# The Semiotics of Type 1 Diabetes: A Qualitative Content Analysis of Publicly Accessible Information

by

Laura Zhao

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A Dissertation Presented in Partial Fulfillment

Of the Requirements for the Degree

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# ABSTRACT

The purpose of this qualitative content analysis was to explore the content and semiotic structure of publicly accessible type 1 diabetes information and assess what content is tailored to the adolescent and young adult population. As an effort to enhance adolescent and young adult self-management practices and outcomes, this research aimed to better understand what information is accessible to the type 1 diabetes community and the ways in which it is categorized. Framed by Greimasian semiotics, ten peer-reviewed sources were selected and coded using frequency and thematic analysis. This comparative process identified five themes including Management, Staying Alive, Type 1 How-Tos, Management is Happening, and Type 1 Management Outcomes. Collectively, these themes revealed two canonical narrative schemas within public type 1 diabetes information. These findings benefit health authorities and professionals, as they provide credible insights into the health information being communicated to and consumed by individuals living with type 1 diabetes and their loved ones.

*Keywords:* type 1 diabetes, online health information, adolescent, young adult, self-management, semiotics

# Copyright Page

# Dedication

This dissertation is dedicated to God, Yeqian, and Kelepo. First, I give all the honor and praise to God for marking my life with His goodness and supernaturally sustaining me throughout this program. Abba, You are the firm foundation of everything that I do. Thank You for the delight I have found in learning more about You and myself during these past three years. Yeqian, there could not be a more supportive husband to stand beside me and remind me of the bigger picture. Thank you for cheering me on and encouraging me to dream big. Lastly, I dedicate this dissertation to Kelepo. In our youth, you showed me how precious education is for girls and women. May every young girl have access to this gift.

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People with Diabetes (PWD)

Qualitative Content Analysis (QCA)

Type 1 Diabetes (T1D)

Type 2 Diabetes (T2D)

World Health Organization (WHO)

# CHAPTER ONE — INTRODUCTION

## Overview

The purpose of this qualitative study was to explore how publicly accessible type 1 diabetes (T1D) information is categorized. This exploration aimed to identify which content is tailored to adolescents and young adults (AYAs) with T1D, lending insights to health communication scholars to better understand how the younger T1D community is receiving communication for effective self-management in the post-pandemic landscape. The T1D community is a speech community which shares an understanding of norms that influence the interpretation of and behavioral responses to health information (Kotani, 2017). Literature has demonstrated that this speech community actively engages in OHIS behaviors related to the self-management of their chronic condition (Lee et al., 2020). The vast environment of online health information has not been explored for its semiotic content and potential impact on communicative significance among the T1D community. A comparative analysis of publicly accessible T1D information influenced by Greimasian semiotics was therefore valuable and warranted. To achieve this, a purposive sample of 1,066 documents were selected and gathered from high search volume and public Internet sources.

This chapter presents an introduction to diabetes and the ecological nature of health communication. First, a history of diabetes is reviewed. Second, health communication prior to, during, and post the COVID-19 pandemic is discussed. Next, the ways in which communication has changed among the juvenile diabetes community are presented. The problem, purpose, and significant statements of the study subsequently follow. The chapter concludes by addressing the study's definition of terms and philosophical assumptions.

## Background

The global pandemic of COVID-19 has had a tangible impact on both the delivery of health information as well as the patient-provider relationship (Doraiswamy et al., 2020). The Internet has become the pinnacle of twenty-first-century healthcare, with providers racing to adopt digital-first frameworks so they may continue to reach their patients through services like telehealth (Freberg, 2019). For patients living with chronic conditions, these events have had serious repercussions. People with diabetes (PWD) were at greater risk of contracting COVID-19 due to their compromised immune systems (Cuschieri & Grech, 2020; Chowdhury & Goswami, 2020). While there has been a growing recognition among scholars of the unique needs and psychosocial burden experienced by this chronic community, the pandemic disrupted their access to and receipt of health information (Oser et al., 2020; Stoian et al., 2020). The way in which PWD use language has possibly changed, as the way in which they access and consume health information has significantly changed (Passanisi et al., 2020). To this end, further investigation was warranted.

### Diabetes Mellitus

*Diabetes mellitus* is a metabolic disease in which the body is unable to effectively process carbohydrates, proteins, and/or fats for energy (Egan & Dinneen, 2019). A hallmark feature is recurring hyperglycemia, which is an abundance of sugar in the bloodstream due to the dysfunctional production and action of insulin (Karamanou et al., 2016). Patients are traditionally diagnosed with one of three forms, which include Type 1, Type 2, and Gestational (Tao et al., 2015). T1D is an autoimmune disease, characterized by the self-destruction of insulin-producing beta cells in the immune system (ADA, 2018). This immune dysfunction results in a devastating blow to a patient’s blood sugar levels, as insulin is the hormone responsible for healthy blood sugar management (Aftab et al., 2021). Attentive self-management is necessary to maintain healthy blood sugar levels, which requires the regular administration of insulin (Fuchs & Hovorka, 2020. While insulin administration is not a permanent solution, a cure for T1D has yet to be discovered and the chronic condition remains irreversible (Helman & Melton, 2021; Katsarou et al., 2017).

Type 2 diabetes (T2D) has different epidemiology, as it is characterized by either an excess of insulin or a resistance to it (Chatterjee et al., 2017). The outcome is dangerously high sugar levels in the bloodstream (i.e. hyperglycemia), which can send the body into a state of shock and lead to serious health complications including vision loss, chronic fatigue, cardiovascular disease, nerve damage, kidney damage, amputations, and states of comatose (Evans et al., 2021). The notable difference with T2D diagnoses is that they are reversible with clean nutrition and an active lifestyle (Pot et al., 2020). As for Gestational Diabetes, this form temporarily afflicts pregnant women and is characterized by an inability of the body to process carbohydrates (He et al., 2021; Egan & Dinneen, 2019).

Collectively, PWD are those who struggle daily with sugar imbalance (Pals et al., 2021; Roglic, 2016). They account for 10.5% of the American population, which is an estimated 34.2 million men, women, and children according to a recent report by the *Centers for Disease Control* (CDC, 2020). This number is rising and forecasted to reach 425 million American diagnoses by 2045 (Murata & Kondo, 2020). Worldwide, there are over 500 million PWD (Sun et al., 2022). Zimmet (2017) framed this grim reality by suggesting that if diabetes were a nation, it would easily overtake the United States of America as the world's third largest.

Diabetes has been afflicting society since ancient times (Barnett, 2018). The Ebers papyrus, one of the earliest Egyptian medical records with a timestamp of 1550 BC, described a disorder in which patients experienced an imbalance of water and sodium (Tattersall, 2017). This condition, *polyuria*, is a hallmark trait of T1D in which PWD experience intense episodes of thirst and excessive urination (Levy et al., 2019). Hundreds of years later in 2000 BC, the Kahun papyrus recorded a prescription for the "treatment of a thirsty woman" (Alam et al., 2021, p.1). While the ancient Egyptians clearly recognized symptoms of diabetes, the disease was not clinically identified until much later in the fifth century BC (Tattersall, 2017). Sushruta, a reputable Indian physician, was the first to characterize diabetes by the term *madhumeha*, which translated as "honey-like urine" (Karamanou et al., 2016, p. 2). His diagnosis made note of characteristics unique to diabetic urine, which included its sweet taste, sticky texture, and tendency to draw ants (Swati & Agarwal, 2015). While medical tradition during this time period acknowledged treatments for other urination dysfunctions, Sanskrit physicians posited that individuals suffering from *madhumeha* (i.e. diabetes) could not be cured (Jörgens & Porta, 2020).

Diabetes was officially labeled in the second century AD by the Greek physicians Apollonius, Demetrius, and Aretaeus (Jörgens & Porta, 2020). They borrowed from the Greek word *diabaino*, which means "to go through" and is used to describe a siphon (Ganesan, 2021, p. 1; Barnett, 2018). As diabetes is a chronic condition characterized by fluid that "does not remain in the body, but uses the man's body as a ladder whereby to leave it", Aretaeus believed *diabaino* to be an appropriate label (Aron & Aron, 2020, p. 51). Ages later in 1809, the adjective *mellitus* was added by the Scottish physician, John Rollo, to form *diabaino mellitus* (Tattersall, 2017, p. 6). Derived from the Latin word for honey, Rollo used *mellitus* to reference the sugary nature of diabetic urine (Porta, 2020). Through these events, diabetes mellitus was established as a clinical diagnosis that now extends into modern healthcare.

The road to identifying effective treatment options for diabetes and self-management has been long and substantiated by scholars. In the first century, physicians prescribed bloodletting, vomiting, medicinal plants, and physical exercises to PWD (Carter, 2017). Aëtius of Amida, a physician from Byzantium (i.e. modern-day Istanbul), was a key contributor to diabetology and proponent of these treatment standards, which influenced medical tradition well into the sixth century (Porta, 2020). Fast-forward to the sixteenth and eighteenth centuries, physicians encouraged patients to abstain from consuming salt and sugar through plant-based diets (Zajac et al., 2010). The Greeks treated "'leiouria' (urinary diarrhea) and 'dipsacos' (to die of thirst)" using remedies aimed to quench PWD's thirst through purgatives, milk, and fruit poultices (Jörgens & Porta, 2020, p. 3). These treatments were the benchmark for treating diabetes until the early 1800s, as physicians turned their attention toward chemical approaches.

The two most notable milestones in the history of diabetes were the discoveries of glucose and insulin. Michel Chevreul, a chemist from France, first identified glucose in 1815 as the sugar present in diabetic urine (Chen, 2021). He countered the medical tradition of his day, positing that the kidney was not responsible for creating glucose. Instead, he believed that PWD have a unique deficiency in which glucose is not correctly processed by the blood (Tattersall, 2017). This monumental discovery paved the way for chemical testing (e.g. Fehling's test), differentiating between T1D and T2D, and glucose monitoring tests (Zivojinovic, 2022). During this time, physicians continued to advocate that PWD exercise and consume restricted caloric diets, which were known as starvation diets (Blagosklonny, 2019). This treatment plan would later shift in the nineteenth and twentieth centuries, largely due to new research that illuminated the pancreas and its influential role in managing glucose levels (Cheng et al., 2021).

Physicians began refining and administering pancreas extracts to diabetic patients, which led to the revelatory identification of insulin in 1913 by John Homans (Wright, 2020). Soon after, Frederick Banting and Charles Best learned how to therapeutically leverage insulin (Cheng et al., 2021). In 1965, physicians were able to shift away from urine glucose testing altogether and adopt blood glucose testing with the invention of *Dextrostix*, the very first test strip for blood glucose (Hirsch, 2021). The way it worked was a substantial sample of a patient's blood was deposited on the strip's surface for the duration of one minute, before being cleared (Kesavadev et al., 2017). Glucose levels were then measured by physicians who would cross-reference the color generated on the strip with a clinical glucose diagram. It is worth noting that *Dextrostix* was initially only accessible to PWD through face-to-face appointments in a health provider's office (Hirsch, 2021). Five years later, *Dextrostix* was followed by the *Dextrometer*. This model proved to not only be more effective and affordable for patients, but it was also an upgraded digital version of *Dextrostix* that extended glucose self-monitoring to the home (Schweiger & Battelino, 2020).

Patients' ability to self-monitor their blood glucose levels quickly became a care benchmark in the 1980s, particularly for the T1D community (Schweiger & Battelino, 2020). This was also a milestone for patient-centered care, as a growing emphasis was placed on the role of disease education for effective treatment. Physicians began to recognize the role of health literacy in improving the self-management of glucose levels among PWD, influenced by the *World Health Organization's* (WHO) agenda (Pleasant et al., 2020). Glucose self-monitoring methods continued to evolve, becoming more efficient and less painful. This culminated in the very first *continuous glucose monitoring* (CGM) device, which was approved in 1999 by the United States Food and Drug Administration (Garg & Akturk, 2018). Fast-forward to the present day, treatment options available to PWD include CGM devices (e.g. Dexcom, Medtronic, FreeStyle Libre), insulin therapy, and oral blood sugar-reducing medications such as Metformin (Didyuk et al., 2021; Bailey, 2017).

## Health Communication

The landscape of health communication and the way in which medical information is shared among patients and providers has undergone a radical transformation over the past two years due to COVID-19 (Contreras et al., 2020). Prior to the pandemic, patients had direct access to providers and favored receiving health information face-to-face. After the pandemic, online sources of health information quickly became accessible staples of public health care and education (Lee et al., 2020). While these changes have appeared abrupt, society has been gradually preparing for more innovative adoption over the past several years. Scholars Kilbride and Joffe (2018) claimed that the rising value of patient autonomy in the United States is primarily responsible for the shifts that are now taking place. Historically, the medical tradition was framed by the paternalistic view that healthcare did not require the participation of the patient (Fernández-Ballesteros et al., 2019). Providers were the experts on patients' conditions and knowledge of the disease was sufficient for delivering care (Tariman & Szubski, 2015). In the 1950s, this disease-centered approach began to evolve by emphasizing the rights of patients in decision-making in healthcare (Kilbride & Joffe, 2018). Today, patients are less reliant on providers for medical information and services directly due to the proliferation of the *Internet* and social media (Smailhodzic et al., 2016). The open access to health information that online platforms now provide has profoundly impacted the modern patient-provider relationship. Scholars Vijayasarathi et al. (2019) have appropriately coined this twenty-first-century phenomenon “patient consumerism” (p. 1). Patients have become consumers of their health care, able to self-navigate medical information and services as they are needed.

In the years leading up to the pandemic, medical information was shared primarily through a mixture of face-to-face visits and health information technologies (Nomura et al., 2019; Holmgren & Adler-Milstein, 2017). The latter began to make their mark on health communication and the patient-provider relationship in 2015 (Duffy & Lee, 2018). It was around this time that patients gained increased access and authority to services through the ease of direct-to-consumer (DTC) tests (Allyse et al., 2018). Tests that had previously required a face-to-face interaction with a provider became adaptable to personal settings in which patients could self-test for a myriad of medical concerns including electrolyte levels, blood cell counts, and organ function (Kidd et al., 2016).

In addition to DTC tests, enhancements to health care quality were demonstrated through patient portals. These platforms safely enable online access to personal health information and allow for direct electronic messaging with providers (Anthony et al., 2018). Information sharing through social media and other digital applications was also gaining trust among patients and providers leading up to the pandemic (Zhao & Zhang, 2017; Tan & Goonawardene, 2017; Crook et al., 2016; AlQarni et al., 2016; Klein et al., 2015). In the midst of these developments, clear distinctions were made between *Internet* usage and telehealth usage for health care needs prior to the pandemic.

According to American Well’s (2019) *Telehealth Index Consumer survey*, only 8 percent of patients in 2019 utilized telehealth, and 66 percent were open-minded to trying it. The data identified several possible barriers to telehealth adoption pre-pandemic, including education and awareness of telehealth offerings, restricted financing, and distrust of telehealth technology present among both patients and providers. Perhaps the most notable barrier identified in the survey was a lack of persuasive arguments for replacing face-to-face visits with virtual ones (Mann et al., 2020; Dorsey & Topol, 2016). Patients were incredibly loyal to their providers and the advantages of telehealth services were not yet widely recognized (American Well, 2019). With the onset of the COVID-19 pandemic, however, telehealth quickly became a standard of care.

In early 2020, a *Pew Research Center* poll reported that the vast majority of Americans preferred accessing health information and services through face-to-face visits with providers as opposed to telehealth video visits (Anderson & Vogels, 2020). Public opinion quickly flipped in March and the months that followed, as the pandemic ensued, and virtual spaces became a staple resource for treatment. According to Hawrysz et al. (2021), telehealth usage increased by 683 percent in 2020. This rapid scale was attributed to the lack of an available COVID-19 vaccine, which meant that social distancing and quarantine mandates were the only preventative measures available to the American public at the time (Mann et al., 2021). To that end, a persuasive argument for the adoption of telehealth and virtual care offerings was made.

States simplified their license requirements for treatment given across state lines and insurance companies were prompted to extend reimbursement and collectively cover telehealth appointments (CMS, 2020; HHS, n.d.). A case report conducted by Mann et al. (2021) reported that between March and April of 2020 alone, face-to-face visits dropped by 80 percent. Conversely, the data revealed a surge in telehealth adoption “from 82 visits… to 1336” across urgent, ambulatory, and other departments within just two weeks of launching (Mann et al., 2021, p. 1133). While access and affordability to health care were relatively maintained throughout the pandemic, the adoption of this patient-facing technology was accompanied by a few unanticipated outcomes.

Prior to the pandemic, telehealth was leveraged in health contexts where either the patient-provider relationship was not the primary priority, results could be measured remotely, or access to treatment was heavily restricted (Moore et al., 2017). As the pandemic swept across the United States, telehealth was then extended to outpatient settings, surgical disciplines, and psychological care (Reeves et al., 2021). Visits requiring physical examinations were restricted in their ability to capture vital diagnostic variables such as motor capabilities, patient movements, and auscultation procedures (i.e. the act of assessing internal organ functioning with a stethoscope) (Saliba-Gustafsson et al., 2020; Chowdhury et al., 2020). Second, numerous studies reported instances of patient-provider miscommunication throughout telehealth consults (Harris et al., 2021; Drossman et al., 2021; Ghosh et al., 2020). Patients voiced a preference for face-to-face consults over telehealth due to their ability to foster deeper provider connections (Lacritz et al., 2020). In a recent study conducted by Predmore et al. (2021), the preference for in-person care held strong among American adult patients. The study discussed possible factors that may contribute to patient preferences, such as age and treatment costs. Considering how young the adoption of telehealth currently is in the United States healthcare system, new research is necessary to explore its impact on treatment delivery and health communication in the post-pandemic era.

Today, the healthcare ecosystem finds itself living in what has been dubbed by scholars “the telemedicine takeover” (Wilhite et al., 2021, p. 353). Digital health is here to stay through *remote patient monitoring*, which enables the exchange of health information and services to occur within the privacy of patients’ homes (Muller et al., 2021). Technology makes this possible through linked devices such as smartphone applications, digital watches, continuous glucose monitoring systems, smart insulin pumps, smart socks, as well as digital online communities (Johnson & Miller, 2022; Akor, 2022; Scholten et al., 2022; Contreras et al., 2020). Patients now have direct digital access to providers, more affordable medical costs, and increased autonomy. These profound transformations in the health care landscape call for new research to explore the accessibility, content, and implications of health information on specific patient populations. These findings will reveal the strategic value of health communication messages and technologies, suggesting best practices to improve health communication in digital spaces (D'Anza & Pronovost, 2022).

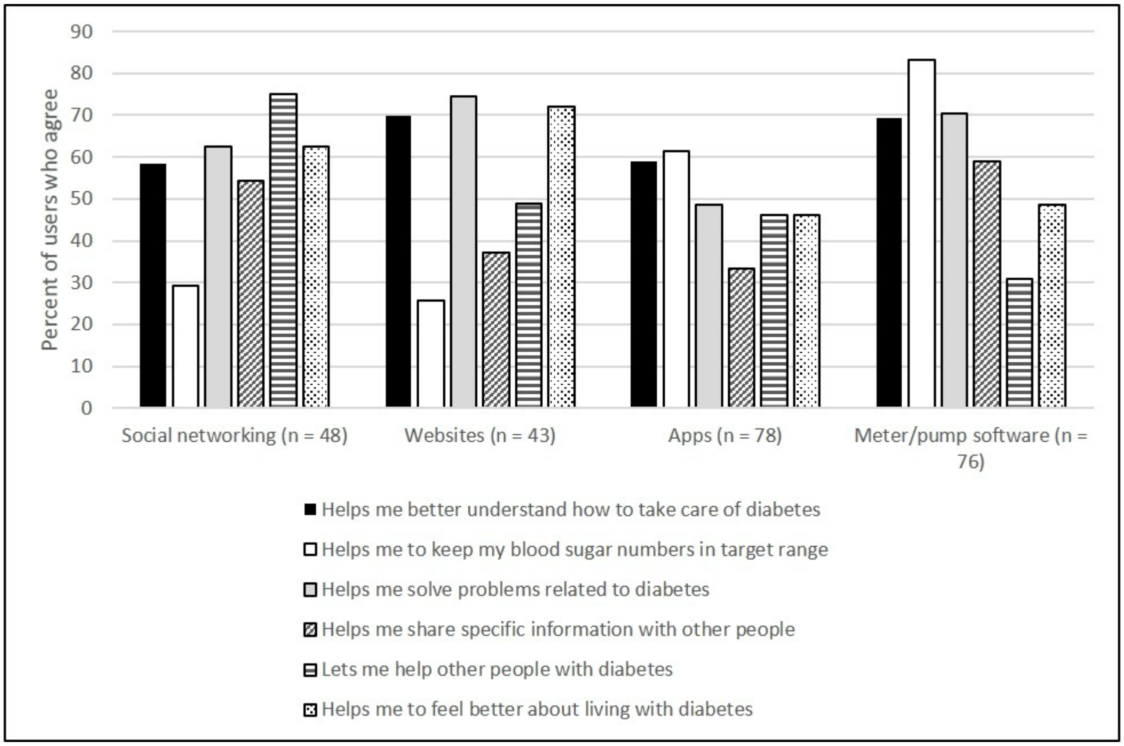
## Research Framework

The T1D community may be experiencing a "post-pandemic double burden of disease" where the strain of navigating COVID-19 has been coupled with the ever-present burden of their diabetes (Chan & Horne, 2021, p. 1). The public health mandates of quarantine and social distancing have led to a digital restructuring of the healthcare system in the United States, which has created disruptions to self-management routines for chronic patients, potentially altering the way in which PWD interact with and perceive health information (Laupacis, 2020; Heckman et al., 2020). AYAs with T1D are especially implicated in this potential double burden of disease.

