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DIABETES 2.0: HOW ARE ONLINE PLATFORMS...

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DIABETES 2.0: HOW ARE ONLINE PLATFORMS CHANGING THE GAME FOR TYPE-ONE DIABETES PATIENTS?

A Master's Thesis

by
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To those on a quest for health

DIABETES 2.0: HOW ARE ONLINE PLATFORMS
CHANGING THE GAME FOR TYPE-ONE DIABETES
PATIENTS?

The Graduate School of Economics and Social Sciences
of
İhsan Doğramacı Bilkent University

by

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By Ece Dede

I certify that I have read this thesis and have found that it is fully adequate, in scope and in quality, as a thesis for the degree of Master of Arts in Media and Visual Studies.

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ABSTRACT

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M.A. in Media and Visual Studies

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Chronic diseases like type 1 diabetes (T1D) require constant management and attention. This creates uncertainties and anxieties for the patients and require additional supporting systems for patients. This thesis examines the roles of online T1D communities in Türkiye in relation to social support, health equity, and eHealth literacy. Qualitative interviews with community members and professionals are used to understand how these communities function. A total of 18 qualitative interviews were conducted with community builders and members to understand the dynamics of these communities. Regarding social support, findings show that instrumental support is a very common type of support in Türkiye. For health equity, members utilize online T1D communities in Türkiye to access necessary services that the healthcare system should provide. The research also investigates how varying levels of eHealth literacy affect members' abilities to use health information and reveals that more literate members often assist others and correct misinformation. Building on uses and gratifications as the main theoretical framework, the study underscores the intertwined link between social support, health equity, and eHealth literacy among different groups within online T1D communities in Türkiye. Significantly, this study indicates that online type one diabetes

communities in Türkiye may lead to inclusive health by reducing health disparities; in light of this, healthcare support systems should be enhanced.

Keywords: Online Health Communities, Type 1 Diabetes, Social Support, Health Equity, eHealth literacy, Health Communication

ÖZET

DİYABET 2.0: ÇEVİRİMİÇİ PLATFORMLAR TİP 1 DİYABET HASTALARI İÇİN OYUNUNU NASIL DEĞİŞTİRİYOR?

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Yüksek Lisans, Medya ve Görsel Çalışmalar

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Tip 1 diyabet gibi kronik hastalıklar sürekli kontrol ve ilgi gerektirirler. Bu durum diyabet hastaları için belirsizliklere ve kaygıya yol açabilir ve ek destek sistemlerine ihtiyaç yaratabilir. Bu tez çevrimiçi Bu tez, Türkiye'deki çevrimiçi tip 1 diyabet topluluklarının sosyal destek, sağlık eşitliği ve e-Sağlık okuryazarlığı açısından rollerini incelemektedir. Topluluk üyeleri ve profesyonellerle yapılan nitel görüşmeler, bu toplulukların nasıl işlediğini anlamak için kullanılmaktadır. Bu toplulukların dinamiklerini anlamak için topluluk kurucuları ve üyeleri ile toplam 18 nitel görüşme gerçekleştirilmiştir. Sosyal desteğe ilişkin bulgular, araçsal desteğin Türkiye'de oldukça yaygın bir destek türü olduğunu göstermektedir. Sağlık adaleti konusunda, Türkiye'de Tip 1 diyabet topluluk üyeleri bu toplulukları aslında sağlık sistemi tarafından karşılanması gereken gerekli servislere erişmek için kullanmaktadırlar. Araştırma ayrıca e-sağlık okuryazarlığının değişen düzeylerinin üyelerin sağlık bilgilerini kullanma becerilerini nasıl etkilediğini araştırıp ve daha okur yazar üyelerin genellikle başkalarına yardım ettiğini ve yanlış bilgileri düzelttiğini ortaya koymakta. Kullanımlar ve doyumlar teorisi üzerinden yapılan bu çalışmada Türkiye'deki çevrimiçi tip 1 diyabet toplulukları içerisindeki iç içe geçmiş olan sosyal destek, sağlık eşitliği ve e-Sağlık okuryazarlığı bağlantısı vurgulanmaktadır. Bu çalışma, öne çıkan bir şekilde Türkiye'deki çevrimiçi tip

1 diyabet topluluklarının sađlık eřitsizliklerini azaltarak kapsayıcı bir alna yol açabileceđini; Bu bulgular ışığında sađlık destek sistemlerinin geliştirilmesi gerektiđini gözler önüne sermekte.

Anahtar Kelimeler: Çevrimiçi Sađlık Toplulukları, Tip 1 Diyabet, Sosyal Destek, Sađlık Adaleti, E-sađlık Okuryazarlığı, Sađlık iletişimi

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CHAPTER 1

INTRODUCTION

In 2018, when I was 19, I was diagnosed with type 1 diabetes (T1D) in the intensive care unit of my hometown's hospital. I had no idea what T1D was, and I only had questions in my mind. Since then, my entire life has been reshaped around T1D. After consulting my doctors, I initially found answers to the questions I had when I was first diagnosed. However, given the constant and life-altering nature of T1D, new questions arose daily. And while I was searching for answers to these questions, I came across a huge universe: online T1D communities. Since then, as a type 1 diabetic, they have become communities that I follow regularly and consult when I face a problem. Having personally experienced the significant benefits of T1D communities in Türkiye, I believe studying them is essential. That's why I decided to do my thesis on online T1D communities.

In today's modern digital age, it is not possible to separate any condition from the online sphere. It is also applicable for T1D. If a patient knows how to use digital sources, they can benefit significantly from them in order to improve their diabetes management.

However, in order to benefit from online resources, the patient should have the ability to navigate the digital environment. Because even if the source provides the exact information the patient needs, if the patient lacks these skills, the patient cannot access this information. This ability to seek and find relevant health data in an online setting is called electronic health literacy (eHealth literacy) (Lee et al., 2022). Patients who are proficient in eHealth literacy are better able to make informed decisions about their health, communicate effectively with healthcare professionals, and actively engage in self-care strategies. To this extent, in today's world, it is very beneficial for T1D patients to be proficient in eHealth literacy to make more informed decisions about diabetes management.

Health is a trendy topic in the online sphere. More and more individuals are turning to the Internet to find information on health (Tanis, 2008). David Feinberg, the Vice President of Google Health, declared that approximately 7% of Google's daily searches, equivalent to 70,000 searches per minute, are health-related (Murphy, 2019). It should come as no surprise that there are a lot of online health communities (OHC) considering the widespread interest in health-related issues on the internet and the amount of searches connected to health. Online health communities (OHCs) can be defined as members interacting socially with a specific health-related purpose in a virtual environment (Preece, 2000; Plant, 2004). OHCs have the potential to substitute traditional health information systems, they can act as a valuable data source for research, patient care, and policy development (Meherali et al., 2020). Furthermore, OHCs can assist these countries in addressing health illiteracy by providing trustworthy

information and knowledge to patients and caregivers (Meherali et al., 2020).

An online community's identity is shaped by various factors, especially its purpose and the technology it utilizes (Eysenbach et al., 2004). In the contemporary era of digital advancement, numerous online communities have emerged, each characterized by diverse specific purposes. They have evolved as common virtual places, providing a new online social communication and interaction mode that may be used for various objectives (Wellman et al., 2002), including health-related purposes (Tanis, 2008). For example, anti-vaccine groups, cancer-focused groups, and type 1 and type 2 diabetes groups can be observed in the online environment as groups framed around a specific health issue.

Anti-vaccine groups focus on discussions related to vaccine concerns and alternatives. Cancer-focused groups offer platforms for patients, survivors, and caregivers to exchange experiences, support each other, and discuss treatments and coping strategies. Similarly, groups for type 1 and type 2 diabetes provide essential resources for managing these conditions, including advice on diet, exercise, medication, and mental health. There are also groups dedicated to mental health issues such as depression and anxiety. It is possible to find an OHC about almost any health issue in the online sphere. This research focuses on online T1D communities.

In Türkiye, many online T1D communities function on popular platforms such as Facebook, Instagram, and WhatsApp. These communities appeal to a large number of followers or members. For example, there are T1D groups on Facebook with up to

16,300 members (@tip1diyabettecrübeleri, 2024). More than 100 posts were made by members of this Facebook group in June 2024. There are accounts on Instagram that appeal to 20,300 people (@diyabetimben, 2024). A total of 3578 posts were posted on this account. These significant online activities show T1D communities' growing role in the digital support network for people with T1D. When examining the online T1D communities and interactions in these communities in Türkiye, it becomes evident that social support, eHealth literacy, and health equity are commonly discussed topics of significant importance in the communities.

T1D is a chronic disease resulting from the pancreas' inability to produce insulin (U.S. Centers for Disease Control and Prevention, n.d.). It arises when the immune system, responsible for protecting the body against infections, mistakenly targets and destroys the pancreas's insulin-producing cells (U.S. Department of Health and Human Services, n.d.). While the exact cause of this condition remains unknown, scientists believe it is linked to a combination of genetic predisposition and environmental influences, such as viral infections, that may initiate the disease (U.S. Department of Health and Human Services, n.d.). Although the cause of the disease is not clear, with the rising number of diabetes cases worldwide, understanding T1D is crucial. In 2021, about 537 million adults in the world had diabetes (Magliano, Boyko, & IDF Diabetes Atlas 10th Edition Scientific Committee, 2021). The International Diabetes Federation predicts this will rise to 783 million, a 46% increase, by 2045 (Magliano et al. Atlas 10th Edition Scientific Committee, 2021). Unfortunately, Türkiye has one of the highest diabetes rates in Europe at 11.1%, with over 6.6 million people (Magliano, Boyko, & IDF Diabetes Atlas 10th Edition Scientific Committee, 2021). According to 2015 data from

the Turkish Ministry of Health, the number of patients with Type 2 Diabetes is 6,095,579, and the number of individuals with T1D is 1,017,043 (T.C. Sağlık Bakanlığı, 2016). By 2045, it is expected that Türkiye will have 10.4 million diabetics and will be among the top 10 countries with the highest rates of diabetes in world (Magliano, Boyko, & IDF Diabetes Atlas 10th Edition Scientific Committee, 2021). Given the expected increase in diabetes cases both in the world and in Türkiye, a better comprehension of T1D will be critical in addressing this global health issue.

Because the patient's body is unable to produce insulin itself, T1D patients require multiple insulin injections daily, and it is a disease that requires the patient to pay attention to their eating habits and daily life (Booth, 2024). T1D, which requires active decision-making on a daily basis, can lead to many complications, from heart disease to organ loss, if not managed well (Booth, 2024). Therefore, it can be said that it is vital for the patient to manage their diabetes well in order to avoid life-threatening complications.

Managing T1D is highly related to self-care, such as keeping a healthy diet, having an active life, and having regular doctor appointments, and the role of social support in enhancing self-care in diabetes management is undeniable (Mohebi et al., 2013). Mohebi et al. (2013) reveal that there is a positive correlation between diabetes patients' health and their received social support. Even healthy people require social support in their lives to function better in different areas of life. So, it is not surprising that a chronic disease such as T1D, which requires a lot of time and active decision-making, benefits from social support to be managed well.

Unfortunately, social support is not the only need for the T1D patient to manage their health conditions. They require insulin, medicines, expensive medical devices, and routine doctor appointments. Those are only some of the needs that will help T1D patients reach their possible healthiest versions of themselves. Unfortunately, not every T1D patient can reach those opportunities for several reasons, such as economic conditions or systematic deficiencies. In an ideal world, every patient deserves the opportunity to be the healthiest they can be. This can be explained by health equity. World Health Organization (n.d.) explains health equity as everyone has a chance to fulfill their full potential for health and well-being. It is not exposed to unjust gaps because of various social, economic, demographic, or other forms of inequality. Therefore, one of the key requirements for T1D patients is health equity.

In this research, social support, eHealth literacy, and health equity are examined under the scope of online T1D communities. It is aimed to find out what benefits these communities provide to their members through their functions. The study addresses the questions of how these online communities offer various forms of social support to T1D patients, how they help patients advocate for their healthcare rights and access essential resources to achieve health equity, and how members navigate and demonstrate proficiency with resources and tools in T1D communities in Türkiye. Hopefully, the functions of these communities can be examined through the findings of this research and can guide the creation of an even more beneficial environment for T1D patients in the future.

CHAPTER 2

THEORETICAL FRAMEWORK

2.1 Online Health Communities

Online communities have undergone a drastic evolution over the decades. They started way before the Internet, in the 1970s, with email technology provided by ARPANET (Preece et al., 2003). However, these early communities were relatively simple, offering limited interaction, with members primarily reading content rather than actively participating (Mandal, 2023). Listservers, bulletin boards, and synchronous technologies emerged in the 1980s and 1990s (Preece et al., 2003). Those developments introduced online communities as the first method of ongoing communication (Mandal, 2023). Community members could engage in communication via text themselves instead of just reading the pages.

In 1991, online communities became more integrated and interactive with the establishment of the World Wide Web (WWW) (Preece et al., 2003). This technological revolution significantly transformed online communities. WWW made it possible for

users to start using websites globally and for online communities to expand their reach (Preece et al., 2003). Unavoidably, the Internet rapidly became the cornerstone of online communities, providing a multifaceted medium for communication, collaboration, and exchanging ideas (Eysenbach et al., 2004).

With online communities evolving and diversifying so much, it has become difficult to fit them into a single accepted definition. Preece (2001) discussed that some people like the idea of an online community experience while others worry about negative connections, and some people see online groups either as a social thing or focus on the technology behind them (pp. 347–348). The meaning of an online community has different connotations, and it often depends on the subject area in which it is being explained (Maloney-Krichmar & Preece, 2002). However, in its broadest sense, Plant (2004), a researcher from the field of information technology, suggested that an online community can be considered as an ensemble of individuals, groups, or organizations that connect by a digital medium, either temporarily or permanently, to engage in specific issues or areas of interest.

Preece (2000), a researcher in the area of human-computer interaction, particularly in the study of online communities, outlined four key factors to define online communities. Her definition covers a wide range of online groups and serves as a framework for understanding their key components. According to Preece (2000), an online community includes “people” interacting socially, a “shared purpose,” “policies” guiding interactions, and computer systems supporting social connections (p. 10). In simpler terms, online communities are groups of people coming together for a common reason,

following specific rules, and using technology to connect. For example, in an online health community, the common reason would be a health-related topic, there would be rules based on the group's dynamics, and finally, there would be a medium that enables the existence of that community. Various online communities with different focuses can be examined based on how they fulfill those criteria. Preece's criteria (2000) is one of the influential frameworks in the field of online communities because it is applicable to many diverse online groups (Maloney-Krichmar & Preece, 2002).

