# BODILY AND BIOSOCIAL USER PRACTICES IN TYPE 1 DIABETES MANAGEMENT

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# BODILY AND BIOSOCIAL USER PRACTICES IN TYPE 1 DIABETES MANAGEMENT

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# ABSTRACT

## BODILY AND BIOSOCIAL USER PRACTICES IN TYPE 1 DIABETES MANAGEMENT

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Aside from the integration of digital technologies that made products compact and connected, the changes in healthcare policies redefined the practice of being ill and the patient profile. Medicine became commercialized and directly targeted individuals as potential consumers. Thus, patients are given responsibility for their own bodies. This study is focused on the user practices of self-monitoring devices as a representative example regarding the changes mentioned above. Despite the increasing number of studies focused on self-monitoring devices, design-related examples are limited to the discussions of user experience and usability. This thesis examines this gap by exploring the changes in care practices and patient profiles with the use of remote health technologies from the perspective of the human body and biosociality. The fieldwork of the thesis consists of semi-structured in-depth interviews with 12 participants using the insulin pump and/or continuous glucose monitoring systems, who were recruited through a social media account. Based on the findings, this thesis offers six main conclusions. First, changes in healthcare have redefined the experiences of being chronically ill. Second, contemporary devices provide the users with dynamic, real-time visualization of an unknown (i.e., anticipated glucose change). Third, in regard to use context, wearable technologies impact the visibility of diabetes. Fourth, the bodily experiences of self-monitoring devices result in the characterization of the human body. By its very nature, in some instances, diabetes requires collaborative management, and apart from the patient, the others also obtain the right for decision making. Within this context, self-monitoring devices may substitute some of the actors in the care network. Last, as technology use in diabetes management arises the need for experiential knowledge, individuals come together and constitute examples of a community of practices.

Keywords: Biosociality, Diabetes, Quantified Self, Community of Practice, Health Technologies.

# ÖZ

## TİP 1 DİYABET YÖNETİMİNDE BEDENSEL VE BİYOSOSYAL KULLANICI PRATİKLERİ

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Ürünleri küçülten ve bağlı olma durumunu norm haline getiren dijital teknolojik gelişmelerin yanı sıra, sağlık politikalarındaki değişikliklerin de etkisiyle, hasta olma pratiği ve hasta profili değişmeye başlamıştır. Tıp ilmi ticarileşmiş, hasta bireyler aynı zamanda birer hedef tüketici haline gelmiştir. Bu değişikliklerin sonucunda, bireylere "kendi vücutlarından sorumlu olma" görevinin atandığı gözlemlenmektedir. Bu çalışma, yukarıda bahsedilen değişikliklerin kolayca okunabildiği örneklerden biri olan öz-takip teknoloji ve ürünlerinin kullanım pratiklerine odaklanmaktadır. Öz-takip cihazları hakkında çeşitli alanlarda yürütülen pek çok çalışma olmasına rağmen, tasarım alanındaki çalışmalar büyük ölçüde kullanıcı deneyimi ve kullanılabilirlik tartışmasıyla sınırlı kalmıştır. Bu tez, literatürdeki bu eksikliğin üzerine eğilerek öz-takip teknoloji ve ürünlerinin, hasta profili ve hasta olma pratiğinin bedensel ve biyososyal olarak yeniden şekillenmesi sürecine etkisini anlamayı amaçlar. Tezin alan çalışması, bir sosyal medya grubu aracılığıyla ulaşılan, insülin pompası ve/veya sürekli glikoz takip sistemi kullanan toplam 12 kişi ile gerçekleştirilen yarı yapılandırılmış derinlemesine görüşmelerden oluşmaktadır. Alan çalışması verilerine dayanarak altı ana sonuca ulaşılmıştır. İlk olarak, sağlık politikalarındaki değişiklikler, kronik hasta olma deneyimini yeniden tanımlamaktadır. Gelişen diyabet teknolojileri kan şekerinin gösterim biçimini dinamik olarak dönüştürmektedir. Bu dinamik gösterim, bireyin kendi kan şekerine ait kavrayışını dönüştürerek, bireylere karar vermenin ötesinde, öngörülebilir tehlikelere karşı da önceden müdahale hakkı tanımaktadır. Üçüncü olarak, öz-takip cihazları, kullanım biçimine bağlı olarak, hastalığın ve hastalıklı beden imajının görünürlüğüne etki etmektedir. Dördüncü olarak, öz-takip cihazlarının insan bedeni ile etkileşimi, beraberinde yeni bir beden karakterize etmektedir. Diyabet pratiği kolektif bir yönetim ihtiyacı doğurmakta ve hasta dışındaki kişiler de hastanın diyabet yönetiminde karar ve müdahale hakkı olan aktörlerden biri haline gelmektedir. Bu çerçevede, öz-takip sistemleri kimi zaman etkileşim ağındaki aktörlerin yerini alabilmektedir. Son olarak, diyabet yönetiminde teknoloji kullanımı ve beraberinde getirdiği bireysel deneyim odaklı bilgi ihtiyacının sonucunda, diyabet deneyimi ve ürün çevresinde bir araya gelen bireylerin, pratik toplumları oluşturduğu görülmektedir.

Anahtar Kelimeler: Biyososyal, Diyabet, Niceliksel Benlik, Pratik Toplumları, Sağlık Teknolojileri.

**‘The things,’ said Ford Prefect quietly, ‘are also people.’**

To My Family

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**BG** : Blood Glucose
**CGMs** : Continuous Glucose Monitoring
**DIY** : Do It Yourself
**EDL** : Everyday Life
**FGM** : Flash Glucose Monitoring
**GUI** : Graphical User Interface
**HbA1c** : Glycated Hemoglobin
**IVF** : In Vitro Fertilization
**Libre** : Abbott Free Style Libre
**NFC** : Near-Field Communication
**RPM** : Remote Patient Monitoring
**rtCGM** : Real Time Continuous Glucose Monitoring
**WHO** : World Health Organization

# GLOSSARY OF TERMS

**Pre-prandial Sugar:** The level of blood sugar before a meal (American Diabetes Association. n.d.).

**Post-prandial Sugar:** The level of blood sugar approximately two hours after the beginning of a meal (American Diabetes Association. n.d.).

**Basal Insulin:** Also defined as "background insulin," it is to keep blood sugar levels stable during the course of fasting. In diabetes treatment, basal insulin types vary in acting durations, which are intermediate, long and ultra-long acting insulin (American Diabetes Association. n.d.).

**Bolus Insulin:** Also described as short-acting or rapid-acting insulin, it is taken at meal times to control the rise in blood sugar levels following a meal (American Diabetes Association. n.d.).

# CHAPTER 1

# INTRODUCTION

## 1.1 Background

It was the winter of 2004, when my mother suddenly applied to the hospital with complaints of abdominal pain and doctors were having difficulty in diagnosing her illness as the symptoms were deceptive and would be indicating many different disorders from any hepatic impairment to pancreatic or uterine cancer. As a result of several medical analyses, including MR screenings, the doctors said that she might have pancreatic cancer as there was metaplasia in the head of the pancreas, and she was immediately hospitalized for further examinations. After spending two weeks at the hospital, it was revealed that her disorder was a hepatic vein thrombosis. However, what caused the blood clot was unknown, and to clarify, the doctors performed some genetic tests. According to the results, my mother was suffering from Factor V Leiden thrombophilia, which is an inherited disorder causing an increase in blood clotting level (Ornstein & Cushman, 2003). At the moment, the whole family was so focused on the fact that she did not have any cancer, we were thinking that things were going to be easier from now on. However, it was just the beginning of a challenging journey.

Before my mother, the only person I know dealing with a chronic condition was my grandmother. She had type 1 diabetes, and all I remember is that she was injecting insulin into her body and not allowed to consume too much fruit. The image of her holding the syringe is still crystal clear. As a child, I was not able to understand the burden of diabetes and how my grandmother was coping with it. In contrast, I have witnessed every difficulty that my mother went through. Her treatment plan has always been exhausting as she uses blood thinner pills and has to perform blood tests regularly as doses are adjusted accordingly. In this regard, the transformation in her everyday life routines has been the most challenging part. For example, she has changed her diet and limited Vitamin K intake as it makes the blood thicker, which means giving up most of her favorite food. Moreover, her daily schedule has become highly dependent on hospital visits as their frequency keeps changing according to her success in management. When she accomplishes the treatment plan, it is convenient to recheck blood levels in ten to fifteen days. On the contrary, if there is anything wrong, she is supposed to undergo those tests every three days, and sometimes she needs additional medications. I do not remember how many times having a last-minute change in family plans due to her fluctuating blood levels. I suppose that witnessing her struggle against all these difficulties is the main reason for my curiosity about the daily life of people with chronic illnesses.

In 2012, my mother's regular doctor changed due to operational reasons, and the new one wanted me to take genetic tests due to hereditary risk factors. The result was upsetting yet not surprising: It was revealed that I have the same disorder. However, due to my age and not having any symptoms or signs, the doctor said that my treatment plan was going to be different. This made me realize the significance of personalized care, which is one of the key concepts discussed in this thesis.

Within years, the way my mother handles her care has changed quite much. At the very beginning, she was not conscious, and her only role was to fulfill the doctor's directives. Today, she is capable of deciding the frequency of hospital visits or how to manage her doses, unless there is an emergency, such as unfamiliar fluctuations. This means that she is more than the one performing doctor's directives, as she is taking responsibility and making decisions about her health. For example, if her blood levels remain in a particular range, instead of visiting the doctor, she manages her doses by her own and sees whether her treatment plan works or not.

In parallel with this behavioral change, in 2015, her doctor mentioned a home-use blood testing system that eliminates unnecessary hospital visits by giving patients freedom of performing care whenever and wherever they want. As a senior product design student, the product aroused my interest at that moment. The product had not been prevalent in the Turkish market yet, but her doctor was quite convinced about the fact that home-testing is going to be the future of care. Moreover, as he thought she was capable of self-management, he encouraged her to try a demo. However, my mother’s attitude towards the product was unexpected. Although she has found finger pricking more comfortable than the venipuncture, she was not able to create a trust bond with the product, and anytime she performed the test, she was feeling concerned about the result. As a designer, witnessing how the product failed to get along with its user sparked my curiosity about the adoption process of the products changing the medium of usual practice.

In the grand scheme of things, through the changes in both medical technologies and healthcare policies (Brownson & Jones, 2009), such as the dissemination of surveillance medicine, products become compact and mobile. The practice of being ill altered, and healthcare was carried outside the hospital walls (Clarke, Shim, Mamo, Fosket, & Fishman, 2003; Casper & Morrison, 2010). At this point, the Internet and social media become first-hand information sources rather than visiting a physician. People with familiar problems have started to gather with the agency of illnesses and medical products as a new way of collectivization explained by the term “biosociality” (Rabinow, 1996).

With the increasing number of users, self-monitoring devices have become the focal point of academic research. However, in the field of design, the studies are mainly focused on user experience and usability (Kuru, 2016; Günay, 2017). But, how do patients come across with these mobile devices and make a decision of purchase and use? What are the problems they face during the embodiment process? How do individuals come together and form "communities," and what is the role of the product in these "biosocial" gatherings? I believe that all these questions shaping the topic of my research are worthwhile to be evaluated from a designer's perspective.

### 1.2 Aim and Scope of the Study

With the technological changes in healthcare, remote health technologies, especially the ones with wearable parts, have gained prominence in current academic research. Most of the critical approaches discuss the topic either from the perspective of user-centered design, usability and performance (Gross et al., 2000; Mastrototaro, Cooper, Soundararajan, Sanders, & Shah, 2006; Free et al., 2013; Polonsky & Hessler, 2013; Bailey, Bode, Christiansen, Klaff, & Alva, 2015; Pickup, Ford Holloway, & Samsi, 2015; Rodbard, 2016; Pettus & Edelman, 2017; Scott, Bilous, & Kautzky-Willer, 2018), or they focus on the effects of mobile digital technologies in diabetes management and technology-based behavior change (Quinn et al., 2008; Beck, 2009; Thoolen, de Ridder, Bensing, Gorter, & Rutten, 2009; Ritholz et al., 2010; Wagner, Tennen, & Wolper, 2012; Storni, 2014; Hood, Hilliard, Piatt, & levers-Landis, 2018). However, very few of these studies draw attention to the social context of use practices and bodily experiences regarding the relationship between human body and technology (Hogle, 2005; Borus, Blood, Volkening, Laffel, & Shrier, 2013; Storni, 2013; Oudshoorn, 2014, 2018). On the other hand, as Internet becomes the most common source to find health-related information, the rise of online health communities have a considerable importance in recent studies and mainly argued in the management, information technology, sociology, and medicine literature (Akrich, Méadel & Rémy, 2009; Akrich, 2010; van der Eijk et al., 2013; Johnston, Worrell, Di Gangi, & Wasko, 2013; Yan, Wang, Chen, & Zhang, 2016; Visser, Bleijenbergh, Benschop, Van Riel, & Bloem, 2016). Notably, the insights of literature on the influence of online health communities on use experiences are usable for the studies focused on topics such as usability or behavioral change. In this regard, this thesis expands on this literature to contribute such insights to the design field (Oudshoorn & Somers, 2006; Guell, 2011). The study aims to understand the changes in care practices and the role of the patients with the use of remote health technologies focusing on user experiences at large, and more specifically, on individual bodies and health communities. To achieve this, diabetes and product-use experiences of people were gathered, and their biosocial practices were investigated in detail.

The subject of this study is an online diabetes community established as a private Facebook group of one of the diabetes associations. The community, as well as the association, was founded by the parents of a child with type 1 diabetes to increase the awareness of the people, especially the ones with type 1 diabetes and their relatives about the recent technologies and how they make a difference in the diabetes management. As Akrich (2010) states, these kinds of discussion groups in which members look for self-help can be considered as an example of practice communities as their activities result in experiential knowledge, which leads individuals to lay expertise even in medical knowledge. That is why shaping know-how through product usage practices and sharing this knowledge with others is significant. This significance is not only about discovering the online community dynamics, but also understanding how the collectives are building information sources that might substitute the medical expertise occasionally in today's "healthcare."

## 1.3 Research Questions

In order to accomplish the aim of the thesis, the study focuses on the research questions listed below.

### Main Research Question

- How do the new diabetes care products with mobile digital functionalities influence, and are influenced by, their users' bodily and biosocial practices?

## Sub Research Questions

- What is the impact of the consumerization of healthcare and biopolitics on medical practices and the role of the patient?
- What are the outcomes of the technological changes in diabetes practice reflecting on patients' everyday lives?
- How are diabetes care products embodied? What are the results of embodiment process in terms of human body?
- What is the impact of online communities on diabetes practice and the construction of "biosocial" patients?

## 1.4 Structure of the Thesis

This thesis is composed of the following five sections;

Chapter 1, *Introduction*, gives a brief introduction to the topics which are covered in this thesis and presents the research questions, aim, scope, and significance of the study. Finally, it demonstrates the structure of the thesis.

Chapter 2, *Literature Review*, presents an overview of the relevant literature, which also provides a basis for data collection, analysis, and conclusions, as well. The chapter starts with a summary of the changes that occurred in the field of medicine and continues with the emergence of politics around socio-biological identities. Then, it presents the theoretical background of this thesis. Finally, it gives a detailed summary of type 1 diabetes.

Chapter 3, *Methodology*, demonstrates the research design of the study. Initially, the research approach is described. Following that, the research design, which includes preliminary research, interview design, sampling methods, conducting interviews, and data analysis, are presented. Finally, the chapter argues about fieldwork related issues.

Chapter 4, *Findings*, presents an analysis of the gathered data through the interviews. Firstly, the chapter provides diabetes stories shared by the participants. Afterward, how diabetes changes people's everyday life is discussed. Then, the methods and the process of diabetes management are explained by focusing on technology use practices. Finally, this chapter examines and discusses how online diabetes communities are cultivated around diabetes practice.

Chapter 5, *Conclusion*, summarizes the overall study, presents the conclusions by discussing the outcomes of the analysis, and provides suggestions for further studies.

# CHAPTER 2

# LITERATURE REVIEW

In this chapter, I present four interrelated topics that provide a basis for the fieldwork. As mentioned in the previous chapter, the subject of my study is an online diabetic community and its members who use wearable diabetes technologies and perform social interactions through the product, and their health state as well. Therefore, changes in medicine, biosociality, healthcare design, and diabetes are the main topics that are discussed in this chapter. Following these topics, the terms which created the theoretical background of this study and guided my analysis are discussed in detail.

The first section describes the changes in medicine over time. Initially, from policies to the role of patient, I highlight the discourse of surveillance medicine and its outcomes. Later on, I discuss how medicine is commodified, and patients also become health consumers. Finally, I explain the effects of technological advancements in the development of new healthcare, which is digital, remote, and personalized.

The second section presents discussions about how humans and their bodies become political with illnesses and medical developments. Moreover, I state the critiques about the interactions between these politicized identities. At last, I explain how these social identities gather and create examples of a community of practice.

In the third section, first, I present the actor-network theory to explain the multidimensional relations between humans and non-humans. Later, I explain the practice of self-tracking and the identity built upon monitoring and measuring practices, called “quantified self.” Last, I discuss about digital bodies as the product of emerging technologies while drawing on the “cyborg” concept.

In the final section, I briefly explain what diabetes is within the perspective of everyday life, from the nature of the illness to the retrospective of management methods. Moreover, I give examples from previous academic studies to present their generic outcomes and clarify the distinction and the importance of this thesis.

## 2.1 Change in Medicine

Through the improvements that led to modern medicine, the social meaning, spaces, and practices of the illness have changed over time. This section represents changes that have occurred on the construction of self-responsible health behavior from its historical background to current healthcare methods and policies.

### 2.1.1 Surveillance Medicine

Ackerknecht (1967) drew attention to the development of different medical approaches during the 18th century that resulted in the rise of modern medicine. First, he started with the early stage of Library Medicine in which the physician's interpretations were valued more than the particular knowledge about the illness. Afterward, in Bedside Medicine, a patient has prevailed against physicians on the diagnosis process, and their complaints, i.e., symptoms, are taken into consideration in the management of illness. Nevertheless, with the emergence of hospitals in the 18th century, Hospital Medicine altered the conventional approach towards medicine, as he stated that "hospital medicine was an important revolution in medical thinking" (Armstrong, 1995, p. 393).

In Bedside Medicine, the disease was defined by the experiences of patients. In this perspective, a symptom such as a headache was the illness itself. This descriptive model in medicine was replaced with causation that involves "symptom, sign and pathology" by Hospital Medicine (Armstrong, 1995, p. 394). However, the shift from

Hospital to Laboratory Medicine made the human and its body even more “objectified” (Jewson, 1976) with the integration of screening technologies, blood analysis, and more.

With the light of these changes, a new medicine that focuses on the surveillance of healthy populations emerged. Until the 50s, the scope of surveillance medicine was limited to severe, and most contagious diseases such as plague or syphilis (Langmuir, 1976). The aim was to isolate the infected people immediately after detecting the symptoms. However, at the beginning of the 50s, the focus of surveillance has shifted from people to taking control of the diseases (Langmuir, 1963, 1971). Therefore, systematic data collection becomes essential to understand the current impact and the evaluation of diseases.

In today’s world, surveillance is associated with the concept of self-surveillance in which people are given the responsibility of their health for prevention. At this point, being able to track the human body becomes crucial. In this regard, today’s healthcare encourages people to use patient monitoring technologies as it is driven by activity data. Moreover, in terms of individuals, the evidence is the key to empowerment (Bauer & Olsén, 2009). However, nowadays, gathering relevant data does not only help to improve current treatments. Hospitals have been using varied data sets such as individuals’ records, body metrics, and current treatment plans (i.e., medications) to forecast and be prepared for emergencies or future risks. In the recent interventions of surveillance, each person in society becomes part of the “big data,” as their activities are tracked and recorded by using surveillance technologies, such as mobile devices (Lupton & Michael, 2017).

Dataveillance (Degli-Esposti, 2014; van Dijck, 2014) is a term that describes the use of personal data in any surveillance activities. The data is not only used in personal level such as self-surveillance but also used in organizational level such as insurance companies to create business value out of it, such as personalized subscription models (Lupton & Michael, 2017). In addition, Earle et al. (2009) stated that in terms of medicine, online surveillance not only affects individuals' experiences with illnesses, but it also becomes the key driver for the production of medical knowledge.

Last, Rich and Miah (2009) discuss that in today's digitalized world, all sources such as the internet or mobile devices are used to seek medical advice, and this resembles the current model of health consumption. This change in healthcare is discussed in the discourse of the consumerization of healthcare in the next section.

### 2.1.2 Consumerization of Healthcare

As discussed in the previous section, with the rise of surveillance medicine, the responsibility of self-care is given to patients, which also raised the concept of "active citizen" (Burchell, Gordon, & Miller, 1991; Barry, Osborne, & Rose, 1996; Rose,1999). In the light of these events, a change is noticed in healthcare terminology: The traditional "patients" became today's "health consumers" as the latter implies the new role of self-responsible subject, or active citizen, which is the involvement in decision making (Brock, 1995). Moreover, Powell and Greener (2009) claim that giving health information in the hand of the patient makes their role transform into healthcare consumers.

Making patients aware of their health is not a novel idea. Two decades ago, for example, Baldry et al. (1986) focused on the benefits of being aware of own health by giving their medical reports to the people in the waiting room. The similar studies (Coleman, 1984; Gilhooly & McGhee, 1991) show that medical awareness has practical benefits for the patients, such as reaching the medical summary without calling or visiting the hospital for help. The behavior of informing people also directed at a governmental level. For example, with the directive in October 1998, the EU obligates each member country to achieve legislation that enables anyone to access their medical records (Eysenbach, 2000).

What consumerization of healthcare covers from a broader perspective is not only informing users about care options but also focusing on individuals' well-being by encouraging them to make reasonable choices to maintain their healthy life. In this context, as Arthur Frank (2002) does, "medical consumerism" is generally criticized in body discourse. He states that "body consumerism is manipulated by messages that pair images of an ideal body with a product that promises to close the gap between the consumer's body and that ideal" (p. 22). The description of an ideal body varies depending on the context. For example, in terms of the cosmetic sector, it is defined by society's aesthetic approach, and beauty products are promoted. However, in medicine, the ideal is defined as a healthy body, and the products such as tracking monitors, apps, and wearables like sensors are the product examples either recommended by authorities or discovered and adopted by users contributing to self-surveillance.

"Medical Informatics" refers to "the field that concerns itself with the cognitive, information processing, and communication tasks of medical practice, education, and research" (Greenes & Shortliffe, 1990. p. 114). The informationalisation of medicine, as well as human bodies, is part of a broader movement in economic, social and political matters (Clarke et al., 2010; Lupton, 2012a) In the past, for a long time, medical informatics just focused on the development of applications targeting health professionals — however, today, this is changing. Coulter (1999) claims that two main factors accelerate this change. The first is the developments in evidence-based medicine, which become crucial with the spread of surveillance medicine. The second is the increasing need for closing the gap between medical authorities and laypeople.

At this point, it is significant to mention that the aim of consumer health informatics is not to replace the medical authority. Instead, the main goal is to empower patients by giving them access to health information, including their health, including diagnoses, test results, and prescriptions (Eysenbach, 2000). In this way, it is believed that healthcare customers can decide whether they need to visit a doctor, and if not, they can handle simple problems with the help of support systems, which brings us back to the core value of self-surveillance.

In brief, with the consumerization perspective, a new way of healthcare has been promoted in which patients are titled and treated as consumers, who are willing to contribute decision making and capable of monitoring and controlling their care by various means of technology. Moreover, the information about individuals' health and experiences is commodified and become accessible via digital mediums. The shift towards the consumerization in healthcare resulted in self-responsible health consumers at a personal level while utilizing the available healthcare resources sufficiently at the organizational level (Smith, 1997). The contribution of emerging technologies, such as digitalization, in the improvement of self-care, is discussed in the following section.

### 2.1.3 Rise of Digital Health

The phenomenon "digital health," which reshaped the provided healthcare and practicing medicine, is described as: "the cultural transformation of how disruptive technologies that provide digital and objective data accessible to both caregivers and patients leads to an equal level doctor-patient relationship with shared decision-making and the democratization of care" (Meskó, Drobni, Bényei, Gergely, & Győrffy, 2017, p. 1). In other words, digital health is the collaboration of both hardware and software technologies that are used to deliver care services (Jolly, 2018).

With the integration of digital technologies, the number of medical products and services developed for commercial use has been increasing day by day. There are over 100,000 health-related apps in the market. Moreover, wearable products are used for gathering biometric data through self-tracking practices. The body functions such as blood sugar, body temperature, heart rate, physical activity, and blood levels can be monitored through sensors either worn or inserted into the body (Lupton, 2013a).

Digital health technologies also have significant contributions to the medicalization of society (Lupton, 2016a). For example, increasing the focus on the good health in parallel with the enhancements in modern science and emerging technologies increased the life expectancy. That result is not necessarily driven by adopting healthy habits, but instead with the availability of early detection and effective treatment methods. In this regard, the most prominent dichotomy of digital health is that people are living unhealthy, yet "technologically-prolonged lives" (Jolly, 2018).

In brief, over the past decade, digitalization in healthcare became inevitable, which resulted in a meaningful transformation of the status quo (Meskó et al., 2017). The digital transformation has started with the availability of personal computers, which resulted in the emergence of e-Health (Eysenbach, 2001). Then, computers got connected to networks and telemedical services developed (Perednia & Allen, 1995). Finally, with the rise of mobile phone technologies, m-Health applications took their place (Steinhubl, Muse, & Topol, 2013). In the following subsections, I explain two of the terms that digital health corporates.

#### 2.1.3.1 E-Health

In his article titled “What is e-Health?” Eysenbach (2001) defined the concept of e-Health as follows:

> e-Health is an emerging field in the intersection of medical informatics, public health, and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve health care locally, regionally, and worldwide by using information and communication technology. (p. 1)

Similar to his approach, a study conducted in 2005 (Oh, Rizo, Enkin, & Jadad, 2005) to compile different definitions of e-Health showed that the term is used for different contexts regarding the technological themes in today’s healthcare, which is based on commerce, activities, stakeholders, outcomes, locations, and perspectives.

At this point, it is not surprising that the “e” at the beginning does not only refer “electronic,” yet it indicates other means of “e”s generating the scope of e-Health together (Eysenbach, 2001). According to his examples, “efficiency” stands for the decreasing costs of healthcare, since telemedicine facilities are “extending the scope of healthcare” and eliminating additional expenses such as transportation, as well as saving time spent on commuting. Nowadays, the use of e-Health is also supported by the governments. For example, since 2014, the regulatory mandate in the USA has been forcing public and private healthcare providers to store personal healthcare data in digital format, i.e., electronic health records, to make them accessible for patients (Evans, 2016). As for Turkey, at the beginning of 2015, the Ministry of Health introduced a web-based personal health record system named “e-Nabız,” and soon after, its mobile version was released (Özkan, 2018).

Under the umbrella of "e"s, Eysenbach (2001) also discusses the opposite edges, such as the term "equity." Though e-Health aims to make healthcare accessible for anyone, the people who do not have access to any means of technology such as computers, or the ones not skilled in technology will not be able to benefit from any solutions or services.

Beyond any doubt, the integration of e-Health transformed the doctor-patient relationship (Ball & Lillis, 2001). As discussed in the previous section, the birth of e-Health consumers who can access any information via online sources resulted in the will for taking control as they feel "empowered and encouraged" (Eysenbach, 2001).

Today, there are many studies conducted to investigate the outcomes of e-Health applications in consumers' health state. For example, a study carried out to understand the effects of e-Health interventions in the management of type 2 diabetes revealed that the outcomes could be clustered in three different categories: "clinical," "behavioral," and "psychosocial" (Bond, Burr, Wolf, & Feldt, 2010; Vorderstrasse, Lewinski, Melkus, & Johnson, 2016). Clinical outcomes can be exemplified with a decrease in HbA1c levels or improved glycemic control (Stone et al., 2010; Salzsieder & Augstein, 2011; Nagrebetsky et al., 2013). Behavioral outcomes are related to diabetes management, such as healthy eating, medication adherence, or monitoring habits. Last, the psychosocial improvement was mostly demonstrated in such contexts as increased "social support" or "self-efficacy" (Trief et al., 2012; Ruggiero et al., 2014; Nundy et al., 2014).

The next section explains how e-Health advancements and compact mobile technologies, such as smartphones, led to the formation of "m-Health."

#### 2.1.3.2 M-Health

M-Health, the abbreviation of “mobile health,” is a subset of information technologies like e-Health in a broader perspective (Klonoff, 2013). WHO (2011) defines any health intervention that takes advantage of mobile technologies such as mobile phones, self-monitoring, self-tracking, and other mobile telecommunications within the scope of m-Health. Moreover, smartphone applications that work with companion sensors or special attachments are typical examples of mobile health systems (Weinstein et al., 2014). In short, m-Health refers to the use of mobile technologies to improve parent’s health and related services.

One distinct aspect of m-Health is that of using mobile digital technologies; it enables collecting data on people’s bodily activities anytime, anywhere (Kirwan, Vandelanotte, Duncan, & Mummery, 2010; Cummiskey, 2011; Swan, 2012). The collected activities are used to produce biometric data, which enables to serve personalized care to health consumers. As Lupton (2012b) states, some researchers focused on m-Health use practices to create a link to preventive care as users tend to use their connected devices with “a greater personal consumer responsibility for healthy lifestyles” (Mays et al., 2010, p. 311).

In terms of healthcare services, m-Health applications offer accessible means of self-management in a cost-effective way. Moreover, in terms of time and effort, m-Health applications ease reaching information by taking advantage of networking (Handel, 2011).

There are many studies mostly focused on measuring the effectiveness of m-Health interventions (Kitsiou, Paré, Jaana, & Gerber, 2017). The subjects of these studies are generally people with chronic illnesses, such as diabetes. The number of apps for diabetes management is increasing exponentially (Chomutare, Fernandez-Luque, Årsand, & Hartvigsen, 2011; Arnhold, Quade, & Kirch, 2014). Most of those studies mentioned that periodical reminders and smart recommendations result in improvement in glycemic (HbA1c) control as a primary outcome. Besides, providing immediate care advice encourages users to take action rather than waiting for authority approval, such as a doctor. Lupton (2012a) states that the production of self-responsible subjects through mobile technologies is a means of surveillance (see Section 2.1.1).

With the spread of m-Health technologies, terms such as “self-tracking” and “the quantified self” are employed regarding the use practices of these technologies (Smarr, 2012; Swan 2012). Besides, monitoring physical activities, tracking mood and behavior (Budinger, 2003; Istepanian, 2004) make m-Health an exciting topic for participatory healthcare studies (Boulos, Wheeler, Tavares, & Jones, 2011).

### 2.1.4 Summary

The mobile digital technologies not only provide access to medical states, such as reports but also “the new ways of monitoring, measuring and visualizing the human body and sharing personal information and experiences with others” (p. 86). Moreover, the digitized data derived from human-technology embodiment is also used for commercial and governmental purposes (Lupton, 2016a).

The political economy critique of emerging digital health technologies focusses on social inequalities of digital health technologies by discussing Foucauldian theory (surveillance, biopolitics, focus on the self and governmentality) and sociometrical perspective adopted from science and technology studies, a.k.a. STS. Therefore, these critical studies acknowledge the association of the human and the non-human and focus on the dynamic nature of human interactions with digital technologies as a part of the everyday life (Lupton, 2015, pp. 23-24). To understand the role of non-humans in nature of human experiences, “Actor-Network Theory”, which was introduced by Bruno Latour and gained a dominant stance in STS is explained in theoretical background (see Section 2.3.1). The following section discusses individuals' sociality through their bio-entities in light of surveillance.

## 2.2 Biosociality and Online Health Communities

In this section, the concept of biosociality is explained. Later, the emergence of online health communities, their collective activities, and the outcomes of these interactions are presented.

### 2.2.1 Biosociality

The concept of "biosociality" is introduced by Paul Rabinow (1996) to identify the new individual identities or groups and the social practices arising from genetic conditions of people and the visualization of risks and susceptibilities through technological enhancements. He states that biosociality occurs when people constitute new identities around their biological conditions and actualize them through genetic narratives and practices. In this way, they can reflect reality through their disease, gather with the people sharing the same disorder and sometimes even establish intimacy with those people. In addition, he has a great interest in the emergence of new individual and collective identities within the context of knowledge about genetic diseases and risks, and he also argues that "in the future people will describe themselves and others in bioscience and genetic terminology, as biomedical vocabulary seeps into everyday language" (Lemke, 2011, p. 97). In other words, similar to how people with diabetes today define themselves in terms of blood sugar levels, in the future, people might describe themselves through their genetic predispositions for diseases.

Similar to his forecast, in today's societies, biosociality reforms the social interactions and the production of "self" according to the biological or genetic conditions, especially similarities. New biosocial individuals have started to change the meanings and dynamics of collectivization, and the practice of being ill and the management of the illness have started to change according to the transformation in self with the contribution of societal institutions. In the construction of biosocial individuals, surveillance medicine and consumerization of healthcare have great importance. The former empowers patients to take responsibility and be open to learn and share to access knowledge. The latter leads people to consume medical technologies, which creates the medium of where biosocial individuals across each other.

At this point, Rabinow (1996) emphasizes that collectives such as self-help groups are the active recipients of medical care as their experiences with diseases results in various social activities. For example, people with illnesses and their families create networks such as online communities in which they share their experiences and knowledge, and sometimes they even collaborate with medical experts. In this way, as Lemke (2011) summarizes, “patient organizations, self-help groups, and family associations represent new collective subjects that remove the borders between laypeople and experts, between active researchers and the passive beneficiaries of technological progress” (p. 98). Therefore, the entanglements of these biosocial identities become a source of health-related information.

### 2.2.2 Online Health Communities

Coping with a health problem might be a challenging process, physically and emotionally. When people are not knowledgeable enough about self-management, oftentimes, they seek help from friends or family to overcome the burden of illness. However, social media and digital technologies have been reshaping this process. As the Internet has become an intensively used medium for health information (Rice & Katz, 2001), people can access medical information and healthcare professionals online. Moreover, they meet and socialize with other people and take an active role in their health management by using the information derived from online sources and other people's experiences (Eysenbach & Diepgen, 1999; Ziebland, 2004; Nambisan, 2011; Yang, Peng, & Tan, 2015).

Online communities are described as the formation of large groups in which members gather around a common interest independent of their location and acquaintance (Brown & Duguid, 2001; Wasko & Faraj, 2005). In particular, online health communities (hereafter: OHCs) either bring patients, health professionals or both profiles together and provide information about specific conditions and treatments, and give members the opportunity of sharing personal experiences by creating virtual environments (Thackeray, Neiger, Hanson, & McKenzie, 2008; van der Eijk et al., 2013).

OHCs can be divided into two groups regarding the accessibility: Open communities and closed communities (van der Eijk et al., 2013). In the former, community content is accessible for anyone, and all members have a right for contribution. On the other hand, within the latter, the content is only visible to its members whose access to the community has granted by the authority. Moreover, participation is tracked by community managers, and member contents are posted after their approval. Within closed communities, it is possible to talk about the sense of belonging, which might result in more personal and intimate sharing activities as "privatizing enhances a feeling of belonging to a community, by clearly delineating an inside and an outside" (Akrich, Méadel, & Rémy, 2008, p. 11).

Within OHCs, it is possible to observe different communication models. Primarily, most of the communities allow their members to have one-to-one communication. The interaction between individuals is made via private messaging. In addition, some OHCs provide features such as instant-messaging to provide more integrating experience. On the other hand, one-to-many communication is carried out with mechanisms such as allowing users to share public posts and comment on others' activities (Ho, O'Connor, & Mulvaney, 2014).

OHCs can be acknowledged as "communities of practice" due to their collective learning activities on a regular basis. These collective learning activities results in knowledge production as people to share and compare their experiences with others and constitute "experiential knowledge," including medical knowledge and lay expertise. In addition, gathering concerned people with similar health conditions and the form of activism they develop within the group might be considered as a new way of politicization (Akrich, 2010).

What individuals expect from a community is to reach diverse information helping them to overview possible opportunities and making the best choice for action. The articulation in the share of personal experiences results in the form of generalization that helps the production of experiential knowledge. Borkman (1976) states that "experiential knowledge is the truth learned from personal experience with a phenomenon rather than truth acquired by discursive reasoning, observation, or reflection on information provided by others" (p. 446). Experiential knowledge is not only questioning an individual's intimate knowledge, but it also questions its relationship with the medical world. Within social communities, individuals are reproduced by the relations among members. Collective activities imply the construction of new identities (i.e., patient profiles) as well as transforming the behaviors and the practices (Lave & Wenger, 1991; Barbot, 2006).

Due to rapid improvements in medical knowledge, especially related to chronic diseases, today, many healthcare professionals lack expertise and experience to meet the specific needs of people with chronic conditions (Institute of Medicine Board on Healthcare, 2008; Anderson, 2010). In the case of adapting medical technologies, doctors might be hesitant as technologies alter their traditional practice patterns, and technology acceptance requires additional time for physicians (Yarbrough & Smith, 2007). At this point, the Internet and collectives such as online communities become primary information sources for individuals who lack information and adequate tools for self-management (Powell, Darvell, & Gray, 2003; Nambisan, 2011).

As mentioned above, one of the most beneficial outcomes of OHCs is considered as "patient empowerment." These collectives support patients by providing a variety of resources such as health information sites. Moreover, they provide personalized information such as experiences and success stories that also serve to build confidence (Butler, 2001; Frost & Massagli, 2008). OHCs also provide intangible benefits through emotional support that makes people realize that other individuals are also living with the same conditions. Active participation in the community also increases members' mastery in medical jargon, which is also significant for an effective decision-making process (Moenaert & Souder, 1996). This mastery also brings the satisfaction of being capable of helping others (Samoocha, Bruinvels, Elbers, Anema, & van der Beek, 2010).

However, regarding patient empowerment, several studies (such as Hill, Weinert, & Cudney, 2006; Homko et al., 2007) presented that social support from OHCs has an important yet limited impact. The benefits of social networking are dependent on individuals' participation in community activities, and these social activities might not result in improvements in self-management all the time (Hampton, Goulet, Rainie, & Purcell, 2011; Reich, Subrahmanyam, & Espinoza, 2012). Indeed, some studies show that social support can also have negative effects (Kaplan, Chadwick, & Schimmel, 1985; Wortman & Lehman, 1985).

Although one of the promises of OHCs is the feel of support, there are several studies that discuss the ambiguity regarding individual-level outcomes of these communities (Lamberg, 2003; Nambisan, 2011). For example, some members indicate their concerns about receiving contradictory information or a lack of empirical evidence (Edmunds & Morris, 2000; Sarasohn-Kahn, 2008; Yang & Tan, 2014).

### 2.2.3 Summary

With the integration of digital technologies into healthcare, patients become more active in their care management. Their participation in the care made health professionals consider patients as engaged partners. The term “biosociality” refers to the novel alliances between patients, healthcare professionals, politicians, and technology representatives that participate in the socialites shaped around biological conditions.

Due to rapid improvements in medical knowledge, especially related with chronic diseases, in case of adapting medical technologies, doctors might be hesitant as technologies alter their traditional practice patterns and technology acceptance requires additional time for physicians (Yarbrough & Smith, 2007). At this point, the Internet and collectives such as online communities become primary information sources for individuals who lack information and adequate tools for self-management (Powell, Darvell, & Gray, 2003; Nambisan, 2011). Moreover, Rabinow (1996) states that self-help groups can be considered as the example of biosocial communities, because their activities help to produce, legitimize and appropriate biomedical knowledge. Studies conducted with chronic patients showed that using online communication tools makes them more knowledgeable, feel empowered and willing to improve clinical outcomes (Gibbons, et al. 2009; Samoocha et al., 2010)

As mentioned in the background of the study, unlike the general focus, the aim of this thesis is to look at the social aspects of technology use in diabetes management. To achieve this aim, several theories from social sciences are adapted to create a broader framework. The next section aims to give a brief understanding of these theories.

## 2.3 Theoretical Background

This section presents the theoretical approaches that define the conceptual framework of this study. First of all, the actor-network theory is introduced to understand the nature of care networks and the agency of products in use practices. Second, the concept of quantified self is explained as it provides the basis for understanding self-tracking practices. Third and last, the concepts discussing the digital transformation of the body are represented to understand the results of human-technology interaction.

### 2.3.1 Actor-Network Theory

Actor-Network Theory, hereafter abbreviated as ANT, was first introduced in the second half of the 1980s, initially by STS scholars such as Bruno Latour, John Law, Michel Callon, and Annemarie Mol (Fallan, 2010). Although it is named "theory," different from seeking the reasons behind why something happens, ANT adopts an empirical perspective and discusses how relational ties assemble or do not (Law, 2008).

The very basic idea of ANT is that the world is made of networks, and therefore, any practice or process can be explained with network terms (Latour, 1987). In addition, each actor is seen as a unique network made of other actors. The nature of networks is everchanging, that is why "an actor can be taken apart, and its components can be disassembled and reassembled" (Bueger & Stockbruegger, 2017, p. 49). In his later works, Latour also (1999) proposes other terms, such as "assemblage," to explain the confrontations and associations among the actors.

ANT locates "material agency" in the core dynamics of a network and focuses on the heterogeneity since both humans and non-humans are involved in a network. "Actant" is a term that defines anything that has an agency to act no matter whether it is a living creature like human or animal, technology, or non-human. In Latour's words, “anything that does modify a state of affairs by making a difference is an actor –or, if it has no figuration yet, an actant” (Latour, 2005, p. 71). In this regard, although both Latour and Law criticize that non-humans are “delegated” specific tasks by humans, there should not be any discrimination between humans and non-humans, according to ANT (Fallan, 2010).

ANT has several key concepts to explain the roles of actants and their entanglements within the network. One concept is delegation, which Latour (1992) describes as a process in which non-humans become “actants” as they are assigned specific responsibilities so that their existence within the network was evaluated whether they do perform these tasks or not. Moreover, delegation refers to the reciprocal relationship between technical and social aspects. For example, in the means of production, the work of humans is delegated to the technologies. In turn, technologies delegate behavior through use practices back onto the social (Cressman, 2009).

Another concept “mediator” refers to any actor that “transform, translate, distort, and modify the meaning or the elements they are supposed to carry” (Latour, 2005, p. 339). Mediators are unpredictable entities and may result in complex engagements. Moreover, this concept also helps to investigate the role of technologies in shaping practices.

“Black box” is a concept used “whenever a piece of machinery or a set of commands is too complex” (Latour, 1987, pp. 2-3). It represents the alliance of several actants, such as a system whose inner dynamics are hidden and not related to its users and the way of use. To explain the concept Latour (1988) analyzes a door-closing technology as an example. A door has the functions of opening and closing to let people in and out as desired. These functions are the results of a complex and attentively formed sociotechnical actor-network that includes the design of the door, the users, and the way it is used, as well. The black box is an artifact that is self-evident. That means, in case of the door, users do not have to know how the door and its components, such as hinges, function, or they do not have to think of how to use it. In this example, the inner mechanics and dynamics of how the door is being used have become invisible (i.e., black-boxed). What matters is the effect that the door produces: enabling people to pass through. In short, like Latour's statement above, black boxing transforms a complex thing into a simple that is used in practice. However, when a black box fails to function, it is reopened, and all its actants, such as its technical elements, become visible. No matter in which discourse or the scope, all black boxes aim to remain as one durable unit.

Within ANT, "translation" is the concept that focuses on the formation of hybrid networks and aims to explain the aspects of relations and associations. Callon (1981) states that "translation involves creating convergences and homologies by relating things that were previously different" (p. 211). In other words, it tries to understand how different actants encounter for the first time and cooperate within the network. Cressman (2009) argues that in sociotechnical networks, the translation might represent the development of technology over time. To explain, he gives an example of how users transform the technology in a way that functions to meet their goals or how the accuracy of engineering knowledge is constructed by making people and institutions believe the same thing.

Within the scope of this study, ANT perspective is associated with two different contexts: product design and medical criticism. Design is a profession in which technology cannot be thought separate from social relations. Katz (1997) defines industrial designer as one "who domesticates new technology and makes it available for human use" (p. 453). Regarding this definition, he claims that these two have a potential for collaboration. For example, a design study might deepen by focusing more on technological history and vice versa. MacKenzie and Wajcman (1999) stated that "it is mistaken to think of technology and society as separate spheres influencing each other: technology and society are mutually constitutive” (p. 41). At this point, ANT aims to create a framework in which these articulations are better suited.

In relation to today’s medical criticism, Prout (1996) proposes that ANT might help to understand “the intricate and mutually constitutive character of the human and the technological in the processes and relationships of sickness and healing” (p. 214). The phrase “sickness and healing” refers to medical anthropologists’ approach in which sickness is considered as “cultural performance” and medical devices are one of the actors.

### 2.3.2 Quantified Self

Quantified self, in short QS, is the term invented by Gary Wolf and Kelvin Kelly in 2007. The quantified self-movement aims to investigate the role of self-tracking practices in the embodiment of self-knowledge. As a beginning, it is significant to explain what self-tracking is. Today, the term is used to describe individuals’ monitoring, measuring, recording, and preferably sharing practices of activities and bodily functions through digital technologies. Moreover, the visualization of the data, such as graphs provides objectivity to self-tracking practices and quantification, in other words, communication through numbers, has become one of the fundamental aspects of modern societies (Moretti, 2016).

Self-tracking encourages individuals to think of their bodies as numbers, which also enable people to compare their biometrics against others (Lupton, 2013). In a social context, these numbers and comparisons create the “ideal” that influences whoever is using self-tracking technologies (Neresini, 2015).

Beyond the rational aspects of numbers, Lupton (2016a) draws attention to the emotional dimension of self-tracking as individuals might establish a bond with the generated data. In this regard, Sassatelli (2016) defines the quantified self also as "the first, and foremost a feeling embodied self" (p. 807).

In today's healthcare, self-tracking is considered as a common practice to monitor and improve one's health (Neff & Nafus, 2016). E-Health interventions made the value of using personal data for prevention visible, and the line between self-care and medical care become blurred. Digital instruments have defined a new patient who is given the responsibility of own care and collecting the personal data used for surveillance (Bruni & Rizzi, 2013).