According to a study conducted by Vaala et al. (2015), AYAs struggle to maintain healthy glucose levels due to hormonal changes and poor self-management behaviors. Digital applications and social media platforms (e.g. *Instagram*, *Facebook*, *Reddit*) provide them with access to diabetes-specific information, emotional support, and peer connections. The AYAs surveyed in the study reported that these technologies primarily help them to manage healthy blood sugar levels, solve problems related to diabetes, and/or help other people with diabetes (see Figure 2; Vaala et al., 2015). Considering that these findings were published prior to the COVID-19 pandemic and that the role of technology in health communication has recently undergone significant transformations, this exploratory content analysis of publicly accessible T1D information was warranted.

**Figure 2**

*Technology Functions for AYA T1D Management* (Vaala et al., 2015, p. 7)



The T1D post-pandemic double burden of disease and the digital transformation of health information was addressed through Robert Craig's (1999) semiotic tradition, which posits that communication is fully reliant on the creation and understanding of signs to share value and information. Words represent specific concepts, which may vary from person to person. As words with distinct or ambiguous meanings are used, communication can quickly break down (Craig, 2016). Semiotic theorists focus on how words are used as symbolic signs to achieve an outcome (Littlejohn et al., 2017).

This study explored publicly accessible T1D information through the theoretical frameworks of the semiotic theory of action and the ethnography of communication (EOC). Through the semiotic theory of action, this study analyzed T1D narrative components among web-based texts using Greimas's canonical narrative schema (CNS) tool (Hébert, 2019). This research approach aimed to identify what health information is being communicated, how it is organized, and what content is tailored to the AYA population. EOC established PWD as a speech community and explored health communication as a creator of T1D culture (Hepburn, 2016).

## Problem Statement

The problem is that AYAs with T1D experience substantial psychosocial stress regularly, which impacts their ability to understand key health information and follow their treatment plans. Forouhi and Wareham (2019) reported that the level of disease burden among the diabetic community ranks the highest in the United States, classifying it as "a major public health priority" that "places unsustainable demands" on AYAs and their social relationships (p. 1). A recent study conducted by Goethals et. al (2020) cited the staggering statistic that "only 17 percent of youth achieve the American Diabetes Association HbA1c goal" (p. 4). In layman's terms, 83 percent of AYAs regularly experience unhealthy blood sugar levels, which puts them at risk of serious health complications including cardiovascular disease, nerve damage, kidney damage, blindness, limb amputation, COVID-19, and mortality (Dal Canto et al., 2019). The weightiness of these projected outcomes is often compounded by mental health episodes of depression and anxiety, which have been reported by scholars to co-exist with diabetes because of the disease burden (Finney et al., 2016).

Previous studies have frequently recognized the tangible impact that these burdens have on the AYA population. According to Adu et al. (2019), self-efficacy, which is the confidence in one's ability to take care of a diagnosis, has been closely linked to effective self-management and sustained health outcomes. Their study discussed how AYAs are more likely to perform self-management behaviors when patient-centered communication, social support, and telehealth tools are present and available to them. Finney Rutten et al. (2016) described self-management as an essential criterion of patient-centered communication and care because it encourages patient participation.

AYAs are characterized as low participants during provider interactions because their minor status requires that a caregiver must accompany them to each visit in which health information is discussed and in terms that are often technical and confusing to understand (Goethals et al., 2020; Becker et al., 2018). Scholars have claimed that understanding how AYAs experience and perceive T1D is key to lifting their disease burden and promoting effective self-management behaviors (Protheroe et al., 2017). To reach this level of comprehension, it is necessary to first understand what T1D information is publicly available and accessible.

Current research literature in this area primarily focuses on the clinical aspects of T1D self-management and/or the perspectives of caregivers and health providers (Goethals et al., 2020). Scholars have not yet recognized T1D as a speech community according to the chronic condition, nor has a comparative analysis of publicly accessible T1D information been conducted to determine how health information messages are organized. These insights may be helpful in understanding the relationship between diabetes education and self-management outcomes. Therefore, the specific problem addressed by this research was the possible disease burden experienced by AYAs and how the narrative components of publicly accessible T1D information may be influencing self-management behaviors.

## Significance of Study

The chronic disease burden experienced by AYAs with T1D is a significant issue for providers and diabetes educators to address. This study benefits providers and diabetes educators by providing fresh insights into T1D as a distinct speech community, revealing what health information is accessible to PWD and the plausible implications of what is being communicated for self-management outcomes. To the researcher's knowledge, this was the first study to view T1D as a speech community on the basis of its chronicity, as opposed to the variables of ethnicity or nationality.

The dissemination of health information in the post-pandemic climate has become vastly digital through technology. Providers and diabetes educators now overwhelmingly employ telehealth and other remote patient monitoring tools to communicate with PWD. Digital platforms such as websites and social networking sites (e.g. *Facebook*, *Instagram*) have become a bedrock resource for the T1D community, providing PWD with unlimited access to health information (Vijayasarathi et al., 2019). This reality sprang up during the COVID-19 pandemic, as physical access to health providers was significantly limited (Contreras et al., 2020). While the merging of technology with health communication has been demonstrated to provide the T1D community with unlimited and timely access to diabetes information, a comprehensive understanding of the information being shared and its intended audience among the T1D community (e.g. adolescents, parents, peers, providers) was deemed critical.

The findings of this study revealed an "intersubjective understanding" of diabetes-related terms and agendas held by health authorities responsible for disseminating health information to

PWD, culminating in two consistent forms of a public T1D narrative (Craig, 2016, p. 5). These insights are significant for the tripartite relationship between AYAs, their co-managing community (e.g. parents, peers), and their health providers for three reasons. One, identifying these communication patterns enhances the ability of providers and authorities, such as the CDC, to better understand current self-management trends and outcomes by shedding light on what information is being communicated to the T1D community. Two, these insights empower parents, as they actively co-manage T1D with their AYA and help them to navigate the disease burden through online health information-seeking (OHIS) behaviors. Three, these insights afford providers and health authorities with clarity as to how publicly accessible T1D information is categorized and the implications of its categorization on the AYA population. This study is significant because it was the first to conduct a comparative semiotic content analysis of publicly accessible T1D information.

## Research Purpose

The purpose of this exploratory *qualitative content analysis* (QCA) was to examine how publicly accessible T1D information is categorized, revealing the similarities and differences among the semiotic content. The researcher was then able to narrow down which messages were tailored to AYAs, lending these insights to health communication scholars to better understand how the younger T1D community is receiving communication for effective self-management in the post-pandemic landscape. A purposive sample of publicly accessible T1D information was collected from *Internet* sources and analyzed for its semiotic content.

A *Google* search using the keywords type 1 diabetes resulted in more than two billion sources. To narrow down the sample, the keywords teen, adolescent, juvenile diabetes, medical journal, information, and community were interchangeably added. This process culminated in 10

*Internet* sources, representing a hierarchy of medical journals, peer-reviewed medical websites, and T1D nonprofit organizations. Among these sources, a sample of 1,066 documents were identified (n = 1,066). Medical journal selections were influenced by a 2017 mixed-methods study, which analyzed the semiotic code for the term diabetes by consulting two well-known diabetes journals (Dunning et al., 2017). To determine which *Internet* sources were the most popular through search volume, the Chrome extension *Keywords Everywhere* was employed. Informed by Greimasian semiotics, a QCA was conducted to identify themes.

## Definition of Terms

This study of publicly accessible T1D information necessitated an understanding of several fundamental terms. The definitions that follow offer an understanding of how these terms were used in the research.

*Adolescence:* The developmental life stage in which individuals ranging from 11 - 19 years old encounter profound physical and psychosocial transformations (Orben et al., 2020).

*Chronic disease burden:* The psychological and societal pressures that are placed on chronic patients due to the extensive self-management regimen to which they must adhere (Forouhi & Wareham, 2019).

*Chronic sorrow:* A distinct form of grief that PWD experience. They face an ever-present disparity between the life they live with diabetes and the life that was expected but lost (Roos, 2014).

*Diabetes distress:* A spectrum of psychosocial responses to living with diabetes and its self-management demands (Skinner et al., 2020).

*Patient-centered care:* An approach that places patients at the center of treatment and communication, empowering them to participate in decision-making (Alpert et al., 2017).

*Speech codes:* Meanings and symbols in speech that are used to communicate and construct culture through social interaction (Milburn, 2021).

*Speech community:* A cultural unit in which members demonstrate a shared understanding of the norms that govern appropriate behavior, and the way speech is interpreted (Hymes, 2013).

*Treatment burden:* The amount of effort that patients must put in to manage and care for their chronic conditions (Sav et al., 2017).

*Type 1 diabetes:* A chronic autoimmune disease in which a patient's insulin-producing beta cells self-destruct in the immune system, resulting in an imbalance of blood sugar levels (ADA, 2018).

## Assumptions

The ambition of qualitative research is to understand and identify the multiple dimensions of human experience (Korstjens & Moser, 2017). This research was informed by social constructivism, which is founded upon two primary assumptions. First, individuals justify their lived experiences by constructing a theory of society and how it operates (Sandu & Unguru, 2017). Second, language is the most fundamental tool that is used to create reality (Amineh et al., 2015). These assumptions are critical to this study, as they legitimize PWD as a speech community and T1D information as a creator of reality (Creswell & Creswell, 2018).

This study assumed that PWD share a collection of lived experiences characterized by what it means to live with diabetes. These shared experiences influence how the T1D community consumes and responds to health information. Likewise, it was assumed that the macro entities disseminating publicly accessible T1D information (e.g. the CDC, Mayo Clinic, WebMD) create eHealth content tailored to the T1D reality. A comparative semiotic analysis was deemed to yield the best assessment of publicly accessible T1D information on the basis of both content and making sense of what is being communicated to PWD. This study is distinguished from other investigations in health communication, as it was the first to extend Greimasian semiotics and the CNS tool to explore public T1D information. The researcher assumed that the insights from this analysis would contribute significantly to the field of health communication and semiotics.

## Summary

This chapter presented an introduction to diabetes and the ecological nature of health communications. First, a history of diabetes and health communication among the pandemic landscape and T1D community was reviewed. Next, the problem, purpose, and significant statements were discussed. Lastly, the study's definition of terms and philosophical assumptions were presented. The following chapter provides a comprehensive literature review of health communication research and chronic disease burden among the T1D community.

# CHAPTER TWO — LITERATURE REVIEW

## Overview

This chapter presents an overview of the literature relevant to the research of health communication and chronic disease burden among the diabetes community. First, a history of health communication is reviewed. Second, the shifting focus of health communication from a disease model to a patient-centered care model is discussed. A brief epidemiology of T1D is then presented. Next, the problem of chronic disease burden among the diabetes community is comprehensively addressed. Lastly, the theoretical frameworks of the ethnography of communication and the semiotic theory of action are presented.

## Literature Search Strategy

The electronic databases of PLOS ONE, Elsevier, SAGE, Springer, and ERIC were searched using myriad combinations of keywords, which included health*,* communication*,* chronic disease*,* burden*,* and diabetes. The search was restricted to English publications. In addition, citations among identified and/or related articles were manually searched for additional and relevant sources to this study.

## Health Communication

The last half-century has seen health communication grow into an essential field of research attuned to the significant functions that human and mediated communication enact in the delivery and promotion of health care for patients and providers alike (Kreps et al., 2003). However, the first intersection of communication and health can be traced back to ancient Greece (Svalastog et al., 2017). Being well both psychologically and physically was a foundational value in ancient Greek society (Ratzan, 2001). According to Karff (2009), the acclaimed physician and philosopher, Hippocrates, posited a psychosocial explanation for health in which patients were advised to heal and recover “simply through their contentment with the goodness of the physician” (p. 788). Implied within this position, however, were the remnants of oral tradition in which health information was hierarchical, passed down to the patient whose well-being was determined by the provider (Nuland, 2001). Evidence for the growing relationship between health and communication has been demonstrated in the history that has since followed.

Health communication research rose dramatically in the 1960s and 70s (Noar, 2006). There was a growing interest among social scientists to understand how communication could prevent and maintain health outcomes (Derzon & Lipsey, 2002). Scholars with backgrounds in humanistic psychology and medical sociology began taking an in-depth look at communicative interactions in healthcare settings (Kreps et al., 2003). The early work of Rogers (1976), Ruesch (1963), and Bateson (1951) emphasized how significant communication was to fostering mental health and was pivotal in establishing the delivery of health care as a cultural value that continues to be upheld today (Kreps et al., 2003). This prompted an entirely new avenue of exploration among communication scholars, demonstrated by an exclusive 1963 *Journal of Communication* issue dedicated to discussing the relationship between human communication and psychological well-being (Kreps et al., 2003). Consequently, the study of health communication was initially developed as a promising area of social psychology in which the effects of communication on health care were investigated (Dunlop et al., 2008; Salovey & Williams-Piehota, 2004).

Communication scholars began to research how communication could be used to promote educational health content that was persuasive to the public. Theories about the influence of mass media and social marketing on public health were formed (Dunlop et al., 2008; Dillard & Shen, 2005). It was during this time that the influence of public television broadcasting was transfigured, merging the industry of public education with healthcare for the first time (Rich, 2009; Stitt & Kunkel, 2008; Dutta, 2007; Beck, 2004). Not only was television a medium capable of distributing health information, but scholars recognized its power to influence health behaviors through educational and entertaining content (Primack et al., 2010; Singhal & Rogers, 2002). To this end, public health campaigns in the 1970s and 80s featured educational messages aimed at preventing and raising awareness of smoking, heart disease, and HIV-AIDs (Hannawa et al., 2015; Hyland et al., 2006; Myhre & Flora, 2000). Three examples of successful campaigns were the *Stanford Heart Disease Prevention Program*, the *Harvard Alcohol Project*, and *Mothers Against Drunk Driving* (MADD) (Wakefield et al., 2010; Hinyard & Kreuter, 2007; Fell & Voas, 2006).

In addition to psychology, sociology was influential in shaping the trajectory of health communication research. According to Kreps et al. (2003), the patient-provider relationship and the macro-organization of healthcare have historically piqued the interest of medical sociologists. In 1966, a scholar by the name of Zola analyzed how culture influences the ways patients communicate their symptoms to providers (Garroutte et al., 2006). His findings were revolutionary in emphasizing the significance of healthcare that delivers culturally sensitive services, meeting the multidimensional needs of each patient. Years later, American psychiatrist, Arthur Kleinman, published a book advocating for ethnic patients to be treated as participatory informants during health consultations (Aggarwal et al., 2015). He reaffirmed the influential role of culture on patient-provider communication and called for more research to explore health communication and its relationship to macro variables (Kreps et al., 2003). This call to action was met with a positive response, evidenced by an influx of new health communication literature that would establish the field's prominence today (Beck et al., 2004). Early examples include

Kreps' (1984) book, *Health Communication: Theory and Practice*, Sharf and Flaherty's (1984) journal, *The Physician's Guide to Better Communication*, and Northouse and Northouse's (1985) book, *Health Communication: A Handbook for Professionals*. As literature continued to grow, academic groups were formed to support health communication scholars and their research efforts. Two groups that were especially influential in the 1970s and 80s were the International Communication Association (ICA) and the Speech Communication Association (SCA) (Kreps et al., 2003). Eventually, health communication solidified as a field in 1989 and 1996 with the launching of two academic journals, *Health Communication* and the *Journal of Health Communication* (Hannawa et al., 2015; Kim et al., 2010). These organizations and academic journals continue to run today.

## Approaches to Health Communication Research

Considering how nuanced the field of health communication is, scholars have conducted research from myriad approaches. They have encountered the difficult task of establishing borders that are fluid yet targeted enough to conduct a meaningful study (Kreps, 2001). Two prominently utilized approaches have included the levels and operational approaches.

**Levels Approach.** The levels approach defines health communication as one of six levels of communication which include "intrapersonal, interpersonal, group, organizational, and societal" (Kreps, 2003, p. 355). Using this framework, scholars are able to better define their investigations and maintain uniformity across the field (Kreps et al., 2003). Among the six tiers, interpersonal and mass communication inquiries have garnered the greatest attention in health communication literature (Jeong & Bae, 2018; Kim & White, 2018; Southwell & Yzer, 2007).

Interpersonal communication research generally explores one-on-one interactions involving two or more individuals. Applied to health communication and care, the relationship between patients and providers is the major focus among scholars (Hong et al., 2020; Peimani et al., 2020; Berdahl & Kirby, 2019; Patel et al., 2018). Interpersonal health inquiries are attuned to the processes through which patients and providers develop, manage, misuse, and adjust their relationships (Haverfield et al., 2020). Among these interactions, meanings are generated and shared between the participants (Wood, 2015). Due to diversity existing on either side of these exchanges, interpersonal health inquiries have quite a broad scope to examine a myriad of influential factors including ethnicity, religion, and gender (Knight et al., 2019; Li et al., 2017; Canzona et al., 2015).

Mass communication research in healthcare contexts explores how mediated channels are used to successfully promote and prevent specific health outcomes, behaviors, and policies (Anwar et al., 2020; Schillinger et al., 2020; Kreslake et al., 2019). Through the dissemination of clear and accurate information, health campaigns are positioned to empower healthy behavior and educate the public, maintaining safety and societal order (Finset et al., 2020). Mass media campaigns by the CDC have employed this approach during widespread crises to prevent misinformation and overcome the stressors of anxiety and depression (Anwar et al., 2020; Mheidly & Fares, 2020; Ophir, 2019). In the early days of health communication as a field, the CDC characterized health communication as strategic messages that were created and distributed to enhance micro and macro health according to the current consumer needs (Noar, 2006; Snyder & Hamilton, 2002; Derzon & Lipsey, 2002).

**Operational Approach.** The operational approach defines health communication according to the research environment. Studies following this approach demonstrate a clear picture of the communication scholar's focus in healthcare. Among the literature, contextual environments of health communication and health topics are the most widely investigated by scholars.

Contextual studies focus on the ecological aspects that influence health communication. Early on, health communication was operationally defined as “the study of communication parameters applied in health situations and contexts” (Cassata, 1980, p. 584). As the health communication field developed, the communication-health relationship evolved to include communicative exchanges within distinct health settings (Ratzan, 2014). The benefit of this new definition was that it allowed health communication scholars to significantly broaden their scope, encompassing each of the communication levels while exclusively paying attention to relevant psychosocial factors during healthcare interactions (Basu & Dutta, 2007). Modern contextual studies have explored patient-centered initiatives, HIV prevention, and reproductive health (Anderson et al., 2020; WHO, 2017; Parkhurst, 2014; Howe, 2006).

Topical studies define health communication as being any communicative interaction, regardless of level or context, that involves health. One of their earliest champions was Loyd Pettegrew, who recognized health communication as a subfield of communication distinguished by any health agenda (Kreps et al., 2003). To this end, topical inquiries boast a broad research purview and are persuasive in nature, encompassing communication topics that are related to health prevention, promotion, policy, and/or wellbeing (Ratzan, 2014). Recently, these studies have informed and persuaded readers about health literacy and the risk of misinformation during the COVID-19 pandemic (Krishna & Thompson, 2021; Mheidly & Fares, 2020; Ratzan et al., 2020).