In the communication field, scholars have delved into various perspectives to unravel the intricate dynamics of OHCs. One of the key elements to define those intricate dynamics is exploring why the participants attend OHCs in the first place. Powell et al. (2011) reveal that the main reasons for searching online health-related content are finding comfort, reaching for a second opinion about health issues, and removing challenges in obtaining traditional information. Building on this foundational understanding of general motivations, White et al. (2018) specifically investigated the motivations of participants' involvement in Online Diabetes Communities. Results show that participants' motivations are complex and often include multiple motivations rather than a single motivation. The study finds that the main motivations were seeking medical advice, technical assistance for medical equipment and systems, and finding an honest emotional support network (White et al., 2018, p.713). These main motivations also highlight the various and crucial roles that OHCs play in the healthcare system (White et al., 2018). Understanding why people join and participate in OHCs is crucial in figuring out how these online groups work. By looking at members' different motivations, we can

learn more about how these communities function and how they contribute to the participants' healthcare.

There are several discussions about whether OHCs are beneficial or harmful. Some of these discussions suggest that some extreme communities also emerged, such as “pro-anorexia” or “pro-suicide” focused communities (Bell, 2007, pp. 449-450); moreover, in some groups, self-harm advocacy is observed (Keipi et al., 2015, p. 635). even though those studies suggest that some OHCs can threaten public health, Eysenbach et al. (2004) contradict those suggestions. After analyzing 45 publications on how peer-to-peer online communities affect both health and society, they concluded that there is no evidence of online communities harming their members (Eysenbach et al., 2004).

In contrast to concerns raised by earlier studies about the potential harm of OHCs, Willis and Royne (2016) offer a more optimistic perspective. Based on a content analysis of posts from the four most searched OHCs to investigate the effects of communication on chronic disease self-management practices, they found that 70% of the studied posts discussed self-management techniques and asserted that OHCs provide a valuable resource for people with chronic diseases to learn from others and improve their symptom management (Willis & Royne, 2016).

Another study conducted by Gong and Lyford (2022) sheds light on how social media can be effectively used to help manage diabetes. In this study, Gong and Lyford (2022) looked at what information diabetes patients want from social media and how it could

help them follow their doctor's recommendations for managing their diabetes. They surveyed patients to see what they were interested in learning about on social media and also analyzed the Facebook pages of major US diabetes organizations to see how effective their communication with patients was (Gong & Lyford, 2022). The results showed that patients were most interested in diabetes management recommendations and that sharing diabetes-related information on social media led to more engagement than social value posts (Gong & Lyford, 2022). The study suggests that social media could be a beneficial platform for communicating diabetes care information with patients. Collectively, these studies (Eysenbach et al., 2004; Gong & Lyford, 2022; Willis & Royne, 2016) offer a compelling argument in support of the potential benefits of OHCs, highlighting their positive impact on individual well-being and chronic disease management.

Peer-to-peer support is one of the possible positive impacts of OHCs. Greene et al. (2010) identified the 15 largest Facebook groups focused on diabetes management and evaluated the content of their posts. They found that patients, family members, and friends used Facebook to share personal clinical information, request guidance and feedback, and receive emotional and social support (Greene et al., 2010). Posts often included unsolicited sharing of diabetes management strategies, specific feedback on the information requested by other users, and efforts to provide support to others as community members (Greene et al., 2010). One of the essential findings of this study is that clinically inaccurate recommendations were infrequent but were usually associated with promoting a specific product or service (Greene et al., 2010). This research shows that Facebook diabetes communities provide a valuable forum for people living with

diabetes, but caution is needed to ensure the quality and accuracy of information shared (Greene et al., 2010). This research underscores the valuable role that Facebook diabetes communities play in offering a supportive environment for individuals living with diabetes, emphasizing the significance of social support within OHCs. This emphasis brings us to discuss the subject of social support, which is one of the main topics addressed in this thesis.

2.2 Social Support in Online Health Communities

The number of online support groups and communities for individuals with health issues has increased dramatically, from a few thousand in the late 1990s to hundreds of thousands by 2021 (National Cancer Institute, 2021). The concept of social support can be described as the experience or perception of receiving affection and care from others, of being respected and valued, and of being a member of a community where roles and assistance exist (Taylor, 2011). Providing social support can have a beneficial impact on people's physical and emotional well-being (Taylor, 2011).

Social support is essential in enhancing well-being, particularly with the increasing use of technologies like the web and social media platforms for health-related support. The rising use of new technologies, such as smart devices and social media platforms, to help people deal with health-related concerns has attracted the interest of many disciplines, including communication (Wright, 2016). There have been many studies focusing on the social support function of OHCs: some tried to identify social support types (Wang et al., 2017; Loane & D'Alessandro, 2013), some examined the outcomes of social support

(Taylor, 2011; Oh & Lee, 2012; Litchman et al., 2018), and some investigated the relationship between social support and community members' actions (Eysenbach et al., 2004; Wang et al., 2023). Social support is crucial in these OHCs, as evidenced by numerous studies focusing on its types, outcomes, and impact on member actions mentioned in the previous sentence.

Members of OHC join these groups with specific motivations and needs, which include social interaction and access to health information (Chen, 2023). Many patients turn to OHCs to seek social support. It can be argued that participants of the OHCs actively participate in these communities with specific motivations. The uses and gratifications framework similarly suggests that media consumers are active about their choices in communication channels, and they have specific “gratifications” to achieve (Katz et al., 1973). This approach was initially developed by Katz et al. (1973) during the 70s. In the internet age, communication studies have widely used uses and gratifications to reveal people's online media choices (Ruggiero, 2000). The web's properties, such as interactivity, customization, and asynchronicity, make it an ideal topic for his framework (Ruggiero, 2000). OHCs dynamic and interactive nature makes it a suitable space to apply the uses and gratifications framework. A recent study built on the uses and gratifications approach discusses that the members of the diabetes communities in Poland and Italy join online diabetes communities with information, social, and emotional support motivations (Ardissone et al., 2024). The study also suggests that future studies are needed to not only prioritize the support provided in diabetes communities but also detect the relationship between people's preferences and gaps that might occur because of healthcare systems (Ardissone et al., 2024).

As individuals with similar health concerns connect and exchange support through forums, messaging, chat rooms, blogs, and health-tracking tools on OHCs, it becomes essential to recognize the diverse manifestations of social support. Understanding these distinctions helps modify interventions and resources to better meet the specific needs of people seeking support within the context of their health challenges (Wang et al., 2017). Wang et al. (2017) emphasize four main types of social support in a cancer online community: "informational support, emotional support, companionship, and instrumental support" (p. 4). Informational support includes exchanging guidance, recommendations, learning materials, and experiences with health-related problems. For instance, someone could post about their journey with a particular treatment, detailing side effects and how they managed that journey. Other members might then respond with advice based on their own experiences, creating a valuable exchange of information within the community. Expressions of comprehension, motivation, empathy, compassion, validation, sympathy, caring, and concern are all considered forms of emotional support (Wang et al., 2017). For example, emotional support might be a member calming and motivating someone anxious about upcoming medical appointments. They could share personal strategies, creating a supportive atmosphere and boosting confidence in facing diabetes challenges. Conversations about everyday events, humor, and non-health-related topics are all part of companionship, also known as network support (Wang et al., 2017).

Finally, offline services are referred to as instrumental support, also known as physical help (Wang et al., 2017). In a health community, instrumental support examples can be members organizing transportation support for someone recovering from surgery or

sending medicines to a needy community member. This hands-on assistance goes beyond online discussions. OHCs frequently receive informational, emotional, and companionship assistance, yet instrumental support is comparatively uncommon because of geographical constraints. Because instrumental support is not widely observable within the selected OHC, Wang et al. (2017) do not include it in the social support classification of this study for the sake of simplicity. However, because it is uncommon, it does not mean that it is not essential. Some of the OHC members seek to reach instrumental support (Smith et al., 2020). Smith et al. (2020) examine the kinds of technology interventions or capabilities linked to instrumental support that patients and caregivers may desire or find useful throughout a cancer experience, and findings also highlight how crucial it is to incorporate elements of instrumental support into OHCs to reach more positive outcomes. So, recognizing the diverse types of social support within OHCs is also essential to discuss social support outcomes.

The outcome of the social support discussion initially starts in a non-online environment in the field of psychology. Today, the importance of social support in a non-online environment is clear, and its positive mental and physical health outcomes are evident (Taylor, 2011). Taylor (2011) suggests that social support is crucial to developing emotional ties and the perception that social assistance is available (pp.197-200). Strong relationships are especially helpful in stressful situations because they help people control their emotions and keep their stress down (Taylor, 2011). Therefore, in the case of health issues, social relationships can help reduce stress due to health conditions. Even though Taylor (2011) discusses the concept of social sport from a psychological perspective while including the increasing involvement in internet support groups, she

also opens a discussion for the field of OHC. She acknowledges the great potential of online communities by discussing that online communities can serve many of the same functions as in-person groups and can, thus, be a valuable source of social and knowledge support (Taylor, 2011, p.207).

Building on Taylor's exploration of social support in both traditional and online settings (2011), more recent studies have delved into specific OHCs, revealing their effectiveness and appeal, especially among younger and well-educated populations (Huber et al., 2017). A study questions the efficiency of online prostate cancer communities by comparing it with face-to-face groups (Huber et al., 2017). Findings align with the broader discussion Taylor (2011) discussed in the psychological realm, highlighting the importance of social support for mental and physical well-being. Huber et al. (2017) find that online prostate support groups provide positive support to their users and play a role in improving their treatment decisions (pp.6-7). Moreover, prostate cancer online support communities are received as effectively as face-to-face groups by their users (Huber et al., 2017). The key difference between face-to-face groups and online groups is the demographics of the members. While traditional face-to-face support groups are perceived as especially beneficial for older patients, providing continuous social support, the emergence of online social support groups introduces a dynamic element that appeals to younger and more educated populations (Huber et al., 2017, p.7). In summary, this study not only supports the broader discussion emphasized by Taylor regarding the significance of social support but also highlights the positive reception and effectiveness of online prostate cancer communities, emphasizing their appeal to the new generation (Huber et al., 2017). Building on the insights from studies on OHCs' effectiveness,

especially in conditions like prostate cancer (Huber et al., 2017), the discussions extend to many other chronic diseases such as diabetes.

Chronic diseases like diabetes are complicated and need constant attention to daily living in order to attain optimal disease management, and the advised self-care practices for diabetes are predicted to need more than two hours each day. (Litchman et al., 2018). Consequently, individuals navigating diabetes find themselves in a complex landscape where the intricacies of self-care demand not only time but also specialized knowledge and support. Therefore, it is not surprising that diabetes disease management requires knowledge and support from professionals. Before the internet, patients' primary knowledge and support sources were healthcare professionals and their close circles (Oh & Lee, 2012). However, with the internet, plenty of health-related information is now available for patients and their caregivers. It led to patients being more active in their health-related decision-making processes (Oh & Lee, 2012). Oh and Lee (2012) focus on the social support outcomes of diabetes online communities and their effect on the patient-doctor relationship. Their findings support that regardless of the type of social support, perceived social support positively leads to a sense of empowerment for patients (Oh & Lee, 2012). Researchers also discuss empowerment as giving patients more control and involvement in their healthcare. Thus, it can be said that online diabetes communities contribute to patients' disease management by empowering them through social support. Lastly, the study also highlights that patients' attempts to interact directly with a medical professional were highly correlated with their boosted sense of empowerment (Oh & Lee, 2012, pp.36-38). In terms of interaction between doctors and patients, this study points to a "communicative consequence of patient empowerment"

(Oh & Lee, 2012, p.38). this interaction with doctors enhances the overall support and management of patients' health.

Even though communicating with healthcare professionals is an ideal way to manage diseases, not everyone has that opportunity. Chronic diseases like diabetes require constant disease management decisions (Litchman et al., 2018), and it is not always possible to consult a professional before every decision. Thus, a supplementary source that binds patients, such as gender, culture, age, or shared experience, might be required (Litchman et al., 2018). OHCs, where people can connect with one another and seek out knowledge and support, can provide a valuable resource for patients (Litchman et al., 2018). Litchman explains that, in essence, participants actively seek information and support on managing diabetes and see diabetes online communities as valuable sources for improving self-management. Members gained a deeper understanding of their diseases, learned about new treatments, and discovered additional strategies for the day-to-day challenges of diabetes (Litchman et al., 2018). Litchman et al. (2018) reveal that while professional healthcare providers were consulted for overall health advice, the diabetes online communities serve as a resource for managing daily issues and staying updated. Community members find these communities easily accessible, providing continuous and complementary diabetes information between appointments (Litchman et al., 2018). Although patients appreciate their healthcare professionals' overall management, they feel disconnected due to their limited understanding of day-to-day challenges (Litchman et al., 2018). Online diabetes communities, on the other hand, offer mutual support and understanding, normalizing frustrations that other support networks could not. Litchman et al. (2018) find that many diabetes patients initially turn

to online communities for daily diabetes-related queries, valuing the experience of other members as credible peers. While healthcare professionals' interactions focus on medical advice, online diabetes communities provide practical information and social support for their members (Litchman et al., 2018). This leads to a recent discussion about how social support in online diabetes communities affects patient engagement (Wang et al., 2023).

Wang et al. (2023) examine the relationship between social support and patient engagement in OHCs, with a focus on diabetes-related contexts. They use a research model that highlights the critical role of different types of social support, including social interactions, emotional support, and informational support from patients (Wang et al., 2023). Earlier discussions highlighted these communities' diverse functions of social support, including informational, emotional, companionship, and instrumental support (Wang et al., 2017). The current study adds a layer of depth by emphasizing the essential role of informational support in positively influencing patient engagement (Wang et al., 2023). Moreover, it introduces the mediating impact of peer involvement, further elucidating how these dynamics shape patient peer engagement within OHCs (Wang et al., 2023). The term "peer engagement" describes how patients actively participate in the online health community by starting conversations, answering questions, and sharing their experiences and knowledge with others (Wang et al., 2023). According to the study, patients' degree of peer involvement moderates the effect of informational support they provide on their own community engagement (Wang et al., 2023). After receiving informative assistance, patients may feel more responsible and accomplished as a result of peer feedback and interactions, which may inspire them to make additional

contributions and become more involved in the community and also more involved in their healthcare decisions (Wang et al., 2023). Integrating these findings provides a comprehensive understanding of the multifaceted role of social support, offering insights that can inform strategies to enhance patient engagement, ultimately contributing to improved health outcomes in the specific context of diabetes-related online communities.

Overall, OHCs play a crucial role in providing support to people dealing with health issues (Wright, 2016). With the rise of technology, these communities offer various types of help, including sharing information, emotional support, companionship, and practical assistance (Wang et al., 2017). Studies on cancer, prostate cancer, and diabetes highlight the positive impact of these online platforms on individuals' well-being and empowerment (Huber et al., 2017; Oh & Lee, 2012; Litchman et al., 2018). These communities act as valuable resources, connecting people with similar health experiences (Wang et al., 2017; Litchman et al., 2018). Beyond emotional benefits, OHCs also influence how engaged individuals are in managing their health and making healthcare decisions (Wang et al., 2023; Oh & Lee, 2012). In essence, the significance of social support within OHCs emerges as a vital thread connecting individuals facing health challenges, fostering well-being, empowerment, and active engagement in healthcare decisions (Wright, 2016; Wang et al., 2017, 2023; Huber et al., 2017; Oh & Lee, 2012; Litchman et al., 2018). Therefore, studying social support in OHCs is important to understand its different types (Wang et al., 2017; Loane & D'Alessandro, 2013), its possible outcomes (Taylor, 2011; Oh & Lee, 2012; Litchman et al., 2018), and

how it is affecting community member's actions (Eysenbach et al., 2004; Wang et al., 2023).