The data derived from self-tracking practices might be categorized into two categories: Small data and big data. The former refers to the details of individuals' engagements with digital technologies. Once people transfer their individual data to a computing cloud, or in daily terms store their data online, they lose their authority on it as the small data transforms into the latter, which is reused by several actors and agencies (Lupton, 2016c).

In its very nature, self-tracking is considered as an activity highly focusing on personal experiences as de Groot (2014) exemplifies: "Me and my data, that is the point of the Quantified Self." (para. 2). However, beyond individualization, some people might also use self-tracking methods to monitor and record the bodies of significant others (Lupton, 2016b).

Last, when we look at the self-tracking literature, the outcomes of the studies represent that digital technologies mostly help people to be more in charge of their health. However, for some users, self-tracking puts pressure on themselves as excessive focus on health makes people feel anxious (Lupton, 2013b). Moreover, giving the responsibility of care from doctors to the hands of the patient might create pressure leading to fear of failure (Moretti, 2016).

### 2.3.3 Digitized Bodies

In today's digital world, the interaction between human bodies and medical technologies is performed in various ways. Products worn on the body, such as insulin pumps, are the familiar representatives of this relation. In addition, mobile digital technologies enable products inserted into the body, such as sensors placed under the skin. With these interpretations, the human body is digitized as never before. This digital transformation is either performed by an individual's behalf or "by other actors and agencies seeking to portray and monitor human bodies" (Lupton, 2017, p. 200).

In regard to human-technology interaction, it is inevitable to discuss multiple bodies and selves as their entities vary depending on the context. Technology-human interaction is co-constitutive: Humans and their bodies shape the meaning and use of technologies. For example, wearable products are becoming an extension of human body; in other words, "a body prosthetic." On the other hand, technologies help people to understand their bodies and discipline them to perform in accordance with people's needs (Lupton, 2017).

These disciplined bodies are the result of contemporary digital technologies. As mentioned above, the human body is digitized in accordance with their technology use practices. While discussing these digital bodies, the term "cyborg" was addressed as an initiatory concept. The term "cyborg" was introduced by Clynes and Kline in 1960 in relation to "the concept of the cybernetic organism in the context of adapting to space travel" and used to describe 'self-regulating man-machine systems" (Haraway 1995). However, in Haraway's writings, the term stands to describe "a cybernetic organism, a hybrid of machine and organism, a creature of social reality as well as a creature of fiction" (1991, p. 149).

Many researchers (Lupton, 1995, 1996; Franklin, 2006; Buse, 2010; Rayvon, 2012) refer to the cyborg concept to investigate the ways of embodiment that are achieved or mediated through digital technologies. These studies on cyborg bodies also established an argument that focuses on the complex nature of interactions between humans and non-humans and questions the dynamics of embodiment (Lupton 2015c). As represented in Section 2.2.1, this perspective recognizes the subject and the object as "even" and claims that while interacting, they co-configure each other (Law & Hassard, 1999; Latour 2005; Law 2008).

To capture the entanglements between humans and humans, many scholars used the term "assemblage" as in their relationship; both actors are always "configured" and "reconfigured" within the concepts of knowledge and experiences of the body (Lupton, 2015, p.572). For example, people "domesticate" digital products by integrating them into their everyday life, making associations with their bodies and assigning specific meanings (Fallan, 2010). At this point, the embodiment can primarily be considered as a "relational assemblage" of human bodies and technologies (Lupton, 2017).

The previous studies about human-technology assemblage identified four fundamental types of cyborg technologies, which are "restorative," "normalizing," "reconfiguring", and "enhancing" (Gray, Mentor, & Figueroa-Sarriera, 1995). Beyond these capabilities, today's health technologies also serve different functions such as monitoring, communication, and surveillance, in particular. Collecting and presenting bodily data help individuals to become self-aware of their bodies, and also with the help of medical technologies, illnesses become predictable even before having any symptoms or signs. In the political perspective, these self-aware individuals are associated as "idealized citizens" (Lupton, 1995b, 2013a) since maintaining health has a greater value in modern societies (Crawford, 1980, 2006).

To describe today's technology and human assemblage, Lupton (2012a) uses the term "digital cyborg" that refers an individual who performs self-tracking practices knowingly with the purpose of collecting information about their bodies and selves, which they can also review and consider improvements accordingly (Lupton, 2016). In medical jargon, the digital cyborg is also named as the “digitally engaged patient” (Lupton, 2013a). This new form of the patient is willing to take active participation in healthcare and “digitize” own body as a part of “personalized preventive medicine” and (Swan, 2012: Topol, 2012). As discussed in Section 2.3.2, these individuals also quantify their bodies as monitoring technologies translate the current state of the body into numeric values.

### 2.3.4 Summary

The theoretical framework of this thesis is shaped around biosociality. The biosocial practices of individuals start with the acceptance of the genetic condition and constructing new selves around it. As Rabinow (1996) stated, in everyday life, biosociality occurs when individuals encounter similar bio-entities and actualize their constructed identities in means of interaction, such as sharing experiences.

Another context in which Rabinow (1996) describes biosociality is the visualization of risk with the help of technological enhancements. Medical products, such as self-tracking tools, help individuals not only maintain their current health by also prevent emergencies. In this thesis, I benefit from the actor-network theory to understand and discuss the role, i.e., material agency, of self-tracking devices in the care networks shaped around illnesses and device-use practices.

In the case of self-tracking practices, quantification is another concept that enables individuals to construct new identities based on their biometrics and even justify their performance in self-care against others through numbers.

With regards to use practices of self-tracking devices, the embodiment process results in the digital transformation of the human body. The concept of digital bodies is defined by Lupton to explain the co-constructive nature of human-technology interaction. Moreover, to criticize the image of those digitized bodies, the cyborg concept of Haraway is explained.

As mentioned in Section 1.2, this research aims to explore the bodily and biosocial practices of people using digital health technologies in the management of type 1 diabetes. Therefore, the following section explains the nature of diabetes and gives examples of the previous studies to understand the current interest and the approach in the academic field.

## 2.4 Diabetes Care Today

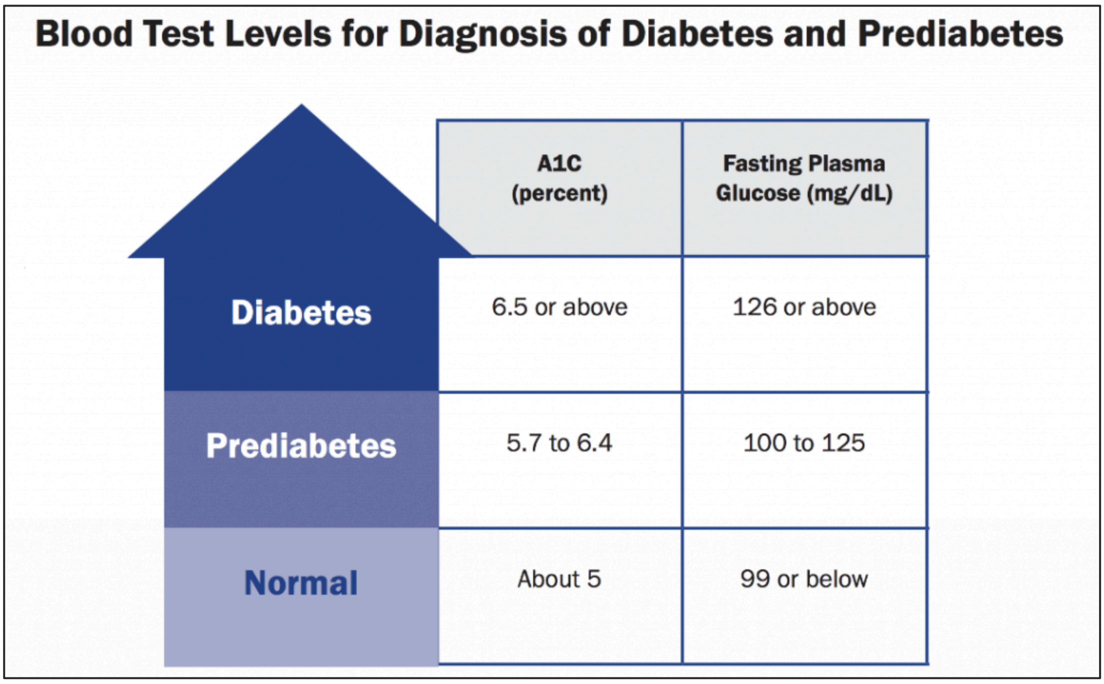
Though the nature of the illness remains the same, with the emergence of connected technologies, the methods of diabetes care have changed. This section briefly explains what diabetes is, presents the current management methods and gives brief summary about the relevant academic literature.

### 2.4.1 Definition of Diabetes

In the simplest definition, diabetes, or diabetes mellitus in Latin, is “a disease in which blood glucose (i.e., sugar) levels rise higher than normal” (American Diabetes Association, n.d.). Excluding diabetes that develops during pregnancy, named “gestational diabetes,” diabetes is divided into two main types: Type 1 and Type 2. In the former, the body attacks the pancreas and destroys the cells producing insulin, the regulatory hormone for blood glucose. In the latter, though the pancreas usually produces a certain amount of insulin, the body itself is resistant to insulin. According to the statistics, only five percent of reported cases represent people with type 1 diabetes, while approximately 90-95 percent of the population is dealing with type 2 diabetes (Centers for Disease Control and Prevention, 2017). As is known, diabetes is not curable. People with type 1 diabetes are required to take insulin to regulate their bodies. However, type 2 diabetes can mostly be controlled with a proper diet and exercise routines (Asif, 2014), though some medications might be required as diabetes tends to progress (American Diabetes Association, n.d.).

### 2.4.2 Diabetes Routines

The routines may be divided into two categories: Clinical and daily routines. Clinical routines refer to the medical care received from health professionals, which includes doctors, nurses, a pharmacist, for example. Glycemic control is an essential routine for the management of diabetes. To understand the adequacy of treatment or medications, people with diabetes are asked to take regular Hemoglobin A1c tests to measure the glycated hemoglobin level, which is represented as an average blood glucose level (WHO, 2011). In general, patients are expected to take the HbA1c test every two or three months to define a current treatment plan. Figure 2.1 represents the relationship between HbA1c levels and diabetes.



**Blood Test Levels for Diagnosis of Diabetes and Prediabetes**

| | A1C (percent) | Fasting Plasma Glucose (mg/dL) |
|---|---|---|
| **Diabetes** | 6.5 or above | 126 or above |
| **Prediabetes** | 5.7 to 6.4 | 100 to 125 |
| **Normal** | About 5 | 99 or below |

Figure 2.1 Blood Test Levels for Diagnosis of Diabetes and Prediabetes. Digital Image. TheDiabetesCouncil.Com (n.d.)

In addition to regular HbA1c tests, people with diabetes also have periodical check-ups for preventing intercurrent illnesses such as diabetes-related kidney or sight problems (National Institute of Diabetes and Digestive and Kidney Diseases, n.d.). The care team defines the frequency of these visits. On a daily basis, the changes in blood levels are the other signifiers of diabetes. Fasting glucose level, i.e., pre-prandial blood glucose, refers to the levels before the meal. On the other hand, the post-prandial glucose level is measured two hours after meals. Non-fasting or random glucose level refers to the results of measurements performed regardless of when the last meal is. In the assessment of glycemic control, monitoring blood glucose is one of the critical routines. The medication plan, such as insulin intake, is adjusted and applied depending on the monitoring results. According to the monitoring results, medication plan covering such as insulin doses is applied. In addition, monitoring glucose level regularly also helps to prevent emergencies such as hypoglycemia, which is the condition of having low sugar (American Diabetes Association, n.d.).

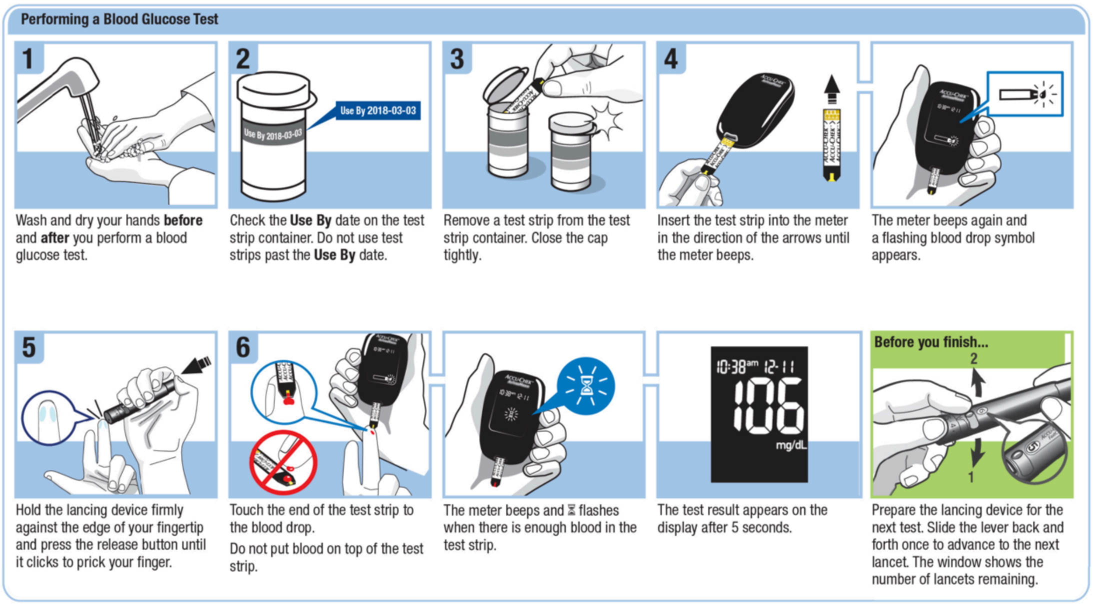
Apart from monitoring and medication, daily routines of diabetes mostly mean diet and exercise habits. In diabetes care, building up a healthy diet and having regular exercise are highly recommended not only for medical management but also for the well-being. Kulkarni (2005) explains carbohydrate counting as a "meal planning approach," not a special diet. According to him, what matters is the total consumption of carbohydrates rather than the type of it. He claims that carbohydrate counting is a meal-planning method that applies to all types of diabetes. To get familiar with carbohydrate counting, he recommends that "measuring cups and spoons, food scales, food package labels, carbohydrate counting books, and the food exchange list books" are the useful tools (p. 121). In today's digital world, several mobile applications provide nutritional values for beverages and food, which makes carbohydrate counting easier and more precise.

### 2.4.3 Diabetes Care Products

This section gives brief information about the products used in diabetes management for different aims: monitoring and medication. First, the products designed with regard to different blood glucose monitoring methods are introduced. Then, three different ways of insulin intake are presented.

#### 2.4.3.1 Monitoring Products

Currently, there are two methods for monitoring blood glucose levels. The first and most used method is “traditional home glucose monitoring” (Mayo Clinic, n.d.). In this method, people are using a device called “glucometer,” which measures the amount of glucose in the blood (Gaev, 2004). Figure 2.2 shows how to perform blood glucose measurement.



**Performing a Blood Glucose Test**

1 Wash and dry your hands **before** and **after** you perform a blood glucose test.

2 Check the **Use By** date on the test strip container. Do not use test strips past the **Use By** date.

3 Remove a test strip from the test strip container. Close the cap tightly.

4 Insert the test strip into the meter in the direction of the arrows until the meter beeps.

The meter beeps again and a flashing blood drop symbol appears.

5 Hold the lancing device firmly against the edge of your fingertip and press the release button until it clicks to prick your finger.

6 Touch the end of the test strip to the blood drop.

Do not put blood on top of the test strip.

The meter beeps and ⧗ flashes when there is enough blood in the test strip.

The test result appears on the display after 5 seconds.

**Before you finish...**

Prepare the lancing device for the next test. Slide the lever back and forth once to advance to the next lancet. The window shows the number of lancets remaining.

Figure 2.2 Performing a Blood Glucose Test. Digital Image. Roche (n.d.), https://www.accu-chek.com

As shown, glucometers need blood samples for measurement, which means for each measurement, users are supposed to prick their fingers. This necessity has been changing with the rise of non-invasive glucose monitoring methods. Ferrante do Amaral and Wolf (2008) describe the method as "the substitution of blood with other fluids that could contain glucose, like saliva, urine, sweat or tears" (p. 542). Since the 1960s, there are many studies for the improvement of non-invasive methods (Clarke & Foster, 2012). Today, many of the continuous glucose monitoring systems, referred to as CGMs in this thesis, use "interstitial fluid" or ISF in short as a medium of a sample, rather than blood (Rebrin & Steil, 2000). Cengiz and Tamborlane (2009) explain the principles of ISF glucose monitoring in a way that, at first, a sensor with glucose-sensing filament is placed into the subcutaneous tissue to reach ISF which comprises glucose that is diffused from blood capillaries. Figure 2.3 represents the visual summary of the process.

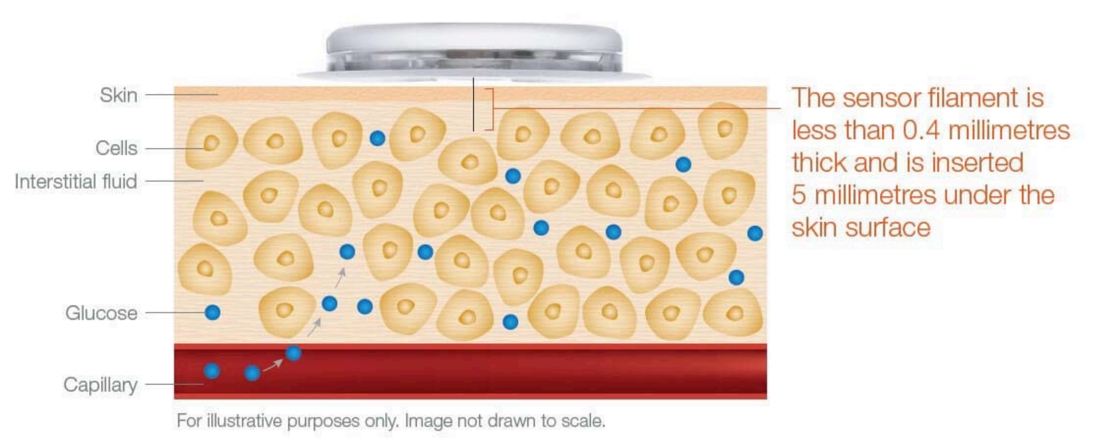
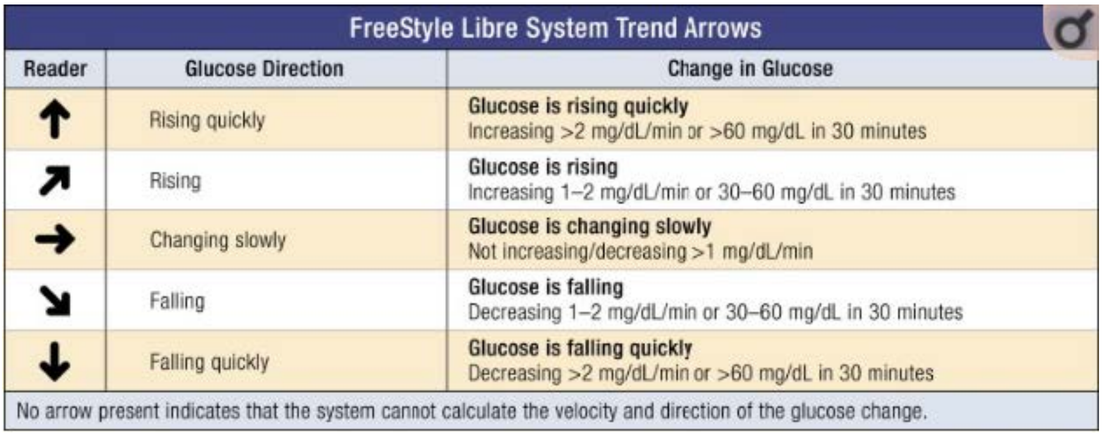


Figure 2.3 Glucose Sensor Measuring Glucose in the Interstitial Fluid. Digital Image. Abbott (2016), https://freestylediabetes.co.uk

Besides enabling glucose monitoring without blood, another revolutionary feature of CGMs is the "trend arrows," the visualization of the direction of the change in glucose levels (see Figure 2.4). Kudva et al. (2018) explain data tracking and mining process behind the feature as follows:

> The system measures glucose concentrations every minute and, when scanned, transmits the current glucose reading and historical glucose readings in 15-minute increments to the reader. The trend arrows are calculated from glucose readings with an emphasis on the most recent 15 minutes. The directionality of trend arrows allows individuals to anticipate future glucose concentrations. (p. 1323)

Trend arrows are considered as revolutionary, as they can make it possible to discover potential risks and prevent emergencies such as hypoglycemia or hyperglycemia (Heinemann & Freckmann, 2015).



FreeStyle Libre System Trend Arrows

| Reader | Glucose Direction | Change in Glucose |
|---|---|---|
| ↑ | Rising quickly | **Glucose is rising quickly**<br>Increasing >2 mg/dL/min or >60 mg/dL in 30 minutes |
| ↗ | Rising | **Glucose is rising**<br>Increasing 1–2 mg/dL/min or 30–60 mg/dL in 30 minutes |
| → | Changing slowly | **Glucose is changing slowly**<br>Not increasing/decreasing >1 mg/dL/min |
| ↘ | Falling | **Glucose is falling**<br>Decreasing 1–2 mg/dL/min or 30–60 mg/dL in 30 minutes |
| ↓ | Falling quickly | **Glucose is falling quickly**<br>Decreasing >2 mg/dL/min or >60 mg/dL in 30 minutes |

No arrow present indicates that the system cannot calculate the velocity and direction of the glucose change.

Figure 2.4 FreeStyle Libre System Trend Arrows. Digital Image. Kudva et al. (2018), https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6243139/

Although CGMs provide many facilities, most of the products cannot provide an independent experience from conventional methods as devices require calibration (Heinemann & Freckmann, 2015). In the 2010s, Abbott launched a product named

FreeStyle Libre (see Figure 2.5), which is referred to as an example of "Flash Glucose Monitoring" or FGM in short.

Figure 2.5 Abbott FreeStyle Libre. Digital Image. Abbott (n.d.), https://www.freestylelibre.us

The main difference between CGMs and FGMs is that the latter does not require any calibration. Also, the sensor life is another distinction as the duration of CGM sensors is seven days, while FGM sensors might be used up to 14 days. (Abbott, n.d.)

### 2.4.3.2 Insulin Intake

As mentioned above, especially in type 1 diabetes, insulin intake is mandatory to regulate blood glucose. From past to present, the syringe has been the most common way of delivering insulin. However, today, it has changed with insulin pens and recently pumps (American Diabetes Association, n.d.).

Insulin pens might be considered as the first design attempts to meet users' needs and solve their problems. Though they are not cost-efficient compared to syringes, they provide several benefits. First, insulin pens are built on spring-loaded mechanisms, so that they provide more accurate dosing compared to syringes. Secondly, studies conducted about the usability of prefilled insulin pens revealed that users find pens less painful.

There are two types of insulin pens regarding their product life cycle. A disposable pen comes with a prefilled cartridge, and the user throws away the entire pen after use. On the other hand, reusable pens come with a reusable cartridge, and users can replace the empty cartridge with the new one. Figure 2.6 shows an example of a reusable insulin pen.

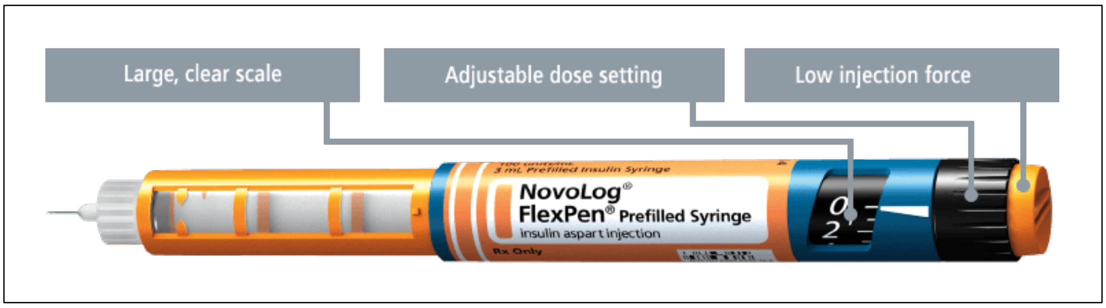


Figure 2.6 Novolog FlexPen. Digital Image. Novo Nordisk (n.d.), https://www.novologpro.com

The newest product designed for insulin delivery is the insulin pump, compact electronic products that provide rapid-acting insulin regularly under the skin. The primary working principle of the insulin pump is to manage doses precisely according to carbohydrate consumption. Unlike syringe or insulin pens, the pump delivers continuous yet tiny doses, instead of larger amounts at one time. That is why the insulin pump only delivers bolus insulin.

The physical and technical features of insulin pumps vary according to the user's needs. Different sizes are available depending on the capacity of the insulin reservoir, i.e., how many units of insulin the device holds. There are also products compatible with CGMs, which provide monitoring and medication capabilities together for holistic care, see Figure 2.7). This product ecosystem is called "Hybrid Closed Loop Systems" (Allen & Gupta, 2019).

Figure 2.7 Medtronic MiniMed 670G System. Digital Image. Medtronic (n.d.), https://www.diabetesdaily.com/blog/automated-insulin-delivery-515969/

### 2.4.4 Summary

In recent years, technology use in diabetes management has become a popular topic in various literature, from health to design. With the spread of new technologies and products that handover the practice from healthcare professionals to the patient themselves, many studies evaluated diabetes and related digital technologies from different perspectives. Some researchers, such as Mol & Law (2004), evaluate diabetes as a bodily practice and focus on the transformation of the ill body and the self. On the other hand, especially in the design field, most of the studies aim to evaluate the performance and usability of digital products and services (Whittemore et al., 2013). In addition, several studies focus on user problems and make recommendations to improve the user experience of diabetes technologies (Pillalamarri, Huyett, & Abdel-Malek, 2018; Grando et al., 2019; Freckmann et al., 2019).

Studies focusing on wearable digital technologies such as CGMs, the main purpose is to find the correlation between the frequency of blood glucose monitoring and the achievement of better blood levels (Lucisano, Kurbanyan, Martha, & Routh, 2017). In general, the outcomes of these studies show that technology use has a positive impact on diabetes care, such as consistent blood levels or better management habits like regular monitoring (See Figure 2.8).

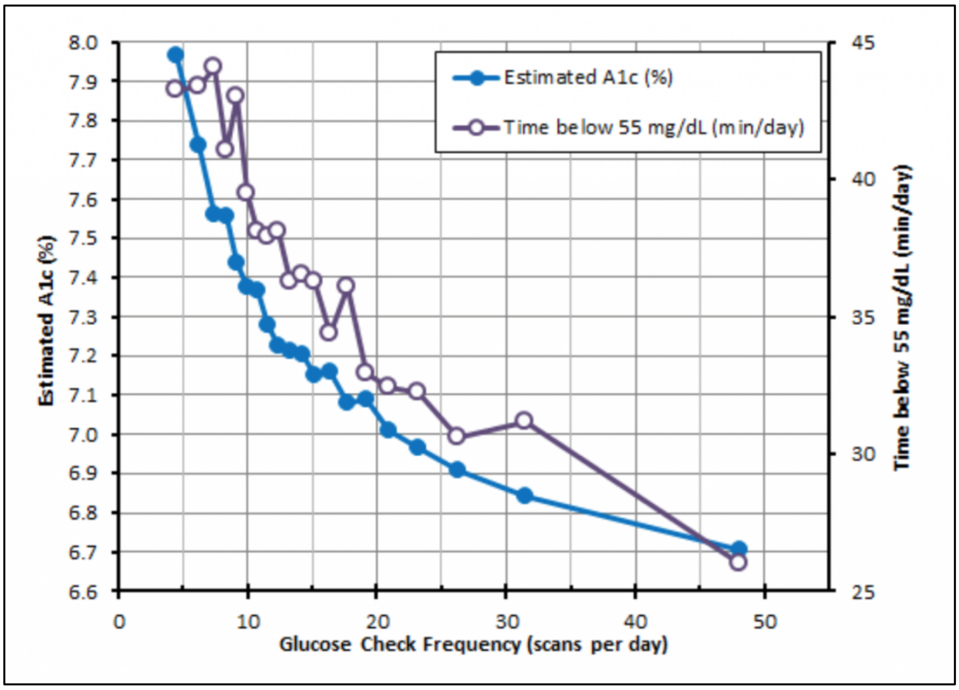


Figure 2.8 The Relation Between Glucose Check Frequency and Estimated A1c. Digital Image, (Lucisano et al., 2017, p.13).

With the rise of digital technologies and spread of online communication tools, today researchers with qualitative approach aim to understand individuals’ interaction within OHCs and document the content derived from their biosocial activities (Greene, Choudhry, Kilabuk, & Shrank, 2011; Stuckey, Olmsted, Mincemoyer, & Gabbay, 2012; Gilbert, Dodson, Gill, & McKenzie, 2012; Zhang, He, & Sang, 2013; Ho, O’Connor, & Mulvaney, 2014).

## 2.5 Conclusion

Although the literature review revealed that there are various studies about the user practices of technology use in diabetes management, there are research opportunities for the study of social aspects of product use, such as the products' role in integrating close relations in the management process, beyond the immediate usability requirements for individual users. This thesis aims to contribute to the existing literature by discussing the capabilities of products beyond evaluating their usability.

The literature review initially presented the changes in medicine over time. As a result of these changes, the patient profile has changed, and individuals become active participants in the practice of care. As discussed in Section 2.2.1, in today’s world, this involvement is a result of the governmentality and has its political dimensions. For example, current healthcare policies aim the empowerment of patients, so that the responsibility of care is intentionally given to them. In this regard, connected technologies have rendered products compact and connected, and medical monitoring has become accessible from anywhere. These digital products also redefined the management of illnesses and introduced a new way of representing the individuals: quantification.

As a result of these medical developments, the management of illnesses and human bodies become political in a new sense. Individuals who are responsible for their care came together in light of shared experiences. Their social activities are discussed under the concept of biosociality, as it is not only about self-empowerment, but also about the collectivization of these politicized identities.

The interaction between wearable technologies and the human body has digitally transformed the image of ill-body. Moreover, beyond maintaining the current state, self-tracking practices also enable individuals to normalize or restore their health. In this regard, this study benefits from several concepts such as cyborg (Haraway, 1985) and digital bodies (Lupton, 2016) while discussing human-product interaction.

In the light of the literature review, this study aims to understand the role(s) of digital health technologies in care networks as actors performing delegated actions or as mediators enabling other interactions. In this way, the thesis sheds light on the relationship between these wearable products and the characterization of new users and their bodies. To accomplish this aim, the case study of this thesis was defined as the user practices of people using CGMs or insulin pumps in diabetes management. That is why, the last section of the literature review is focused on living with diabetes as a daily life practice.

The next chapter presents the details of the research design.

# CHAPTER 3

# METHODOLOGY

The purpose of this thesis is to understand the effects of remote health technologies on today's care practices and investigate the biosocial activities and bodily experiences of users within the context of use. In this chapter, I present the details of the research design: The research approach, sampling method, data collection, and data analysis. I explain the reasons for selecting interviews as a research method for this qualitative study. Afterward, I present the sampling criteria for participants, the process of conducting interviews, and data analysis. Lastly, I argue about the limitations of the fieldwork and the challenges that I encountered during the data collection.

## 3.1 Scope of the Study

*Tip 1 Diyabet Tecrübeleri* is a diabetes online community, established as a Facebook group of an Ankara-based diabetes association named *Tip 1 Diyabet ve Teknolojileri Derneği*. The association was founded in 2016 in the leadership of Hüseyin Devecioğlu, the father of a son with type 1 diabetes, to raise awareness about developing diabetes technologies and their contribution to the management process. Although the majority of the activities arranged by the association target children with diabetes, the user profiles and modes of interactions are diversified in the Facebook group. Fundamentally, user profiles can be classified depending on the experience with diabetes. At this point, the word "experience" refers to two different connotations: The first stands for how long people live with diabetes. In this regard, user profiles can be described as newly-diagnosed and experienced ones. The second meaning refers to individuals' interaction with the other actors, such as their doctors, families, or management devices. Furthermore, when it comes to product use practices, the definition of experience is ambiguous because an experienced diabetic might be a novice user of a product. This multidimensionality in user profiles, depending on the context, leads to different levels and means of interactions and makes this online community special in my point of interest.

As exemplified above, selecting *Tip 1 Diyabet Tecrübeleri* as the scope of this study has several reasons. However, it is significant to explain my motivation for deciding diabetes as the main focus of this research. As mentioned in the background of this study (see Section 1.1), my mother and I suffer from thrombophilia, a type of coagulation disorder (Segers, Dahlbäck, & Nicolaes, 2007). That is why focusing on chronic illnesses would be easier to understand and empathize with the people's accounts on living with chronic conditions. On the other hand, as an industrial designer, I always believe that behind its functionality, a product's hidden power is in mediating various interactions in cultural, sociological, and even political backgrounds, and these relations are always valuable to argue about. This is the point where all my interests and objectives intersect and create the basis that this study built on: Discovering chronic disease practice through the agency of the product.

Concerning this aim, I conducted a benchmark on medical product designs used for the self-management of the following chronic conditions: coagulation disorders, diabetes, and respiratory diseases. As an outcome of this study, I prepared a detailed product matrix that presents the brand and model information, visual, short description, and the target user of the product (see Appendix D for complete version). The aims of creating a product matrix were to:

- Gain knowledge about the diversity of the products designed for self-care,
- Categorize products according to their target group and use environment,
- Get an idea of the availability of self-care products in the local market.

Table 3.1 Example from the Product Matrix

| | ***Product*** | ***Image*** | ***Description*** | ***Target User & Environment*** |
|---|---|---|---|---|
| ***PT-INR Testing*** | Siemens Xprecia Stride Coagulation Analyzer |  | Xprecia Stride Coagulation Analyzer that test PT/INR with a small sample (blood) volume USB port sends and receives patient results. Barcode scanner enters IOT calibration information and operator and patient IDs. | Healthcare Professionals & Hospitals |
| | Roche CoaguCheck INRange System |  | CoaguChek INRange is a self-testing meter that enables patients to test their PT/INR. Built-in wireless, Bluetooth technology allows physicians to be connected to the patients, who can transmit their results from device to the doctors. | Health Consumers & Indoors-Outdoors |
| | Roche CoaguCheck XS |  | CoaguChek® XS system is a portable instrument for monitoring oral anticoagulation therapy. It determines the INR value (International Normalized Ratio) from a drop of capillary whole blood. | Health Consumers & Indoors-Outdoors |
| ***Blood Glucose Testing*** | Ascensia Contour Next One |  | By integrating blood glucose (BG) meter with a smartphone app, Contour Next One simplifies the management of diabetes. BG results captured throughout the day can be automatically synced and logged. | Health Consumers & Indoors-Outdoors |
| | Abbot FreeStyle Libre |  | FreeStyle Libre is a FGM system. Scan the sensor worn on the body with the reader for results in a second. Each scan gives current glucose reading, a view of the last 8 hours and shows the anticipated glucose change. | Health Consumers & Indoors-Outdoors |
| | Dexcom G5 Mobile CGM System |  | The Dexcom G5 CGM System provides real-time glucose readings for patients with type 1 or type 2 diabetes every five minutes. With Dexcom G5 Mobile, dynamic glucose data can be accessed and shared safely to smart devices. | Health Consumers & Indoors-Outdoors |

In parallel, I started to search for foundations, associations, and online help communities related to the selected chronic conditions as my purpose is to discover the biosocial practices of users (see Section 2.2.1). Similar to the product matrix approach, I created a contact list for all the organizations I found via the Internet and got in touch with the people in charge to obtain information about their activities and availability to contribute to my study (see Table 3.2). The initial research process played an important role while deciding on the case of this study. I evaluated the outcomes according to the variety of products and their use cases, and the possibility of reaching potential participants through contacted communities.

Table 3.2 Contact Information Details of Health Communities

| | *Name* | *Contact Information* | *Response* |
|---|---|---|---|
| ***Respiratory care*** | Türkiye Solunum Araştırmaları Derneği | http://www.solunum.org.tr/ | Negative |
| | Türkiye Ulusal Alerjik ve Klinik İmmünoloji Derneği | https://www.aid.org.tr/ | Negative |
| | Türk Toraks Derneği | https://www.toraks.org.tr | Negative |
| | Koah Hastaları Derneği | http://www.koahhastalaridernegi.org/ | Positive |
| | Akciğer Hastaları Dayanışma Derneği | http://www.ahdader.com/ | Tentative |
| ***Blood Disorder Care*** | Türk Hematoloji Derneği | http://www.thd.org.tr/ | Positive |
| | Kan Hastalıkları Federasyonu | http://kanhastaliklarifederasyonu.com/ | Negative |
| ***Diabetes Care*** | Diyabetimben | https://www.diyabetimben.com/ | Positive |
| | Türkiye Diyabet Vakfı | https://www.turkdiab.org/ | Positive |
| | Türkiye Diyabet Cemiyeti | http://www.diabetcemiyeti.org/ | Negative |
| | Tip 1 Diyabet ve Teknolojileri Derneği | https://www.tip1diyabetveteknolojileri.org.tr/ | Positive |
| | Tip 1 Diyabet ve Tecrübeleri | https://www.facebook.com/groups/1114517271895864/ | Positive |
| | Diyabetle Yasam Derneği | http://diyabetleyasamdernegi.com/ | Positive |
| | Diyabetiz | http://www.diyabetiz.com | Tentative |

These preparatory studies showed that the variety of products designed for blood diseases is highly limited compared to others. Most of the examples primarily target healthcare professionals. In terms of home-use versions, the design approach is weak in terms of mobility as they are used less frequently during the day, and their home-use versions do not have a considerable market share in Turkey. In addition, the organizations where people with blood diseases meet are very few, which makes it hard to recruit participants for my study. However, the key reason why I did not prefer to focus on coagulation meters is that I might be counted as an insider considering my and my mother's experiences with coagulation disorder, even though neither of us are actual users. Hence, as Asselin (2003) mentioned, familiarity with the setting of the disorder may have arisen issues related to the objectivity of observations and analysis.

Regarding spirometers, the transition period from clinical use to home use devices is still ongoing. That is why, according to my research, most of the design attempts are for making the product portable and connected, yet there are not many examples mainly designed for home use. Moreover, the existing ones are not available in Turkey yet, which makes it nearly impossible to get in contact with the actual users. Although there are several communities of people with respiratory diseases, most of the members do not use any technology in their management process, which means their collective activities do not entirely match with the aim of this study.

When it comes to diabetes technologies, the variety of the products is enormous, not only because diabetes is one of the well-known chronic diseases, but also diabetes care has been focused on self-management since the very beginning. Therefore, there is a high number of diabetes communities, from small-scaled examples, such as Facebook pages, to large-scaled ones, such as foundations. As a researcher, my goal was to focus on product use practices within the perspective of everyday life. That is why I focused on online diabetes communities, which reflect today's means of interaction. Before making any decision, I became a member of each community and conducted a netnographic study to observe members’ social interaction. These online observations also helped me to learn common diabetes terms.

Back to the reasons for choosing *Tip 1 Diyabet Tecrübeleri* as the focus of this study, although there are other Facebook groups, most of them are respectively on a smaller scale, and sometimes the content of the shares is not directly related with diabetes. On the other hand, there are also several Facebook pages established by people with diabetes and aim to share information from the perspective of personal experiences. Although all these organizations are considered as useful information sources, the main distinction between the groups and pages is that the former allows members to share posts and make comments leading to bilateral communications, while the latter is administrated by the founders and the members are expected to behave within the limits of granted authorities (see Section 2.2.2).

### 3.2 Research Approach

Park and Park (2016) compare two applicable ways of investigating phenomena as:

> The goal of a qualitative method is to understand and explore the descriptive accounts and similarities and differences of various social events. The qualitative method is focused on applied and theoretical findings or discoveries, based on research questions through field study in natural conditions. Comparatively, the objectives of the quantitative method in social science are to predict and control social phenomena. Researchers measure, evaluate, and generalize the findings to a population and encourage replication of the findings. (pp. 3-4)

As this study is based on in-depth inquiries into individuals with diabetes to investigate their everyday lives and understand their perceptions about technology use in the management of illness, I adopted the qualitative research approach in the thesis.

Strauss and Corbin (1998) state that the findings of qualitative research are not derived from any statistical procedures or different methods quantification. Therefore, in this study, the data consist of multiple sources, such as interviews, photographs, and official recordings. Interviews took place in the participants' everyday environment as their natural setting, and the gathered data were analyzed in an interpretive and holistic account to fulfill the requirements of qualitative research (Creswell, 2009).

## 3.3 Research Design

This study consists of five main stages (see Figure 3.1). In this section, I explain which research method is applied for data collection and the reasons for method selection. Then, I present the interview design and argue about the ethical considerations regarding the selected method.

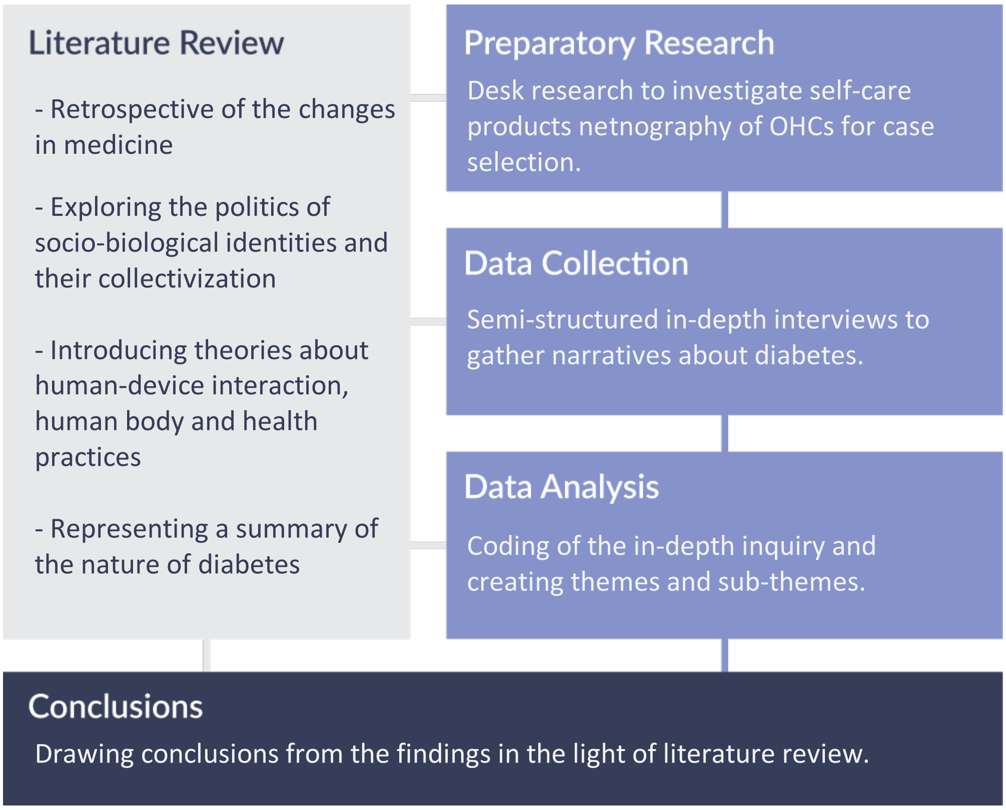


Figure 3.1 Research Stages of the Study

### 3.3.1 Interview Approach

As Miller and Glassner (1997) discussed;

> Interviews can provide access to the meanings people attribute to their experiences and social worlds. While the interview is itself a symbolic interaction, this does not discount the possibility that knowledge of the social world beyond the interaction can be obtained. (p. 100)

Interviewing is a collaborative process in which the researcher and participants share their reflections and inquiry (Douglas & Moustakas, 1985). In other words, the interviewer becomes a "knowledge-producing participant" (Brinkmann, 2013). Gray (2009) pointed out that an interview is the most suitable research technique when a study aims to explore and examine the participants' feelings, values, attitudes, preferences, and knowledge. In addition, he suggested that interviews may function better than questionnaires when subjects have personal stories to tell. Similar to his account, Seidman (2006) also stated that interviews are the enablers to understand the context of people's behaviors.

According to the purpose of this thesis, interviews were conducted in a semi-structured form with open-ended questions. Gray (2009) explained that semi-structured interviews are meaningful to explore the connotations of concepts or events since the method allows the researcher to elaborate on participants' insights, by probing participants' views or opinions (p. 214).

### 3.3.2 Interview Design

Gray (2009) states that semi-structured interviews are in a flexible manner, which leaves room for the researcher to add or leave out some questions, depending on the progress while interviewing. An interview guide (Appendix B) was prepared in order to cover all the topics during each session. The order of the questions was structured from broader to a specific perspective to prevent data corruption. My first question set was on the participants' demographics, which might be considered as a warm-up session. Secondly, I asked participants about their diabetes history in order to obtain detailed narratives. Then, participants were asked about their technology use practices in diabetes management. The fourth set of questions intended to learn the effects of diabetes in participants' daily life. The fifth and the last set of questions aimed to discover the group's dynamics, which involves diabetes and technology-use practices, and social aspects of the community as well.

### 3.3.3 Ethics and Consent

Ritchie and Lewis (2003) explain the necessity of consent in terms of ethical considerations as follows:

> As in any research study, sample members' informed consent to participate must be obtained. This means providing them with information about the purpose of the study, the funder, which the research team is, how the data will be used, and what participation will require of them - the subjects likely to be covered, how much time is required and so on. (pp. 66-67)

While scheduling the interviews, I sent a written consent form (see Appendix C) to the participants via e-mail to inform them about the details mentioned above. Also, I informed interviewees that their participation is voluntary, and they have the right to quit the study at any time. Also, participants were ensured for the data anonymity. Before each interview, I renegotiated the written consent with the participant if it takes longer than the estimated duration. Then, participants were asked to sign two copies of printed consent, and one of the copies were given to them. By approving the consent form, participants accepted being recorded during the interview and allowed me to take photos of their products. As a researcher, by signing the form, I also confirmed that the recorded data could be used only for academic purposes and could not be shared with any third parties. In the following section, I describe the sampling methods and the data collection process.