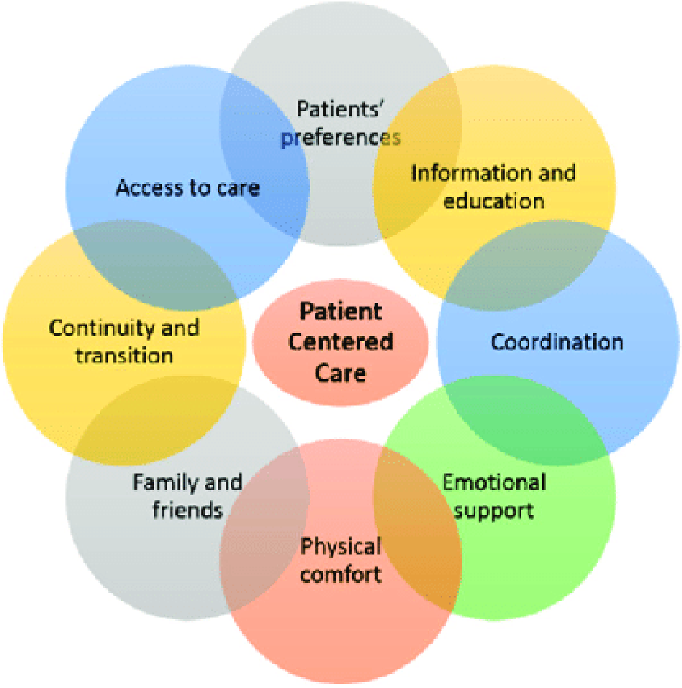
## Disease to Patient-Centered Communication and Care

Healthcare has historically grappled with negotiating the commonalities that patients share with the experiential aspects of their condition that are uniquely theirs (Mezzich et al., 2010). Early technological innovations established an evidence-based model, which prioritized treating the disease as a collective unit. According to Bensing (2000), disease orientations framed the provider's ideology with health information derived solely from clinical evidence of collective patient populations. In this way, individual patients were robbed of their role to participate in their care through the neglect of their preferences and experiences (Bardes, 2012; Tinetti & Fried, 2004). Technology played a significant role, starting with the stethoscope which first disrupted the patient-provider relationship by fostering the belief that technology, not the patient, was the key to understanding disease (Reinhart, 2020).

During the 1980s, the healthcare industry in the United States experienced a diagnoses craze (Cutler, 2005). Advancements in technology led to a rise in surgical procedures and drug delivery processes, which maintained the disease orientation of care (Cutler & McClellan, 2001). Healthcare essentially lost sight of the patient, caught up in the excitement of progress and profit (Simpson, 2003). By the 2000s, the industry recognized that any technological progress would be in vain if there was no recognition of patient preferences and concerns (Heath, 2005). Specifically, the trends of patient safety and consumerism repositioned the patient, not the diagnosis, as the center of care (Simpson, 2003). To this end, the patient-centered care model was developed.

**Figure 1**

*Picker Institute Framework of Patient-Centered Care* (Kuipers et al., 2021)



Patient-centered care is universally recognized today as a standard of care which stresses patients as are far more than their disease (Bensing, 2000). The pioneering work of Stewart et al. (2013) was pivotal in its development. They proposed that patient-centered communication and care models "explore both the disease and the illness experience, understand the whole person, find common ground, incorporate prevention and health promotion, and enhance the patient-physician relationship" (Hudon et al., 2012, p. 170). This modern approach is mindful of and attentive to the patient experience, which empowers patients to act as co-laborers of their own healthcare (Alpert et al., 2017).

Patients are the decisive party during health exchanges, as they are the experts of their lived experiences. Providers must sensitively reconcile the unique needs of their patients with the clinical care that they deliver (Sabee et al., 2015). This is achieved through comprehensive frameworks, one of which was developed by the *Picker Institute* in which patient-centered care addresses patient preferences, health information and education, care coordination, emotional support, physical comfort, relationships with family and friends, as well as the continuity, transition, and access to care (see Figure 1; Kuipers et al., 2021). Recent literature has explored patient-centered communication in several health contexts including substance abuse, chronic disease, pediatrics, and mental health (Ayed et al., 2021; Pinho et al., 2021; Marchand et al., 2019; Paul-Savoie et al., 2018).

## Type 1 Diabetes

Diabetes is among the most prevalent chronic and longstanding diseases beginning in childhood. While T2D is rising at an astonishing pace in American youth, T1D is distinguished by insulin deficiency, which to date has no cure and involuntarily occurs between the ages of 4 and 14 years (Robinson et al., 2019). T2D, conversely, is characterized by insulin resistance in which the beta cells of a child's pancreas are fully functioning and produce insulin, however, they evolve to resist insulin and can no longer absorb blood sugar. As a result, excessive concentrations of insulin and blood sugar (i.e. glucose) circulating in the body are the outcome. These two features define T2D diagnoses (Galicia-Garcia et al., 2020). While children and AYAs are able to reverse T2D, there has yet to be a cure for T1D diagnoses.

T1D among children and the AYAs population fluctuates by variables such as region, gender, age, and ethnicity (Shah & Nadeau, 2020). With each passing year, its global prevalence is increasing (Ross et al., 2022). In a recent study, Patterson et al. (2019) reported that Europe and the United States have the highest prevalence. Countries with the lowest rates included Ethiopia, Rwanda, and Tanzania. Moreover, the findings estimated that T1D affects over 98,000 new children under the age of 15 every year. Currently, close to 700,000 children between the ages of 1 and 15 years are living with insulin deficiency (Patterson et al., 2019). According to Chiang et al. (2018), the *SEARCH for Diabetes in Youth* study revealed that the prevalence and incidence of T1D is rising among children and adolescents between the ages of 4 and 19 years old in the United States. Despite this growing crisis, they noted how scholars have yet to propose solutions that will remedy it. The *American Diabetes Association* (ADA) issued a Position Statement to highlight the seriousness of T1D, clarifying how children "are not little adults" (Chiang et al., 2018, p. 2026). Due to its unique pathogenesis and epidemiology, as well as developmental factors, T1D among AYAs is strikingly distinct from adult-onset diabetes (Joseph et al., 2021; Nadeau et al., 2016; Wherrett et al., 2015).

T1D literature has primarily centered around the three topics of physical health, psychosocial health, and disease self-management. Scholars have recently delved deeper into how children and AYAs are at higher risk of developing gum disease, cardiometabolic disease, cardiovascular disease, as well as multimorbidity (Maffeis et al., 2021; Welser et al., 2021; Essuman et al., 2021; Zainal Abidin et al., 2021). Scholars have explored the ways in which the COVID-19 pandemic and its lockdown measures impacted physical health metrics including exercise and blood sugar levels (Okuyama et al., 2021; Tinti et al., 2021). In addition, the impacts of interventions aimed at measuring physical health metrics among children and AYAs with T1D have been addressed in the literature (Shorey et al., 2021; Czenczek-Lewandowska et al., 2019; Schiel et al., 2011).

Literature addressing psychosocial health among children and AYAs with T1D is extensive. Scholars have conducted studies assessing the quality of life (Hilliard et al., 2020; Cobham et al., 2020; Munkácsci et al., 2018). The impact of T1D on peer and family relationships has been addressed across micro and mezzo settings (Andrade & Alves, 2019; Fried et al., 2018; Te Velde et al., 2018). Moreover, the burden of living with T1D has been analyzed and characterized (Cousin et al., 2022; Shorey & Ng, 2020; Musolino et al., 2019; Mueller-Godeffroy et al., 2018).

Reviewing the self-management literature, the impact of technology on the lived experiences of AYAs with T1D is evident and growing. A plethora of studies have recently been conducted exploring the benefits of game-based interventions, *Internet* devices, telehealth, and social media applications for effective diabetes self-management (Faulds et al., 2021; Rewolinksi et al., 2021; Xu et al., 2021; Faulds et al., 2020; Gal et al., 2020). Additional studies have explored general self-management efforts including nutritional tracking, continuous glucose monitoring, and insulin pump therapy (Cummings et al., 2021; O'Donnel et al., 2021; Rankin et al., 2018; Smart et al., 2014).

## Chronic Disease Burden

Chronic diseases are responsible for a large percentage of global mortality (WHO, 2018). The WHO has defined them as non-contagious conditions that are characterized by a long lifespan and slow disease progression (WHO, 2019). They cannot be cured; only managed. Cardiovascular disease, diabetes, cancers, and chronic respiratory disease are examples of the most widespread (Wou et al., 2019). Annually, 15 million adults, within the age bracket of 30 to 69, pass away early from complications (WHO, 2018). Among these deaths, it is estimated that cardiovascular disease and diabetes account for over 50 percent (Wou et al., 2019). This difficult reality places chronic patients under a tremendous amount of burden as they try to consistently self-manage their conditions (Forouhi & Wareham, 2019). The following sections will review literature on the psychosocial and treatment burden of diabetes, highlighting their impact on the AYA population.

## Psychosocial Burden

The psychosocial burden that follows a diabetes diagnosis is profound. PWD face a lifetime of insulin injections to maintain healthy blood sugar levels, or otherwise risk severe health complications which may include blindness, kidney failure, and nerve damage (Khouja et al., 2019). This reality is received similarly to a prison sentence and is often difficult to accept (Kalra et al., 2018). What was normal before for PWD will never be normal again. As personal efforts to maintain blood sugar levels fail, or simply do not meet expectations, onsets of diabetes distress are easily triggered among patients. *Diabetes distress* has been described as a spectrum of psychosocial responses to living with diabetes, particularly those connected to adhering to treatment meeting self-care requirements (Skinner et al., 2020; Berry et al., 2015).

As PWD navigate life with the condition, they experience *chronic sorrow*, which is a concept first coined by Olshansky in 1962 to reference a distinct type of grief or "living loss" that is long-standing and has been associated with speech and cultural changes (Harris & Gorman, 2011, p. 4). Burke et al. (1999) defined chronic sorrow as "grief-related feelings that emerge in response to an ongoing disparity resulting from the loss of the anticipated 'normal' lifestyle of these persons" (p. 374). This perfectly captures the crux of chronic sorrow, which according to Roos (2014) is "a painful discrepancy between what is perceived as reality and what continues to be dreamed of" (p. 26). While the literature has demonstrated that AYAs living with T1D are afflicted by long-standing feelings of grief as well as a loss of normality, scholars have yet to target chronic sorrow among their speech patterns. In a recent qualitative study, Stuckey and Peyrot (2020) generally explored the living losses of diabetes. Their findings painted a vivid picture of the discrepancy that is regularly faced by this population. Adult patient narratives described how "everything is a mountain to climb" in which PWD experience identity crises, feeling negatively set apart from society and desperately desire to belong (Stuckey & Peyrot, 2020, p. 498). Future research focusing on chronic sorrow among AYAs might yield additional and promising insights.

Numerous research has been devoted to exploring the ways in which PWD ride this rollercoaster. Two prominent themes include uncertainty management through online health information-seeking behaviors and peer support through the diabetes online community. *Online health information seeking* (OHIS) is a term used by scholars to describe any use of the *Internet* to obtain health information (Xiang & Stanley, 2017). PWD perform OHIS behaviors to manage feelings of uncertainty (Dean & Street, 2015). A recent study conducted by Lee et al. (2020) reported that in the United States, one out of every three adults uses the *Internet* to seek information on how to effectively manage diabetes and other chronic illnesses. As AYAs are a digitally-adept generation, future OHIS research might be extended to explore how this community manages feelings of disease uncertainty.

A second way PWD manage their psychosocial burden is through active participation in online support groups, which account for well over 12 million adults in the United States (Xiang & Stanley, 2017). Litchman et al. (2019) defined the *diabetes online community* (DOC) as "a user-generated term that encompasses people affected by diabetes who engage in online activities to share experiences and support in siloed or networked platforms" (p. 487). The value in DOC membership for AYAs with T1D lies in its provision of buddy systems and motivational activities through mHealth applications (Wong et al., 2020). Numerous studies have demonstrated the benefits of the DOC on psychosocial outcomes (Oser et al., 2020; Gavrila et al., 2019; Litchman et al., 2018; Kingod et al., 2017; E Hilliard et al., 2015).

## Treatment Burden

*Treatment burden* refers to the amount of effort that patients must put in to manage and care for their chronic conditions through finances, medication, administration, daily healthy habits, and time (Sav et al., 2017). Unlike psychosocial burden, this form of burden emphasizes the necessity of treating diabetes in order to improve its progression and mitigate the adverse consequences that arise from its prolonged management (Sav et al., 2015). Negative outcomes of treatment burden have been documented as non-adherence to treatment, low quality of life, irresponsible stewardship of resources, jeopardized employment, and unfavorable ramifications among social relationships (Sav et al., 2015). To prevent these outcomes, PWD must thoroughly educate themselves about effective self-management and its effects, perform necessary administrative tasks (such as tracking blood sugar levels), commit to following complex routines prescribed by their health providers, monitor their prescriptions, and adjust lifestyle habits as necessary (Sav et al., 2015; Tran et al., 2012). Qualitative studies have reported that PWD have the most difficulty with affording their treatment, taking medications, and facing restrictions on daily activities (Sav et al., 2013; Eton et al., 2012).

Health communication literature has just begun to explore resources that might assist PWD in effectively managing their treatment burden. Recent studies have primarily focused on clinically assessing the treatment burden among PWD and validating their patient experience (Hardman et al., 2022; Haider et al., 2021; Spencer-Bonilla et al., 2021; Rogers et al., 2017). That being said, the roles of digital applications and health technologies, such as telehealth and digital insulin pumps, have been indirectly indicated as viable solutions for alleviating burdens related to self-management. They offer PWD numerous treatment benefits, three of which include alleviating time and travel to routine visits, easing administrative tasks, and making management costs more affordable (McVean & Miller, 2021; Huang et al., 2018; Tippey & Weinger, 2017). However, further research is needed to better characterize treatment burden and identify tools that are effective in its alleviation among PWD (Sav et al., 2015).

## The Living Loss of AYAs

Diabetes distress among adult and elderly patients has been equally demonstrated among the AYA population (Hagger et al., 2016). *Adolescence* is defined as the developmental life stage in which individuals ranging from 11 - 19 years old encounter profound physical and psychosocial transformations (Orben et al., 2020). One's environment and social relationships grow to be especially essential during adolescence (Hill et al., 2019). Peers begin to replace family, which fosters AYAs to mature into autonomous adults with a strong sense of self (Pfeifer & Berkman, 2018). At the same time, mental capabilities develop during adolescence, allowing AYAs to better understand themselves, consider different perspectives, and navigate the culture and/or communities in which they are surrounded (Burnett Heyes et al., 2015). This life stage is also a vulnerable time for mental health. According to Kessler et al. (2012), three-quarters of adults with a poor mental health experience claim that the crisis began during adolescence. Studies conducted by Arseneault (2018) and Platt et al. (2013) demonstrated that negative peer exchanges in adolescence, including rejection, verbal abuse, and solitude, increase the likelihood of depression and other mental health conditions. It goes without saying then that a significant social development, such as the disclosure of a chronic diagnosis to one's peer group, may profoundly impact AYAs' psychosocial development (Orben et al., 2020).

Adolescence and young adulthood are known to be especially difficult periods for those who are living with diabetes (Ingersgaard et al., 2021; Henríquez-Tejo & Cartes-Velásquez, 2018; Rankin et al., 2018; Luyckx et al., 2008). According to Babler and Strickland (2015), the most widespread chronic disease impacting young people is type 1 diabetes. Due to the necessity of glucose tracking, regular insulin doses, and attentiveness to self-care, AYAs with T1D undergo an added challenge of achieving independence that is imposed by their dependent health status (Ingersgaard et al., 2021; Marshall et al., 2006). Within moments of receiving their diagnosis, they must adapt to a radically new way of life and face a jeopardized future of demanding disease management. Psychosocial and treatment burden is therefore unique and strongly experienced among AYAs, marking them as a vulnerable population.

Studies by Ramchandani et al. (2019) and Jonker et al. (2018) reported that diabetes not only impedes the sense of self among AYAs but also their ability to develop confidence, ego, and sociocultural identity. As a result, they encounter delays in psychosocial development and are at a higher risk of suffering from poor mental health (Pierce, 2021; Clarke et al., 2018). Anxiety, despair, low self-esteem, coping challenges, and difficulty with peer and family relationships characterize their burden experience (Helgeson et al., 2007; Davidson et al., 2004). According to King et al. (2017), AYAs with type 1 diabetes in particular are at greater risk of suicide. This is due to the complex nature of their treatment burden, which requires them to complete roughly 600 tasks in order to successfully control blood sugar levels (Babler & Strickland, 2015). These include storing insulin at a specific temperature and that opened vials are accurately labeled with the date, rotating insulin injection sites (e.g. the stomach, arm, and/or hip), checking the syringe for bubbles prior to administration, administering insulin as necessary, maintaining a consistent schedule for checking blood sugar levels, leaving home with an emergency bag in case of a low or high blood sugar episode, and timing meals according to one's insulin activities (Coffen, 2009). Due to the magnitude of these daily tasks, AYAs with T1D live with a distinct and long-standing form of grief.

Within 30 years of receiving their diagnoses, it is ensured that AYAs will encounter mortal complications including cardiovascular issues, kidney deterioration, and retina disease, regardless of self-management efforts (Robinson et al., 2018; Young & Dietrich, 2015; Marshall & Flyvbjerg, 2006; Olsen et al., 2000). While numerous qualitative and quantitative interventions have been conducted, AYAs with diabetes continue to struggle with complex disease burden and poor self-management (King et al., 2017; Babler & Strickland, 2015; Lehmkuhl et al., 2010; Mulvaney et al., 2010; De Wit et al., 2008; Channon et al., 2007). New research is needed to address these challenges.

## Communication 101

Communication research has a history of being fragmented among numerous areas of inquiry and analysis (Waisbord, 2019). The term *communication* itself is understood relationally as “a pattern of interconnections” (Sillars & Vangelisti, 2018, p. 243). It is a process in which information is encoded by one entity (i.e. the transmitter) and passed to a second (i.e. the receiver), who is then able to decode the information and respond accordingly (Beattie & Ellis, 2017). From this working definition, each and every communicative act consists of a transmitter of information, a transmission of information, and a receiver of the information. Moreover, instances of miscommunication occur due to defective encoding, transmission, and/or receipt of information (Beattie & Ellis, 2017). Another definition posited communication as “a basis for understanding and bridging experiences… and creating social reality” (Dainton & Zelley, 2017, p. 4). Evidently, the function of communication can fluctuate according to its contextual form. As such, communication is divided into nine research contexts which include cognitive, individual, social, interpersonal, intercultural, persuasive, group, organizational, mediated, and mass communication (Dainton & Zelley, 2017). This study will fall within the context of intracultural communication, which is closely linked to intercultural communication and distinguished as “interactions between members of a relatively definable speech community” (Kecskes, 2018, p. 118). This form of communication is valuable for analyzing how AYAs with T1D use language to describe and make sense of their life with diabetes.

Scholars have equated communication research to a wide tent housing theoretical and disciplinary approaches (Corner, 2013; Peck et al., 2013). According to Waisbord (2019), its fragmentation has been rooted in myriad reasons, one of which is the academic nuance around the labeling of communication literature. He pointed out how division in academia is evident through debates concerning whether communication research should be organized as a field or as a science, as well as the conflicting use of interchangeable terms, such as communications versus communication studies. To this end, communication research takes a variety of forms, as there is no singular and unified understanding of it (Anderson & Baym, 2004). Research, which takes both qualitative and quantitative approaches, is influenced by a wide range of ideologies and conceptual approaches that are rooted in the humanities and social science research (Waisbord, 2019).

## Theoretical Framework

The purpose of theoretical frameworks is to make sense of human experience (Casmir, 2013). Scholars have described frameworks as logically ordered groups of ideas, justifications, and guidelines that represent a component of lived reality (Littlejohn et al., 2017). As such, each framework is partial in its research approach and characterizes the “behaviors, outcomes, and cognitive processes” that are integrally rooted in communication (Van Ruler, 2018; Heath & Bryant, 2013, p. 10). This design proves value because it offers scholars a clear and targeted vantage point at which to frame their studies (Dainton & Zelley, 2017).