2.3 Health Equity Through Online Health Communities

In healthcare practice and research, the notion of "health equity" has become a growing trend during the last two decades (Braveman et al., 2018). The increasing popularity of health equity studies also leads to more than one understanding of the topic. Despite the multiple annotations of health equity, the main explanation is similar. World Health Organization explains that health equity is only achieved when everyone has the chance to fulfill their full potential for health and well-being and is not exposed to unjust gaps because of various social, economic, demographic, or other forms of inequality. Based on this definition (World Health Organization, n.d.), health equity can be described as a goal to be achieved by giving everyone an appropriate and fair chance to live as healthily as possible. However, health equity can also be described as an ongoing process that requires a constant removal of emerging social and economic obstacles to health by reducing social and financial barriers to health (World Health Organization). When studies in this field are reviewed, the main contrast in definitions of health equity is whether it is seen as something to achieve as an outcome or as an ongoing process (Braveman et al., 2018). The World Health Organization's definition provides a blend of these two perspectives so that health equity can be seen as both a process and a goal. Therefore, in this thesis, the issue of health equity was examined using the integrated definition provided by the World Health Organization.

Long-lasting health issues and chronic diseases such as T1D greatly affect a person's quality of life and are a leading cause of disability and early death globally (World Health Organization, 2023). Because of their nature, chronic diseases such as T1D can cause multiple side health complications over time and require constant, expensive, complicated management (Turnbull et al., 2020). Healthcare spending on diabetes varies significantly among regions and countries. 75.4% of the population with diabetes lives in low- and middle-income countries, but only 19% of global health expenditures on diabetes are spent in these countries (Öcal & Önsüz, 2018). This disparity highlights how health equity is not just about individual health outcomes but also about systemic factors like healthcare funding and policy implementations in different countries, which can lead to unequal access to essential health services and support for chronic conditions like T1D.

Unfortunately, Türkiye is one of the countries that does not have enough healthcare spending to meet the needs of people with diabetes. The Social Security System of Türkiye stated that 8.6 Billion Turkish Liras, corresponding to 2.5% of health expenditures, was spent on diabetes (2022). In 2012, the number of people diagnosed with diabetes in Türkiye was much lower than in 2021, but the proportion of spending on diabetes was 23% (Öcal & Önsüz, 2018). The issue stems from the fact that while the healthcare budget for diabetes has not changed much since 2012 (Öcal & Önsüz, 2018), the costs of diabetes-related products have skyrocketed due to increased prices of imported drugs and materials (Cansu, 2018). So, the prices of essential medicines and tools for diabetic patients went up because of inflation; however, the government's spending on these items did not increase enough to match these higher prices (Cansu,

2018). This meant that patients had to pay the extra costs themselves. This leads to unequal access to vital health resources and support. Uneven distributions of wealth and power in society are often reflected in health inequalities (Nolen et al., 2005). For example, we can observe these inequalities in the form of being able to reach new technology diabetes support devices. If the health policies do not cover those products, the patients would have to access these devices on their own. And it would lead to inequality because not every patient can afford them.

Türkiye serves as an example of health inequality due to challenges in healthcare spending distribution, disparities in access to healthcare services, rising costs of essential medical products like diabetes treatments, and potential gaps in effective policy implementation. These factors contribute to unequal access to healthcare and financial burdens for patients. Unfortunately, economic obstacles are not the only source of health inequality for T1D patients. Access to health information is another problem, as some individuals may struggle to access accurate and timely information about managing their condition, leading to disparities in healthcare outcomes and quality of life (Van Pinxteren et al., 2022). Even though it is acknowledged that health information is essential in the healthcare system, not everyone with health issues has equal access to it (Van Pinxteren et al., 2022). Therefore, health equity in terms of access to health information can also be discussed.

Health equity in health-related information is defined as being able to access information that can help someone achieve their healthiest self without any barriers (McCurry et al., 2023). In the ideal version of health equity, medical information is directly provided by

professionals such as doctors, nurses, pharmacists, or other experts with advanced medical qualifications (McCurry et al., 2023). Unfortunately, the reality does not fit with the ideal distribution of health information. Reaching health professionals can be impossible due to systematic, economic, locational, or time-related restrictions (Van Pinxteren et al., 2022). For example, access to information about a chronic disease such as T1D will be critical as this disease requires full-time decision-making and control (Turnbull et al., 2020). If the patient consults a professional before making any health-related decisions, this will result in a situation that requires a lot of time and budget. Additionally, depending on the health policies of the country where the patient lives, a situation may occur where the patient cannot make an appointment whenever they want to access health information. So, systemic, economic, locational, or time-related restrictions can create a health inequality in reaching health information (Chamakiotis et al., 2021; Van Pinxteren et al., 2022).

As previously discussed under the title of social support, one of the reasons why OHCs are used by patients is to access informational support (Wang et al., 2023; Wang et al., 2017; Litchman et al., 2018). By providing patients with access to information, OHCs can reduce systemic, economic, locational, or time-related constraints. In the online sphere, patients can access information without going anywhere physically. If patients went to the hospital, they would need to make an appointment and would have access to health information for a limited time, but through OHCs, they have access to OHCs at any time of the day, regardless of the restrictions of the healthcare system. Additionally, OHCs can provide a much more economical option in countries where healthcare is not covered by the state. Studies indicate that online communities can provide an effective

tool for reaching health equity in the distribution of health information (Chamakiotis et al., 2021; Van Pinxteren et al., 2022; McCurry et al., 2023; Schermuly et al., 2020; Parker et al., 2012).

Some of the studies of health information equality highlight why it occurs and how it can be reduced (Van Pinxteren et al., 2022; McCurry et al., 2023). There are also other studies adding another layer emerging from health inequalities, which is activism (Schermuly et al., 2020; Parker et al., 2012). Patients often express their concerns at OHCs when they want to access health information or when they have difficulty accessing other needs related to their illness. They often do this not for direct activism purposes but to share their own experiences or seek solutions to their questions (Schermuly et al., 2020). For example, in OHCs, it is very often that patients share personal experiences about their struggles with accessing specific medications or navigating complex healthcare systems (Schermuly et al., 2020). Schermuly et al. (2020) discuss that OHCs give patients a platform for activism because they allow patients to voice their questions and experiences and criticize the status quo. Even though the participants in this community effort do not openly identify themselves as activists, it still increases awareness, impacts medical services, and encourages change (Schermuly et al., 2020). This situation can be observed especially in countries with problematic health systems (Van Pinxteren et al., 2022). For example, Van Pinxteren et al. (2022) investigated the strategies an OHC in South Africa used to promote improved healthcare in their low-income community by utilizing online communities and shared health data. Therefore, it can be said that in areas where access to healthcare is difficult, OHCs help achieve health equity.

Parker et al. (2012) argue that promoting health can be a form of activism. In OHCs, members post about their experiences with health issues, questions, and information related to health (Litchman et al., 2018). Even though those posts are not intentionally posted for activism purpose, it may be considered as a form of activism. The social support, information, or any other needs necessary for patients to reach health equity are not adequately provided by the system; patients can consciously or unconsciously use OHCs to meet these needs partially. Digital platforms can facilitate knowledge sharing, support, and advocacy, potentially empowering individuals and communities to address these health inequalities (Parker et al., 2012). Parker et al. (2012) emphasize the need to consider the social and political factors that influence peoples' shared or accessed health-related posts in the digital sphere and use health information and experience to empower communities and challenge power structures. Thus, OHCs can play a crucial role in promoting health equity by enabling patients to share information, support each other, and advocate for systemic changes, even when their actions are not explicitly labeled as activism.

In conclusion, OHCs play an essential part in reaching health equity by providing members with access to information, support, and a platform for advocacy (Van Pinxteren et al., 2022; McCurry et al., 2023; Schermuly et al., 2020; Parker et al., 2012). These communities help overcome systemic, economic, and locational barriers to health information, which is particularly important for chronic conditions like T1D (Turnbull et al., 2020). OHCs not only facilitate the distribution of health information but also empower patients to voice their concerns and experiences, indirectly fostering activism

(Schermuly et al., 2020). By enabling patients to share knowledge and support each other, OHCs contribute to reducing health inequalities and advocating for systemic changes (Parker et al., 2012), thus aligning with the World Health Organization's integrated definition of health equity as both a goal and an ongoing process (World Health Organization, 2023).

2.4 eHealth Literacy in Online Health Communities

From what has been discussed so far, it is clear that OHCs have functions such as providing social support and promoting health equity. In other words, it is possible for OHC members to access these functions with the opportunities provided by the digital environment. However, the kinds of abilities members should have in order to benefit from these opportunities offered by online platforms raise a different discussion about members' qualifications. Finding relevant health information on the internet takes various knowledge, know-how, and skills. These include not just the fundamental skills of reading, writing, and comprehending health data but also the ability to seek and find that data while using digital devices in an online setting (Lee et al., 2022). In 2006, a set of qualities known as electronic health literacy, eHealth literacy, was established and defined as the ability of a patient to search for, identify, comprehend, and assess medical data in the digital sphere and use that information to deal with or fix a health issue (Norman & Skinner, 2006). This scale explores an individual's competency in navigating health information online. They assess whether a person knows how to locate correct health resources, utilize the Internet to find answers to health-related questions and

identify the usability of these resources (Norman & Skinner, 2006). Additionally, Norman & Skinner (2006) examine the individual's ability to use the health data they find efficiently, evaluate the quality of these resources, and feel confident using online data to make health decisions. This scale reflects the necessity for eHealth literacy for members of OHCs to utilize digital resources and make informed health decisions effectively.

The importance of eHealth literacy is growing as more people turn to the internet, particularly social media, to receive medical information (Li & Liu, 2020). The majority of eHealth literacy studies have been conducted on specific populations or demographic groups within various countries; however, it has yet to be widely studied among users of OHCs (Petrič, Atanasova, & Kamin, 2017). Petrič et al. (2017) explains that OHCs are frequently used online platforms that focus to, but are not restricted to, healthcare-related subjects. Patients, caretakers, and other interested parties may take part in these communities, engage with other members, or simply observe the interactions without any active participation. The variety of interactions among the OHC members indicates a highly interactive environment. Therefore, because of the interactive nature of OHCs, users should have a specific skill set (Petrič et al., 2017; Paige, Krieger, & Stellefson, 2017). The dynamic and relatively challenging skills needed to use medical sources offered by social media platforms may discourage patients from finding reliable online sources for accessible health information (Paige et al., 2017). So, understanding eHealth literacy is crucial for members of OHCs to effectively access, evaluate, and utilize digital health resources, ultimately enabling them to benefit from these platforms' opportunities.

Even though people still primarily rely on expert-generated health data on the internet, they are more and more using OHCs to access peer-generated health information (Rupert et al., 2016). Although peer-generated information provides the opportunity for members to learn from others' experiences, questions, and problems, the danger of misinformation also arises, considering that not everyone sharing is a healthcare professional (Huh, 2015). Huh (2015) discusses this danger and highlights the importance of moderation in avoiding misinformation in OHCs. OHC moderators, who may be medical experts, staff members, or the initial creators of the community, offer external governance to lead community interactions (Huh, 2015). Diverse viewpoints on the function of moderators in OHCs can be found in the literature. Some studies find the functions of moderators in OHCs essential in maintaining group rules and preventing undesirable situations, such as health issues caused by misinformation or misguidance (Resnick, Janney, Buis, & Richardson, 2010; Saha, Ernala, Dutta, Sharma, & De Choudhury, 2020). However, According to Maloney-Krichmar and Preece (2005), strong group dynamics reduced the impact of external corrections such as moderators, indicating that the roles of community members are more important than those of moderators. Peer mentors significantly outperformed professional mentors in a randomized controlled trial to improve diabetes management, regardless of the accuracy of the information (Maloney-Krichmar & Preece, 2005). As a result, although moderators play an essential role in ensuring compliance with the rules, they are not sufficient to prevent the danger of misinformation or misguidance. In this case, it becomes important for OHC members to have the ability to assess the health data and avoid misinformation or misguidance.

A strong grasp of eHealth literacy is essential for individuals in online health communities to navigate digital health resources effectively making informed decisions. Paige et al. (2017) investigate the correlation between eHealth literacy levels and perceived trust in OHCs. They use the scale developed by Norman and Skinner (2006). Based on the findings, individuals with lower eHealth literacy levels reported higher trust in online health information in OHCs (Paige et al., 2017). Therefore, those less equipped to assess online sources might be more open to believing health information without adequately questioning the accuracy of information. Lower eHealth literacy levels can influence trust in online health information within OHCs (Paige et al., 2017), potentially impacting individuals' critical assessment abilities and disease management outcomes.

Whether OHC members apply the knowledge in the groups, find solutions to their problems, or improve their health conditions is another topic of discussion. How do eHealth literacy levels affect health behaviors? Refahi, Klein, & Feigerlova (2023) analyze studies in the field measuring eHealth literacy levels of people with chronic diseases and their correlation to disease management. In spite of the fact that there are not many studies in this area, the review brings out a positive relationship between high eHealth literacy and improved aspects of healthcare in individuals with chronic diseases (Refahi et al., 2023). Those aspects include better interactions with healthcare professionals and peers, better healthcare habits, and potentially better disease management (Refahi et al., 2023). This analysis underscores the great potential of high eHealth literacy in positively influencing various aspects of healthcare for individuals with chronic diseases. Another study analyzes the relationship between education levels

and eHealth literacy of diabetes patients in Türkiye (Çizmeci & Deniz, 2017). The study reveals that diabetes patients with higher education levels in Türkiye have higher eHealth literacy (Çizmeci & Deniz, 2017). This study further emphasizes the importance of understanding how eHealth literacy varies among different education levels and its impact on managing diabetes (Çizmeci & Deniz, 2017). There are many members with different levels of education in online T1D communities. Given the positive correlation between high eHealth literacy and improved healthcare practices, it becomes clear that enhancing eHealth literacy could be a powerful tool in promoting healthier behaviors and more successful disease management. A study conducted in Türkiye highlights the harms of low eHealth literacy, linking it to riskier behaviors, poorer health outcomes, and reduced self-management (Çam et al., 2021). A study conducted in Türkiye highlights the harms of low eHealth literacy. Low eHealth literacy is linked to riskier behaviors, poorer health outcomes, and reduced self-management (Çam et al., 2021). Therefore, prioritizing the improvement of eHealth literacy among individuals with chronic diseases like T1D could be crucial in reducing these risks and enhancing overall health outcomes.

In conclusion, eHealth literacy is a crucial skill for members of OHCs to maximize the benefits these platforms offer. Studies show a positive correlation between eHealth literacy, effective navigation of digital health resources, informed decision-making, and potentially improved health outcomes (Paige et al., 2017; Refahi et al., 2023). However, the challenge of misinformation within OHCs requires further investigation into the role of moderators and community dynamics alongside the development of eHealth literacy among members.