### 3.3.4 Sampling

Ritchie and Lewis (2003) stated that probability samples are essential for providing statistically representative data. However, as qualitative research is not interested in statistics, the non-probability sample is recommended to reflect the particularities of each participant. So, purposive sampling was used to answer the research questions which require in-depth information about participants' experiences and perceptions (Matthews & Ross, 2010).

Concerning the aim of the study, research questions, and the opportunities discussed communities above, *Tip 1 Diyabet Tecrübeleri* was selected as a study population. Then, to create a sampling frame, an online survey, which aims to gather demographic information and gain insights about people's diabetes and device use experiences, was designed and posted in the Facebook group (see Appendix A). At the end of the survey, people were also asked for their participation in further studies. Beyond the demographic classification, the survey helped to group people according to two decisive criteria, which are technology-use habits and interaction with the community. Although the survey received 92 responses in total, only 22 people matched the targeted participant profile, which is the people aged 18 or older, using wearable diabetes technologies and has an active participation in the online community. From the selected 22 members, 17 responded to my interview request. However, two of them did not reply to any e-mails or phone calls later on.

Out of 15 participants that I got in contact, seven were living in Ankara, four in Istanbul, one in Izmir, one in Denizli, one in Antalya, and one in Bursa. Due to time and availability, the first 12 participants who live in Ankara, Istanbul, and Izmir were selected as final participants. Table 3.3 presents the information of people with diabetes. Among the participants, Cem and Gözde is a married couple who was interviewed together. Similarly, some of the participants preferred to participate in interviews with their significant others (see Section 3.4 for further detail).

Table 3.3 Sampling

| ***Participants*** | ***Diabetes Experience*** | ***Sex*** | ***Device Type*** | ***Location*** |
|---|---|---|---|---|
| *Turan* | 20 years | Male | CGM | Izmir |
| *Ebru* | 19 years | Female | Insulin Pump | Ankara |
| *Burak* | 13 years | Male | Insulin Pump | Ankara |
| *Meral* | 16 years | Female | CGM, Insulin Pump | Ankara |
| *Eren* | 4 years | Male | CGM | Ankara |
| *Güzin* | 3 years | Female | CGM | Ankara |
| *Cem* | 16 years | Male | CGM, Insulin Pump | Ankara |
| *Gözde* | 19 years | Female | CGM, Insulin Pump | Ankara |
| *Esra* | 23 years | Female | CGM, Insulin Pump | Istanbul |
| *Aslı* | 15 years | Female | CGM | Istanbul |
| *Hande* | 2 years | Female | CGM, Insulin Pump | Istanbul |
| *Ahmet* | 5 years | Male | CGM, Insulin Pump | Istanbul |

Regarding the number of participants, Ritchie and Lewis (2003) stated that qualitative samples are respectively in small size because there is no requirement to determine outcomes statically. Once a phenomenon appears, it takes part in the analytical map without the need for repetitions. This means there is a point of saturation in which no new evidence can be found despite the growing number of participants (Glaser & Strauss, 1967).

Before scheduling interviews, I primarily sent informative e-mails to the participants providing brief information about the researcher, the purpose, and the estimated duration of the interviews. Then, I asked each participant to provide time and location information, considering the dates I could travel. As I was residing in Izmir while doing the field study, almost all of the interviews required traveling to two different cities: Ankara and Istanbul. Interviews were conducted on the scheduled date without any problem. Moreover, all conducted interviews were valid in terms of participant profile, consent, and data quality.

### 3.4 Data Collection

Before starting the field study, a pilot interview was performed with a 22-year-old engineer who has been using CGMs for the last two years. The pilot study made it possible to test the interview guide and decided on the research method, as well. As a result, some of the questions were improved to prevent ambiguity. Also, it gave an insight into the expected duration of the interviews. The outcomes of the pilot study were not included in the analysis process as the participant was not a member of a selected community.

11 interviews were conducted in February 2019 and took place in three different cities: Izmir, Ankara, and Istanbul. Only one interview was conducted in the city I live, and for the majority of the fieldwork, I traveled to other cities. Thus, participants were asked to schedule a meeting within the dates I recommended according to my travel

plan. The interview environment was defined according to the participants' preferences. Two interviews were conducted in the participants' homes, one interview took place in the participant's workplace, and the other eight were performed in cafés. The duration of the interviews ranged from 60 to 120 minutes.

As exceptions, three interviews were conducted in different settings compared to the others. First, a married couple, Gözde and Cem, who use wearable diabetes technologies, wanted to be interviewed together due to their limited time. Second, one member of the community, Sertan, filled out the online survey on behalf of his fiancée, Meral, who has type 1 diabetes and using both CGMs and the insulin pump. Once the situation was revealed, Meral wanted to bring him along by stating that she has been dealing with diabetes for a long time, and sometimes she is blind to its outcomes. Moreover, as Sertan is witnessing any moment of her, she thought that he might have better insights to share. By the same token, Ahmet wanted his wife next to him while interviewing as she is the one who involved in the community more actively than the patient himself.

I started interviews by stating my appreciation for their contribution to the study and introduced myself and the reason why I conduct this study in brief. Though the written consent was sent to the participants beforehand via email, I went through the conditions and asked participants for their approval about audio recording once more. While introducing myself, I also mentioned my chronic condition to make participants feel familiar. During the interviews, I felt that sometimes participants did not give details as they thought that I could relate to the subject. Then, I asked them further questions to learn more about the topic.

According to Ritchie and Lewis (2003), a researcher should perform several roles while conducting an in-depth interview. The most important role is being a facilitator encouraging participants to talk about their "thoughts, feelings, views, and experiences." They said that a facilitator always has an active role, even while listening to participants to make sure that all topics are covered, and detailed insights are gathered. During the interviews, I let interviewees talk without interruption in general (Glesne, 2011). When they started to discuss unrelated topics, I waited in patience until they finished their word and led them into the core topic by asking additional questions or signposting previous ones.

In the book titled *Qualitative Interviewing: The Art of Hearing Data*, Rubin and Rubin (2011) mentioned that the nature of an in-depth interview is interactive, which means the next question should be defined by the participant's answer. Although I prepared an interview guide, which made it easier to conduct semi-structured interviews regarding time limitations, during the session, I re-ordered the questions following the story told by the interviewee.

While participants shared their ideas, I took notes to show my interest. At the moment of silence, as a researcher, I tried my best to give each interviewee enough time until being ready to share some insights as Ritchie and Lewis (2003) stated that "moments of silence in in-depth interviews are usually very productive," because they indicate that the interviewee is thinking (p. 157).

Before ending the interviews, I double-checked my interview guide to understand whether there are any unmentioned issues left. At the end of each session, I again thanked participants for their contribution and briefly mentioned how their help will contribute to the research.

## 3.5 Data Analysis

This section presents the stages of the data analysis process in detail. After completing the field study, the data collected through interviews and audio recordings were transcribed into digital text files as preparation for qualitative analysis. Then, several coding methods were applied to generate meanings from qualitative data.

### 3.5.1 Transcription of Interview Data

As mentioned above, all the interviews were conducted face-to-face, and participants were audio-recorded both with a digital voice recorder and a mobile phone to have a backup file. During the interviews that took place in a cafe environment, I made sample recordings by the permission of participants in order to prevent any possible problems related to the environment, such as background noise, which might affect the quality of audio recordings.

All recorded interviews were transcribed into written documents. Although transcription is time-consuming, doing it on your own helps to "build an intimate knowledge of your data" (Bazeley, 2013, p. 73). While transcribing, no corrections are made for incomplete sentences, and events that interrupted the interview flow were also noted in verbatim transcriptions.

Translating recorded data into searchable and analyzable files is a significant step, especially in qualitative research (Tessier, 2012). In addition, it is crucial to keep the data safe and accessible because it can be used and analyzed again in the context of another study (Heritage, 1984).

Transcribing audio records into digital text documents was more challenging than I expected. For instance, the transcription of a 60-minute interview took approximately four hours. The first two interviews were transcribed immediately to evaluate and improve my interviewer skills. For example, while transcribing these interviews, I realized that I interrupted interviewees' speech to stick to the interview schedule, which might affect the sequence of the data and result in missing out important details. In consideration of these points, I tried to keep my silence as a researcher in the following interviews. The rest of the interviews were transcribed at the end of the field study.

As all of the interviews were conducted in Turkish, I had to translate all the quotations presented in this study in English. I translated selected quotes after the data analysis process and did not make any correction that would change the core meaning. Figure 3.2 represents the stages of data analysis.

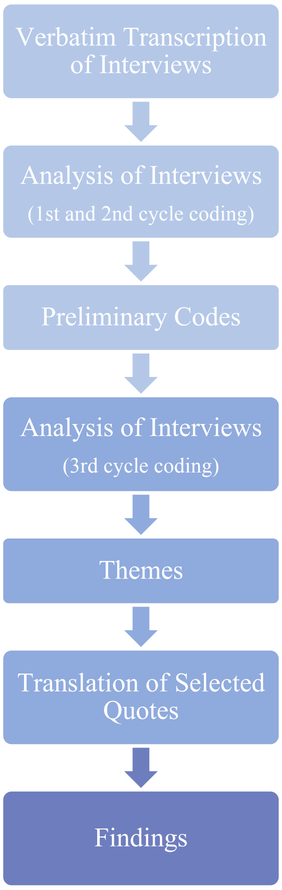


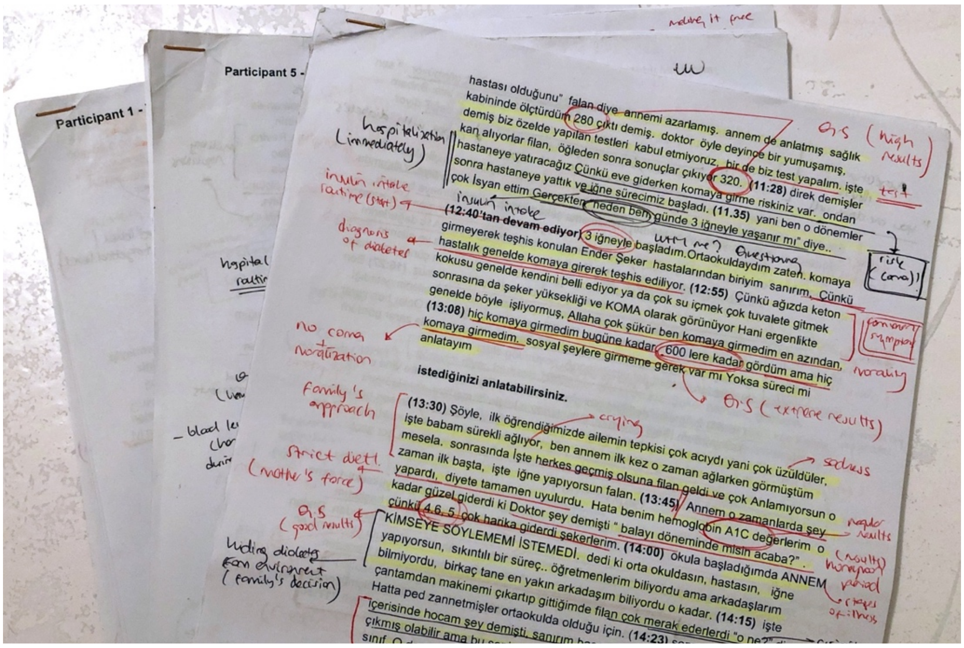
Figure 3.2 Data Analysis Process

### 3.5.2 Analysis of Interviews

As Seidman (2006) argues, in-depth interviews generate an excessive amount of data in a written format, which requires the work of reducing to the most meaningful and significant parts. For a researcher, it is the time to be open-minded and search to find what is essential. Before starting the analysis, I read all transcriptions once more and re-listened some of the audio records to have a broader understanding of collected data. At this point, I added time flags in the transcriptions, which were time-saving while checking the original source for accuracy.

After transcribing and overviewing the data, I started the coding process. As Saldana (2013) explains, “code is a researcher-generated construct that symbolizes and thus attributes interpreted meaning to each individual datum for later purposes” (p. 4). The data was coded in three cycles, and four different coding methods, which are “initial coding,” “axial coding,” “theoretical coding,” and “simultaneous coding,” were used abiding by the “coding canon” of grounded theory (Saldana, 2013).

The first and second cycle coding was completed manually by taking notes on printed transcripts (see Figure 3.3). In the first cycle, I used the initial coding method as my aim was to generate as many codes as possible from the written data. Initial coding is an appropriate method, especially recommended for beginner researchers, to learn how to code (Saldana, 2013). The method aims to divide the data into discrete parts and deeply examine them to investigate similarities and differences with an open-ended approach (Strauss & Corbin, 1998). The initial coding process is also considered as the beginning of discovering categories. However, as Saldana (2013) states, all provided codes during the first cycle are “tentative” and “provisional,” and some of them might be reconsidered and renamed in further stages.


Participant 1 -

Participant 5 -

hastası olduğunu" falan diye annemi azarlamış. annem de anlatmış sağlık kabininde ölçtürdüm 280 çıktı demiş. doktor öyle deyince bir yumuşamış, demiş biz özelde yapılan testleri kabul etmiyoruz, bir de biz test yapalım. işte kan alıyorlar filan, öğleden sonra sonuçlar çıkıyor 320. **(11:28)** direk demişler hastaneye yatıracağız Çünkü eve giderken komaya girme riskiniz var. ondan sonra hastaneye yattık ve iğne sürecimiz başladı. **(11.35)** yani ben o dönemler çok İsyan ettim Gerçekten "neden ben günde 3 iğneyle yaşanır mı" diye..

**(12:40'tan devam ediyor)** 3 iğneyle başladım.Ortaokuldaydım zaten. komaya girmeyerek teşhis konulan Ender Şeker hastalarından biriyim sanırım. Çünkü hastalık genelde komaya girerek teşhis ediliyor. **(12:55)** Çünkü ağızda keton kokusu genelde kendini belli ediyor ya da çok su içmek çok tuvalete gitmek sonrasına da şeker yüksekliği ve KOMA olarak görünüyor Hani ergenlikte genelde böyle işliyormuş, Allaha çok şükür ben komaya girmedim en azından, **(13:08)** hiç komaya girmedim bugüne kadar. 600 lere kadar gördüm ama hiç komaya girmedim. sosyal şeylere girmeme gerek var mı Yoksa süreci mi anlatayım

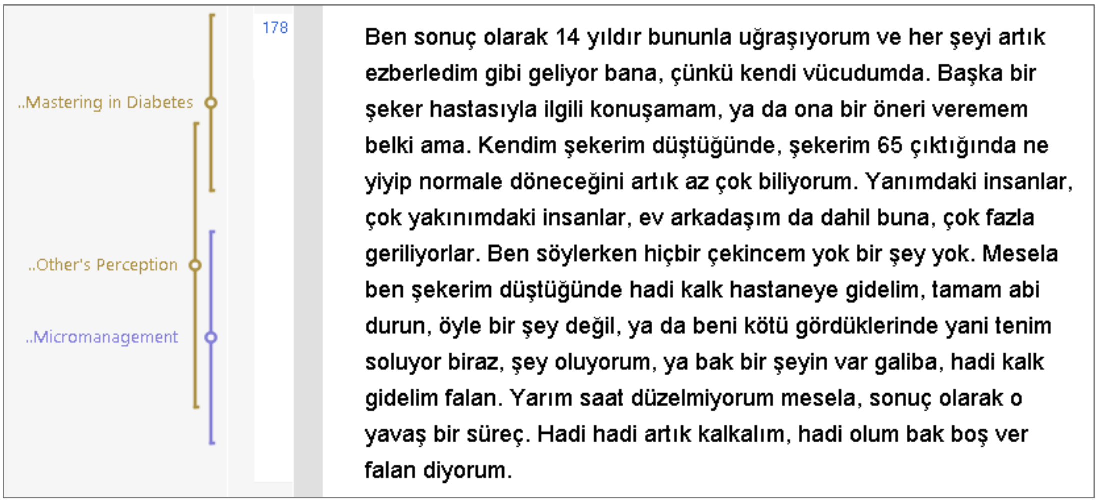
**istediğinizi anlatabilirsiniz.**

**(13:30)** Şöyle, ilk öğrendiğimizde ailemin tepkisi çok acıydı yani çok üzüldüler, işte babam sürekli ağlıyor, ben annem ilk kez o zaman ağlarken görmüştüm mesela. sonrasında İşte herkes geçmiş olsuna filan geldi ve çok Anlamıyorsun o zaman ilk başta, işte iğne yapıyorsun falan. **(13:45)** Annem o zamanlarda şey yapardı, diyete tamamen uyulurdu. Hata benim hemoglobin A1C değerlerim o kadar güzel giderdi ki Doktor şey demişti " balayı döneminde misin acaba?". çünkü 4.6, 5 çok harika giderdi şekerlerim. **(14:00)** okula başladığımda ANNEM KİMSEYE SÖYLEMEMİ İSTEMEDİ. dedi ki orta okuldasın, hastasın, iğne yapıyorsun, sıkıntılı bir süreç.. öğretmenlerim biliyordu ama arkadaşlarım bilmiyordu, birkaç tane en yakın arkadaşım biliyordu o kadar. **(14:15)** işte çantamdan makinemi çıkartıp gittiğimde filan çok merak ederlerdi "o ne?" di
Hatta ped zannetmişler ortaokulda olduğu için. **(14:23)** so
içerisinde hocam şey demişti, sanırım ha
çıkmış olabilir ama bu
sınıf

Figure 3.3 First Cycle Coding

In the second cycle, axial coding was applied as the transitional cycle between the initial and theoretical coding processes (Saldana, 2013). The aim was to rearrange data that were "split" or "fractured" during the first cycle coding (Strauss & Corbin, 1998). In addition, the axial coding process helped to define which codes are dominant and which ones have less importance (Boeije, 2010). In the light of defined categories and subcategories, indicative connections were made. However, Corbin and Strauss (1990) suggested that the relations proposed during the axial coding process should be considered "provisional until verified repeatedly against incoming data" (p. 13).

As mentioned above, the purpose of first and second cycle coding was to generate all potential codes. After two cycles of coding, all transcripts and generated codes were transferred to MAXQDA, a qualitative data analysis software. With the help of technology, all quotations were split into "segments" and highlighted. Then, each extract was sorted to define main codes and subcodes. Simultaneous coding was applied for the qualitative datum that contains multiple codes (see Figure 3.4).



Ben sonuç olarak 14 yıldır bununla uğraşıyorum ve her şeyi artık ezberledim gibi geliyor bana, çünkü kendi vücudumda. Başka bir şeker hastasıyla ilgili konuşamam, ya da ona bir öneri veremem belki ama. Kendim şekerim düştüğünde, şekerim 65 çıktığında ne yiyip normale döneceğini artık az çok biliyorum. Yanımdaki insanlar, çok yakınımdaki insanlar, ev arkadaşım da dahil buna, çok fazla geriliyorlar. Ben söylerken hiçbir çekincem yok bir şey yok. Mesela ben şekerim düştüğünde hadi kalk hastaneye gidelim, tamam abi durun, öyle bir şey değil, ya da beni kötü gördüklerinde yani tenim soluyor biraz, şey oluyorum, ya bak bir şeyin var galiba, hadi kalk gidelim falan. Yarım saat düzelmiyorum mesela, sonuç olarak o yavaş bir süreç. Hadi hadi artık kalkalım, hadi olum bak boş ver falan diyorum.

Figure 3.4 Multiple Codes

The mapping feature of the software called “Hierarchical Code-Subcodes Model” was used to illustrate the order between codes and its subcodes (Figure 3.5). For example, for a quote placed under the main code “management,” “insulin intake,” and “measurement” were the subcodes. At this point, being able to see all data in an organized way was helpful to recognize the relations among the codes.

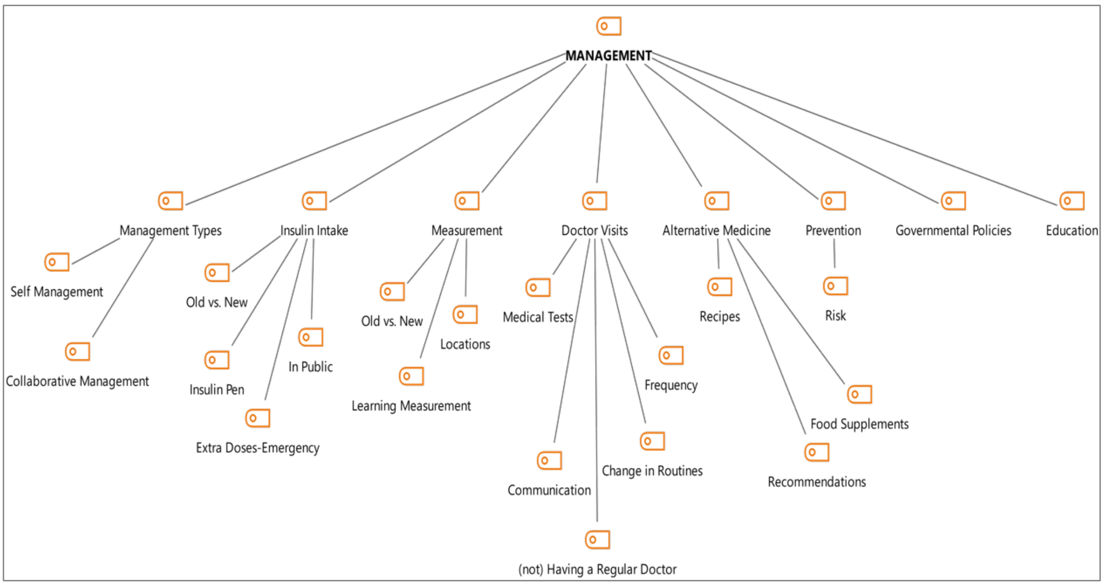


Figure 3.5 Example of Code Hierarchy

The third cycle of coding was theoretical coding, which defines the potential relations between categories and takes the analytic story a step further in a theoretical direction (Charmaz, 2006). The purpose of theoretical coding is to define the "core category" that explains what "this research is all about" (Strauss & Corbin, 1998, p. 146).

Therefore, in the third cycle, some codes were merged and reworded, and new codes were created when required. This process also revealed that sometimes, the same code was used for different interpretations by different participants.

Table 3.4 demonstrates the main codes transformed into themes, which are "Construction of Chronically Ill Self," "Living with Diabetes," "Managing Diabetes," "Technology Use in Type 1 Diabetes," and "Online Health Communities." The final analysis was conducted and presented in accordance with these themes.

Table 3.4 Codes and Related Themes

| Main codes and Subcodes | Themes |
|---|---|
| Diagnosis<br>Acceptance<br>Risks<br>Sharing illness with others | Construction of chronically ill self |
| Daily life routines<br>Challenges<br>Positive aspects<br>Perception of diabetes | Living with diabetes |
| Insulin intake<br>Blood glucose monitoring<br>Expertise<br>Collaborative management | Managing diabetes |
| Device Use<br>Quantification<br>Collaborative management<br>Digital body | Technology use in type 1 diabetes |
| Introduction to the community<br>Interaction with the community<br>Inside dynamics<br>Benefits of the community | Online health communities |

### 3.6 Limitations of Data Collection

As mentioned in Section 3.3.4, this study uses criterion-based sampling, or purposive sampling as commonly used in the literature (Ritchie & Lewis, 2003), and targets people with particular characteristics. Although the members of the selected online community share similar characteristics, the people above 18 and using wearable diabetes technologies were in a limited number compared to the total members.

Location was another challenge of the fieldwork because the people who agreed to participate in the study were residing in different cities. Due to time and travel constraints, the scope of the field study was limited to 12 participants living in the following cities: Izmir, Ankara, and Istanbul.

The decision of sharing or not sharing my personal experience with chronic disorder was the biggest dilemma throughout the study as sometimes it made the user feel intimate and comfortable while sharing information, whereas some of them considered me as an expert and they tended to summarize their insights instead of sharing in detail by stating “as you know…” (see Section 3.4).

Besides, there are two points that might have affected the quality of data. The first one is a limitation of the selected method. The inquiry was gathered through interviews, which means it mainly reflects individual experiences and does not include direct observation of contextual inquiries. Moreover, during the interview, participants are asked about their past experiences, and the responses are based on what they remember. Hence, the gathered data is cross-sectional.

The second point is related to the unexpected nature of the couple interviews. During the first couple interview, which was held with Gözde and Cem, one of the parties was dominating the environment with own thoughts and experiences and did not spare enough time for the other party to share insights. The insights derived from this meeting was relatively limited and vague. On the contrary, other couple interviews were rather advantageous to investigate the role of significant other in diabetes management.

### 3.7 Summary

This chapter presented the scope of the study, research approach and design, sampling method, data collection, and, finally, the analysis of the gathered data. As the study aims to analyze the community practices shaped around diabetes and related technologies, a qualitative research approach was adopted. Semi-structured interviews were conducted to obtain user insights about predefined topics. Before the field study, I conducted a pilot study to test the interview guide. However, I was not able to test community-related questions as the participant was not a member. That is why the interview guide was updated after conducting the first two studies in order to improve the community section. For the main research, I conducted 11 in-depth interviews in total, and each session took between 60 to 120 minutes. All interview data were transcribed verbatim, and the gathered data was coded by using open coding, axial coding, and theoretical coding. Themes were derived from relevant codes, and quotations were selected to support the meaning. In the following chapter, the findings of the analysis are demonstrated.

# CHAPTER 4

# FINDINGS

The methodology chapter has demonstrated the stages of the fieldwork. As I mentioned in the previous chapter, a series of interviews were conducted with the members of an online diabetic community.

In this chapter, I initially describe how participants become “chronically ill selves” in the first section. Later, I explain how participants integrate diabetes into their everyday life. Thirdly, I present how participants manage diabetes in everyday life, which also demonstrates their routines and introduction to device use. Afterward, in the fourth section, I explain how technology use in diabetes affects the management process bodily and behaviorally. In the final section, I clarify the role of online communities in the management of diabetes and the participants’ perceptions regarding the characteristics and the benefits of these communities.

## 4.1 Construction of Chronically Ill Self

In this section, I present the participants’ journeys of becoming a self with diabetes, starting from the moment of diagnosis to the time when they accept their illnesses regarding its potential risks and the impacts on their everyday lives.

### 4.1.1 Diagnosis of Diabetes

The participants’ diagnosis stories mostly meet on common ground: The signs and symptoms. However, when and how they were diagnosed with diabetes are where their stories vary. Among the participants, there are three kinds of stories observed during the study. The first one is associated with the participants who were diagnosed with diabetes in their early teen years with well-known symptoms, including unexplained weight loss, increased thirst, and frequent urination. Esra exemplified how she "became diabetic" as follows:

> I was doing sports during my middle school years. I was playing basketball and during that time, I lost weight really fast. However, I never felt ill [*hasta duygusu*] even though I was feeling thirsty and drinking so much water. I remember going to the bathroom a lot and feeling thirsty a lot as well. I guess it was my mom or someone from my family who insisted on going to the doctor. I went to the hospital without knowing what they suspected and gave blood for tests. When the results came, I learned my family doubted about this result and the doctor wanted to check for my blood sugar levels. With the results, it was confirmed that I have high blood sugar and I was diagnosed with diabetes.

The second story represents the participants who were diagnosed at relatively later ages, yet shares common signs and symptoms mentioned above. Eren, who was diagnosed at age 27, described his diagnosis story as follows:

> I was on military duty during that time and started to drink water frequently. I was feeling extreme thirst and going to the toilet too often as well due to drinking too much water. There was also some weight loss, but I could not realize during my time in the military. I learned when I was weighed in a hospital. I went to the infirmary, thinking I caught a cold. However, when I was transferred to a hospital, I learned I had diabetes.

Another participant Güzin, who was diagnosed at age 32, mentioned that she has a form of type 1 diabetes that develops in adulthood called Latent Autoimmune Diabetes of Adulthood or LADA in short. Moreover, she also mentioned that in her perspective, being diagnosed at later ages makes the acceptance of diabetes relatively easier (see Section 4.1.3). Güzin explained her diagnosis story as follows:

> My story doesn't have a deep past. Type 1 diabetes is usually diagnosed during childhood, but mine is rather new; it will be two years in March. I was in a sugar come of which I wasn't even aware. I went to the doctor, thinking I had some poisoning. The doctor said, "Let's check your blood sugar levels" and I learned my average HbA1c level for 3 months is around 11. I was immediately hospitalized and stayed there for a week.

The third story describes the participants who were also diagnosed with diabetes at further ages, yet as a result or side effect of another health problem. Interviewees mentioned that they had several doctor visits or were hospitalized for a certain period of time for different reasons before they were diagnosed with type 1 diabetes. Ahmet explained this situation as follows:

> I can say that I am an interesting case. I got my tests done in Adnan Menderes University Research and Application Hospital, and they sent the results to Ankara. Before diabetes, I had flu, which lasted around 9 months. During that time, I used any medication and natural treatment I could, but it didn't pass. According to what doctors said, that flu microbe killed my pancreas, and I became a type 1 diabetic. This happens one in a billion, and I had it. 12 students in that research hospital wrote their thesis on my case because it is really interesting.

Another participant, Hande, mentioned her hard times while she was hospitalized and the ongoing mystery about what caused her diabetes as follows:

> I had some problems with my intestines and was diagnosed with ulcerative colitis. With the results of the tests followed, I was told I had pancreatitis and

> was hospitalized for 10 days. After a month following this incident, I was diagnosed with type 1 diabetes. All came back to back. Pancreatitis was attacking the beta cells producing insulin, and while this can cause my type 1 diabetes, ulcerative colitis can have a possibility to trigger it. So, reason can be all.

Get back to early age diagnosis stories; some of the interviewees mentioned that the symptoms were misjudged by their families and friends. Though type 1 diabetes is recorded as one of the most common chronic illnesses among children in the world (Torpy, 2010, p. 682), what Meral stated illustrates a prejudice towards the reality of early age diagnosis:

> One day someone asked my mother whether drinking a lot of water, and my frequent visits to the bathroom could be related to diabetes. My mother rejected saying a small kid my age could not have diabetes. My family has never heard of type 1 diabetes, and I think it is a general assumption in the society that diabetes is associated with older people, not with little children.

The words of Meral highlights one of the significant points about the social construction of diabetes within society. Most of the interviewees mentioned that when they say "I am diabetic" [*şeker hastasıyım*], it is perceived as type 2 diabetes, known as non-insulin dependent diabetes and generally diagnosed above the age 40. Moreover, most of the participants indicated that before their personal experiences with diabetes, they thought that the only reason which causes type 1 diabetes was an inheritance. However, medical information sources emphasize that the inheritance pattern of type 1 diabetes remains unknown separate from the reality of predisposition (U.S. National Library of Medicine, 2019). One of the interviewees, Aslı, exemplified how this misbelief resulted in not noticing her diabetes as "I had the most common symptoms; however, we could not understand as we did not have any diabetics in the family before."

Ebru, another interviewee, stated nearly the same situation by explaining how her family's wrong interpretations about diabetes symptoms and their treatment interventions led to a coma as follows:

> I was 8 years old when I suddenly lost weight and started to drink water and go to the toilet frequently. My family thought I had tuberculosis after my weight loss, and they tried to help with honey and grape syrup. Consequently, I went into a coma and lost consciousness. They rushed me to the hospital at the last minute.

These stories show that the prejudice towards the early age diagnosis and the strict belief in that type 1 diabetes only occurred with inheritance result in low-level awareness of diabetes. By neglecting obvious symptoms, families' interpretations might cause misdiagnosis or missed diagnosis. The story narrated by Ebru shows that low awareness of diabetes can have critical results, which may even lead to hospitalization.

In brief, beyond the commonalities, participants mentioned three different types of diabetes. Moreover, they argued about the importance of social circles and their awareness about diabetes, which has a substantial role in the acceptance of the illness, which is discussed in Section 4.1.3 thoroughly.

### 4.1.2 Reactions to Diagnosis with Diabetes

Most of the participants who were diagnosed with diabetes at an early age mentioned that they were not capable of understanding the responsibility of being diabetic in the beginning, while it was also emotionally challenging for their families. Meral exemplified this as:

> When we first learned about diabetes, it was excruciating for my family. My parents couldn’t stop crying, and seeing them like that was a first for me. All the acquaintances came to visit. At first, you do not really understand what this is all about; you just count your injections.

Type 1 diabetes brings along many lifestyle modifications, such as constructing new dietary habits, which might be hard to adapt for younger diabetics. These challenging facts of diabetes made Ebru experience anger and rebellion towards her parents, as she stated:

> I got ill-tempered [hırçınlaşmıştım], I remember that. Whenever the doctor prohibited me from eating something, I yelled at my parents, “If you love me, you will let me eat that!” as I could not go against the doctor. I even cried out against God saying, “You have the power for everything, the power for making me sick. Then why can’t you heal me?” When everything I like got banned, I just wished to blame somebody.

As Ebru stated, most of the participants mentioned their self-questioning to find a convincing reason that was hidden beneath their diabetes. This victim mentality makes handling the illness even harder for the diabetics. Below, Aslı explained how the chronic nature of diabetes affected her psychological well-being, and she required medical help to cope with the changes in her life besides her family’s and the significant other’s supports.

> I got depressed at first. After all, it is a chronic illness. You are told to have injections 4 times a day, and you cannot eat particular foods. At first, these sounded horrific. I got both psychologic and psychiatric support to cope with

> my crying hysterias. All I was asking was why me. At the university, while everyone else was fasting, I had to go to the cafeteria to eat. During classes, my blood sugar dropped abruptly, and I had to leave. It was hard to accept, but my family and my husband supported me during every stage of my journey.

Hande is one of the participants who were diagnosed at later ages, yet the reality of becoming diabetic was still shocking for her and the family. Similar to Aslı, she also stated that her family was the biggest support to overcome hard times. Moreover, she indicated that her characteristics also played a significant role in accepting diabetes (see Section 4.1.3). Hande explained how her family's reaction was affected by the way she handled diabetes also changes her family's reaction as follows:

> It was a tough time, but I did not receive any psychologic support or treatment. I got through it with the support of my family. I tend to accept things easily, so I accepted this new fact rather fast despite my shock and fear. I knew that despite their effort for masking, my parents were very upset. I kept seeing the miserable expression on their faces. However, I think they believed I could cope with it when I got used to my new fact and returned to my normal life rather easily.

Another participant drew attention to the point that families are also having difficulty in accepting the chronical nature of diabetes and looking for a cure. Burak exemplified this as follows: "When I was first diagnosed, my family thought of going to Belgium, where my aunt lives and searching for treatment there. However, such a treatment doesn't exist. It is a chronic illness". In addition, Ebru exemplified how her family insisted on alternative treatments such as therapeutic recipes to cure diabetes below:

> Back then, my mother looked into aloe-vera, she insisted that aloe-vera would cure me if I drank a mixture of its juice and milk every day, my pancreas would start working again. I drank it every day for my mother, I tried it so she would not be upset. Others say squeeze a lemon into the yogurt before going to bed…and yes, I will try that too. But, how can you re-function a defective organ (pancreas) with that stuff! That is very difficult to explain to people.

Aside from the emotional reactions or alternative treatment methods, some participants who were diagnosed at an early age stated that their parents did not let them share their illness with other people. According to these participants' statements, hiding their diabetes from others led them to ignore their condition, which was one of the reasons for the problems related to diabetes management. Esra pointed out this issue as follows:

> My mother's motivation was not telling anybody about my diabetes. This decision was not something that we had discussed, and I agreed. I applied their decision, but I also lived as if I did not have diabetes. I think not telling about diabetes has the biggest impact on wrong diabetes management. It was really bad because if you hide that you have diabetes, you think you can continue living like a "normal" person.

What Esra meant with this phrase is primarily about dietary habits, which have a critical impact on managing diabetes. Moreover, her emphasis on "acting like normal people" also leads to the discussion of how chronically ill self is perceived different from others in terms of capabilities, which is discussed in further sections (see Section 4.2.3.2).

To summarize, the diagnosis of diabetes is emotionally challenging for the participants and their families. Most of the time, the chronic aspects of diabetes, which require critical adjustments in daily life habits, make people experience anger, and it might take some time for people to get used to living with diabetes. Apart from this, the diagnosis age also has an impact on how people handle their chronic conditions as younger diabetics might not be able to realize the responsibilities of diabetes. As it is understood from the words of participants, family support plays an essential role in handling the diagnosis of diabetes. However, overcoming the emotional challenges of diabetes does not necessarily mean accepting the illness. In the following section, I discuss the experiences of participants on the way to acceptance in detail.

### 4.1.3 Acceptance of Diabetes

In this section, I discuss acceptance. First, I define what it means for different participants. Then, under separate subsections, I focus on two aspects of acceptance: recognition of risks and sharing diabetes. Most of the participants mentioned that there was a specific time or event which made them realize the reality of being chronically ill regardless of the moment of their diagnosis while they were talking about their experience with type 1 diabetes. Those events were presented as milestones in the acceptance of the illness by participants. Ebru stated that it took a long time to accept diabetes, and her awakening moment was the time when she started to use an insulin pump (see Section 4.4.3). Previously, diabetes had been a thing to be cared about only because of her parents' insistence.

> I have recently accepted [*kabullenmek*] my diabetes, even though I was diagnosed 19 years ago. At first, I was guided by my parents' concerns. For example, I had my injections when they said I should, but when I was alone at home, I did not have them. I did not want to admit it, but after the pump, I have faced my reality because I am carrying a device on my body, and I have to take care of my diabetes as long as I have it.

Ebru's statement shows that the ubiquitous presence of the product (i.e., insulin pump) mediated such acceptance. Moreover, with the agency of product, she has started to the responsibility of care, which might be considered as the beginning of her "biosocial practices" (Rabinow, 1996). Similar to her, another participant Esra narrated that how changes like the visibility of diabetes through device use or socializing through diabetes such as joining a diabetic running team led her to adopt a diabetic identity: "For a long time, diabetes was not a part of my identity. Later on, as I went by here is my pen, here are my devices, it became something also known by others."

Integration of diabetes into everyday life through management and exercise routines makes it inevitable to describe a diabetic identity. Hande, who has launched a personal blog to share first-hand experiences, explained why she does not share any personal information in her blog, rather the experiences of 35 years of diabetic woman as follows: "There is no point in people knowing that I am Hande and how I live my life… what matters is the story of a 35-year-old, type 1 diabetic's struggle with IVF [*tüp bebek*]". Her statements also revealed the importance of experiential knowledge and how communities are perceived as one of the information sources, which are discussed in further sections (see Section 4.5).

To get back to the reasons why Ebru denied her diabetes for many years, Ebru mentioned that her family was not aware of the difficult conditions of the illness, and as an eight years old child, she was not capable of understanding them by herself. She exemplified her struggle as follows:

> My family did not tell me about diabetes, and I did not understand. For example, I was eating prohibited food because, in my child's mind, insulin was fixing everything, so why should I keep myself. Even my grandmother would put sugar in my tea, saying that little amount would not harm, and a child could not drink tea sugar-free. All doors lead to unawareness. When I

> say I would eat salad and would not drink coke, they say I should not worry and continue my old habits as everything will be fine. It puts pressure on me that makes me indifferent to my situation.

As stated, she got used to believing that she could consume anything as long as she kept taking her insulins. This turn of mind resulted in neglecting diabetes, which also caused not managing her diabetes properly. The cultural aspect of such an experience is also related to the misbeliefs about diabetes in children, as in the example of her grandmother. Moreover, families might regard their children as inadequate, and for this reason, they may not be willing to give them the entire responsibility of care.

Burak, who had also been diagnosed with diabetes at an early age, mentioned the time when he started to approach his diabetes more seriously as follows: “I started to visit my doctor frequently, and we began to have serious conversations about what I should do. That was when I started to comprehend that I had diabetes”. Furthermore, he claimed that his family’s reaction to his diabetes made it difficult for him to accept his illness. He explained this in detail as follows:

> My family got stressed because they could not believe and struggled for me to continue my life like before. I think this was making acceptance hard for me. When I stop eating chocolate or drinking coke for a while, I do not miss them because they were not my habits in the first place. However, I remember my father coming home with diabetic labeled chocolates every evening and told me to eat without getting worried. I think the hardest part of acceptance is that our family has a hard time accepting this.

As it is understood from participants’ statements, even though a person fulfills the responsibilities of diabetes, it does not mean that the same person accepts the reality of diabetes. Acceptance is a demanding process, in which each individual has their turnaround moments while dealing with both personal and societal challenges. For example, the family's manner of recognizing the reality of diabetes plays a significant role in individuals' perception of diabetes.

#### 4.1.3.1 Recognition of Risks

People who have type 1 diabetes are at the risk of having long term complications, which are gradually developed and might result in serious harm on the body by affecting eyes, heart, legs, kidneys, nerves, and more (International Diabetes Federation, n.d.). During the interviews, nearly all of the participants mentioned their awareness of these risks. For example, fluctuating blood sugar levels might cause low or high sugar, which is terminologically named, respectively as hypoglycemia and hyperglycemia. Although both of the conditions arise from inadequate diabetes management, Esra explains how their outcomes and effects on a patient's everyday life differ in practical level as follows:

> Both are very bad. Hypoglycemia can cause unconsciousness, even has death risk, and this means I am in desperate need of someone's help. Let us say my blood sugar level drops to 50. At that moment, I must have something that can increase the sugar level. If someone does not give me glucose through my mouth or veins, I might even die. Hyperglycemia means the blood sugar level to increase up to 300, even 500. I have lived around these levels for years. Even though these levels do not cause abrupt damage, I might have gone blind or might be on dialysis now if I had not gone to the doctor and given up on my old habits.

According to the participants' statements, being aware of the risks of diabetes makes them feel the fear of experiencing any long-term complication, which plays a significant role in acceptance. While indicating the change in their attitudes towards diabetes management, participants also mention the impact of medical authority. Esra, who described her diabetes as a routine activity in the previous section, exemplified her behavioral change after facing the potential risks of diabetes as follows:

> When I went to the doctor and got tests done, he said, “What are these values? Are you doing this to kill yourself?” This was a critical moment for me; it shook me off and made me realize the facts. I realized my values were very high, and I had to fix them to continue with my life. Then after my marriage, I became extra cautious about having a child and of the fear of kidney failure. I have embraced the fact that I accepted my diabetes after the age of 25 with my adult identity. I can say I started doing what I should have done from the beginning after I was 25.

This quote also demonstrates her moralization regarding appropriate diabetes care. Hearing the critical approach of the doctor led Esra to conduct a self-assessment about her diabetes management, and, as a consequence, she accepted her diabetes and its potential outcomes. She described this situation as “the adoption of diabetic identity.” Also, she emphasized the role of maturity in acceptance. Regardless of her experience with diabetes, she started to take unstable blood levels seriously as she grew older, by considering the risks she could face in the forthcoming years.

Meral’s comments regarding not being aware of what diabetes is (see Section 4.1.2) brings up the discussion for the tendency of associating diabetes management only with medical care routines such as insulin intake.  This might result in considering the illness as a routine activity with medical requirements, which can be interpreted as a kind of denial. On the other hand, the routinization of diabetes may pose an obstacle to realize critical matters, such as risks of diabetes. Similar to Meral’s statements, another participant Esra pointed out this significant matter as follows:

> For years, I lived as if I wasn't diagnosed with diabetes. I started to accept my place in the diabetes community [*diyabet toplumu*] at the end of my 20s. Social media with many groups has a significant impact on that. Until that time, I didn't know anyone with diabetes. For me, diabetes was something for what my doctor wrote prescriptions, I received medication and got tests done in a hospital once in a year. I felt like I was taking some routine blood pressure pills, and as long as I was doing that, I could continue my life the way I wanted.

This quote also highlighted how the diabetic communities on social media had an impact on the awareness about responsibilities and acceptance. As Esra stated above, through online communities, the illness and people with diabetes become visible and reachable, which helps people to normalize their condition. I discuss the benefits and the dynamics of diabetic communities and their effects on the management of diabetes in detail in further sections (see Section 4.5).

#### 4.1.3.2 Sharing Diabetes with Others

As it is discussed above, the participants' tendency not to share diabetes with other people might be related to their parents' attitudes. At this point, participants' statements showed that the reason why families want to hide diabetes is mostly related with their concerns regarding cultural stigma in diabetes as Meral indicated below:

> When I started school, my mother didn't want me to tell anyone because she didn't want me to look weak [aciz]. However, I started to tell everyone at high school. Even now, my mother doesn't talk to her colleagues about my diabetes and she also doesn't want me to tell either saying they don't need to know. I am not sure whether it is acceptance or otherwise, but my mother does not see me as ill. She says I am fine, and I am doing everything I want.

Meral's statement showed that her mother was afraid of the perception that her daughter is not well, in the sense that she is lacking or vulnerable as the society perceives diabetes like a deficiency. That is why she wanted Meral to hide her vulnerability from others, which might be considered as a coping mechanism.

However, most of the participants using wearable technologies emphasized that they are willing to share their experiences as they believe that making diabetes visible contributes to raising awareness about diabetes and the related technologies, as well. Meral exemplified this as follows:

> Contrary to my mother, I want people around me to know I have diabetes. I am using wearable diabetes technologies like a pump and many people with diabetes do not know about them. Neither do their families. One of my colleague's daughter started to the use of the insulin pump and sensor after she learned it from me. I tell anyone who asks. I explain that diabetes can be seen in children and talk about the symptoms. I want to create awareness.

Aside from the reasons mentioned above, sharing diabetes is also crucial for the prevention of any crisis. Nearly all of the participants emphasized that they educated their friends or colleagues about how to recognize an emergency and treat any seizure correctly. Güzin explained this as:

> I let my colleagues know about my condition in case they find me fainted, unconscious, or in any situation that I need help. I have told everyone around me about my doctor, the devices I am using, insulin, and glucagon hormone.

Cem also stated that experiencing any emergency at work, such as hypoglycemia, also makes diabetes visible, and it becomes impossible to hide their condition from other people. Moreover, he claimed that in business life, expectations from the people with diabetes could not be equated with the others, which brings the up the discussion of the (im)possibility of being normal (see Section 4.2.3.1) as follows:

> Everyone around you should know about your condition. A person with diabetes can’t be treated as a normal person. Let us say your employer wants you to work extra during lunchtime, but you cannot skip any meals. We can have blood sugar level fluctuations leading to hypoglycemia or hyperglycemia; therefore, we do not always have the strength for challenging tasks. Everyone in your workplace from your colleagues to your boss must know about all these. Hiding is not an option.