All communication theories, according to Robert Craig (1999), are applicable to a shared and pragmatic public sphere wherein communication is established as a profound concept. Recognizing the need for scholars to interact with objectives, concerns, and conflicts that are significant to society and span beyond academic traditions and ideologies, he organized theories into seven traditions and established communication as an orderly field. These traditions, which include the semiotic, phenomenological, cybernetic, sociopsychological, sociocultural, critical, and rhetorical, continue to frame communication research today, providing scholars with strategic methods of analyzing myriad concerns and processes of human communication (Craig, 2009; 1999).

The present study is framed by the sociocultural tradition, which posits communication as "a symbolic process that produces and reproduces shared sociocultural patterns" (Craig, 1999, p. 144). In other words, communication is the code that individuals and larger society use to create, experience, preserve, and alter the environment or reality. We live in a social milieu largely defined and sustained by meaning (Craig, 2009). The way in which communication occurs is representative of the culture in which it takes place. The "reproduction" of sociocultural patterns refers to the paradox of how cultural values and meanings are both shared and recreated. Put another way, communicators both rely on and participate in generating the culture in which they are members. This is achieved through *codes*, which are "socially constructed systems of terms, meanings, premises, and rules pertaining to communicative conduct" (Gudykunst & Mody, 2002, p. 56). They may be understood as shared insider knowledge, collective sense-making, or "interpretive repertoires" which offer individuals the capability to either accept or debate what something means within a cultural community (Craig, 2009, p. 335). This qualitative semiotic study analyzed publicly accessible T1D information through the EOC and the semiotic theory of action.

## Ethnography of Communication

EOC was previously coined as the ethnography of speaking. The theory builds upon the revelatory work of anthropologists and linguists Geertz (1973), Hymes (1972), Schneider (1976), and Philipsen (1992). Using the notion of culture as a network of symbols and associated meanings, it defines a *speech community* as a cultural unit in which members demonstrate a shared understanding of the norms that govern appropriate behavior and the way speech is interpreted (Kotani, 2017; Hymes, 2013).

Literature is clear in distinguishing EOC from *ethnography*, which is an alternative method used to describe cultural trends in a community. Ethnography aspires to analyze societal interaction, correctly capturing the unique characteristics that define culture and its associated identity markers (Hepburn, 2016). While EOC makes use of the term, ethnography, its focus is not on culture but rather on language and its role in constructing culture through social interactions (Hepburn, 2016; Milburn, 2004). For these reasons, EOC is referenced among scholars as a research approach that explores “situated communication” (Zhu & Bargiela-Chiappini, 2013, p. 391). To this end, there are a plethora of opportunities for future research to extend ethnographic research, attuned to the role of language among cultural communities. Moreover, the criteria for belonging to a cultural community might be extended to those living with a shared and severe condition, such as a chronic disease like T1D.

The primary aim of communication ethnographers is to analyze language within specific social contexts (Sprain & Boromisza-Habashi, 2013). Hymes (2013) argued that language is used according to codes established by a community and its members are not only cognizant but also accountable to those codes. Communication ethnographers aim to explore how these codes are understood by community members and the ways in which they are adopted, as this signals communicative competence (Kotani, 2017).

*Communicative competence* refers to the capacity of speech community members to effectively communicate among evolving contexts (Wodak et al., 2011). The underlying premise is that there are specific ways of organizing communicative behavior, which "implicate a culturally distinctive system of meanings pertaining to communicative conduct itself" (Philipsen & Coutu, 2005, p. 355). Framed by the sociocultural tradition, this study's comparative content analysis employed EOC to establish T1D as a cultural unit whose members share an intersubjective understanding of words and concepts, which may be represented among publicly accessible T1D information (Craig, 2016). Future studies will have the additional opportunity to explore additional EOC concepts, such as communicative competence and Hyme's SPEAKING mnemonic.

**Semiotic Theory of Action.** The theoretical framework of semiotics was championed by the linguists Ferdinand de Saussure and Charles Sanders Peirce (Dunleavy, 2020). Their characterization of semiotics as language research laid the groundwork for the numerous studies of signs and sign systems that have subsequently developed in the field of communication (Hodge, 2020). Scholars conducting social research gravitate towards Greimasian semiotics, which is the branch of semiotics in which this study is rooted (Feix & Philippe, 2020; De Luca Picione et al., 2020; Yekini, 2017; Lagopoulos & Boklund-Lagopoulou, 2017).

Greimas semioticians stress the chronology of a narrative as the system of signs and are interested not only in the author's motivations and behavior but also how those motivations might impact the audience (Yekini et al., 2021). *Signs* are a collective unit of expression and content, which is distinct from Saussurean semiotics in which they represent a “signifier and signified” (Pikkarainen, 2021, p. 191). The primary research objective in Greimasian semiotics are the indicative units of expression and content that are negotiated through communication, rather than the sign itself (Pikkarainen, 2018).

As the audience is able to discover the meaning behind the text by examining the subject’s actions, the process of *signification* is achieved (Pikkarainen, 2016). Especially key in Greimasian semiotics is the belief that the motivations and behavior behind a narrative matter more for deriving insights from it than the language used to describe the behavior in the text (Yekini et al., 2021). Provided that the *Internet* allows participating eHealth leaders (e.g. health institutions, researchers, providers, diabetes educators, and nonprofits) to widely disseminate T1D information to influence PWD’s health literacy and self-management behaviors, the Greimasian semiotic theory of action was deemed appropriate for this study to explore the content of publicly accessible T1D information.

The semiotic theory of action, also known as action theoretical semiotics, was developed by Eetu Pikkarainen (2021) as an extension of Greimasian semiotics to contribute to education philosophy (Stables et al., 2018; Pikkarainen, 2018). The theory is hinged on the principle that meaning and action are intertwined (Pikkarainen, 2021). Moreover, communication is described as action that leads to outcomes, whether purposefully or not. Here, *action* refers to a subject’s deliberate behavior in connection to the context. *Meaning* is described as “a meaning effect”, referring to the impact of the text on the subject’s behavior. Notably, Pikkarainen theorized that action has a two-sided nature where it may be characterized as either external and publicly visible behavior or internal and privately processed by the subject. This is heavily influenced by the Greimasian principle of *competence,* which Pikkarainen describes as a particular capability or disposition of the subject that enables (and thereby explains) behavior. As the capabilities of the subject change, *learning* occurs. This research applied these principles and the associated CNS analytical tool to explore the principle action and subsequent narrative components of competence, performance, manipulation, and sanction within publicly accessible T1D information (See Figure 3; Hébert, 2019).

**Figure 3**

*The Canonical Narrative Schema* (Yekini et al., 2021; Hébert, 2019)

| Action | Manipulation | Competence | Performance | Sanction |
|---|---|---|---|---|
| The act itself | A compelling force to the action (Having to do) | What is needed to perform the action (Knowing how to do, Being able to do) | The actualization of the action (Causing to be) | Outcome of performing the action (Being of being) |

**Relevance to Study.** The collective research approach of EOC and the semiotic theory of action was relevant to this study for two reasons. First, EOC established the T1D community as a cultural unit in which PWD demonstrate a shared understanding of norms that influence self-management and the way health information is communicated (Kotani, 2017). Literature has demonstrated that this speech community actively engages in OHIS behaviors related to the self-management of their chronic condition (Lee et al., 2020). A semiotic content analysis of health information that is publicly accessible to the T1D community was therefore valuable and warranted. Second, the semiotic theory of action and CNS tool, both rooted in Greimasian semiotics, allowed for the public T1D narrative to be explored. This study was the first application of Greimas's CNS tool to explore publicly accessible health content intended for the T1D community. The *Internet* fulfills a significant role in disseminating health information to chronic patient populations and these theoretical applications yielded remarkable insights as to which narrative components (e.g. action, competence, manipulation) and strategies are at work among publicly accessible T1D information sources.

**Presence in Literature.** The literature demonstrates a rich application of EOC primarily within the research areas of cross-cultural communication, interpersonal communication, education, and mass communication. Cross-cultural applications have been the most extensive (Kvam, 2017; Kotani, 2017; Kihara, 2015; Zhu & Bargiela-Chiappini, 2013; Sprain & Boromisza-Habashi, 2013; Carbaugh et al., 2011). Interpersonal implications, though fewer, have been equally valuable (Witteborn & Sprain, 2020; Carbaugh, 2014; Townsend, 2013; Ojha & Holmes, 2010). The areas of higher education and mass communication have also benefited from Hyme’s theory (Karanfil, 2020; Farrokh, 2019; Giyoto et al., 2019; Fatma et al., 2019; Pujianto & Laila, 2016; Hepburn, 2016; Zand-Vakili, 2012; Radford et al., 2011; Ray et al., 2011). The semiotic theory of action has solely been employed in the fields of education and edusemiotics (Pikkarainen, 2018; 2021; Stables et al., 2018). Greimasian semiotics has been applied within social research, management studies, educational philosophy, organizational communication, as well as digital and visual communication (T Meza & Thue, 2021; Feix & Philippe, 2020; Signori & Flint, 2020; Mattozzi, 2019; Marotta et al., 2017).

## Summary

This chapter reviewed health communication research and chronic disease burden among the diabetes community. First, the historical background of health communication, its research approaches, and patient-centered communication and care were presented. Next, epidemiology of T1D and an overview of chronic disease burden were provided. Lastly, the value of conducting EOC and Greimasian semiotics research was justified. Chapter Three outlines the methodology that guided this study.

# CHAPTER THREE – METHOD

## Overview

The purpose of this exploratory QCA was to examine how publicly accessible T1D information is categorized, revealing the similarities and differences among the semiotic content. The T1D community is a speech community that shares an understanding of norms that influence the interpretation of and behavioral response to health information (Kotani, 2017). Literature has demonstrated that this speech community actively engages in OHIS behaviors related to the self-management of their chronic condition (Lee et al., 2020). The vast environment of online health information, made possible through the *Internet*, has not been explored for its potential impact on communication and significance among the T1D community. A semiotic content analysis of publicly accessible T1D information was therefore valuable and warranted.

This chapter provides a comprehensive description of the study's methodology. First, the qualitative paradigm of the research is justified. Explanations for the qualitative study design and research questions follow. Lastly, a discussion of the search strategy and inclusion criteria, QCA, and ethical considerations is provided.

## Qualitative Paradigm

This study analyzed the semiotic content of publicly accessible T1D information. The research maintained a constructivist lens and is hermeneutic in orientation. Through an analytical process of both the disposition of PWD, who are the information's audience, as well as the goals of the creators of the T1D content (e.g. medical journals, websites, and nonprofits), the study aimed to grasp the value and meanings embedded within the health information being communicated (Selvi, 2019). These characteristics are best aligned with the qualitative research paradigm.

Qualitative research is concerned with interpretation and comprehension, so much so that it is often referenced as a science of interpretation (Aspers & Corte, 2019; Alase, 2017). Qualitative researchers are interested in understanding both the subjective and objective nature of human experience and how meaning is created (Hammarberg et al., 2016). Data is often gathered in a naturally occurring and realistic manner, with an emphasis on the meaning that is placed on human actions and lived experiences (Creswell & Poth, 2018). In this study, publicly accessible T1D information from highly trafficked *Internet* sources was analyzed using MAXQDA software to identify (1) what information is being communicated, (2) how the information is organized, and (3) the implicated meaning-effects of the T1D information.

## Research Design

This exploratory study employed QCA, which is regarded as the most solidified social research approach used for analyzing texts (Selvi, 2019). QCA is distinguished by its categorical system, focus on *latent meaning* (i.e. meaning that is influenced by context), development of data coding frames, and emphasis on data interpretation (Mayring, 2019). There are many definitions of QCA represented in literature. Roller (2019) defined QCA as “the systematic reduction of content, analyzed with special attention to the context in which it was created, to identify themes and extract meaningful interpretations of the data” (p. 1). Assarroudi et al. (2018) described it as a descriptive and interpretative approach to textual data in which systematic coding is key. Moreover, they clarified how QCA uses linguistic and environmental cues to explore meaning within the text.

Depending on the research purpose, QCA may be classified as taking either a conventional, summative, or directed approach (Assarroudi et al., 2018). Conventional QCA is an inductive approach exercised by scholars whose aim is theory development or understanding phenomena (Renz et al., 2018). Summative QCA is known for its contextual interpretation of core keywords (Mayring, 2019). Directed QCA takes a deductive approach and is commonly applied in healthcare contexts (Doukani et al., 2021; Subu et al., 2021; Nejatian & Joulaei, 2018).

According to Roller (2019), two characteristics that set QCA apart from alternative qualitative methods include the researcher's relationship with participants and the researcher's role as a study instrument. In QCA research, the researcher is separated from participants and is interacting instead with textual or multimodal content. Roller emphasizes how this is unique from other qualitative approaches in which the researcher-participant relationship is an essential factor during data collection. As a result, QCA does not give much credence to how the integrity of the coded information may have been endangered by the researcher-participant relationship (Roller, 2019). Moreover, Roller clarified how the QCA researcher is the instrument developing the codes for content analysis, as opposed to the instrument role of data collection, and this lends a potential for research bias that must be acknowledged.

## Research Questions

This content analysis explored three research questions among publicly accessible T1D information.

RQ1: What T1D information is being strategically communicated?

RQ2: How is publicly accessible T1D information categorized?

RQ3: Among publicly accessible T1D information, what content is tailored to AYAs?

## Selection Strategy and Data Collection

Data selection often takes precedence over data collection in document analysis, a form of QCA, considering the method draws on existing data (Puppis, 2019). As this study explored

T1D information that is publicly accessible, implementing an appropriate search strategy was key. The search engine selected for this exploratory content analysis was *Google*. This decision was supported by *Pew Research Center* data demonstrating how 80% of OHIS actions originate from *Google*, which the public perceives as an accessible and effective health communication resource (Sbaffi & Zhao, 2020).

The initial search term, type 1 diabetes, yielded over two billion results. To narrow down the sample and allow for effective comparison, the Chrome extension and research tool *Keywords Everywhere* was installed to screen for *Internet* search volume. Search terms including information, community, self-management, and adolescent were interchangeably added. The search volume highlighted 10 top sources including three medical journals, four peer-reviewed medical websites, and three nonprofits. Sources that ranked lower in search volume were excluded from the study. It is also worth noting that social media data was deemed inappropriate for the current study, as the analysis was kept to peer-reviewed sources. Future research can explore publicly accessible T1D information among social media communities, where the narrative schema may be strikingly different (Elnaggar et al., 2020; Oser et al., 2019; Malik et al., 2019; Litchman et al., 2019; Hansen et al., 2018; Vaala et al., 2015). Below, Table 1 illustrates this study's selection of the top 10 peer-reviewed *Internet* sources providing publicly accessible T1D information.

**Table 1**

*Top Sources of Publicly Accessible T1D Information*

| Medical Journals | Medical Websites | Nonprofits |
|---|---|---|
| Diabetes Care | WebMD | Beyond Type 1 (BT1) |
| Diabetes Spectrum | Mayo Clinic | Juvenile Diabetes Research Foundation (JDRF) |
| PubMed Central | CDC | ADA |
|  | Cleveland Clinic |  |

Data collection was first conducted among medical journals, as they provide the most authoritative medical terminology. To identify the most relevant documents for analysis, the researcher searched each journal for T1D articles published recently within the last year. Additionally, health communication literature has demonstrated that T1D affects children and adolescents. To ensure that this QCA was representative, the keywords adolescent, adolescents, and AYAs were intentionally included in the search. Collectively, this search strategy yielded 40 medical journal articles. Once this selection was made, each article was opened, and its text was manually collected and transferred into a separate, secure *Microsoft Word* document for analysis.

Data collection among peer-reviewed websites and nonprofits was more time-consuming. Health information on these sites is updated regularly and consistently relevant to the T1D community. For example, web pages educating PWD on how to inject the appropriate dosage of insulin safely will never be considered outdated information. Additionally, health information specific to T1D can also overlap with T2D and diabetes diagnoses in general. What’s more, the peer-reviewed websites and nonprofits selected did not provide the search filter capabilities as the medical journals. Considering these factors, data was collected meticulously from each source. For example, pages that specified the target audience as being solely T2D were excluded from the sample while pages that addressed diabetes in general and/or directly mentioned T1D were included. The texts of approved web pages and linked resources (e.g. PDFs, handouts, eBooks) were manually collected and transferred into separate, secure *Microsoft Word* documents for analysis. This meticulous process yielded 1,026 documents from peer-reviewed websites and nonprofits. In total, data collection among all three peer-reviewed sources reached saturation with 1,066 documents of publicly accessible T1D information (see Table 2).

**Table 2**

*Number of Documents Per Publicly Accessible T1D Information Source*

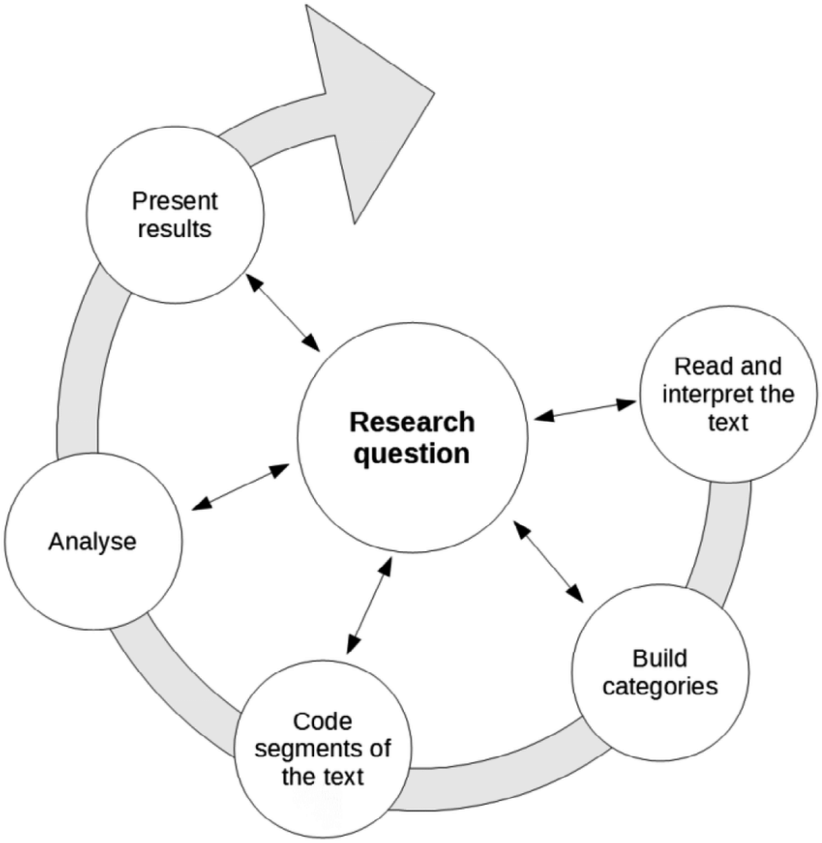
| T1D Information Source | Document Sample |
|---|---|
| Medical Journals | 40 |
| Medical Websites | 261 |
| Nonprofits | 765 |

## Qualitative Content Analysis

Documents were analyzed according to QCA (see Figure 4). There are three main stages of QCA which include preparation, organization, and reporting (Kuckartz, 2019). The preparation stage was completed through the meticulous collection of data. The second stage, organization, included word frequency and thematic analyses of the documents. The reporting stage of QCA is covered in Chapters Four and Five, where the analysis findings are reported through a final discussion.

**Figure 4**

*Circular Process of QCA* (Kuckartz, 2019)



## Frequency Analysis

A word frequency analysis of the documents (n = 1,066) was first conducted using MAXQDA software, which generated a coding frame of 18 keywords. MAXQDA and other computer-assisted software are recommended as powerful instruments for qualitative research (Gizzi & Rädiker, 2021). C*oding frames* are pivotal to QCA research, as they allow the researcher to filter down mountains of textual data into distinct and organized categories (Mayring, 2019). This, in turn, makes interpretation of the findings easier down the road. In this way, the quantitative component of the textual frequencies recorded for each code contributed to the qualitative nature of this study. They enabled the researcher to look past the frequencies and explore the underlying value and context of the T1D information, which was conducted subsequently through thematic analysis (Lochmiller, 2021).

### Thematic Analysis

Using the coding frame (see Figure 3), a thematic analysis of the documents was conducted manually by the researcher. This approach was selected because thematic analyses of documents assume that the information is an honest representation of the reality being explored and must therefore be considered as equally trustworthy and reliable as personal accounts given by participants themselves (Lochmiller, 2021). Puppis (2019) described documents as sociocultural artifacts deserving of independent analysis. Moreover, qualitative researchers conduct thematic analyses of documents to explore how the recorded information sheds light on a particular question or offers a fresh theoretical perspective (Lochmiller, 2021). In this QCA, the T1D information was collected and analyzed thematically as a credible representation of health communication among PWD.

