“What can I eat?”

Designing to support diabetes self-management in Mitchells Plain, South Africa

Lone Lægreid & Ingrid Smørgrav Viddal

Master Thesis
Informatics: design, use, interaction
120 credits

Department of Informatics
The Faculty of Mathematics and Natural Sciences

The UNIVERSITY OF OSLO

May 2018

Abstract

This thesis presents a research process aimed at understanding the struggles people in a resource-poor setting face with having diabetes type 2. The objective is to propose an appropriate design aimed at helping people achieve diabetes self-management.

In this thesis we present our understanding of the needs of patients in Mitchells Plain. To support our analysis, we use Amartya Sens capability approach (1999) as a lens to understand the personal, environmental and social factors that influence the capability to lead a diabetes-friendly life. Further, we expand the capability framework to include the aspect of automatic and reflective motivation to help us understand how we can build and support diabetes self-management abilities.

Based on this, we propose a method for supporting diabetes-self management by focusing on providing tools for community health workers to facilitate support for the patients during home-visits. We contribute with suggestions of how to design tools that address motivation and diabetes-self managing, and that function as a resource for action, based on the theory of plans and situated action, by Lucy Suchman (1987). Thus, the design suggestions in this thesis serve as examples of methods we have used to inform our design. The aim is for the design-examples to serve as inspiration for health workers and other designers to create adaptations for their own contexts, or as inspiration to create new ideas.

Acknowledgements

We feel lucky to have so many great people around us, that have supported us throughout the work of this thesis. Many thanks shall be given.

First of all, we would like to thank our supervisor Hanne Cecilie Geirbo. Thank you for all the guidance, encouragement and fun conversations throughout this experience. Also, we would like to thank Tone Bratteteig for your guideance and inspiring discussions about theory and design, and Jens Kaasbøll for your guidance and support.

We owe a huge thanks to all the interesting, helpful and inspiring people we met in Cape Town. Thank you Verona, for assistance on our research proposal, and for making us feel at home in Cape Town. Thank you Gavin, for sharing your knowledge, answering questions, showing us cape town, helping us find contacts, and for introducing us to your lovely family. Thank you Gaynor, Nola and all the other marvelous women from Arisen Women. And not least, thank you Neal, our new hero, for all your help and inspiration. Your work, wisdom, kindness and empathy is endlessly admirable and we can only hope this thesis is of use to the clinic, and the Mitchells Plain community. We would also like to thank all the great people we have talked to in the Mitchells Plain community, especially all the people who shared their stories and homes with us. We will always remember your warm greetings, wonderful life spirit, and your care for each other.

Further, we would like to thank our great team of fellow students. This process would never have been the same without you. A special thanks to Øyvind, Mathias, Magnus and Ingeborg, Elin and Kenneth who gave us feedback along the way. To our girls, Oda, Veronica and Pernille, this thesis would never have been the same without your encouragement, fun talks and great sense of humor. We value the friendship we share deeply.

Family and friends, thank you for being patient with us, we promise to never be as isolated in our own work again. A special thanks to our partners Jon Magnus and Torgrim being the best support we could have had. We are thankful that you waited for us while we were away, and that you (somehow) continued to like us through the ups and downs that writing a master thesis brings along.

Last, but not least, a huge thank to each other for sticking through to the end. Even the days we didn't eat enough food our friendship remained as strong as ever.

Table of Contents

List of Figures

List of Tables

1 Introduction

The user-centered design tradition aims to support people in achieving their goals, to delight and to excite people. In some cases, this might entail simplifying work-processes, or make engaging solutions to a person's private life. In other cases, it might mean trying to solve bigger problems. Wicked problems. Problems that surround us, have many sources and not only one right answer. In this thesis, we frame diabetes type 2 as a wicked problem, and explore how we can design to strengthen diabetes self-management in a resource poor setting.

1.1 Motivation

Recent decades, we have experienced a rise of non-communicable diseases . These are lifestyle diseases, disproportionately affecting the poorer communities of the world. Lifestyle diseases like diabetes type 2 offers no simple solutions as opposed to communicable diseases that can be defeated by medicine or vaccines. From a health management perspective, managing the diabetes epidemic is therefore not as much about finding a cure or distributing vaccines, as it is about addressing individual and cultural factors that make up the way we live, the recipes we cook, the food we buy and how we use our bodies. If the affected individual does not change her lifestyle, serious and life-altering complications may occur.

