affects the type of health-related support message communicated to the person with diabetes. While the diabetes health literacy level is analyzed in the quantitative section by an index level t-test through SPSS, the type of health-related support message is initially analyzed qualitatively from the fourth and eighth open-ended questions, and then analyzed quantitatively using crosstabs through recoding as the types of support into SPSS.

Health-Related Support Messages

To examine RQ1, two open-ended questions, one asking the participants to describe how they generally provide support to a person with diabetes, the other asking participants to describe a specific time when they interacted with a person with diabetes and provided support, were collapsed into one large health-related support messages category. There were a total of 95 responses to each of the two questions.

The open-ended question asking the participants to describe a specific time when they interacted with a person with diabetes and provided support also asked the participants to provide the context of the situation, what was said, and what happened. Several of these responses described specific events without any particular support being shown. All of these then counted towards the category of those who do not provide support.

Each individual response to the original two questions was analyzed qualitatively using grounded theory method. Between the two original questions, and based upon High and Steuber's (2014) five types of support, a total of six categories emerged: informational support, emotional support, esteem support, network support, tangible support, and those who do not provide support to a person with diabetes. Several of the responses to the two questions described more than one type of support.

To analyze the questions quantitatively, each participant was given a number, which was then entered into SPSS as one variable. If a participant described informational support in answering the first open-ended question regarding health-related support messages, and described informational support and tangible support in the second open-ended question, their participant number was entered two times: once for informational support and once for tangible support.

In the two sets of 95 responses, a total of 177 occurrences of the six categories were found. The six categories are listed in order of frequency: tangible, do not show support, informational, emotional, network, and esteem. Table A.9 demonstrates the data.

The category of tangible support appeared the most frequently, n = 69 (30%). The majority of these responses examined a particular event, usually related to a low or high blood glucose episode. One participant stated,

> My dad came out of the restroom and looked a little dazed. So when he sat down on the couch I checked his sugar; which was really low. So I ran to the kitchen and got him sprite from the fridge and within minutes he was feeling fine again.

Other types of tangible support were present as well. In one response, a participant described giving an insulin shot, while another described taking the person with diabetes to the hospital. In another example, this particular one a multiple-category response, one participant in addition to describing an event with her identified person with diabetes, also described events where she supported others with diabetes:

> As an employee of a pharmacy, I deal with diabetic patients. I try to do the best that I can in order to get them their medication that they need. I have had to deal with many issues with money. We work with them in order for them to be able to afford their medication or if they are in need of it at the moment. Also, many diabetics have issues with blood circulation and so I have helped many people pick the right kind of diabetic socks and shoes that they need.

Other examples varied from something as simple as “Cooking her healthy foods” to ensuring persons with diabetes have the proper medication, “Ask him if he needs anything, or if he has his insulin just in case. Sometimes, we go back to his apartment to get insulin if we know we are going somewhere he might need it.”

The category with the next highest response rate was that of those who did not provide support, n = 53 (29.9%). While some merely stated “never” or “don’t know,” others gave a more detailed explanation as to why they did not provide a person with diabetes support. One person explained, “I know they are around me and I interact with them maybe on a daily basis although I don't exactly know they have diabetes and so I don’t really `support’.” Others detailed an interaction event with a person with diabetes, but did not describe any type of support. One participant stated, “Sadly I don't do anything,” to a reason why the participant does not provide support, “I don’t really support them hands on. I just know they have it. They are very quiet about it.” Each of these responses demonstrates something different about the respondent’s view of diabetes. The participant shows a form of remorse, “sadly,” indicating that she realizes that a person with diabetes needs a form of support, but she does not provide it. She does not mention, however, whether she feels this is because she is incapable or whether she doesn’t wish to provide support.

Informational support received 18 responses (10.2%). This category focused on letting a person with diabetes know about a particular meal plan providing information about advanced medical technology and/or advice. The majority of the responses here are from multi-category responses. This category focuses on providing advice to the person with diabetes, as shown in this response, “I try to remind him to take his medicine and encourage him to make better health choices. ”The majority of the single-category responses detailed an event that focused on food. It seemed that the respondents typically had a better knowledge of what a person with diabetes should and should not eat than the persons with diabetes themselves. Many of the respondents gave the person with diabetes information or an explanation as to why a high blood sugar or something related was occurring. For example, one participant responded,

> This past summer [in late July], we went out with my visiting parents [who permanently reside in the D.R. Congo]. While at a pizzeria, my mom was craving pizza; the rest of us ate our food without any problem but my mother couldn't ... because earlier in the day, she consumed a certain kind of bread that quickly rose her sugar level. From there, I had to explain to her that she wasn't at fault. From there, we ended up going home and she was able to feed herself something that wouldn't cause her any trouble.

Another respondent detailed a similar event, focusing on the snacks that the person with diabetes should consume.

> Once as I entered my kitchen at the same time as my dad was packing his lunch for work I noticed that the snack he had put in his lunch box to eat in case his blood sugar was getting low were the snacks that my mom usually bought for me. Since I knew that these snacks were not that healthy because they were usually used in my lunch and I knew the health facts, I informed my dad that there were better snacks he could use to balance out his sugar and also eat healthier which is important.

Emotional support also received 18 responses (10.2%). The responses showed that the respondents primarily focused on how their actions emotionally affected the person with diabetes. One participant described an event at a meal with family:

> I went over to my grandparents' house for dinner one day and my uncle was there. He normally doesn't like to eat with people but my grandma made his favorite meal, her famous homemade lasagna. When we all sat down to eat, I was asked to say a blessing. I don't remember exactly what I said but I did ask that my uncle's diabetes not prevent him from doing the things he loves and eating the things he wishes. He had a big smile on his face the entire meal. Afterwards, as I was taking my dishes into the kitchen, he came up and gave me the biggest possible bear hug you could imagine. I knew he felt loved. It felt great to see the happiness he had!

Emotional support, according to High and Steuber (2014) is said to be accomplished through moral support, sympathy, and/or empathy. One participant responded, "Help her by talking to her about what is going on. I just be there by being her friend. If she's going through a tough month or week I'll try to talk to her more." Another participant, one with diabetes, said, "I talk to her about our relatively common problem. I bet it's a lot easier for me to understand what she goes through since I have a similar problem." In both of these cases, the participant showed comprehension of the importance of conversation and feeling when showing support.

Network was the next category in frequency, with 17 responses (9.6%). Each of these participants listed, in their responses, what it was that the person with diabetes was changing in response to their diagnoses, and what they (the respondents) were changing in their lives to support the person with diabetes. One participant explained that she made the change in her life to make it easier on the person with diabetes:

> I have changed my diet and lifestyle to be supportive and make the change easier for him. He does his best to cut out refined sugar and carbs from his diet. I also do my best to monitor what he eats and let him know that something is bad for him when he is about to eat it. At times it works and at times it doesn't.

The participant demonstrated support through networking, "changed my diet and lifestyle" to make the change "easier," informational support, "let him know that something is bad for him" and through tangible means, by "monitor[ing] what he eats." Another participant described her change as a complete change of diet for the entire family:

> My mom, sisters, and I had received a call from the hospital because he had come in with high blood sugar levels. It was when we all found out he had diabetes. I'm sure the doctor had prescribed him with some type of medicine, but he also stated that his diet must change. I remember all of us agreeing we will eat what he ate from now on. My mom cooks much healthier and is always finding new dishes for us to try.

This category focused on social activities like working out with a person with diabetes. These were typically “I eat healthy with her” or “I eat what they eat,” which focuses on an activity the two, supporter and person with diabetes, do together.

Finally, the category of esteem received 2 responses (2.2%). This category focused on increasing one’s self-perception. “Treat them like a regular person,” was one response. Because of the lifestyle changes a person with diabetes is typically required to make, it could be easy for a person close to a person with diabetes to see the changes as something completely different. By treating them like a “regular person,” the participant is noting that the person with diabetes likely wants to be treated like everyone else, which is essential for having self-esteem. These participants focused on the person with diabetes feeling “fine” and motivating the person to keep going. For example, one response stated, “I met father the other day. He is diabetic, but he just started to take care of his diet. I give him motivation and tell him that he will be fine [sic].”

Of the 190 total responses, several included more than one category, n = 27 (14.2%). Of these, most focused on two core categories, n = 25 (92.6%). The combinations included the following: network and tangible, n = 8 (32%); emotional and tangible, n = 6 (24%); informational and tangible, n = 4 (16%); informational and network, n = 3 (12%); esteem and tangible, n = 2 (8%); emotional and network, n = 2 (8%). Of the remaining two multi-category responses, both contained three categories. They were: informational, emotional, and tangible, n = 1 (50%); informational, network, and tangible, n = 1 (50%).

Diabetes Health Literacy and Support Messages

To quantitatively answer RQ1, an index was created consisting of the levels of diabetes health literacy. The index further organized the data by creating and renaming the categories of the types of support (High & Steuber, 2014), which had appeared in the order of tangible, does not provide support, informational, emotional, network, and esteem. A crosstabs analysis was conducted on the diabetes health literacy levels and types of support data, according to the levels of the four classifications of health literacy based on the scaling used in the National Assessment of Adult Literacy (Kutner, Greenberg, Jin, & Paulsen, 2006): below basic; basic; intermediate; proficient. All diabetes health literacy levels were more likely to present tangible support over any other type of support. Esteem support was the least common support reported. The total number of participants in each level of diabetes health literacy level is displayed in Table A.7, as noted before.