Five sub-codes were assigned to each main code that formed the coding frame. The sub-codes were applied from an existing communication theory, Greimasian semiotics. In this way, the researcher followed a deductive approach in the thematic analysis process (Selvi, 2019). Data saturation was reached once 25% of the document sample had been thematically analyzed ($n = 266$), which generated five recurrent themes. To ensure that the remaining documents did not offer any new findings, the researcher conducted a randomized stratified sampling technique on 40 additional documents, where one per every 20 documents in the remaining dataset was selected and coded ($n = 306$). This additional sampling did not yield any new findings and further confirmed the five generated themes. It is worth noting that, had there not been time constraints while conducting this study, the remaining documents may have been analyzed. However, the identified themes would have remained consistent.

## Ethical Considerations

Social research requires the utmost integrity and ethical conduct (Schwandt & Gates, 2021). While the methodology of QCA, specifically document analysis, is not endangered by a relationship between participants and the researcher, the role of the researcher as an instrument of coding must be addressed for potential research bias (Roller, 2019). The categorization of textual data in QCA is an exercise of interpretation (Mayring, 2019). To address these ethical considerations, Selvi (2019) emphasized the necessity for researchers to conduct analyses in accordance with a series of clear guidelines. Researchers must record how data was selected, sustain a constructive interaction with the data, as well as be clear and explicit about their dispositions towards the data that may influence the coding process in which they are the instrument (Karppinen & Moe, 2019). Moreover, the origin and credibility of public data (i.e. source criticism) as objects of research must be routinely assessed throughout the analysis process to preserve authenticity and credibility (Karppinen & Moe, 2019). These ethical considerations were kept at the forefront of this study's analysis.

## Validation Strategies

In qualitative research, the validation of findings is a necessary process to evaluate their level of accuracy according to how the researcher, respondents, and/or consumers have represented them (Creswell & Poth, 2018). According to Creswell and Poth's (2018) perspective, each qualitative study constitutes the lens of the researcher who conducted it. They recommend that qualitative approaches utilize a minimum of two validation strategies, providing evidence that the findings are indeed accurate. This QCA employed the strategies of data triangulation, bias disclosure, and dependability to validate findings.

### Data Triangulation

This QCA collected data from three different peer-reviewed sources of publicly accessible T1D information including medical journals, medical websites, and nonprofits. The documents were analyzed for corroborating semiotic content, of which the researcher used to interpret the data's significance (Creswell & Poth, 2018). This process established credibility, as these three sources provided corroborating evidence and allowed the researcher to triangulate five themes of the T1D narrative.

### Bias Disclosure

There are three researcher disclosures relevant to the shaping of this study. First, the researcher brings a personal background in linguistics. She was born and raised in a third-world country for 18 years where her parents worked as linguists among a remote people group. The lived experiences that came from this upbringing shaped her lens of the unique relationship between language and culture. The researcher's semiotic approach to publicly accessible T1D in this QCA was informed by these lived experiences. Second, the researcher brings a professional background in clinical social work. Her extensive work with vulnerable populations influenced her interpretation of publicly accessible T1D information, favoring PWD as the recipient speech community. Lastly, the researcher has professional experience working with the T1D community during employment at a diabetes biotechnology company. The communications she shared with AYAs and their caregivers influenced how the researcher interpreted the publicly accessible T1D information analyzed in this QCA. Moreover, her perspective is not as one living with T1D but rather a qualitative researcher who is interested in T1D health communications.

### Dependability

A study's dependability is a measure of its trustworthiness (Creswell & Poth, 2018). Dependability was achieved in this QCA through MAXQDA, a reputable computer-assisted software for qualitative data analysis. MAXQDA ensured intercoder reliability by identifying the correct coding frame according to word frequencies. Moreover, the software provided a digital audit trail through the software's logbook which was used by the researcher to document the analysis process and procedures (Creswell & Poth, 2018).

## Summary

This chapter provided an in-depth description of the study's methodology. First, the qualitative paradigm and QCA design were justified. Second, the research questions and search strategy procedures were explained. Lastly, the semiotic analysis process and ethical considerations of QCA were addressed. Chapter Four presents the qualitative research findings.

# CHAPTER FOUR - FINDINGS

## Overview

Health communication research has not qualitatively explored what communication is taking place among the T1D community through publicly accessible information. What's more, the health information landscape has changed significantly post-pandemic. How publicly accessible T1D information is categorized, and which content is geared toward the AYA population, is unknown. The purpose of this study was therefore to explore the content and semiotic structure of publicly accessible T1D information. The following research questions directed this study:

RQ1: What T1D information is being strategically communicated?

RQ2: How is publicly accessible T1D information categorized?

RQ3: Among publicly accessible T1D information, what content is tailored to AYAs?

The main findings of this study are presented in two sections. First, word frequency findings from each of the three sources (i.e. journals, websites, nonprofits) are reviewed. Tables of column data are provided to illustrate the commonalities and differences of T1D-specific keywords, represented by a word glossary of 18 terms that were found to be consistent among three different peer reviewed sources. Next, five themes of publicly accessible T1D information are presented from the thematic analysis, which include (1) *Management*, (2) *Staying Alive*, (3) *Type 1 How-Tos*, (4) *Management is Happening*, and (5) *Type 1 Management Outcomes*. Definitions and textual examples of each theme are provided. Chapter Five provides an in-depth discussion of these themes and their significance.

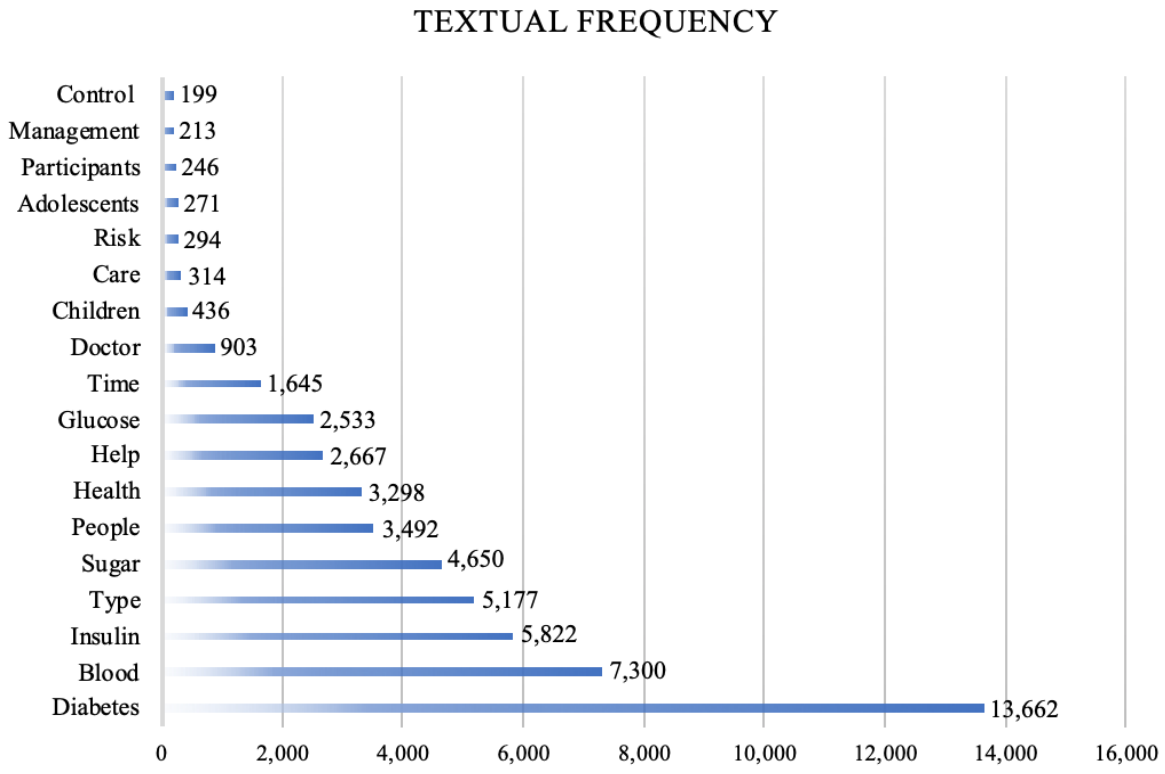
## Findings

### Frequency Analysis

MAXQDA software was used to conduct a word frequency analysis among 1,066 peer-reviewed documents collected from ten medical journals, websites, and nonprofits. Word frequency analysis is a function within MAXQDA that allows qualitative researchers to identify which words are ranked the highest for usage within a dataset (Kalpokas & Radivojevic, 2022). This analysis produced a collective glossary of 18 keywords as shown in Figure 5. Ranked in the order of their textual frequency, they included diabetes, blood, insulin, type, sugar, people, health, help, glucose, time, doctor, children, care, risk, adolescents, participants, management, and control. These words formed the study's coding frame, which guided the thematic analysis of the documents. The following sections break down these frequency findings according to each of the three peer-reviewed sources.

**Figure 5**

*Glossary of Most Frequent Words among Publicly Accessible T1D Information*



**Medical Journals.** The medical journal sample included 40 documents (n = 40). MAXQDA software revealed the most frequent words including diabetes, insulin, children, care, health, risk, adolescents, participants, management, and control (see Table 3). These findings were solidified after the researcher created a stop list to automatically omit grammatical articles and conjunctions from the word frequency search (e.g. and, or, the, a, an, etc.) (Kalpokas & Radivojevic, 2021). This allowed for an accurate understanding of which T1D-related words are prioritized among medical journal documents.

**Table 3**

*MAXQDA Word Frequency Ranking among Medical Journal Documents*

| Word | Rank | Frequency |
|---|---|---|
| Diabetes | 1 | 1,723 |
| Insulin | 2 | 585 |
| Children | 3 | 436 |
| Care | 4 | 314 |
| Health | 5 | 307 |
| Risk | 6 | 294 |
| Adolescents | 7 | 271 |
| Participants | 8 | 246 |
| Management | 9 | 213 |
| Control | 10 | 199 |

**Medical Websites.** The medical website sample included 261 documents (n = 261). After creating the stop list, MAXQDA software revealed the most frequent words as diabetes, blood, sugar, insulin, type, people, help, glucose, doctor, and health (see Table 4). Word frequencies drastically increased in comparison to medical journal documents. Notably, the analysis demonstrated a clear overlap between the medical journal information and medical website information, where diabetes, insulin, and health were identified for the second time.

**Table 4**

*MAXQDA Word Frequency Ranking among Medical Website Documents*

| Word | Rank | Frequency |
|---|---|---|
| Diabetes | 1 | 4,612 |
| Blood | 2 | 3,519 |
| Sugar | 3 | 2,447 |
| Insulin | 4 | 1,843 |
| Type | 5 | 1,338 |
| People | 6 | 1,013 |
| Help | 7 | 1,011 |
| Glucose | 8 | 944 |
| Doctor | 9 | 903 |
| Health | 10 | 888 |

**Nonprofits.** The nonprofit sample included 765 documents (n = 765). After creating the stop list, MAXQDA software revealed diabetes, type, blood, insulin, people, sugar, health, help, time, and glucose as the most frequently used words (see Table 5). Once again, the analysis reported overlapping words with the previous document samples including diabetes, type, blood, insulin, people, sugar, health, and glucose. To form an accurate coding frame, the three frequency lists were combined, and any repeating keywords were counted once. This produced a representative coding frame of 18 keywords.

**Table 5**

*MAXQDA Word Frequency Ranking among Nonprofit Documents*

| Word | Rank | Frequency |
|---|---|---|
| Diabetes | 1 | 7,323 |
| Type | 2 | 3,839 |
| Blood | 3 | 3,781 |
| Insulin | 4 | 3,394 |
| People | 5 | 2,479 |
| Sugar | 6 | 2,203 |
| Health | 7 | 2,103 |
| Help | 8 | 1,656 |
| Time | 9 | 1,645 |
| Glucose | 10 | 1,589 |

Once this coding frame was established, emoticon symbols were selected and assigned to each keyword (i.e. code) within the dataset. Using MaxQDA's auto-code function, all documents (n = 1,066) were coded with the coding frame. This completed the first phase of analysis and set the foundation for thematic analysis, which was guided by Greimasian semiotics and the CNS tool. A brief description of Greimas's CNS will now follow, as it is necessary to understand how the thematic analysis of this study was framed.

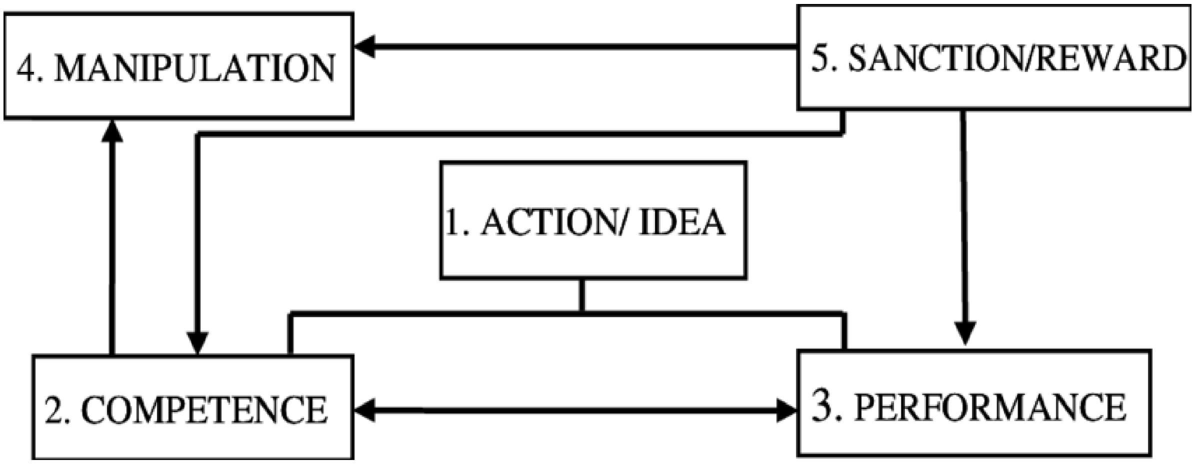
## Canonical Narrative Schema

The CNS is an analytical tool that allows the researcher to demonstrate the formal and semantic organization of an action's core elements within a narrative (Hébert, 2019). There are five core elements, or narrative components, that are assessed as shown in Figure 6. First, an action will serve as the focal point of a narrative and can be further divided into competence and performance. Competence is concerned with necessity and asks what is necessary to complete the action.

Two competence criteria are “knowing-how-to-do and being-able-to-do” the action (Hébert, 2017, p. 332). The performance component then piggybacks off of competence and is concerned with executing the action. Fourth, the component of manipulation is concerned with the reason underlying the action. It deals with desiring to do the action and/or having to do the action, as well as the retaliatory consequences if the action is not performed (Hébert, 2019). Lastly, the component of sanction is focused on analyzing the performed action and the associated outcome. This study employed the CNS to characterize the narrative schema of publicly accessible T1D information.

**Figure 6**

*Components of the Canonical Narrative Schema* (Yekini, 2017)



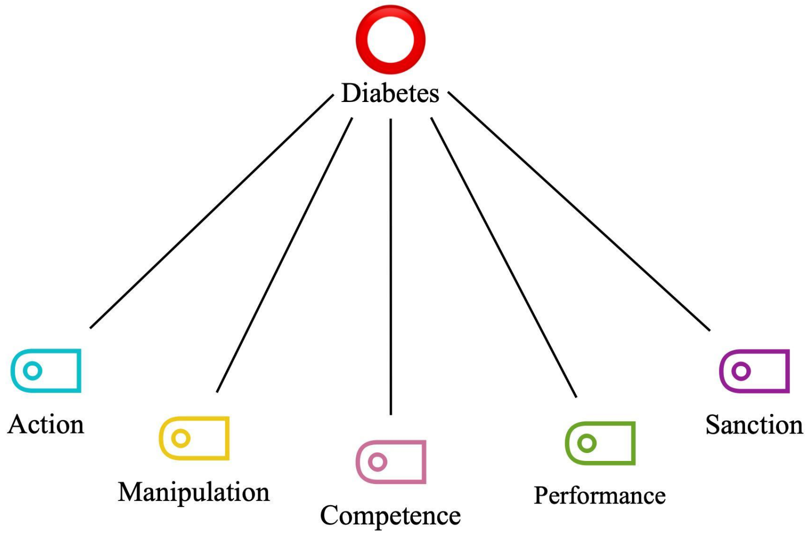
### Thematic Analysis

Thematic analysis followed a deductive approach and was organized within MAXQDA by a hierarchical code system. Deductive QCAs develop themes by drawing from established theories, research, and/or experiences (Selvi, 2019). Previous applications of deductive QCAs have commonly been among healthcare contexts (Doukani et al., 2021; Subu et al., 2021). In this study, the CNS tool was utilized to identify narrative themes among public T1D information.

Hierarchical code systems in MAXQDA are considered beneficial for a number of reasons. According to Kuckartz and Rädiker (2019), they afford the researcher flexibility within the dataset by providing both "top-level codes and multiple levels of subcategories" (p. 94). This umbrella system provides a clearer picture of the data because the researcher is able to identify complex patterns and any overlap among the codes within the documents (Kuckartz & Rädiker, 2019). In this study, the coding frame of 18 keywords served as the top-level codes. The five components of the CNS tool were then assigned to each top-level code as the subcategories. For example, the top-level code of Diabetes had the subcodes Action, Manipulation, Competence, Performance, and Sanction as shown in Figure 7. Thematic analysis using this coding system revealed five themes among the T1D information: 1) *Management*, 2) *Staying Alive*, 3) *Type 1 How-Tos*, 4) *Management is Happening*, and 5) *Type 1 Management Outcomes*. The following sections break down these findings with textual examples and MAXQDA visualizations.

**Figure 7**

*Diabetes Hierarchical Code-Subcode Model in MAXQDA*



**Management.** The central action of the T1D information analyzed in this QCA was *Management*. The instruction to manage T1D was frequent and directly mentioned among all three peer-reviewed sources, with a collective of 346 mentions. Characterized primarily by the words diabetes, management, and type as shown in Table 6, *Management* is at the very heart of the health narrative that is publicly available to PWD. The remaining four themes, though distinct, all point to T1D management and fall under its umbrella. Together, they form what the CNS tool dubs the "comprehensive action" (Hébert, 2019, p. 107). In other words, the primary focal point of publicly accessible T1D information is the effective management of the disease.