2.5 Current Study

The literature review has established the significance of online health communities in providing social support, promoting health equity, and enhancing eHealth literacy so far. This thesis explores how online T1D communities in Türkiye function, building on the uses and gratifications framework, focusing on social support, health justice, and eHealth literacy. Understanding how these communities operate is crucial given their role as significant support networks for individuals managing chronic conditions T1D. The research questions are designed to uncover key aspects of these communities' dynamics and their impact on members' well-being and healthcare access. In Türkiye, where healthcare spending distribution and access to essential resources for chronic conditions like type 1 diabetes present challenges (Öcal & Önsüz, 2018; Cansu, 2018), understanding the role of online communities becomes even more crucial.

Exploring how these communities function in providing social support is particularly significant. Social support has been identified as a fundamental component in managing chronic conditions, including T1D (Wright, 2016; Wang et al., 2017). Comprehending the various kinds of social support offered in these online communities can facilitate the development of interventions designed to enhance support systems and participants' overall well-being. Especially for countries like Türkiye that cannot provide enough social support within the health system, discovering OHC's function helps us understand what T1D patients are seeking. Based on the uses and gratifications approach, members of T1D communities seek social support, and what they obtain for these needs shows the intricate dynamics of these communities. Based on the gratifications, findings about the

members' needs will be obtained. Exploring the social support needs of T1D patients can lead to improving online T1D communities and the healthcare system to satisfy patients' needs better.

Additionally, the study delves into how online T1D communities contribute to health justice and advocacy efforts. This aspect is crucial in Türkiye, where disparities in healthcare access and resources for chronic conditions like T1D are evident (Öcal & Önsüz, 2018; Cansu, 2018). The thesis questions how members seek support in online T1D communities and how they obtain improvement in health equity as gratification. By examining the role of these communities in advocating for healthcare rights and essential resources, the research seeks to identify avenues for promoting health equity and addressing systemic inequalities.

Lastly, the study explores eHealth literacy within online T1D communities. In an era dominated by digital information, proficient eHealth literacy is essential for effectively navigating online health resources (Paige et al., 2017). It delves into how eHealth literacy helps members obtain what they are seeking, in other words, how members are more easily gratified with eHealth Literacy. Understanding members' capabilities and preferences in utilizing digital tools and resources can guide the development of targeted interventions to enhance eHealth literacy and ensure equitable access to health information and services.

In conclusion, this study's significance lies in its comprehensive exploration of how online T1D communities function in providing social support, advocating for health

justice, and enhancing eHealth literacy in Türkiye. By addressing these key aspects based on the uses and gratifications framework, the research aims to contribute valuable insights that can lead to improved healthcare outcomes and well-being for individuals managing T1D in Türkiye. The following questions will guide this study's investigation.

Main Question

How do online type 1 diabetes communities function in providing social support, health justice, and eHealth literacy in Türkiye?

RQ1

What kinds of social support do online type one diabetes communities provide in Türkiye?

RQ2

How do online type one diabetes communities in Türkiye help patients advocate for their healthcare rights while contributing to achieving health equity?

RQ3

How do members navigate, utilize, and demonstrate proficiency with resources and tools in online diabetes communities?

CHAPTER 3

METHODOLOGY

This thesis explores how online T1D communities in Türkiye function regarding social support, health equity, and eHealth justice and investigates the research questions using qualitative methodology. The method of a study defines the overall approach that guides our selection and execution of particular techniques for the expected findings; nonetheless, the choice of a specific method relies upon the subject matter and characteristics of the research topic (Jamshed, 2014). For this thesis, qualitative research methods are pretty suitable because it deals with the question of how. Qualitative research is investigative and aims to explain "how" and "why" questions a specific social situation in a selected setting (Mohajan, 2018, p. 24). For this research, the selected setting is online T1D communities in Türkiye. The social phenomenon is that online diabetes communities function in terms of social support, health equity, and eHealth literacy. Moreover, it questions how online T1D communities in Türkiye function in this setting and phenomenon. Overall, by using qualitative methodologies, the goal is to comprehend the reasons behind the current state of the situation in a very flexible way (Mohajan, 2018)

The capacity of qualitative research to effectively express the depth and variety of participants' experiences and viewpoints (Hennink et al., 2016) is another critical factor in selecting this method for the thesis. In this study, the focus is on online T1D community members' personal experiences and perspectives. Qualitative methods such as interviews, ethnography, and participant observations allow for an in-depth and detailed grasp of the lived experiences of individuals within these online T1D communities. The ability to capture “human perspectives” is one of the critical benefits of qualitative methods in diabetes studies (Hennink et al., 2016, p.211). This approach helps the researcher explore nuanced social support, health equity, and eHealth literacy aspects. By delving into personal narratives and interactions, qualitative research provides a comprehensive view of how these communities operate and impact their members. It offers valuable insights contributing to the broader understanding of their social dynamics and effectiveness. For these reasons, semi-structured interviews were chosen as the main methodology for this thesis.

3.1 Ethical Procedures

Since the research topic is related to health, it is a subject that requires sensitivity. When asking questions to participants, it is very important to ask questions that will not offend them or put them in a vulnerable situation. Interview questions were prepared with these sensitivities in mind. After the questions were prepared, they were approved by the Bilkent University Ethics Committee. Following the initial steps, the interview phase started. The purpose of the research and the conditions for participation were clearly explained to the participants. Before the interview, participants were informed about

their rights over the data they provided and the storage conditions of the data. An information form was sent to each participant, and a consent form was signed before the interview.

During the interviews, the aim was to create an environment that made the participants feel comfortable engaging in the conversation. Since the subject may include sensitive health-related issues, great importance was given to creating an environment of trust. This involved establishing an empowering atmosphere where participants felt safe and respected. In this way, it was anticipated that more elaborate answers would be reached. As a result, the interviewees were not shy in their responses; they answered the questions sincerely. Interviews offered trustworthy and thoughtful insights that significantly improved the quality of data gathered.

3.2 Data Collection

The semi-structured interview method's ability to successfully enable mutual active communication between the person conducting the interview and the participant is one of its key benefits (Galletta, 2016). It is a very effective method for the interviewer to generate follow-up questions according to the participants' answers while providing room for each participant to explain themselves verbally (Galletta, 2016). The thesis topic might touch on sensitive areas like health, and participants may find answering some questions challenging. However, in-depth interviews offer a solution. The interview becomes more conversational by allowing follow-up questions and comments from both the interviewer and the participant. This allows participants to clarify initial

answers, recall forgotten details, and add insightful comments, ultimately leading to richer, more descriptive responses that provide a deeper understanding of the functions of online T1D communities.

The adaptability of semi-structured interviews guarantees that the conversation stays relevant to the study's goals while permitting the investigation of unknown subjects (Galletta, 2016). This flexibility is beneficial when dealing with intricate and multidimensional problems, like the personal experiences of people in online T1D communities. Semi-structured interviews can reveal complex viewpoints and intimate experiences (Kallio, Pietilä, Johnson, & Kangasniemi, 2016). Since it is about a health issue, sensitive experiences may be mentioned, in which case the interviewer can continue the interview in the most topic-oriented manner thanks to the flexibility of the semi-structured interview. Therefore, within the scope of the subject of this thesis, data collected through interview methodology can improve the quality of findings by providing reliable and thoughtful insights.

3.3 Sampling

During the sampling process, a set of criteria is established to decide who can be suitable for the interview sample. Establishing clear criteria is essential so the results can efficiently address the research questions (Robinson, 2013). So, the criteria are decided based on the aim of the study. First, participants must be over 18 and a member or founder of an online T1D community. The online T1D community can take place on any platform that provides interactivity to its members. This interactivity is defined as the

participant being able to do something other than just reading in the community. Another requirement for the participants is that the member or the founder is in a community for T1D in Türkiye. Lastly, participants who live at a distance where interviews cannot be held face-to-face must be able to use video conferencing applications such as Zoom or WhatsApp video calling.

The sampling strategy used in this study is a combination of purposive and snowball sampling. Initially, purposive sampling was employed to identify participants who were suitable for the study. These individuals were selected either through personal connections or because they were founders of online communities on platforms like Instagram, Facebook, and WhatsApp. Community founders were contacted via social media and asked to participate in the interview. Although such requests were sent to more than 20 community founders and members, positive feedback was received from only 5 of them. Six participants were people the researcher knew from his own social circle. Once those key participants were identified and interviewed, they were asked to recommend other members of online T1D communities who could also provide valuable insights. This approach allowed the sample to grow through the referrals of the initial participants, thus incorporating elements of snowball sampling. By combining these two strategies, the study was able to effectively reach a diverse and relevant group of participants, ensuring a comprehensive understanding of the functions of online T1D communities. After using the snowballing strategy to recruit additional participants, the sampling phase concluded with a total of 18 participants, achieving saturation. Demographic information regarding participants' education levels, gender, and position in the community can be observed in Table 1.

Table 1: Participant Demographics

Education Level	Post-graduate Degree	Undergraduate degree	High school degree
	3	14	1
Gender	Female		Male
	17		1
Position in Community	Member		Founder
	12		6

3.4 Semi-Structured Interview Process

Since this research focused on the functions of online T1D communities, not the characteristics of the participants, only two demographic questions were asked. These questions were age and education level. The purpose of these questions is to reach an understanding of the homogeneity of the research.

Every interview subject should have a clear connection to the study's goal, and the interview's arrangement should demonstrate the researcher's purposeful approach to conducting an in-depth investigation (Galletta, 2016). Interview questions were created with the focus of seeking answers to research questions. Although the questions were in the same direction, separate sets of questions were prepared for the questions asked to community members and the questions asked to community founders, as they addressed different perspectives. Since community founders have access to tools different from those of members, community founders were also asked questions about the organization of the community in order to understand the structure of the communities

better. Community members were asked questions that they could answer based on their experiences within the group. Questions targeting the understanding of social support function were created by adapting the study of Litchman et al. (2018) to online T1D communities in Türkiye. The eHealth Literacy questions were developed by adapting the eHealth Literacy Scale of Norman and Skinner (2006) to T1D communities in Türkiye. Lastly, Health equality questions were developed based on the studies of Kim and Backonja (2024) and Blount et al. (2023). As a researcher, being a long-term member of online T1D communities and being able to see from the perspective of type one diabetic members also helped me develop more targeted questions.

The prepared questions were pre-tested by a member of an online T1D community via a pilot interview in February 2024. It was tested how long the interview lasted, whether the questions were understood, and which questions opened up discussion areas. This test interview was not included in the analysis and was used only to develop more targeted interview questions. Table 2 lists the interview questions for the community members, and Table 3 lists questions for the community builders.

Table 2: Interview Questions for the Community Members

Question Number	Questions
	Demographic Questions
1	How old are you?
2	What is your education level?
	Initial Questions

1	Which online type 1 diabetes community/communities are you a member of?
2	How did you join online type 1 diabetes communities, and how long have you been in these communities?
3	Why did you join online type 1 diabetes communities?
4	How often do you use these groups?
	Questions Targeting Social Support
1	What are your expectations from the communities?
2	What roles do you take on in the communities?
3	Do you share posts in the communities? If so, what kind of posts do you share? What kind of interaction do you expect from other community members when you share?
4	What kinds of posts do you come across? Do you interact with these posts? (comments/likes/shares, etc.)
5	Are there any topics that particularly interest you or that you think should be given more attention in the communities? If so, what are they?
6	How do the interactions and connections in the communities provide support for you?
7	Have you met people or made new friends through the communities?
	Questions Targeting Health Equity
1	Have you overcome any difficulties in accessing healthcare services or obtaining health-related information through these groups? If so, could you explain?
2	Have you observed any sharing of information or experiences related to difficulties in accessing healthcare services in the community? Or have you shared such experiences yourself?
3	Have you come across positive or negative posts about health policies? Or have you made such posts yourself?
	Questions Targeting eHealth Literacy
1	What are your experiences in using e-resources?

2	What technological device/devices do you use to access the groups?
3	Have you encountered any technology-related issues when accessing the communities?
4	Do you implement the suggestions you come across in the groups? How do you verify the accuracy of these suggestions?
5	Have you faced any difficulties in evaluating and verifying health information in the groups?
6	Have you encountered misinformation in the groups? If so, what did you do?
7	How do you apply the information you obtain from the communities in your daily life? How important is this information to you?

Table 3: Interview Questions for the Community Builders

Question Number	Questions
	Demographic Questions
1	How old are you?
2	What is your education level?
	Initial Questions
1	What is your community/ account? On which online platforms does it operate?
2	Can you describe the process and purpose of establishing the type 1 diabetes community? Why did you decide to establish this community?
3	Who is this community aimed to reach?
4	Does the community have any rules? If so, what are they? What kind of moderation policy do you follow in your community?
	Questions Targeting Social Support
1	What kind of growth and development has your community experienced since its establishment? Can you provide a general assessment of the

	interactions within the community?
2	Does your community have a culture of solidarity? What kind of environment have you tried to create?
3	How do you facilitate interactions among your members? What is the importance of interactions and connections among members in your community? How do you think these interactions shape the dynamics within the community?
	Questions Targeting Health Equity
1	Have you overcome any difficulties in accessing healthcare services or obtaining health-related information through this community? If so, could you explain?
2	Have you included any positive or negative posts about current health policies in your community? If so, how did the community members interact with these posts?
3	Have you observed any sharing of information or experiences related to difficulties in accessing healthcare services among community members? If so, could you share these experiences?
	Questions Targeting eHealth Literacy
1	How do you ensure the accuracy of health information in your community? How do you deal with the sharing of misinformation?
2	Considering the purpose and target audience of your community, how important do you think it is for your members to be knowledgeable about digital health topics? What are your observations or experiences in this regard?
3	What do you think about the quality and accuracy of the content shared by community members? Do you have an assessment of how aware your members are about digital health topics?

Interviews were conducted face-to-face with six people and via video meeting with 12 people. For participants who live at a distance, interviews were not conducted face-to-face. These video meetings were held by priorly determining a time when the participants were available. Then, interviews are conducted via video meeting

applications such as Zoom or WhatsApp video calling. The interviews were conducted over a period of approximately two months.

In some cases, such as the participant not being able to answer the question adequately or giving an incomplete answer due to not fully understanding the question, probing questions were asked to reach elaborate answers. Particularly in the eHealth literacy questions, since participants generally described the events they observed through other members' posts, probing questions were asked to direct them to a more objective explanation of the event. All interviews were captured as audio recordings for in-depth analysis.

When the main categories exhibit dimensional range, preciseness, density in terms of qualities, and well-integration, then appropriate sampling has taken place (Corbin & Strauss, 2015). In this thesis, the saturation is achieved with 18 participants. A total of 520 minutes of voice recordings were collected. Based on the 18 interviews, enough dimensional range, preciseness, and density are achieved in the main categories: social support, health equity, and eHealth literacy.

3.5 Data Protection

The recordings of the interviews were accessed and transcribed only by the researcher. The audio recordings will be stored digitally until the end of the research period but will not be shared with third parties. These records are stored on a personal hard drive and in an encrypted cloud area for protection. As participants were informed priorly in the

interview information form, full access to the interview transcript will be limited only to the researcher and her advisor.