According to the qualitative analysis of open-ended questions #4 and #8, the types of support messages utilized by those with proficient diabetes health literacy are the following: tangible, n = 6, network, n = 3, emotional, n = 3, information n = 0, and esteem, n = 0. The types of support messages utilized by those with intermediate diabetes health literacy are the following: tangible, n = 11, network, n = 5, informational n = 4, emotional, n = 2, and esteem, n = 1. The types of support messages utilized by those with basic diabetes health literacy are the following: tangible, n = 15; information, n = 4; network, n = 4, emotional, n = 4, and esteem, n = 1. The types of support messages utilized by those with below basic diabetes health literacy are the following: information, n = 7, emotional, n = 3, informational, n = 2, esteem, n = 0, network, n = 0. There were 34 responses that were categorized as not offering support.

A crosstabs evaluated the five types of support to the four levels of health literacy: below basic, basic, intermediate, and proficient. The test found no relationship between the five types of support and the four levels of health literacy and was insignificant.

According to the crosstabs, participants with basic diabetes health literacy level, the most common level, used more tangible support and emotional support than any other level. Participants with intermediate diabetes health literacy level used more network-related support than any other level, but the finding itself was not significant.

The participants with below basic diabetes health literacy level or a proficient diabetes health literacy level did not use any particular support message more than any other diabetes health literacy levels. However, the total participants between the four diabetes health literacy levels and five types of support were a smaller sample than that of those who had responded that they were close to a person with diabetes, n = 75. This is because not all participants stated that they provided support. When compared to the five types of support, only 12 participants scored in the below basic level of diabetes health literacy (16%), while 28 scored in the basic level (37.3%), 23 in the intermediate level (30.7%), and 12 in the proficient level (16%).

Health Information Sources and Support Messages

Both RQ2a and RQ2b focus on the types of support messages individuals utilize to support a person with diabetes given the health information sources used. RQ2a focuses on the types of support messages used by those who employ health professional information sources, while RQ2b concentrates on the types of support messages used by those who employ non-health professional information sources. For example, a non-health professional information source could be a friend or family member without professional health knowledge, an Internet website like a blog, or the news media.

Diabetes Health Information Sources

To examine RQ2a and RQ2b, respondents who identified that they are close to a person with diabetes were asked where they obtained their health information about diabetes. No options were provided; the question was open-ended. In the 95 responses, 7 core categories were identified containing 114 total occurrences: health professional sources (e.g., a doctor or nurse); online health professional sources (e.g., medical website like WebMD); printed health professional sources (e.g., a hospital brochure on diabetes); personal sources (e.g., a friend or family member with diabetes); the Internet (a non-health professional source); academic courses; and those who do not seek health information. Of the 95 responses, some were unusable, n = 6 (6.3%). The most common category of health information sources used in obtaining health information about diabetes, by a large margin, was personal sources, with 51 total responses (44.7%). All of these responses identified the personal source as the person with diabetes either directly by stating “my friend that has diabetes” or indirectly by stating “from perants [sic]” after having identified the person with diabetes as their parent.

The participants identified multiple ways of obtaining information from the person with diabetes that they were close to. Some responses were “I have learned most everything about diabetes from her [the person with diabetes] and what she has gone through” and “just by seeing what she goes through.” One participant noted, “I honestly don’t know much about it except for what I have seen my grandparents do.” This indicates that, while the majority of health-related information is obtained from a personal source, the information may not be adequate or accurate. For example, just because an individual sees a grandparent (or any other person with diabetes) treat a low blood sugar, that individual may not know what do in a hyperglycemic event. This also shows that the primary source of information is the actual person with diabetes. Because of this, the diabetes health literacy of a person with diabetes directly affects the knowledge of those attempting to support them.

Following in frequency was the category of the Internet, which was included in 19 responses (16.7%). Many participants simply stated “the Internet” as a source of information, or their only source of information, without detailing exactly where on the Internet the information was procured. Only unspecified Internet research was integrated into this category; so while “Google…” was a part of one person’s response, “Google…” does not indicate a specific website and is thus categorized broadly.

The category of health professional sources was also found in 11 responses (9.6%). These included “my endocrinologist,” “from my parent’s doctor, my step mom because she is a nurse,” and “doctors.” Each of these responses show a varying level of diabetes health literacy by the title given to the health practitioner. Every endocrinologist (a specialist who treats the endocrine system and its diseases) is a doctor, but as not every doctor is an endocrinologist, the information obtained from an endocrinologist would likely be more expert and detailed than that of a primary care doctor.

The category of academic courses was found in 10 responses (8.8%). “Biology classes” and “anatomy and physiology” were common answers. Participants did not indicate within their responses whether the course(s) were taken in high school or college. While biology is a fairly common core science course college students can enroll in, anatomy and physiology is typically taken by those who aim to continue study in health-related fields. This could lead to a greater depth of knowledge for the anatomy and physiology respondents than a biology for non-science majors course might (the participants did not specify whether the courses were major or non-major).

The same number of respondents, n = 10 (8.8%) indicated they do not seek out health information. Reasons varied from a reluctance to seek out information, “If I really wanted to know I would google my questions,” to a vague sense of a bare-bones knowledge, “Through general talks. I have heard of it from people, and the fact that a lot of people have it has given me certain information on what the disease is. Other than that, I do not know much about it.” Another respondent only entered “I don’t.”

The category of online health professional sources was found in 8 responses (7%). This category was reserved for responses that specifically stated a credible website. Examples of this were “Primarily on the Internet (through outlets like the CDC website)” and “Web MD.” The specification of particular websites is important because it shows that not only are the respondents seeking information, but they are cognizant of where they obtain their information.

In the final core category of health information sources, 5 respondents obtain health information about diabetes from printed health professional sources (4.4%). Only one of the four responses solely stated “Pamphlets from the doctor’s office,” while the other three stated responses that were categorized under printed health professional sources as one of their primary sources, but not their only primary source of health-related information.

The majority of the 95 units of analysis, n = 65 (68.4%), contained one core category only; however, 24 answers (25.3%) contained multiple core categories. The highest occurring combination of responses was that of those who obtain health information from the Internet and from a personal source, n = 6 (25% of multiple-category responses). Other combinations occurring more than once included a personal source with diabetes and academic coursework, n = 3 (12.5%); a personal source with diabetes and printed health professional sources, n = 3 (12.5%); a personal source with diabetes and online health professional sources, n = 3 (12.5%); a personal source with diabetes and health professional sources, n = 2 (8.3%); health professional sources and academic coursework, n = 2 (8.3%). All other combinations appeared only once each. These are as follows: health professional sources and online health professional sources, n = 1 (4.2%); health professional sources and the Internet, n = 1 (4.2%); printed health professional sources and the Internet (4.2%). Only 2 responses (8.3%) of the multi-categorized) contained three categories, and no responses contained more than three categories. These combinations were: professional health sources, online professional health sources, and personal source with diabetes, n = 1 (4.2%); health professional sources, personal source with diabetes, and the Internet, n = 1 (4.2%). Interestingly, 16 of the 24 responses included personal source with diabetes (66.7%).

A follow-up question inquired as to the reason behind the selection of information sources by the individual. Of the 95 responses, 85 (89.5%) were single-category, 6 (6.3%) contained multiple categories, and 4 had unusable data (4.2%). Excluding the four unusable units of analysis, 7 categories were identified: convenience (easy access, speed), qualities related to credibility (detail, thoroughness, reliability), firsthand experience (a person who has diabetes), prevention (information so they do not become a person with diabetes), educational purposes (for knowledge and understanding), and those who do not seek out or use health information sources.

The core category with the largest number was that of credibility, n = 32 (32% of total units of analysis). Participants particularly cited reliability and trust as two main components of the reasons why they chose a specific source. “Because it is reliable,” “They’re reliable,” and “Reliable” were three separate, complete answers yet were very specific as to why a source would be chosen. Likewise, trust was a major component of credibility for respondents. One person stated, “Because its trusted and I trust the ones who inform me these information [sic],” while another responded,

> I trust my parents and grandparents. They all have knowledge and experience in certain areas so I believe them. If I was ever diagnosed

> with diabetes, then I would do more research but, as of now, I have no need to.

While there were other components that were seen throughout this category, these were the two predominant ones.

Following in frequency was the category of the firsthand experience with 18 responses (18%). Convenience was third, with 15 respondents (15%) including references to it in their responses. One person explained, “Because it gives me fast results” while another simply stated that “It was easy to look up and find general info.”

The category of prevention was found in 12 responses (12%). While some respondents were quite clear about their reasoning, “I use these sources of information so I can become well aware of the situation and so I can try to prevent it by living a healthy and active lifestyle,” others were quite vague but still conveyed the same message.

> I use these sources because I know that it runs in the family and I dont want to get it. I have a very unhealthy eating lifestyle but I ask to see if I will get it and how not to get it [sic].