Sharing diabetes with other people is considered to be closely related to the acceptance of illness (Babler & Strickland, 2015). Correspondingly, my findings show that there are three ways in which sharing illness and acceptance are related: First is raising awareness about diabetes and related technologies. This is not only significant to have a common understanding with other people, but also to share knowledge with the other diabetes regarding the latest technologies and treatment methods. Second is dealing with emergencies because, most of the time, it is not possible to cope with the situation alone. That is why sharing diabetes also means accepting illness and its possible drawbacks. The third is making the particular requirements of the illness visible, as Cem exemplified with the relation between changing his routines according to the expectations at work and its possible effects on blood sugar.

### 4.1.4 Summary

Section 4.1 presented the diagnosis stories of individuals and their stance on the way to acceptance. Although in some points, participants went through similar experiences, the age when participants were diagnosed and the medical opinion about what caused their diabetes are the two points that considerably differentiate their stories. Regarding the diagnosis age, the term maturity was mentioned in the context of acceptance. The statements of the participants diagnosed with diabetes at an early age revealed the cultural misbelief about the appearance of type 1 diabetes among children. The parents were not able to interpret the symptoms and the physical signs of diabetes as they got used to believing that diabetes is not an illness that develops at an early age. Moreover, this attitude is also related to the difficulties experienced by the acceptance of diabetes.

The stories are to contextualize later discussions of diabetes management and product use. As Ebru stated, having difficulties and starting to use wearable technologies made her realize the reality of diabetes, which is more than a routine activity regarding its potential risks. Therefore, acceptance is also associated with the recognition of these risks. With the light of this awareness and the social support of online communities, individuals construct diabetic identities, which are capable of self-management in contrast to society's perception.  Hence, their acceptance also plays a significant role in how their families or friends perceive living with diabetes.

Building upon the topics explained in Section 4.1, in the next section, I discuss how living with diabetes is perceived at the personal and social context and how participants integrate diabetes into their everyday life by adapting new routines in the direction of having "normal" values like other individuals.

## 4.2 Living with Diabetes

In this section, I present participants' insights about how the integration of diabetes in everyday life transformed their habits and routines. Moreover, I discuss the social construction of diabetes with regards to patient and society's perceptions. Two participants of the study, Gözde, and Cem were a married couple, whom I interviewed together as described in the methodology (see Section 3.4). Cem, who also spoke on behalf of his wife, described living with diabetes from a broader perspective with the following statements:

> Diabetes is the most crucial fact in our lives. It is our priority. As the first thing in the morning, we check our blood sugar level before going to the bathroom. Diabetes is everywhere from our home to our workplaces.

Since fluctuating blood glucose levels might lead to dramatic results, which are mentioned as risks of diabetes above (see Section 4.1.3.1), people with diabetes are obliged to change their behaviors in order to have consistent blood glucose levels. Consequently, type 1 diabetes becomes the thing that is placed “in the middle of people’s lives” not only by altering their everyday life routines, as mentioned by Cem, but also by occupying participants’ minds every second. In connection with this, Güzin commented on how she feels about being in control all the time as follows:

> There is no moment that I do not think about diabetes. It is on my mind whenever I go out for a walk, have my meal, and afterward. It is like an app running in the background. Diabetes means “control” to me.

In the following subsections, first, I discuss how diabetes change individuals’ daily life routines, such as dietary and exercise habits. Then, I demonstrate personal and social perceptions of diabetes in everyday life with the stories from school and work-life interactions.

### 4.2.1 Changes in Daily Life

Ahmet commented on the effects of integrating diabetes in his everyday life as follows:

> It is really challenging as you now have to live in a way that you are not used to. All of your habits and all your life has to change. I truly had hard time getting used to that new life.

As he stated, what makes being diagnosed with diabetes difficult is the fact that the disease alters people's everyday life routines. Almost all other participants mentioned that taking responsibility for the burden of care also might result in the feel of frustration.

On the other hand, most participants' statements showed that they perceive their home as a safe place to keep their diabetes under control, and they were afraid of performing the care outside their homes. Hande exemplified this as follows:

> At first, I was very anxious. I was thinking about what I would do when I went out, and my blood sugar dropped or increased. What would happen when I got on a plane? What would I eat outside? What kind of life I would have when I was not at home? These were distressing me. During that time, I gave a break to my social life hence going out. My fingers were all pierced due to measuring blood sugar levels very often. Then I said to myself I couldn't continue living my life in this panic mode all the time. I learned to live cautiously. I am always carrying some snacks in my bag, and this is making me feel safe. I can say that I returned to my routine two years ago before diabetes.

In the earlier times, she was afraid of having an emergency outside the home because she was not aware of how to behave in emergencies, especially the ones that might occur in an unknown environment or particular conditions, such as traveling by plane. Moreover, she mentioned being a lack of social life due to two reasons: The first is feeling panicked about the risk of emergencies in unfamiliar places, as mentioned above. The second is related that as she was over-controlled and measuring BG level quite often, there were scars on her fingers, making her diabetes visible. In time, as she becomes experienced in diabetes, she started to develop strategies such as carrying a snack with her, which make her feel safe and prepared. Furthermore, she started going back to her pre-diabetes routine as a consequence of accepting and integrating diabetes into everyday life.

When they are outside the home, participants always need to carry several supplies to take care of their diabetes, which is described as a diabetes setup in this study. The scope of the diabetes setup depends on which management methods that participants use and the different circumstances, as well. Most of the participants, including Aslı, mentioned that not forgetting their diabetes supplements has a great importance on their daily routines. She explained the content of her diabetes setup as follows:

> I have a small bag that I put all of the stuff like my insulin, my sugar tablets, and others. Consider it like I have my wallet with me. It is even more precious than my wallet.

Similar to Eren, Hande also mentioned almost the same issues and shared her concerns as follows:

> I cannot be spontaneously deciding on going down to the beach for a walk freely [*elimi kolumu sallayarak*], because I have things that I should always carry with me. For example, I came here without my bag, but I have my glucometer and sugar cubes in my pocket. Even though it is a close distance, I do not want to leave things to chance.

To continue, Hande stated that no matter how far away from home, they have to carry at least the essentials of their diabetes setup due to the perception of risk. Apart from taking a walk, other everyday activities that participants mentioned are swimming and preparing for a vacation. Swimming becomes challenging because participants mentioned that sweating and dehydration might affect their blood glucose levels. In regard to traveling, for instance, Hande explains how she has to plan and pack everything carefully as follows:

> Before going somewhere, I have much preparation to do. I have to pack my pump set, insulin pen, their back-ups, and many others. Half of my suitcase is usually packed up with this stuff. Before, I could go to trekking just with a very small bag and could spend a week away without worry. However, now, it cannot be like this.

As she stated, in the past, she got used to traveling with a few items. However, since diabetes changed most of the daily life routines due to the perception of risk, now she has to make sure that she takes anything that might be needed in case of an emergency during the vacation. Beside traveling, participants mentioned extreme changes in their dietary and exercise habits, which are discussed as the dimensions where diabetes reveals itself in the following sections.

#### 4.2.1.1 Diet

As participants stated, discovering the effects of food on their blood level is an exploratory process that consists of many trials and failures. Moreover, what makes changing the dietary habits challenging is not the part of developing a healthy diet. Instead, maintaining these habits all the time, especially outside the home, is the hardest part. Eren explained his approach regarding the change in his dietary habits as follows:

> You cannot always be cautious about what you eat; one day, you can follow a strict diet and the other day, otherwise. This made me feel like I should redeem myself for the times that I cannot control what I eat. At first, we almost stopped eating outside. We were hesitant that we could ever find something proper to eat. Now, we got used to our new diet. We mostly go to specific places where we are sure about the meal. When we go somewhere new, we look for the meals that we can predict its effect on the blood sugar. However, of course, you feel a restriction.

On the contrary, the participants who used to have a healthy diet did not describe the changes as difficult. Aslı stated that getting used to taking insulin before the meals took some time for her.

> I have always been careful about eating healthy and having an exercise routine. Therefore, I didn’t encounter a great challenge in changing my lifestyle. However, I had a hard time getting used to taking insulin. In the beginning, I would always forget I should have had my insulin shots before the meals.

As explained in Section 2.4.2, among people with diabetes, building up a healthy diet is mainly achieved with carbohydrate counting. The participants using the insulin pump stated that they were taught about the method at hospitals during the introduction to the product, while others gained the knowledge through online sources or printed materials. In this regard, participants mentioned that online communities are one of their information sources, as Ebru stated: “In the group, they share recipes by indicating how much carb they contain, which is very useful. I have learned a lot from the posts that explain the carb amount of different foods.” However, these kinds of informational contents also raise the question of confidentiality (see Section 4.5.4 for further discussion). Hande questioned the reliability of shared information as follows:

> One of the parents of children with diabetes asked about the carbohydrate amount of Ashura (a type of pudding) as her child likes it a lot, and someone directly replied with a numeric value before asking the recipe details such as size of serving and which kind and how much of the dried fruits and nuts are used. If you want to keep a proper diet, it is not possible to talk without knowing such details.

Last, Burak emphasized another critical aspect of carbohydrate counting: helping calculate the amount of insulin required after meals (see Section 4.3.1.1). He stated that “eating healthy is not enough; this is a greater responsibility as you need to calculate and integrate this habit into your life.” With regards to these statements, having a healthy diet is not only about being aware of what you eat or how to count carb values, what matters is the consistency in healthy dietary habits.

#### 4.2.1.2 Exercise

As stated in Section 2.4.2, having regular exercise habits is highly recommended for better diabetes management. However, the capabilities of the ill-body might differ depending on the type and the intensity of the exercise. In this manner, there is an adaptation period in which individuals discover the limits of the body with diabetes and built their exercise routines accordingly. For instance, Esra was a basketball player before being diagnosed with diabetes. After her diagnosis, she had to give a break while getting used to adjusting her exercise routines in parallel with her monitoring and insulin intake routines.

> I gave a break for a while during the time I was getting used to taking insulin and my fluctuating blood sugar levels. After a while, I started to think that I could return to my old sports routine. Then, I started playing basketball again.

What Esra stated shows that the reason why she gave a break was more related with the anxiety of daily diabetes routines. Once she become experienced in diabetes and got used to these routines, she overcame this anxiety and got back to her old routines. Moreover, she has become a professional runner who takes part in races with her team. She explained her story as follows:

> I am interested in running since 2012. One day, I saw a news on the TV about a runner with type 1 diabetes and then started to follow him on Instagram.

> Through social media, we started to talk about how he manages his exercise routines and diabetes. After a while, we met in person and have become good friends. In, 2017 he told me that one of the well-known diabetes organizations is going to form a running team only for people with type 1 diabetes, and he invited me to participate. At the beginning of 2018, we had our first meeting, and since the day I joined the team, I have a diabetic identity. Previously, I got used to knowing only a few people with diabetes virtually through social platforms, but now I have many real [*gerçek*] friends with diabetes.

In her story of commitment, she emphasized the adoption of a diabetic identity, which may be related to the acceptance, as discussed above (see Section 4.1.3). Moreover, her statement also represents two different facts: The first is that illnesses become more visible and familiar through social media. Second, health communities provide support for the empowerment of individuals.

Although the effects of exercise might differ depending on the type of it, in general, physical activities are considered to lower the blood glucose level (Joslin Diabetes Center, 2007). The most challenging part is the adjustment of diet and insulin intake routines around exercise habits. For example, taking an excessive level of insulin before the exercise or too much physical activity can result in hypoglycemia (Riddel et al., 2017). Hande mentioned that because of the fear of getting tired, the only exercise routine that she maintains is short distance walks.

> My exercise routine changed a lot after my diagnosis. Before diabetes, around 2 years ago, I was doing trekking. I love walking and nature so that I would go trekking for a minimum of 15-25 kilometers every weekend with my group. After my diagnosis, I got very nervous and scared to start again. When you push yourself too much in sports, you get tired, and this lowers your blood sugar level. My ultimate exercise now is having short distance walks.

Getting used to all these changes in life was overwhelming, and participants got used to feeling restricted until they got autonomy in their lives. Nevertheless, besides its challenging nature, participants referred that diabetes also has positive impacts on their lives, which are discussed in the following section.

### 4.2.2 Positive Aspects of Diabetes

Despite the everyday difficulties of diabetes, participants also mentioned that type 1 diabetes in some ways contributed to their life in a positive manner. To begin with, nearly all of the participants mentioned that diabetes helped them to adopt a scheduled lifestyle through management routines. Turan exemplified this as follows:

> I think diabetes helped me organize and plan my life. Now, my mealtimes are scheduled. I should have an early breakfast and dinner. I know that when I have my dinner around 7 PM, my blood sugar level will reach its peak around 9 PM, and then become stable before I go to bed. I think a person with diabetes has to be punctual.

Turan describes his food intake and its effects on BG levels in terms of the parabolic curve, which shows that he interprets his biological condition quantitatively. This objectification might represent his acceptance and realist approach to diabetes. Moreover, with the phrase "organize my life," he mentioned diabetes as the key factor motivating him to have a well-planned schedule in life.

Aside from the connotation above, the phrase "organize" is also used in different manners by other participants. Ahmet indicated how diabetes helped him to organize his dietary habits as follows:

> I sometimes find myself thinking like, especially when it comes to eating habits, I wish everyone should assume they have diabetes. I think, as a

> society, we have very unhealthy eating habits. When you embrace the fact that you have diabetes, you become cautious about what you eat and drink, and this increases your life standard. When you compare that to eating habits of people without diabetes, you can understand why there is a saying that people with diabetes live longer. I believe this is very true.

People with diabetes need to maintain a healthy diet also to manage their weight as it effects their BG levels and triggers the risks of diabetes. At this point, as Ahmet stated, helping people to develop healthy and balanced eating habits is another positive association of diabetes.

In addition to developing healthy eating habits, for some participants, diabetes is also a source of motivation to build an exercise habit. Eren stated that after being diagnosed, he started to keep up with walking routines as physical activity has a positive effect on blood sugar levels (see Section 2.4.2).

> Now I am focusing on completing my 10,000 steps a day. Some days it is around 7,000 or 8,000 steps, especially during wintertime. However, I do my best to keep up with daily 10.000 steps. I don’t go to fitness, but I think I should start because it helps regulating blood sugar level. For example, if your blood sugar level increases up to 300s after meals when you do not do sports, during the days you exercise, you see that the peak value drops to 220s.

In contrast to Hande, who is reluctant to exercise and gave up trekking in favor of short distance walks due to the perception of risk (see Section 4.2.1.2), Eren emphasized that walking is somehow the “least” he can for maintaining exercise habits. Moreover, by giving quantitative example, he made it more apparent how exercise helps to lower his BG levels.

Apart from its tangible contributions like helping people to develop healthy lifestyles, some participants also stated that they experience new challenges throughout their lives, which makes them stronger compared to the others. For instance, Aslı exemplified how people with become resistant to pain both physically and emotionally with these statements: “Especially the people diagnosed with diabetes during their childhood have strong personalities. They become resistant to pain which is probably because of taking insulin shots on their own.”

The last positive aspect of diabetes mentioned by participants is showing compassion to others. Diabetes can cause instant mood swings and aggressive behaviors with no reason (Felman, 2019). In this regard, Ebru stated that realizing her behaviors helped her to empathize with others as follows:

> I started to approach others in a more empathetic and understanding way. I realized this emotional shift firstly on the change of my behavior. Before, I was ill-tempered, but I was not aware of that. For the last 6-7 years, I calmed down, and I started to think, “That person might have his struggles in life”.

As discussed above, building up healthy habits for better diabetes care also results in behavioral changes that contribute to individuals’ self-improvement. Therefore, despite all the difficulties and challenges, some participants interpret diabetes itself as a key factor in empowerment.

### 4.2.3 Perception of Diabetes

In this section, I analyze the relevancy between patients’ experience of living with diabetes and how the public perceives it in the lights of participants’ statements. The quotations represent personal experiences and myths about diabetes, as well.

#### 4.2.3.1 Perceptions of People with Diabetes

The section represents the participants' account of what diabetes means. According to the interviews, half of the participants used the word illness [*hastalık*] to define diabetes, while the other half using the phrase lifestyle [*yaşam biçimi*] for description. As Turan expressed:

> This is not an illness! I am against this description. It is a hormone deficiency and lifestyle, indeed. What I am using is not a medication; it is a hormone. I am taking what my body cannot produce itself from outside. It is not something that should make you pity yourself. It is not something desperate. You just have to change your lifestyle, and this is my perspective.

As mentioned in the previous sections, people with diabetes have to make severe adjustments in their lifestyles to control diabetes onset and prevent risks. The continuous process of building new habits and integrating them into everyday life might be the reason that participants, including Turan, associate diabetes as their lifestyle. He mentioned hormone deficiency to explain the condition that his pancreas does not produce insulin hormones sufficiently. Even though his statements revealed incapability of his body, the reason why he does not call diabetes an illness might be related to how public perceive chronic conditions as piteous.

In addition to Turan's approach, another participant, Güzin, stated that thinking diabetes as her lifestyle had a positive impact on acceptance. Nevertheless, she argued about the burden of living with diabetes as follows:

> I have never seen myself as ill. This is only a hormone deficiency, and I can take that hormone from outside. I see this more like a lifestyle. Accepting diabetes also has an impact on my approach. Of course, there are restricting

> sides. You can do whatever you want as long as you have the control. You always have to be in control.

On the other hand, the difficulties of diabetes that were stated by Güzin forms the main argument of the participants who associate diabetes with the term "illness." As Meral's words above emphasized that their bodies do not function properly, it might be proper to describe it as ill-body. Esra commented on that: "when people say diabetes is not an illness, it sounds like a joke. It sounds like you are trying to deceive yourself. If diabetes is not an illness, I wonder what can be called as one."

With regard to this argument, some of the participants stated that diabetes might cause a drop in their performances in everyday life activities. For this reason, they strive harder than others. As Aslı indicated:

> At the end of the day, we are lacking one organ [*organ eksiğimiz var*], and to compensate for that deficiency, we have to put in the extra effort. When I take a look at my daily life, I notice that I work harder and put in more performance compared to non-diabetics because I think we have an over compensative mindset, and this is reflected in all aspects of life.

Besides the reality of making an extra effort, Aslı's statement also reveals a normative discussion. In daily life, what is expected from people does not differ depending on whether they have type 1 diabetes or not. The effects of diabetes are not physically visible in general, although they make themselves felt in every aspect of life. In addition, some people with diabetes desire to feel "normal" by aiming to perform equal to the others and as a consequence, they put in extra effort to fulfill their responsibilities. However, this approach sometimes makes them feel overwhelmed due to the burden of responsibility. Esra reflected her feelings on this topic as follows:

> “Diabetes is my friend,” “I live a great, healthy life with diabetes,”; such romantic lies! If you can live a healthy life without diabetes, do so, but with diabetes, we continuously try to achieve that and pay the price [*bedel ödemek*] nevertheless. Okay, I am a part of this and try my best; the more I try, the longer I will live. However, we merely are trying to achieve what a normal person effortlessly [*çaba sarfetmeden*] has. For example, I exhaustingly [*kendimi parçalayarak*] keep my HbA1c levels barely at 6, while a healthy person usually has 5.5. Eventually, I do everything to stay healthy, but actually, I do it out of obligation while not being all that happy.

These two statements demonstrated that some participants describe themselves as *not normal* since the nature of diabetes brings lots of restrictions. Moreover, with regards to everyday life practices, the necessity of making an extra effort to perform like *normal people* creates both physical and emotional burdens, which is one of the challenging parts of living with diabetes.

The perception of diabetes might vary between the people who experience diabetes and the ones who witness their diabetes management, such as significant other. For instance, Sertan described diabetes as a lifestyle. At this point, Meral opposed to her fiancée’s statement as follows:

> I think diabetes is not a lifestyle; it is indeed an illness. My pancreas is not working, and I have to live attached to two devices. Therefore, it is an illness. In diabetes groups, people keep saying it is not an illness; it is a lifestyle, we are this and that. What interesting is that relatives of the people with diabetes embraced this view more than the patients themselves. Maybe I am biased because I am the one who lives with that illness.

The reason why Meral insists on describing diabetes is that she does not want people to underestimate her condition and the difficulties she experiences, such as the incapability of the body and is dependent on medical devices to maintain a healthy life are. Besides, the contradiction between Meral and her fiancée points out that how participants describe their experience with diabetes might not be consistent with how it is perceived by other people, which is discussed in the following section.

#### 4.2.3.2 Perceptions of Other People

As mentioned in Section 4.1, the people who are not familiar with diabetes do not differentiate between type 1 and type 2 diabetes, as both of them are associated with having high blood sugar levels. In addition to this misunderstanding, many participants mentioned that they got used to encountering with the questions about the inheritance pattern of type 1 diabetes as it is accepted as the only reason by them. On the other hand, participants stated people who do not encounter young people with diabetes or the ones who perceive having a chronical illness as misery might give offending reactions. Esra exemplified this as follows:

> People can mix type 1 diabetes with type 2. They ask whether it was about the unhealthy diet or hereditary like passing from my mother or father. It is hard to explain these things. In hospitals, 60-65+ aunts and uncles would say to my face, "You are just a 15-year-old. What are you doing here, poor thing?" In society, we have this insensitivity to talk about diabetes in the same way as talking in a pitying tone towards the blindness of a child as if he is not hearing. You just stare speechless in shock to these remarks. When you grow up, you can just curse at them and mind your own business, but for children, it is a tough situation to be in and deal with.

Her statements revealed one of the most common social stigmas: Blaming parents for diabetes in children. Inheritance is the first reason, but the second one is related to not keeping a healthy diet for their children. Apart from these, her words recall the discussion of maturity, which does not only play a role in the acceptance but also in coping with the societal challenges of diabetes. Aslı criticized another social stigma about people with diabetes as follows:

> People say you can’t get married or have a child and you won’t have a social life. These are all wrong. We can live just like other normal people. All it matters is the effort to cope with the deficiency.

Her statements revealed that society interprets diabetes as an impediment more in a social context, while she described diabetes as a deficiency due to its medical challenges. She also mentioned that people with diabetes are supposed to make extra effort to maintain a healthy life like others, which brings up the discussion of capabilities discussed in the previous section.

As it is understood from the participants’ statements, people’s perception of diabetes also depends on the context of interactions. For instance, regarding romantic relationships, Ebru stated that: “I don’t know what men think of diabetes, but I understand that they get nervous. Diabetes is not a difficulty for me. However, they seem to approach it as a problem”. Similar to what Aslı discussed above, the reason behind Ebru’s interpretation might be related to lacking knowledge of how diabetes affects sexual health.

Likewise, Meral also experienced that one admirer had evaluated her diabetes as a deficiency that cannot be accepted by anyone else. Meral explained how she felt about this attitude as follows:

> At the university, one guy wanted to be with me. He said he loved me so much and tried hard to just talk to me. When I said, “I do not want to” a couple of times, he responded that he accepted me despite my illness, but how come I

> did not want to be with him. That was the moment I realized people in my life regard diabetes as a burden that should be accepted. Maybe this incident was the reason why I have told Sertan about my diabetes on our first date.

Regarding her statements, Sertan emphasized that he never felt any fear of diabetes as Meral made an introduction about her condition when they first met. Also, he had spent time to do detailed research to understand how he could help his fiancée in the management of diabetes. Sertan's understanding and effort to help his fiancée represent how people perceive diabetes depends on personal manner and awareness.

When it comes to the interactions which are shaped around the dynamics of the workplace, as Cem mentioned earlier (see Section 4.1.3.2), sharing diabetes with colleagues is significant for receiving proper help during any emergency as well as letting employers know how much workload they can undertake at the moment. However, some employers who are ill-informed about type 1 diabetes might react out of fear. Meral reflected on this condition by sharing the discrimination that she experienced at work as follows:

> My department at work was changed a few days ago. I told my employer that I did not understand why. Then I learned my colleague thought I would get stressed or upset easily due to my diabetes, and he was hesitant to give me work. That made me upset more than anything. I am not escaping from work. Yes, I have diabetes, and I tell people when my blood sugar increases or drops; however, I do not want to be treated as ill in the workplace or any part of my daily life. Positive or negative discrimination truly offends me, and on social occasions, I feel it very obviously.

Above, why Meral insisted on describing diabetes as an illness was against the under-estimation of the illness as "no big deal." However, when it comes to working life, she complained about the discrimination she has experienced as a consequence of another social stigma that diabetes might interfere with the performance at work. As she stated that she is aware of her medical condition feels free to share her illness with colleagues, especially if there is an emergency. Therefore, the stigmatization about the ability to work is offending and emotionally challenging.

Different from the examples above, how people perceive diabetes might also be related to the visibility of diabetes, which is discussed further in detail later (see Section 5.3.3). Sometimes diabetes is considered as an "invisible illness", because it does not have considerable bodily signs instead of routines like insulin injection or major long-term complications such as amputation. Burak narrated how his friends' perceptions of diabetes differ depending on the image of the ill body as follows:

> When I say that my blood sugar dropped and I should leave the class, people think I am lying. For my friends, I just leave because I am feeling bored and there is no reason for me to lie to them. I am also using a pump, and it is something new for others. When we go on holiday, they say, "Can you get into the water? If you can't, we can just leave". During that period, when I am trying to tell and show I can continue with my life; they think as if I am making sacrifices.

As he stated, diabetes may be perceived as "ordinary" when the symptoms or signs are not visible. On the contrary, when his diabetes becomes visible through the product (i.e., insulin pump), this changes his friends' attitude towards the qualification of ill-body.

To sum up, as it is seen from the examples above, people's perceptions of diabetes vary depending on the context of interactions. The burden of diabetes might not be visible all the time, and this makes it hard for other people to realize. On the other hand, in a social context, people with diabetes are stigmatized in many ways. Participants mentioned that raising awareness about the nature and course of diabetes is the way to overcome the other's concerns regarding the capabilities of the ill-body.

### 4.2.4 Summary

In brief, Section 4.2 discussed the integration of diabetes into everyday life. Beyond the management of blood glucose levels, the critical aspect of diabetes is the transformation of daily life routines to perform proper care, and risk management to prevent long-term complications. Building up new routines are challenging and take time while evolving into a lifestyle. For some participants, this transformation is considered as a burden of diabetes, while some of them interpret diabetes in a positive manner: having healthy habits and organized lives.

Apart from these, the discussion in Section 4.2.3 revealed that culture and the society have greater impacts on the social construction of diabetes. Besides medical incapability of diabetes such as being not able to produce insulin or sugar intolerance, society perceives diabetes as a deficiency, and the human body is stigmatized in different contexts such as performance at work or reproductivity of women with diabetes. The next section represents how individuals master diabetes in the lights of their management practices.

## 4.3 Management of Diabetes

As mentioned in the previous sections, type 1 diabetes is a chronic condition that requires serious adjustments in everyday life to maintain a healthy life. This section represents participants' management practices to prevent both short and long-term complications of diabetes (see Section 4.1.3.2) and their self-empowerment as a result of these repetitive practices.

People with diabetes have to keep their glucose levels around the targeted level, however, “the ideal” BG level ranges might vary from person to person in regard to their age or exceptions such as pregnancy or secondary diseases. Moreover, having consistent blood glucose levels depends on the balance between diet and insulin intake routines. In this regard, it is necessary to monitor glucose levels, also described as the measurement in this study, several times during the day to decide on what to eat as well as the timing and doses of insulin.

Beyond the daily management routines, participants also mentioned that diabetes care includes regular doctor visits and blood tests, which are necessary to evaluate the medical success of treatment. In this section, I discuss all these dimensions of diabetes care in separate sections.

### 4.3.1 Insulin Intake

Type 1 diabetes is called “insulin-dependent diabetes” because the pancreas does not produce enough insulin to regulate glucose levels on the body (The Diabetes Control and Complications Trial Research Group, 2018). That is why in the management of diabetes, people take insulin as medication. Hence, there are several routines that are shaped around daily dose taking and discussed in detail in this section.

#### 4.3.1.1 Doses and Methods

The daily insulin requirement varies from person to person regarding their demographic characteristics, biological conditions, and insulin intake methods. During the interviews, participants stated two different types of insulin: bolus insulin and basal insulin (see Glossary). It is important to remember that basal insulin has a long-time regulatory effect on BG levels. With regards to this terminology, Eren explained his personal insulin intake regimen as follows:

> Some people take basal insulin in the mornings, actually, but since I take my doses at night, I call it night insulin. That is the long-acting one. Its effect time is longer, varying between 20 to 22 hours. It is taken to regulate insulin levels throughout the day. Others [*bolus insulin*] are taken before meals, and effective for 3 to 4 hours.

In addition to his statements, Eren also mentioned a problem that he experienced while learning how to use insulin as follows:

> Only, in the beginning, I took morning insulin instead of night insulin by mistake. Since you do not know what to do, you panic. Later on, you get used to taking doses according to how much you eat.

Learning different insulin types and when and how to use them, calculating doses, and shaping an insulin routine might be confusing, and patients require time and experience. In addition to confusing insulin types, Eren also mentioned that when he forgets whether he took his scheduled dose or not, it is always an uncertainty of taking extra insulin as not taking enough insulin can drop blood levels instantly. On the other hand, taking excessive amounts might result in an overdose. Eren talked about a product that records users' injection times (see Figure 4.1) as a solution to this problem.

> There are times I forget whether I took insulin or not. Just yesterday, I thought I took an injection before the meal, but as I was eating, I figured otherwise and took an injection. If I do not, it is risky, but if I do, it is risky, too, because you've taken twice as much. There is a device that can be attached to insulin pens. When you press its button, it shows how many doses you took and when you took them. It is a very simple thing; it shows how much you injected, and when you took the injection.

Figure 4.1 InsulCheck for Flexpen. Digital Image. InsulCheck (n.d.), https://www.insulcheck.com

The product that he mentioned “delegates” the role of keep tracking on injection times, which might be considered as an example of how products are one of the “actants” in diabetes management and aim to improve patient care and experience (see Section 2.3.1).

In terms of different insulin taking methods, participants’ statements presented the improvements of different methods and technologies in time and how these changes transformed their insulin intake routines and the interactions that shape around those routines. The nature of diabetes requires help from other people, especially in times of emergencies when patients themselves cannot perform self-care properly. I describe such interactions as *collaborative management* (see Section 4.4.2.4 for further discussion). Esra described why and how her family contributed to her care and how the dynamics of collaborative care has changed over time as follows:

> When I was first diagnosed, I took insulin day and night. Back then, technology was not as advanced. Syringes were filled from vials, and a nurse or a pharmacist had to do the injections. Later on, when I was told that the injections had to be done at home, first, my father learned how to do them.

> For years, my father did my injections until I figured I should do the injections myself, and I started doing them. Syringes became pens, pens became pumps in time, and I started using them. Nowadays there are injections with quick-acting or long-lasting effects. Back then, when I was taking injections day and night, the insulin I took were both quick-acting and long-lasting. Then that drug type changed. After many years, I started using quick-acting and long-lasting insulins separately, hence I was taking an injection of Novorapid with every meal and a long-lasting insulin day and night, adding up to 5 injections per day. When I switched to Novorapid, which I took 3 times every day with my meals, my diabetes came out in the open, and I stopped hiding it. You cannot hide the injections when you have to eat outside.

As she explained, when Esra was diagnosed, insulin intake methods were not practical enough, and she was not ready to handle the burden of care alone. Hence, her father used to help her. She mentioned that, within time, by the improvements in insulin intake methods, she took over control and started to take her doses by herself. This behavioral change might be associated with autonomy. Furthermore, in regard to the increase in her necessary doses, she also stated that this change made her diabetes visible and something to be shared instead of keeping it as a secret.

Regarding insulin use, some participants mentioned that they got used to facing problems while learning how to calculate the required amount of insulin. The daily amount of required insulin differs from person to person. An average dose for someone might cause an overdose in another. Turan explained how he makes his calculations for extra doses according to his doctor’s instructions as follows:

> When blood sugar levels start to rise, 2 extra shots of insulin are taken, for example, 5 doses or 10 doses, depending on the blood sugar level. I calculate my injections as such: for every 20 points of blood sugar above 180, I add an

> extra dose of insulin. There is a way of calculation made by my doctor. My blood sugar stays elevated if I do not take additional doses, which lowers my quality of life.

Apart from the personalization in doses, there might be some circumstances that require readjustments in personal insulin intake routines. In the study, three of the female participants were currently pregnant, and all of them discussed how their insulin use patterns changed because of pregnancy. One of them, Güzin, exemplified this change regarding insulin types, calculations, and required doses as baby grows with the statements below.

> I used to take 1 unit of insulin per 15 grams [*carb consumption*], which was reduced to per 10 grams during pregnancy. The doctor said that insulin need increases during pregnancy gradually. Some people tend to require less insulin while I required more. For example, I started to do 7 doses with a meal, which I was previously taking 4 doses. This means that you have to forget all that you have learned and start a new regimen. My doses are quite different now, and they change as my baby grows.

Participants' statements pointed out that insulin intake routines may change quite often, and every time individuals need to get along with their current dosage and adjust their counting methods correspondingly. The following section represents participants' preferences on body sites for insulin intake and their criteria for selection.

#### 4.3.1.2 Insulin Injection Sites

As participants use insulin regularly, it is recommended to rotate injection sites, because always injecting in one part of the body might cause lumps, which makes insulin less effective. Eren explained his experience as follows:

> After some time, insulin injections cause lumps growing on your abdomen, and those lumps prevent insulin from taking effect. They prevent insulin from reaching the lower layers of the skin where the injection is supposed to reach. For that reason, insulin injection sites on your body should be changed from time to time.

Relevant to this matter, Eren also talked about a product that is aimed to guide users while injecting insulin (see Figure 4.2). Moreover, he evaluated the promises of the design in terms of efficiency and sustainability.

> There is also a device you attach to your belly where you take doses in which you inject the needle. You do not change your injection site. But what the device offers is that it mixes insulin with blood more efficiently. Since the device has its own needle, you inject insulin where it is supposed to be injected; thus, it is more effective. You have to change the location of the device after some time. It has to be changed every 1 or 2 weeks. But, having to pay for it, again and again, makes me question it.

Figure 4.2 i-Port Advance™ Injection Port. Digital Image. Medtronic (n.d.) https://www.medtronicdiabetes.com

Although he has not experienced the product yet, he criticized the product-life cycle as it is needed to change quite often and brings the responsibility of replacing the product regularly. In terms of sustainability, he stated that the product is not cost-efficient. Moreover, the place it is worn should be rotated like injection sites.

Following their personal experiences, some participants indicated that somebody parts absorb injected doses quicker compared to others. Güzin mentioned her preferences for injection sites and the reasons why she prefers those parts of the body as follows:

> Some meals increase blood sugar slowly when that is the case; I take insulin from my legs or my thigh since they are where insulin mixes with blood at the slowest rate. The fastest location would be the abdomen, while arm injections are in between. Sometimes I inject depending on the meal, but usually, my arm is the safest location to inject. But if my blood sugar is too high, I inject in my abdomen to regulate it quickly.

Apart from his product-related comments above, Eren also indicated the social and practical circumstances as a fact that affects participants' preferences in injection sites as follows:

> For example, when you are among people or in winter, you cannot take an injection at your convenience. Right now, for instance, since I am wearing a sweater, I cannot roll my sleeves that easily. For that reason, I inject from my abdomen, which is much more comfortable.

To summarize, participants pointed out different injection sites, which are the abdomen, arm, leg, and thigh. Moreover, they emphasized the significance of rotating injection sites as using the same area can cause lumps that interfere with how body absorbs insulin. Selecting injection site is mostly performed tactically. For instance, when there is a need for urgent insulin absorption, participants prefer to inject insulin into the abdomen as a result of their past learnings. In a similar manner, if they consume some food affecting blood sugar relatively late, their preferred site for injection is either leg or thigh.

Apart from medical facts, participants also discussed how daily life factors play role in their preferences. As Eren mentioned during wintertime, it becomes hard to use arms because of cloth preferences. In addition, he indicated the fear using the arm for insulin injection in public as it might connote drug use, which shows that the social perception of diabetes also plays a role in their management methods. In accordance with this finding, the next section discusses how participants perform insulin injection in public places.

#### 4.3.1.3 Insulin Intake in Public

The accounts of participants revealed that most of them got used to having considerations about taking insulin in public places early times on their diabetes journey. That is because they believe that taking insulin in public makes their diabetes visible. Moreover, once diabetes becomes visible, it draws some people's attention, and their curiosity about diabetes might be overwhelming. In regard to this social fact, Aslı stated that she was going to the restroom instead of taking insulin in public not to be exposed to questions about her diabetes.

> When I first started taking insulin, I was shy and whenever I was in a restaurant for example, I would take my injections in the bathroom. People were asking questions like “why do you use insulin?”, “is your diabetes too advanced?”, “how much is your blood sugar?” which I didn’t like at all.

By the same token, Güzin mentioned the change in her behavior within time as follows:

> At first, I was taking my injections secretly, thinking everyone will stare. For example, back then, when we were sitting here, I would not be as comfortable. However, now I do not care at all; it is entirely natural to me. Injections are like drinking tea or water to me now. I would die if I did not do them. I am so glad that insulin exists.

Insulin treatment is the only method for type 1 diabetes management. Therefore, in time, participants do not hesitate anymore to take insulin in public, which might be an outcome of accepting their chronic condition (see Section 4.1.3). Moreover, some participants stated that they mainly prefer to take insulin in public places. For example, during the interview, Eren suddenly took out his insulin pen and put it on the table, but he did not have any insulin injections throughout the meeting. When he was asked about taking insulin in public places, his statements not only explained the reason for his attitude but also recalled the discussion about people's perception of diabetes as follows:

> Whenever I enter an environment, I deliberately take my insulin in public. Yes, I do it everywhere. Right now, my insulin sits on the table. I can take the injection whenever I want to. Time to time, especially when I take injections in my arm, it looks as if I am taking illegal drugs. Although you might wonder if people perceive it like that, you do not truly care about it.

As discussed in the section about injection sites, Eren repeated his assumption of how people connote taking insulin shots with drug use. Hence, his statements show that there might be a relation between individuals' hesitation and social stigma in diabetes (see Section 4.2.3.2), as they believe that taking insulin in public makes their diabetes visible. The following section discusses participants' monitoring routines, which is the key activity for arranging an insulin regimen and keeping diabetes in control in a broader perspective.

### 4.3.2 Monitoring Blood Glucose Levels

As participants mentioned, measuring blood sugar level is one of the essentials of day-to-day diabetes management because it helps to understand the effects of diet and exercise habits on diabetes and to calculate required insulin doses. Moreover, keeping track of glucose levels is also important to prevent any emergencies such as hypo.

Monitoring routines differ among the participants, depending on how many times they measure blood glucose by which kind of device they use. As it is known, there are two kinds of monitoring, which are finger stick glucose monitoring (Olansky & Kennedy, 2010), i.e., glucometers, and non-invasive glucose monitoring (Ciudin, Hernandez, & Simo, 2012), i.e., sensors. Regarding these two different monitoring methods, this section only refers to participants' experiences with glucometers, and the dimensions of technology use in diabetes management will be discussed in detail in the following sections.

#### 4.3.2.1 Learning Self-Monitoring

Like insulin intake, monitoring glucose levels is also not challenging for participants. Nearly all of them mentioned that only a brief introduction was sufficient to learn about the process. At this point, the age when participants were diagnosed with diabetes plays a role in whether they needed collaborative management or not. Ebru exemplified this as follows:

> As I was young, they taught my mother how to do the monitoring. Later on, I started monitoring myself after all those tests. Maybe I was a little upset since I did not want to come to terms with reality, and I didn’t want to monitor. But I remember being able to do it when I was first shown how.

Apart from the need for help, as she mentioned in the earlier sections, how her management routines changed after using an insulin pump as follows: “Before using an insulin pump, I used to monitor my glucose levels only when I felt dizzy or tired, as they might be the signs of low sugar.” Similar to her, many participants stated that they did not get used to having proper measurement routines, because performing regular measurements was making diabetes, the reality they did not want to accept, more visible. In this regard, what Ebru stated also resembles the discussion about the acceptance of diabetes and the impact of device use practices in behavioral change.

#### 4.3.2.2 Frequency

Most of the participants stated that they monitor their glucose levels about eight times a day. Turan commented on how he performs measurements as follows:

> I do about eight measurements with glucometer [parmaktan ölçüm] a day. The first thing I do every morning is to monitor my blood sugar as I have to adjust my breakfast based on the measurement. I also measure it every night before going to bed. I carry two different glucometers with me, and I cross-check the devices to see whether they are working correctly. They give out results more or less in parallel with how I feel. For example, when I guess that my blood sugar will be 100-ish, it turns out to be 107. We even bet on it with my wife; she urges me to measure to see the result. She learned to calculate based on what I eat; she usually gets it right.

His statements are an example of collaborative management as there is an obvious social help from his wife, who is also mastering diabetes with him. They gamify the monitoring process to overcome the burden of measurement and also challenge their expertise. Moreover, he also mentioned the issue of carrying two devices all the time, which indicates trust-related problems in technology use.

As I discussed in Section 4.3.1.1, pregnancy not only affects insulin doses but also the frequency of glucose monitoring. Aslı explained how her monitoring routines changed during pregnancy as follows:

> Different from ordinary times, during pregnancy, post-prandial blood sugar measurement is monitored after one hour instead of two hours. I remember monitoring my blood sugar level as many as 24 times a day. My blood sugar level should be in a specific range, as above 180 is harmful to the baby. So that, I was monitoring too often.

Her statements showed that the measurement routines of individuals might change during pregnancy because of medical imperatives. However, the reason why she performed excessive numbers of measurement is mostly related to the perception of risk and fear of affecting her baby's health.

Apart from its medical dimensions such as treatment plan, recent healthcare policies also play a role in the frequency of measurement, as Ahmet criticized in detail below.

> The number of measurements supporter by governmental policies is five times per day. I have to measure during each meal; as I have six meals a day, it means six measurements a day. When I calculate, I come up short one box at the end of the month since the government doesn't support more. For that reason, I measure my main meals, but I have to trust the value the sensor shows during snacks.

What he stated revealed that socio-economic factors and governmental policies also have an impact on individuals' treatment plans, which might be considered as an example of the political construction of diabetes and its care.

#### 4.3.2.3 Monitoring Blood Glucose in Public

Similar to insulin intake, most of the participants stated their concerns about monitoring blood glucose in public as it makes their diabetes visible (see Section 4.3.1.3). Ahmet commented on the reasons behind why he got used to feeling uncomfortable while measuring blood sugar in front of people as follows:

> The way people look at you makes you uncomfortable; especially older people stare pitifully. You want to say I am not miserable, but how many people can you respond to. For that reason, it was annoying at first but frankly, after a while, I started saying, “who cares!” For example, I do measurements even when I am using public transport if needed.

His narratives indicate that society’s perception of diabetes has an impact on how individuals perceive their condition and feel about it, especially the times when their illness becomes more visible. However, Ahmet also indicated that as he has become more aware of diabetes, he gave up considering other people’s perceptions and started to perform his routines in public without hesitation.

Below, Aslı’s statements show that in everyday life, it is tactically possible to hide her diabetes while measurement in contrast to taking insulin in public as injection presents more parts of the body.

> When you are measuring, you can put your bag on your lap and conceal the whole measurement process, but insulin is a different case since you have to expose either your belly, arm, or leg. For that reason, no, I did not have any problems while measuring.

In addition to these examples, Burak pointed out that sharing his diabetes with other people helped him to perform the measurement in public freely. At this point, his statements also indicated that awareness also plays a role in the attitudes of other people towards the ones with diabetes.

> I could measure comfortably at school. Everybody in my class was well aware of that, and no one scorned or stared pitifully. For that reason, I was very comfortable; people were supportive in that matter. I could easily measure when I was about to eat.

The statements above represent that why people with diabetes may hesitate to perform their management routines is mainly related with how the illness perceived by other people, as discussed in Section 4.2.3.2. Nevertheless, in time, as people accept their illness, and they become self-aware and responsible, their concerns about social appropriation become less significant. The next section argues about the changing role of physicians in the current healthcare.

### 4.3.3 Doctor Visits

Participants mentioned that they need to visit their doctors on a regular basis to have several examinations, such as hormone levels and HbA1c level tests. Moreover, kidney tests, visual inspection, and foot exams are required due to the complication risks of diabetes. According to their statements, most of the participants visit their doctors at around once in three months. Esra summarized these routines as follows: “I get a routine check-up done every three months. The check-up consists of general blood values, hormone values, and HbA1c values. I visit different doctors for kidney functions and eye examinations annually.”

Although these examinations do not require any necessity to stay in the hospital, some participants, such as Meral, prefer hospitalization while having regular checks. Meral commented on the reasons why she prefers to stay in the hospital as follows:

> I admit myself voluntarily to the hospital once a year. All kidney and liver functions and hormone levels are checked. I find it very beneficial for me and the progression of my condition since it is also a general checkup, we get to track it.

Besides the examinations, doctor visits are also important to discuss with one's doctor about the course of diabetes. However, Eren criticized current healthcare services and related issues by also giving some recommendations as follows:

> At first, I used to take prints of my blood values recorded in the glucometer to my doctor for him to check. However, the doctor has only 5 minutes available for you, especially on state-run hospitals; hence, they cannot take a detailed look. A personal health consultancy service would be better, perhaps those kinds of services will be available in the future.

He pointed out the need for expert commentary on blood levels, and its importance to review whether the current management plan is working properly. However, most healthcare professionals do not have enough time to discuss current health state in detail with their patients unless there is something abnormal. Regarding this issue, some participants emphasized the benefits of having a regular doctor as that person knows better about the course of their diabetes, including the changes in their management plan and the frequency of having complications. Moreover, this becomes even more important for participants with exceptional circumstances, such as pregnancy. Gözde commented by also mentioning how pregnancy affected the frequency of her doctor visits:

> You must have a regular doctor who knows you the best. Usually, Dr. İlhan required measurements every three months in routine controls, but during my pregnancy, we visit him every week. He wants me to track my sugar value weekly, and I bring him the measurements every week. He is indispensable for me [*o olmazsa, olmaz*].