3.6 Data Analysis

As the first step of data analysis, the answers to the interview questions were qualitatively coded according to their relevance to the main themes: social support, health equity, and eHealth literacy. In this process, each response was examined carefully, and the theme or themes that best fit each were determined. Some responses were relevant to multiple themes because of the interconnected nature of the themes; they involved overlapping examples. In this case, the same data was assigned for more than one theme. For example, a participant's answer, an example of how they could not access the medication and met this need after sharing it in the online T1D group, was categorized as both health equity and social support. Relevant answers given in the interviews were categorized in this way to capture the full range of their implications.

After the qualitative coding process, the data was analyzed using the constant comparative method (Glaser, 1965; Glaser & Strauss, 1967). As the method suggests, the cases within each category are contrasted comprehensively. Comparisons revealed that multiple participants similarly mentioned common issues. Via this comparative approach, the connections and repeating patterns are detected. For example, within the social support theme, 13 of 18 participants mentioned an instrumental support example that they have experienced or witnessed another member have experienced. Based on the constant comparative approach, a theory should be developed that is characterized by

connections and contrasts (Glaser, 1965; Glaser & Strauss, 1967). For the given example, the theory is developed as instrumental support is observed as common in online T1D communities in Türkiye.

It is crucial to delimit the theories and categories in the analysis process to maintain the focus of the study (Glaser & Strauss, 1967). Based on preliminary online field research within several online T1D communities, the primary categories identified were social support, health equity, and eHealth literacy. Theories are limited according to their uniqueness, recurrence, and relevance. When the data were analyzed with a constant comparative method, a finding was reached based on the pattern that occurred if a theme was clearly repeated in different interviews. If the finding is irrelevant to the main categories, it is eliminated. Uniqueness played an important role in limiting theories. For example, the finding of instrumental support is common in Türkiye was a finding contrary to the existing literature (Wang et al., 2017; Smith et al., 2020). So, it was suggesting a unique finding for the Türkiye case. In conclusion, using the constant comparative method helped this thesis find recurring themes in the interviews and develop theories for the main topics, meeting standards for what was unique and relevant.

CHAPTER 4

FINDINGS & DISCUSSION

Based on the preselected themes of social support, health equity, and eHealth literacy, the interviews are analyzed through comparison and contrast. The constant comparative analysis (Glaser, 1965) revealed recurring events and examples for each theme from the participants' responses.

4.1 Social Support Findings

The social support aspect of the online T1D communities in Türkiye is very prominent. All of the participants mentioned some type of social support they received or witnessed another community member receive via these communities. As Wang et al. (2017) discussed, informational support and emotional support are the most common types of social support. The types of informational and emotional support detailed in the literature review were the types of social support that all participants received or witnessed being received by someone else in the community. This finding, aligned with the literature, highlights the critical role of online T1D communities in providing essential informational and emotional support to their members in Türkiye.

Contrary to the literature (Wang et al., 2017; Smith et al., 2020), an exceptional observation is the frequent occurrence of instrumental support within online T1D communities in Türkiye. Instrumental support, which is explained in detail in the literature review, can be summarized as members' access to social support by extending the support from online to offline. Although previous research (Wang et al., 2017; Smith et al., 2020) has indicated that instrumental support is rare in OHCs, in this study, 13 of 18 participants mentioned examples of this social support type they have been observed in online T1D communities. For example, one participant described instrumental support they witnessed in an online T1D community operating via WhatsApp. This WhatsApp community is a community of 85 people including T1D individuals from the same city. One member of the group goes to another city, 15 hours away, and forgets to take the insulin they need to use. Since the insulin prescription date has not expired, they can not access the medicine through the health system in the city they visit, and they consult the WhatsApp community to seek solutions.

As stated by the Participant 1:

“Everyone in the group suddenly started looking for a solution. People who had friends or acquaintances in that city called them and asked for insulin, someone directed them to a relative in a nearby district, and finally, they delivered the insulin to that person through someone's relative's pharmacy. Even if they were in another corner of Türkiye, that insulin was somehow delivered to that person within 1 hour.” - Participant 1

As seen in this case, when a participant could not access insulin, thanks to other participants, the support went beyond the online sphere and expanded to physically delivering insulin to the patient, creating an example of instrumental support.

The person who stated that they could not access insulin in another city did not share this with the intention of obtaining it through the group and only asked to consult others. Here, even though the member seeks informational support from the community, they manage to obtain instrumental support as gratification. Thirteen out of 18 participants mentioned situations similar to this example where support went beyond online and expanded to offline. Participant 6, owner of the Whatsapp and Instagram T1D community, Participant 6, the owner of a Whatsapp and Instagram T1D community, gives an example from an incident from the Whatsapp group, reinforcing that the support in the groups goes beyond online.

“A Turkish citizen living in Germany came to Türkiye for a holiday and ran out of medicine at that time. The medicine he used was not sold in Türkiye. He wrote to the group on WhatsApp and asked what else he could get instead of this medicine. Luckily, someone already had that exact medicine and shipped it to him immediately.” - Participant 6

As a result of these findings, it can be said that instrumental support is not an uncommon situation for online T1D communities in Türkiye. So, this study confirms the crucial role of online T1D communities in Türkiye, providing essential informational and emotional support as seen in the existing literature. Moreover, the frequent occurrence of instrumental support within these communities challenges previous assumptions, demonstrating their unique ability to effectively extend assistance from online to offline environments.

Another key finding is that through "peer engagement," members of online T1D communities in Türkiye experience a sense of belonging. Peer engagement in online health communities involves participation through conversations, answers, and

knowledge sharing (Wang et al., 2023). The essence of this engagement lies in the term "peer," suggesting that most participants directly or indirectly relate to and benefit from the experiences shared by other participants. This connection often involves referencing posts made by peers that are relevant to events they have encountered or may encounter in their own T1D experiences.

The interviews delve deeper into the various dynamics of peer engagement within online T1D communities in Türkiye. During the interviews, every participant mentioned other participants' experiences shared in the communities at some point during the interview. They gave examples of other participants' failures, challenges, or achievements. They frequently made references to other participants' posts and how those posts affected their own experiences.

Participant 3, who has been a type one diabetic since childhood and is an active member of Facebook groups and Instagram communities, emphasizes the importance of sharing experiences:

“You see examples of events and troubles similar to your own, and sometimes you share your own experiences. In this way, you both learn and do not feel alone.” - Participant 3

Participant 16, the owner of an Instagram account dedicated to sharing content for T1D and an active member of several communities, also highlights the learning aspect from others' experiences:

“Maybe one day we will make the same mistake, but when we see and read about someone else's mistake, we also learn. If the same thing happens to us, we don't make the mistake” - Participant 16

Participants 3 and 16's remarks about learning from similar events and sharing experiences indicate a critical aspect of these communities: the collective knowledge gained through shared narratives. In simpler terms, participants learn from the shared content in these communities to gain insights for themselves or share their own experiences to help others in the group. While explaining about learning from others, both mention other members; in other words, they mention peer engagement.

As discussed in the literature, these online communities provide valuable resources that link individuals with similar health experiences (Wang et al., 2017; Litchman et al., 2018). This process not only transfers practical knowledge but also fulfills a crucial emotional need by reducing feelings of isolation. Most of the participants say that they do not feel alone after engaging with other type one diabetic people. It's not just about exchanging information; it's about creating a space where individuals find solace in knowing they are not alone in their journey with T1D.

Beyond offering emotional benefits, OHCs play a significant role in how actively individuals participate in managing their health and in the decisions they make regarding their healthcare (Wang et al., 2023; Oh & Lee, 2012). Participant 16's perspective adds

another layer by highlighting the learning opportunities embedded in peer engagement. The concept of "learning from others' mistakes" is powerful within these communities. The shared experiences and advice help members navigate complex healthcare systems, making informed choices that are often fitting to their specific needs and circumstances. It reflects a proactive approach to managing T1D, where members can preemptively avoid potential pitfalls by drawing insights from others' experiences. This aspect reflects the transformative nature of peer engagement, where individuals not only support each other emotionally but also contribute to each other's growth and resilience in managing their health. In conclusion, peer engagement within online T1D communities in Türkiye provides a collective learning environment where members draw from shared experiences, enhancing their sense of belonging and contributing to their overall health management experience.

The last key finding for the social support theme is that online T1D communities in Türkiye provide motivation to their members while coping with T1D. These communities play a crucial role in providing encouragement to their members as they manage the complexities of living with this chronic condition. As stated in the interviews, suggestions, supportive, encouraging, and inspiring experience content for members to manage their diabetes more effectively are frequently encountered in communities. For instance, members often share personal stories of overcoming challenges, offer practical tips on insulin management, and recommend resources such as educational videos or articles on nutrition and exercise.

In-depth interviews show that these online communities curate various resources and interactions, helping uplift and empower their members. One common theme in these communities is the prevalence of suggestions and practical advice. Members often share personal stories, anecdotes, and strategies they find effective in managing their diabetes. Those stories and recommendations carry a role as guidance for other members. For example, discussions might revolve around tips for healthier eating, sportive activities, insulin-dosing strategies, or ways to cope with blood sugar fluctuations. These exchanges provide valuable insights and a sense of motivation among members.

Participant 4, 34 years old type one diabetic teacher and an active member of several communities on WhatsApp and Instagram, points out the inspiring aspect of other members' posts:

“In one of the groups, some shared that they did so much exercise today, and the other shared that they ate very healthily. These kinds of posts get me pumped up too. For example, it makes me want to exercise when I don't think about exercising that day, or it encourages me to eat healthier. This inevitably helps me control my blood sugar better.” - Participant 4

This motivational aspect is further reinforced by the supportive and inspirational content shared within these communities. As Participant 4 highlights, the active sharing of personal achievements and healthy behaviors not only fosters a positive environment but also serves as an impulse for members to adopt healthier lifestyles. When members share their exercise routines or healthy eating habits, it creates a contagion effect, inspiring others to adopt these behaviors in their lives. Dealing with a chronic disease can be overwhelming because of its constant management, and it may lead to motivation loss from time to time. A participant mentions that during those times, other members'

positive posts inspire them. So, it can also be said that online T1D communities are used to obtain motivation. Participant 6 also supports that finding by explaining how others' posts are effecting their enthusiasm.

“ I am someone who takes action when I see what others do. That's why I am filled with enthusiasm when I see people who keep their blood sugar levels at good levels and try to live healthily. I say I can do better.”
-Participant 6

This collective motivation assists individuals in overcoming the daily challenges associated with diabetes management. In other words, it motivates fellow members to handle their diabetes effectively. Observing the successes of others encourages members to set and achieve their own health goals, resulting in improved disease management and overall well-being. This dynamic of mutual encouragement and shared experiences exemplifies the strength and impact of these online communities in encouraging people with T1D to take care of their health.

The founders of T1D communities in Türkiye are very aware of the motivational function of the communities and aim to highlight this function. Community builders state that they especially wanted to bring out the motivational function and that one of their goals in establishing these communities was to inspire other individuals with diabetes to a healthier lifestyle. They recognize the powerful impact that shared experiences and mutual support can have on individuals managing a chronic condition like T1D. By creating a space where members can share their successes, challenges, and strategies for managing their condition, the founders aim to foster a positive and uplifting environment.

One of the key strategies employed by these founders is to emphasize the importance of positive personal stories and real-life experiences. They encourage members to share their journeys, including the obstacles they have overcome and the victories they have achieved. This sharing not only provides practical tips and advice but also serves to motivate and inspire others in the community. The strategy employed by the community builders also supports the idea that seeing peers successfully manage their diabetes can give members the confidence and determination to improve their own health behaviors. Therefore, online T1D communities in Türkiye provide motivation and encouragement to members with type 1 diabetes by sharing personal stories, practical tips, and supportive content. This finding highlights the motivational role of online T1D communities in Türkiye, where members share personal stories, practical tips, and their positive experiences to encourage and inspire each other in managing their diabetes effectively, creating a supportive environment that may support healthier lifestyles for the members.

4.2 Health Equity Findings

T1D is a disease that the patient must manage by making active decisions many times in daily life. If the patient cannot manage their diabetes well, it often leads to various additional health problems over time and demands ongoing, costly, and complex management (Turnbull et al., 2020). According to health equity, appropriate opportunities should be provided to patients to manage diabetes well and reach the healthiest state possible. In the literature review, health policies and services in Türkiye were discussed (Öcal & Önsüz, 2018; Cansu, 2018) and it was revealed how these led to

inequality for T1D patients (Chamakiotis et al., 2021; McCurry et al., 2023; Nolen et al., 2005; Turnbull et al., 2020; Van Pinxteren et al., 2022). The problems occurring due to health inequalities are very common discussion topics in the online T1D communities in Türkiye. Frequently, members seek solutions for their problems via these communities and may achieve positive results. Sometimes, they use these communities to draw attention to their unmet needs. Therefore, they are using those communities as a tool to reach health equity. The findings show that, online T1D communities in Türkiye fulfill a need for their members by reducing economic disparities due to health policies and providing access to necessary services that should be offered by the healthcare system.

The first key finding of the health equity topic reveals that online T1D communities in Türkiye fulfill a need for their members. As discussed earlier, proper opportunities should be given to patients to achieve health equity. However, in Türkiye, these necessities are not provided by the relevant institutions (Öcal & Önsüz, 2018; Cansu, 2018; Sosyal Güvenlik Kurumu, 2022). Therefore, it creates a discussion about individuals with T1D having unmet needs that are necessary to achieve health equity. T1D patients whose needs are unmet by the healthcare system or relevant institutions use their own resources to meet these needs or at least raise their voices about them. One of these resources in Türkiye is online T1D communities.

Participant 3, 27 years old online T1D community member who has had T1D since 16 years old, answers the question of why you joined an online T1D community:

“There was no one around me who was knowledgeable about diabetes, so I joined out of necessity. Especially in the early days of the diagnosis of the

disease, people panic even at the smallest thing because they do not know about the disease. You can not go to the doctor for everything. So, people handle it with their own means.” - Participant 3

Participant 3's experience highlights the personal challenges faced by individuals with type 1 diabetes in Türkiye. They talk about why they had to join this group out of simple need because there is no local support system or knowledge for managing their diabetes effectively. Thus, participant 3 turns to online T1D communities for unmet needs after being diagnosed at age 16. Similar to this example, participant 17 also emphasizes that these communities meet a need. Moreover, Participant 17 provides an example of how they meet their changing needs over time via online T1D communities.

“ I use these groups for many different purposes. I look at some posts more, depending on my periodic needs. For example, if I'm going to switch to a new insulin and need information about it, I look at posts related to that more.” - Participant 17

In the ideal condition, the health system should provide local support and knowledge to the patient so that health equity can be achieved. This situation is consistent with the finding that many patients in Türkiye do not receive adequate opportunity from healthcare institutions to reach their full potential of health leading to a feeling of panic and uncertainty. Consequently, individuals seek alternative sources to satisfy their needs. Most of the interviewees responded to the question of why they joined these online groups in a manner similar to Participant 3, emphasizing the necessity of these communities. In Türkiye, where formal healthcare systems may fall short, these online communities become lifelines, offering a path towards greater health equity by bridging gaps in support and knowledge. So, online T1D communities in Türkiye fulfill a need for their members.