Educational purposes also had 12 total responses (12%). These responses focused on education or increasing knowledge. “I wanted to educate myself” and “personal knowledge” are examples of the participants’ responses who fit into this category. The respondents, while seeking education, did not state a specific purpose for seeking the information.

Finally, those who either did not seek informational sources or did not use informational sources comprised the rest of the responses, n = 11 (11%). “I don't `use’ them” was one participant’s response, while another explained why he/she didn’t use informational sources, “I have never really read up on diabetes because it hasn't really affected me personally.”

The highest occurring combination of responses was that of those who choose convenience and credibility, n = 3 (50% of the multiple-category responses). The other two-category combination included firsthand experience and prevention, n = 2 (33.3%). Only one respondent (16.7%) identified more than two categories in his answer: convenience, credibility, and educational purposes. The participant self-identified as a person with diabetes in an earlier response, and he also supports a friend that has diabetes. His response is interesting given how much depth he put into his answer compared to others. He stated,

> I trust her, and she would have no reason to give me misinformation. The American Diabetes website was also used, however I found some of that information lacking, BUT it was a good start. And then, the other sources were doctors, so I felt like their information was probably accurate. (Even though my General Medicine doctor was less informative and lacked details my Endo gave me.) The ADA website I used because it was easy to access and I was slightly panicked when I was first diagnosed.

Quantitative Analysis

In order to answer RQ2a and RQ2b, after qualitatively analyzing the responses to the second open-ended question, the original core categories were collapsed into three categories: health professional sources, non-health professional sources, and do not use sources. Because each response may have contained more than one category, responses containing multiple categories were counted towards each of the categories found within the data. As a result, a total of 108 responses were analyzed in SPSS. A total of 24 (22.2%) responses identified health professional sources, while 74 (68.5%) identified non-health professional sources. As before, 10 (9.3%) of the responses fell into the category of does not seek information.

A crosstabs analysis was then conducted on the six categories of support, consisting of High and Steuber’s (2014) five types of support plus the category of does not support, and the three categories of health information sources, which were health professional, non-health professional, and those who do not seek information, as shown in Table 4.10. The test was found to be insignificant. The types of support, in relation to the categories of health information sources, were not significant. Overall, the category of tangible support had the most cases, n = 39 (36.1%). Following in frequency was the category of does not provide support, n = 33 (30.6%); emotional, n = 12 (11.1%); network, n = 12 (11.1%); informational, n = 10 (9.3%); esteem, n = 2 (1.9%). In all types of support, other than esteem, the category of non-health professionals contained the majority of any type of support.

Of the 24 responses that were in the category of those who utilize health professional sources, a response detailing no support or a response not directly related to diabetes was the most common response, n = 10 (41.7%). Tangible support followed in frequency, n = 8 (33.3%). Network support, received 3 responses (12.5%), and each of the remaining categories (informational, emotional and esteem) received 1 response (4.2% each).

Of the 74 responses that were categorized as obtaining health information from non-health professional sources, tangible support was the most common, n = 25 (33.8%), followed in frequency by those who do not support, n = 21 (28.4%). Informational, emotional, and network all received the same amount of responses, n = 9 (12.2% each). Finally, esteem received 1 response (1%).

Additional Analyses

In the open-ended section of the survey, participants were asked about the skills and knowledge needed to support a person with diabetes. This is important because oftentimes friend or family member is expected to support a person solely based on the personal relationship, while not always taking into account that a person attempting to support another person, particularly one with a chronic illness like diabetes, may need certain skills or knowledge to properly support that person with diabetes.

The majority of responses, n = 71, (74.7%) consisted of one category, while 22 (23.2%) had paired categories, and 2 responses were unusable (2.1%). Five core categories were formed: basic information and informative understanding (awareness, general information), understanding, empathy, and sympathy (emotional support), networking, tangible skills, and those who did not specify skills.

Information and understanding as necessary to support a person with diabetes was the most prominent category, with 74 responses (60.1%). The responses ranged from the most rudimentary of answers, “The basic of what diabetes is,” to more complex answers,

> I feel that you need to be knowledgeable about diabetes and how it effects someone before you begin to support them. You need to know what is bad or good for them. How often should they eat, what kind of diet should they have.

Some respondents were quite specific in what kinds of knowledge they would need. For example, one stated that “What their blood sugar levels mean” would be most important. Another mentioned, “I need to know their medication and eating habits.” Because of the multiple layers of a chronic illness like diabetes, this is not surprising. Having a solid understanding of an illness, especially one as complex as diabetes, would be most helpful in attempting to support a person in any of the five types (informational, emotional, esteem, network and tangible).

Tangible support appeared 26 times (21.3%). One person stated that the most important skill was,

> What to do when their blood sugar is high or low. Make sure they have a tag showing what medication they are on and also what type they are. Also be mindful of what they can't or can eat because it might make them feel bad if everyone goes eat where he/she can't go.

Another specified that “doing the insulin” was the most important skill in supporting a person with diabetes. It is important to note that the person who was close to the participant was his 78+ year-old grandparent. This may not be the case for an individual supporting a person with diabetes that is a friend or perhaps a young adult.

Emotional support was found 13 times (10.7%). “Compassion and understanding,” “sensitivity, self-awareness, communication skills, “and “support and understanding” were answers whose categories were reflected throughout the other responses.

Those who did not specify skills appeared 8 times (6.7%). One person stated that she did not know what skills and knowledge were needed to support a person with diabetes, while another said that he did not need “much knowledge about diabetes to support the person.”

Networking appeared 1 time (0.8%), and only in a multi-category response.

Three combinations of paired categories appeared. First in frequency was basic information/understanding and tangible support with 18 responses (81.8% of multi-category responses). These typically involved having a basic knowledge of a process, and the ability to enact the process. For example, “Whether there insulin levels are high or low-knowing how to read the pump and what the machine does when they prick their finger. Also if they have the injections, knowing how and what to inject at the correct time [sic].” Another response indicated similar feelings.

> Just in case the person falls and has a serious reaction it is important to know what type of diabetes they have so you can tell the paramedics. Also, it is best to be prepared what to do in these situations. I've heard that giving sweets to the person helps, but I am not sure.

Following in frequency were basic information/ understanding and emotional support with 3 responses (13.6%). One participant stated,

> You need to have some type of knowledge about the certain type of diabetes that individual has or else how are you going to be aware of the health risks they could have. You also need to be very patient and understanding with people who have diabetes, because there are times that they will not listen and will want to keep living the life they were living prior to their diagnosis.

Finally, the pairing of those who prioritize skills relating to emotional support and networking received 1 response (4.5%). One participant stated, “You just need to know ways to encourage the person. Maybe by exercising together, or finding healthy recipes and cooking together as well.” While the only participant to explicitly draw the line between encouragement (emotional support) and networking skills, it is important to see that these lines are being drawn for some individuals.

Participants were then asked what made it easier to support a person with diabetes. From these responses emerged six categories. These included information, closeness, networking, tangibility, positivity and control, and no particular method. Of the 95 responses, 8 were unusable (8.4%). While 86 responses (90.5%) consisted of a single core category, only 1 response had more than one category (1.1%). A total of 87 categories were counted.

The category of information had the highest number of responses, with 36 (41.4%). While “knowing the treatment” and “knowing the information” were responses that had many similar answers, there were others, such as one participant’s response that “Having knowledge about the person and their personal case of diabetes and how it affects their daily life” is what makes it easier to support a person with diabetes.

Following in frequency was the category of closeness with 16 responses (18.4%). This category enveloped the two original categories of emotional support and building esteem, as many times the two can overlap. The responses in this category were exemplified by comments like, “I never want her as my mother to go through it alone, she gets talked about her weight a lot” and “Showing them the love and respect that they deserve. When you support someone, especially a family member or close friend, you shouldn't push them out and treat them differently."

Positivity and control received 14 responses (16.1%). This category focused on the positivity of the person with diabetes and the person with diabetes' own control of their illness, which are often linked together. One individual was specific in their definition of control, "If they are good about keeping their blood sugar where it needs to be. They remember to eat regularly so they don't go into shock." Another respondent echoed the sentiment, "When they want to help themselves and watch their own health it makes it easier on me because they don't fight me."

The category of tangibility had 8 responses (9.2%). Some responses focused on medical developments, like the insulin pump, "Having a pump rather than the injections! It's so much easier for the individuals and those who help care for them." Others looked at a longer-term solution.

> structural changes in our life style as a society, less gov money for corn and less substates for foods that are only exacerbating the problem. also public transport, places to walk. many many things i can probably write a book about them [sic].

A focus was also on networking, with 6 responses (6.9%). Participation with the person with diabetes in different facets of life was the priority for these respondents. One participant simply stated "Events" as being the best way to support a person with diabetes, while another said, "If you motivate them and participate with activities." All of these are important. In another example, the following quote explains two different ways a person can interact positively with a person with diabetes.

> If you actually go though it with them. Meaning, try to do the positive things with them that would actually help them in controlling the disease. For example, if they need to diet, try dieting with them from time to time. When they need to exercise, go on a walk with them.

The final category was developed around the categories of responses without identified methods of easier support. For example, one participant stated, “I don’t know” while another said, “It is not easy.”

Only one response included two categories. These were the categories of information and tangibility. The respondent stated, “Being with them often and taking care of them also the more knowledge you have the better.”