As another effect of pregnancy on diabetes, Güzin explained the change in her care team, which is visiting another professional in addition to her primary doctor to prevent pregnancy-related complications:

> I am seeing two gynecologists because of my pregnancy. One of them is a high-risk pregnancy expert because people with type 1 diabetes must see a high-risk pregnancy expert. The doctor I see now is the one who figured that I have type 1 diabetes after my miscarriages. Nowadays, I am looking for an endocrinologist again. Perhaps additional examinations are needed regarding my diabetes.

Another important point regarding the doctor-patient relationship is the discussion of expertise. Some participants mentioned that most of their daily life, they took initiative rather than following medical recommendations. This shows that personal experiences help individuals to gain autonomy on their illness as Gözde described below:

> We live with it! Reading about diabetes or searching for information has a limit. We experience everything ourselves. We are learning by experience. You cannot know it unless it happens to you unless you experience it. We are our own doctors now.

As she stated, gaining self-expertise is inevitable within years and also essential for learning how to live with diabetes as it requires lifetime care. Moreover, most of the participants also emphasized that since they gained experience about diabetes management and integrated their treatment plan into everyday life, they have been feeling less dependent on medical authorities and only visiting their doctors either for routine examinations or for the situations in which their self-expertise is not enough to overcome. Esra's statements below explained this substitution by also emphasizing the limits of expertise and doctor's trust on her as follows:

> After 25 years of diabetes, I only require a doctor's consultation if I have different results in my tests; if my already high cholesterol levels are even higher, for example. Other than that, my doctor does not intervene or tell me anything new regarding my insulin dosage or my eating regimen anymore.

To summarize, learning diabetes management with time by also experiencing challenges results in the autonomy of participants on their health. Moreover, this mastery also reduces the role of the doctor in the interaction network as it changes depending on different occasions.

### 4.3.4 Blood Levels

As mentioned in Section 4.3, the ideal blood glucose and HbA1c levels differ depending on the individuals' current state of diabetes. With regard to daily blood glucose levels, there are two different values, which are pre-prandial blood glucose and post-prandial blood glucose (see Glossary). Eren indicated his targeted glucose levels as: "We can say that ideal values are between 70 and 140. 70-100 interval is pre-prandial, 140 is post-prandial blood sugar, but values around 160 can be considered normal in diabetics." Likewise, another participant Turan connoted his targeted BG level with happiness; "The blood sugar level interval, which doctors suggest and in which you are the happiest is the 90-100 interval."

With regards to keeping BG levels in a particular range, Meral mentioned below that a simple eye examination could not be performed because high blood sugar causes a blurry vision.

> When blood sugar levels are elevated, eyesight is impaired. Therefore, if my eye is -3, my eyesight is similar to someone with -5 because of my high blood sugar. For that reason, I couldn't take an eye examination for a year. Because my blood sugar level occasionally rises above 200. It is not a very high number, but it prevents me from taking eye examinations. What I ask is as simple as this, but the condition hinders my life.

This quote shows that she has to keep her blood sugar in targeted levels not only for diabetes management but also for ordinary examinations, as diabetes might affect many other health-related topics. Hence, some participants may feel that they sometimes need to make an extra effort for what they perceive as mundane practices, as previously discussed in Section 4.2.3.1.

Participants mentioned that blood sugar fluctuates during the day, and extremely low or high glucose levels might cause emergencies, which can be treated themselves or may require medical help. Since immediate changes in daily blood sugar is a common fact, a person's success in self-management is evaluated with the HbA1c level, which defines the average amount of glucose in the blood (American Association for Clinical Chemistry, 2018) and is generally tested every three months.

Most of the participants, including Aslı, defined "the ideal" HbA1c level as: "6-6.5 interval is ideal to avoid any complications and to feel better." Moreover, Turan's statements recall the discussion of *quantified self* (see Section 2.3.2) among people with diabetes.

> 5.5-6 is ideal. People with hemoglobin levels less than 6 are excellent [*mükemmel*] diabetics. People with 6-7 are self-conscious. We can say that in people with HbA1c values higher than 8, there is an element of deceit [*hırsızlık*]; they are virtually dead people. Still, values between 7-8 are acceptable [*bir nebze kabul edilebilir*], but people above 8 have no judgement [*beyin ölümü gerçekleşmiş*] at all; there is no point in pursuing a conversation or bringing up topics. Just do not waste any time with people who have an HbA1c level higher than 8.

His narratives open up a discussion of normativity as he qualifies the success in diabetes management through quantified self, which is identified with their hemoglobin levels. Therefore, the participants who are relatively consistent in achieving their targeted BG and HbA1c levels assess themselves more conscious and successful than other people.

In terms of management, most of the participants indicated that sometimes there is no standardization in diabetes care and personalization becomes crucial. Moreover, they believe that discovering their own body within time results in mastery, as Burak stated: "I cannot speak for another diabetic or give them advice, but I am a master of my own diabetes [*kendi şekerimin ustasıyım*]." Moreover, experiencing difficulties, such as having low blood sugar, made them explore how to cope with different circumstances. Aslı exemplified learning through experiences as follows:

> Actually, two plus two does not make four in diabetes. As I was saying, personal things are important. Experience! [*tecrübe*]. I experienced all this. No one told me to drink milk before going to bed instead of taking long-acting insulin when my blood sugar level is 86. If I had asked about it, my doctor would be furious, but I knew that my blood sugar would be stable if I drank milk before going to bed.

Her statements recall the discussion of expertise in Section 4.3.3. By the same token, Esra comments on what ideal blood level is, which represents the contradiction between medical authority and the self-assessment. As she expressed:

> Lately, my HbA1c values are elevated a little, to 6.5. According to my doctor, it is fine, but I find it a little high because I do not want it to rise above 6, to keep being in control. There is some controversy here, because what you and the doctor consider as normal are different. As most people have poor diabetes control, the targeted range is 7-8. But personally, I aim to be in the range of the levels of a healthy, in other words, a non-diabetic person.

From the medical perspective, ideal levels are subjective and defined in parallel with the current state of the illness. However, for the patients who consider themselves conscious and self-responsible like Turan and Esra, controlling diabetes means achieving the blood levels of people without diabetes, or as Esra calls "normal people".

Different from the medical perspective in normal BG levels for diabetes, this section represented the difficulties of having unstable BG levels and how individuals construct diabetic identities through quantification, which are associated with the virtue of awareness.

### 4.3.5 Summary

Section 4.3 presented the opinions of participants on the different dynamics of diabetes care, starting from management routines to the self-expertise on their health. First of all, participants indicated that establishing routines is one of the fundamentals of a successful diabetes management. In this regard, they mentioned their daily routines, such as insulin intake and monitoring blood sugar.

Performing these routines brought different topics into the discussion, such as the visibility of diabetes. Participants discussed how they manage the visibility of illness depending on the context and location. After that, participants' arguments revealed that their monitoring routines result in quantifying the self, and according to this quantification, individuals evaluate their performances in diabetes by criticizing and comparing other people's management routines.

Last, participants talked about the context of their doctor visits, including routine examinations and emergencies. In addition, they discussed self-expertise as they believe that beyond the medical recommendations, experiencing every aspect of diabetes is the best source to learn about the nature of the illness and create a personalized treatment strategy.

The next section presents practices of technology use. In this regard, the role of technologies in diabetes management and the construction of new patient profiles and the interaction network shaped around product use practices are discussed in detail.

## 4.4 Technology Use in Type 1 Diabetes

As mentioned in the previous section, there are several routines performed by participants in their diabetes care. With regard to technology use, the first routine is monitoring blood sugar, and there are two different methods for measurement: finger-stick glucose monitoring and non-invasive glucose monitoring. The former uses the blood samples and glucometers to measure the glucose level in the blood, while the latter uses wearable technologies to measure the glucose level in the interstitial fluid rather than blood.

Apart from blood glucose monitoring, another routine where the integration of technology use is observed lately is insulin intake by using insulin pumps. As explained in the literature review (see Section 2.4.3.2), the insulin pump is a device that delivers both *bolus insulin,* according to the carbohydrate amount of the consumed food, and *basal insulin* in the form of a steady dose as defined in the treatment plan. In addition, there are some systems in which the insulin pump is compatible with non-invasive monitoring methods.

According to the interviews, it is observed that there are different levels of technology use among participants, as some of them prefer to use glucometers and take insulin with multiple injections, while others use non-invasive monitoring methods. The highest level of technology use is observed in participants who use compatible systems that provide continuous insulin delivery and continuous glucose monitoring at certain intervals.

In this section, I analyze the use practices of different kinds of technologies in the management of diabetes, which are glucometers, continuous glucose monitoring systems, and insulin pumps and their impact on defining the relations of care. Moreover, the mutual shaping of self-monitoring devices and biosocial individuals at the level of user experience are explored in detail.

### 4.4.1 Glucometers

Turan described monitoring blood sugar with a glucometer as: "it is like using a straight gear car, constant stop-and-go [*dur kalk dur kalk*]." His words indicate monitoring BG levels several times by finger pricking. Most of the participants declared Accu-Check Performa Nano as their current device, which is shown in Figure 4.3. In particular, they have emphasized their trust in the brand, Roche, as a reason for their satisfaction.

Figure 4.3 Accu Check Performa Nano. Digital Image. Roche (n.d.), https://www.productreview.com.au/listings/accu-chek-performa-nano

While talking about the use of glucometers in general, participants also gave information about their evaluation of the product. Cem pointed out one of the milestones in the change of glucometer design, which is the integration of no-coding test strips. He explained this improvement in detail as:

> Let us say you bought the device; it comes with a weird chip kind of something, and with that chip, you could only use the test strip also comes with the same box. New generation devices do not have code anymore. For instance, I went to a pharmacy and bought an AccuCheck device. Then, I came home and put inside the strip I already had, and it worked! We changed our devices just because of this reason, why would we spend time with codes! Instead, we bought a device that does not need code.

What Cem values about the new generation glucometers are their compatibility with several strips. He stated that individuals no more needed to throw away their previous strips as they can use it with their new glucometers, which does not have strip coding.

Some participants mentioned that they have more than one glucometer as a backup, either the same or a different device, and these backup devices are placed where participants spend most of their time in daily life. Güzin stated: “I have three of the same devices, one at work, one in my bag, and one in the car. I surely have it with me, and if I forget, I have substitutes.” The reason why she has several devices in different places is being able to monitor her BG levels anytime, anywhere, regarding the sense of prevention.

Beyond the overview of participants’ statements about glucometers above, this section analyzes the participants’ experience with glucometers, in order of how they made the purchase decision and learned to perform the measurement, what kind of problems they faced and the role of devices in the visibility of diabetes and care relations.

#### 4.4.1.1 Purchase Decision

According to the statements of participants, several factors play a role in their decision-making about which device to buy. Most of the participants stated that they bought their first glucometers according to the recommendation of an authority, which can be their doctor, diabetes nurse, pharmacist, or product representatives as they did not have the knowledge of devices in the market. Nowadays, as participants mentioned, users’ experiences are considered as useful and important references. In this regard, Cem emphasized the role of online sources in decision-making as follows:

> At that time, since we did not have enough knowledge, you go to a shop, you say, “I am a diabetic patient, give me a device.” He gives you whatever the device he has [*elinde ne varsa*], “Here use this.” Now, on Instagram,

> Facebook, twitter kind of social media spaces, everybody shares their experience saying, “I use this device, and I am satisfied; I suggest it.

What Cem primarily values as important from those reviews is whether other users are satisfied, which can be interpreted as one of his decision criteria. Another decision criterion is the cost of the product as he stated: “people also state how much it costs in different places.”

The most common and well-known problem regarding glucometer use is the cost of supplements as governmental policies only cover a certain amount of the expenses. Participants mentioned that within the scope of current healthcare policies, only a certain percentage of the device supplements, i.e., strips, are paid by the government, and they are required to pay the difference and the entire cost of their devices, as well. Meral exemplifies how she has changed the brand of her glucometers due to the cost related reasons as:

> While leaving the hospital after diagnosis, they gave me Abbot’s device, and I used it. That time my family was paying 80 TL surplus charges, and SGK was paying it afterward. Once state insurance was giving the machine, for those who bought the strips, the machine was for free. Then, I changed the device. A while later, the government started to take surplus charges from that one as well. More than 20 TL per box and my monthly use are more than six boxes. That was the reason why I started to use brands for which the state insurance does not take any surplus charges.

Moreover, in the free market economy, there is no fixed price, and most of the vendors aim to profit from supplement sales. Ahmet complained about this problem in detail as follows:

> The biggest difficulty is the surplus charges you pay for strips. Instead of the device itself, they are making more money from spare parts. Also, there is no consistency in the charges. One pharmacy gives it to you with 25 TL difference, and the other may give you 5 TL difference; it is entirely black-market [*karaborsa*].

Another problem that is mentioned by participants is related to supplements' availability in the local market. For example, Eren indicated that being not able to find his current device's strips made him decide to be back his prior device as:

> I bought this device when I was in America hoping that strips come to Turkey eventually, but they brought another device that needs another kind of strip. Now that I cannot get strips from abroad, I am turning back to my old device.

These statements above reveal that for the first-time purchase, participants and their families do not play active roles compared to medical authorities. In addition, cost-related problems are the most common reason why individuals decide to change their glucometers. Other problems are mostly experienced while using the products.

#### 4.4.1.2 Introduction to Device

Most of the participants stated that they have been using a glucometer since the day they were diagnosed with diabetes. Esra described participants' common introduction to the glucometer as "All diabetics are given a glucometer on their hands [*Ellerine tutuşturulur*] when they are diagnosed." The basic information about how to use the device is generally given by either doctors or diabetes nurses. Moreover, sometimes pharmacists or product representatives undertake this responsibility. With regards to participants' statements, from whom they get their device introduction might depend on whether they were hospitalized at the moment of diagnosis or not.

Regarding introductory briefing, Meral criticized the context of the information by sharing her experience as follows:

> Diabetes nurses are not conscious enough. The first time I was hospitalized, the diabetics nurse said that I could use the lancets until it becomes blunt. Then, I used it until it becomes blunt. However, when I went to a pharmacy, I learned that those were single-use from the pharmacist.

Her statement recalls the discussion of expertise (see Section 4.3.3). Although in medical hierarchy, diabetes nurses may be expected to be more knowledgeable than pharmacists, in Meral's example, the one who sells the product has the reliable information than the one who introduced the device.

Regarding their first-time use, all participants mentioned that they were able to understand how to measure blood sugar with a glucometer quickly. In addition, some of them stated that they had checked the user manual right after their first introduction to gain a deeper understanding of the device.

#### 4.4.1.3 Using the Product

Hande summarized how to monitor BG levels with a glucometer (see Figure 4.4) as follows: "You put the strip when the light blinks, you drop blood, and you get the result immediately." Some of the participants stated that they have been using glucometers for more than 10 years and witnessed many improvements in glucometer design. For example, Esra exemplified the change in product dimensions: "Once, the device was really huge, now it is like 5 cm or something, I guess." The change in the dimensions of the products also discussed within the concept of portability as participants stated that the smaller that devices get, the more frequent participants monitor their blood sugar as they carry their devices with them willingly. In addition, Esra also commented on the improvements in the time spent on monitoring as follows: "Before, it was taking like one minute to get the result. Now, after dropping the blood sample, it only takes like three seconds."

Nearly all participants mentioned the problems that they experienced while performing the measurement in different conditions. For instance, Güzin commented on the unpractical aspects of using the glucometer while monitoring her blood glucose on the go:

> For instance, while driving my car if I feel my blood sugar lowers, and if I want to measure blood glucose while waiting for the red light, first I need to find the strip, put it on the device, prick my finger, and you have to be fast while doing so. It has that kind of difficulty.

Similarly, she also pointed out the difficulties about the night use as: "That is to say, waking up 3 in the morning, putting up the lights on, having glucometer on the hand, piercing the finger, putting the strip and measuring is really a torture." Regarding this problem, Eren stated that his glucometer, which is shown in Figure 4.4, has indicative lighting that shows the area where the strips are placed. Moreover, the screen has a background lighting, and he interpreted these two features for the ease of night use. However, he discussed the problem that he experienced as: "While using it at nights, the place I put the strip is lighted. However, the place you drop the blood should be lighted as well, as I cannot aim at the right place at dark."

Although in the case of night use, such design implementations like indicative lighting might work, the main problem which makes it hard to perform effortless measurements with glucometers in the preparation stages as Güzin stated above.

Figure 4.4 Contour® Next One. Digital Image. Bayer (n.d.), http://www.multivu.com/players/uk/7954951-contour-next-one-bgms-ascensia

As discussed in Section 4.3.2, self-monitoring is one of the most crucial routines of diabetes management. In use practices, the reliability of monitoring devices is critical as important decisions such as insulin doses are defined according to the measurement result. In this regard, as a trust criterion, Güzin indicated the margin of error as: “It has a 10% margin of error, it gives almost the same results blood tests you have at the hospital, I really trust in the glucometer.” Her narratives indirectly express that she has compared the BG levels derived from the device with the blood analysis results at the hospital to build a trust relationship with her glucometer. By the same token, one of the common problems that participants come across is having inconsistent glucose levels. Apart from a broken device, participants mentioned several reasons which might cause this problem. First, Cem explained his personal experiences related to temperature in detail below:

> In really hot and cold weather, glucometer gives an error. Let us say you go for a ski. In cold weather, the device freezes in and does not show results. Alternatively, let us say you are at the beach in the summertime, and if you

> leave the glucometer under the sun, it measures wrong. You have to be in room temperature conditions for an accurate measurement.

Similarly, Esra explained the battery problem that she experienced in low temperatures as follows:

> Since I started to exercise outside, the device is giving a battery warning, but the real reason is cold weather. The battery does not work in cold, same as mobile phones. Then, a friend from the group told me that "take the battery out, warm it in your palms, set it inside again, and then it works immediately."

Esra's statements represented how users apply their previous experiences into practice to provide solutions by hacking their products. In her experience, it is also possible to mention community involvement as she reached the information for how to hack the device through another member.

This section represented the fundamental device use practices in diabetes as in current treatment methods, and all individuals are experienced in monitor their BG levels with glucometers. The following two sections will represent participants' experiences with wearable diabetes technologies.

### 4.4.2 Continuous Glucose Monitoring Systems

As explained in Section 2.4.3.1, continuous glucose monitoring systems cover Flash Glucose Monitoring, i.e., FGM, and Real-Time Continuous Glucose Monitoring, i.e., rtCGM, systems. Although, most of the participants who use CGM systems do not know the exact difference between the two, Eren, an engineer, and a tech-savvy participant, explained the primary difference between rtCGM and FGM systems comprehensibly as follows: "The one that I use called as flash glucose monitoring makes instant measurement in a word, the other one is real-time, it measures constantly." Meral highlighted another difference between FGM and rtCGM systems, according to her experiences with different devices, which are *FreeStyle Libre*, an example of FGM, and *Guardian Connect*, an example of rtCGM.

> From time to time, I used Guardian Connect. Just today, I have removed the Guardian Connect sensor and put Libre on. I use both, more often the Libre. That is because the adjustment is a nettlesome thing for me since I do not want to prick my finger; I use the sensor system. Hence, most of the sensor at the market right now need adjustment but for Libre adjustment is not a must, I do not prick my finger, I am not hurt, it is much easier.

As she mentioned, some devices require calibration, which means double-checking the results through glucometers. For the patients using wearable technologies, being able to monitor BG levels without finger pricking is a decision criterion as Meral explained why she mostly prefers using one product over the other.

When it comes to the overall experience with CGM, most of the participants describe it in comparison with glucometer use. For example, Turan described his assessment of CGMs as follows:

> It is like driving a straight gear car (showing the glucometer), and this one (showing sensor) it goes instantly [*basınca gidiyor*]. It is like buying an automatic gear car; it is expensive, but it is really comfortable.

According to the participants' statements, the history of CGMs in Turkey extends the 2010s. Most of them mentioned that they were informed about these systems through online and mostly international sources, yet they had to wait until these products' launch onto the market. Turan exemplified this period as follows:

> I was following the product via the Internet. My process of the order was going to start with the help of my friends in the UK, and then I heard that it was going to be released in Turkey as well in 6 to 8 months, then I started to follow the website. As soon as it arrived, I ordered it online.

Regarding his statements, the reason why Turan ordered the product was that technology seemed promising to him, and this might be one of his decision criteria. Similar to my approach in Section 4.4.1, below, I investigate participant's experience with CGMs, from the decision of purchase to the time when they talk about not only the functional aspects but also bodily practices regarding these devices.

#### 4.4.2.1 Purchase Decision

The participants' statements showed that there is a serious decision-making process in which they evaluate the advantages and disadvantages of CGMs. In this regard, one of the biggest motivations of participants for using CGMs is the possibility of measuring blood glucose without finger pricking, as Cem mentioned: "No finger pricking, at the moment you scan the device you instantly see the results. That is a big convenience; this is the most motivating part, no pain!"

While decision making, it is revealed that recommendations of authorities and end-users are the most significant sources of motivation. While some of the participants started to use *Abbott's FreeStyle Libre*, one of the most known FGM systems as mentioned in the Section 2.4.3.1, with the guidance of their doctors; another participant, Güzin, made her decision at the recommendation of a person with diabetes that she had met via the Internet. Below, Güzin explained her purchase decision by also indicating her concerns about wearable technologies in detail:

> I have a friend who has early age diabetes like me, while I was talking to him, he said I bought Libre, and my life became much more comfortable. When

> he said that, I thought about searching for it, but my decision-making process is longer than usual, I read the blogs, watched videos and so, than I said I was going to try than we ordered like that.

As it is understood from her statements, the recommendation of a person, who also has a similar background and truly empathize in the sense of living with diabetes, has a more significant impact on the decision making. In addition, the other dynamics that also play a role are the online information sources which are official websites of the devices or the online platforms where first-hand experiences are shared, as she decided to use CGMs after watching related videos and reading user reviews. Güzin continued as follows:

> The fact that I made too many measurements while I was pregnant also pushed me through this. To be honest, if I were not pregnant, I would reject using it. I said that before, I was against being bionic. I had the thought that my illness should not be understood from outside. However, having my fingers full of holes saddens me and pushed me to Libre.

Similar to the discussions in previous sections, her measurement routines have changed during pregnancy, and having finger pricking up to 25 times in a day made her feel overwhelmed. Hence, she decided to use CGMs together with the glucometer. At this point, it is important to point out that she was distant towards using wearables as she thinks that wearable products make diabetes visible by characterizing the body in a form that she described as "bionic," which recalls the discussion of *cyborg* (see Section 2.3.3). As my findings mirror the literature, self-tracking practices digitize the body, not only through recording and representing the body in numeric values but also with the integration of the body and the wearables. The visual perception of the body-device embodiment is discussed in Section 4.4.2.6 in more detail.

Participants mentioned that they were mostly doubtful about the availability of devices and their supplements, as they were informed about these technologies a lot before their launch in the local market. The ones who were willing to use CGMs had to find alternative solutions to order them. Eren explained how he accessed his *Libre* as follows:

> First, I saw it on the Internet, and we found someone who was coming from abroad, we requested from him and he offered to send it to us. We looked at the price; at that time, foreign currency was low, so we decided to buy two boxes of the sensor. When we saw that we were satisfied, we started to request it from everyone who goes abroad.

His statements represent a different kind of collaboration that other people help him to provide his device supplements and sustain his device-use practices. Overall, this section represented participants' assessments, and criteria play a role in a purchase decision. In the following section, participants' experiences while learning to use CGMs are presented.

#### 4.4.2.2 Learning to Use CGMs

The best sources of information about these systems mentioned by the participants are the official webpages or accounts and online platforms such as forums or Facebook pages where actual users share their experiences. In this regard, most of the participants were introduced to their devices by watching tutorial videos. Although, some brands provide either online or personal training programs, Aslı, one of the participants who attended those educations, commented on the qualification of those as: "They claim that all useful Libre instructions are given, but they are absolutely not doing that, they just show 'put it like this, measure it like that' kind of things."

Another information source is the manuals which are checked by participants either for the first use or the moment of emergency. Turan is one of the participants who checked the user guide at the time when he received his *Libre.* In a broader perspective, he described all the stages from opening the package to wearing the sensor and pairing, which might be considered as an example of ritualization, as follows:

> In the box, there is an alcohol wipe to clean the body site. Then, there is an applicator that helps you to wear the device [*çakma aparatı*] and a biological bag to collect waste sensors. Also, there is a sensor reader. Once you wear the sensor [*çaktıktan sonra*], first, you need to activate it, which takes around an hour. In the display of the reader, there is a button saying, "start with a new sensor," in which once you launch it, your life changes.

In short, nearly all of the participants who use CGMs had their self-introduction to the device through personal research, sometimes even before the decision of purchase. Apart from the brands' official sources, as participants stated, online platforms, including online communities where users share experiences, are the most preferred and useful information sources, which are discussed thoroughly in Section 4.5.

#### 4.4.2.3 Wearing CGM Sensor

Wearing the sensor, especially for the first time, might be challenging as it is understood from participants' statements. Some of them received professional help, while others had to take care of oneself or asked for help from their family. Meral commented on not only her first-time experience but also her routine about wearing sensor as follows:

> When we bought it, the company officer showed us how to wear it, but while wearing the sensor for the first time, we watched it from a video. In general,

> Sertan is helping me to wear the sensor. I can do it by myself, but I think he likes to do it.

Similar to Meral, another participant Eren, also stated that he wore the sensor with the help of his wife for a couple of first times till he got used to managing it by himself. These two stories can be considered as an example of collaborative management in diabetes. Moreover, Eren also commented on having a fear while placing the sensor for the first time due to the uncertainty of feeling any pain.

In the case of body site selection, some of the brands recommend specific areas that are declared as suitable for use. In addition to her words above, Meral clarified this limitation as: "Libre can only be worn on the arm in warranty cover. If you wear it on the belly and have a wrong result, the company does not take responsibility."

Another reason why some participants prefer to use wearing a sensor on a single body site was explained by Güzin as follows:

> I always wear it on my arm. I have never tried on somewhere else. It is because Mrs. Esra [a famous blog author] mentioned that she tried it on her belly and leg, but in the end, the best results come on the arm, she said, and I just put it on my arm since then.

Once again, her statements revealed that online platforms have a significant impact on device users, not only for their purchase decisions but also in the way of using their technologies.

Get back to the topic of sensor sites, most of the participants were open to try different body sites and discover which one is working best occasionally. Moreover, similar to insulin intake, they also emphasized the importance of rotating these sites. Esra exemplified that how she was not comfortable with the body site that device representatives recommended and tried different areas for her comfort follows:

> The first time, it was put by the authorized person on my arm. However, I did not use it on my arm; I am more comfortable on my belly. That is why I put sensors on the belly and or upper hips.

Similarly, Aslı also pointed out that she uses sensors on different parts of the body as the experiences of the blogger that she follows made her feel encouraged and decided to give it a try of wearing the sensor on her leg. As she stated, one of the motivations behind this decision was related to the visibility of the product, similar to her concerns about taking insulin in public, because people's questions might be disturbing (see Section 4.3.1.3). She explained which sensor sites she uses and why as follows:

> In the beginning, I was only using it on my arm. Then I saw a foreign blogger was wearing it on legs too because, in the summertime, it really bothers me when I wear tank tops, people are always asking questions. I do not want my arms to become tough since I regularly inject insulin. Later, I tried it on my leg, and it works well on my legs as well. It works on the leg as well as on the arm. A foreigner blogger even put it on the chest; I am not that brave! [*O kadarına cesaret edemem.*]

Although she stated that the results of placing the sensor on legs were satisfying on a par with wearing on arms, some of the participants refused to use legs as a sensor site due to the fear of peeling off the sensor while dressing up. Cem exemplified this as: "For instance, if you wear it on the leg when you take your trousers, it can go off with it, it can be a problem when you lie down, that is why I do not prefer wearing on legs."

No matter whether they wear sensors on different sites or not, almost all of the participants mentioned the importance of rotation due to several reasons. Above, Güzin indicated that she rotates sensor sites according to the seasonal changes such as clothes preferences. In addition, she commented on her concern for the accessibility of the sensor, especially while monitoring over thicker clothes such as winter jackets as follows: "At first I doubted whether I could easily measure in wintertime, but even with the thickest coat, it measures really good."

Eren, who wears sensors only on his arms, explained the hygiene-related reasons as follows:

> Each time I change a sensor, I put a new one on the other arm that I can clean the previous one. It is because you have to apply the sensor on a clean arm. The possibility of going off is higher when the arm is dirty or greasy.

With regards to wearing sensors, another dimension is about how users feel with the sensor in the daily life. As mentioned earlier, most of them feel scared or nervous while wearing the sensor. However, most of the time, they even do not feel the existence of the sensor as Güzin stated: "I forget its presence, I even lie down on it. Right now, I do not feel it." Her statement shows that there is an embodiment process in which participants become integrated with the device and accept it as a part of their own body.

There are several problems that participants face while wearing the sensor on their bodies. The most common problem which nearly all of the sensor users mentioned is that the sensor itself is not sticking on the body, no matter that participants followed the given adhesion guide. Therefore, participants stated that they apply DIY solutions such as putting sticky patches over the sensor. Esra explained how she fixes her sensor by also mentioning the additional products which seem working as follows:

> The tapes of the sensor are not sticky enough; when you sweat, it may fall. When the tapes of the sensor come unstitched, since the needles inside are

> capillary, the possibility of moving or falling goes higher. I tape the sensor around my arm just in case. Moreover, before wearing the sensor, I clean my arm with an alcohol wipe. After that, the sensor sticks better.

Another problem related to wearing the sensor is that on the user guides of the sensors, it is recommended to apply sensors on the body parts, which has more body fat. However, as one of the most common side effects of type 1 diabetes is the excessive weight loss, some participants like Eren complain about not having many alternatives where to wear sensors as follows: “Since I have a bit skinny arm, the area I can place the sensor is limited. Sometimes, the needle of the sensor might touch a bone or a muscle, and you feel afraid of hurting yourself accidentally.

In addition, participants also mentioned that there might be problems because of water contact. As emphasized in their user manuals, sensors are not waterproof yet water-resistant. That is why, as Güzin exemplified, it constrains the time that participants can spend while swimming or taking a shower. Moreover, Eren also stated that he refrains from exposing sensors to water often as he thinks that it weakens the adhesive, and his sensor might come off.

To sum up, several criteria play a role in the preference of where to wear a sensor. At the beginnings, participants tend to wear the sensor to where it is shown or recommended by device representatives. The statements of the participants, especially the ones following online sources frequently, show that other people’s experiences might lead users either to be experimental or conservative. In addition, as Meral stated, warranty coverage might be another reason why some users do not prefer trying alternative parts of the body.

Placing sensors onto alternate body sites might also be a tactical decision. Primarily, depending on environmental conditions, such as wearing several layers in wintertime, users might prefer a more reachable body site. At this point, beyond the connotation of efficiency, reachability might refer to the practicality of wearing a sensor. As some of the participants stated, sometimes they appeal to another person for placing the sensor onto the body, which might be considered as another example of collaborative management.

The other tactical decision might be related to the belief that wearable devices make the illness visible. With the freedom of being able to wear the sensor in different areas, users can decide the representation of diabetes, and the ill-body as well.

#### 4.4.2.4 Monitoring with CGMs

In the Literature Review, the working mechanisms of CGMs are explained in detail (see Section 2.4.3.1). To briefly remind, FGM systems, such as Libre, have a hand-held reader that users need to scan the sensor to see the current BG. However, in the rtCGM systems, such as Dexcom, there is a transmitter that is attached to the sensor and transfers the BG to the receiver or the compatible mobile app.

The fundamental advantage of wearable technologies is the ease of measurement under different circumstances, as Güzin summarized:

> Since I started to use it, I feel satisfied. My life quality increased. For instance, when I was attending a meeting at the office, I was always bringing sugar with me. Now I only bring the sensor reader, and I test during meetings whenever I want. For example, during pregnancy, they want you to test it at 3 in the morning. It is such a torture, waking up at 3 in the night, turning the lights on, finding glucometer, pricking a finger, putting it to that, and testing. With the sensor, I get up, hold the reader, and monitor my blood sugar. If the result comes normal, I say "Good" [*Aa iyi*] and go back to bed.

In contrast to the difficulties of monitoring with glucometers, non-invasive technologies make monitoring at work and during the night more comfortable.

Based on the interviews, it is shown that there is an increase in the frequency of monitoring blood sugar after starting to use CGMs, as no finger pricking is required (see Figure 4.5). Güzin, a *Libre* user, described her monitoring routine according to the affordance of the device as: "I continuously [*şak şak*] monitor it. Probably, I look at it like 50 times in a day. My doctor says I do not need to check my BG levels that frequently."

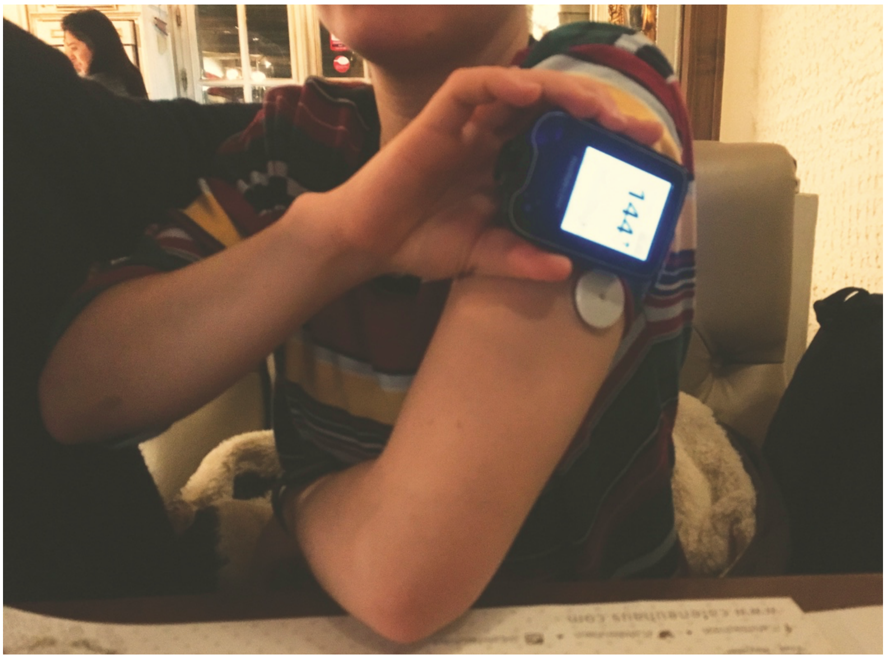


Figure 4.5 Participant Monitoring Blood Sugar with FreeStyle Libre

In addition, my findings of the frequency of monitoring mirror the literature (see Section 2.4.4), as Esra exemplified: "If you are using a sensor, this is a serious plus for diabetes control. The more you know, the better you can adjust. So, the sensor has a positive effect on management." Eren narrated his monitoring routines with the sensor as follows:

> After starting to use the sensor, the numbers of measurements I perform per day are not more than 10-15 times in a day. Mrs. Esra [a famous blog author] even said that “you have such technology on your hands, why don’t you take advantage of it, I would make 30-35 measurements in a day if I were you.” Also, an international community stated the average number of daily measurements per day as 15-16 times. A bit below or above those numbers, I am an average user as well.

The reason why Eren described himself as an average user reveals that how many times users measure their BG levels with CGMs is also a quantification. Furthermore, this quantification brings up another normative discussion about technological literacy. As my findings mirror the literature (see Section 2.4.4), Eren’s comments on how Mrs. Esra interprets using technology efficiently related to the numbers of measurements. The users having high numbers of measurement might be perceived as more responsible users or diabetics from a broader perspective.

According to the participants who use *Libre*, one of the most beneficial features is that the device visualizes the anticipated change in the blood sugar with arrows, which is called *trends* (see Section 2.4.3.1). For most of the participants, it was like a milestone in their diabetes history as it changes their understanding of blood sugar in a more dynamic way and living. For instance, Esra described her impression about this benefit of the sensors as follows:

> The first time I wore the sensor, I continually measured my BG level, because, through my 25 years of diabetes history, I could only test it with my fingers, and now seeing it live [*canlı görmek*] was unbelievable. It is like someone put a camera inside you and showing what is going on. Because it is always something unknown for you.

*The trend* feature gives participants the freedom to decide whether they need any micromanagement or not, unlike glucometers, where the anticipated change is unknown. At this point, one of the aspects which differ CGMs from glucometers substantially is the dynamic, real-time visualization of an unknown, i.e., which direction the user's glucose is going (see Figure 4.6). In this way, potential emergencies become predictable with real-time data. Güzin explained this feature in detail as follows:

> When you measure with the glucometer, you cannot see what is the direction, whether it will go higher or lower, or stays constant. That is why, my favorite feature of Libre is the trends. For instance, if I measure it with a glucometer and the result comes 150, I have to take an additional dose of insulin in general. However, when this (Libre) shows 150, but the trend arrow is going lower, I say that I do not have to take extra insulin shot [*vurmama gerek yok*]. The arrows have different meanings; for example, arrows show completely down, my blood sugar falls fast, if arrows show like this middle, it is stable, and if it is slightly inclined, it falls but not that fast, it means.

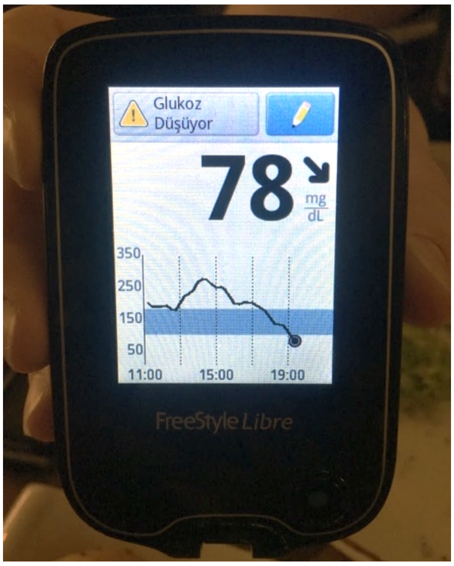


Figure 4.6 Dynamic and Real-Time Visualization of Blood Sugar

As the device gives the decision of micromanagement to its user, it again brings up the discussion of expertise in Section 4.3.3. In addition, Güzin stated that this feature is also helpful for managing her diet as she is able to see the instant effects of any kind of food on the blood sugar with quick monitoring. Moreover, she pointed out that being able to see the change in blood sugar might be motivating as: “For instance, if I see it stabile on the graphic, I am brightened. That is good; this can be eaten, well done! [*Aferin.*]” Güzin’s statement reveals that apart from giving the right to decide on micromanagement, this dynamic representation of blood glucose also entitles participants to approach their diet in a more exploratory manner.

Another feature of CGMs mentioned as beneficial by nearly all of the participants is that keeping BG history to show the fluctuations on BG and also processing the archived data to create graphs, which shows the average sugar levels (see Figure 4.7).

Figure 4.7 The Average Glucose Graph on FreeStyle Libre

When it comes to discussing users’ problems, the most crucial point is the inconsistency in results. Due to the measurement method of CGMs (explained in Section 2.4.3.1), it is expected to have some delay in BG levels, when the instant results of sensors and glucometers are compared. Moreover, participants stated that the delay in the results might be challenging while managing high or low sugar. Aslı exemplified this as: “For hypoglycemia and hyperglycemia, the sensor has difficulties pulling itself together, but after realizing that, there is no problem at all.”

With regard to the delay in results, participants stated that it stops them from trusting the sensors completely and prompts them to check their blood glucose with glucometers as a confirmation. As Güzin stated: “I do not trust sensor at all, a glucometer is more reliable. That is because the sensor comes 15 minutes behind in measurement. I think that it should be confirmed and double-checked 3-5 more times.” Moreover, she also claimed that the sensor’s margin of error is higher than brands’ declarations as: “Even if they claim that the margin of error in the sensor is 10%, it can go up to 30%, and this makes me uneasy about it.”

In addition, another participant Turan pointed out that there is an adaptation period after wearing a new sensor, in which the BG results might be inconsistent. He explained how he overcomes this mistrust as:

> One should not trust the sensor all the time. For example, following two days after wearing the sensor, I cannot be sure about its accuracy, but after two days, when it starts to go together with a glucometer, I say now it is okay [*artık tamam*].

No matter if participants are familiar with diabetes and conventional device use practices, when they switch to CGMs, even experienced diabetics become novice users. Therefore, it takes time until users gain experience in connected devices. Although non-invasive methods provide many features which makes monitoring and following BG easier, participants mentioned that they use wearable technologies in collaboration with glucometers, because they do not entirely trust the recent technologies and feel the need for calibration.

### *Companion Apps and Products*

In addition to the benefits of CGMs, participants gave information about some compatible products that enable FGM systems to work as rtCGM. One of them is the *NightRider BluCon,* which is shown in Figure 4.8. Eren gave information about the working mechanism of the product as follows:

> BluCon is a device that is placed on Libre, works as a scanner, and helps to transfer data to the phone. It is only sold abroad. According to your time preferences, it sends data to your phone. It performs approximately 300 scans every day.

Figure 4.8 NightRider BluCon. Digital Image. Ambrosia Systems Inc (n.d.), https://www.ambrosiasys.com

In the use of BluCon, the function of sensor reading is delegated to this additional product so that users do not need to carry the external reader anymore. Moreover, the product has a companion mobile app that helps participants to manage blood glucose at the moment of emergencies easier with its additional features such as: “With the mobile application you can set ‘warn me when this specific value goes lower, goes up, warn me every half an hour’ alarms on your phone. With this feature, we could be more prepared and overcome difficulties.”

In addition, there are some open source applications that are developed for devices that do not have their official mobile apps. However, the configuration process of these open source apps is quite complicated, especially for the ones who are not familiar with the technology. Esra exemplified how she received help while hacking her product to make it enabling collaborative management through mobile devices as:

> My device does not have a remote monitoring feature; that is why I downloaded another application to my phone. There is a guide explaining how to monitor BG remotely, and you make it accordingly, but it is not like something that any person could do. You connect the phone you use to the device with a cable, and they remain connected to each other. Then the data goes online through the Internet, then the people who are permitted to see the data can reach on the Internet when your blood sugar goes down, their alarm goes off.

On the other hand, participants stated that although some of the CGMs have their official mobile apps that are compatible with the sensors, due to unknown reasons, currently they are not available for use in Turkey. Hence, some participants, who are confident with technology, pointed out that they are also using third-party applications that promise compatibility with their devices. Eren exemplified this problem as follows:

> The sensor I use has an application that is not available in the Turkish market yet. We have been warning them for two years, saying it is still not available in Turkey, release it, but they still did not. It might have problem; I do not know why. We are tolerating it with other applications claiming that they are compatible, but they do not work seamlessly.

To summarize, measuring BG levels with non-invasive methods has improved participants' self-monitoring habits, and dynamic representation of blood glucose redefined their understanding of diabetes management. Moreover, connected aspects of contemporary technologies contribute to self-surveillance by documenting long-term health records of individuals.

### ***Collaborative Management***

While talking about assistive technologies, the participants mentioned the power of the connectivity, which makes the data, i.e., blood glucose levels, accessible from different devices and by different people, as well. The interaction that is shaped around these technologies might be considered as another collaborative management example since they also make the other people, who are given autonomy by the actual user to see the BG results, have a voice in the management process. Especially for the times when collaborative management is acknowledged as necessary, enabling collaboration is one of the most important benefits of the diabetes technologies that are mentioned by the participants. As an example, below, Esra explained how the possibility of collaborative management had an impact on making one of the decisions of her life as follows:

> In 2016, I was going to the Netherlands and needed to stay there for a while due to business-related topics. As I was going to be alone, I was wondering how I would make it, and what would happen if my blood sugar goes down. Then we started to look for a way to monitor all together with the changes in

> my blood sugar. We realized that it could be Dexcom because it has remote access methods that convinced us. So that we said Let us install Dexcom's remote access system to our phones, and anybody could reach and monitor my blood sugar changes.

On the other hand, she also indicated the drawbacks of these connected technologies as sometimes they update themselves quite late and present inconsistent results, which might cause a panic, especially for the ones who are able to see the results. This situation is one of the specific examples of where the participants call glucometers for help. In addition to her words above, Esra also exemplified how she manages device-related issues such as displaying inconsistent results as follows:

> Sometimes the device's caliber has deviations. It says your instant blood sugar is 50, but when you test it with a glucometer, it shows 90 in reality. Also, the other way around, your blood sugar is 50, to make it higher, you eat something, but the device shows 50 for a while and displays low sugar sign. So, your partner becomes worried somewhere else. You call him to say, "My blood sugar is normal, I measured it, sleep now." Then you unplug the device again: "I am okay, Dexcom, stay where you are. [*Ben iyiyim, dur sen şurada durduğun yerde*]."

Esra's narratives revealed that one of the roles of connected technologies is to inform users about BG levels through notifications. Moreover, with the agency of the device, Meral delegated the role of management also to her fiancé. However, at the moment when the device is not reliable, she takes the initiative of being the only authority on her diabetes. She turns off the device, which eliminates the other actors, as well.

Similarly, Meral pointed out that she feels disturbed when her fiancée texts her in the middle of the night by indicating that her BG is falling, regardless of the fact that she also receives the same notification. Moreover, she also stated that her fiancée does not approve of the systems which do enable this connectivity. Sertan, her fiancée, explained the autonomy on Meral's diabetes with these words: "Thanks to the system, I omit Miray [*aradan çıkarıyorum*], I open web portal and monitor her BG levels. It is all between me and my explorer page." With regard to his statements, it is possible to discuss that technology, a non-human actor, either substitutes or eliminates the main actor, the person with diabetes, in the interaction network, which is mainly shaped around Meral, her fiancée and diabetes itself.

To sum up, the most significant contribution of CGMs in diabetes management might be the dynamic representation of blood glucose in which people have a chance to evaluate the overall situation, instead of instant results as in glucometers. Therefore, people get familiar with their condition and gain authority in their care as these devices support them to be more flexible and experimental rather than strictly relying on the treatment plan. This situation also recalls the discussion of the role of the doctor as well as the limits of self-expertise (see Section 4.3.3). Last, connected technologies enable close relations to take part in diabetes management, which makes the care easier and safer in general. However, the distribution of roles and power relations on collaborative management is also criticized by some participants.