**Table 6**

*Document Segments of Management*

| Lexical Words | Narrative Context | Source |
|---|---|---|
| Management, Type, Diabetes | "Effective management of chronic conditions such as type 1 diabetes (T1D)" | Journal \| PubMed Central |
| Diabetes | "Diabetes self-management" | Journal \| PubMed Central |
| Management | "Management of T1D in adolescence" | Journal \| PubMed Central |
| Management, Children | "Management of T1D in children" | Journal \| PubMed Central |
| Diabetes, Care | "Incorporated into routine diabetes care" | Journal \| Diabetes Care |
| Type, Diabetes, Management | "Their child's type 1 diabetes management" | Journal \| Diabetes Spectrum |
| Diabetes | "You can manage your diabetes" | Website \| CDC |
| Diabetes | "Take care of your diabetes" | Website \| CDC |
| Diabetes | "Manage and live well with diabetes" | Website \| CDC |
| Type, Diabetes | "Manage Type 1 or Type 2 diabetes" | Website \| Cleveland Clinic |
| Diabetes | "To manage your diabetes confidently and independently" | Nonprofit \| ADA |

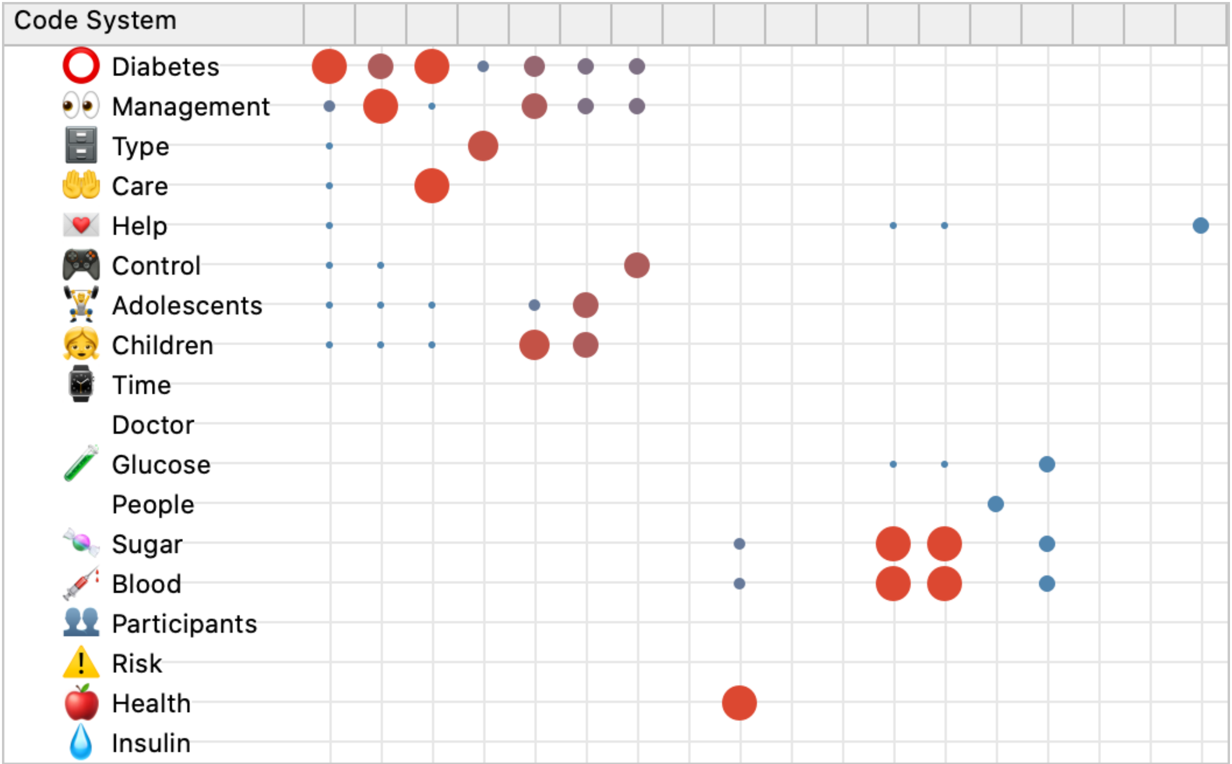
| Lexical Words | Narrative Context | Source |
|---|---|---|
| Diabetes | “Manage diabetes at school” | Nonprofit \| ADA |
| Type, Diabetes, Management | “The daily demands of type 1 diabetes management” | Nonprofit \| BT1 |
| Diabetes, Management | “Diabetes management is based on a 24-hour cycle” | Nonprofit \| BT1 |

*Management* was directly mentioned 105 times among the medical journal documents, 146 times among the medical website documents, and 95 times among the nonprofit documents. It was interesting to note which words within the coding frame were more commonly assigned to this theme as well as their relation to one another within the narrative. As illustrated by Figure 8, the primary keywords used to describe T1D management included diabetes, management, and type. Not only was this in regard to their textual frequency but also in their relation to one another within the text.

The same observation was made for the keywords blood and sugar, which often were present in the same segments discussing the management of blood sugar levels. Documents from each of the three sources used similar language when addressing the action of *Management*, though nonprofit and website documents more commonly assigned personal ownership to the T1D audience through segments such as “manage your diabetes confidently” (ADA, n.d., para. 12) (see Table 6). Conversely, document segments from medical journals maintained objective and academic prose.

**Figure 8**

*MAXQDA Code Relations Browser for Management*



**Staying Alive.** Thematic analysis revealed the second theme as *Staying Alive*. The defining factor of manipulation identified in the narrative of T1D information is PWD's having-to-do reality in reference to disease self-management. The documents were very clear in communicating that T1D must be managed, otherwise, PWD will face serious health complications which include premature death. The narrative around this theme discussed diagnoses, the duration of diabetes, the chronic nature of the disease, as well as aspects of the pathology as illustrated in Table 7. The action of T1D management is preceded by a diagnosis, which the documents frequently mentioned through statements such as "a type 1 diagnosis means life-long dependence on insulin" (BT1, 2022, para. 4). PWD have to manage T1D because once they are diagnosed, it is a life sentence of keeping one's blood sugar levels steady.

Moreover, the duration of diabetes was coded under this theme because it speaks to the chronic nature of T1D. The duration (e.g. 5 years of living with T1D) was described as a symbol of good management and, along that same vein, longevity. In this way, the documents described a direct correlation between effective management of T1D and longevity. The narrative frequently reminded the T1D audience of the necessity of self-management for their survival and quality of life.

**Table 7**

*Document Segments of Staying Alive*

| Lexical Words | Narrative Context | Source |
|---|---|---|
| Diabetes | "Diagnosed with any type of diabetes" | Journal \| PubMed Central |
| Diabetes | "There is no cure for type 1 diabetes" | Journal \| PubMed Central |
| Diabetes, Children | "Type 1 diabetes (T1D) is one of the most common chronic diseases in children" | Journal \| PubMed Central |
| Children | "A chronic childhood illness is seen as a stressor to which children and families attempt to adapt" | Journal \| PubMed Central |
| Diabetes | "The diagnosis of type 1 diabetes" | Journal \| Diabetes Care |
| Diabetes | "Particularly as diabetes duration increases" | Journal \| Diabetes Care |
| Insulin | "They depend on insulin to live" | Website \| CDC |
| People, Diabetes | "Younger people have more years with diabetes ahead" | Website \| CDC |
| People, Diabetes | "More than 37 million people in the United States have diabetes" | Website \| CDC |
| Type, Diabetes, Insulin | "If you have type 1 diabetes, your body doesn't produce enough (or any) of the hormone insulin." | Website \| Cleveland Clinic |
| Blood, Sugar | "That means you have to stay on top of your blood sugar levels." | Website \| WebMD |

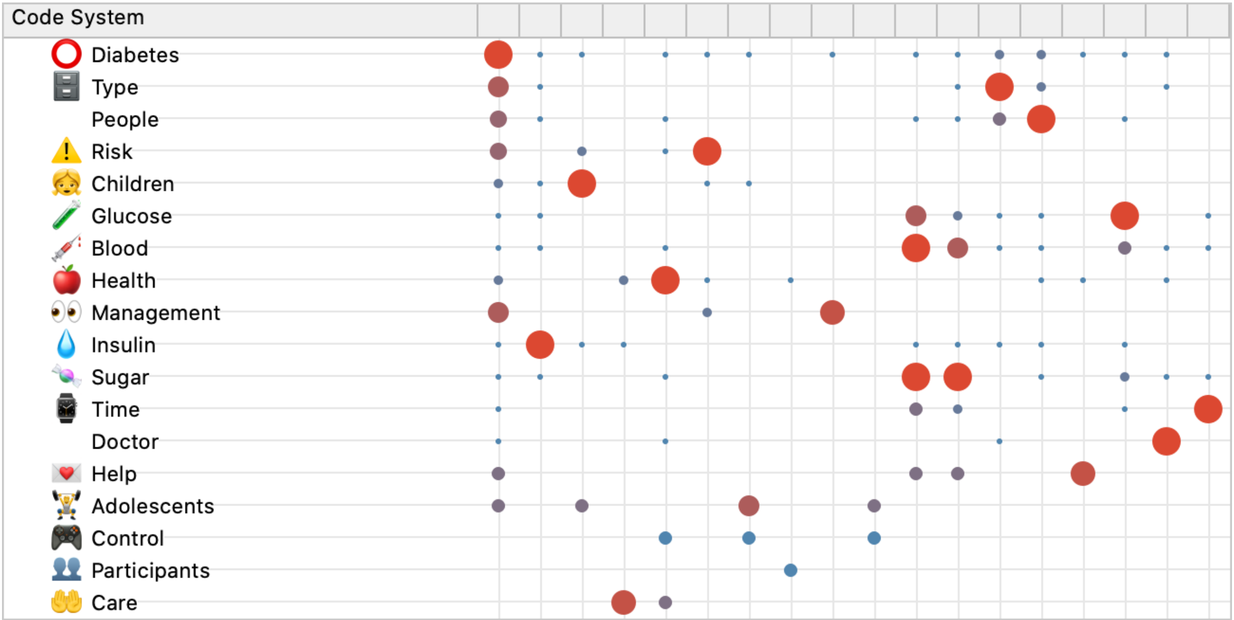
| Lexical Words | Narrative Context | Source |
|---|---|---|
| Sugar | "If you have type 1 diabetes and your sugar level is above 240 mg/dL" | Website \| WebMD |
| Diabetes | "Diabetes is constant – children must manage it all day and all night and it never goes away." | Nonprofit \| ADA |
| People, Type | "The people who need to be most careful about lows are people with type 1" | Nonprofit \| ADA |
| Type, Insulin | "A type 1 diagnosis means life-long dependence on insulin" | Nonprofit \| BT1 |
| Type | "Type 1 diabetics must do this" | Nonprofit \| BT1 |
| Type, Diabetes | "Those with type 1 diabetes should be paying careful attention" | Nonprofit \| BT1 |

The theme of *Staying Alive* was mentioned 271 times among the medical journal documents, 445 times among the medical website documents, and 490 times among the nonprofit documents. Collectively, it ranked as the third most prominent theme among publicly accessible T1D information. Looking at the coding frame, diabetes, blood, and type were most prominently assigned to this theme (see Figure 9). Less common keywords (e.g. health) alluded to the health consequences of poor management, such as a document segment from the *ADA* (2022) in which PWD were cautioned that "having diabetes puts your kidney health at risk" (para. 7). Here, the codes health and risk were used to remind PWD of the potential health consequences that are ensured by a T1D diagnosis.

Another segment from the *ADA* (n.d.) educated PWD about the pathology of the disease. "In people with type 1 diabetes, the pancreas no longer makes insulin" (para. 4). In this example, the code insulin was used to identify the underlying reason for T1D management, which is the body's lack of the essential hormone. A final and notable observation of the *Staying Alive* theme was that it only ever addressed the having-to-do aspect of T1D management and never once the wanting-to-do aspect. This finding came as no surprise, as T1D management is never a choice for those who are diagnosed, nor is there a reward granted for its effective management other than sustaining one's life and reaching for quality of life.

**Figure 9**

*MAXQDA Code Relations Browser for Staying Alive*



**Type 1 How-Tos.** The most prominent theme of publicly accessible T1D by far was identified as *Type 1 How-Tos*, with a collective code count that surpassed the other themes by four times. This theme fulfilled the competency component of the CNS, which addresses knowing how and being able to carry out the action of T1D management. Segments heavily discussed a plethora of resources and capabilities that are required by PWD to keep their type 1 under control (see Table 8). Among the three sources of publicly accessible T1D information, the proportional representation of how to manage T1D was the same. The documents namely described the ability to monitor glucose levels, inject insulin dosages, use T1D devices (e.g. continuous glucose monitoring devices, insulin pumps), and balance physical activity with

nutrition intake. Resources including diabetes educators, health professionals, and the help they each provide were also addressed by this theme.

**Table 8**

*Document Segments of Type 1 How-Tos*

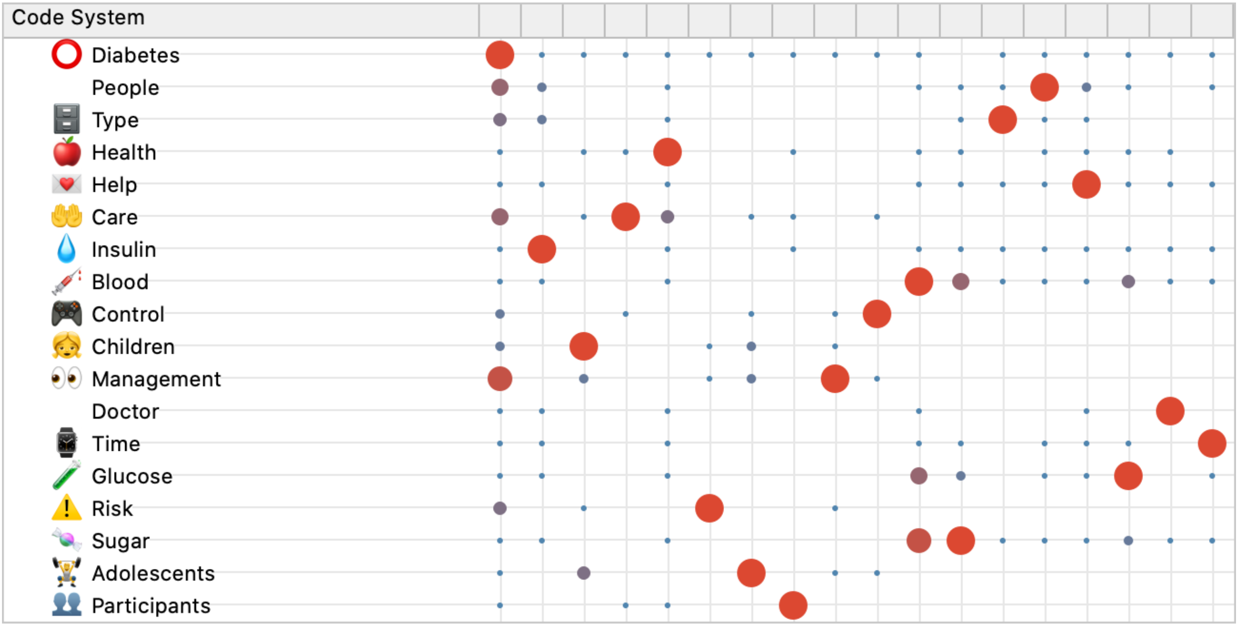
| Lexical Words | Narrative Context | Source |
|---|---|---|
| Adolescents, Management | "Adolescents gradually take over the management control" | Journal \| PubMed Central |
| Children, Adolescents, Diabetes | "All children and adolescents with type 1 diabetes should monitor glucose levels" | Journal \| Diabetes Care |
| Diabetes, Management | "Develop a personalized Diabetes Medical Management Plan (DMMP)" | Website \| CDC |
| Help, Insulin | "Help your child plan insulin use" | Website \| CDC |
| Blood, Doctor | "Try to keep your blood pressure below 140/90 mm Hg (or the target your doctor sets)" | Website \| CDC |
| Insulin | "Alter your insulin dose" | Website \| CDC |
| Glucose | "Check your glucose levels frequently" | Website, Cleveland Clinic |
| Blood, Sugar | "Learn how to check your blood sugar" | Website \| Cleveland Clinic |
| Insulin | "You may need to increase your daily dose of insulin" | Website \| WebMD |
| Blood | "Use your lancing device on the side of your fingertip to get a drop of blood" | Nonprofit \| ADA |
| Type, Diabetes, Insulin | Treatment for type 1 diabetes is insulin" | Nonprofit \| ADA |
| Insulin | "Make sure there are no 'clumps' inside the bottle of insulin" | Nonprofit \| BT1 |
| Help | "Doctors will even provide a chart to help you keep track" | Nonprofit \| BT1 |

| **Lexical Words** | **Narrative Context** | **Source** |
|---|---|---|
| Glucose | "Insert a glucose meter strip into the meter" | Nonprofit \| BT1 |
| Time | "Write down where you inject each time" | Nonprofit \| BT1 |
| Diabetes | "Ask your diabetes team what angle is the best for your body" | Nonprofit \| BT1 |
| Sugar | "Be mindful of how certain chemicals and sugar alcohols tend to affect your BG" | Nonprofit \| BT1 |

*Type 1 How-Tos* was mentioned 691 times among the medical journal documents, 1,404 times among the medical websites documents, and 1,949 times among the nonprofit documents. This theme is the only one in which the entire coding frame was represented. The two most common codes assigned to it were diabetes and insulin. A segment from *Diabetes Care*, a medical journal, described the necessity of automated insulin delivery systems and how they "should be offered for diabetes management to youth with type 1 diabetes who are capable of using the device safely (either by themselves or with caregivers" (Draznin et al., 2022, p. 218). AYAs must not only know how to use these devices but they must also be capable of using them to manage their T1D effectively. This segment is representative of how the majority of T1D information analyzed in this QCA focused on what is necessary for executing safe and effective T1D management, which is the principal action of the public T1D narrative.

**Figure 10**

*MAXQDA Code Relations Browser for Type 1 How-Tos*



**Management is Happening.** Thematic analysis revealed the fourth theme as *Management is Happening*. Identified as the second least prevalent theme among the dataset, there were a total of 760 coded segments. This theme fulfilled the performance component of the CNS, which demonstrates how the action of *Management* is being realized. This is only achieved by piggybacking off of the *Type 1 How-Tos* theme, as PWD cannot actively manage the condition without the necessary knowledge and abilities. Due to the overlap between these two themes, document segments describing T1D being actively managed were meticulously coded (see Table 9). For example, segments advising PWD to check their blood sugar fell under the *Type 1 How-Tos* theme because they spoke to what is necessary to manage T1D, while segments describing the continuous act of PWD checking their blood sugars fell under the *Management is Happening* theme because they addressed the active performance of T1D management.

**Table 9**

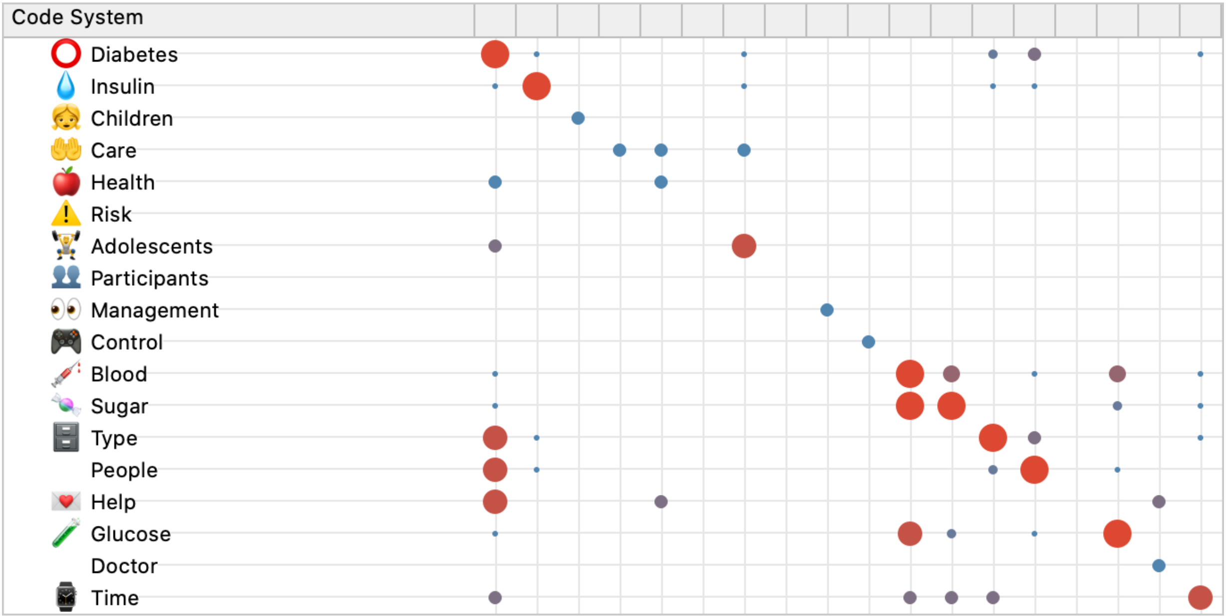
*Document Segments of Management is Happening*

| Lexical Words | Narrative Context | Source |
|---|---|---|
| Adolescents, Diabetes | "For adolescents living with type 1 diabetes" | Journal \| PubMed Central |
| Diabetes | "People living with diabetes" | Journal \| Diabetes Spectrum |
| Insulin, Diabetes | "Taking your insulin and diabetes pills as usual" | Website \| CDC |
| Blood, Sugar | "Checking your blood sugar, checking your blood sugar again" | Website \| CDC |
| Diabetes | "Managing diabetes is not easy" | Website \| CDC |
| Diabetes | "Diabetes that's not well managed" | Website \| Cleveland Clinic |
| Diabetes | "The best way to avoid the disease is by managing your diabetes" | Website \| Cleveland Clinic |
| Insulin, Diabetes | "The dose of insulin or oral diabetes medication that you are taking" | Website \| Cleveland Clinic |
| Diabetes | "Managing diabetes at home" | Website \| Mayo |
| Blood, Glucose | "Testing blood glucose multiple times each day" | Nonprofit \| ADA |
| Type, Diabetes | "Living day-to-day with Type 1 diabetes" | Nonprofit \| BT1 |
| Blood, Glucose | "Doing blood glucose tests before and 90 minutes after your meals" | Nonprofit \| BT1 |
| Insulin | "Administering insulin" | Nonprofit \| JDRF |

Findings revealed variations of what constitutes as performances of T1D management, making use of present particles and continuous verb forms. These included both positive examples such as actively taking one's insulin and checking one's blood sugar levels, as well as negative examples in which daily self-management is being neglected (see Table 9). The most frequent keywords from the coding frame used to describe the execution of T1D management were diabetes, blood, and people. Moreover, the relations of the keywords diabetes, type, and people as well as blood, sugar, and glucose were frequently observed within the content (see Figure 11).