Diabetes has in fact become one of the most significant challenges to public health globally, with over 400 million known cases. Further, it is estimated that 90% of all cases of diabetes, are diabetes type 2 (World Health Organization, n.d.). The International Diabetes Federation estimates that the number will rise to 592 million by 2035. (International Diabetes Federation, 2017). In comparison, the number of known diabetes cases was 108 million in 1980. This rapid rise is the reason why several health organizations, such as the World Health Organization, and International Diabetes Federation characterize diabetes type 2 and other lifestyle diseases as an epidemic (International Diabetes Federation, 2017).

Type 2 diabetes is the type of diabetes that is lifestyle induced and hence is preventable and curable by eating healthier and becoming more active. While this may seem simple, changing one's lifestyle remains a difficult task for many individuals, and success is dependent upon fiscal and environmental resources and requires knowledge, guidance, and motivation. To build on this, we know that the highest prevalence of diabetes (79%) are in low- and middle-income countries (International

Diabetes Federation, 2017). As the most rapid spread of diabetes is happening in low and middle-income countries, we believe it is crucial for management of diabetes to research ways to turn this negative trend by looking to those who are most at risk and has the least resources to handle the disease.

This research is conducted in Mitchells Plain, a sub-district in Cape Town in South Africa. Mitchells Plain is an example of an area that is deeply affected by increased levels of diabetes type 2. This is an area characterized by low educational levels, low income level and high crime rates. Our motivation for this research lies in the opportunity to gain insight into what it is like to live with, and manage, diabetes in a context where living-conditions can sometimes be extreme. Further, we wish to research if and in what ways user-centered design can contribute to help people in Mitchells Plain manage their disease.

1.2 Knowledge and Research Context

This thesis is written with the two research groups *Design* and *Information Systems* at the University of Oslo. It is based on a total of thirteen weeks fieldwork in Cape Town, South Africa.

Based on a collaboration between the University of Western Cape and the University of Oslo. The final research context, and the choice to focus on diabetes type two emerged through the initial three-week preliminary field study we conducted in the beginning of 2017. Here we learned that one of the leading health challenges the city face are lifestyle diseases such as diabetes type 2. We had the opportunity to get to know and work closely with Mitchells Plain Community Health Clinic (hereby referred to as Mitchells Plain CHC) who at the moment are working out new strategies to cope with the burden of disease in the area.

The empirical data for this thesis was collected in the Mitchells Plain sub-district of Cape Town, where we have been working with Mitchells Plain CHC and a non-governmental organization (NGO) called Arisen Women. Arisen Women is a group of community health workers (CHWs) who provide home-based care services for sick people, and support for their vulnerable family members. Arisen Women and Mitchells Plain CHC is connected through a pilot-project for *community oriented primary care* (COPC) that is a strategy to decentralize care, by letting Arisen Women bringing public health care in to the homes in the community.

1.3 Research Questions

The goal of this research is to contribute to the understandings of how technology might make a positive difference when dealing with the diabetes epidemic. During our preliminary fieldwork in Cape Town, we learned that lifestyle diseases were a burden for the healthcare providers and the urban population, especially those in the lower-income contexts in Cape Town. The outset of this thesis is thus based on the need – identified by Mitchells Plain CHC – to find better ways to provide health assistance to their community.

Therefore, our research interest can be defined as such:

> *By looking at the struggles with having diabetes type 2 in Mitchells plain, the goal is to propose an appropriate design that will help people achieve diabetes self-management.*

The research interest was based on our preliminary fieldwork and functioned as our guiding focus during the main fieldwork. The research questions we have formulated below were reworked during the first weeks our fieldwork. Some weeks in to the main fieldwork we became familiar with the above-mentioned *community oriented primary care project* (the COPC-project) initiated at Mitchells Plain CHC, featuring community health workers through Arisen Women. As a result of learning more about the COPC-project, and the struggles faced by Mitchells Plain CHC and diabetes patients, it became apparent that community health workers could play a positive role in diabetes management.