The next question asked the participants to identify the difficulties in supporting a person with diabetes. Of the 95 responses, only 1 was unusable. A total of six categories were found, with 94 responses total; as each answer only held one category. The categories are as follows: attitude of person with diabetes, tangibility, lack of information, do not support, attitude of the person supporting the person with diabetes, and the person supporting the person with diabetes not having diabetes.

The attitude of the person with diabetes was the category that was shown to affect the difficulty of supporting a person with diabetes, with 29 responses (30.9%). One participant briefly stated, “When they clearly don't care,” while another elaborated, “The difficulty comes when they don't want to listen to the people around them who are trying to help them stay healthy and out of the hospital.” Stubbornness, pride, and negativity were all common in this category.

Following in frequency was the category of tangibility, with 26 responses (27.7%). “Expensive equipment” was one response, which was echoed by another participant.

> For example if they want to go swimming and they have a pump... they can't just jump in the water, they need to check it, take it off, make sure everything is ok. When you're on holiday you have to make sure that everything you're doing, eating etc. fits in with them and they're ok to do it.

The category of lack of information received 18 responses (19.1%). These participants primarily focused on the fact that they did not have “much information about their [the person with diabetes’] diabetes or their diet or how it impacts their life on a daily basis.” Some also commented more specifically, stating they would not know how to help a person if a certain event would occur. One patient commented on blood glucose levels, “Not knowing what to do in case his sugar level rises or lowers” would be the biggest problem to supporting a person with diabetes.

Those who did not show support, or find difficulties, had ten responses (10.6%). Some stated similar responses to previous questions, like “I don’t know” and “Nothing really.” Another stated, however, “nothing you just need to tell them its not big deal and everything going to be alright [sic].” It would be interesting to hear what a person with diabetes would think of this response.

The attitude of the person supporting a person with diabetes emerged late in the data collection, with 6 responses (6.3%). One stated, “Knowing that no matter what you do, you can't take it away. You can stay positive and motivational, but even that is hard sometimes when you see their health declining due to diabetes” demonstrating depth from a person who supports a person with diabetes. Another participant noted, “I dont want to also get diabetes so its difficult for me to support them because im so worried about me getting it [sic],” which is interesting, since diabetes is not a contagious disease.

The final category described the participants’ feelings of not understanding because they did not have diabetes, with 5 responses (5.3%). This category is important because it shows a level of understanding from some participants, that may not have been able to be seen from previous question. One person summed up the category in one sentence, “I think not knowing exactly what they are dealing with makes it difficult to support someone with diabetes.”

Chapter 4

Discussion

There has been little research examining the diabetes health literacy level of those close to a person with diabetes, and how a person's diabetes health literacy level impacts the way in which he/she can support a person with diabetes. Additionally, there is not a large amount of research that addresses communication, diabetes, and social support "even though socially-enacted dimensions such as social support are recognized as important to diabetes" (McGrew, 2008). Hence, this research contributes to the gap of knowledge in this particular area. The implications of support for the hypothesis, the frequent appearance of tangible support throughout the open-ended responses, and the majority of health informational sources being the person with diabetes are significant.

Diabetes Health Literacy Level and Close Relationships

H1 examined the differences between the diabetes health literacy level of those with a close friend or family member diagnosed with diabetes and those who did not have a close friend or family member with diabetes. Specifically, it predicted that those who have a close friend or family member diagnosed with diabetes will have a higher diabetes health literacy level than those without a close friend or family member diagnosed with diabetes.

After analysis of the data collected, creation of an index, and independent sample t-testing through SPSS, the hypothesis was found to be supported. There was a significant difference in the diabetes health literacy levels between those who were close to someone with diabetes and those who were not close to someone with diabetes ($p=0.006$). The implications of a person close to a person with diabetes having a higher diabetes health literacy level than a person not close to a person with diabetes not only is understandable, but important for the person with diabetes to understand. Because many participants stated they received their knowledge primarily from the person with diabetes, and also had a higher diabetes health literacy level than those not close to a person with diabetes, it is conceivable that the quality of information obtained by the person with diabetes is better than the general information easily available to the public. Further, one can postulate that the diabetes health literacy level of the person with diabetes has an effect on the person supporting the person with diabetes.

A person close to a person with diabetes would likely consider diabetes to be more relevant to him/her than a person who is not close to a person with diabetes. However, this does not mean that every person that has a person close to him/her is highly involved in the person with diabetes' life or that the two discuss elements of the disease. The majority of responses detailed tangible support as being the type of support most given across all diabetes health literacy levels. While one study states that it is the least valued, it does not mean that this requires the least amount of knowledge. In fact, to fully and effectively support a person with diabetes tangibly, at least some information and knowledge is paramount. As indicated in the fifth open-ended question which asked participants to identify what skills and knowledge made supporting a person with diabetes easier, participants largely identified information and understanding of the disease, n = 74 (60.1%).

The level of involvement in a person with diabetes' life is likely to have some effect on the type of support one gives to the person with diabetes. Someone heavily involved in a person with diabetes' life is more likely to see the effects of the chronic illness on the person with diabetes and should be more willing to support the person with diabetes. However, the supporter's intent could be affected by his/her ability. For example, if someone wanting to provide support does not know how to best support a person with diabetes, he/she might not offer support at all. He/she could not want to make the person with diabetes feel self-conscious, not want to appear incompetent, or may not feel comfortable giving the type of support the person with diabetes prefers.

Because a person with a higher diabetes health literacy level would be likely to be more knowledgeable of the disease, the more likely it is that he or she processes centrally, as information content is typically processed centrally. Further, a health-related message, especially if relevant to a person who is close to a person with diabetes, would be more likely to be processed centrally because of the person who is close to the person with diabetes' involvement in his/her life. A higher diabetes health literacy level should be indicative of more centrally processed health-related messages, but further research should be conducted to verify.

Health Literacy and Support Messages

Social support has been shown as essential to studies of human communication. Both direct and indirect links have been established between supportive acts and a person's health (Kennedy, Kiecolt-Glaser, & Glaser, 1991; Hobfall & Stephens, 1990): increased life expectancy, quicker recovery from illnesses, alleviated distress, (Albrecht, Burleson, & Goldsmith, 1994), and positively influenced self-perception, which includes "feelings of control, self-efficacy, esteem, relational closeness, and life satisfaction" (High & Steuber, 2014, p. 157). Several studies, focused on a person with diabetes, have found that increased social support of a person with diabetes reduces their emotional distress and is typically tied to better adjustment in different areas of life (Bukberg, Penman, & Holland, 1984; Hann, Oxman, Ahles, Furstenberg, & Stuke, 1995; Serovich, Kimberly, Mosack, & Lewis, 2001; Trunzo & Pinto, 2003). Further, a proficient health literacy level requires skill in four different sets (Oldfield, 2005): reading, comprehension, numeracy, and communication. Eadie (2014) specifies that communication is the most important of the four. Without effective communication of information between person with diabetes and caretaker, or person with diabetes and a friend, or any number of other scenarios, diabetes health literacy would decline.

The first research question of the study, RQ1, examined the diabetes health literacy level of those close to a person with diabetes and the type of health-related supportive message communicated by that person to a person with diabetes. This question used both quantitative and qualitative methods of analysis.

The quantitative results of the relation between the five types of support and the four levels of health literacy were interesting, although they were found in the crosstabs of the five types of support and the levels of diabetes health literacy to be insignificant. Because of the decreased sample size of this particular question, this is understandable. It is interesting that both below basic and proficient levels of diabetes health literacy contained the number of responses, n = 12, the five types of support were distributed much differently. Tangible support appeared the most for each level; n = 7 for below basic and n = 6 for proficient. While below basic support had 2 responses of informational support, proficient had none. Neither below basic nor proficient diabetes health literacy levels contained any esteem support responses, but both levels had the same number of emotional responses, n = 3. The proficient diabetes health literacy level contained 3 network responses, while below basic had 0. This could be indicative of a relation between a higher quantity of network support messages and a higher diabetes health literacy level. It could be that a higher level of diabetes health literacy means an understanding of the importance of network support, which could mean that a person with a higher diabetes health literacy level would be more likely to provide network support as they understand its importance. Although the size of the current sample allows no definitive claims, there is an indication that the ability of the person supporting a person with diabetes could have an effect on the type of supportive message he or she offers. A higher diabetes health literacy level could be indicative of ability, which could mean that a person with a higher diabetes health literacy level would be more likely to offer support beyond tangible. Further research would have to be conducted, as the sample size nor purposive sample is not generalizable in this instance.

Types of support messages, as examined in two open-ended questions (#4 and #8) had some variance, but the participants largely focused on tangible support throughout the survey. The questions asking participants to generally describe how they support a person with diabetes and to also describe a specific event where they provided support to a person with diabetes were qualitatively analyzed using High and Steuber's (2014) five types of support, plus a sixth category for those who do not provide support. The data were also analyzed through frequencies in SPSS. Results indicated that tangible support was one of the only two types of support to be used by supporters at all four levels of diabetes health literacy, with the other type of support being emotional. Tangible was the dominant type of support in all comparisons of diabetes health literacy levels.