**Figure 11**

*MAXQDA Code Relations Browser for Management is Happening*



**Type 1 Management Outcomes.** The final theme identified by thematic analysis was *Type 1 Management Outcomes*. Ranked as the second most prominent theme among the publicly accessible T1D information, it was coded 154 times among medical journal documents, 516 times among medical website documents, and 547 times among nonprofit documents. The most frequent keywords from the coding frame were diabetes, blood, and sugar (see Table 10). The *Type 1 Management Outcomes* theme fulfilled the sanction component of the CNS, defined as an evaluation of the T1D management documented as happening (or not) and the associated outcomes.

**Figure 12**

*MAXQDA Word Cloud for Type 1 Management Outcomes*

Document segments described both direct and forecasted outcomes of self-managing T1D. For example, a segment from the *Cleveland Clinic* described the forecasted outcome of increasing one's blood sugar levels by eating or drinking 15 grams of carbs (see Table 10). Another segment from the *ADA* (2022) cautioned PWD about hypoglycemia, a dangerous and common low blood sugar condition. The segment warned how one's blood glucose can drop too low if certain medications are being taken, particularly insulin. Additional segments made similar mentions of this outcome.

**Table 10**

*Document Segments of Type 1 Management Outcomes*

| Lexical Words | Narrative Context | Source |
|---|---|---|
| Control | “Dietary adherence is associated with better glycemic control in youth with type 1 diabetes” | Journal \| Diabetes Care |
| Diabetes | “Self-management behaviors can improve diabetes self-efficacy, adherence, and metabolic outcomes” | Journal \| Diabetes Care |
| Blood, Sugar | “High blood sugar can lead to nerve damage called diabetic neuropathy” | Website \| CDC |
| People, Type, Diabetes | “DKA happens most in people with type 1 diabetes” | Website \| CDC |
| People, Diabetes, Blood, Sugar | “People with diabetes may experience low blood sugar as often as once or twice a week” | Website \| CDC |
| Blood, Sugar | “Eat or drink 15 grams of carbs to raise your blood sugar” | Website \| Cleveland Clinic |
| Type | “Adults who’ve had type 1 for a long time have slower physical and mental reactions” | Website \| WebMD |
| People, Diabetes, Type | “Approximately 80 percent of people with diabetes will develop some type of diabetic eye disease” | Nonprofit \| ADA |
| Blood, Glucose, Diabetes | “This can cause high blood glucose levels and cause you to go into diabetes ketoacidosis, which is very serious and dangerous” | Nonprofit \| ADA |
| Blood, Glucose | “Your blood glucose can go too low if you take certain medications” | Nonprofit \| ADA |
| Blood, Sugar, Insulin | “Hypoglycemia is the state of low blood sugar and is caused by too much insulin or too little sugar in the body” | Nonprofit \| BT1 |

Other segments discussing the *Type 1 Management Outcomes* theme made mention of the long-term health consequences of managing T1D (see Figure 12). They included cardiovascular disease, diabetic ketoacidosis (DKA), diabetic neuropathy (i.e. nerve damage), diabetic retinopathy (i.e. eye damage), skin conditions, low blood sugar episodes (i.e. hypoglycemia), high blood sugar episodes (i.e. hyperglycemia), and diabetes burnout and distress. Notably, the language used among these segments described T1D-related health outcomes as prolongable but not necessarily preventable. According to the *ADA* (2022), many of these health complications are inevitable for those living with T1D regardless of how effectively one self-manages their blood sugar and insulin levels.

## Summary

This chapter presented the main findings of the QCA. First, the word frequency findings were reviewed from each peer-reviewed source of publicly accessible T1D information. Second, the five themes of *Management*, *Staying Alive*, *Type 1 How-Tos*, *Management is Happening*, and *Type 1 Management Outcomes* were presented from the thematic analysis. Visualizations of the findings were generated with MAXQDA to aid readability and comprehension. Chapter Five provides an in-depth discussion of these findings and their interpreted significance.

# CHAPTER FIVE: CONCLUSION

## Overview

The purpose of this QCA was to explore the content and semiotic structure of publicly accessible T1D information and assess what content is tailored to the AYA population. As an effort to enhance AYA self-management practices and outcomes, this research aimed to better understand what information is accessible to the T1D community and the ways in which it is categorized. This new understanding offers profound value, as the health information landscape is ever-evolving and has undergone significant changes since the COVID-19 pandemic. OHIS behaviors among chronic communities have increased, including PWD who were forced to self-manage in isolation (Mikkelsen et al., 2022; Oser et al., 2020; Stoian et al., 2020).

This study explored the semiotic content of publicly accessible T1D information. The analysis produced two CNS models of T1D information composed of five themes. These findings will advise health authorities and professionals working with the T1D community (e.g. diabetes educators and healthcare providers) about what information is accessible to and consumed by PWD to enhance AYA self-management practices and outcomes.

This chapter presents a thorough discussion of the research findings, framed by empirical and theoretical lenses. First, a summary of the findings is presented. Second, each of the three research questions is addressed through the data. Next, the five thematic findings are discussed in relation to the literature. The chapter closes with a discussion of the implications, limitations, and recommendations for future research.

## Summary of Findings

This qualitative research conducted a semiotic content analysis of publicly accessible T1D information to explore three research questions. The study design followed a two-prong approach, beginning first with a word frequency analysis followed by a thematic analysis. Data was coded deductively, guided by Greimasian semiotics and the CNS analytical tool. Findings revealed two narrative schemas including (1) an individual T1D CNS, where the subject (i.e. the individual with T1D consuming the public health information) ensures that s/he manages T1D, and (2) a communal T1D CNS, where the community of a PWD (e.g. family members, peers, teachers) ensures that s/he manages T1D.

## Research Questions

The nature of this QCA was exploratory, aimed at identifying what information is being communicated to the T1D community through publicly accessible sources. A distinct priority of the research was to determine the CNS of T1D information, revealing the semiotic structure of health communication addressing PWD. A directed QCA was conducted to address the following three research questions, as this approach is regarded as being the most solidified and appropriate for analyzing healthcare documents (Doukani et al., 2021; Selvi, 2019):

RQ1: What T1D information is being strategically communicated?

RQ2: How is publicly accessible T1D information categorized?

RQ3: Among publicly accessible T1D information, what content is tailored to AYAs?

Research questions were addressed through data triangulation, collecting publicly accessible T1D information from three peer-reviewed sources including medical journals, medical websites, and nonprofits. This validation strategy provided reliability for the findings. Through the analysis of 1,066 documents, this QCA developed a comprehensive understanding of the public T1D health communication narrative.

**RQ1: What T1D information is being strategically communicated?** This analysis revealed that the information strategically communicated to those with T1D is centered around the three areas of T1D education and statistics, treatment burden, and psychosocial health. This finding aligns with T1D research literature, which has similarly prioritized these areas (Cummings et al., 2021; Cobham et al., 2020; Robinson et al., 2019). Among each of the peer-reviewed sources, T1D education and statistics were the first communication focus.

Narrators of the health information (i.e. the authors publishing on behalf of the medical journals, websites, and nonprofits) collectively provided pages of content disclosing the most recent T1D statistics, how the chronic disease develops and progresses, and life-prolonging self-management measures PWD should be aware of such as consuming a nutritious diet and maintaining a healthy lifestyle. Document segments from journals, websites, and nonprofits collectively shared statistics cited from the same credible sources including the CDC’s latest Diabetes Report Card and the SEARCH for Diabetes in Youth study. These sources have been prevalently cited in T1D research literature and marked as credible (Chiang et al., 2018). In this way, T1D education and statistics shared among publicly accessible diabetes journals, websites, and nonprofits correlate with those published in the existing research literature.

Treatment burden was the second, most prevalent communication focus identified in this analysis. Scholars have described it as the amount of effort that PWD must invest in managing T1D through finances, medication, administration, daily healthy habits, and time (Sav et al., 2017). This QCA confirmed this definition, with documents among each peer-reviewed source heavily discussing the necessity of T1D self-management tasks (e.g. nutritional tracking, continuous glucose monitoring, insulin pump therapy), the financial costs associated with having T1D and how to best navigate them (e.g. health insurance coverages for insulin medications), as well as the myriad health outcomes of T1D (Cummings et al., 2021; O’Donnel et al., 2021). The complications of cardiovascular disease, kidney failure, eye disease, and DKA were extensively covered and correlated with what has been previously reported in the research literature (Robinson et al., 2018). Documents discussing treatment burden validated newly diagnosed adults through segments such as “Adjusting to life with T1D isn’t always easy, but we’re here to help” (JDRF, n.d., para. 1). This finding supports recently published studies, which have reported how the T1D treatment burden is effectively addressed through patient validation (Hardman et al., 2022; Haider et al., 2021). Most notably, this finding validates the reason behind OHIS behaviors performed by PWD, which is uncertainty and disease management (Xiang & Stanley, 2017).

Psychosocial health was the third communication focus among the publicly accessible T1D information. Document segments discussed two aspects of psychosocial health, which included the phenomenon of diabetes distress and burnout that is commonly experienced by those living with T1D and quality of life. Segments addressing distress and burnout validated the overwhelming reality of facing a lifetime of blood sugar management. This content is backed by existing research literature about the T1D psychosocial burden, which has described its diagnosis and chronic nature as being incredibly difficult to accept (Kalra et al., 2018). Distress segments were additionally paired up with the quality-of-life segments, sharing how those living with T1D can still live a full and rewarding life through peer support and DOCs, which are demonstrated in existing literature as prominent psychosocial resources for those living with T1D (Oser et al., 2020; Gavrila et al., 2019). To this end, the three areas of T1D education and statistics, treatment burden, and psychosocial health strategically communicated by diabetes journals, websites, and nonprofits analyzed in this QCA were found to correlate and complement the findings of existing research literature.

**RQ2: How is publicly accessible T1D information categorized?** This QCA explored categories of publicly accessible T1D information through the lens of Greimasian semiotics, specifically the semiotic theory of action and Greimas' CNS tool. The analysis revealed five categories including *Management*, *Staying Alive*, *Type 1 How-Tos*, *Management is Happening*, and *Type 1 Management Outcomes*. These categories correspond to the CNS components of action, manipulation, competence, performance, and sanction (see Figure 13). Collectively, they reveal two narrative schemas in publicly accessible T1D information including (1) an individual T1D CNS, where the subject (i.e. the individual with T1D consuming the public health information) ensures that s/he manages T1D, and (2) a communal T1D CNS, where the community of a PWD (e.g. family members, peers, teachers) ensures that s/he manages T1D. The bulk of publicly accessible T1D was found to be categorized under competence, defined as *Type 1 How-Tos* in this analysis. The following discussion will break down each of these categories and their implications.

**Figure 13**

*An Individual CNS of Publicly Accessible T1D Information*

The Greimas Canonical Narrative Schema

| **Action** | **Manipulation** | **Competence** | **Performance** | **Sanction** |
|---|---|---|---|---|
| The act itself | A compelling force to the action (Having to do) | What is needed to perform the action (Knowing how to do, Being able to do) | The actualization of the action (Causing to be) | Outcome of performing the action (Being of being) |

Applied to publicly accessible T1D information

| **Management** | **Staying Alive** | **Type 1 How-Tos** | **Management is Happening** | **Type 1 Management Outcomes** |
|---|---|---|---|---|
| Manage T1D | Diagnosed with T1D by doctor | Learn how to safely inject an insulin dose | Actively taking insulin | Blood sugars are kept stable |

**RQ3: Among publicly accessible T1D information, what content is tailored to AYAs?** This QCA identified 708 document segments addressing children and adolescents living with T1D. The information was primarily centered around the two themes of *Type 1 How-Tos* and *Staying Alive*, which addressed AYAs having to manage their T1D, knowing how to manage it, and being able to manage it. Most notable about these segments is how they followed the communal CNS model, as opposed to the individual CNS model. The information was directed toward the community of the AYAs, where segments made direct and indirect nods to parents, grandparents, teachers, coaches, and other caregivers who co-manage T1D with AYAs. A nonprofit segment advised parents, "If it's possible to connect your adolescent with other adolescents with diabetes through a camp or local events, that support can be really important as well" (BT1, 2023, para 14.). In contrast, segments that were age neutral in the discussion of any of the three concentrations of T1D information (i.e. statistics and education, treatment burden, psychosocial health) and made no direct mention of AYAs followed the individual CNS model.

This finding correlates with a study conducted by Vaala et al. (2015), which reported that diabetes websites were the least utilized by the AYA population for health information when compared to other forms of self-management technology such as apps, messaging platforms, or insulin pump software. This may suggest that the latter forms of health communication technology may provide a narrative that feels more patient-centered, making them a preferred choice among AYAs. In addition, it may also suggest that messaging platforms and apps are framed by an individual CNS model and that this narrative structure is best received among AYAs. Future qualitative research is warranted to extend the CNS model identified in this study to other digital spaces, such as messaging platforms and DOCs, to explore these implications and their effect on T1D management outcomes.

# Discussion

Scholars refer to any use of the *Internet* to access and consume health information as online health information seeking (OHIS) (Xiang & Stanley, 2017). Since the COVID-19 pandemic, it has been reported that one out of every third adult in the United States performs OHIS behaviors in direct relation to self-management of chronic diseases including diabetes (Lee et al., 2020). Exploring the semiotic content of publicly accessible T1D information and how it is categorized reveals which health information is prioritized and made accessible to the T1D community. This analysis identified five themes including *Management*, *Staying Alive*, *Type 1 How-Tos*, *Management is Happening*, and *Type 1 Management Outcomes*. Together, these themes form two narrative schemas of publicly accessible T1D information which include the individual T1D CNS and the communal T1D CNS.

## Management

The central action of publicly accessible T1D information is *Management*. This is where the narrative starts. PWD achieve optimal self-management when they are able to maintain steady blood sugar and insulin levels in their body. As there is no cure for T1D, there is no end to its management once a diagnosis is received. In this way, the management of T1D is closely correlated with maintenance because it is a repeating cycle. Its success requires disease knowledge, technical abilities, and the daily execution of these resources. These components fulfill the narrative components of competency and performance, which are addressed by the *Type 1 How-Tos* and *Management is Happening* themes.

The reflexive nature of *Management* in T1D information is particularly unique. To understand this, we must look to Greimas' CNS where the action in a narrative is (1) accomplished by a subject of doing and (2) applied to a subject of state (Hébert, 2017). There are transitive actions where the subject of doing is different from the subject of state as well as reflexive actions where they are one and the same. For example, the narrative of Christianity illustrates a transitive action where the resurrection of Jesus (i.e. subject of doing) secures the eternal salvation for all of humanity (i.e. subject of state) (Hébert, 2017). A fictional example would be a prince who rescues a princess from a tower, where the prince is performing the rescue and the princess is reaping the reward of the rescue.

Management of T1D was revealed to be a reflexive action in this analysis, where the individual with T1D is both the subject of doing and the subject of state. PWD function as both the prince and the princess, responsible for self-managing their T1D in order to reap the rewards of the management. This was made apparent through segments addressing individuals with T1D to "take care of your diabetes" (CDC, 2022, para. 9) and "manage your diabetes confidently and independently" (ADA, 2022, para. 10). Authorities of the information, which include medical journals, websites, and T1D nonprofits, strategically use this language to communicate the sole responsibility of self-management that falls to those living with the chronic condition. This strategy may be largely due to the fact that health authorities are aware that PWD "are responsible for 95% of their care" (Hamilton et al., 2022, p. 2).

Management is a prevalent focus among research literature, explored in the contexts of disease education, treatment burden, and psychosocial health. Scholars have described daily management practices to include exercising, blood glucose monitoring, eating a balanced diet, and adjusting both psychologically and socially to a life with T1D (Planalp et al., 2022). Numerous studies have analyzed self-management trends and technology (Zhu et al., 2022; Schmidt et al., 2022; Ding et al., 2021). Hamilton et al. (2022) recognized management as the "central component of diabetes care" (p. 2). Most notably, while effective self-management has the potential to minimize the probability of T1D-related complications down the road by 30 to 75 percent, only 70 percent of the adult T1D community in the United States achieve the average level of blood sugar control (Planalp et al., 2022). Poor self-management among the AYA population is even more alarming, with recent studies reporting just 17 percent of AYAs with T1D achieve their blood sugar goals (Faulds et al., 2021). These reports give credence to the role management plays as the focal point of publicly accessible T1D information.

### Staying Alive

According to the CNS, "if there is an action, then there had to be manipulation" (Hébert, 2019, p. 111). Manipulation in a narrative may be either positive or negative. Positive manipulation is characterized as causing-to-do and encourages the performance of an action that will result in a favorable outcome, while negative manipulation is characterized by causing-not-to-do and involves the performance of an action with a negative outcome (Yekini et al., 2019). Put differently, positive manipulation equates to causation in a narrative, and negative manipulation to prevention. Publicly accessible T1D information is characterized by positive manipulation, with one's survival as the contract underlying self-management.

No one chooses to live with T1D. PWD are driven to manage the chronic disease as soon as they receive the diagnosis in order to survive. Violating this contract via either inaction or poor self-management leads to health consequences. In this way, publicly accessible T1D information is densely overlaid with a having-to-do reality. This is significant because other forms of health communication often incorporate a wanting-to-do reality in which individuals are encouraged to perform or cease specific behaviors for the desired health outcome. For example, messages encouraging the public to get vaccinated or to stop smoking are examples of wanting-to-do strategies (Cottrell-Daniels et al., 2022; Ashworth et al., 2021). Authorities of the information, such as the CDC, are able to assume that people *want* to protect their loved ones from COVID-19 and have healthy lungs, thereby creating messages that compel these actions. After all, there is no better manipulation than one's personal health or that of their family members (Ashworth et al., 2021). The manipulative strategy underlying T1D information is distinct in that it is designed around PWD *having* to manage the disease, as opposed to wielding any personal desire to do so.

The authorities responsible for the information have assumptions about T1D problems that need to be addressed, the personal preferences held by the T1D community, and what is in the best interest of PWD (Oxman et al., 2022). Problems addressed in the information relate to physical and psychosocial concerns of having T1D such as unsteady blood sugar levels, deficient insulin, health risks associated with blood sugar imbalances (e.g. cardiovascular disease), and emotional burdens such as diabetes distress. While one could argue that each of these concerns suggests a wanting-to-do reality (e.g. where PWD want to have stable blood sugars), the content is discussed in the context of having T1D. The action of management, then, remains the target of the manipulation to ensure survival. For example, segments encourage PWD to take care of their feet as a form of self-management in order to prevent complications such as amputation. Other segments educate PWD about the warning signs of cardiovascular disease and other health risks that come with having T1D. In this way, health authorities address T1D problems by prioritizing causation (i.e. causing-to-do) and the having-to-do reality of management.

These assumptions held by the CDC and other health authorities of publicly accessible T1D information are transparent and grounded in evidence-based research findings (e.g. the *SEARCH for Diabetes in Youth* study). While feelings about having T1D are validated in the information, personal preferences held by PWD about self-management are not. Authorities have no need to manipulate PWD through messages of *wanting* to manage T1D, as the disease itself imposes the necessity. Management is in the best interest of those living with T1D and its necessity is conveyed clearly in the analyzed information through matter-of-fact segments reinforcing how PWD "depend on insulin to live" and must regularly control their blood sugar levels (CDC, 2022, para. 5). These findings are relevant to this study, as they shed further light on what information is being strategically communicated to the T1D community and its organization. They demonstrate that a significant piece of the "cultural grid" of publicly accessible T1D information is the positive manipulation of one's having to manage T1D in order to stay alive (Ferri, 2015, p. 85).