After a process of learning, analysis and focusing, the research questions we answer in this thesis are formulated as such:

1) What are the needs of people living with diabetes type 2 in Mitchells Plain, and what are the design implications of these needs?

While our research interest remains the overarching goal of this thesis, the second research question represents the context of intervention we design for. Namely that of supporting CHWs in their work to facilitate diabetes self-management education and support in Mitchells Plain. Thus, our second research question is:

2) How can tools be designed to support community health workers with managing diabetes?

1.4 Chapters

This thesis is structured as follows:

In chapter 2 we present the background for our research. Here we provide a presentation of diabetes type 2 and of South Africa and Mitchells Plain. We end the chapter by looking at existing technology aimed to support diabetes.

In chapter 3 the conceptual framework for this thesis are presented. We start with looking at wicked problems, and how the theory may influence how design for a complex problem. Further, we present *the capability approach* provided by Amartya Sen, and end the chapter by presenting Lucy Suchmans theory of plans and situated actions.

In chapter 4 we present our methodology and state the methods we used to gather data from the participants. We end the chapter by describing ethical considerations.

In chapter 5 the empirical findings from the field work are presented. The aim of the chapter is to convey the multifaceted views on having and managing diabetes in Mitchells Plain.

In chapter 6 we present our analysis using Amartya Sens *capability approach* as a lens, however, as the capability approach does not account for lack of rationality in how people make choices, we expand the capability framework to include motivation.

In chapter 7 our design proposals are shown. The design proposals are meant to illustrate the value of appealing to both reflective and the automatic motivation, and to illustrate the method we propose for designing for the context of this case.

In chapter 8 we present our discussion on the thoughts and reasonings behind our design suggestion, and the ways our they are rooted in the theories we have used in this thesis.

In chapter 9 we seek to end the study by summarizing our findings and to answer our research questions. Additionally, we present contributions of this thesis.

2 Background

2.1 Diabetes

At its core, diabetes is a disease where the body struggles or fails to regulate blood glucose levels (often referred to as blood sugar levels). It comes in many forms, and the main classifications are diabetes type 1 and diabetes type 2. When talking to friends and family about diabetes, we have experienced that many people mix up diabetes type 1 and type 2. Because the two diseases are quite different, and this thesis regards type 2 diabetes, we will briefly clarify the difference between the two.

Diabetes type 1 is an autoimmune disease, where the pancreas does not produce insulin. That is why people with diabetes type 1 are dependent on insulin injections on a daily basis for the duration of their lifetime. The insulin regulates the amount of glucose in the blood stream. Therefore, the insulin dosages has to be calculated to match the amount of glucose that enters the body via the diet, and the amount of activity the person undertakes. Miscalculating the dosages can lead the blood glucose levels drop too low or too high. Cases where the blood glucose levels go beneath 3.6 are referred to as *hypoglycaemia*. This can have severe and fatal consequences, like loss of consciousness, seizures, or death (Medical doctor, personal communication, March 19, 2018; Harvey & Ferrier, 2011).

With Diabetes type 2, the insulin production is relatively functional. The problem is that the cells that store glucose have become resistant to insulin. The disease evolves over time, mainly in patients that are 40 years or older. But, during the past years, it is common that people in the 30s and even 20s, develop the disease. This is connected to overweight and obesity in the population. In addition, diabetes type 2 is preventable, and in many cases reversible by changing lifestyle (Medical doctor, personal communication, March 19, 2018; Harvey & Ferrier, 2011).

Because this thesis lays within the field of technology and design, we will try to present a simplified version of diabetes type 2 and focus mainly on the need-to-know-facts. However, we wish for the reader to get a picture of all the facets of information the patient has to navigate when receiving the diagnose. Hence, our description will include an explanation of why people get diabetes, what happens in the body, and what the potential medical and lifestyle treatments are.