When the category of those who do not support a person with diabetes was eliminated, tangible support was found to be the primary support message chosen across all of the participants' diabetes health literacy levels. Because it is the most concrete and the easiest to accomplish, this is understandable. Those with a basic diabetes health literacy level, the average level of diabetes health literacy across the survey, strongly employed tangible support messages compared to all other levels of diabetes health literacy as well. This is a significant finding, and important for health practitioners to note; this could affect the way treatment of diabetes is handled. For example, if tangible support is the type of support most often given to a person with diabetes, and is based on a need for information as show in the additional analyses, a health practitioner could help both the person with diabetes and the person supporting a person with diabetes bridge the knowledge gap by requesting both attend a medical appointment; this would provide the medical practitioner with the opportunity to explain and demonstrate other ways one can support a person with diabetes that may offer even more value to the health outcomes of the person with diabetes.

Several of the eligible responses detailed a blood glucose event. According to WebMD, the blood glucose test “measures the amount of a type of sugar, called glucose” in a person’s blood (2013). No participants explicitly mentioned “blood glucose” but did reference “blood sugars” or “sugar levels.” Still others spoke of the need for food or snacks that kept the person with diabetes from feeling lightheaded in a blood glucose event. This included both simple references to the need for food and juices and the description of an event where the participant fetched something to help the person with diabetes feel better. It is interesting that the participants overwhelmingly identified “blood glucose” as “blood sugars,” even though the American Diabetes Association describes it as “blood glucose.” One technological advancement, the continual measuring of blood glucose (or blood sugars, as the participants would state) is officially known as the Continuous Glucose Monitor (NIDDK, 2013). Further, the meters used to test the levels of glucose, or sugar, in the blood are named glucose monitors. Because the majority of the names of diabetes-related technology references glucose, rather than sugar, it is interesting that the participants so closely identify diabetes with sugar rather than glucose. Some websites, like Mayo Clinic, describe “blood sugar (blood glucose)” testing (2012). This could be, in part, due to the design and intent of the two sites, but can easily cause or impact confusion. While the ADA site focuses solely on diabetes, the Mayo Clinic covers a wide range of diseases. It could be assumed that the explanations on a website devoted to the chronic illness would be more specific, and medically accurate, than one for general consumption. However, the fact that credible sources use semi-professional terminology, compared to professional terminology, is interesting. A person looking to expand his/her knowledge of diabetes might visit a website he/she thinks is credible, but if the website uses the semi-professional term, the person will be likely to use that same term. The term “blood glucose” would typically imply a person familiar with diabetes, while a person using the term “blood sugar” might be looked at as someone unfamiliar with the illness. Because there are more than one

It would be interesting to see how a person with diabetes, who has had the chronic illness for several years, might process new information from a person supporting him/her. Many participants responded that they supported the person with diabetes by focusing on how the person with diabetes should take care of him/herself. Several of the participants felt that this was a supportive act, as evidenced by their responses to the questions asking the participants to describe acts of support. However, a person with diabetes might not view new information, which could be different from what has worked for her for the last few years, or decades in some cases, as a supportive message. One participant described a situation where support was attempted, but was unsuccessful because of the person with diabetes’ attitude based on his knowledge.

> I was sitting with my father in the living room trying to convince him to change his eating habits. I explained how he could take it slow at first and not give up his favorite foods completely. Maybe substitute them with healthier alternatives. I used the example of buying whole wheat tortillas. He looked at me said that he was going to die fat.

Several participants stated that the person with diabetes had his/her diabetes under control. Many times, the same participants stated that they did not provide support to the persons with diabetes. This could be that the participants felt that it was not needed to provide support because of the person with diabetes’ control of the illness.

According to High and Steuber (2014), “Whereas emotional support may be the most desired type of support, tangible support may be the least valued” (p. 161). In this particular sample, tangible support was the norm, and value was not examined. High and Steuber (2014) state that informational and emotional support may be the most wanted of the five types as well as the most received. Informational and emotional support were not observed as the most received types of support in the present study, however. Overwhelmingly, tangible support was described as given when the participants were asked to both generally describe how they support a person with diabetes and to specifically describe an event where they supported the person with diabetes. This may be because it is the easiest to achieve; for example, practically any adult can change a battery in an insulin pump or fetch some juice from the refrigerator at a person with diabetes’ request. High and Steuber (2014) noted that support in the forms of network, tangible means, and esteem may not apply to every situation. They cite Reinhardt, Boerner, and Horowitz’s 2006 study, stating “The receipt of tangible support has even been associated with decreased well-being.” In the present study, the primary type of tangible support, when described by a participant, was food-related. Some participants described support as taking away a piece of cake from a person with diabetes or something similar. Of course, to many people, having things taken away that are wanted would not be considered support. It would be interesting in a future study to gauge differing perceptions of support between a supporter and the person with diabetes’ perspective as related to measures of well-being.

While tangible support was the most common type of support offered, the majority of responses (60.1%) to the question asking participants to describe what skills and knowledge are most important to support a person with diabetes indicated that participants felt that information and knowledge were the most important elements to supporting a person with diabetes. Participants widely identified their responses with a need for “basic knowledge” or “knowledge about the disease.” One participant stated that basic would be needed “in the case that something goes wrong.”

The overall level of diabetes health literacy in the sample was 11.03, which falls into the second-lowest category of health literacy – basic. According to High and Steuber (2014), emotional support is the most desired type of support. Because information and knowledge were the most common responses to the question asking participants to describe what was needed to support a person with diabetes, it could be quite difficult for a person to properly support a person with diabetes emotionally if they do not have the correct knowledge.

Emotional support messages are important to those who are diagnosed with a chronic illness. Baek, Tanenbaum, and Gonzalez (2014) state that psychosocial resources, such as emotional support, consistently correspond with better health in multiple ways. As a person with diabetes is already battling a chronic illness, that oftentimes cannot be reversed or cured, and where the most hopeful outcome is typically control, having options to increase health in alternative methods is quite important. Further research is required, however, to effectively reach a conclusion.

Diabetes Health Information Sources - Professional

RQ2a focused on the type of support messages used by those who employ health professional information sources. The results indicated that there was no significant relationship between the use of a health information source and a particular type of support. In one study (Shea-Budgell, Kostaras, Myhill & Hagen, 2014) researchers found that patients seeking health-related information were more likely to obtain information from a professional health source, like a doctor. This was not, however, the case in the present study examining supporters’ sources of health information. Only 24 of the respondents (22.2%) stated that they used health professional information sources, and 10 of those participants indicated that they did not provide any type of support (41.7%). Responses containing more than one type of support were analyzed using each type of support. Because of the small sample size of 24 responses stating they utilized health professional sources compared to the 74 responses describing non-health professional sources, an even comparison could not be conducted on the two sets of data.

It was surprising to see that, of those who identified their health informational sources as professionals, the majority of respondents stated that they did not provide support. This could possibly be that, while they showed no support being given to a person with diabetes in certain open-ended responses, participants felt that selecting a socially appropriate response related to health information source would be best. The question was designed to let participants describe health information sources without any prompts, but it is possible that participants were mindful of what could be considered socially appropriate and wrote those sources in their responses.

Only 14 responses identified the source as a health professional and as giving one of the five types of support. Although not significantly related, the two categories of support most utilized by those who seek out information from health professionals, whether it be in person, printed, or online, were tangible, n = 8 (57.1%) and informational, n = 3 (21.4%). Tangible support was the most common type of support given across all levels of diabetes health literacy, so for it to have the highest frequency here was understandable. A health professional source might be more likely to describe certain ways to help a person with diabetes. For example, many of the websites focusing on diabetes, including the American Diabetes Association and WebMD, provide a list of symptoms of events relating to diabetes and treatment options. In addition, a person using a health professional source might be more likely to give informational support because of the information given to the person by the health professional source.

Because the majority of participants identified their health professional sources as credible, including the American Diabetes Association website, WebMD, and an endocrinologist among others, it can be assumed that the health professional sources are well-established within their fields.

Motivation and ability, two key components of the Elaboration Likelihood Model (Petty & Cacioppo, 1979; Chmielewski, 2012) are both required when attempting to process information, particularly health-related information, centrally, regardless of the type of support attempted. While informational support was assumed to be indicative of central processing, results from the survey showed that those with proficient diabetes health literacy, the highest level, did not provide any informational support. It could be that while the person supporting a person with diabetes knows that the person needs support, he/she has had interactions in the past where providing informational support was not beneficial. For example, several participants explained scenarios in which they talked to the person with diabetes and gave advice on how to handle the disease. However, in these cases, the persons with diabetes did not take the advice but generally remarked that they would do what they pleased. In fact, those with a proficient diabetes health literacy level identified that they provided tangible support, network support, and emotional support only.

The closeness between someone supporting a person with diabetes and the person with diabetes was operationalized in the present study as frequency of interaction. How close the two people are could affect the ability or the motivation of someone supporting a person with diabetes. If someone is closer to the person with diabetes, he/she might feel more confident or capable of providing support, whereas someone who is not as close to a person with diabetes might not have that same confidence. In the present study, the majority of participants identified the person with diabetes as a parent, n = 42, followed by a tie between grandparent and friend, n = 25, and finally, significant other, n = 3. Because the majority of persons with diabetes were family members older than the participants, the type of support might differ between the groups of those supporting a family member (e.g., child to parent) and those supporting a friend (e.g., peer to peer).