#### 4.4.2.5 Economic and Political Dimensions of Using CGMs

As mentioned in the several parts of this thesis, using wearable diabetes technologies are considered as a luxury rather than a need in the management of diabetes at the policy level. That is why current healthcare policies in Turkey do not provide any economic support for CGM users. Eren complained about this manner of the government by also stating the importance of using sensors, especially for children who are not able to perform self-management properly as follows:

> There is still no governmental support. Sometimes you say like “Why should I care [*bana ne*],” but you feel sad for the people who cannot afford it. Families have two-three children with type 1 diabetes, for instance. Not for the adults, but for the children, the use of a sensor must be obligatory, and the state has to pay for it.

In contrast to the current situation in Turkey, Esra gave details about her experience of using CGMs while living in the Netherlands. Moreover, her critiques draw attention to the challenges that people with diabetes are experiencing in Turkey as:

> Before going to the Netherland, I searched whether company insurance was covering the sensor. I even pushed the company that they have to pay for it; otherwise I would not move. As soon as I got there, I realized that in the Netherlands, the state insurance pays for all diabetes-related supplements. The things that cause massive problems for us here is not even a problem there.

In general, the product life cycle of the sensors varies from 7 to 14 days, depending on the brand. In this regard, participants stated that this duration is pretty short when the cost of the sensors is considered. Güzin, who uses *Libre*, exemplified her disappointment as: “It makes me upset about changing sensors in every 14 days. I wish it could be used for a longer time. They probably can do it, but since the companies want to make more money, they would not extend the product lifecycle.” Her statements criticize that brands give more priority to making profits than their users’ needs and satisfaction with devices.

Although non-invasive technologies provide better and comfortable management opportunities, they are considerably expensive compared to the finger-pricking method. First, these products are not locally manufactured, and the currency difference makes their costs even higher. Second, beyond the device itself, what makes CGMs more expensive is the need for changing sensors regularly, which are usable for short intervals compared to their high cost. As participants stated above, CGMs are considered as luxury products by the government and not covered by the insurance, which makes them accessible only for some groups of people. Therefore, as discussed in Section 4.3.3, participants may experience a lack of medical support, since healthcare professionals do not come across many patients using wearable technologies. Following this situation, how individuals search for experiential knowledge and involve in collectives are discussed in Section 4.5 thoroughly.

#### 4.4.2.6 Visual Perception of CGMs

Güzin narrated the reason why she was unwilling to use wearable devices as follows:

> I was against becoming bionic because I did not want people to know my illness. However, during pregnancy, I got used to having excessive numbers of finger pricking, which caused scars and made my illness even more visible. This led me to use Libre. If I were not pregnant, I would refuse to use sensors.

What Güzin meant by saying “becoming bionic,” recalls the body discussion in Section 2.3.3. Here, the word “bionic” refers to the body configured as a result of the human-body assemblage, in other words, embodiment. The word “bionic” also recalls the cyborg concept. Cyborg was defined as a fictional character with super-human powers. However, today’s cyborg is the person using digital technologies to monitor their own body to perform self-care, or self-surveillance in general.

In a positive manner, some participants mentioned that it does not matter whether the visibility of sensors also makes their ill-body visible, as they considered this visibility as an opportunity to familiarize other people with diabetes and the related technologies, as well. Eren explained how she turns the perceptions of the body into an advantage of raising awareness both about diabetes and technologies. Moreover, he also stated how he socializes through diabetes as follows:

> When I wear a t-shirt at the office, I realize furtive glances [*kaçamak bakış*] of the people. It attracts people's attention. Especially, people with diabetes ask what a sensor is, and where can they obtain it. Also, another person sees you using the sensor in social spaces says, "Oh, you have that, too?" Then, there comes a sympathy and sincerity.

On the other hand, Güzin also criticized the external image of the sensors in terms of their aesthetic concerns. Most of the time, it is possible to hide sensors successfully as their dimensions are considerably small, and there are several body sites on which participants can apply the sensors. However, most of the *Libre* users, like Aslı, prefer to follow the rules written on the manual and generally use the sensor on their arms. As such, she indicated below that she considers the image of the sensor as a thing that ruins the visual harmony of the body:

> For example, when I wear a tank top, that look bothers me visually. It may be because I pay too much importance to the look. The device does not look like an accessory, after all. I do not know; maybe other people's reactions make me think in this way. For example, I do not think about how the sensor looks in wintertime, but during summer, it becomes harder to use the sensor.

The reason why she wants to hide the sensor might be related to her concerns at first glance, but then she addressed the perception of other people. The device makes the illness visible and then how ill-body is perceived by other people affects individuals' approach to their bodies, and sometimes their illness from a broader perspective.

As my findings mirror the literature again (see Section 2.3.3), the devices are worn or carried on the body configure the new forms of bodies. Moreover, they become body prosthetics and open to discussion due to the visibility of the device, and the illness as well. Beside body characterization, what Eren stated about socializing at work is the example of biosociality as people gather and interact with the mediation of the device and the illness, implicitly.

This section represented the use practices of CGMs and how they reshaped the monitoring habits and human bodies. In the following section, use practices of insulin pumps, which are the wearable devices for insulin intake, are presented.

### 4.4.3 Insulin Pump Therapy

As explained in Section 2.4.3.2, insulin pump therapy is the latest method used for continuous insulin delivery through a computerized device worn on the body. Unlike other technologies in diabetes care, the transition period from syringe or pens to insulin pump therapy has its challenges, which are also called "pre-requirements" by medical authorities. Burak narrates his journey of being ready for the device as follows:

> The transition to the pump was a long process; for example, they want you to learn the carbohydrate count. We knew about the device from the very beginning, but at that time doctor said that it would not be the right time to wear it because I was very young and not able to adjust the carbohydrate counting myself. Also, I was going to carry it with me all the time. What if something happens, when you jump, run, or fall? As a child, you cannot take care of the device properly. So, we were told that we had to wait a few years.

As explained in Section 2.4.3.2, the use principle of insulin pumps relies on carbohydrate counting. The users are responsible for counting the carb amount of their food, and the device calculates exact insulin doses required for their carb consumption. That is why, as Burak mentions, doctors do not approve the use of insulin pumps without the knowledge. Moreover, what Burak stated about his age also revealed the concerns about how to take the responsibility of the device, such as carrying it all the time, which is discussed thoroughly in further sections.

### 4.4.3.1 Purchase Decision

To continue with the example above, Burak stated that they were aware of the insulin pump therapy and how he decided to use the device was mostly his own intention. Similar to him, Hande told about how she started to use an insulin pump as follows:

> Then I realized that there was this thing (i.e., the pump) there, and in six months, I learned about carbohydrate counting and installed a pump. I wanted to do whatever was the best and also wanted to continue my routine life. That is why I made such a quick transition.

In her statement, Hande not only talks about how she put an effort to be able to use an insulin pump. What is more, she talks about her goal in diabetes care and expectations from the device. As a person with diabetes, Hande wants to make sure that she is doing the best, which means using the latest technology in this context. This might be related to feeling responsible for her health. She expected that the pump would help her to get back to old routines, which recalls the discussion of change in everyday life in Section 4.2.1. Moreover, she delegates the role of management to the pump and counts it as a contributor to diabetes management.

As Hande decided to use the insulin pump by her own will, she made detailed research on different brands and devices before making her purchase decision. The way she did her research might be a good example of benchmarking. She explained her decision-making process as follows:

> While deciding a brand, I worked like this: I made an Excel file and listed the brands, and features one by one, then added their monthly or annual costs, and so on. I did a study like this, and then I made my decision.

In her decision, features and the price of the device were the main criteria for selection. Similarly, Ahmet also did very detailed online research and mentioned that user reviews had an impact on his decision as follows: “When I searched on the Internet, all user comments were saying it is the best. It is like the Ferrari of insulin pumps. At the same time, it is much more expensive than the others”.

Unlike these participants, who were already aware of the technology and decided to use it by themselves, for some participants deciding to use an insulin pump was more than a well-being decision. Ebru, who was recommended to use insulin pump by medical authorities, explained the factual background as follows:

> I was in a period that not able to manage my diabetes, and doctors decided to hospitalize me as they thought it is not going to work. I started to stay in the hospital, at the end of two weeks, my infection recovered, but my blood sugar was not still going down. It was high during the daytime and going down towards the morning. So far as I understand, doctors recommend people to use insulin pump after this kind of situation because insulin doses have to be given hourly and in different amounts. The pump is something invented for this. It is so, at least for me. Then, I accepted by saying that I should start trying as it is time to be good. When people ask me why I use insulin pumps, I answer that when I intake one dose, my body cannot transmit the insulin by itself; for that reason, to have different doses in different hours, I started to use more professional methods.

As Ebru stated, why she started to use an insulin pump was because she was not able to manage her diabetes properly. So, doctors had a belief that technology would help her to maintain better care. Following doctors' recommendations, there is an assigned meaning to the product as an enabler by her. In addition, the way she describes the reason for using the insulin pump also recalls the discussion about the boundaries of the ill body. Here, Ebru says that technology substitutes her organ deficiency, and together with the pump, as a team, they accomplish a proper treatment.

Similar to the discussions in Section 4.4.2.1, pregnancy is the main reason for using an insulin pump for some participants. As it is mentioned, during pregnancy, the changing hormone levels also affect blood glucose. Aslı explained the relation between her purchase decision and pregnancy below:

> I started to use an insulin pump one year before my pregnancy; in other words, while I was thinking about having a child. My doctor did not do something about it, saying I was also doing a good job with an insulin pen. However, I did not want to take a risk during that period as the pump is more regular, though my blood glucose levels were already going regular. Apart from that, counting the times after pregnancy, I used the insulin pump for almost two and a half years. My friends using the pump insisted for me to use it too. Although I said, I would never wear that bulky [*koca, kaba*] thing on me, in the end, they convinced me, and indeed my pregnancy went much easier with the pump.

Here what Aslı mentioned is that though she was capable of managing her insulin doses properly with an insulin pen, the fear of risk during pregnancy made her start using an insulin pump. People experienced with diabetes generally can tolerate floating BG levels; however, during pregnancy, it may affect the baby's health. Here, beyond her personal perception, her motivation for using the pump is the moralization of technology. In addition, the way she described the product also gives an idea about her concerns regarding the image of the device, which is discussed in further sections.

In short, participants' statements showed that, beyond economical dimensions, purchase criteria for insulin pumps might be related to demographics such as age or the current status of diabetes treatment.

#### 4.4.3.2 Learning Insulin Pump Therapy

Compared to CGMs, learning how to use an insulin pump might require more effort. First of all, with compatible sensors, insulin pumps perform insulin intake and monitoring together, which makes the use and the maintenance of the device relatively harder. As introduces in the previous sections, different from CGMs, insulin pump therapy requires a transition period. In this regard, participants are varied in the need for hospitalization to attend training to gain prior knowledge about several topics. Burak narrated his experience as follows:

> Many years after my doctor did not let me participate in insulin pump therapy, there was an opportunity. In his opinion, I was not completely ready to take this responsibility yet, but we decided to give it a try. Then, I was hospitalized for 4 days for adjusting my basal-bolus regimen. The first day, they checked my sugar values. The day after, a brand representative came and explained to me how to wear sets, how to fill the reservoir, and so on. In the following three days, diabetes nurses taught us carbohydrate counting and the amount of insulin needed. The last day was also the time for changing infusion sets, so they wanted me to change them by myself, but still supported me during the process. While learning how to use the device, there was a great effort, especially from the brand representative.

In his story, although there is a medical authority decision, Burak was already aware of the therapy as many of the other participants. Hande explained how she started to use the insulin pump as follows:

> When I decided to use an insulin pump, I shared my device decision with the doctor and asked for his opinion. He also recommended the one I chose. Then, the next day, I went to the hospital again, and he invited the brand representative. They explained the basics of the pump and made me wear the demo device. For the following four-five days, I went to the hospital to adjust my basal-bolus regimen. I heard that many people were hospitalized around three days during their transition period to the pump. However, I was not hospitalized.

Although Hande made her market research and had one option on her mind, she felt a need for an authority approval, which may be considered as an example for the limits of self-expertise. As a part of the transition period, she was given a demo device to explore the features as well as experiencing its bodily relations before making the final decision. Moreover, different than Burak, she was not needed to stay at the hospital, but she had daily visits for the procedure during the process.

Different from these two stories, Esra was recommended to use an insulin pump by her doctor, and once he requested, she decided to give it a try without any hesitation. She narrated her story as follows:

> My doctor wanted me to use an insulin pump, so with his directive, we went to the medical store. The lady who was supposed to introduce me to the device also had diabetes and using an insulin pump. She showed the basics of how to use the device and then placed the infusion set on my belly and hung the pump in my pocket. I was really excited and did not really question, just put

> it in my pocket and walked away. At night, I slept with it without any problem; I never had a fear. In essence, I continued my life like there was nothing on my body. The other day, I went back to the store, and she made me wear the set by myself and filled my reservoir for real use.

Similar to Hande, she was also not hospitalized during the transition process and was given a demo device for trial. Her statements show that she adapted the device quite easy and. She stated that the person who introduced the device was also having type 1 diabetes and using an insulin pump, and what she was sharing might be considered as personal experiences rather than a promotional activity. The importance of personal experiences in diabetes and device use practices are discussed in detail in the following sections.

Getting back to the hospitalization experiences, Ahmet criticized the insulin pump training he attended at the hospital as follows:

> They taught me how to use the pump in the hospital. However, to be honest, they did not share any proper information. The reason is that you should be knowledgeable about teaching something to someone. It is not directly the fault of healthcare professionals because they are also trained under certain conditions and in limited times. That is why learning the device is entirely the patient's responsibility.

The way he criticized the qualification of the training also resembles the problem of the current healthcare system as professionals have a limited time and facilities to master their knowledge. As a result, the training is not sufficient to gain more in-depth information. At this point, Ahmet emphasized that mastering the device is a personal responsibility. By the same token, Ebru also stated the importance of personal effort as follows:

> The education in the hospital was not bad but inadequate. However, my own opinion is that if you want to learn something, then you need to ask, you need to wonder and search for it. So, if you want to learn, somehow you will learn it.

Both of the participants mentioned the will of learning and doing research accordingly and being responsible for their own care in broader, which are related to the concepts of self-surveillance and biosociality, in which responsibility of health is given patients' themselves.

#### 4.4.3.3 Wearing Infusion Set and Insulin Pump

Similar to CGMs, while using an insulin pump, placing the infusion set on the body may be difficult for individuals. Ahmet narrated how he attached the pump to the body for the first time as follows:

> When we first came home from the hospital, we watched the video from YouTube and tried it. I remember that we had a serious argument with my wife because she placed it in the wrong area, and it hurt so much. As I was not able to intervene at that moment, I felt like I had to blame her as she was responsible. Then, we watched the video once again and managed to do it. Nowadays, as I lost weight, it is really hard for me to find a place on my body to wear either sets or sensors. I cannot wear any sensors or sets on my abdomen, because the wounds have come out as there is no fat in that area.

The first thing he mentioned is the use of online resources, such as video tutorials. As many other participants mentioned, brands generally provide live tutorials, rather than written information as it is found more explanatory by users. To get back to Ahmet's statements, there is an example of collaborative management as he cannot wear the sets alone, and his wife also becomes a part of the insulin pump therapy. The reason why Ahmet requires help is also related to his preferences in body sites that are not reachable alone. In addition, he also mentioned his difficulties in wearing sets because it became painful since he lost weight. In addition to his words, Ahmet also mentioned about the discomfort he experiences with infusion sets below.

> It bothers me while sleeping. So, when I go to bed, I lie on my right side for the first five minutes and then turn to my left. I always feel the fear of what if something happens while I am turning. These questions on my mind make me wake up at least 3-4 times, which causes low-quality sleep.

As he is afraid to damage his pump unintentionally during his sleep, he gets low-quality sleep that may have physical and psychological outcomes. In addition, his words also refer to the embodiment of the product. Ahmet narrated his embodiment process as follows:

> At first, it did not seem very attractive, because if you think about it, you are going to live with cables 24/7 and the device will be like a part of your body. However, when you see the improvement in your diabetes management, then you start to think like, how can I get used to living with these cables on my body.

From a broader perspective, what Ahmet emphasized is the difficulty of living with a chronic illness as there is always body-device interaction. In terms of wearable devices, which makes the embodiment challenging is the necessity of carrying the device all the time, as he mentioned. In his experience, what encouraged him was the positive outcomes of insulin pump therapy. So, he decided to leave his bodily concerns behind, and instead, he started to handle this problem in a more solution-oriented manner. Similarly, Hande also got used to having concerns about breaking the device during her sleep. Now, her body and the device are assembled as she stated:

> At first, I was quite worried like what if I break the device, but now I leave it in the middle of the bed, and while sleeping whichever side I turn, it also turns with me. It became like a part of my body.

Different from these two examples, Esra stated that for her, the embodiment of the product was somehow like a natural process, as she indicated below.

> I remember the lady in the medical store told me that “I have never seen anyone accepted the device right away like you.” She said some people might find it odd for a while, but I wore it as if it was there all the time. My husband also got used to it so fast; he acts like it does not exist, maybe even more than I do.

Where participants carry, their pump is generally related to where they wear your infusion set. As Burak stated, “since I generally wear my sets on my belly, I hang the pump on my belt or my waist. I carry it like a cellphone all the time, and no one even realizes it.”

Although users are told to wear infusion sets either arm or belly area, as Ahmet stated above, this limitation is related to the scope of the device warranty. Most of the users mentioned that they place infusion set in different areas, and their preferences vary in the context. Ebru exemplified how she decides body site as follows:

> I generally wear the sets on my waist, belly, leg, and arm. I do not prefer to wear them on my belly too often because, after a while, there might be some lumps. Also, if it is an exam period, I do not use my arms, or if I am having busy days and always standing, I am not using my legs for 2-3 days. For example, they made me wear on my hips for the first time. Sometimes I use that area too, but it may make me feel uncomfortable.

Similar to wearing CGM sensors (see Section 4.4.2.3), deciding where to place the set is a multidimensional decision. Ebru mentioned that she wears them in five different areas of her body, and her preferences are mostly tactical on a personal level. In a similar manner, Hande also mentioned her approach of wearing the infusion set in different parts of the body as follows:

> I generally wear the sets either on my arms or my hips. For the first time, they also placed it in my arms as it is considered the safest area. Because of the pregnancy, I cannot use the belly area right now. But also, in general, I do not prefer to wear it on my belly, because the needle of the set might be broken while you lean. As I am using arms or hips, I need help while wearing it. I am generally open to different body parts, but now I cannot dare to do this because nowadays, it is really hard to find sensors or sets, and I do not want to waste any of them.

Although it is not recommended in the user manual as Ahmet claimed above, the brand representative made Hande wear the set in her hips, and it has become one of her preferable body sites. In addition, although it is not one of her first choices in general, currently, she is not able to place the set on her belly as another example of how pregnancy affects diabetes management. There is also a more tactical decision that makes her feel concerned to be experimental, i.e., using different body sites as the supplements of insulin pumps may not be available in the local market all the time.

To sum up, were to wear an infusion set might be a very tactical or rule-based decision. However, as the wearable technologies give the freedom of being more experimental in device use, most of the participants mentioned their trials of placing sets in different areas. The decision of where to wear the infusion set might affect where the device is carried on, which has a direct relation with individuals’ perceptions of the device, their bodily experience, and the embodiment, as well. Once products are embodied, they become like an external part of the body, and the visual aspects of the devices (see Section 4.4.3.6) may be more bearable.

#### 4.4.3.4 Using Insulin Pump

The working principle of the insulin pump is based on the calculation of required insulin for the amount of carbohydrate consumed. In this manner, Cem mentioned about the benefit of using the insulin pump as follows:

> When you use the pump, there is nearly nothing you cannot eat. If you know how to carbohydrate amount correctly, then you can send the proper amount of insulin, and they will compensate each other. This is where technology is involved in diabetes care.

As he explained, the device gives its users the chance of being flexible in their diet, which might also help them to feel less stressful in the management process. Moreover, the way he described the role of the technology as a contributor in care also brings up the question of morality: Is he the one performing carbohydrate management properly, or is it the device that leads him to do it that way. In this example, it might be possible to say that beyond his intentions, in the use of an insulin pump, “accurate calculation of carb consumption” is implicitly enforced.

As mentioned in Section 4.3.3.3, infusion sets have a short product life-cycle and needed to be changed every three days. However, most of the participants try to hack their devices to extend this time. For example, Hande explained her routine for changing infusion sets as follows:

> You need to change the infusion sets every three days. In the beginnings, I got used to changing them on time, but now I extend it up to 5-6 days, if my pump reservoir still has enough insulin and if there is no related problem. The

> user manual says there is a risk for infection, but until I experience something bad, I think I will continue to use like this.

In her assessment, what matters is her experience with the insulin pump rather than the written rules. At this point, mastery in the device becomes significant. In addition to her words above, she explained how she gained confidence in time as follows:

> It is all about the experience. I got used to feeling panicked when I see inconsistent results, but now I do not, because I am used to that sometimes the sensor does not work correctly. For example, if you have high sugar, then, soon, you will feel the signs. If there is no sign, then you will understand that it is about the device itself.

Similar to Hande, below Ahmet also explained how the role of governing changed hands:

> When I started to use an insulin pump, in the beginnings, it was ruling me, but now I am the ruler. Everything goes as to how I want, and this is very important. This is my success in device use. Now I can say that I know how to use this device.

Since digital technologies redefine the management practices, all individuals are becoming novice users no matter their experience with diabetes and starting to learn management again within the rules of devices. In the beginning, technologies are the ones leading the user until individuals gain authority on the device and reshape their use patterns according to their personalized treatment plans.

Ahmet continued his words by exemplifying how he built a trust mechanism to check the reliability of the insulin pump as follows:

> Yesterday, I changed my infusion sets and wore them on my right leg as a diabetes nurse recommended. A couple of hours after the meal, the sensor showed that my blood sugar is around 200s. I was surprised because I have never seen such high values for a while. Then, I understood that there is a problem in insulin delivery, so I took out the set and wore a new one to my belly. Then, instantly the results were normal.

In his example, the significance is that his self-assessment is based on an overview rather than the instant results. As discussed in Section 4.4.2.4, one of the most beneficial features of digital technologies is the opportunity of extending the management in more prolonged periods unless there is an urgency.

To summarize, as insulin pump continuously delivers insulin to the body, it prevents emergencies such as sudden highs or lows in general and helps people to perform better management. Participants stated that in time, they feel more authority on the device, which courage them to take initiatives in management through the guidance of technology.

#### 4.4.3.5 Economic and Political Dimensions of Using Insulin Pump

When it comes to the political dimensions of technology use, different than CGMs, the government provides a little support for insulin pump therapy and pays a certain amount of the total cost. Ebru explained how the system works as follows:

> The government provides support once in five years. So, I made a very detailed online research, because if I have to use it for five years, why should I get a low-quality device?

As she emphasized, it is significant to know about the different brands and devices supported by the government as individuals are expected to use the same device for five years until their right for device purchase is renewed. In addition to her words, Ahmet mentioned the procedure of getting support from the government for insulin pump therapy as follows:

> Once you ask, they give you an informational paper explaining the features and the monthly cost of the device. The device paid by state insurance has no continuous monitoring features, so I had so search for myself.

As he stated, the governmental support for these technologies is limited. The compatible sensors for the insulin pump are considered as the secondary needs and not paid. In addition to Ahmet, Burak also criticized the quality of the device given by the state insurance as follows: “It only pays for a device made in China, so if you want to have a better-quality device, you have to pay surplus charges.”

Participants’ statements show that as these technologies are quite expensive and have a precise procedure before and after purchase, their decision process is crucial for making the most suitable choice. Like other digital technologies, insulin pump therapy is quite costly compared to conventional methods; however, at the policy level, the device is not considered as a luxury like CGMs. Moreover, most of the participants mentioned that they were willing to pay extra for better quality devices.

#### 4.4.3.6 Visual Perception of Insulin Pump

Referring to the discussions in 4.4.2.6, using an insulin pump also results in a body characterization, which is even more recognizable compared to the CGMs. As Aslı stated above, the only way she justified wearing “a bulky thing” on her body was the will to protect her baby from potential risks. However, to remember Güzin, even her doctor’s recommendation to use an insulin pump during pregnancy did not convince her. She narrated why she is distant to use an insulin pump as follows:

> I am still not easygoing with the pump. My doctor recommended me to use an insulin pump during pregnancy, but as I said, I do not want my illness to be visible very much from the outside. I do not want to feel or look “sick”.

The reason why Güzin does not want to use an insulin pump is that she thinks it makes her illness visible, in contrast to insulin pens, which are not carried on the body all the time and easy-to-hide. By the same token, Aslı exemplified how she got back to using insulin pen as she was concerned about the image of her body as follows:

> When people see the pump, they ask like “what is it? A cellphone or a pager?” Seriously! Is anyone left using a pager! Also, I got back to using pens two months ago, because it is much more challenging to use it in summer. Instead of people’s reaction, when you are apart from the pump while swimming, you feel like your blood sugar is rising again. Also, when I look in the mirror, what I see is really disturbing me while wearing sleeveless tops. In winter, it is easy to hide it, so it does not bother much. As a lady, to hide the device, we put it on our jeans, sometimes we put it in our underwear, but it is very uncomfortable. I might start again using an insulin pump, but I am just waiting if it gets a little smaller.

Her statements revealed difficulties of using insulin pumps, especially during summer, because it is not possible to swim with the pump, and leaving the device from the body for longer than a certain period might affect blood sugar values. However, the main reason why she gave up using the pump seems more related to the perception of her body, as she criticized how it looks when it is uncovered by also emphasizing its size.

Therefore, what Ahmet stated about the people’s perception of the device might legitimize their concerns.

> What bothers me most is the pitiful stares of people. They say, "you are a young man, but wearing cables on you." Some of my colleagues even ask like, "are you a Robocop?"

As the body gets digital and even science-fictional with the insulin pump, the way other people describe the relationship between his body and the pump might be considered as one of the examples of *cyborg embodiment*, as discussed in the Literature Review (see Section 2.3.3). Similarly, below Ebru narrated a story she heard, which was about both body characterization of insulin pump and also the awareness of society about diabetes:

> I have heard of a girl who was using the pump suddenly fainted in public due to hypoglycemia. She was suffering on the floor and trying to show her pump to the people, as insulin delivery was needed to stop, and she was not able to move. Most of the people ran away instead of helping her because they thought she was a suicide bomber, as she was wearing a device, and there were cables around.

In her story, the visual connotation or visually assigned meaning was not related to the tech-nature of the product. Instead, what made an ill-body turn into a criminal was mainly related to the past experiences of society. However, being not aware of diabetes and related technologies was the second reason why she was rejected while seeking help.

Different from most of the participants who were concerned about their body image and would like to hide their devices, Esra seemed more easygoing as she stated that she never thought that people would like to hide their devices. She commented on how she realized people's concerns about the device and body relation as follows:

> While we were sitting with my friend, she suddenly took her pump out from her chest, and I was shocked. She said that she is always carrying the pump there, no matter her clothes have a pocket or not. Then, she asked me like "so your device is always visible!" It was the first time I realized that there might be people who would like to hide their device. I mean, when she takes it out from the chest for insulin delivery, it becomes visible anyway! I only carry the pump on my chest if I am wearing tight dresses. I do not mind whether the device is visible. All the people around me, including colleagues, know me with my pump. Apart from that, during summer, when I wear a bikini and hang the pump on it, it is always visible.

As emphasized in previous sections, Esra is a good example of the acceptance and embodiment of the device. This explains why she was surprised about a counterargument about the visibility of the device. As she indicated, she only makes efforts to hide her device, if there is no possibility to attach the pump on her clothes. In this manner, Esra questioned the paradox of visibility. As she stated, although people can hide their devices, when it comes to performing the management, they become visible even in a more unexpected way. There might be a relation between the reason why people would like to hide their devices, and the illness as well, and the social stigma in diabetes discussed in Section 4.2.3.2.

To summarize, the engagement between digital technologies and patients results in the digitalization of the body (see Section 2.3.3). This digitalization might have two dimensions. The first one is related to the image of the body. Although some people try to hide their insulin pumps, as they are always worn or carried on the body, they generally become visible in everyday life. The visibility of human-device assemblage might result in the image of the body needs technology to function properly. This interpretation is the reason why some users believe that wearable technologies make their illnesses "more" visible.

Apart from this, the second dimension is related to why these characterized bodies are unintentionally associated with the cyborg concept by patients and other people. My findings mirror the literature discussed in Section 2.3.3 that before the era of digital technologies, human- device assemblages were fictional as they were promising to restore, normalize, and enhance the body and reconfigure new forms of human-device interaction. However, ubiquitous health technologies are capable of fulfilling all these functions and even perform new ones like monitoring and connectivity. For instance, the insulin pump collaborates with its user to normalize the insulin-releasing mechanism of the body by mimicking the way how the pancreas works. Today, the cyborg is not the creature with superhuman powers; instead it is the people embodied technologies to perform self-care activities.

### 4.4.4 Summary

Section 4.4 covered the type 1 diabetes management methods as an outcome of the changes that occurred in healthcare technologies. Currently, there are three different management methods, which are glucometers, non-invasive monitoring technologies, and insulin pump treatment. The statements of the participants showed that the shift in the methods from glucometers to wearable technologies not only changed the management routines but also most of the participants stated that they become more experimental to try new methods in time as they have mastery in the device. As participants emphasized, the number of people using wearable technologies in Turkey is relatively low, because these products are not locally manufactured, and their cost is quite high. As a result, participants criticized that healthcare professionals might not have enough knowledge and experience to support them adequately, as Ahmet stated that he had to explain the working principles of the insulin pump to one of the well-known doctors in Istanbul. In addition, in light of these critics, they also emphasized the self-responsibility in diabetes care from a broader perspective, as one of the virtues or the characteristics of biosocial individuals.

Apart from these critiques, participants also discussed that wearable devices become an external part of the body. In light of this, participants commented on how the embodiment of digital technologies results in the characterization of the body, which might be described between the human and post-human, as discussed in the cyborg concept (Haraway, 1985). For some of the participants, this digitized and also fictionalized body image is the main reason why they reject using wearable technologies, especially the insulin pump, as it is hard to hide with tactical adjustments compared to glucometers or CGMs. The next section presents how the need for diabetes and technology related information leads these individuals to become social and construct examples of the communities of practice, such as online health communities.

## 4.5 Online Diabetes Communities

In the last section, I initially discuss the changing research habits of the participants through the online diabetes communities. With the spread of the Internet, there is a drastic change in the number of information sources, which made people reach information easier and quicker. Online sources not only increased the availability of information but also altered the research habits in a way that people question the reliability of the information.

In this section, I explain how individuals' need for first-hand information results in different types of social interactions and lead to different types of collectives, and the inner dynamics of these collectives regarding collective knowledge production.

As explained in Section 3.1, the subject of this study is the diabetes online community, named *Tip 1 Diyabet Tecrübeleri*, which was founded by the parents of a child with type 1 diabetes. As the founder of the group, Hüseyin said, "the group aims to share the latest information about diabetes technologies and create an environment in which people can share their experiences and learn from each other at the same time. This interactive and multidimensional structure of the group is the reason why I prefer to focus on their biosocial activities, instead of personal self-help blogs, in which only the person experiencing the diabetes share insights and no possibility for members to contribute to the knowledge production process.

Before focusing on the inner dynamics of the selected community, it is significant to understand how individuals reach information in the digital era. With regards to the online resources, Cem stated that as it is much easier to access information, diabetes management might be considered less challenging compared to the earlier times as: “Nowadays, no one has a difficulty to reach information as academic resources, online groups, videos and blogs are helpful enough.”

Besides its reachability and practicality, another reason why participants appeal to online sources is that they describe the medical support that they currently receive as inadequate. Ahmet explained this as: “I do my research via Internet because, in state hospitals, they do not pay attention and share reliable information adequately.” In this regard, most of the participants stated that healthcare professionals especially the ones at state hospitals are not knowledgeable enough about the contemporary diabetes technologies, which might be related to that as they are expensive, and consequently, not many people using them yet compared to the population of people with diabetes in Turkey.

### 4.5.1. Introduction to Community

Most of the participants encountered the community through either someone’s recommendation or as a result of their online research. Ebru explained how she was introduced to the community when she was hospitalized as:

> When I was hospitalized to wear an insulin pump, a pregnant lady was staying in the next room, who was also using the insulin pump. While I was asking

> her about the device, she told me, “Let me add you to Facebook pages so that you can check the news.” This is how I found the group.

Different from Ebru, Ahmet came across to the communities when he was hospitalized and spending time by making online research as: “while staying in the hospital, I was constantly searching on the phone, and I found the group.”

In addition, he also stated that as none of the people tells you about the difficulties you would experience while using technologies beforehand, it is possible to find people who already experienced them within communities.

Moreover, Eren commented on how his wife takes the initiative of doing online research on diabetes. As a result, they found the community, and both became a member as follows:

> I do not search for things about myself [diabetes related] on the Internet, but my wife does. I think it was the time I was going to America for work, and we wanted to check what kind of innovations we can buy there, and while doing online research, we came across diabetes groups.

What Eren stated may be another means of collaborative management, as his wife is responsible for finding related information to him. Moreover, how he comes across the community is based on the need for experiential knowledge for purchase decisions.

In short, people either encountered the community as a result of online research or other people with diabetes recommended them. At this point, beyond the illness and medical knowledge, topics related to technology use, and the need for experiential knowledge make people interested in being a part of this kind of collectives.

### 4.5.2 Interaction with Communities

The participants' statements showed that their interaction level with the communities varies, and this results in the definition of different user profiles. Some participants actively follow the posts shared in the community and even contribute the information flow through their shares. However, on the other hand, some of the participants have a low-level interaction with the community, as Esra exemplified: "I do not have an active role within the community, I do not post much. People are doing a lot of nice things, like meetings, events for info share, but all I do is to support them by liking their posts."

As she indicated, some people play more participatory roles within the community by attending events arranged to share knowledge or experience. In this manner, it is possible to say that Esra has a low-level interaction with the community and acts more like an observer.

On the contrary, Eren stated that he regularly checks group posts and contributes to the discussion. Moreover, he creates content to share his knowledge with others, as he exemplifies below.

> I check the group nearly every day. Generally, I post about the news I read to satisfy people's curiosity, more or less. Libre has a user manual in English. Once, I translated the parts I found important to Turkish, for those who do not speak English. For example, for specific meals, do not take the result into considerations or do not take high and low values into account, something like that. Also, I translated the meanings of error codes.

Apart from being more active in the community, the effort he makes to acquaint other members with useful information differentiates his role from any regular member and might be titled as an “informative” member, who shares not only personal experiences but also insights from printed or digital resources.

### 4.5.3 Benefits of Online Communities

In the digital era, online communities are considered as one of the best information sources by the participants as their polyphonic structure extends the variety of shared information (see Section 2.2.2). Explicitly, most of the participants stated that they generally check these communities for the first-hand experiences shared by wearable technology users. Besides, members’ shares about their doctor experiences were also considered as interesting and very useful for the others. For example, Burak stated that the reason why he became a part of the community was to find a doctor recommendation.

Apart from making access to information more comfortable and faster, as mentioned above, there are other benefits of the communities that are emphasized by the participants and might be described as the values of this kind of organization.

To begin with, Güzin stated that beyond its functional aspects, seeing a majority, which is formed by mostly the people with diabetes, made her feel as: “I thought like I am not alone, there are people like me.” Moreover, another participant, Esra, described this interaction as a unity, which is considered very important, especially for the participants who do not have any other person living with diabetes in their environment.

In addition to her statements, Cem emphasized that as these kinds of organizations have the ability to gather a significant amount of people, this crowd helps to the recognition of diabetes with other people, which might be helpful in the raise of awareness.

Apart from these, participants indicated that the existence of online communities where people share their experiences for the good of others also encouraged them to share their stories. Furthermore, some participants even created their own online communities. One of them, Hande explained the reason behind her decision as follows:

> Right after getting married, we decided to have a baby. Therefore, I was supposed to get hormonotherapy for IVF, then anesthesia for embryo transfer. Then, I looked for someone who already experienced these, but when I could not find it, I have experienced all my own. Then, I created my own page with the idea that someone like me might need it. On my Instagram, I share information about type 1 diabetes and IVF related issues, regardless of my identity.

Although the community that she launched is based on the structure of the single-person help group, it is a good example of individuals' biosocial activities. Moreover, the significance is the fact that her existence within *Tip 1 Diyabet Tecrübeleri* made her realize the value of the experiences of a person with diabetes beyond the personal level, and encouraged her to share it with others.

The (bio)sociality of online health groups help people in the acceptance of the illness and encourage them to be good and responsible patients. At this point, the need of first-hand knowledge and technology use practices are the first two reasons why individuals like to be a part of supportive collectives. Moreover, this biosociality also results in health activism. Meral exemplified this as follows:

> I honestly appreciate what Mrs. Hüseyin (the founder) tries to achieve. He even keeps contact with the Ministry of Health, conducts signature campaigns, and prepares reports about technology use in diabetes to make CGMs covered by state insurance as they are considered "luxury". Although

> it seems not possible to accept the government to pay technologies for adults, maybe with the effort of the people from the community, it will be reachable for children, which would be a critical improvement in their care.

As she stated, the collectives not only support people at a practical level by providing useful information but also try to raise awareness about the rights of patients and make an effort for them to receive better care facilities with the solutions on a political level.

### 4.5.4 Common Problems of Online Communities

As explained in the methodology, the participants who attended the study are members of the same diabetes community. However, regardless of which online diabetes community that participants actively take part in, they all complained about the similar problems which cause disappointments problems and will be discussed below.

#### *Power Relations in Communities*

Online communities are ruled under the admin control, who are assigned by the founder of the community, and their main role is to control the content of shares and interfere if there is any communication problem within the community. Admins are generally selected from the people who have been involved in the community since its formation. Moreover, as these people have a right to evaluate the reliability of the shared information, they are valued as the representation of power. Participants stated that sometimes, this administrative ability works for the good of members, especially when there are deceptive shares. For example, Güzin shared her observation about how admins react to misinformation as: "As far as I observe, where there are unconscious information or demotivating comments, people are warned as 'please do not write such things' or the post is deleted."

Although having the power of administration might be needed for polyphonic majorities, it might also result in the misappropriation as Ahmet complained by also stating his recommendation for the solution of these kinds of problems below:

> In some groups, admins reprehend some members, even dismiss the people they disagree with. Who are you, my friend! His thoughts may not be the same as yours. What if he desperately writes to the group to seek for information, and you kick him out? If I were the admin, I would never give the authority to expel people from the group to anyone. If you do not have patience when people ask you in misery, you should not be in the group either.

Moreover, participants stated that the division among the communities sometimes creates conflicts between different groups, which results in the loss of unity, especially regarding the topics that cover all people's wishes, such as the expectation of subvention for wearable technologies. Esra criticized the discordances among the different diabetes communities as follows: "To begin with, having lots of unconnected associations or groups is disadvantageous. I find it ridiculous, it is a bad thing that people are so dissociated and unable to stand together to act for diabetes."

#### ***Content of Shares***

Participants stated that for some of the communities, the interaction rate is nearly 100 posts in a day, and most of them are the emergency posts in which people are seeking help for the moments that they cannot manage their BG. Although participants mentioned that they have no doubts about the good intentions of the people whom both share emergency posts and the ones who reply and give recommendations, they indicated that applying the written recommendation without questioning the suitability of personal treatment plan might have serious results. Cem criticized the content of the shares in a broader perspective by also highlighting the benefits of the shares, such as creating a dynamic of exchanging supplements or giving recommendations about diabetes technologies as follows:

> I think most of the posts have a positive content. People ask each other about where to get the insulin, which insulin pump is better, which doctor is better, all kinds of things like that. Just do not play doctor [*doktorculuk yapılmasın*], that is enough. For example, some people say that if your sugar level is high, take an extra three or five units of insulin. We cannot decide for him; anyone's insulin dose is different. That is the biggest problem. Let us say someone wrote, "take 10 units". So, you did, got hypoglycemia and died. Who will be responsible? That is why giving prescriptions is a serious responsibility. Other than that, what is written about the products is very useful. I can say that 95% of the shares are positive, while the rest 5% is negative.

What Cem emphasized is the limit of expertise, which is highly related with the awareness that diabetes is an individual experience in the end. Moreover, awareness is also essential to filter some misleading advertisements as in Ahmet exemplified below:

> There are hope mongers [*umut taciri*] in the groups. They claim having bought this who-knows-what mixture from someone, and they share to the group claiming it was beneficial. Someone used Dr. Nowzaradan's picture, printed on the mixture they are selling. Sadly, perhaps 100 people shared that post with the belief that it is helpful for diabetes. There is too much ignorance out there. Desperation, as you know, turns people ignorant. Desperate people are ignorant, and as they are desperate, they are classified as ignorant, unfortunately.

Ahmet commented on the morality of alternative treatment. People's trust in alternative medicine is the hope for a cure as the feel of despair makes them believe any recommendation without questioning. However, as Cem criticized above, wrong treatments can cause dramatic results in diabetes. Therefore, the admins of the Facebook group have the right for deleting misleading content. However, as Ahmet stated, in online communities, the spread of the information is quite fast; that is why self-awareness becomes crucial to filter the useful content.

### 4.5.5 Summary

Section 4.5 presented that information has become easily accessible with the help of the Internet media, and individuals turned into collectives through experiential knowledge. The participants mentioned that they were introduced to the community, either through personal research or with the mediation of another person. They indicated that online communities have a role in the acceptance of diabetes as people come across the others in similar conditions, which makes them feel like they are not alone. Moreover, participants emphasized that within communities, there is a unique exchange culture that people do not only share experiences but also fundamental needs such as insulins or glucometer strips. Although participants mostly highlighted the benefits of online communities, they also argued about the hazardous aspects of lay expertise. They stated that, as online communities have an organic and polyphonic medium, all members are able to give recommendations to others, which might cause very critical results. The diabetes treatment plans are meant to be personal, which means the same methods might not work for another person with diabetes. In this context, the statements of the participants might be associated with the discussion about the limits of self-expertise.

## 4.6 Conclusion

In this chapter, I presented an analysis of the interviews conducted with the community members. The findings of the fieldwork were divided into five main sections. The first section provided insights about what diabetes is in medical dimensions. As it is seen from the participants' statements, although the signs and the symptoms of diabetes are similar, diagnosis stories and the acceptance of the illness vary from person to person. The age when people are diagnosed, being familiar with diabetes and other people's reactions play a crucial role in the acceptance.

The second section focused on the everyday life aspects of the diabetes as it alters people's routines, including their diet and exercise habits. In addition, participants stated that diabetes makes them live a very scheduled life. For example, as they stated, planning a short vacation becomes harder as they have to think about many responsibilities, from daily diabetes management to possible emergencies. Apart from daily life routines, what makes a living with diabetes challenging is the society's approach towards the image of ill-body. Within time, as individuals experienced in diabetes, the management of the illness becoming relatively less burden. However, regardless of the perception of people with diabetes, the illness is perceived as a deficiency by society. Moreover, the human body is stigmatized, considering individuals' daily life practices, from their performance at work to their reproductive capabilities.

In the third section, I explained the management of diabetes, which not only covers care methods such as insulin intake and blood sugar monitoring but also builds a diabetic identity between different dynamics and authorities, such as doctors. In diabetes management, developing care routines, and performing them properly is the key to success. However, participants discussed that depending on the context and the location, these routines might increase the visibility of diabetes. Apart from this, participants' arguments also highlighted the normative discussions based on their monitoring routines and blood sugar levels.

With regard to their doctor visits, participants discussed how the frequency and the context of visit changes within time. Individuals gain self-expertise by experiencing every aspect of diabetes and develop personal strategies for management. In parallel with the mastery, the power relations between medical authority and patients themselves are changing, and the need for medical expertise becomes less frequent.

The fourth section explained the technology use practices in type 1 diabetes. The participants' insights provided a deeper understanding of the latest improvements in healthcare technologies, which are CGMs and insulin pumps, and the shifts in the care methods by the introduction of these wearable devices. Moreover, digital technologies also define new patients, who are more curious about and willing to be in charge of their health state.

While discussing user practices of digital products, participants also criticized the socioeconomic and political dimensions of technology use in type 1 diabetes. Besides, participants' insights also revealed how wearable technologies characterize the human body that is connoted with the cyborg concept, as explained in Section 2.3.3.

Finally, the last section described the sociality of these new patients in the concept of creating experience-based communities. As explained in the first section, type 1 diabetes is a chronical illness, which requires a lifetime care. At this point, first hand experiences become the real knowledge for people. The statements of the participants showed that online groups that provide self-help and emotional support play an essential role in today's diabetic life. In addition, these groups are the main information sources regarding the latest diabetes technologies as the frequency of provided customer services in Turkey is relatively low. Apart from these, within these communities, there are multidimensional interactions, in which the same person who cannot perform proper diabetes management can have autonomy in someone else's diabetes.

With regard to these analyses, I will represent my conclusions in the following chapter.

# CHAPTER 5

# CONCLUSIONS

This chapter presents the conclusion of this study. First, I provide an overview of this thesis, followed by explaining the limitations of the study. Then, I present the conclusions obtained from the literature and data analysis. Last, I discuss the implications for design practice.

## 5.1 Overview of the Study

This study aims to understand the changes in care practices and the role of patients with the use of remote health technologies. These expectations reflect on individual bodies and health communities. In order to achieve this, participants' experiences with diabetes and product use, and their biosocial practices within online communities are investigated in detail.

Chapter 1, Introduction, explained the background, aim, and scope of the study and highlighted the importance of this research by reflecting upon previous studies and their outcomes. Then, I introduced my main research question and five sub-research questions that are aimed to be answered. Last, I present the structure of the thesis.

Chapter 2, Literature Review, overviewed the related literature aiming to provide a theoretical background for discussion. To begin, I discuss the changes in medicine as a result of emerging technologies and economic and governmental influences, as well. The focus point was the shift in care from hospital to more personal spaces like home. Hence, surveillance medicine and digital health technologies are related to key concepts that are used in data analysis.

Moreover, I explained the ongoing sociological and political discussions about healthcare within the frame of humans and their bodies. At this point, as an example, the emphasis was on the practice of being chronically ill. According to this paradigm, I represented the changes in medical product design by focusing on remote patient monitoring systems. Afterward, to draw a holistic understanding of technology use practices, I discussed the actor-network theory in detail as the outcomes of the study were grounded on this approach. In addition, Harraway's cyborg (1985) and Lupton's quantified self (2016) concepts were used to demonstrate the association of technologies and human body. Finally, I gave information about diabetes and its reflections on everyday life practices. Moreover, I presented examples of previous studies to understand the academy's approach to the topic.