The necessities of T1D patients in online communities in Türkiye are mainly rooted in social problems, health policy insufficiencies, and economic obstacles. As discussed in social support findings, social needs can sometimes be met through the social support function of these groups. In this way, online communities play a role in achieving equity by meeting members' social support needs.

Another need of group members is health opportunities they cannot access due to health policies. The current health policies of Türkiye do not provide sufficient sources and help for T1D patients (Öcal & Önsüz, 2018; Cansu, 2018; Sosyal Güvenlik Kurumu, 2022). Nearly all the interviewees give examples from their personal experiences to explain that they often struggle to manage their diseases because of health policy-related issues. Online activism is a common practice in these groups. For example, patients often organize signature campaigns to advocate for changes in health policies. Many interviewees either supported or came across such petitions in online T1D communities. Members see these campaigns as a way for patients to make their voices heard and push for improvements in the healthcare system. However, members do not think that such activities are taken into consideration by those authorized to change health policies. It is observed that even if members participate in such online activism activities, they are not hopeful they will succeed. Although actions such as petitions are not successful, T1D online communities provide an environment for their members to achieve health justice in response to the shortcomings of health policies.

As discussed previously, ideally, health information should come directly from professionals like doctors, nurses, and pharmacists (McCurry et al., 2023). However, in

reality, many people face barriers such as systemic, economic, locational, or time-related issues that prevent them from accessing these professionals (Van Pinxteren et al., 2022). As a result of the interviews, it can be said that there is a problem with access to health professionals in Türkiye. Some participants mention having a difficult time getting an appointment at public hospitals, accessing suitable medical personnel, and having a very short time frame to consult doctors. These problems show that current health policies in Türkiye are not sufficient for the needs of T1D patients. Therefore, members utilize online T1D communities in Türkiye to access necessary services that should be provided by the healthcare system.

Participant 3 explains how they use online T1D communities for the problems they faced after the T1D diagnosis:

“When I was first diagnosed, I would go to the hospital even if I had the slightest question. Of course, I had to go to private hospitals. It is like a dream to be able to find appointments at public hospitals so frequently. As you can imagine, this required both a lot of time and money. Later, I learned to find the answers to the questions myself. I researched and asked in groups if necessary. When you have to, you handle it somehow.”
- Participant 3

Participant 3's example highlights the necessary shift from relying on inaccessible public healthcare to seeking answers within T1D online communities. They described the initial struggle of securing timely appointments at public hospitals, often resorting to costly private options for urgent medical advice. This systematic, financial, and logistical burden led them to seek alternative solutions within online T1D communities. Based on the interviewers' answers, those communities helped them find a solution.

Participant 8 is a 40-year-old type one diabetic engineer who is highly interested in technology. This interest in technology extends to the management of diabetes, and they use several medical devices to control their blood sugar levels. During the interviews, Participant 8 mentions a problem they experience when they want to change one of their medical devices. Like Participant 3, this problem also arises from the inadequacy of the healthcare system.

“I couldn't find an appointment after trying for about two months. So, I had to replace my insulin pump with my own resources without going to the doctor. I learned how to use it by reading what people wrote and watching shared videos.” - Participant 8

Participant 8 explains the insulin pump change they have to make themselves without any professional supervision. Insulin pumps are medical devices that deliver insulin to the human body via an automated pump system (American Diabetes Association, 2024). In an ideal environment where health equity is achieved, the patient should be able to consult a professional in case of medical device replacement, such as an insulin pump. Participant 8 was faced with a two-month wait for a hospital appointment and found themselves without professional guidance when they needed to replace their insulin pump. This clearly demonstrates health inequality because of the healthcare system. Members overcome this inequality thanks to online communities. As in Participant 8's example, members can learn the details of using and maintaining their medical equipment through posted videos, experiences, and advice from peers. These online T1D communities help fill gaps left by inadequate health policies to manage their healthcare needs effectively. This collective effort helps members to satisfy the healthcare needs they might otherwise struggle to obtain due to systemic issues.

Another health inequality for T1D patients in Türkiye is the result of economic disparities. It has been discussed that T1D is a disease requiring constant and expensive management (Turnbull et al., 2020). It was also explained in the literature review how Türkiye presents an unequal environment for T1D patients in healthcare spending distribution and rising costs of essential medical products. The participants in the interviews expressed this economic inequality many times. This was also an issue about which online petition campaigns were made within online groups. This inequality cannot be discussed independently of the state's health policies. In an optimal health system, a T1D patient should have free access to all the medications and medical equipment they need. However, this is not the case for Türkiye. A few of the participants complained about the low share paid by the state for medical equipment during the interviews. It is possible to encounter many complaints in the community about the high prices that patients pay when purchasing their medicines and medical devices. Findings show that online T1D communities are used to solve some health inequalities related to economic disparities. Participant 14, who runs a T1D Instagram account, says:

“Some pharmacies have agreements with companies. In this case, we have much less of a price difference to pay. For example, there was a post asking which pharmacies in Istanbul sell glucose measurement strips and for how much TL. Everyone wrote in the comments which pharmacy they bought it from and how much it cost. I found out which pharmacy was the most affordable and went there.” - Participant 14

Through exchanging information regarding pharmacies that sell glucose measurement strips at a lower cost, community members enable one another to manage the high expenses of diabetes care. In addition to saving people money, this pragmatic trade addresses a critical component of health equity by helping T1D patients have access to

the resources they need for medical care, regardless of their financial situation. For example, Participant 6, who is a community owner, mentions about second-hand diabetes technology sales within the groups:

“Since diabetes technologies are very expensive, we cannot even access most of them in Türkiye. Sometimes, those who have extra sensors that are about to expire put them up for sale as second-hand at a more affordable price and share them in groups. If I see such posts, I buy them immediately. Sensors never go on sale, and their prices increase all the time.” - Participant 6

The sensor is a technology that allows T1D patients to check their blood sugar without pricking their fingers with a needle (Edge et al., 2017). This device, which is provided free by the state in most countries with developed health services, is not covered by the state in Türkiye. This technology, which makes diabetes control much easier (Edge et al., 2017), can only be accessed by those who can afford it. In this case, it can be said that there is a great inequality. In the example of Participant 6, although there is no solution to this economic inequality in the community, it can be said that there are situations that can help members with insufficient financial status to access technology at a more affordable price.

Other participants also gave examples of posts where community members collaborated to find the most cost-effective options available for various diabetes-related products. Therefore, it is evident that these communities may help T1D patients reduce the health inequality related to the economy. Unfortunately, this health inequality cannot be eliminated unless T1D patients have free access to the drugs and medical devices they need. Therefore, online T1D communities in Türkiye alone cannot overcome this health

equity, but they may reduce it. The last key finding of the health equity topic can be summed up as follows: Through online T1D communities in Türkiye, economic disparities due to health policies can be reduced.

4.3 eHealth Literacy Findings

There are many members from various eHealth Literacy levels in online T1D communities in Türkiye. Unfortunately, almost all of the participants interviewed in this thesis were people with high eHealth Literacy. Therefore, all findings about low eHealth Literacy are based on these individuals' observations within the group, not the self-reports of members with low eHealth Literacy. While discussing topics related to eHealth Literacy, such as the various tools and resources offered by online platforms and how individuals use these tools to manage their health, most participants shared their experiences and concerns about encountering misleading or misinformation content within the online T1D communities. The members with high levels of eHealth literacy who were interviewed in this study were confident in their ability to spot deceptive posts. They provided various examples of such posts and noted instances where other members, lacking similar literacy skills, failed to recognize the misleading information. These less literate members often engaged with misleading posts, presenting their vulnerability to inaccurate health information. Participant 7 is the mother of an 11-year-old girl with type 1 diabetes. As her daughter's caregiver, she frequently follows online T1D communities. Participant 7 says that:

“I frequently come across absurd and unscientific recommendations, such as boiling a particular herb and drinking it on an empty stomach for several days. I have observed people practicing and commenting on these methods, and it is very dangerous.” - Participant 7

Participant 7 expresses their concern about the danger of misleading recommendations shared in online communities based on their frequent encounter with deceptive posts.

Participant 7, who is well-educated and knowledgeable about technology, notices misguiding health advice. However, she also mentions that not everyone in the T1D community can recognize these false recommendations. Unfortunately, participant 1, a specialist diabetes nurse, confirms with their examples and statements that Participant 7's concern is indeed justified. Participant 1, who is a specialist diabetes nurse, reports that a patient, influenced by a recipe shared by someone else, drank a large amount of thyme juice, resulting in a coma, and ended up in an intense care unit.

“Unfortunately, I can't say that everyone is very conscious. There are those in the groups who believe and apply everything they read. We see people coming to the hospital because of these situations. Like the patient who drank thyme water, there are those who squeeze and drink random herbal juices. They make ridiculous mixtures and use them. There are patients who have severe liver problems because of this.” - Participant 1

As Participant 1 stated, the outcomes of misleading information can be life-threatening. It is crucial to recognize that these online communities have a multifaceted dynamic because of the existence of individuals with different levels of eHealth literacy. High eHealth literacy allows one to evaluate and navigate information critically, often seeing and avoiding incorrect data. On the other hand, Interviews supported the idea that individuals with less eHealth literacy are more prone to false information, which may have health-threatening consequences. Therefore, frequent instances of misleading or

inaccurate information circulated within online T1D communities in Türkiye highlight the crucial role of eHealth Literacy.

As can be seen from the examples given by interviewees with high eHealth literacy, they are aware of the existence of members with low eHealth literacy in the online community. Moreover, due to their high literacy, they are more likely to detect misleading content in the communities than members with lower eHealth Literacies. Findings show that they use this ability to help other members. Strategies include eliminating disinformation, guiding people in the direction of credible sources, and offering straightforward explications of intricate medical concepts. These informed people frequently assume unofficial responsibilities in the community as instructors or moderators, creating a space where truthful information can be shared and comprehended by all participants. Via those interactions, some members became “peer mentors” (Maloney-Krichmar & Preece, 2005) within the online T1D communities in Türkiye. Participant 11 gives an example of peer mentorship:

“When I see something questionable in a post, I am generally skeptical. If someone has shared something that I know is wrong, I immediately warn them so that others do not see it and be affected by it. Sometimes, someone shares wrong information because they do not understand. They post about a source they encountered, but the information is actually for another disease. In this case, I warn them politely” - Participant 11

Participant 11 highlights the need to be cautious in online T1D communities. They state that, while being aware of the possible consequences of false information, they view posts with suspicion when they come across questionable material. In order to stop the spread of false information and potential harm, they take an active role by quickly

notifying others about it. It appears that Participant 11 is a peer mentor in this given example. Similar examples are given by various participants. One of them states that they try to help other members when they encounter a technological obstacle in the online environment, such as photo sharing.

“Sometimes people share links, but the link is missing. They try to share photos, but they either take really bad photos. For example, they ask about a problem they are having with a device, but instead of the problematic part, they take a photo of a completely different part of the device. Usually, older people do this more. I always try to help in these situations. Because they are the ones who need the most help.” - Participant 18

Participant 18 demonstrates their proactive role in addressing and resolving technological challenges other members encounter. This example highlights that Participant 18 is very aware of the obstacles faced by members with lower eHealth literacy and tries to help them to overcome those obstacles. In the online T1D communities, members with high eHealth literacy help solve problems that arise within the community due to eHealth Literacy differences.

Not only members with high eHealth literacy do recognize the differences in eHealth Literacy among the community members, but community builders are also aware of this disparity. Builders of the online T1D communities in Türkiye recognize the presence of members with lower levels of eHealth Literacy and employ user-friendly content creation strategies to reach them. Participant 13 has an Instagram account and a blog page that produces T1D content. Participant 13 states that:

“I try to write my content in a way that every age group and every segment can understand as much as possible. When I look at my followers, I see that I have been successful. There is an aunt who is a primary school graduate, a

professor, and a secondary school student who follows me. I don't want anyone to misunderstand or feel left out when they read what I wrote.”
- Participant 13

Participant 1 is a specialist diabetes nurse who is also the builder of diabetes WhatsApp groups, a YouTube channel, and an Instagram account. They discuss a tactic they use to enable members with lower eHealth Literacy levels to access content more easily:

“I can't teach elderly patients to open a YouTube account and then come to my channel and find the videos one by one. Now, there are QR codes. When you scan them with the camera, they immediately transfer to the video. I plan to use them.” - Participant 1

These insights highlight the community builders' active efforts to decrease the eHealth literacy gap by employing practical tools and strategies. Participant 13 recognizes their followers from different literacy levels. Indicates this difference by referring to their educational levels. They try to reach everyone in the community by using understandable language in their content. Similarly, Participant 1 adopts different strategies to interact with members with lower eHealth literacies. By simplifying language, using visual aids like QR codes, and creating easily digestible content formats, they ensure that even those with lower health literacy can access and benefit from the information shared.

The last key finding for the eHealth literacy topic is that members with high eHealth literacy tend to primarily question the source of a post. In contrast, those with low eHealth literacy prioritize assessing the accuracy of the information in online T1D communities in Türkiye. In the interviews, almost all of the interviewees mentioned the source of the post while talking about its accuracy. According to many interviewees, the

first step in questioning the accuracy of the health information shared in the groups is to check the source. The most commonly mentioned criteria when deciding the accuracy of information are that the source is based on scientific data or written by an expert. If the source is a scientific source or the information is provided by an expert, then the information is trustworthy. One interviewee states that even if these criteria were met, they could still never completely trust the information they saw online without consulting a doctor.

When the same interviewees were asked about the misleading posts they encountered, the examples they gave were of members questioning the effectiveness of the shared information or interacting over the information. When the same interviewees were asked about the misleading posts they encountered, the examples they gave were of members questioning the effectiveness of the shared information or interacting over the information. None of the examples provided a situation where a community member who believed in a misleading post questioned where the information came from but questioned the information's efficiency. Participant 10 says that:

“I often see fake treatment posts that are obvious lies. Someone suggests taking some medicine. Someone else makes up a diet and recommends it. Another person comes and shares that if you drink this herbal tea, you will get better in 3 days. Some conscious people immediately question: What is this medicine, who shared it, and is it an authorized person? But some people immediately write back to find out if it works or if anyone has tried it. There are people there who would immediately go and apply it if someone said yes, it worked.” - Participant 10

Participant 10 reveals a situation that may risk human health due to the eHealth literacy gap within online T1D communities in Türkiye. Frequent posts that may endanger

human health can be observed in these groups. People with low eHealth literacy levels are at greater risk. In addition, the example given by Participant 10 also supports the finding of members with high eHealth literacy question post sources, while those with low eHealth literacy focus on assessing information accuracy in Turkish online T1D communities.