Diabetes Health Information Sources – Non-Professional

Although it was not found to be significant, RQ2b focused on the type of support messages used by those who employ non-health professional information sources. The majority of respondents, n = 74, identified themselves as utilizing non-health professional sources (68.5%). The majority of these 74 participants gleaned their information from the person with diabetes themselves (68.9%), the Internet (25.7%), and academic coursework (13.5%). Interestingly, these participants also were more likely to support their person with diabetes tangibly (64.1%) compared to those who obtain health information from a health professional or from those who do not support a person with diabetes. The fact that so many participants identified the person with diabetes as the primary source of health-related information was quite interesting, and in and of itself warrants future research.

Tangible support was, by a margin, the type of support reported most often by those who use a non-health professional source. Specifically, many of the participants who supported the person with diabetes with tangible means made statements about the support they give being food- or sugar-related. One participant stated that his primary source of information came “from my parents.” He had previously identified “parent” as being the person closest to him with diabetes. When asked to describe the ways he supported his parents, he stated, “make sure he doesn't et to many sweats [sic].” Another participant described how she supported the person with diabetes, “I support the person with diabetes by never offering things to her that she cannot eat and to remind her to take her pills.” She also stated that,

> Primarily I get my information about diabetes from a person who has it. I find that a person’s real life experiences makes the information more reliable than information found through other sources. I also would believe that a person diagnosed with diabetes would be well informed from their doctor, therefore more reason to believe in information is reliable.

The focus on tangible support messages, specifically the food-related and sugar-related statements, from those who use non-health professional information sources, often the person with diabetes, is interesting. This could be, in part, because of the information the person with diabetes gives the person supporting. If a person with diabetes goes to the doctor, receives information, and gives that information to the person supporting her, then the information that is relayed to the person supporting the person with diabetes is filtered through the person with diabetes’ frame of reference and what he/she thinks is important. If the person with diabetes perceives knowledge of food-related and sugar-related ideas as most important, then that will be the information he/she is sure to disseminate to the people who are attempting to support him/her. The person with diabetes’ own diabetes health literacy level then becomes paramount.

The type of support messages used by participants to support a person with diabetes was primarily tangible. Because of the concreteness of providing tangible support, and because of the identification of health-related information sources being primarily non-professional, namely the person with diabetes, it is likely that the participants provided tangible support more often to the person with diabetes because of information he/she had received from the person with diabetes, and because of the relative ease of giving tangible support.

It was interesting that the primary source of health information across the sample was the person with diabetes, yet many of the participants' responses described persons with diabetes who did not care, or a person with diabetes who had an attitude of stubbornness or pride. If the person with diabetes does not seem to care enough to take care of herself, yet she is the primary source of health-related information, it is possible that the only way a person can feel confident supporting the person with diabetes is through tangible means, which, in this case, seems to be the easiest way to provide support. Nonetheless, according to High and Steuber (2014), tangible support is the least valued by the person with diabetes; it could be that the person with diabetes may not even feel supported by a person's actions. For example, several participants stated that the way they support the person with diabetes close to them is by not allowing him/her to eat sweets or by feeding the person with diabetes only healthy foods. To an average person, having things they enjoy taken away from her would not be considered support. Of course, it is possible that tangible support could have different dimensions, which could affect how persons with diabetes gauge the value.

Because tangible support is the least valued, according to High and Steuber (2014), there are implications for both the persons supporting a person with diabetes and medical practitioners. It could be important for medical practitioners to encourage people who support a person with diabetes to attend medical appointments with the person with diabetes. This would give medical practitioners the opportunity to different ways to support a person with diabetes directly to a supporter, rather than hoping that the patient will let the supporter know what was said. Further, while the support may not be valued by the person with diabetes, it does not mean that the supportive message is not valuable.

Because of a lack of information about the illness, or perhaps an unwillingness to make the person with diabetes uncomfortable by asking further questions (as more than one participant noted in their open-ended responses), the ability of the person attempting to support a person with diabetes can be limited. This assumption is based upon the idea that those seeking to support a person with diabetes prefer to utilize health professional sources, or are purposely seeking information to process centrally. For some, a brief look, or basic understanding of the information needed in order to support a person with diabetes would be sufficient.

While the majority of the participants who directly support a person with diabetes would likely be assumed as being highly motivated, this might not always be the case. For example, many participants stated that the most difficult thing in supporting a person with diabetes was the person with diabetes' attitude. The category of attitude was composed of those who stated stubbornness, pride, and unwillingness to do something generally perceived as beneficial to their health. Because this was apparent across many of the participants' responses, it would not be a stretch to assume that this could affect the respondent's motivation to process health-related information as he/she attempts to support the person with diabetes.

A common problem with diabetes is the control of the disease. Control is achieved through medication, exercise, blood glucose monitoring, and diet. Wang, Song, Ba, Zhu, and Wen, (2014) cite previous research (Asha & Mohan, 2004) and state "specific interventions aimed at improving patients' knowledge can improve diabetes control" (p. 2357). Other research has found that the tighter control a person with diabetes has on blood glucose, that the risk for diabetes-related complications is significantly decreased in multiple areas: progression of retinopathy, progression of nephropathy, and peripheral neuropathy. If the person with diabetes does not know how certain foods affect his/her blood glucose, how to best control his/her blood glucose levels, or the best way to raise blood glucose in a hypoglycemic event, it is unlikely that a person supporting the person with diabetes, who receives information from the person with diabetes, will have accurate knowledge.

However, while the majority of participants obtained their information from a person with diabetes, 20 of the 51 responses including the person with diabetes as the source of information also included at least one other source (39.2%). Further, of the 20 responses including a person with diabetes as one health information source and one other source, 12 responses stated that the other source was a health professional source (60%). Thus, according to this particular set of data, while the majority of responses indicated a non-professional health information source, typically the person with diabetes, several of the 51 responses, n = 12 (23.5%) also indicated that the participant used a health professional source in addition to the person with diabetes. This indicates that the person with diabetes is not the sole source of information for many people. This also shows that, while the accuracy of information a person with diabetes gives to a person supporting her is imperative, that it is not only on the person with diabetes to provide this information.

Chmielweski’s (2012) study seems to indicate that high involvement, based on a person’s various activities of support that reflect cognitive and behavioral participation in the person with diabetes’ life, would be considered a central cue in the Elaboration Likelihood Model. Likewise, a person having a low involvement (not showing support) could be indicative of a peripheral cue, and subsequently, peripheral processing of a message, or perhaps it could be that the person is not processing the message at all. Miniard, Dickson, and Lord (1988) state that the message is typically centrally processed (1988), as long as the receiver of the message has a high involvement. If a person were to obtain incorrect information, regardless of health information source, and process it centrally, the person would still not have a higher diabetes health literacy level, which could affect the support he or she could provide to a person with diabetes. If the person supporting the person with diabetes does not have the ability to process the messages, supportive messages would not be able to be communicated.

More research is required to examine the issue further, as neither RQ2a nor RQ2b had significant findings.

Additional Analyses

Two questions not directly related to the hypothesis or research question were asked. One question asked the participants to describe the skills and knowledge that a person needed to support a person with diabetes. The second question asked participants to describe what made it more difficult to support a person with diabetes.

Responses to the question asking participants to identify the skills and knowledge needed to support a person with diabetes overwhelmingly stated information and understanding were the most needed. While a person with diabetes might be close to someone attempting to support her, she might not share the information given to her by the doctor to the person attempting to support. Because of this, the person attempting to support may not feel confident in communicating about diabetes and providing a particular type of support or any support at all. Further, a person with diabetes might expect support solely because the person supporting is a close family member or friend, without regard as to the knowledge that the person supporting currently has. Since the majority of respondents stated that their primary health information source was the person with diabetes, it is important for the person with diabetes to realize this and to examine the information she communicates to the person attempting to support her.

An interesting feature of many responses to the second question, asking participants to describe what made it more difficult to support a person with diabetes, was that participants largely focused on external attributes rather than internal attributes. For example, the majority of responses were fixated on the person with diabetes' attitude, rather than the person supporting either not understanding or his/her own attitude. This could be because someone supporting a person with diabetes might feel that the illness is something that should be controlled by the person with diabetes without outside interference.

Having a lack of information was a frequent response as well. This was reflected in the question asking participants to identify what skills and knowledge made it easier to support a person with diabetes. A person who is not confident in the information he or she does have, if he or she has information, could be less likely to offer a form of support.

Another common response was that the person supporting the person with diabetes felt he/she was not capable of properly supporting the person with diabetes because he/she did not have diabetes. This makes sense, as many times we try to sympathize with others when going through some kind of hardship, but are told that we couldn't possibly know how the hardship felt. Because of this, a societal barrier of sorts is created, further generating a feeling of incapacity and unwillingness to communicate.

Strengths and Limitations

One of the many strengths of this study was the initial sample. While only 95 participants were asked the qualitative questions because of their relationship to someone with diabetes, there were a total of 212 participants' levels of diabetes health literacy analyzed, which gave strength to the analysis of H1. Further, the design of the survey was also strong, particularly with the skip-logic survey question design and mixed-methods approach to the analysis of the questions. The demographics of those surveyed were fairly representative of the population, with a wide ethnic and age distribution. This ethnic, age, and educational diversity enhances the validity of the responses and serves to decrease a bias that might have occurred otherwise.