Chapter 3, Methodology, demonstrated the way that the study was conducted. I embraced the qualitative research approach and conducted semi-structured in-depth interviews with 12 people using wearable diabetes technologies and residing in Izmir, Ankara, and Istanbul. Interview data were transcribed into text documents, which helped me have a command on the data.

Analysis of the data was completed in three cycles, and several coding methods were used. The first two cycles were performed by taking notes on prints, and potential codes were generated by using initial coding and axial coding. Then, all transcripts and codes were transferred to the data analysis software. In the third cycle, theoretical and simultaneous coding methods were used. The methodological limitations and challenges were that data were cross-sectional, and the research topic was sensitive for some participants to share detailed insights (see Chapter 3).

Chapter 4, Findings, presented the analysis of the data derived from the analysis of interview data. In this chapter, first, I demonstrated the construction of the chronically ill-self through how people were diagnosed, realized, and finally accepted their chronical condition. Second, I discussed how diabetes transforms people's everyday life in terms of routines and responsibilities. Third, I explained the management methods like insulin intake and blood glucose measurement, and how these repetitive practices result in individuals' mastery in diabetes. Fourth, I presented how wearable diabetes technologies redefined diabetes care practices and the interaction between diabetic people. Fifth and the last, I discussed how online communities provide critical experiential knowledge and support individuals for technology use, as well as characterizations of a good patient.

At the end of each chapter, I presented a summary covering the related discussions.

In this chapter, I present the conclusions concerning data analysis and literature review. First, I discuss the limitations of the study. Then, I describe the prominent conclusions. Last, I discuss the implications for design practice.

## 5.2 Limitations of the Study

In the frame of being chronically ill, this research focused on diabetes and its social aspects concerning online communities. So, the findings of patient roles and interactions are limited to diabetes practice. They may not be observed among people with different chronic conditions.

The research topic brings its own limitations. First of all, coping with a chronic illness has its difficulties, not only on a practical level but also on an emotional state. Hence, it might be sensitive for some people to talk about the topic. That is why, it was challenging to convince people to contribute to the study. Most of the people who filled out the survey about demographic characteristics of wearable diabetes technology users did not want to participate in the main study made of in-depth interviews. More information on the sampling and recruitment process can be found in Section 3.3.4.

In terms of probability, the sampling of the study might be biased as participants were selected from a specific area, wearable technology users. Moreover, participant profile also represents a specific socioeconomic group as these technologies are relatively expensive and not affordable for many people in Turkey (see Section 4.4.2.5).

Besides, the study only reflects the patients' perspectives in care-network. However, including other actors such as healthcare professionals might be more comprehensive. For example, within the scope of this study, two expert interviews were planned. Hüseyin Devecioğlu is the founder of *Tip 1 Diyabet Tecrübeleri* Facebook group, and Esra Avcı is the founder and editor of *DiyabetimBen* web blog, which is mentioned by the participants quite often. Unfortunately, those interviews could not be performed due to time limitations. Understanding the founders' primary purpose of creating online information sources comprehensively and comparing to today's networking might be valuable to discover the role of members in the transformation of communities.

### 5.3 Discussions of Findings

The purpose of this study was to understand the impacts of remote health technologies on today's care practices and to explore the biosocial activities and bodily experiences of users within the context of use. The literature review has presented the changes in healthcare in accordance with the rise of enhancement technologies, which regard patients themselves as subjects capable of and responsible for having a claim on their own health. In addition, examples of studies on technology use in type 1 diabetes management mostly focus on usability and do not address the social and behavioral aspects of these technologies on patient profiles. Therefore, this study was built on a qualitative research approach to understand patients' technology use practices and their impacts on patients' personal and social experiences, and the main research question was formulated as follows:

How do the new diabetes care products with mobile digital functionalities influence, and are influenced by, their users' bodily and biosocial practices?

In order to provide a comprehensive answer to this question, this study investigated the technology use practices in type 1 diabetes, with an online observation of the diabetes community and in-depth interviews with 12 community members. In accordance with the findings of the fieldwork, this study draws six prominent conclusions.

1. Changes in healthcare have redefined the experiences of being ill and contributed to the construction of self-responsible patients.
2. Contemporary technologies provide users with dynamic, real-time visualization of an unknown.
3. Depending on the context, contemporary technologies impact the visibility of diabetes.
4. Contemporary technologies characterize new bodies that are digitized and quantified.
5. Contemporary technologies enable close relations to take part in diabetes management in specific manners, which (re)shapes the relations of care.
6. Online communities provide critical experiential knowledge and support for technology use, as well as characterizations of a good patient.

In the following sections, these prominent findings are presented in detail. First of all, in light of the relevant literature and the findings, I discuss the construction of self-responsible patients as a result of the change in healthcare. Second, I discuss how dynamic presentation of blood sugar transforms diabetes practice. Third, I demonstrate how wearable technologies transform the (in)visibility of illness. Fourth, I discuss the characterization of new bodies through wearable devices in the lights of the post-human concepts introduced in the literature. Fifth, I discuss how connected technologies integrate close relations in the management process and the dynamics of collaborative management. Last, I elaborate on the organization of selected online community and the experience-based knowledge production contributing to patient empowerment.

### 5.3.1 Self-Responsible Patients

To figure out the impacts of the consumerization of healthcare and biopolitics on medical practices and the role of the patient, a detailed literature review was conducted. According to the literature, changes in healthcare policies and recent developments in medical technologies have redefined the experiences of being ill. Individuals are given the responsibility for their own bodies, which resulted in the construction of the new patient profile.

Self-responsible patient represents the individual actively taking part in decision making and capable of managing their own care with the help of contemporary health technologies. In the digital era, the Internet has become the most prevalent source to seek medical advice, and this exemplifies the health consumption model of self-responsible patients. Moreover, depending on the context, "lived experience" is equated to "patient expertise," as there is a growing demand for experiential knowledge. This need encourages individuals to share their personal experiences, as an example of their biosocial practices.

Self-monitoring technologies create the basis for micromanagement by representing the anticipated change in blood sugar, predicting emergencies, and notifying the user when action is needed. Ultimately, this results in the development of patient expertise, whereby patients domesticate, even hack their devices according to personal needs. Concerning their use practices, these devices help people to gain expertise in their chronical condition and make them feel safe and capable in case of emergencies.

Apart from the dynamics of the digital era, experiencing a lack of medical support also obliged patients to be more active in their care. In today's healthcare, especially in state hospitals, doctors might not have enough time to invest in each patient and discuss their concerns in detail. In the case of technology use, another reason why medical authority cannot provide proper support may also be related to the lack of experience with these contemporary devices as discussed in Section 2.3.3

### 5.3.2 Visualization of Unknown

The biggest impact of contemporary technologies in diabetes practice reflecting on patients' everyday life is the dynamic and real-time presentation of blood sugar. As I mentioned in the analysis (see Section 4.4.2.4), trend arrows are considered as the most revolutionary contribution of connected technologies in diabetes management. This is because CGMs visualize not only the current blood glucose but also its direction and velocity, as well. This information enables people to make real-time decisions (Kudva et al., 2018), which was not possible with conventional products, i.e., glucometers. Beforehand, care was predefined and highly dependent on the number presented on the device display. For extreme cases, but not emergencies, people needed to execute the plan, which was defined by their doctors and not open for negotiation. By making the unknown visible, connected devices give the power of decision to its users, or in other words, the role of *doctoring* (Mol, 2008).

Beyond decision making for instant management, visualization of the unknown also gives the opportunity of prevention of emergencies by acting in the light of trends as a decision support system (Gonul et al., 2019). Once the person sees that the glucose level is falling quickly, there is no need to wait for any sign. People can take action, and it does not need to be taking extra insulin. There can be micro-level management, such as consuming the food that is believed to have positive effects on blood sugar.

On the contrary, in glucometer use, most of the instant measurements are performed when people feel any sign of low blood sugar. People need to check glucose levels as soon as possible to take action.

In this case, acting is only limited to extra insulin doses, the safest, as it is not possible to know the direction of blood glucose in conventional devices. However, CGM users have the chance to decide whether to take insulin or to use other means of micromanagement, the chance which is provided by the product. Moreover, CGMs implicitly encourage people to have trials and errors as well, in the way of learning self-management. As a result, what products make possible results in patient empowerment as they feel capable and willing to take responsibility for their health. Moreover, providing the other means of micromanagement through technology brings up a normative discussion that individuals who are able to cope with extreme cases without taking extra insulin doses are considered as “more conscious and successful” in diabetes management. This discussion also signifies how individuals tend to compare the performance of their biosocial identities constructed as a result of the illness and device use practices.

The contribution of trend arrows is not only about handling emergencies. As discussed in Section 4.2.1.1, discovering how different foods affect blood sugar is an experimental process. At this point, displaying blood glucose direction becomes a feedback mechanism that is fast and reliable. Moreover, people interpret it as an achievement when the food they prefer or try for the first time does not affect the blood sugar negatively.

### 5.3.3 Visibility of Diabetes

Another impact of contemporary devices on patients’ daily life is covered in the discussion of the body and its connotations in various diabetes-related topics. The discussion about the body has different contexts regarding the product itself (Oudshoorn, 2018).

According to participants’ statements, glucometers make the ill body indirectly visible. The product is stored inside people’s bags, their pockets, or their drawers at the office and only taken out for measurement. While measuring blood glucose, finger pricking, or dropping blood on a test strip, the process, in short, attracts people’s attention and makes the illness hidden inside of the body visible. Therefore, many people got used to hiding while testing blood sugar or taking insulin shots, as they do not want to share their illnesses with others, or it may be connoted with inappropriate actions, such as drug use, as Eren discussed in Section 4.3.1.3.

Nevertheless, as participants stated in Section 4.4.1, it is possible to hide diabetes on a tactical level while using glucometers. For instance, the product is small enough to hide behind the bag, so it is possible to do blood sampling without being exposed. Eventually, people with diabetes mostly have a turnover that made them feel free to fulfill the responsibilities of diabetes by taking no notice of others’ perceptions.

On the other hand, wearable diabetes technologies, CGMs, and insulin pumps make the body visible in different contexts. In conventional devices, the way of use makes the illness visible. However, in wearables, the product itself that makes diabetes visible. The sensor technology eliminates the need for blood sampling or taking insulin with a syringe yet replaces that with the necessity of carrying a pocket-sized device, the reader of CGMs, or the pump’s itself. This necessity has its dependencies. For example, without the reader, most of the CGMs cannot perform any measurement. So, there is a need for a companion product. The product is placed on the sensor and enables Bluetooth connection with smartphones to send digital info. Though the sensors are considerably small in size, the companion products increase the visibility of the sensor and diabetes as well. In the use of CGMs, the visibility of diabetes is also highly dependent on the seasons. During winter, according to cloth preferences, the ill body can be hidden without any extra effort. However, during summer, it is the other way around.

The analysis showed that CGM users might not effort to hide their condition. Instead, they share their diabetes knowingly and willingly to raise awareness. This approach might also have a relation with the empowerment of patients discussed above.

When it comes to the use of insulin pumps, there is another dimension. Technically, insulin pumps are more visible and limit the bodily activities of people. The product is big and carried all the time. Besides, how to carry it on the body also calls some problems that might address the gender discussion in use practices. Regarding cloth preferences, compared to men, women have more difficulty with clothing. As female users stated, placing the insulin pump on the chest helps to hide it, yet is less practical while using it. On the other hand, carrying the pump in the pocket or hanging on the belt is considered as the manly way of carrying the device as Esra discussed in Section 4.4.3.3.

### 5.3.4 Digital Bodies and Quantification

As my findings mirror the literature (Ritholz et al., 2010), people discuss their concerns about body image, especially in terms of public appearance. Technologies that are external to bodies yet access inside the body, e.g., insulin transfer from the reservoir beneath the skin through cable, results in a specific body characterization. As discussed in Section 4.4.3.6 in detail, most people define this characterization with the words bionic or mechanic, addressing today's post-human discussion. As Lupton (2015) discussed, self-monitoring practices through technologies resulted in the construction of “digitally engaged” people, who are digitizing their bodies with the use of contemporary devices, such as insulin pumps. Moreover, this characterization sometimes motivates people as they feel self-conscious and dedicated to managing their diabetes at its best. On the other hand, for some people, their concerns about body image are the only reason why they are reluctant to use wearable diabetes technologies.

The term *quantified self* (Ferriss, 2013) refers to the measurability of the current health state and its representation in numbers. In this regard, numerical values such as blood levels are determinant in diabetes management. For example, treatment plans are defined regarding the participant’s current health state and the targeted goal. Even more critical, most of the micromanagement decisions are also dependent on instant values. For example, if somebody has hyperglycemia, the amount of extra insulin doses is defined according to the blood glucose levels.

The quantification of self also brings up another normative discussion. As mentioned in the literature (see Section 2.3.2), the success of diabetes management is evaluated based on HbA1c levels. In other words, keeping HbA1c levels in the target range is considered an accomplishment. Thus, as findings of the study mirror the literature, people with diabetes aim to keep their HbA1c levels closer to non-diabetic adults’ results not only for being healthy but, more importantly, for feeling normal. Though the range 7-7.5% is accepted by medical authorities, the people who can achieve lower HbA1c levels find these values critical. Moreover, they consider themselves the conscious [*bilinçli*] ones while criticizing others. This comparison signifies the normativity in perception. The quantified self is no more just the representation of health, but also the virtue of being responsible.

Apart from blood levels, the number of blood sugar measurements also is a means of quantification. Participants identify their use practices and user profiles depending on how often they perform measurements during the day. The meanings assigned vary depending on the type of measurement tool. In glucometer use, the excessive numbers of measurements are generally observed in extraordinary conditions like pregnancy. In general, frequent measurements are not recommended by medical authorities as they may cause damages such as sore fingers. Moreover, the number of daily measurements is also limited, as the state insurance only pays the precise number of supplements, such as strips per month.

However, people who use CGMs associate the glucose check frequency by taking advantage of the technology, since connected devices have transformed the monitoring into an easy process. This mindset might also recall a discussion of appropriation in the use of CGMs. As stated in the literature review (see Section 2.4.4), previous studies showed that there is a negative correlation between the glucose check frequency and estimated HbA1c values, which means the more glucose monitoring, the more consistent blood values. In the lights of these, CGM participants are evaluated in regard to their performance in technology use, and most concrete example is the number of average BG monitoring as Eren narrated in Section 4.4.2.4. Moreover, the normativity in technology use also reminds the broader discussion of "active citizen" presented in Section 2.1.2. In healthist discourse (Crawford, 1980, 2006), active citizens, the ones collaborating and taking responsibilities in care, are considered as the "ideal citizens" of the era.

### 5.3.5 Collaborative Management and Care Networks

The findings of the study revealed once more that diabetes is a practice that requires support for management. This is not only because sometimes people cannot cope with emergencies alone, but also because of the emotional burden in general. Beginning from the diagnosis, at each stage of diabetes, people need support from their family, significant other, and even colleagues. As a result of collective management, especially in emergencies, apart from the patient, the others also become one of the actors who might decide and even intervene in the patient's diabetes management.

What Latour (1993) indicated by “the differences between human and non-humans should not be taken granted” might be associated with the changing nature of actors in diabetes management. Connected technologies redefine the nature of the actors, which is mobile, and their agency in the care networks become interchangeable. For example, in Esra’s story, the product substitutes the agency of her husband with its screening features and makes the interaction system work appropriately without any disruption. In the use of self-monitoring systems, there is a distribution among all actors equally or not, and the product itself is also involved. In Meral’s story, though she is the one experiencing the illness, the product gives the right of decision to her fiancée, too.

Apart from its benefits, Meral discussed that in daily life, it might lead to discussions if the other actor, Sertan, did not appreciate her decisions. In addition, by his words “eliminating her through product,” Sertan refers to that with its agency, the product enables him to pacify the main actor, Meral.

Within this framework, one of the most important conclusions of the study is that self-monitoring systems sometimes substitute some of the actors and reorganize their agency. Although participants mostly talked about how technologies enable close relations to take part in the management, sometimes the device itself collaborates with its user to perform better management.

With regards to the examples presented above. Figure 5.1 summarizes the dynamic nature of the care networks defined through the agency of the product. As it is seen, there are four different means of collaborative management which are; patient-device, patient-close relation, patient-medical authority, and patient-community.

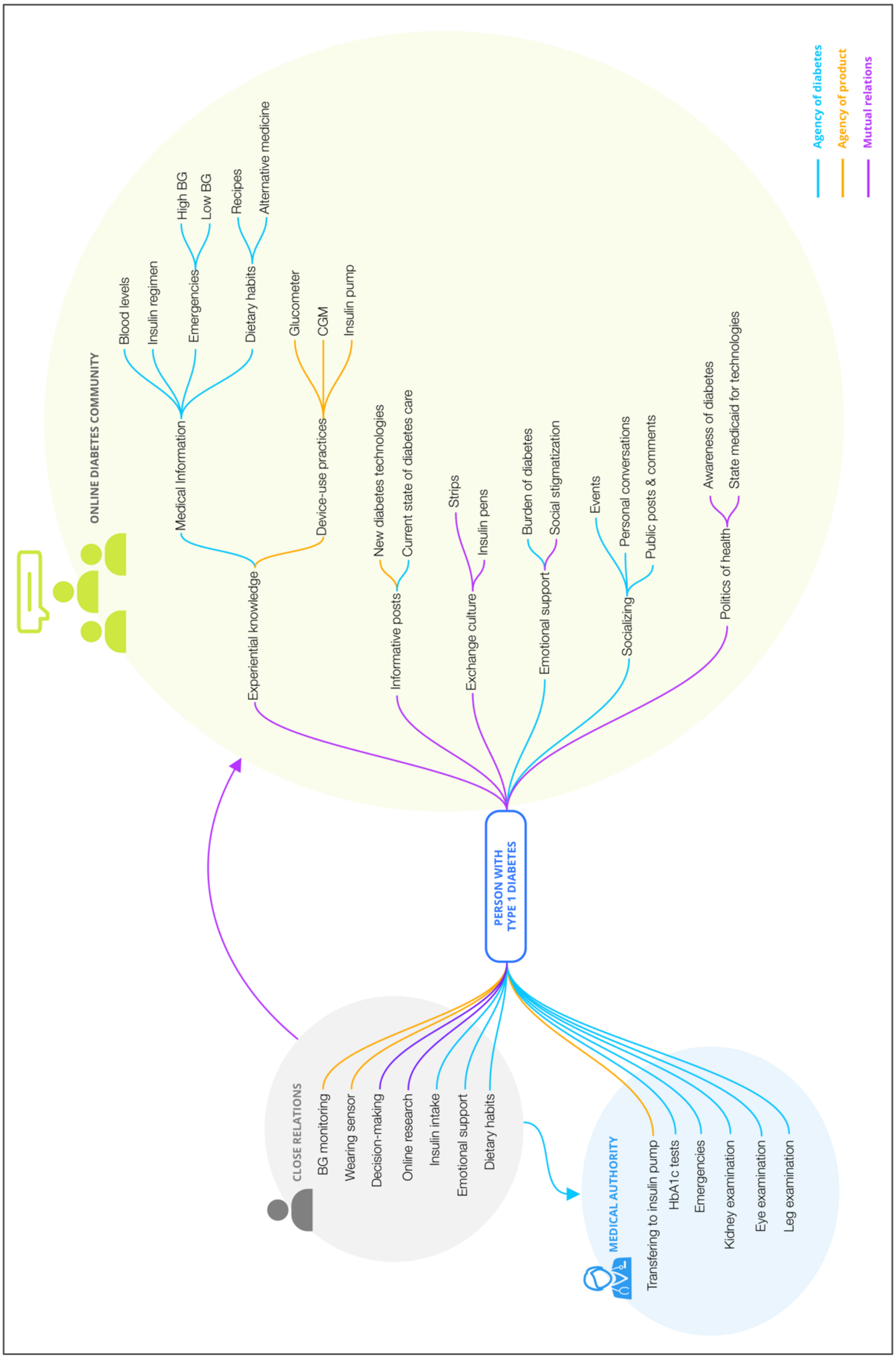


Figure 5.1 Care Networks

### *Patient-Device*

The interaction between the patient and the device varies in the type of products. In the case of glucometers, the device is only delegated with monitoring the instant blood glucose level. Therefore, it only becomes an actor in the moment of use. In the case of insulin pumps, the relationship between the patient and the device is an example of self-management, and the device is delegated with calculating and delivering the required amount of insulin. However, what makes insulin pump different than glucometer is that, as the device is worn on the body all the time while it is in use, the product-human assemblage is always represented in the network.

When it comes to CGMs, it is possible to discuss the means of collaborative management, as the device performs the monitoring together with the patient, and the dynamic representation of the blood sugar gives the right of decision to the patient. Similar to the insulin pump, CGMs are always a part of the network as long as they are in use.

### *Patient-Close Relation*

As mentioned above, connected devices are capable of shaping the relations of care and make close relations take part in the management process in specific manners through the agency of the product. The patient has a right to delegate the contributor role to anyone they prefer by giving the right to access data from the device. As the power of delegation belongs to the patients, the existence of close relationships within the network is dependent on the immediate decisions. On the other hand, apart from accessing the quantified representation of the body, close relations can also be a part of the network in different conditions. For instance, families or friends provide emotional support to overcome the burden of diabetes. Moreover, they collaborate with individuals for adjusting daily routines, searching online information to helping patients to place the sensor onto the body.

### *Patient-Medical Authority*

As diabetes is a chronical condition, from the outside, it might be seen that there is ongoing collaborative management between patients and the medical authorities. However, in everyday life, the reflection of medical authority might only be seen in performing the treatment plan.

Regarding technology use practices, individuals might require medical expertise in the decision-making process. For example, in the case of insulin pump treatment, people need the approval of the doctor, that is reflecting medical trust in their qualification of technology use and management process.

Although contemporary devices promise the users a connected experience in which they can access professional help with ease and transfer instant data for collaborative decision making, participants' insights revealed that in current healthcare policies, participants only rely on medical authority in emergencies, or provide routine care only via prescriptions.

### *Patient-Community*

There is a multidimensional relationship between people with diabetes and online health communities. As represented in Section 4.5, most of the individuals come across these organizations either through recommendation or as a result of searching for experiential knowledge. In this regard, the agency of digital health technologies is one of the significant motivators for individuals to take part in the communities. Apart from the need for experiential knowledge, communities are the medium through which people can be aware of the latest improvements in diabetes management in the light of informative posts.

The dynamic nature of online communities also brings the culture of exchange in commodities. Individuals post their needs for diabetes supplements such as insulin pens or glucometer strips, and the ones who have extra might share it with those people. Beyond their practical benefits, online health communities are the mediums in which individuals having similar bio-identities meet and socialize. Participants' statements revealed that through the communication facilities of open communities, such as personal messaging, people make friends and even meet in real life and maintain close relations.

The outcomes of these collective organizations are discussed thoroughly in the following section.

### 5.3.6 Building Collectives through Diabetes

One of the questions this study aims to discover is how people gather around diabetes and the role of the product in this organization. My observations in online communities and the outcomes of the fieldwork revealed that what makes people come together is the need for first-hand information; in other words, experiential knowledge (Borkman, 1976). Once people who have no familiarity are diagnosed with diabetes, they feel the need to take advice from someone experienced. In today's world, the Internet is the primary source for information as it is practical, fast, and has no defined place (Rice & Katz, 2001). As Cem stated in Section 4.5, the variety in online sources, from academic papers to self-help groups, makes reaching information a lot easier.

Referring to the analysis (see Section 4.4), the integration of emergent technologies also increased the demand for experiential knowledge. In Turkey, products such as CGMs are becoming popular yet not very recognized by even healthcare professionals. Moreover, the cost of wearable technologies is also another reason why they are not highly accessible. This outcome refers to the dilemma of equity in e-Health once more.

As mentioned in the literature review (see Section 2.1.3.1), one of the aims of e-Health is to make care adequate and accessible for anyone. However, in Turkey, CGMs are the output of non-domestic production, and that is why the cost of these products is considerably high, which makes them accessible for people from particular socioeconomic classes. Moreover, independent from economic dimensions, as the supplements such as sensors are not available in the local market all the time, users need to switch back to glucometers occasionally until they procure product supplements.

Getting back to the topic, there are online communities organized around diabetes, and the agency of product plays a crucial role in this collective action. Within these collectives, there is a cross-learning process in which personal experiences are shared, commented on, criticized, or appreciated. So, these collectives are considered as means of "community of practice" (Lave & Wenger, 1991), not only because diabetes itself is a knowledge required practice, but also the characteristics mentioned above suit the definition.

There is a unique exchange culture within the communities, in which people do share not only knowledge or experience but also diabetes related commodities such as product supplements. In terms of sharing knowledge, some members aim to enable other people to be knowledgeable, too. For example, Eren translated the user manual from English to Turkish to make it accessible to anyone.

Besides, depending on the level of interaction, there are outstanding members whose knowledge is appreciated without any judgment. This insight is valuable to exemplify how the trust mechanism is regulated. As Güzin exemplified, the people such as the founder of the community or the members who frequently share about latest improvement in diabetes technologies are considered knowledgeable. That is why they become like opinion leaders, and not many people worry about the accuracy of the information. On the other side, these people mostly share informative rather than prescriptive content.

There is a co-creation dynamic where the shared information is fed and extended with the contribution of other members. However, this co-creation of knowledge also brings the problem of reliability. Once a person posts on the groups, that post is visible to anyone, which means whoever reaches that information is free to use it. To think about extreme cases mentioned in the fieldwork, let us focus on emergencies. When there is an emergency post, how members act differs depending on the context of their comments. Some people, no matter what their expertise, preferably recommend reaching out to an authority. On the other hand, some people directly share treatment advice, which can even be very specific in numerical values. At this point, empowerment and awareness are critical for deciding whether the information is reliable or not.

No doubt that online communities are one of the comprehensive information sources in healthcare, but there are still ongoing issues regarding the verification of information. In some groups, admins are the watchers of the posts, and they are authorized by deleting the contents interpreted as misleading or irrelevant. However, this brings another issue about the power relations within communities, which might be discovered by further studies.

## 5.4 Design Implications

This study is focused on the user practices of type 1 diabetes management that are discussed as a biosocial practice with the agency of wearable technologies. Moreover, it also took a closer look at the inner dynamics of online communities. Therefore, in lights of the literature review and field study, the outcomes of this research might be beneficial for practitioners taking role in the different areas of design practice, from medical design to interaction design.

1. Design implications related to the change in healthcare:

The literature review of this study represented the changes in medicine in parallel with the rise of emerging health technologies. As the practice of care becomes more digital and is carried outside the hospital, the profile of patients has changed accordingly. The new patients, i.e., healthcare consumers, are involved in care practices actively. Their participation in care also affects their behaviors and expectations as medical product users. Beyond informative features, today's users are looking for products that are compact, easy to use and integrating user into the process.

2. Design implications for designing GUI interactions:

With the help of technological developments, the information about blood sugar is based on real-time feedback. According to this improvement, the visual design of the device display evolved in a more dynamic way. Moreover, the provided graphs have changed users' understanding of their BG levels comprehensively. These observations emphasize the significance of designing GUI in accordance with the use pattern of the product.

3. Design implications related to the representation of the user:

Wearable technologies transformed diabetes management in a way that is mobile and independent from the location. However, the ability to perform care practices anywhere has brought the discussion about the visibility of diabetes. In the case of CGMs, the sensors worn on the body are relatively small in size and easy-to-hide. However, as insulin pumps are comparatively bigger in dimension and the cable of the infusion set is harder to hide, the image of ill-body might become more visible.

4. Design implications related to the embodiment of wearable products:

While discussing the representation of the human body in the context of using wearable devices, this study provides information about critical concepts such as digitization of the body. So, the reviewed literature highlights what medical designers may benefit from the digital health discourse.

The way how patients domesticate and even hack their devices according to personal needs is similar to the *do-it-yourself* approach in design practice, and designers could evaluate user insights as design opportunities.

Besides, participants' insights regarding the embodiment of the products revealed the gendered ways of use as a result of the form of the device. Therefore, it is significant for designers to bear in mind not to design wearables having gender-specific features, such as how an insulin pump cannot be carried on chest due to its dimensions.

5. Design implications for the analysis of hybrid networks:

With the integration of connected technologies, the role and the presence of the actors in the networks become contemporary. In the interactions shaped around diabetes management, different types of materiality, i.e., humans and non-humans, take part. In this regard, this study provides designers a different point-of-view by integrating social theories to understand the dynamic nature of relations and changing roles of the actors in the analysis of such hybrid networks.

6. Design implications related to the dynamics of online communities:

While defining primary healthcare networks, understanding the role of online health communities may provide information. Online communities are the alternative type of organizations in which members collectively produce knowledge based on their lived experiences. The practice of diabetes management also facilitates the role of community building. When individuals come together through the agency of the products, communities of diabetes practice are formed, which results in collaborative knowledge production.

The recommendations and guidance of other people who are experienced in device use are found very useful as this kind of information is not found in any user manual. Also, there is much practical information regarding how to manage emergencies as they are grounded more on daily life experiences than on medical prescriptions. At this point, designers might find useful insights regarding how to design for communities that can support individuals in self-care or preventive care. Moreover, what design practice could benefit from the dynamics of such organizations is that in such collaborations, the roles of members are not fixed. For example, individuals might be considered as laypeople depending on their competencies.

## 5.5 Further Recommendations

This study investigated the use practices and experiential knowledge production of chronically-ill selves through *Tip 1 Diyabet Tecrübeleri* diabetes online community, in which knowledge production is handled as a collective process. Related literature and participants' insights indicated the differences in types of collectives regarding the participation of individuals. A comparative exploration of different communities, such as personal blogs providing medical knowledge and experience of a single person and communities in which the information produced by their members could provide insights about the patient profiles constructed through community interaction.

This research has revealed the various practices around chronic illnesses by investigating type 1 diabetes as a representative example. Today, design scholars can learn a lot from qualitative studies on chronical conditions that take into consideration both their medical experiences and device-use practices that also cover collective learning and production. Moreover, in the case of body-product relation, design practice might help not to marginalize bodies constructed through wearable devices by focusing more on the embodiment process and visual aspects of product design, as well.

# REFERENCES

Ackerknecht, E. H. (1967). *Medicine at the Paris hospital 1794-1848.* Baltimore: The Johns Hopkins Press.

Akrich, M. (2010). From communities of practice to epistemic communities: Health mobilizations on the Internet. *Sociological Research Online, 15*(2), 1-17.

Akrich, M., Méadel, C., & Rémy, C. (2008, January). Building collectives via the web? Information and mobilization on cancer websites. *Virtually Informed*, (pp. 13-40).

Allen, N., & Gupta, A. (2019). Current diabetes technology: Striving for the artificial pancreas. *Diagnostics, 9*(1), 31.

Anderson, G. (2010). *Chronic care: Making the case for ongoing care.* Princeton: Robert Wood Johnson Foundation.

Armstrong, D. (1995). Thare rise of surveillance medicine. *Sociology of Health & Illness, 17*(3), 393-404.

Arnhold, M., Quade, M., & Kirch, W. (2014). Mobile applications for diabetics: A systematic review and expert-based usability evaluation considering the special requirements of diabetes patients age 50 years or older. *Journal of Medical Internet Research, 16*(4):e104. doi:10.2196/jmir.2968.

Asif, M. (2014). The prevention and control the type-2 diabetes by changing lifestyle and dietary pattern. *Journal of Education and Health Promotion, 3*(1). doi: 10.4103/2277-9531.127541

Asselin, M. E. (2003, March). Insider research: Issues to consider when doing qualitative research in your own setting. *Journal for Nurses in Staff Development, 19*(2), 99-103.

Bailey, T., Bode, B. W., Christiansen, M. P., Klaff, L. J., & Alva, S. (2015). The performance and usability of a factory-calibrated flash glucose monitoring system. *Diabetes Technology & Therapeutics, 17*(11), 787-794.

Ball, M. J., & Lillis, J. (2001). E-Health: Transforming the physician/patient relationship. *International Journal of Medical Informatics, 61*(1), 1-10.

Barbot, J. (2006). How to build an “active” patient? The work of aids associations in France. *Social Science & Medicine, 62*(3), 538-551.

Barry, A., Osborne, T., & Rose, N. (1996). *Foucault and political reason: Liberalism, neo-liberalism and rationalities of government.* London: UCL Press Ltd.

*Basal bolus - basal bolus injection regimen*. (n.d.). Retrieved July 2019, from Diabetes.co.uk: https://www.diabetes.co.uk/insulin/basal-bolus.html

Bauer, S., & Olsén, J. E. (2009). Observing the others, watching over oneself: Themes of medical surveillance in post-panoptic society. *Health, Medicine and Surveillance, 6*(2), 116-127.

Bazeley, P. (2013). *Qualitative data analysis: Practical strategies.* London: SAGE.

Beck, U. (2009). Critical theory of World Risk Society: A cosmopolitan vision. *Constellations, 17*(1), 3-22.

Boeije, H. (2010). *Analysis in qualitative research.* London: SAGE.

Bond, G. E., Burr, R. L., Wolf, F. M., & Feldt, K. (2010). The effects of a web-based intervention on psychosocial well-being among adults aged 60 and older with diabetes. *The Diabetes Educator, 36*(3), 446-456.

Borkman, T. (1976). Experiential knowledge: A new concept for the analysis of self-help groups. *The Social Service Review, 50*(3), 445-456.

Borus, J. S., Blood, E., Volkening, L. K., Laffel, L., & Shrier, L. A. (2013). Momentary assessment of social context and glucose monitoring adherence in adolescents with type 1 diabetes. *Journal of Adolescent Health, 52*(5), 578-583.

Boulos, M. N., Wheeler, S., Tavares, C., & Jones, R. (2011). How smartphones are changing the face of mobile and participatory healthcare: An overview, with example from eCAALYX. *BioMedical Engineering OnLine, 10(1).* doi: 10.1186/1475-925X-10-24

Brinkmann, S. (2013). *Qualitative interviewing.* Oxford: Oxford University Press.

Brock, S. C. (1995). Narrative and Medical Genetics: On ethics and therapeutics. *Qualitative Health Research, 5*, 150-168.

Brown, J. S., & Duguid, P. (2001). Knowledge and organization: A social-practice perspective. *Organization Science, 12*(2), 198-213.

Brownson, R. C., & Jones, E. (2009). Bridging the gap: Translating research into policy and practice. *Preventive Medicine, 49*(4), 313-315.

Bruni, A., & Rizzi, C. (2013). Looking for data in diabetes healthcare: Patient 2.0 and the re-engineering of clinical encounters. *Science and Technology Studies, 26*(1), 29-43.

Budinger, T. F. (2003). Biomonitoring with wireless communications. *Annual Review of Biomedical Engineering, 5*(1), 383-412.

Bueger, C., & Stockbruegger, J. (2017). Actor-network theory: Objects and actants, networks and narratives. In D. R. McCarthy (Ed.), *Technology and World Politics: An Introduction* (pp. 42-59). Abingdon, UK: Routledge.

Burchell, G., Gordon, C., & Miller, P. (Eds.). (1991). *The Foucault effect:Studies in governmentality.* London: Harvester/Wheatsheaf.

Buse, C. E. (2010). E-scaping the ageing body? Computer technologies and embodiment in later life. *Ageing & Society, 30*(6), 987-1009.

Butler, B. S. (2001). Membership size, communication activity, and sustainability: A resourcebased model of online social support structures. *Information Systems Research, 12*(4), 346-362.

Callon, M. (1981). Struggles and negotiations to define what is problematic and what is not: The socio-logic of translation. In K. Knorr, R. Krohn, & R. Whitley (Eds.), *The social process of scientific investigation* (pp. 197-219). Dordrecht, Holland: D. Reidel Publishing Company.

Casper, M. J., & Morrison, D. (2010). Medical sociology and technology: Critical engagements. *Journal of Health and Social Behavior, 51*, 120-132.

Cengiz, E., & Tamborlane, W. V. (2009). A tale of two compartements: Intestitial versus blood glucose monitoring. *Diabetes Technology & Therapeutics, 11*(1), 11-16.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* Thosand Oaks, CA: SAGE.

Chomutare, T., Fernandez-Luque, L., Årsand, E., & Hartvigsen, G. (2011). Features of mobile diabetes applications: Review of the literature and analysis of current applications compared against evidence-based guidelines. *Journal of Medical Internet Research, 13*(3):e65. doi: 10.2196/jmir.1874.

Ciudin, A., Hernandez, C., & Simo, R. (2012). Non-invasive methods of glucose measurement: Current status and future perspectives. *Current Diabetes Review, 8*(1), 48-54.

Clarke, A. E., Shim, J. K., Mamo, L., Fosket, J., Fishman, J. R., & Fosket, J. R. (2003). Biomedicalization: Technoscientific transformations of health, illness, and U.S. biomedicine. *American Sociological Review, 68*(2), 161-194.

Clarke, S. F., & Foster, J. R. (2012). A history of blood glucose meters and their role in self-monitoring of diabetes mellitus. *Journal of Biomedical Science, 69*(2), 83-93.

Corbin, J., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative Sociology, 13*(1), 3-21.

Crawford, R. (1980). Healthism and the medicalization of everyday life. *International Journal of Health Care Services, 10*(3), 365-388.

Crawford, R. (2006). Health as a meaningful social practice. *Health, 10*(4), 401-420.

Cressman, D. (2009). A brief overview of actor-network theory: Punctualization, heterogeneous engineering & translation. Centre for Policy Research on Science and Technology.

Creswell, J. W. (2009). *Research design : Qualitative, quantitative, and mixed methods approaches* (3rd ed.). Thousands Oaks, US: SAGE.

Cummiskey, M. (2011). There's an app for that: Smartphone use in health and physical education. *The Journal of Physical Education, Recreation & Dance, 82*(8), 24-29.

de Groot, M. (2014). *Quantified self, quantified us, quantified other*. Retrieved from https://qsinstitute.com/quantified-self-quantified-us-quantified-other/

Degli-Espoti, S. (2014). When big data meets dataveillance: The hidden side of analytics. *Surveillance & Society, 12*(2), 209-225.

Douglas, B., & Moustakas, C. (1985, Summer). Heuristic inquiry: The internal search to know. *Journal of Humanistic Psychology, 25*(3), 39-55.

Earle, S., Foley, P., Komaromy, C., & Llyod, C. E. (2009). Health, medicine and surveillance in the 21st century. *Surveillance & Society, 6*(2), 96-100.

Edmunds, A., & Morris, A. (2000). The problem of information overload in business organisations: A review of the literature. *International Journal of Information Management, 20*(1), 17-28.

Evans, R. S. (2016). Electronic health records: Then, now, and in the future. *Yearbook of Medical Informatics, 25*(1), 48-61.

Eysenbach, G. (2000). Consumer health informatics. *British Medical Journal, 320*, 1713-1716.

Eysenbach, G. (2001). What is e-health? *Journal of Medical Internet Research, 3*(2):e20. doi: 10.2196/jmir.3.2.e20.

Eysenbach, G., & Diepgen, T. (1999). Patients looking for information on the Internet and seeking teleadvice. *Journal of American Medical Association, 135*, 151-156.

Eysenbach, G., Powell, J., Englesakis, M., Rizo, C., & Stern, A. (2004). Health related virtual communities and electronic support groups: Systematic review of the effects of online peer to peer interactions. *BMJ* (Clinical Research Ed.)*, 328*(7449), 1166. doi: 10.1136/bmj.328.7449.1166.

Fallan, K. (2010). *Design history: Understanding theory and method.* Oxford: Berg Publishers.

Felman, A. (2019, May 24). *How does diabetes affect mood and relationships?* Retrieved from https://www.medicalnewstoday.com/articles/317458.php

Ferrante do Amaral, C. E., & Wolf, B. (2008). Current development in non-invasive glucose monitoring. *Medical Engineering & Physics, 30*(5), 541-549.

Foucault, M. (1995). *Discipline & punish: The birth of the prison.* (A. Sheridan, Trans.) New York: Vintage Books.

Franklin, S. (2006). The cyborg embryo: Our path to transbiology. *Theory, Culture & Society, 23*(7-8), 167-187.

Freckmann, G., Link, M., Kamecke, U., Haug, C., Baumgartner, B., & Weitgasser, R. (2019). Performance and usability of three systems for continuous glucose monitoring in direct comparison. *Journal of Diabetes Science and Technology, 13*(5), 890-898.

Free, C., Phillips, G., Galli, L., Watson, L., Felix, L., Edwards, P., Patel, V., Haines, A. (2013). The effectiveness of mobile-health technology-based health behaviour change or disease management interventions for health care consumers: A systematic review. *PLos Medicine, 10*(1):e1001362. doi: 10.1371/journal.pmed.1001362.

Frost, H. J., & Massagli, P. M. (2008). Social uses of personal health information within PatientsLikeMe, an online patient community: What can happen when patients have access to one another's data. *Journal of Medical Internet Research, 10*(3):e15. doi: 10.2196/jmir.1053.

Günay, A. (2017). *Conceptualization of positive pregnancy experience with the integration of mobile health technologies.* PhD Thesis, Middle East Technical University, Industrial Design, Ankara.

Gaev, J. A. (2004). Technology in health care. In J. F. Dyro (Ed.), *Clinical Enginering Handbook* (pp. 342-345). Burlington, Academic Press.

Gibbons, M. C., Wilson, R. F., Samal, L., Lehman, C. U., Dickersin, K., Lehmann, H. P., Aboutmatar, H., Finkelstein, J., Shelton, E., Sharma, R., Bass, E. B. (2009). *Impact of consumer health informatics applications.* Evidence Reports/Technology Assessments. Rockville, MD: Agency for Health Care Policy and Research.

Gilbert, K., Dodson, S., Gill, M., & McKenzie, R. (2012). Online communities are valued by people with type 1 diabetes for peer support: How well do health professionals understand this? *Diabetes Spectrum, 25*(3), 180-191.

Glaser, B. (1978). *Theoretical sensitivity: Advances in the methodology of grounded theory.* Mill Valley, CA: The Sociology Press.

Glaser, B., & Strauss, A. L. (1967). *The discovery of grounded theory; strategies for qualitative research.* Chicago: Aldine Publishing Company.

Glesne, C. (2011). *Becoming qualitative researchers: An introduction* (4th ed.). Boston, MA: Pearson.

Gonul, S., Namli, T., Huisman, S., Laleci Erturkmen, G. B., Toroslu, I. H., & Cosar , A. (2019, March). An expandable approach for design and personalization of digital, just-in-time adaptive interventions. *Journal of the American Medical Informatics Association, 26*(3), 198-210.

Grando, M. A., Bayuk, M., Karway, G., Corrette, K., Groat, D., Cook, C. B., & Thompson, B. (2019). Patient perception and satisfaction with insulin pump system: Pilot user experience survey. *Journal of Diabetes Science and Technology, 13*(6), 1142-1148.

Gray, C. H., Mentor, S., & Figueroa-Sarriera, H. (1995). Cyborgology: Constructing the knowledge of cybernetic organisms. In C. H. Gray (Ed.), *The Cyborg Handbook* (pp. 1-14). London: Routledge.

Gray, D. E. (2009). *Doing research in the real world* (2nd ed.). New Castle: SAGE.

Greene, J. A., Choudhry, N. K., Kilabuk, E., & Shrank, W. H. (2011). Online social networking by patients with diabetes: A qualitative evaluation of communication with Facebook. *Journal of General Internal Medicine, 26*(3), 287-292.

Gross, T. M., Bode, B. W., Einhorn, D., Kayne, D. M., Reed, J. H., White, N. H., & Mastrototaro, J. J. (2000). Performance evaluation of the MiniMed continuous glucose monitoring system during patient home use. *Diabetes Technology & Therapeutics, 2*(1), 49-56.

Guell, C. (2011). Candi(e)d action: Biosocialities of Turkish Berliners living with diabetes. *Medical Anthropology Quarterly, 25*(3), 377-394.

Hampton, K. N., Goulet, L. S., Rainie, L., & Purcell, K. (2011). *Social networking sites and our lives: How people's trust, personal relationships, and civic and political involvement are connected to their use of social networking sites and other technologies.* Washington, DC: Pew Internet & American Life Project.

Handel, M. J. (2011). mHealth (mobile health)-using apps for health and wellness. *Explore: The Journal of Science and Healing, 7*(4), 256-261.

Haraway, D. (1985). Manifesto for cyborgs: Science, technology, and socialist feminism in the 1980s. *Socialist Review, 80*, 65-108.

Haraway, D. (1995). Foreword: Cyborgs and symbionts: Living together in the new world order. In C. H. Gray (Ed.), *The Cyborg Handbook* (pp. 11-20). New York: Routledge.

Haraway,D.(1997). *Modest_Witness@Second_Millennium.FemaleMan_Meets_OncoMouse.* London: Routledge.

Heinemann, L., & Freckmann, G. (2015). CGM versus FGM; or, continuous glucose monitoring is not flash glucose monitoring. *Journal of Diabetes Science and Technology, 9*(5), 947-950.

Heritage, J. (1984). *Garfinkel and ethnomethodology* (1st ed.). Cambridge: Polity Press.

Hill, W., Weinert, C., & Cudney, S. (2006). Influence of a computer intervention on the psychological status of chronically ill rural women: Preliminary results. *Nurse Research, 55*(1), 34-42.

Ho, Y. X., O'Connor, B. H., & Mulvaney, S. A. (2014). Features of online health communities for adolescents with type 1 diabetes. *Western Journal of Nursing Research, 36*(9), 1183–1198.

Hogle, L. F. (2005). Enhancement technologies and the body. *Annual Review of Anthropology, 34*(1), 695-716.

Homko, C. J., Santamore, W. P., Whiteman, V., Bower, M., Berger, P., Geifman-Holtzman, O., & Bove, A. A. (2007). Use of an internet-based telemedicine system to manage underserved women with gestational diabetes mellitus. *Diabetes Technology & Therapeutics, 9*(3), 297-306.

Hood, K. K., Hilliard, M., Piatt, G., & levers-Landis, C. E. (2015). Effective strategies for encouraging behavior change in people with diabetes. *5*(6), 499-510.