This example shows how differing levels of literacy impact members' interactions with health information. It illustrates a possible scenario where misleading health advice is shared, such as unverified treatments or diets. Those with higher eHealth literacy tend to question the credibility of such posts by investigating the source and seeking scientific validation or professional endorsement. In contrast, individuals with lower eHealth literacy often prioritize practical considerations like the effectiveness of the suggested treatment without necessarily questioning its source or reliability.

Based on the last key finding regarding eHealth literacy online T1D communities in Türkiye, it is clear that members' levels of literacy significantly influence their approach to health information. Examples and experiences of the interviewees suggest that members with high eHealth literacy tend to mostly question the source of a post, whereas those with low eHealth literacy prioritize assessing the accuracy of the information in online T1D communities in Türkiye. This distinction underscores the critical role of eHealth literacy in navigating online health content effectively, highlighting both the benefits of online T1D communities and the risks associated with inadequate information evaluation practices. Table 4 presents a summary of all the findings of this study.

Table 4: Themes and Key Findings

Themes		Findings
Social Support	1.	Instrumental support is observed as common in online T1D communities in Türkiye.
	2.	Through 'peer engagement,' members of online T1D communities in Türkiye gain collective knowledge from shared narratives and experience a sense of belonging.
	3.	Online T1D communities in Türkiye provide motivation to their members while coping with T1D.
Health Equity	1.	Online T1D communities in Türkiye fulfill a need for their members.
	2.	Members utilize online T1D communities in Türkiye to access necessary services that should be provided by the healthcare system.
	3.	Through online T1D communities in Türkiye, economic disparities due to health policies can be reduced.
eHealth Literacy	1.	Frequent instances of misleading or inaccurate information circulated within online T1D communities in Türkiye highlight the crucial role of eHealth Literacy.
	2.	In the online T1D communities, members with high eHealth Literacy help solve problems that arise within the community due to eHealth Literacy differences.
	3.	Builders of the online T1D communities in Türkiye recognize the presence of members with lower levels of eHealth Literacy and employ user-friendly content creation strategies to reach them.
	4.	Members with high eHealth literacy tend to mostly question the source of a post, whereas those with low eHealth literacy prioritize assessing the accuracy of the information in online T1D communities in Türkiye.

4.4 Intersection of Social Support, Health Equity, and eHealth Literacy

In this thesis, the functions of online T1D communities in Türkiye were investigated through three primary dimensions: social support, health equity, and eHealth literacy from the uses and gratifications approach. All of the key findings from those dimensions are summarized in Table 3. While each theme was analyzed individually, the research revealed significant interconnections among them. These three main areas are intricately intertwined with each other. When talking about social support, its function in achieving health equity is indisputable. Social support within these communities was found to play a crucial role not only in providing emotional and informational support among members but also in contributing significantly to the promotion of health equity. Members contribute to their health by accessing social support through these groups. In this way, they also reduce the inequalities that may occur if they cannot access social support.

When discussing health equity, eHealth literacy levels differ among community members, which raises a separate topic of inequality discussion. Different levels of digital health literacy affect how well people can use online resources, which in turn affects their health results. The findings suggest that people with higher eHealth Literacy levels are less likely to believe misleading information shared in online T1D communities. The results also point out that individuals who were more skilled in eHealth literacy are most likely to act as mentors or guides within the community. They help others who are less literate navigate health information, which strengthens the

community's supportive environment. It can be argued that the finding that members with high eHealth literacy are aware of low literacy members and help them is also an example of social support. Therefore, the primary dimensions of social support, health equity, and eHealth literacy are highly connected with themselves. Participant 1, a community builder, gives an example of those dimensions that can be observed in one case:

“There are even elderly members in the WhatsApp group who are illiterate. These people also need to be in these groups. Especially after a certain age, these patients cannot come to the hospital every day and consult, so it is very valuable for them to have such a group that they can reach. Of course, since they are illiterate, they cannot return or read the messages written. But when they have a problem, they communicate somehow. They send a voice, we send a voice in response, and we solve their problem by talking.”
- Participant 1

Participant 1 exemplifies the connected nature of the dimensions of social support, health equity, and eHealth literacy in online T1D communities in Türkiye. From this example, it can be observed that these dimensions are not standing alone but intertwining with each other. Participant 1 shows how social support is given to address it in the case of elderly illiterate members: if they have difficulties, they now have access to a community that helps them. This may include informational, emotional, or companionship support. Thus, assistance from fellow members is an example of social support offered to older individuals through the T1D community on WhatsApp. This linking of the elderly members not only provides social support but also facilitates health equity in that all members are able to access necessary health information and assistance, even if they have a low level of eHealth literacy.

This example also supports the eHealth literacy finding that members with high eHealth literacy help solve problems that arise within the community due to eHealth literacy differences. When an illiterate member asks for help, other members answer this help in a voice message format that the illiterate member can understand. So, as members of higher levels of eHealth literacy, they help lower-level members. This instance also supports that community builders employ user-friendly content creation strategies to reach members from different literacy levels. Participant 1, as the founder of the community, states that one of the rules of the community is not to send voice messages in order to maintain a professional atmosphere. However, this rule does not apply to illiterate people and the elderly, so they can reach support more easily when they have a problem.

Uses and gratifications theory also reveals the interconnectedness of social support, health equity, and eHealth literacy. The main reason members join online T1D communities is mostly because of social support. They seek informational, instrumental, or emotional support within these groups. However, while they are obtaining social support, they also sometimes obtain health equity. As observable in Participant 1's example, elderly people join the communities to consult when they are faced with a problem. So, they seek informational support. If they were not members of this community, it would be tough for them to obtain that support because of the health system. But, via the T1D community, they can reach what they seek from their homes. One of the gratifications they obtain is improved health equity. eHealth literacy plays the role of making it easier to achieve this gratification. While a member with a high eHealth literacy level can access health equity much more easily, a person with a low

level may have more difficulty. He/she can believe misguidance or misinformation more easily. Moreover, they may have to resort to different methods to meet their needs, such as older members communicating via voice notes.

In conclusion, different dimensions and dynamics of the online T1D communities in Türkiye expose the complex interaction between social support, eHealth literacy, and health equity. Considering social support from the uses and gratifications approach, one of the gratifications obtained is health equity, and what makes it easier to achieve this is eHealth literacy. The overlap of these dimensions clearly becomes observable. Online T1D communities provide T1D patients, their caregivers, and health professionals an area to connect. Different social support types provided in these communities lead to inclusivity to the very ends of all members of the community, even for the most vulnerable. These online T1D communities carry a great potential to benefit all members regardless of their backgrounds, eHealth literacy levels, or socioeconomic places. This connection contributes not just to personal advances in health outcomes but also to a collective attempt to reduce inequities in health. The complex connection between social support, health equity, and eHealth literacy underlines the critical questions of how online T1D communities in Türkiye should be further enhanced in order to develop themselves as stronger support systems for all their members and why online T1D communities in Türkiye have some functions that need to be fulfilled by the healthcare system and institutions.

CHAPTER 5

CONCLUSION

5.1 Summary of the Findings and Implications

By building on the existing literature on social support types (Wang et al., 2017; Loane & D'Alessandro, 2013) and the relationship between social support and community members' actions (Eysenbach et al., 2004; Wang et al., 2023), The findings of this study reflect how T1D online communities in Türkiye support their members in different dimensions, thus fully answering the research questions. For the question of What kinds of social support do online type one diabetes communities provide in Türkiye, the study reveals that besides various types of social support, such as informational or emotional support, exceptionally there is commonly observable instrumental support in online T1D communities in Türkiye. By revealing the positive outcomes of social support, this finding also contribute to the studies of outcomes of social support (Taylor, 2011; Oh & Lee, 2012; Litchman et al., 2018). Through these communities, members provide a sense of belongingness and collective knowledge through peer engagements, where members

share their experiences and learn from one another. Further to this, the communities provide emotional motivation to keep one positive and manage their health better.

For health equity, research aimed to reveal how online type one diabetes communities in Türkiye help patients advocate for their healthcare rights and access to essential resources and how they contribute to achieving health equity. Building upon the health inequities identified in Türkiye (Cansu, 2018; Öcal & Önsüz, 2018), this study analyzed how online T1D communities affect these inequalities. Expanding upon the literature of OHCs play an essential part in reaching health equity (Van Pinxteren et al., 2022; McCurry et al., 2023; Schermuly et al., 2020; Parker et al., 2012), findings showed that online T1D communities play an essential role in bridging the remaining gaps in the healthcare system when it comes to overcoming health inequalities. They provide members with access to services and resources that would otherwise be difficult to obtain and help members advocate for their health care rights. In addition, online T1D communities help reduce the financial disparities resulting from inadequate healthcare coverage and contribute to allowing members to access the care they need regardless of their income status.

Elaborating on the existing literature, this study underscores the critical role of eHealth literacy in navigating and utilizing online diabetes communities effectively. The findings align with Norman and Skinner's (2006) conceptualization of eHealth literacy as essential for managing digital health resources and making informed decisions. The study revealed what tools members commonly use to manage their ability to navigate and utilize online diabetes communities and how proficient they are. While there are

members with high eHealth literacy levels who are able to utilize tools in the community, such as questioning a source of information, there are also members with low levels. Findings highlight the importance of eHealth literacy. There are frequent incidents of misleading or inaccurate information, making it necessary for members to navigate and use online resources effectively. The study also reflects Refahi et al.'s (2023) assertion that higher eHealth literacy enhances healthcare interactions and disease management by showing that members with advanced skills contribute to problem-solving and quality control within the community. Those with high eHealth literacy skills often help solve problems by questioning information sources and guiding others. Community builders also recognize varying levels of eHealth literacy among members and create user-friendly content to ensure that everyone can benefit from the information shared.

While building upon the social support, health equity, and eHealth literacy functions of the online T1D communities in Türkiye, this study's significant finding reveals the interconnected structure of these functions. Based on the uses and gratifications theory (Ardissone et al., 2024; Katz et al., 1973; Ruggiero, 2000), every member of the community comes with a need to satisfy. In online T1D communities, this need is mostly social support (informational support, emotional support, or instrumental support) (Wang et al., 2017; Loane & D'Alessandro, 2013). Consequently, they obtain social support as a gratification, but besides social support, members also obtain improved health equality as gratification. During this process, eHealth literacy plays an important role. If the members have a higher level of eHealth literacy,, then they can reach the intended gratification more easily. EHealth literacy is an element that facilitates this

process. By uses and gratification framework, this study reveals the intertwined structure of social support, health equity, and eHealth literacy. Overall, this study indicates that online T1D communities in Türkiye function in providing crucial social support, achieving health equity by bridging gaps in the healthcare system, and benefit many members despite varying levels of eHealth literacy among their members.

5.2 Limitations

The interview sample of the thesis was limited in terms of age, socioeconomic and educational background. The ages of the 18 participants varied between 22-54. T1D is a chronic disease that can occur at any age, from infancy to old age (U.S Centers for Disease Control and Prevention, n.d.). However, in this study, the interview sample includes only participants of young adults and middle-aged adults. With a broader age range of participants, the findings might differ because older and younger participants have different literacy levels and media consumption habits. This indicates that the results of this study can not be generalized to all age groups of online T1D members. In addition, the socioeconomic levels of the participants were not homogeneous. The interview sample is from middle and upper-middle economic levels. Therefore, findings are not applicable to the lower and higher economic levels.

Another significant limitation is educational background. Seventeen out of 18 participants are university graduates. One participant is a high school graduate but is particularly conscious and involved in T1D. Thus, all of the participants have high eHealth literacy levels. Since eHealth literacy is one of the main themes of this study,

this limitation is quite restrictive. In order to overcome this limitation, participants were asked questions about examples of low eHealth literacy examples they encountered in online T1D communities. However, since the results are based on observations of those with high eHealth literacy levels, not people with low eHealth literacy levels, the limitation cannot be eliminated entirely. In addition, the eHealth literacy levels of the participants are not quantitatively calculated. There is an eHealth literacy scale, EHEALS, to define someone's eHealth literacy level (Norman & Skinner, 2006). However, time constraints and the need for more analytical research prevented the use of the EHEALS scale in this thesis. For this reason, participants' eHealth literacy levels were assessed based on their own self-reports. Therefore, there is a possibility that participants might overstate their eHealth literacy skills.

Another limitation of this study is that the researcher is an active member of some of the online T1D communities. While the researcher's involvement in these communities offers a unique advantage, allowing for an insider's perspective and deeper insights into group dynamics and interactions, it also presents potential challenges. The involvement of the researcher may affect the researcher's objectivity, personal experiences, prior experiences, and relationships with other group members could introduce bias. To address this limitation, the researcher tried to remain as objective as possible by focusing on the interview responses and not letting her personal experiences in the groups influence the findings. Even with these efforts, it's important to recognize that achieving complete objectivity can be difficult, and there may still be some personal bias affecting how the study's results are interpreted.

5.3 Policy Implications

The thesis findings could provide valuable guidance for enhancing institutional practices related to T1D and improving health policies. It is clear that online T1D communities have valuable benefits for their participants, such as accessing health equity or providing social support. It is clear that online T1D communities have valuable benefits for their participants, such as accessing health equity or providing social support. Associations, foundations, or health organizations operating on behalf of T1D must recognize the potential of these communities. In this way, they can use these groups more effectively. By deliberately collaborating with and supporting these groups, institutions can increase their influence and effectiveness in meeting the needs of T1D patients. Since institutions have more opportunities than average community members, results that will benefit members can be achieved with a strategic approach. Currently, there are health professionals who voluntarily post in groups or address T1D audiences through their own accounts. However, these benefits can be significantly extended through collaboration with well-funded entities such as associations, foundations, or private institutions. By integrating health professionals into these groups, members can access correct information directly. This leads to reducing health inequalities by ensuring that all members, whether or not they have the means, can access reliable information. Also, by making corrections to the misinformation, experts can prevent problems that may arise due to eHealth literacy differences. Therefore, by strategically engaging with online T1D communities, these organizations can enhance their effectiveness.

Another important implication is related to health policymakers in Türkiye. The intertwined structure of eHealth literacy, social support, and health equity shows that individuals with type 1 diabetes in Türkiye use online communities to meet their needs in these dimensions. In other words, the health system cannot adequately meet their needs in these areas. The findings, especially in the field of health equity, reveal the inadequacies of the system. Policymakers can make systemic improvements by taking into account the deficiencies revealed by this thesis. Online T1D communities must be transformed into systems-supporting places rather than places where patients seek to address needs that the system is not meeting.

5.4 Future Studies

Even though online T1D communities have been studied from various perspectives within the literature so far, there is still a lot waiting to be discovered. Among this study's three main themes, social support, eHealth literacy, and health equality, most studies are the social support. Although it is a highly studied area, its connection with eHealth literacy or health equity has yet to be researched in the scope of online health communities. This thesis revealed the connections between social support, health equity, and eHealth literacy. The interconnected nature of social supports with other themes in online T1D opens new areas of study for researchers. Further studies can delve deeper into these connections and reveal more about the complex interactions between online support systems, health equity, and eHealth literacy, potentially uncovering additional factors to help us understand T1D communities in Türkiye. Future studies should be

aware of the limitations listed in this study and design the research to overcome those limitations.