Yet another strength was noted in the ability of respondents to provide their answers to the open-ended questions, providing a depth to the otherwise quantitative information provided. Because each question asked the participant what he/she felt or thought without prompts, the participant was able to honestly evaluate what he/she felt appropriate and respond as such, rather than responding with what he/she felt the researcher might be asking for if further prompts had been provided.

Another strength was that while many participants responded briefly, many others provided extended narratives. These extended narratives further added to the depth of the research. Further, the ability of the participants to explain the types of support they show as well as providing examples, rather than selecting from a pre-determined list of types of support, gave the researcher a much clearer picture of the types of support given to a person with diabetes.

Of course, as with any research, there were several limitations. First, while a purposive sample, only 95 participants interacted with a person with diabetes they were close to often. Further, the survey for this study was administered via the Internet in a lab on campus. This could have excluded any potential participants who only have the time to attend classes on campus and nothing more. The survey was only presented to certain on-campus lectures and was also not presented to any online-only courses, limiting the number of potential participants as well. Certain questions further limited the sample, particularly when examining the types of support and different health information sources. Further, because of the nature of a survey, follow-up questions were not able to be asked. Several responses could have easily been clarified had an interview been utilized as a part of the method. Because of this, the generalizability of this study is limited.

The questionnaire was completed primarily by young college students, with the average age being 23 years old. The relationship most reported as being the person with diabetes was that of a parent, followed by grandparent, friend and then significant other. Because of this, a limitation is that other variations of relationships were not examined. Different types of support might be used depending on the relationship of the person supporting a person with diabetes and the person with diabetes.

Having no information related to the physical distance between the person with diabetes and the person offering support was another limitation. Participants were not asked the physical distance separating them from the person with diabetes, which could affect the types of support offered. Further, “closeness” was operationalized as “frequency” in this particular study. While closeness was considered based off of the frequency of interactions between the person with diabetes and the person supporting a person with diabetes, a scale was not utilized in determining closeness quantitatively.

Among the sample, two participants self-identified within the qualitative responses as not only being a supporter of a person with diabetes but being a person with diabetes themselves. While a small percentage, this could have affected the results.

Another limitation was that the survey was only offered in English and, in some cases, the questions were not necessarily understood by the participant. When asked to describe a specific interaction where the participant interacted with and provided support to the person with diabetes, responses included phrases like, “I do it all the time.” Another question asked the participant to identify what makes it difficult to support a person with diabetes. One response stated, “Try not to let him extend.” Thus, the participant’s understanding of the English language could have inhibited otherwise coherent responses to the questionnaire.

Another limitation to the study could be that, although three coders were used to analyze the open-ended questions, the researcher served as a coder and, being a person with diabetes, could have a bias in conducting analysis.

Future Research

There are many opportunities for future research that are identifiable from this study alone. Future research should examine the accuracy of the information a person with diabetes communicates to the person attempting to support her, as well as the topics of the information, and how these two factors affect the types of support messages. It is important to discover what types of support should be offered by a person supporting a person with diabetes. The ability of the individual supporting a person with diabetes is important to consider as well, particularly as some people may not be able to provide the types of support a person with diabetes most needs.

The final open-ended question asked participants to describe a specific interaction with the person with diabetes where they provided support to the person with diabetes. While a person with diabetes may talk about specific foods or drinks being “for my diabetes,” the person supporting the person with diabetes may not know how the specific foods or drinks hurt or help the person with diabetes’ illness. Because several participants also indicated that they use a combination of non-health professional and health professional sources, it would be interesting to see how a person uses the two sources in comparison.

High and Steuber (2014) examined the differences between the levels of desired and received support and found that, in all but one type of support, people looked for more support than they received. The discrepancies between the levels of desired support and received support was not examined in the present study, but should be studied in relation to diabetes in future research. Another avenue of future research should examine the relationship of type of support to the frequency of that type of support used when supporting a person with diabetes. Another direction future research should take is to look at the type of relationship between the person with diabetes and the person supporting the person with diabetes (child to parent, friend to friend, etc.) in relation to the types of support.

Research should also examine the types of support further. While the quantitative portion of RQ1, the crosstabs, did not reveal any significant findings regarding the level of diabetes health literacy and the type of health-related support message communicated to a person with diabetes when compared with all five types of support, tangible support was found to be the primary form of support given to a person with diabetes in qualitative analysis, which is significant in that prior research had identified it as the least valued by patients with illnesses (High & Steuber, 2014). This could be partially because of the sample size. It is likely that the diabetes health literacy level of the person supporting a person with diabetes affects the type of support given to the person with diabetes. It is also likely that the diabetes health literacy level of the person with diabetes has a large effect on a potential supporter, as well as the types of support given to the person with diabetes, as the majority of participants identified the person with diabetes as their primary source of information. Future research should examine the above, as the implications for the person with diabetes could be quite significant.

Diabetes health literacy should be examined in future studies in comparison with the information source used, and how the information source selected impacts processing of a message. The Elaboration Likelihood Model could be used to study this particular idea. As mentioned earlier, the ability of the person attempting to support a person with diabetes could greatly affect the type of support message used. If a person does not have a certain level of ability, it could be that he/she is incapable of communicating the support messages most needed by the person with diabetes.

Another direction future research should take would be to offer new diabetes research information to persons who are close to a person with diabetes, as well as to persons who are not close to a person with diabetes to compare the information retention rates and overall processing of information. Elaboration Likelihood Model could also be utilized here to examine the differences in processing the new research information related to diabetes.

This is the first study to examine how support is communicated to a person with diabetes while also examining the role of health literacy. One key finding was the prevalence of tangible support throughout participants' open-ended responses. Although previous research has deemed tangible support the least valued, it is clear that it is widely used. This is important information for medical practitioners as they look to create communities of support for well-being and reduce recurrences of diabetes-related illnesses. Another key finding was the discovery that, of all health-related diabetes informational sources mentioned, the most common source of health-related diabetes information was the person with diabetes. This is also important information for medical practitioners as they attempt to provide quality diabetes-related health information, and is important information for the person with diabetes to understand, as he/she can greatly affect the level of knowledge and skill set of someone attempting supporting him/her. Finally, H1, which examined the relationship between closeness to a person with diabetes and the effect on the supporter's diabetes health literacy level, was supported. This is important for both the person with diabetes and medical practitioners to understand. Since the diabetes health literacy level is higher for someone supporting a person with diabetes than someone not supporting a person with diabetes, it is important for the person with diabetes to realize that he/she affects the diabetes health literacy levels of people surrounding him/her, which could affect the types of support given.

Appendix A

Tables

Table A.1

Relationships of Participants and the Person with Diabetes

Relationship	**Frequency**	**Percent**
Parent	42	44.2
Significant Other	3	3.2
Grandparent	25	26.3
Friend	25	26.3
Total	**95**	**100.0**

Table A.2

Crosstabs of Diabetes Health Literacy Levels and Types of Support

	Informational	**Emotional**	**Esteem**	**Network**	**Tangible**
Below basic	2	3	0	0	7
Basic	4	4	1	4	15
Intermediate	4	2	1	5	11
Proficient	0	3	0	3	6
Total	**10**	**12**	**2**	**12**	**39**

Table A.3

Person With Diabetes – Age Ranges

Age Range	**Frequency**	**Percent**
18-28	14	14.7
28-38	1	1.1
38-48	8	8.4
48-58	38	40.0
58-68	15	15.8
68-78	13	13.7
78+	6	6.3
Total	**95**	**100.0**

Table A.4

Participant Gender

Gender	**Frequency**	**Percent**
Male	78	36.8
Female	134	63.2
Total	**212**	**100.0**

Table A.5

Participant Ethnicity

Ethnicity	**Frequency**	**Percent**
Caucasian	56	26.4
African American	52	24.5
Asian	31	14.6
Hispanic	56	26.4
Other	17	8.0
Total	**212**	**100.0**

Table A.6

Participant Education

Education	**Frequency**	**Percent**
High school	19	9.0
Some college	116	54.7
Associate’s degree	61	28.8
Bachelor’s degree	16	7.5
Total	**212**	**100.0**

Table A.7

Participant Diabetes Health Literacy Levels

Health Literacy Level	**Frequency**	**Percent**
Below basic	47	22.2
Basic	75	35.4
Intermediate	66	31.1
Proficient	24	11.3
Total	**212**	**100.0**

Table A.8

T-test Results Comparing Diabetes Health Literacy Levels of Those Who Are Close to and Interact With a Person With Diabetes' Against Those Who Are Not Close With a Person With Diabetes.

Close to a PWD?	**n**	**Mean**	**SD**	**t**	**df**	**p**
Yes	95	11.62	2.88	2.804	210	0.006*
No	117	10.55	2.68			
Total	**212**					

*p < 0.05

Table A.9

Frequencies of Types of Support

Support Type	**Frequency**	**Percent**
Informational	18	10.2
Emotional	18	10.2
Esteem	2	1.1
Network	17	9.6
Tangible	69	39.0
Does not provide	53	29.9
Total	**177**	**100.0**

Note: Data taken from open-ended questions #4 and #8 and combined.