2.1.1 What is diabetes?

Diabetes is commonly known as *sugar-disease*, and the correct focus is on one component of sugar, *glucose*. The focus of the disease is to manage the patients' *blood glucose* levels. The mundane reference to diabetes as a sugar-disease may cause some misunderstandings. The problem doesn't lie with the level of sweetness in the food a person with diabetes eats, but with the levels of glucose that enters the bloodstream. Carbohydrates are the key food source that converts into glucose during digestion. In this simple explanation of diabetes, we first have to explain the roles of *glucose, insulin*, and *cells* where the glucose is used or stored.

Glucose is the body's principal source of energy and can be seen as fuel to the body. When we eat carbohydrates, the body converts this to glucose, and the glucose enters the bloodstream. From the bloodstream, it finds its way to *cells* in organs who need fuel (such as the brain and muscles), or to storage cells to be kept as a reserve (Medical doctor, personal communication, March 19, 2018; Harvey & Ferrier, 2011).

The *insulin's* function is to move the glucose to the cells mentioned above. Imagine insulin as being the key to a lock, where the lock is the storage cell or the cells in the organ that needs fuel. Without insulin, the glucose is not allowed passage and remains in the bloodstream. In a healthy body, the pancreas produces the right amount of insulin, and the receiving cells respond to every attempt the insulin makes at clearing the glucose out of the bloodstream. Common for bodies with either diabetes type 1 or diabetes type 2, is that the body struggles to clear the glucose out of the bloodstream, leading to a buildup over time (Medical doctor, personal communication, March 19, 2018).

In the figure below, the scale of ideal blood glucose levels are shown.

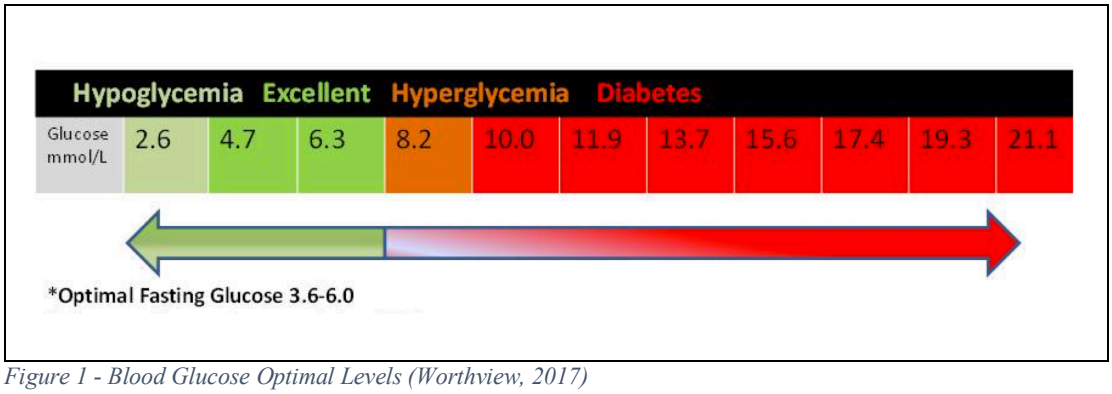

Figure 1 - Blood Glucose Optimal Levels (Worthview, 2017)

2.1.2 What is diabetes type 2

As we mentioned above, in bodies with diabetes type 2, the initial problem is not the insulin production. A combination of genetics and a lifestyle characterized by inactivity, overweight and poor eating habits, leads the cells that store or use glucose to become insulin-resistant. Nearly 90% of all diabetes type 2 incidents are connected to five major lifestyle factors: diet, physical activity, smoking, obesity and alcohol consumption. Genetics and family history also play an important role with diabetes type 2, but high body weight, physical inactivity and unhealthy diet is the primary cause (Medical doctor, personal communication, March 19, 2018; Harvey & Ferrier, 2011).

To explain how diabetes type 2 unfolds, we build on the key-and-lock-example above. In a body with diabetes type 2 the cells have become resistant to the insulin's tireless attempts at "unlocking their door" for the glucose. The increased insulin-resistance in the cell results in a build-up of excess glucose in the bloodstream (Medical doctor, personal communication, March 19, 2018; Harvey & Ferrier, 2011).