The current research also reveals that contrary to the literature, online T1D communities in Türkiye include frequent instrumental support. This finding creates another topic of discussion as to why such a situation exists in Türkiye, contrary to the findings of other studies made in different countries. This future study topic might require a more diverse sample and a broader range of methodological approaches.

Health equity through online communities is a topic that is very understudied in the literature. This study showed how online T1D communities can help their members to reach health equity. Based on these findings, health equity through T1D communities can be studied in a more detailed way. The interview sample of this study only includes members, and the study focused on members's perspectives. However, when health policies and institutions also play a role in health equity, the scope of the study can be expanded by adding their perspectives to future studies. Health officials and health policy decision-makers can be included in the interview sample.

Future studies on e-health literacy should expand the scope of the study by adding e-health literacy scales such as EHEALS (Norman & Skinner, 2006). This way, they can work on more precise data. In addition, by adding participants with different eHealth literacy levels to the interview sample, future studies can reach generalizable results. The findings regarding eHealth literacy in relation to health outcomes in this study were obtained through the members' own statements. Further studies may include the

perspectives of health professionals since they are more qualified to state health outcomes. It deepens eHealth literacy by adding a professional's perspective to it.

5.5 Concluding Remarks

In exploring the dynamics of online T1D communities in Türkiye, this study has illuminated the invaluable role these platforms play in providing social support, improving health equity, and promoting eHealth literacy among their members. Beyond the academic findings, as a type T1D patient since 2018, I am once again inspired by the members' usage of these communities while trying to manage their diabetes and diabetes-related complications. It is very encouraging to observe how T1D patients seek solutions to their unmet needs and create an environment of solidarity through online communities.

The connection between social support, health equity, and eHealth literacy within online T1D communities reveals a considerable area for further exploration and hope for the potential of online T1D community members. This intertwined connection may provide new ideas about how online T1D communities can be designed more effectively for T1D patients in the future. In this way, it can help make the lives of individuals with T1D easier. Although research has demonstrated the functions of online T1D communities in different areas, hopefully, the problems of T1D patients can be easily solved without the need for these online communities.

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APPENDICES

APPENDIX A: ETHICS COMMITTEE APPROVAL FORM



Bilkent Üniversitesi

Akademik İşler Rektör Yardımcılığı

Tarih : 5 Şubat 2024
Gönderilen : Ece Dede
Danışman : Ayşenur Dal Tokdemir
Gönderen : H. Altay Güvenir
İnsan Araştırmaları Etik Kurulu Başkanı
Konu : "Diabetes 2.0: ..." çalışması etik kurul onay

Üniversitemiz İnsan Araştırmaları Etik Kurulu, 5 Şubat 2024 tarihli görüşme sonucu, "Diabetes 2.0: How Are Online Platforms Changing The Game For Type-One Diabetes Patients" isimli çalışmanız kapsamında yapmayı önerdiğiniz etkinlik için etik onay vermiş bulunmaktadır. Onay, ekte verilmiş olan çalışma önerisi, çalışma yürütücüleri ve bilgilendirme formu için geçerlidir.

Bu onay, yapmayı önerdiğiniz çalışmanın genel bilim etiği açısından bir değerlendirmedir. Çalışmanızda, kurulumuzun değerlendirmesi dışında kalabilen özel etik ve yasal sınırlamalara uymakla ayrıca yükümlüsiniz.

Kovid-19 salgını nedeniyle konulmuş olan kısıtlamaların yürürlükte olduğu süre içinde, tüm komite toplantıları elektronik ortamda yapılmaktadır; aşağıda isimleri bulunan Bilkent Üniversitesi Etik Kurulu Üyeleri adına bu yazıyı imzalama yetkisi kurul başkanındadır.

Etik Kurul Üyeleri:

Ünvan / İsim	Bölüm / Uzmanlık	
Prof.Dr. H. Altay Güvenir	Bilgisayar Mühendisliği	Başkan
Prof.Dr. Haldun Özaktaş	Elektrik ve Elektronik Müh.	Üye
Doç.Dr. Işık Yuluğ	Moleküler Biyoloji ve Genetik	Üye
Dr. Öğr. Üyesi Bureu Ayşen Ürgen	Psikoloji	Üye
Dr. Öğr. Üyesi A.Bariş Özbilen	Hukuk	Üye
Prof. Dr. Özgür Ulusoy	Bilgisayar Mühendisliği	Yedek Üye
Dr. Öğr. Üyesi Bariş Özçelik	Hukuk	Yedek Üye

Kurul karar/toplantı No: 2024_02_05_02

APPENDIX B: INFORMED CONSENT FORM

Mülakat Bilgi Formu

Değerli katılımcı, Bilkent Üniversitesi İletişim ve Tasarım Bölümü yüksek lisans öğrencisi Ece Dede'nin yarı yapılandırılmış mülakat formatındaki tez çalışmasına davet edilmiş bulunuyorsunuz. Çalışmanın amacı Türkiye'de çevrimiçi tip 1 Diyabet toplulukları sosyal destek, sağlık adaleti ve e-Sağlık okuryazarlığının sağlanmasında nasıl işliyor incelemektir.

Görüşmeyi yapacak olacak araştırmacı 2 adet genel demografi sorusu ve yaklaşık 20 adet temel çalışma sorusu soracaktır. Temel sorular Türkiye'de çevrimiçi tip 1 diyabet topluluklarının sosyal destek, sağlık adaleti ve e-sağlık okuryazarlığı fonksiyonlarını nasıl yerine getirdiğini detaylı bir şekilde anlamak için ek sorular içerebilir.

Mülakat sorularının sorulması ve cevaplandırılması yaklaşık olarak 25-30 dakika sürecektir. Görüşme sırasında katılımcının söylediği hiçbir şey doğru ya da yanlış olarak değerlendirilmeyecektir.

Görüşme sırasında katılımcının cevapları ses kaydı ile kaydedilecek ve sonrasında yazıya aktararak bir transkript üretilecektir. Görüşmenin transkripti araştırmacı tarafından bizzat yapılacaktır. Gerçek ses kayıtları araştırma süresinin sonuna kadar dijital olarak saklanacak ancak üçüncü taraflarla paylaşımı kesinlikle yapılmayacaktır.

Bilkent Üniversitesi'nin etik yönergeleri uyarınca, yanıtlarınız, not dökümlerinden ve nihai rapordan isimleriniz çıkarılarak gizli kalacaktır. Çalışmanın konusu kronik bir hastalık etrafında kurulan gruplara odaklandığından bazı kişiler için hassasiyet yaratabilecek sağlık konularına değinebilir. Görüşme soruları bu hassasiyetler göz önünde tutularak hazırlanmıştır. Katılımınız tamamen gönüllülük temellidir. Araştırmacı her bir katılımcının bu çalışmaya kendi özgür iradesiyle katkıda bulunmasını ve katılımcıların farklı deneyim ve bakış açıları hakkında bilgi edinmeyi amaçlamaktadır. Mülakat çalışmasına katılmamayı seçebilir ve katılmayı seçerseniz bile, çalışma sırasında istediğiniz zaman çıkabilirsiniz. Buna ek olarak herhangi bir şekilde rahatsız olursanız, bilgilerinizin çalışma bulgularından çıkarılmasını talep edebilirsiniz.

Görüşme metnine tam erişim sadece araştırmacı Ece Dede ve danışmanı Dr. Öğr. Üyesi Ayşenur Dal Tokdemir ile sınırlı olacaktır.

Bu bilgi formunun ve bir sonraki sayfadaki onay formunun kopyası saklayabilmeniz için temin edilecektir. Bu çalışma ile ilgili herhangi bir sorunuz veya endişeniz olursa, Bilkent Üniversitesi Etik Kurulu ile etik@bilkent.edu.tr adresinden veya Bilkent Üniversitesi İletişim ve Tasarım Bölümü'nden yüksek lisans öğrencisi Ece Dede ile ece.dede@bilkent.edu.tr adresi üzerinden veya 05348260926 telefon numarası ile iletişime geçebilirsiniz.

Bilgilendirilmiş Onam Formu

Araştırmanın içeriğini ve amacını anlıyorum ve Ece Dede tarafından yürütülen çalışma ile ilgili olarak hem sözlü hem de yazılı olarak aldığım bilgiler ışığında çalışmaya katılmayı kabul ediyorum. 18 yaşın üzerindeyim. Mülakat görüşmeleri öncesinde, sırasında veya sonrasında soruları cevaplamama veya katılımımı tamamen bitirme hakkım olduğunun farkındayım.

Katılımcının adı :

Katılımcının İmzası:

Tarih (GG/AA/YY):

Katılımcının Adresi :

.....

Araştırmacı: Ece Dede

Araştırmacının İmzası:.....

APPENDIX C: INTERVIEW QUESTIONS

Araştırma Sorusu: Çevrimiçi tip 1 Diyabet toplulukları Türkiye'de sosyal destek, sağlık adaleti ve e-Sağlık okuryazarlığının sağlanmasında nasıl işlev görüyor?

Her iki gruba da sorulacak demografik sorular:

1- Yaşınız kaç?

2-Eğitim seviyeniz nedir?

Topluluk üyelerine sorulan görüşme soruları:

Size Türkiye'deki çevrim içi tip 1 diyabet topluluğu üyesi olduğunuz için ulaştım. Bu grupta/gruplarda yaşadığınız deneyimler hakkında sorular soracağım.

1- Hangi online tip 1 diyabet topluluğu/toplulukları üyesisiniz?

2-Online tip 1 diyabet topluluklarına nasıl katıldınız ve ne kadar süredir bu topluluklarda bulunuyorsunuz?

3-Online tip 1 diyabet topluluklarına neden katıldınız?

4-Bu grupları ne sıklıkla kullanıyorsunuz?

5-Topluluklardan beklentileriniz neler?

6-Topluluklarda hangi roller üstleniyorsunuz?

7-Topluluklarda paylaşım yapıyor musunuz? Yapıyorsanız ne tür paylaşımlar yapıyorsunuz? -

- Paylaşım yaptığınızda diğer topluluk üyelerinden nasıl bir etkileşim bekliyorsunuz?

8-Ne tarz paylaşımlarla karşılaşıyorsunuz?

- Bu paylaşımlarla etkileşimde bulunuyor musunuz? (yorum/beğeni/yeniden paylaşım vb.)

9-Topluluklarda en çok ilginizi çeken, daha fazla yer verilmesi gerektiğini düşündüğünüz konular var mı? Varsa neler?

- 10-Topluluklardaki etkileşim ve bağlantılar sizin için nasıl bir destek sağlıyor?
- 11-Topluluklar sayesinde tanıştığınız veya yeni arkadaşlıklar kurduğunuz kişiler oldu mu?
- 12-Sağlık hizmetlerine erişimde veya sağlık konularındaki bilgiye ulaşımında yaşadığınız herhangi bir zorluğu bu gruplar sayesinde aştığınız oldu mu? Olduysa anlatabilir misiniz?
- 13-Toplulukta sağlık hizmetlerine erişimde yaşanan zorluklarla ilgili bilgi veya deneyim paylaşımları gözlemlediniz mi? Veya siz böyle bir paylaşımda bulundunuz mu?
- 14-Sağlık politikaları hakkında olumlu veya olumsuz paylaşımlarla karşılaştınız mı? Veya kendiniz bu tür paylaşımlarda bulundunuz mu?
- 15-Online kaynakları kullanma konusundaki deneyimleriniz nelerdir?
- 16-Gruplara hangi teknolojik alet/aletler ile erişim sağlıyorsunuz?
- 17-Topluluklara erişim sağlarken teknolojiden kaynaklı yaşadığınız bir sorun oldu mu?
- 18-Gruplarda karşılaştığınız önerileri uyguluyor musunuz?
- Bu önerilerin doğruluğunu nasıl kontrol ediyorsunuz?
- 19-Gruplardaki sağlık bilgilerini değerlendirme ve doğrulamada zorlandığınız durumlar oldu mu?
- 20-Gruplarda yanlış bilgi paylaşımı ile karşılaştınız mı? Karşılaştıysanız ne yaptınız?
- 21-Topluluklardan edindiğiniz bilgileri günlük yaşamınızda nasıl uyguluyorsunuz? Bu bilgiler sizin için ne kadar önemli?

Topluluk kurucularına sorulan görüşme soruları

Size Türkiye’deki çevrim içi tip 1 diyabet topluluk kurucusu olduğunuz için ulaştım. Bu grubu yönetirken yaşadığınız deneyimler hakkında sorular soracağım.

- 1-Topluluğunuzu/topluluğa hitap eden hesabınız nedir? Hangi çevrimiçi platformlarda faaliyet göstermektedir?

2-Tip 1 diyabet topluluğunu kurma sürecini ve amacınızı anlatır mısınız? Neden bu topluluğu kurma kararı aldınız?

3-Bu topluluk kime/kimlere hitap ediyor?

4-Topluluğun kuralları var mı? Varsa neler?

- Topluluğunuzda nasıl bir moderasyon politikası izliyorsunuz?

5-Topluluğunuzun kuruluşundan bu yana nasıl bir büyüme ve gelişme süreci yaşadı? Topluluk içi etkileşimleriniz hakkında genel bir değerlendirme yapabilir misiniz?

6-Topluluğunuzun bir dayanışma kültürü var mı? Nasıl bir ortam yaratmaya çalıştınız?

7- Üyeleriniz arasındaki etkileşimi nasıl yönlendiriyorsunuz? Üyeler arasındaki etkileşim ve bağlantıların topluluğunuzdaki önemi nedir? Bu etkileşimlerin topluluk içindeki dinamikleri nasıl şekillendirdiğini düşünüyorsunuz?

8-Sağlık hizmetlerine erişimde veya sağlık konularındaki bilgiye ulaşımında yaşadığınız herhangi bir zorluğu bu topluluk sayesinde aştığınız oldu mu? Olduysa anlatabilir misiniz?

9-Topluluğunuzda güncel sağlık politikaları hakkında olumlu veya olumsuz paylaşımlara yer verdiniz mi? Veriyorsanız topluluk üyeleri tarafından nasıl bir etkileşim aldı?

10-Topluluk üyeleri arasında sağlık hizmetlerine erişimde yaşanan zorluklarla ilgili bilgi veya deneyim paylaşımları gözlemlediniz mi? Gözlemlediyseniz, bu konudaki deneyimleri paylaşabilir misiniz?

11-Topluluğunuzda sağlık bilgilerinin doğruluğunu nasıl sağlıyorsunuz? Yanlış bilgi paylaşımı ile nasıl başa çıkıyorsunuz?

12-Topluluğunuzun amacını ve hedef kitlesini düşündüğünüzde, üyelerinizin dijital sağlık konularında ne kadar bilgi sahibi olması önemli bir etken olabilir. Bu konuda gözlemleriniz veya deneyimleriniz nelerdir?

13-Topluluk üyeleri tarafından paylaşılan içeriklerin kalitesi ve doğruluğu konusunda ne düşünüyorsunuz? Üyelerinizin dijital sağlık konularında ne kadar bilinçli olduklarına dair bir değerlendirmeniz var mı?