### Type 1 How-Tos

The bulk of publicly accessible T1D information focuses on what is necessary for executing safe and effective self-management. This is significant, as it demonstrates knowing how and being able to manage T1D are the two main agendas that health authorities strategically address for PWD and their surrounding social network (e.g. family members, peers, teachers). Considering management is at the core of diabetes care and yet poor self-management rates are alarmingly high among the T1D community, it is well-founded for competency to be the heart of publicly accessible T1D information in the post-pandemic landscape (Hamilton et al., 2022; Faulds et al., 2021). While the management of T1D has always required personal responsibility over one's care, the pandemic solidified its autonomy through face-to-face restrictions between patients and providers and fueled new OHIS trends (Turner & Rainie, 2020). Those living with T1D in the post-pandemic landscape now turn to publicly accessible information sources and consume the know-how necessary to personally manage their diabetes (Vijayasarathi et al., 2019).

Knowledge and the ability to manage T1D are addressed through maintenance messages since there is no cure for T1D and its management is ongoing. Segments advise the individual with T1D, the subject of doing and state, to periodically check blood sugar levels, administer insulin doses, inspect management devices, develop a diabetes medical management plan, track nutritional intake, and plan physical exercise according to blood glucose levels. In addition to these responsibilities, segments also provide links to resources that are necessary for managing T1D such as school toolkits and weekly meal planners.

These resources fulfill what the WHO defines as health literacy, which is "the social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health" (Protheroe et al., 2017, p. 1). Health authorities behind the public information recognize that PWD need to access and understand information about T1D in order to effectively manage it (Pashaki et al., 2019). Competency is a joint effort between individuals with T1D and their communities. This pivots to another interesting finding, which is that the know-how necessary to manage T1D represented in publicly accessible T1D information does not discriminate by age.

The rules of T1D management do not change. Once an individual is diagnosed, their task list remains consistent with time. Their capability to perform the task list may change and their social support system may fluctuate as they transition to different life stages, however, what is necessary to manage their condition does not change. Whether the individual is five years old or 30 years old, s/he will still need to monitor blood sugar levels, administer insulin doses, and track nutritional intake. The same is true for riding a bike, where the rules will always require the know-how to balance on wheels and travel forward. Beginners, often children, start off with training wheels and the guiding support of their parent's hand until they are competent to ride the bike on their own. Similarly, the diagnosis of T1D is predominantly received during childhood and eventually transitions to independent self-management in adulthood.

Management for AYAs involves emotional and clinical support from their parents and the surrounding community. The transition to autonomous self-management will eventually occur as AYAs become young adults and move away from home, however, the clinical task list necessary to manage their condition remains the same. This finding is significant, as it may imply publicly accessible T1D information is not very age-specific because the know-how required to manage T1D does not change. While the information discusses children, adolescents, and young adults with T1D, the bulk of the content is not tailored to specific ages but is instead rather generalized and clinically focused. This may suggest why AYAs with T1D are the least likely to consume health information from diabetes websites such as those analyzed in this study, as they desire "positive feedback and social support" found among social media and messaging applications (Vaala et al., 2015, p. 9).

### Management is Happening

The performance of T1D management is never complete. There is a clear establishment of its beginning through the receipt of a diagnosis, however, there is no definitive end as T1D does not have a cure. Management is always happening. Publicly accessible T1D information demonstrates this cycle by equating living with diabetes with managing diabetes. Segments described "living day-to-day with Type 1 diabetes" (BT1, 2022, para. 1), "managing diabetes at home" (Mayo Clinic, n.d., para. 2), and "diabetes that's not well managed" (Cleveland Clinic, 2021, para. 9) (see Table 9). PWD may manage their condition poorly and experience a low quality of life. Alternatively, they may manage their condition effectively and experience a high quality of life. The standards of one's self-management do not change the fact that management is in fact happening. Examples of this theme in publicly accessible T1D information include administering insulin, monitoring blood sugar levels, and changing the location of one's continuous glucose meter device.

Similar to the action component of publicly accessible T1D information, the performance of T1D management is reflexive in nature. PWD are not only performing self-management as subjects of doing (of which there is no finite accomplishment) but are also receiving management as subjects of state, according to the CNS (Hébert, 2019). The T1D narrative is not one of fiction where the prince rescues the princess, but rather PWD represent the princess who must rescue herself on a daily basis for the rest of her life. This communication strategy represented in publicly accessible information is a reflection of what health authorities understand, which is again that PWD are "responsible for 95% of their care" (Hamilton et al., 2022, p. 2).

Recurring management is necessary for the recurring condition, which makes the public T1D narrative vague in terms of whether management is ever actually achieved since there is no finish line. This may explain why the bulk of publicly accessible T1D information is not organized around performed management but rather management itself, the having-to-do reality underlying it, and the know-how necessary to perform it. Zhu et al. (2022) recently described the reality of T1D as "lifelong self-management to maintain glucose in a safe range" (p. 1). Other scholars have defined the purpose of performed management as achieving "near-normal blood glucose levels" in addition to prolonging health complications such as cardiovascular disease (Schmidt et al., 2022; p. 2172). These reports corroborate the findings of this analysis, which found health authorities are communicating to PWD that performed management is the key to prolonging additional health complications. In a segment discussing diabetes-related retinopathy from the *Cleveland Clinic* (2021), PWD are advised, “the best way to avoid the disease is by managing your diabetes” (para. 22).

### Type 1 Management Outcomes

As T1D is a chronic disease with no cure, the retribution for its recurring management is the action of management itself. The performed action of managing one’s diabetes is the crowning reward. There is no prince or kingdom waiting for the princess once she is rescued. She has rescued herself and will now end up back in the tower, where she will have to rescue herself again. This cycle is clearly represented in publicly accessible T1D information where the evaluation of performed T1D management is reflexive, centered around physical and psychosocial self-retributions experienced by PWD.

Physical self-retributions always accompany performed T1D management. For example, the successful administration of insulin produces the desired outcome of lowered blood sugar. Adherence to a structured meal plan will ensure better glycemic control (see Table 10). These are examples of the immediate, physical outcomes of managing T1D and they are not always predictable. Authorities behind the public information caution PWD that although they may manage their T1D correctly, there may be unwarranted side effects. For example, a nonprofit segment cautioned how some insulin medications might cause one’s blood sugar levels to plummet, even though they are prescribed by a doctor (see Table 10). In this way, managing one’s T1D can itself lead to an emergency that needs to be managed once more. Hypoglycemia and hyperglycemia, which are dangerous episodes of low and high blood sugar, are the most common examples of this paradox and can be experienced periodically by PWD despite good management (Zhang et al., 2022; Chatwin et al., 2021).

Forecasted health complications associated with managing T1D are the second form of physical self-retributions discussed in publicly accessible T1D information. PWD are educated about the health risks associated with having diabetes which include cardiovascular disease, kidney disease, DKA, nerve damage, eye damage, and foot health (Chiesa & Marcovecchio, 2021). This information is strategically addressed by health authorities across journals, websites, and nonprofits due to its risk likelihood, which literature has extensively covered. Despite attentive management efforts, it is guaranteed that those living with T1D will experience life-threatening complications within 30 years of being diagnosed (Robinson et al., 2018; 2019). Publicly accessible T1D information aims to address these risks by educating PWD about their symptoms and what measures can be taken to ensure their quality of life, if at all feasible.

Psychosocial self-retributions are the second outcome of performed management discussed in publicly accessible T1D information. PWD are informed about the psychological and social burdens associated with having T1D which can include anxiety, depression, stress, low self-esteem, and strained relationships with peers or family members. These mental health states are discussed under the umbrella of diabetes distress and burnout, which are reported to cause psychosocial developmental delays among AYAs and hinder their quality of life (Pierce, 2021; Ramchandani et al., 2019; Clarke et al., 2018). Quality of life appears to be a psychosocial self-retribution that is conjoined with T1D management. While segments do not focus on the life-long burden of managing T1D, they do validate this outcome as being arduous to accept and share how PWD can attain quality of life as they manage their condition (Oser et al., 2020; Gavrila et al., 2019; Kalra et al., 2018). Authorities of publicly accessible T1D information understand that while the action of management is the ultimate end goal, quality of life is also a critical outcome of managing T1D (Chatwin et al., 2021).

## Two CNS Models of T1D Information

This thematic analysis revealed two CNS models in publicly accessible T1D information. The individual T1D CNS describes where the subject (i.e. the individual with T1D consuming the public health information) ensures that s/he manages T1D. PWD are individually responsible for 95% of their management, which is reflected in this schema (Hamilton et al., 2022). Upon developing T1D and receiving their diagnosis, they enter a having-to-do contract of life-long management (i.e. action and manipulation), they must attain the necessary know-how to perform the management (i.e. competence), the act of management must be performed (i.e. performance), and then the cycle repeats itself with accompanying physical or psychosocial retributions (i.e. sanction). The bulk of publicly accessible T1D information follows the individual T1D CNS model.

The communal T1D CNS describes where the community of a PWD (e.g. family members, peers, teachers) ensures that s/he manages T1D. Many segments in publicly accessible T1D information address the relevant relationships in the lives of children and AYAs living with T1D who actively participate in their self-management. These can include parents, family members (e.g. siblings, grandparents, aunts, and uncles), teachers, coaches, mentors, peers, and the DOC. The narrative components are the same, though instead of being applied solely to the individual with T1D, management is performed through a communal partnership between AYAs and their social support system. This is illustrated in publicly accessible T1D information through resource links and downloadable PDFs for creating meal plan schedules, finding the nearest T1D summer camps, and accessing available T1D school support (e.g. the ADA's *Safe at School* campaign).

## Implications

The purpose of this comparative analysis was to explore the semiotic content and organization of publicly accessible T1D information that is being heavily consumed by PWD. The analysis inspired the development of a new CNS model applied to T1D information. The findings provide credible implications for healthcare authorities and professionals to consider as they continue to come alongside the T1D community to enhance self-management practices and outcomes, specifically on behalf of the AYA population.

### Practical

Reliance on publicly accessible T1D information intensified in 2020 as the COVID-19 pandemic restricted face-to-face access to health professionals (Oser et al., 2020). Public mandates of quarantine and social distancing produced a digital restructuring of how health information and care are delivered in the United States (Laupacis, 2020; Heckman et al., 2020). In response to this restructuring, those living with T1D increasingly performed OHIS behaviors (Lee et al., 2020). The role of the *Internet* in strategically communicating health information to PWD quickly became prioritized by health authorities and professionals. This two-way communication medium was leveraged for its ability to offer access, convenience, and immediacy to those living with T1D (Faulds et al., 2021; Rewolinksi et al., 2021; Xu et al., 2021; Faulds et al., 2020; Gal et al., 2020). The findings of this analysis build on this existing evidence, demonstrating how publicly accessible T1D information can be leveraged as a credible source of communication for PWD. Moreover, the value it offers is not in lieu of the patient-provider relationship but is rather supplementary since 95% of T1D management is independently conducted by PWD (Hamilton et al., 2022). Health authorities behind publicly accessible T1D information strategically communicate its value through numerous in-text prompts for PWD to connect with their doctor to discuss specific diabetes care concerns.

The bulk of publicly accessible T1D information addresses competency in the sense of knowing how and being able to manage one’s diabetes. Health authorities communicate steps that are actionable for PWD to follow as they strive to self-manage their disease. This finding suggests health authorities are unitedly decisive in the messages they choose to communicate to the T1D community, as the content across all three triangulated sources of information analyzed in this study was informed by the most recent evidence-based research (Oxman et al., 2022). In addition, this competency finding implies that health authorities prioritize equipping PWD to self-manage T1D over meeting the emotional burden of having T1D. The latter is validated and addressed in the information, however, PWD are referred out to connect with DOCs for support. Health authorities are intentional in constructing these messages because they understand that the know-how of managing diabetes is a more pressing problem that must be addressed for PWD. This implication is well founded, as the problem of poor self-management has been prolifically addressed by past scholars (Planalp et al., 2022; Faulds et al., 2021).

This comparative analysis also revealed how competency to self-manage T1D in publicly accessible T1D information does not appear to discriminate by age. What is necessary to manage one’s T1D looks the same in adolescence and in adulthood. This finding is specifically in relation to the clinical aspect of managing diabetes. While having T1D as an adolescent presents unique psychosocial needs, AYAs must attend to the same self-management behaviors as their adult counterparts such as monitoring blood sugar levels and administering insulin (Hardman et al., 2022; Haider et al., 2021). In this analysis, while the information made occasional mentions of children and AYAs, the context was clinical and often incorporated directives for parents and caregivers.

The implications of this finding are conflicting. On the one hand, it can be argued that the answer to this study's third research question (i.e. "Among publicly accessible T1D information, what content is tailored to AYAs?") is that all publicly accessible T1D information is tailored to AYAs since self-management necessitates the same duties with the only distinction being parental involvement. After all, authorities have decisively communicated the actionable steps for self-management, which are age neutral. Their way of addressing the psychosocial burden of AYAs with T1D may be demonstrated in the referral links to DOCs that are provided in the document texts. In this way, AYAs have access to both the clinical know-how of managing T1D and the option of outsourcing to DOCs for emotional support. However, past scholars have made the case for self-management in adolescence as being clearly distinct from adult-onset T1D, stating how AYAs are "not little adults" and require a different approach (Chiang et al., 2018, p. 2026). We do know from past research that AYAs are not prone to accessing diabetes websites to aid their self-management efforts (Vaala et al., 2015). It is possible that while publicly accessible T1D information is inclusive of AYAs, this is a moot point for peer-reviewed sources whose aim is to disseminate authoritative and clinical health information. Considering AYAs have preferred consuming psychosocial content to aid the act of self-management, the necessity for future research to extend this analysis to DOCs is implicated (Wong et al., 2020).

### Theoretical

This study extends the application of the ethnography of communication and the semiotic theory of action to OHIS contexts within the field of health communication. The ethnography of communication aids the understanding of publicly accessible T1D information as "situated communication" in a healthcare context and PWD as a speech community that shares a collective understanding of what is necessary to manage their health (Kotani, 2017; Zhu & Bargiela-Chiappini, 2013, p. 391). Positioning publicly accessible T1D information as a creator of T1D culture suggests that health authorities and the chronic nature of T1D itself play a significant role in governing self-management behaviors among PWD (Kotani, 2017; Hymes, 2013). T1D is reflexive in nature, meaning that a diagnosis ensures a repeating cycle of self-management behaviors and norms for PWD. Through the EOC lens, this suggests that the having-to-do reality that comes with a T1D diagnosis is a governing authority in and of itself that joins hands with health authorities and influences what language they use to communicate with PWD about self-management behaviors.

In this study, the language used by health authorities included 18 code words and primarily discussed what is necessary for an effective T1D self-management culture. These findings correlate with Hyme's (2013) research on the rules of a speech community, where members are not only aware of codes but are also accountable to them. Publicly accessible T1D information is consumed by PWD who are aware of these 18 code words, aware of their meaning, and whose health is held accountable by them. Moreover, health authorities accurately disseminate T1D health information using these codes because they are established by the nature of the disease itself.

The semiotic theory of action is extended to publicly accessible T1D information in this study, providing a new CNS model of how action and meaning are intertwined in chronic health communication narratives. Branching from Greimasian semiotics, it aims to explore the structure of a health narrative, the motivations of its authors, and how those motivations might impact the patient subjects who are consuming the information (Yekini et al., 2021). The theory defines communication as a comprehensive action that produces an outcome (Pikkarainen, 2021). This study is the first to apply these concepts to a health communication context, as past research has solely focused on educational settings (Pikkarainen, 2021; 2018; Stables et al., 2018).

Findings support the concepts of the semiotic theory of action, where the comprehensive action in publicly accessible T1D information was identified as management and the outcomes of its performance including physical and psychosocial self-retributions. This research contributes to the semiotic theory of action literature by exploring the motivations of the health authorities responsible for the publicly accessible T1D narrative and the implications of how the T1D audience might be impacted. The analysis suggests motivations are influenced by the latest evidence-based research, determining what information takes precedence to address for PWD (Oxman et al., 2022).

The narrative structure of publicly accessible T1D information was explored through the application of the Greimasian semiotics CNS tool. Past applications of this tool have explored the narrative discourses of health contexts, though they are considerably limited (Mocini, 2022; Törrönen, 2022). Findings support these past applications, where the underlying narrative schema for T1D information in which PWD aim to manage T1D can be compared with Greimas' fictional story of a prince who rescues a princess and inherits a kingdom (Mocini, 2022). The T1D CNS is distinguished, however, by its reflexive nature.

Health communication strategies are predominantly transitive, where there is a direct and one-way trajectory from the action to the health outcome. This is due to the fact that in the United States, most of the underlying causes of death are related to health behaviors and are thereby avoidable (Reynolds-Tylus, 2019). As a result, the narrative structure of the majority of these messages is guided by a manipulative wanting-to-do reality because health authorities accurately assume that people want to protect their personal health and that of their loved ones (Ashworth et al., 2021). Curiously, this study's analysis revealed that the narrative structure found in publicly accessible T1D information is different.

The reflexive nature of having T1D serves as the underlying manipulation that drives PWD to perform self-management. Once the narrative reaches the physical or psychosocial retributions of managing T1D, it immediately returns to the central action of management. In other words, PWD are always managing their condition. As soon as they successfully perform the act of self-management and encounter the consequence of that performance (e.g. injecting meal-time insulin and then experiencing the insulin's impact on their blood sugar levels), they return to square one of having to self-manage once again.

This finding suggests that chronic diseases such as T1D require a far different communication strategy compared to other health communication efforts. Moreover, it implies that the underlying motivations of health authorities who are responsible for the public T1D narrative, and how those motivations impact PWD consuming the narrative, are distinct from other health communication contexts. Future research should explore these implications.

## Delimitations and Limitations

The purpose of this comparative analysis was to explore the semiotic content and organization of publicly accessible T1D information that is being heavily consumed by PWD. Data selection was restricted to peer-reviewed sources that were identified through *Google* search volume. *Pew Research Center* data was leveraged to support this decision, demonstrating how 80% of OHIS behaviors are performed through *Google*, which is perceived by the public as an accessible and credible source of health information (Portillo et al., 2021; Sbaffi & Zhao, 2020). What's more, peer-reviewed sources including medical journals, medical websites, and nonprofits were selected due to their authoritative status and provision of medical terminology (Kulkarni et al., 2022; Portillo et al., 2021; Ye et al., 2021). Consequently, other sources of publicly accessible T1D information such as social media platforms and DOCs were excluded from this analysis.

Additionally, this analysis was restricted by time constraints. Data saturation was reached once 25% of the dataset had been thematically coded (n = 266). Randomized stratified sampling was conducted on 40 additional documents, where one per every 20 documents in the remaining dataset was selected and coded (n = 306). While this step solidified the findings and did not yield any new insights, analyzing the remaining data would have made this study more robust.

## Recommendations for Research

The bulk of peer-reviewed sources of publicly accessible T1D information is centered around competency and what is required of PWD to manage T1D. Future research should explore social media sources to determine whether the role of psychosocial support in DOCs influences the T1D narrative schema revealed in this analysis. Past studies have demonstrated that AYAs prefer social media platforms for aiding self-management efforts, as this population desires the psychosocial support they offer (Vaala et al., 2015). Their self-management outcomes have been proven to improve when they have access to social support (Adu et al., 2019). This research might also investigate whether the T1D information accessible through social media sources is similarly age neutral or whether it is more clearly directed toward the AYA audience and follows the individual CNS model.

## Conclusion

The purpose of this qualitative QCA was to explore the semiotic content and structure of publicly accessible T1D information, assessing what content is tailored to the AYA population.

Ten peer-reviewed sources of publicly accessible T1D information were selected and coded using frequency and thematic analysis, guided by the ethnography of communication and semiotic theory of action. This process identified five themes and two new CNS models of T1D information. First, the comprehensive action of the T1D narrative is management. Second, PWD are under a contract of having-to-manage T1D in order to survive and live a quality life. Next, the knowledge and abilities to manage T1D are necessary to actually perform self-management. Finally, there are physical and psychosocial self-retributions that result from managing one's T1D.

The reality of having T1D is a life-long commitment. The narrative schema of publicly accessible T1D information reflects this through its reflexive and having-to-do nature. These findings benefit health authorities and professionals, as they provide credible insights into the health information being communicated to and consumed by individuals living with T1D and their loved ones.

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