Table A.10

Crosstabs of Health Information Sources and Types of Support

	Informational	**Emotional**	**Esteem**	**Network**	**Tangible**
Health professional	1	1	1	3	8
Non- health professional	9	9	1	9	25
Does not support	0	2	0	0	6
Total	**10**	**12**	**2**	**12**	**39**

Appendix B

Survey Questionnaire

Please answer the following questions honestly and completely. The information you provide will not be linked to your name, your ID number, or any other information that will identify you as the respondent. The survey will take an estimated 30 minutes to complete.

Do you have someone who is close to you and with whom you interact on a regular basis (at least once a week) that has been diagnosed with diabetes?

Yes No

1. Who is the person who is close to you that has diabetes?

   Parent Sibling Spouse Significant Other Grandparent Friend

2. What is his/her age?

   18-28 38-48 48-58 58-68 68-78 78+

3. What type of diabetes does he/she have?

   Type 1 (sometimes called juvenile-onset) Type 2 (sometimes called adult-onset) Gestational I don't know

4. Please pick a treatment that is closest to how his/her diabetes is treated.

   Insulin (1-2 times a day) Insulin (3+ times a day) Insulin pump Tablets (oral medication) Diet with or without exercise I don't know

5. How often do you interact with this person on a weekly basis? This could mean talking face-to-face, on the telephone, via Skype or FaceTime; emailing, messaging on Facebook, etc.

   Daily 6 times a week 5 times a week 4 times a week 3 times a week 2 times a week 1 time a week

6. How do you most often interact with him/her?

   Face to face Telephone (phone calls) Text messaging Email Social media Other ______________

There is no right or wrong answer to the following set of questions. Please answer with what you think or feel, not what someone else might think or feel. Please be thorough in answering.

7. Describe what you know about the person's diabetes.
8. Where do you get your information about diabetes? (please be specific)
9. Why do you use these sources of information?

10. Describe the ways you support the person with diabetes.
11. What skills and knowledge do you need to support a person with diabetes?
12. What makes it easier to support a person with diabetes?
13. What makes it difficult to support a person with diabetes?
14. Describe a specific time when you interacted with the person with diabetes and provided support. Try to record as much as possible, as accurately as possible. Please give the context of the situation (what happened before the conversation, what led up to the conversation, the setting, etc.) as well as describe what was said and what happened.
15. On a scale of 1 to 10, where 1 means "no change at all" and 10 means "an extreme change."

    To what extent did this interaction affect:

    A. What you know about diabetes?

    B. What you feel about diabetes?

    C. How you can support the person with diabetes?
16. Is there anything you think you could have done to be more supportive? What is that?
17. A person with diabetes is told to follow the sliding scale shown here. The sliding scale indicates the amount of insulin the person with diabetes would take based upon his or her blood sugar levels.

If blood sugar is:	Units of insulin:
130-180	0
181-230	1
231-280	2
281-330	3
331-380	4

How much insulin would a person with diabetes take for a blood sugar of 295?

ANSWER _____ units

18. After seeing the doctor, a person with diabetes is given the following instruction to lower a high blood sugar level before a meal:

"Starting with a blood sugar of 120, take 1 unit of Humalog insulin for each 50 points of blood sugar."

How much insulin should a person with diabetes take for a blood sugar of 375?

ANSWER ______ units

19. How often do you do the following:

1 (never)	2	3	4	5 (always)	Does not apply

A. Remind the person with diabetes to take insulin shots?
B. Let the person with diabetes know it is difficult to take insulin shots?
C. Ask the person with diabetes about the results of their blood tests?
D. Ask the person with diabetes about the results of their blood sugar tests?
E. Remind the person with diabetes to test their blood sugar?
F. Watch the person with diabetes for signs that their blood sugar is low or high?
G. Encourage the person with diabetes to eat the right foods?
H. Let the person with diabetes know you understand how important it is to eat right?
I. Ask the person with diabetes if certain foods are okay for them to eat?
J. Remind the person with diabetes about sticking to their meal plan?
K. Join the person with diabetes in eating the same foods?
L. Avoid tempting the person with diabetes with foods or drinks they shouldn't have?
M. Eat at the same time as the person with diabetes?
N. Buy special foods the person with diabetes can eat?
O. Tell the person with diabetes not to eat something they shouldn't?
P. Suggest ways to exercise with the person with diabetes?
Q. Invite the person with diabetes to join in exercising with you?
R. Exercise with the person with diabetes?
S. Are available to listen to concerns or worries about diabetes care?
T. Encourage the person with diabetes to do a good job taking care of their diabetes?
U. Let the person with diabetes know that you understand that sometimes he/she makes mistakes in taking care of their diabetes?

Choose one answer for each question of the following.

21. The diabetes diet is:
    a. the way most American people eat
    b. a healthy diet for most people
    c. too high in carbohydrate for most people
    d. too high in protein for most people
22. Which of the following is highest in carbohydrate?
    a, Baked chicken
    b. Swiss cheese
    c. Baked potato
    d. Peanut butter
23. Which of the following is highest in fat?
    a. Low fat milk
    b. Orange juice
    c. Corn
    d. Honey
24. Which of the following is a “free food”?
    a Any unsweetened food
    b. Any dietetic food
    c. Any food that says “sugar free” on the label
    d. Any food that has less than 20 calories per serving
25. Glycosylated hemoglobin (hemoglobin A1) is a test that is a measure of person with diabetes’ average blood glucose level for the past:
    a. day
    b. week
    c. 6-10 weeks
    d. 6 months
26. Which is the best method for testing blood glucose?
    a. Urine testing
    b. Blood testing
    c. Both are equally good
27. What effect does unsweetened fruit juice have on blood glucose?
    a. Lowers it
    b. Raises it
    c. Has no effect
28. Which should not be used to treat low blood glucose?
    a. 3 hard candies
    b. 1/2 cup orange juice
    c. 1 cup diet soft drink
    d. 1 cup skim milk
29. For a person in good control, what effect does exercise have on blood glucose?
    a. Lowers it
    b. Raises it
    c. Has no effect
30. Infection is likely to cause:
    a. an increase in blood glucose
    b. a decrease in blood glucose
    c. no change in blood glucose
31. The best way to take care of a person with diabetes’ feet is to:

a. look at and wash them each day
b. massage them with alcohol each day
c. soak them for one hour each day
d. buy shoes a size larger than usual

32. Eating foods lower in fat decreases a person with diabetes' risk for:
    a. nerve disease
    b. kidney disease
    c. heart disease
    d. eye disease
33. Numbness and tingling may be symptoms of:
    a. kidney disease
    b. nerve disease
    c. eye disease
    d. liver disease
34. Which of the following is usually not associated with diabetes:
    a. vision problems
    b. kidney problems
    c. nerve problems
    d. lung problems
35. Signs of ketoacidosis include:
    a. shakiness
    b. sweating
    c. vomiting
    d. low blood glucose
36. If a person with diabetes is sick with the flu, which of the following changes should he or she make?
    a. Take less insulin
    b. Drink less liquids
    c. Eat more proteins
    d. Test for glucose and ketones more often
37. If a person with diabetes has taken intermediate-acting insulin (NPH or Lente), he or she is most likely to have an insulin reaction in:
    a. 1-3 hours
    b. 6-12 hours
    c. 12-15 hours
    d. more than 15 hours
38. A person with diabetes realizes just before lunch time that he or she forgot to take his or her insulin before breakfast. What should the person with diabetes do now?
    a. Skip lunch to lower blood glucose
    b. Take the insulin usually taken at breakfast
    c. Take twice as much insulin as usually taken at breakfast
    d. Check blood glucose level to decide how much insulin to take
39. If a person with diabetes is beginning to have an insulin reaction, he or she should:
    a. exercise
    b. lie down and rest
    c. drink some juice
    d. take regular insulin
40. Low blood glucose may be caused by:

a. too much insulin
b. too little insulin
c. too much food
d. too little exercise

41. If a person with diabetes takes his or her morning insulin but skips breakfast his or her blood glucose level will usually:
a. increase
b. decrease
c. remain the same

42. High blood glucose may be caused by:
a. not enough insulin
b. skipping meals
c. delaying a snack
d. large ketones in your urine

43. Which one of the following will most likely cause an insulin reaction:
a. heavy exercise
b. infection
c. overeating
d. not taking insulin

44. What year were you born?
____

45. What is your gender?
Male Female

46. What is your ethnicity?
African American Asian Caucasian Hispanic Other
____

47. What is your highest level of education?
Some high school High school Some college
Associate’s degree Bachelor’s degree Master’s degree Professional degree/Ph.D.

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Biographical Information

Grace Ellen Brannon has a Bachelor of Arts degree in Communication Studies with a focus in Organizational Communication from the University of Texas at Arlington, earned in 2012, and is pursuing a Master's degree in Communication from the University of Texas at Arlington.

Her research interests include health communication, diabetes, health literacy, interpersonal communication, social support, and persuasion.

Grace Brannon is currently a Graduate Teaching Assistant and Instructor of Record at the University of Texas at Arlington.

She plans to pursue her doctoral degree after successful completion of her Master of Arts in Communication.