The symptoms and complications that follow diabetes type 2 are many. A person with diabetes type 2 can feel tired, experience frequent urination and are “unusually” thirsty. Over time, the high blood glucose levels will damage blood vessels and can lead to hardening of the arteries (this process is called *arteriosclerosis*), which in turn leads to the narrowing and dysfunction of the blood vessels (called *atherosclerosis*). This process leads to low blood circulation, meaning that the blood will circulate less oxygen and nutrients. The complications typically start in the smaller blood vessels that can be found in hands, feet and eyes. In addition, complications can affect the kidney (*nephropathy*) and the nervous system (*neuropathy*). The patient can experience a loss of feeling or sensation, impaired eyesight (*retinopathy*), and chronic pain. A common complication is diabetes *polyneuropathy*, where the patient loses the feelings in arms and legs. These complications evolve over time, as the high blood glucose levels creates damage. The more tangible results can be chronic soars, which further can lead to inflammation. In some cases, the patient might have to amputate. Diabetes also leads to higher risk of developing *ischemic strokes* and *coronary heart disease* (Medical doctor, personal communication, March 19, 2018; Harvey & Ferrier, 2011).

To state the obvious: diabetes complications can have severe effects on life quality. It is therefore important to regulate and treat the disease, to avoid late complications.

2.1.3 How is it treated?

The main treatment goal with diabetes type 2 is to increase insulin-sensitivity, and the most effective means to achieve increased sensitivity is through reducing calorie intake and the amount of adipose tissue (fat) in the body (Medical doctor, personal communication, March 19, 2018; Harvey & Ferrier, 2011).

Hence, intensive lifestyle changes are aimed at weight loss, and involves increased physical activity and change of diet. In addition, pharmacological interventions such as oral medicine can be added to delay the progression of diabetes (Chen, Magliano, & Zimmet, 2012). Yet, in many cases, diet and exercise can be sufficient treatments if the disease hasn't progressed too much (Medical doctor, personal communication, March 19, 2018; Harvey & Ferrier, 2011).

While medication can help, it is important to note that medication cannot do the job by itself. If the patient continues to "strain the system" by eating too big portions, too much fat or too much refined carbohydrates, the insulin resistance will hardly improve by medicine alone (Medical doctor, personal communication, March 19, 2018; Harvey & Ferrier, 2011). In addition, the effect of the medication will likely wear off. So, to be clear, treatment of diabetes type 2 is absolutely dependent on addressing the causes for obesity in the patient and moderating the diet.

There are two positive outcomes of exercise. The first is the potential to lose weight, the second is the potential to experience increased insulin sensitivity in the hours after an exercise (Borghouts & Keizer, 2000, p. 1).

In addition, the way different bodies regulate the blood glucose levels are not only affected by diet and exercise, but will also vary from individual to individual. This is based on factors like physiological differences, diseases, mental state, and stress-levels (Medical doctor, personal communication, March 19, 2018; Harvey & Ferrier, 2011).

In cases where blood sugar levels have remained uncontrolled and high over a long period of time, the pancreas tries to produce even larger amounts of insulin in an attempt to move more of the glucose out of the blood stream. This can cause the insulin-making cells (beta-cells in the pancreas) to be worn out and essentially stop or damage insulin-production. These beta-cells can in effect be damaged "beyond repair". In such cases, the patient with diabetes type 2 will become dependent on insulin-injections, in addition to the above-mentioned treatments (Medical doctor, personal communication, March 19, 2018; Harvey & Ferrier, 2011).

2.1.4 Diet advice

We would like to clarify some notions about a healthy diet, and the available advice. From what we have learned, advice about diet has two goals.

First, the goal is to avoid products that have a very high level of refined carbohydrates. These are typically chocolates and sweets, but also *fast-acting carbohydrates*, typically found in processed foods like one-minute-oats, pastries and white bread. These products release their glucose quickly during digestion, and lead to quick fluctuations in the blood glucose levels. Healthy alternatives are *complex carbohydrates* such as peas, beans, whole grains and vegetables. These are made up of *sugar molecules* that are strung together in long, complex chains, meaning they release energy more slowly (U.S. Department of Health and Human Services, 2018).