Institute of Medicine Board on Healthcare. (2008). *Retooling for an aging America: Building the health care workforce.* Washington, DC: National Academies Press.

Istepanian, R. (2004). Introduction to the special section on m-health: Beyond seamless mobility and global wireless health-care connectivity. *IEEE Transactions on Information Technology in Biomedicine, 8*(4), 405-414.

Jewson, N. (1976). The disappearance of the sick-man from medical cosmology: 1770-1870. *Sociology, 10*(2), 225-244.

Johnston, A. C., Worrell, J. L., Di Gangi, P. M., & Wasko, M. (2013). Online health communities: An assessment of the influence of participation on patient empowerment outcomes. *Information Technology & People, 26*(2).

Johnson, J. (1988). Mixing mumans and nonhumans together: The sociology of a door-closer. *Social Problems, 35*(3), 298-310.

Jolly, V. (2018, Spring). *The state of digital health.* London: Woodside Capital Partners.

Kaplan, R. M., Chadwick, M. W., & Schimmel, L. E. (1985). Social learning intervention to promote metabolic control in type 1 diabetes mellitus: Pilot experiment results. *Diabetes Care, 8*(2), 152-155.

Katz, B. (1997). Review essay: Technology and design-a new agenda. *Technology and Culture, 38*(2), 452-466.

Kirwan, M., Vandelanotte, C., Duncan, M., & Mummery, K. (2010). Using smartphones to increase physical activity: Usability testing of the 10,000 steps iPhone application. *Journal of Science and Medicine in Sport, 13*(1):e28. doi:10.1016/j.jsams.2010.10.520.

Kitsiou, S., Paré, G., Jaana, M., & Gerber, B. (2017). Effectiveness of m-health interventions for patients with diabetes: An overview of systematic reviews. *PLoS One, 12*(3):e0173160. doi:10.1371/journal.pone.0173160.

Klonoff, D. C. (2013). The current status of m-health for diabetes: Will it be the next big thing? *Journal of Diabetes Science and Technology, 7*(3), 749-758.

Kozinets, R. V. (2010). *Netnography: Doing ethnographic research online* (2nd, Ed.). London: SAGE.

Kudva, Y. C., Ahmann, A. J., Bergenstal, R. M., Gavin, III, J. R., Kruger , D. F., Midyett, L. K., Miller, E., Harris, D. R. (2018). Approach to using trend arrows in the FreeStyle Libre flash glucose monitoring systems in adults. *Journal of the Endocrine Society, 2*(12), 1320-1337.

Kulkarni, K. D. (2005). Carbonhydrate counting: A practical meal-planning option for people with diabetes. *Clinical Diabetes, 23*(3), 120-122.

Kuru, A. (2016). Exploring experience of runners with sports tracking technology. *International Journal of Human–Computer Interaction, 32*(11), 847-860.

Lamberg, L. (2003). Online empathy for mood disorders. *Journal of the American Medical Association, 289*(23), 3073-3077.

Langmuir, A. D. (1963). The surveillance of communicable diseases of national importance. *New England Journal of Medicine, 268*(4), 182-192.

Langmuir, A. D. (1971). Evolution of the concept of surveillance in the United States. *Proceedings of the Royal Society of Medicine, 64*(6), 681-684.

Langmuir, A. D. (1976). William Farr: Founder of modern concepts of surveillance. *International Journal of Epidemiology, 5*(1), 13-18.

Latour, B. (1987). *Science in action: How to follow scientists and engineers through society.* Cambridge, MA: Harvard University Press.

Latour, B. (1992). Where are the missing masses? Sociology of a few mundane artefacts. In W. Bijker, & J. Law (Eds.), *Shaping Technology, Building Society: Studies in Sociotechnical Change* (pp. 225-259). Cambridge, MA: The MIT Press.

Latour, B. (1993). *We have never been modern.* Cambridge, MA: Harward University Press.

Latour, B. (1999). On recalling Ant. *The Sociological Review, 47*(1), 15-25.

Latour, B. (2005). *Reassembling the Social: An Introduction to Actor-Network-Theory.* Oxford University Press.

Lave, J., & Wenger, E. (1991). *Situated learning: Legitimate peripheral participation.* Cambridge: Cambridge University Press.

Law, J. (2008). Actor-network theory and material semiotics. In B. S. Turner (Ed.), *The new Blackwell companion to social theory* (3rd ed., pp. 141-158). Oxford: Blackwell Publishers.

Law, J. (2008). On sociology and STS. *The Sociological Review, 56*(4), 623-649.

Law, J., & Hassard, J. (1999). *Actor-network theory and after.* Oxford: Blackwell Publishers.

Lemke, T. (2011). *Biopolitics: An advanced introduction.* New York: New York University Press.

Lucisano, L., Kurbanyan, L., Martha, S., & Routh, T. (2017). Clinical update with a long term, unobtrusive, fully-implanted continuous glucose monitoring system. *10th International Conference on Advanced Technologies & Treatments for Diabetes*, (pp. 12-13).

Lupton, D. (1995). T*he imperative of health: Public health and regulated body.* London: SAGE.

Lupton, D. (2012a). *Medicine as culture: Illness, disease and thebBody* (3rd ed.). London: SAGE.

Lupton, D. (2012b). M-health and health promotion: The digital cyborg and surveillance society. *Social Theory & Health, 10*(3), 229-244.

Lupton, D. (2013a). Quantifying the body: Monitoring and measuring health in the age of m-health technologies. *Critical Public Health, 23*(4), 393-403.

Lupton, D. (2013, January 11). *Living the quantified self: The realities of self-tracking for health*. Retrieved from https://simplysociology.wordpress.com/2013/01/11/living-the-quantified-self-the-realities-of-self-tracking-for-health/

Lupton, D. (2015). Donna Haraway: The digital cyborg assemblage and the new digital health technologies. In F. Collyer (Ed.), *The palgrave handbook of social theory in health, illness and medicine* (pp. 567-581). London: Palgrave Macmillan.

Lupton, D. (2016a). Digital health technologies and digital data: New ways of monitoring, measuring and commodifying human embodiment, health and illness. In F. X. Olleros, & M. Zhegu (Eds.), *Research handbook on digital transformations* (pp. 85-102). Cheltenham, UK: Edward Elgar Publishing.

Lupton, D. (2016b). *The quantified self.* Cambridge: Polity Press.

Lupton , D. (2016c). Response: Cohabiting with our lively data. *Rassegna Italiana di Sociologia, 57*(4), 811-816.

Lupton, D. (2017). Digital bodies. In M. Silke, D. Andrews, & H. Thorpe (Eds.), *The Routledge handbook of physical cultural studies* (pp. 200-208). London: Routledge.

Lupton, D., & Michael, M. (2017). 'Depends on who's got the data': Public understandings of personal digital dataveillance. *Surveillance & Society, 15*(2), 254-268.

MacKenzie, D., & Wajcman, J. (Eds.). (1999). *The social shaping of technology.* Buckingham, UK: Open University Press.

Mastrototaro, J. J., Cooper, K. W., Soundararajan, G., Sanders, J. B., & Shah, R. V. (2006). Clinical experience with an integrated continuous glucose sensor/insulin pump platform: A feasibility study. *Advances in Therapy, 23*(5), 725.

Matthews, B., & Ross, L. (2010). *Research methods: A practical guide for the social sciences.* Harlow, UK: Pearson Longman.

Mays, D., Cremeens, J., Usdan, S., Martin, R., Arriola, K., & Bernhardt, J. (2010). The feasibility of assessing alcohol use among college students using wireless mobile devices: Implications for health education and behavioural research. *Health Education Journal, 69*(3), 311-320.

Meskó, B., Drobni, Z., Bényei, É., Gergely, B., & Győrffy, Z. (2017). Digital health is a cultural transformation of traditional healthcare. *Mhealth, 3*(38).

Miller, J., & Glassner, B. (1997). The "inside" and the "outside": Finding realities in interviews. In D. Silverman (Ed.), *Qualitative research: theory, method and practice* (pp. 99-112). London: SAGE.

Moenaert, R. K., & Souder, W. E. (1996). Information utility at the R&D/marketing interface. *Management Science, 42*(11), 1592-1610.

Mol, A. (2008). *The logic of care: Health and thepProblem of patient choice.* London: Routledge.

Moretti, V. (2016). Dealing with numbers. Looking beyond the self-monitoring for a new technology of the self. *EASST Review, 35*(4), 90-93.

Nagrebetsky, A., Larsen, M., Craven, A., Turner, J., McRobert, N., Murray, E., Gibson, O., Neil, A., Tarassenko, L., Farmer, A. (2013). Stepwise self-titration of oral glucose-lowering medication using a mobile telephone-based telehealth platform in type 2 diabetes: A feasibility trial in primary care. *Journal of Diabetes Science and Technology, 7*(1), 123-134.

Nambisan, P. (2011). Information seeking and social support in online health communities: Impact on patients' perceived empathy. *Journal of American Medical Information Association, 18*(3), 298-304.

Neff, G., & Nafus, D. (2016). *Self-tracking.* London: The MIT Press.

Neresini, F. (2015). Quando I numeri diventano grandi: Che cosa possiamo imparare dalla scienza. *Rassegna Italiana di Sociologia, 56*(3-4), 405-431.

Nundy, S., Mishra, A., Hogan, P., Lee, S. M., Solomon, M. C., & Peek, M. E. (2014). How do mobile phone diabetes programs drive behavior change? Evidence from a mixed methods observational cohort study. *Diabetes Educator, 40*(6), 806-819.

Oh, H., Rizo, C., Enkin, M., & Jadad, A. (2005). What is eHealth (3): A systematic review of published definitions. *Journal of Medical Internet Research, 7*(1):e1. doi:10.2196/jmir.7.1.e1.

Olansky, L., & Kennedy, L. (2010). Finger-stick glucose monitoring: Issues of accuracy and specificity. *Diabetes Care, 33*(4), 948-949.

Ornstein, D. L., & Cushman, M. (2003). Factor V Leiden. *Circulation, 107*(15): e94-e97. doi:10.1161/01.CIR.0000068167.08920.F1.

Oudhsoorn, N., & Somers, A. (2006). Constructing the digital patient: Patient organizations and the development of health websites. *Information, Communication & Society, 9*(5), 657-675.

Oudshoorn, N. (2014). Sustaining cyborgs: Sensing and tuning agencies of pacemakers and implantable cardioverter defibrillators. *Social Studies of Science, 45*(1), 56-76.

Oudshoorn, N. (2018). Hybrid bodies and the materiality of everyday life. How people living with pacemakers and defibrillators reinvent everyday routines and intimate relations. *Sociology of Health & Illness, 40*(1), 171-187.

Özkan, Ö. (2018). *Essential design components of genetic data enabled mobile personal health record systems.* Doctoral dissertation, Middle East Technical University, The Graduate School of Informatics.

Park, J., & Park, M. (2016). “Qualitative versus quantitative research methods: Discovery or justification? *Journal of Marketing Thought, 3*(1), 1-7.

Perednia, D. A., & Allen, A. (1995). Telemedicine technology and clinical applications. *Journal of the American Medical Association, 273*(6), 483-488.

Petersen, A., & Lupton, D. (1996). *The new public health: Health and self in the age of risk.* London: SAGE.

Pettus, J., & Edelman, S. V. (2017). Recommendations for using real-time continuous glucose monitoring (rtCGM) data for insulin adjustments in type 1 diabetes. *Journal of Diabetes Science and Technology, 11*(1), 138-147.

Pickup, J. C., Ford Holloway, M., & Samsi, K. (2015). Real-time continuous glucose monitoring in type 1 diabetes: A qualitative framework analysis of patient narratives. *Diabetes Care, 38*(4), 544-550.

Pillalamarri, S. S., Huyett, L. M., & Abdel-Malek, A. (2018). Novel bluetooth-enabled tubeless insulin pump: A user experience design approach for a connected digital diabetes management platform. *Journal of Diabetes Science and Technology, 12*(6), 1132-1142.

Polonsky, W. H., & Hessler, D. (2013). What are the quality of life-related benefits and losses associated with real-time continuous glucose monitoring? A survey of current users. *Diabetes Technology & Therapeutics*, *15*(4), 295-301.

Powell, J. A., Darvell, M., & Gray, J. A. (2003). The doctor, the patient and the world-wide web: How the Internet is changing healthcare. *Journal of the Royal Society of Medicine, 96*(2), 74-76.

Prout, A. (1996). Actor-network theory, technology and medical sociology: An illustrative analysis of the metered dose inhaler. *Sociology of Health & Illness, 18*(2), 198-219.

Quinn, C. C., Sysko Clough, S., Minor, J. M., Lender, D., Okafor, M. C., & Gruber-Baldini, A. (2008). WellDoc™ mobile diabetes management randomized controlled trial: Change in clinical and behavioral outcomes and patient and physician satisfaction. *Diabtes Technology & Therapeutics, 10*(3), 160-168.

Rabinow, P. (1996). Artificiality and enlightenment: From sociobiology to biosociality. In *Essays on the Anthropology of Reason.* Princeton, NJ: Princeton University Press.

Rebrin, K., & Steil, G. M. (2000). Can interstitial glucose assessment replace blood glucose measurements? *Diabetes Technology & Therapeutics, 2*(3), 461-472.

Reich, S. M., Subrahmanyam, K., & Espinoza, G. (2012). Friending, IMing, and hanging out face-to-face: Overlap in adolescents' online and offline social networks. *Developmental Psychology, 48*, 356–368.

Rice, R. E., & Katz, J. E. (Eds.). (2001). *The Internet and health communication: Experience and expectations.* Thousand Oaks, CA: SAGE.

Rich, E., & Miah, A. (2009). Prosthetic surveillance: The medical governance of healthy bodies in cyberspace. *Surveillance & Society, 6*(2), 163-177.

Riddel, M. C., Gallen, I. W., Smart, C. E., Taplin, C. E., Adolfson, P., Lumb, A. N., Kowalski, A., Rabasa-Lhoret, R., McCrimmon, R. J., Hume, C., Annan, F., Fournier, P. A., Graham, C., Bode, B., Galassetti, P., Jones, T. W., Millán, I. S., Heise, T., Peters, A. L., Petz, A., Laffel, L. M. (2017). Exercise management in type 1 diabetes: A consensus statement. *The Lancet Diabetes & Endocrinology, 5*(5), 377-390.

Ritchie, J., & Lewis, J. (Eds.). (2003). *Qualitative research practice: A guide for socialsScience students and researchers.* London, UK: SAGE.

Ritholz, M. D., Atakov-Castillo, A., Beste, M., Beverly, E. A., Leighton , A., Weinger, K., & Wolpert, H. (2010). Psychosocial factors associated with use of continuous glucose monitoring. *Diabetic Medicine, 27*, 1060-1065.

Rodbard, D. (2016). Continuous glucose monitoring: A Review of successes, challenges, and opportunities. *Diabetes Technology & Therapeutics, 18*(2), 3-13.

Rose, N. (1999). *Powers of freedom: Reframing political thought.* Cambridge: Cambridge University Press.

Rubin, H. J., & Rubin, I. S. (2011). *Qualitative interviewing: The art of hearing data* (3rd ed.). London: SAGE.

Ruggiero, L., Riley, B. B., Hernandez, R., Quinn, L. T., Gerber, B. S., Castillo, A., Day, J., Ingram, D., Wang, Y., Butler, P. (2014). Medical assistant coaching to support diabetes self-care among low-income racial/ethnic minority populations: randomized controlled trial. *36*(9), 1052-1073.

Saldana, J. (2013). *The coding manual for qualitative researchers* (2nd ed.). London: SAGE.

Salzsieder, E., & Augstein, P. (2011). The Karlsburg diabetes management system: Translation from research to eHealth application. *Journal of Diabetes Science and Technology, 5*(1), 13-22.

Samoocha, D., Bruinvels, D. J., Elbers, N. A., Anema, J. R., & van der Beek, A. J. (2010). Effectiveness of web-based interventions on patient empowerment: A systematic review and meta-analysis. *Journal of Medical Internet Research, 12*(2), 23.

Sarasohn-Kahn, J. (2008). *The wisdom of patients: Health care meets online social media.* Oakland, CA: California Health Care Foundation.

Sassatelli, R. (2016). Taming bodies, alluring affects. *Rassegna Italiana di Sociologia, 57*(4), 806-810.

Scott, E. M., Bilous, R. W., & Kautzky-Willer, A. (2018). Accuracy, user acceptability, and safety evaluation for the FreeStyle Libre flash glucose monitoring system when used by pregnant women with diabetes. *Diabetes Technology & Therapeutics, 20*(3), 180-188.

Segers, K., Dahlbäck, B., & Nicolaes, G. A. (2007). Coagulation factorV and thrombophilia: Background and mechanisms. *Thrombosis and haemostasis, 98*(3), 530-542.

Seidman, I. (2006). *Interviewing as qualitative research: A guide for researchers in education and the social sciences* (3rd ed.). New York: Teachers College Press.

Smarr, L. (2012). Quantifying your body: A how-to guide from a systems biology perspective. *Biotechnology Journal, 7*, 980-991.

Steinhubl, S. R., Muse, E. D., & Topol, E. J. (2013). Can mobile health technologies transform health care? *Journal of the American Medical Association, 310*(22), 2395-2396.

Stone, R. A., Rao, R. H., Sevick, M. A., Cheng, C., Hough, L. J., Macpherson, D. S., Franko. C. M., Anglin, R. A., Obrosky, D. S., DeRubertis, F. R. (2010, March). Active care management supported by home telemonitoring in veterans with type 2 diabetes: the DiaTel randomized controlled trial. *Diabetes Care, 33*(3), 478-484.

Storni, C. (2014). Diabetes self-care in-the-wild. *Information Technology & People, 27*(4), 397-420.

Strauss, A. L., & Corbin, J. (1998). *Basics of qualitative research: Grounded theory procedures and techniques* (2nd ed.). Thousand Oaks, California, US: SAGE.

Stuckey, H. L., Olmsted, T., Mincemoyer, R. S., & Gabbay, R. A. (2012). What do people with diabetes talk about on a diabetes social networking web site? *Journal of Diabetes Science and Technology, 6*(3), 716-717.

Swan, M. (2012). Health 2050: The realization of personalized medicine through crowdsourcing, the quantified self, and the participatory biocitizen. *Journal of Personalized Medicine, 2*(3), 93-118.

Tessier, S. (2012). From field notes, to transcripts, to tape recordings: Evolution or combination? *International Journal of Qualitative Methods, 11*(4), 446-460.

Thackeray, R., Neiger, B., Hanson, C., & McKenzie, J. (2008). Enhancing promotional strategies within social marketing programs: Use of web 2.0 social media. *Health Promotion Practice, 9*(4), 338-343.

Thoolen, B. J., de Ridder, D., Bensing, J., Gorter, K., & Rutten, G. (2009). Beyond good intentions: The role of proactive coping in achieving sustained behavioral change in the context of diabetes management. *Psychology & Health, 24*(3), 237-254.

Trief, P. M., Izquierdo, R., Eimicke, J. P., Teresi, J. A., Goland, R., Palmas, W., Shea, S., Weinstock, R. S. (2012). Adherence to diabetes self care for white, African-American and Hispanic American telemedicine participants: 5 year results from the IDEATel project. *Ethnicity & Health, 18*(1), 83-96.

van der Eijk, M., Faber, M. J., Aarts, J. W., Kremer, J. A., Munneke, M., & Bloem, B. R. (2013). Using online health communities to deliver patient-centered care to people with chronic conditions. *Journal of Medical Internet Research, 15*(6):e115. doi:10.2196/jmir.2476.

van Dijck, J. (2014). Datafiction, dataism and dataveillance: Big data between scientific paradigm and secular belief. *Surveillance & Society, 12*(2), 197-208.

Visser, L. M., Bleijenbergh, I. L., Benschop, Y. W., Van Riel, A. C., & Bloem, B. R. (2016). Do online communities change power processes in healthcare? Using case studies to examine the use of online health communities by patients with Parkinson's disease. *BMJ Open, 6*(11):e012110. doi:10.1136/bmjopen-2016-012110.

Vorderstrasse, A., Lewinski, A., Melkus, G. D., & Johnson, C. (2016). Social support for diabetes self-management via eHealth interventions. *Current Diabetes Reports, 16*(7), 56.

Wagner, J., Tennen, H., & Wolper, H. (2012). Continuous glucose monitoring: a review for behavioral researchers. *Psychosomatic Medicine, 74*(4), 356-365.

Wasko, M., & Faraj, S. (2005). Why should I share? Examining social capital and knowledge contribution in electronic networks of practice. *MIS Quarterly, 29*(1), 35-57.

Weinstein, R. S., Lopez, A. M., Joseph, B. A., Erps, K. A., Holcomb, M., Barker, G. P., & Krupinski, E. A. (2014). Telemedicine, telehealth, and mobile health applications that work: Opportunities and barriers. *The American Journal of Medicine, 127*(3), 183-187.

Whittemore, R., Jaser, S. S., Faulkner, M. S., Murphy, K., Delamater, A., Grey, M., & TEENCOPE Research Group. (2013). Type 1 diabetes eHealth psychoeducation: Youth recruitment, participation, and satisfaction. *Journal of Medical Internet Research, 15*(1):e15. doi:10.2196/jmir.2170.

WHO. (2011). *MHealth: New horizons for health through mobile technologies: Second global survey on eHealth, global observatory for eHealth series.* Geneva: WHO Press.

WHO. (2011). *Use of glycated haemoglobin (HbA1c) in the diagnosis of diabetes mellitus.* Geneva: WHO Press.

Wortman, C. B., & Lehman, D. R. (1985). Reactions of victims to life crisis: Support attempts that fail. In I. G. Saranson, & B. R. Saranson (Eds.), *Social support: Theory, research and applications* (pp. 463-489). Boston: Martinus Nijhoff Publishers.

Yan, L., & Tan, Y. (2014). Feeling blue? Go online: An empirical study of social support among patients. *Information Systems Research, 25*(4), 690-709.

Yan, L., Peng, J., & Tan, Y. (2015). Network dynamics: How can we find patients like us? *Information Systems Research, 26*(3), 496-512.

Yan, Z., Wang, T., Chen, Y., & Zhang, H. (2016). Knowledge sharing in online health communities: A social exchange theory perspective. *Information & Management, 53*(5), 643-653.

Yarbrough, A. K., & Smith, T. B. (2007). Technology acceptance among physicians: A new take on TAM. *Medical Care Research and Review, 64*(6), 650-672.

Zhang, Y., He, D., & Sang, Y. (2013). Facebook as a platform for health information and communication: Acase study of a diabetes group. *Journal of Medical Systems, 37*(3), 9942.

Ziebland, S. (2004). The importance of being expert: The quest for cancer information on the Internet. *Social Science and Medicine, 59*(9), 1783-1793.

# APPENDICES

## A. ONLINE SURVEY FOR SAMPLING FRAME (IN TURKISH)

### Sürekli Glikoz Ölçüm Sistemleri

Merhabalar.

Sensör kullanıcılarının demografik özelliklerini öğrenmeyi amaçlayan bu ankete katılımınız için teşekkürler. Bu anket; tip 1 diyabetli bireylerin, gündelik hayat ve sensör kullanım deneyimleri hakkında Orta Doğu Teknik Üniversitesi Endüstri Ürünleri Tasarımı Bölümü yüksek lisans öğrencisi Sezgi Kaya tarafından, Dr. Öğr. Üy. Harun Kaygan danışmanlığında yürütülen tez çalışmasının hazırlık aşamasını oluşturmaktadır. Anketi tamamlama süresi yaklaşık 3 (üç) dakikadır. Bu çalışma gönüllülük esasına dayanmaktadır. Paylaştığınız bilgiler yalnızca araştırmacı ve tez danışmanı tarafından görülecek, üçüncü şahıslarla paylaşılmayacaktır. Anket hakkında merak ettikleriniz ve görüşleriniz için araştırmacı ile iletişime geçebilirsiniz.

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Ankete başlamak için lütfen geçerli bir e-posta adresi belirtiniz.

E-posta adresi:

**1. Katılımcı Bilgileri**

İsim veya Rumuz:

İletişim numarası (tercihe bağlı):

Katılımcı profiliniz

☐ Tip 1 Diyabetli Birey
☐ Tip 1 Diyabetli Yakını

2. Kişisel Bilgiler

(Eğer tip 1 diyabetli yakınıysanız, lütfen aşağıdaki soruları, tip 1 diyabetli kişinin bilgilerini içerecek şekilde yanıtlayınız)

Cinsiyetiniz:

Yaşınız:

Yaşadığınız Şehir:

Ne kadar zamandır tip 1 diyabet ile yaşıyorsunuz?

Ne kadar zamandır sensör kullanıyorsunuz?

☐ Sensör kullanmıyorum.
☐ 3 aydan az
☐ 3 ay – 1 yıl
☐ 1 yıl – 3 yıl
☐ 3 yıldan fazla

Hangi marka sensör kullanıyorsunuz?

☐ Sensör kullanmıyorum.
☐ Dexcom
☐ Medtronic Guardian Connect
☐ Medtronic Enlight G2 Link
☐ Abbot FreeStyle Libre
☐ Diğer:

### 3. Tip 1 Diyabet Tecrübeleri Grubu

Ne kadar zamandır Tip 1 Diyabet Tecrübeleri grubuna üyesiniz?

Tip 1 Diyabet Tecrübeleri grubunu hangi sıklıkla ziyaret ediyorsunuz?

☐ Her gün
☐ Haftada 3 kez ve üzeri
☐ Haftada 1 kez
☐ Yalnızca gönderi paylaştığımda
☐ Diğer:

### 4. Çalışma Katılım İzni

Yürütülen çalışmanın ileri aşamalarında gerçekleştirilecek mülakata katılmak üzere, araştırmacı Sezgi Kaya'nın yukarıdaki iletişim bilgileri aracılığıyla benimle iletişime geçmesine izin veriyorum.

☐ Evet
☐ Hayır

# B. INTERVIEW GUIDE (IN TURKISH)

**Adı Soyadı:**

**Tarih:**

**Saat:**

☐ Bilgilendirme

☐ Rıza Formu

☐ Ekstra süre izni

**1. Demografik Sorular**

- Yaşınız?
- Mesleğiniz?
- Son zamanlarda diyabetle ilgili herhangi bir doktor/hastane ziyareti yaptınız mı?
    - Ne zaman? Sebebi? Sonuçlar nasıldı?

**2. Diyabet Hikayesi**

- Diyabetli olduğunuzu ne zaman ve nasıl öğrendiniz?
- Ailenizde diyabet geçmişi var mı?
- Diyabetli olduğunuzu öğrendiğinizde ne hissettiniz?
- Diyabetli olduğunuzu çevrenizle paylaştınız mı?
    - Ne zaman paylaştınız?
    - Nasıl tepkiler aldınız?
- Doktorlar diyabetteki en kritik süreçlerden birinin hastalığın kabulü olduğunu söylüyorlar. Siz diyabeti nasıl kabullendiniz?
    - Ne gibi zorluklar yaşadınız?
    - Bu süreçte size kimler / neler yardımcı oldu?
- Diyabetle birlikte hayatınızda neler değişti?
    - Beslenme rutinleri
    - Spor rutinleri, vs.

- Doktorların görüşlerine göre kan şekerinin takibi de kritik olarak görülüyor. Bu süreci nasıl yönetiyorsunuz? (Şeker ölçüm rutinleri)
    - Günde kaç defa ölçüm yapıyorsunuz?
    - İlk zamanlardaki ve şu anki ölçüm sayısında bir fark var mı?
    - Ölçüm sayısı nasıl belirleniyor? Neye göre değişiyor?
    - Ne zaman / Nerede / Nasıl ölçüm yapıyorsunuz?
- İnsülin yapma rutinleri
    - Günde kaç defa insülin yapıyorsunuz?
    - İnsülin miktarı neye göre belirleniyor? Değiştiği durumlar oluyor mu?
    - Ne zaman / Nerede insülin yapıyorsunuz?
    - Yanınızda taşıyor musunuz? Nasıl?
    - Vücuda uygulama bölgeleri ve tercih sebebi?
- Diyabetle yaşamı nasıl tanımlarsınız?
    - Zorlandığınız zamanlar? Ne zaman? Neden?
    - Ne kadar sürdü? Nasıl atlattınız?
    - Yardım aldınız mı? … size yardımcı oldu mu?

### 3. Cihaz Kullanımı

- Şu an hangi cihazı / cihazları kullanıyorsunuz?
    - 1'den fazla cihaz kullanıyorsa, sebebi?
    - Cihazlar arasındaki farklar?
- İki cihaz arasındaki ölçüm değerleri farklıysa ne yapıyorsunuz?
    - Hangisine güveniyorsunuz? Nasıl karar veriyorsunuz?

### 3.1 Glukometre Kullanımı

- Ne kadar süredir kullanıyorsunuz?
    - Marka bilgisi, eğer cihaz değiştirdiyse sebebi?
    - Cihazı satın alma motivasyonları? Nasıl haberdar oldu? Eğer tavsiye üzerine aldıysa, kim önerdi?
- Cihaz kullanmayı nasıl öğrendiniz?
    - Kim gösterdi? Hangi kaynak?
- Cihaz kurulumu nasıl gerçekleşti?
    - Hangi kaynaklardan faydalandınız? Ör. Kullanım kılavuzu
- Öğrenme aşamasında herhangi bir sorun yaşadınız mı?
    - Sebebi? Nasıl çözdünüz?
- Cihaz kullanım pratikleri
    - İç mekanlar (ev, iş. vb.)
        - Nerede / Ne zaman / Nasıl / Ne sıklıkla ölçüm yapıyorsunuz?
    - Dış mekanlar (kafe, ulaşım halinde, vb.)
        - Ev dışında ölçüm yapıyor musunuz? Nerede / Ne zaman / Nasıl / Ne sıklıkla?
- Beklenmedik durumlar yaşadınız mı? (Ör. Strip bitmesi, insülin bitmesi, vb.)
    - Ne oldu? Nasıl çözdünüz?
- Cihazla ilgili herhangi bir sorun yaşadınız mı?
    - Sorun? Nasıl çözdünüz? Yardım aldınız mı?
    - Bu sürecin size bir katkısı oldu mu?
- Cihazla ilgili genel deneyim
    - Olumlu / olumsuz özellikleri?
    - Neyi değiştirmek isterdiniz? Neden?

## 3.2 Sensör Kullanımı

- Sürekli Glikoz Takip Sistemi cihazlarından nasıl haberdar oldunuz?
  - Kaynaklar?
- Sensör / İnsülin pompası kullanmaya nasıl karar verdiniz?
  - Nasıl haberdar oldunuz? Tavsiye üzerine karar verdiyse, kim önerdi?
  - Motivasyonlar
  - Karar verme kriterleri
- Ne kadar süredir sensör / insülin pompası kullanıyorsunuz?
  - Hangi marka? Bilgi kaynağı? Tercih etme nedenleri?
  - Hiç cihaz değiştirdiniz mi? Neden?
- Cihazı kullanmayı nasıl öğrendiniz?
  - Yardım aldınız mı? Kaynaklar?
  - Zorluk yaşadınız mı? Sebebi? Nasıl çözdünüz?
- Cihazın genel özellikleri nelerdir?
- İlk kullanım deneyimi
  - Kurulum, kutu içeriği
  - Kullanım bilgisi
  - Kılavuzu okudunuz mu?
  - Sensörü giyme (deri altına yerleştirme)
  - Sensör ve cihazı eşleştirme
  - İlk ölçüm / insülin gönderme
  - Veri okuma (grafikler vs.)
  - Verilerin saklanması / paylaşımı
- Ölçüm yapımı / insülin gönderimi
  - Nerede? (İç-dış mekân, seyahatler, vb.)
    - Nasıl karar veriyorsunuz?
  - Ne zaman? Ne sıklıkla?
  - Değişiklikler? Sebebi?

- Taşınabilirlik
    - Yanınızda cihazla ilgili neler taşıyorsunuz? Nerede / Nasıl?
- Cihazla ilgili herhangi bir sorun yaşadınız mı?
    - Ne oldu? Nasıl çözdünüz? Yardım aldınız mı?
- Beklenmedik durumlar
    - Örneğin, cihazda bilmediğiniz bir hata oluştu. Ne yapardınız?
- Cihazla ilgili genel deneyim
    - Memnun musunuz? Neden?
    - Olumlu özellikler
    - Olumsuz özellikler
    - Neyi değiştirmek isterdiniz? Neden?
- Sensör / İnsülin pompası kullanmaya başladıktan sonra hayatınızda neler değişti?
- Cihazı kullanmaya başlarken beklentileriniz nelerdi?
    - Cihaz bu beklentilerinizi karşıladı mı?
- Sensör kullananlar için: Glukometre ve sensörü karşılaştırdığınızda, neler söyleyebilirsiniz?
- Pompa kullananlar için: İnsülin iğnesini ve pompayı karşılaştırdığınızda neler söyleyebilirsiniz?
- Cihazı herhangi birine tavsiye eder miydiniz? Neden?
    - Tavsiyeniz üzerine kullanmaya başlayan oldu mu? Memnunlar mı?

### 4. Diyabet ve Gündelik Hayat

- Diyabeti nasıl tanımlarsınız?
- Diyabetle tanıştıktan sonra hayatınızda neler değişti?
    - Gündelik rutinler
    - Zorluklar
    - Çevrenin tepkisi
    - Sorumluluklar

- Hiç kısıtlanmış hissettiniz mi?
    - Hangi konuda? Neden?
    - Üstesinden nasıl geldiniz?
- Gündelik hayat
    - Bana bir gününüzün nasıl geçtiğini anlatır mısınız? Diyabet bu anlattıklarınızın neresinde duruyor?
- Beslenme rutinleri
    - Diyabet sonrasında beslenmeniz nasıl etkilendi?
    - Yememeniz gereken bir şeyi yediğiniz oluyor mu? Neden?
- Egzersiz rutinleri
    - Diyabetten önceki egzersiz rutinleriniz? Diyabetin etkileri?
    - Diyabet ve egzersiz ilişkisi
- Şeker ölçüm rutinleri
    - Ne zaman? Nerede? Mekân tercih sebepleri?
    - Nasıl ölçüm yaptığınızı gösterir misiniz?
    - Ölçüm yapmadığınız oluyor mu?
        - Sebebi?
        - Nasıl hissediyorsunuz? Sonuçları neler?
- İnsülin yapma rutinleri
    - İnsüline ne zaman ihtiyaç duyuyorsunuz?
    - Nasıl ve nerede yapıyorsunuz? Mekân tercih sebepleri?
    - Yanınızda insülin taşıyor musunuz? Nasıl?
    - Acil bir durumda insülininiz yoksa ne yaparsınız?
- Sensör / İnsülin pompası kullanmaya başladıktan sonra gündelik hayatınızda değişen bir şey oldu mu? Neler?
- Sensör / insülin pompası kullanımı ile ilgili çevrenizin yaklaşımı nasıl?
    - İşlev
    - Görsel algı

## 5. Online Diyabet Toplulukları

- Tip 1 Diyabet Tecrübeleri grubu ile ne zaman ve nasıl tanıştınız?
- Toplulukla ilgili ilk izlenimleriniz nelerdi?
    - Grup oluşumu hakkında ne düşünüyorsunuz?
- Facebook grubunu ne sıklıkla ziyaret ediyorsunuz?
    - Grubu hangi amaçla kullanıyorsunuz?
- Grupta paylaşım yapıyor musunuz?
    - Ne hakkında?
    - Hiç yardım amaçlı paylaşımda bulundunuz mu?
    - Genellikle hangi paylaşımlar ilginizi çekiyor?
- Acil durumlarda diyabet yönetimi ile ilgili yapılan öneri paylaşımları hakkındaki düşünceleriniz neler?
- Grupta paylaşılan bilgilerin doğruluğundan nasıl emin oluyorsunuz?
    - Grupta yanlış bilgi paylaşılması gibi bir duruma şahit oldunuz mu?
- Gruptaki kişilerle iletişim içinde misiniz?
    - Reel hayatta tanışıp görüştüğünüz insanlar oldu mu?
- Sizce grubun diyabet yönetimi üzerindeki etkileri neler?
- Sizce grubun diyabet teknolojilerinin bilinirliği üzerindeki etkileri neler?
- Başka insanlara gruptan bahsettiğiniz oldu mu?
    - Tepkileri ne oldu? Örneğin; sizin aracılığınızla gruba üye olan birisi oldu mu?
- Bu grup ile tanışmanız sizi nasıl etkiledi?
- Gruptan beklentileriniz neler?
- Grupla ilgili sizi hayal kırıklığına uğratan veya elinizde olsa değiştirmek isteyeceğiniz bir şey var mı?

# C. CONSENT FORM (IN TURKISH)

## Araştırma Gönüllü Katılım Formu

Bu çalışma, Orta Doğu Teknik Üniversitesi, Endüstri Ürünleri Tasarımı Bölümü yüksek lisans öğrencisi Sezgi Kaya'nın tez çalışması kapsamında yürütülmektedir. Çalışmanın amacı doğrultusunda, Tip 1 Diyabet Tecrübeleri Grubu üyelerinin gündelik hayat ve sensör kullanım deneyimleri hakkında anket çalışması gerçekleştirilmiştir. Çalışmanın devamında grubun üyeleriyle yüz yüze mülakat gerçekleştirilmesi gerekmektedir.

Çalışmaya katılım gönüllülük esasına dayanmaktadır. İstediğiniz anda çalışmadan ayrılabilirsiniz. Çalışmadan ayrılmanız durumunda sizden toplanan veriler çalışmadan çıkarılacak ve imha edilecektir.

Mülakatlar için öngörülen süre yaklaşık bir saattir. Mülakat yeri ve tarihi, katılımcılarla ortaklaşa belirlenecektir.

Araştırma kapsamında toplanan verileri yalnızca araştırmacı ve tez danışmanı görecek, veriler üçüncü kişilerle kesinlikle paylaşılmayacaktır. Veriler sadece bilimsel amaçlar doğrultusunda yayın ve sunumlarda kullanılacak; bu yayın ve sunumlarda kimliğiniz tamamen gizli tutulacaktır.

Araştırma kapsamında röportaj boyunca ses kaydı tutulacak ve üzerine konuşulan ürünlerin fotoğrafları çekilecektir.

Herhangi bir sorunuz olması durumunda, araştırmacı tarafından mülakat esnasında ya da sonrasında ivedilikle cevaplandırılacaktır.

İlginiz ve desteğiniz için teşekkür ederim.

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İstediğim takdirde çalışmadan ayrılabileceğimi, verdiğim bilgilerin sadece bilimsel amaçlarla kullanılacağını ve kimliğimin gizli kalacağını anladım. Bu çalışmaya tamamen kendi rızamla ve bu koşullarda katılmayı kabul ediyorum.

**Katılımcı Ad ve Soyadı:**

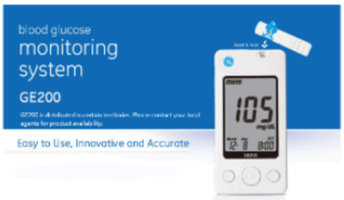
**İmza:**

**Tarih:**

## D. PRODUCT MATRIX

| | ***Product*** | ***Image*** | ***Description*** | ***Target User & Environment*** |
|---|---|---|---|---|
| ***PT-INR Testing*** | Siemens Hemochron Signature Elite |  | The Hemochron Signature Elite is a coagulation monitoring system. Regardless of sample type or clinical setting, it provides fast, accurate and reproducible results for clinical decision making. It is easy to learn and use, and measures to the laboratory standard of fibrin formation. | Health Consumers& Healthcare Professionals |
| | Alere In Ratio Series |  | Alere InRatio2 PT/INR Monitoring System combines reliable results with practical convenience, making it an excellent solution for anticoagulation patient management in professional medical practice and patient home testing. | Health Consumers& Healthcare Professionals |
| | Coag-Sense® Prothrombin Time (PT)/INR Monitoring System |  | The Coag-Sense® meter directly measures clot formation, so the time required to perform a test is the actual prothrombin time in seconds. After each test, patients notify their physician of the results and the physician will determine if any treatment adjustments are required. The goal of self-monitoring PT/INR levels is to improve control and reduce the potential for adverse events. | Health Consumers & Indoors-Outdoors |
| | iLine MicroINR |  | The microINR test meter using capillary blood to determine INR levels. It also offers the best qualities for a portable INR testing device: no buttons to be pressed during testing, automatic strip identification, minimum sample volume and easy-to-use design. | Health Consumers& Healthcare Professionals |

|  | ***Product*** | ***Image*** | ***Description*** | ***Target User & Environment*** |
|---|---|---|---|---|
| ***PT-INR Testing*** | Siemens Xprecia Stride Coagulation Analyzer |  | Xprecia Stride Coagulation Analyzer that test PT/INR with a small sample (blood) volume USB port sends and receives patient results. Barcode scanner enters IOT calibration information and operator and patient IDs. | Healthcare Professionals & Hospitals |
|  | Roche CoaguCheck INRange System |  | CoaguChek INRange is a self-testing meter that enables patients to test their PT/INR. Built-in wireless, Bluetooth technology allows physicians to be connected to the patients, who can transmit their results from device to the doctors. | Health Consumers & Indoors-Outdoors |
|  | Roche CoaguCheck XS |  | CoaguChek® XS system is a portable instrument for monitoring oral anticoagulation therapy. It determines the INR value (International Normalized Ratio) from a drop of capillary whole blood. | Health Consumers & Indoors-Outdoors |
| ***Blood Glucose Testing*** | Ascensia Contour Next One |  | By integrating blood glucose (BG) meter with a smartphone app, Contour Next One simplifies the management of diabetes. BG results captured throughout the day can be automatically synced and logged. | Health Consumers & Indoors-Outdoors |
|  | Abbot FreeStyle Libre |  | FreeStyle Libre is a FGM system. Scan the sensor worn on the body with the reader for results in a second. Each scan gives current glucose reading, a view of the last 8 hours and shows the anticipated glucose change. | Health Consumers & Indoors-Outdoors |
|  | Dexcom G5 Mobile CGM System |  | The Dexcom G5 CGM System provides real-time glucose readings for patients with type 1 or type 2 diabetes every five minutes. With Dexcom G5 Mobile, dynamic glucose data can be accessed and shared safely to smart devices. | Health Consumers & Indoors-Outdoors |

| | ***Product*** | ***Image*** | ***Description*** | ***Target User & Environment*** |
|---|---|---|---|---|
| ***Blood Glucose Testing*** | Abbott FreeStyle Optium Neo |  | Xprecia Stride Coagulation Analyzer that test PT/INR with a small sample (blood) volume USB port sends and receives patient results. Barcode scanner enters IOT calibration information and operator and patient IDs. | Health Consumers & Indoors-Outdoors |
| | BodyTel GlucoTel Blood Glucose Meter B2B Services |  | BodyTel is a German Teleahealth Company and offer products and services for patients as well as solutions and services for the medical industry. Their glucose meter called GlucoTel is supported with BodyTel glucose app that creates a remote and mobile controlling system for people with diabetes. | Health Consumers & Healthcare Professionals |
| | Johnson & Johnson One Touch Flex |  | ColorSure™ technology instantly shows when blood sugar numbers are in or out of range. Compact, slim design. Syncs data with OneTouch Reveal® mobile app. Color display and illuminated test strip port for testing in the dark. | Health Consumers & Indoors-Outdoors |
| | Roche Accu-Check Series |  | The Accu-Chek Glucose Meters provide advanced accuracy, for reliable test results. Small, sleek design fits in the palm of people's hands, and backlit display makes reading numbers easy. Some models also have mobile phone integration that means the results are directly send to people's phone to be tracked and stored easily. | Health Consumers & Indoors-Outdoors |
| | General Electric GE200 |  | Eliminates the needs for manual coding and delivers better accuracy. Larger, thicker test strips help with dexterity issues. The side-insert design ensures better hygiene. Utilize gold electrodes and a patented strip structure to provide highly accurate and reliable results in 5 seconds. | Health Consumers & Indoors-Outdoors |
| | TelCare EcoSystem |  | Right after each test, patients receive personalized, contextual messaging. In response to specific levels of blood sugar readings, triggered messages can be automatically generated. Custom messaging tool lets clinicians send individual messages to the meter, a cellphone, or email address. all designed to provide | Health Consumers & Indoors-Outdoors |

| | ***Product*** | ***Image*** | ***Description*** | ***Target User & Environment*** |
|---|---|---|---|---|
| ***Blood Glucose Testing*** | iHealth Smart Wireless Glucocose Monitoring System |  | iHealth Smart adds a digital twist to conventional glucometers. Its app becomes al logbook that presents the data in simple and easy to understand ways such as color-coded data, charts, and graphs. All readings are also stored in brand's cloud. Users have the option to export results as an Excel, PDF, or CSV file and send it to their healthcare provider. | Health Consumers & Indoors-Outdoors |
| ***Air Flow Meters*** | AeroCrine Niox Vero |  | NIOX VERO® is a point-of-care device for assessing airway inflammation in patients with respiratory problems such as asthma. | Healthcare Professionals & Hospitals |
| | Respiri AirSonea |  | AirSonea device connects via Bluetooth® to the app, which provides asthma management diary features; medication usage and reminders, and symptoms and triggers to help asthma sufferers gain a better understanding of how their condition affects them. | Health Consumers & Indoors-Outdoors |
| | SpiroBank Smart Smartone |  | MIR Spirobank®Smart is ideal for monitoring respiratory illness and in the self-management of Asthma, COPD, Lung Transplants care, Cystic Fibrosis and for use in Clinical Trials. Ultra-portable, Real Time test via Bluetooth (BLE) connection. | Health Consumers & Indoors-Outdoors |
| | Minispir SpiroBank 2 Spirolab |  | Spirolab is a multitasking and versatile spirometer ideal for accurate and early diagnosis of respiratory diseases (like COPD and Asthma). Easy to use for family doctors screening or pharmacy quick tests. All in one portable Desktop Spirometer with Oximetry option and available with adult / pediatric finger probe. | Healthcare Professionals & Hospitals |
| | Inofab SpiroHome |  | Spirohome is a personal spirometer designed for asthma, COPD and cystic fibrosis patients along with health enthusiasts who want to be aware of their lung condition. Spirohome enables patients to monitor their disease and prevents attacks while avoiding unnecessary hospital visits. | Health Consumers & Indoors-Outdoors |