Second, the goal is to address the need to reduce weight (adipose tissue). In order to achieve weight loss, we need to address the reasons why a person is overweight. The main factor can be portion-sizes, too much carbs, too much fat, too little exercise, or a combination of these factors. For this reason, diet advice connected to diabetes type 2 diverges. Making a clear-cut rule-based diet that is simple to follow can be difficult. We see that advice ranges from low-carb/high-fat diets, to advocating a balanced diet (U.S. Department of Health and Human Services, 2018).

We do not claim to have the answer to what is right and wrong. The main takeaway from this section is that what to eat and not can be difficult to distill in to easy rules to follow. What we see is that it is easier to promote a balanced diet and focus on adding more vegetables, rather than trying to make rules of do's and don'ts. However, achieving a balanced diet requires more knowledge and more explaining. As such, pamphlets and learning material have a tendency to attempt to make rules.

2.1.5 Managing diabetes

Our research questions are formulated around the concept of diabetes management. In this section, we would like to clarify the meaning we ascribe to this phrase.

The phrase "diabetes management" is frequently used to refer to how the patient ideally should manage or cope with having diabetes. Most countries have official diabetes-organizations that publish diabetes management guidelines, to aid the patients' effort to control their disease.

In this thesis, we refer to "diabetes management" on a public health level. We look at the struggles health providers face in aiding their community with managing diabetes. Hence, diabetes management refers to the work health providers have to do to reduce diabetes prevalence and complications in their community.

When searching for variations over the phrase "managing diabetes" in google scholar, the majority of the literature reveals a clinical interpretation of what it means to manage diabetes. This approach implicitly targets existing patients and have a curative approach, meaning that the clinical approach ensures that diabetes management strategy follows the "best practice" related to treating the disease. The main focus in much of the literature has been on understanding the physiological phenomenon of how diabetes manifest in the body, and to uncover the "recipe" the body has to be put through to be declared "cured" of the disease.

While the curative focus is vitally important to understand in order to offer advice to diabetes patients, the "recipe" to follow does not happen without a context. It entails a lifestyle change to be carried out by the patients in the context of their daily lives. This context also plays a big part in the reasons why a person developed diabetes type 2 in the first place. Culture, knowledge and local constraints makes it more difficult to have a healthy lifestyle for some people, particularly among the urban poor (Bradley & Puoane, 2007).

For this reason, we opt to expand the focus of diabetes management to include the cultural and contextual aspects that enables the spread of diabetes, and that will have to be addressed in the diabetes management strategy. This entails taking a public health approach to managing the diabetes epidemic.

Winslow (1920) coined the most widely used definition of public health almost 100 years ago:

> *"Public health is the science and art of preventing disease, prolonging life and promoting physical health and efficacy through organized community efforts for the sanitation of the environment, the control of communicable infections, the education of the individual in personal hygiene, the organization of medical and nursing services for the early diagnosis and preventive treatment of disease, and the development of social machinery which will ensure every individual in the community a standard of living adequate for the maintenance of health"(Winslow, 1920)*

A shorter and also commonly used definition of public health is from a 1988 Institute of Medicine (IOM) report. In it, public health is described as:

> *"fulfilling society's interest in assuring conditions in which people can be healthy." (Medicine, 1988)*

Koplan et al. (2009) identifies an emphasis on prevention rather than curative care within public health. This is a definition that is useful when it comes to communicable diseases such as HIV and tuberculosis. When it comes to diabetes type 2, however, the actions an individual must undertake to be treated of diabetes are virtually the same as those needed to prevent it. Thus, prevention and curative care can be seen as "two sides of the same coin", and the need to distinguish between prevention and curative care becomes redundant.

It is important to understand the clinical approach to diabetes type 2 in order to understand how to cure "the body". However, to understand how a person can perform the actions needed to cure "the body" we need to address the context these actions will be conducted in. Thus, framing diabetes management as a public health issue function as a means to give emphasis to the importance of addressing the context, and to give some extra weight to the importance of prevention.

The concept of managing diabetes in this thesis, is thus about addressing the reasons why people get diabetes, which in turn helps address the reasons why people struggle to adapt their lifestyles after being diagnosed with it.

2.1.6 Achieving diabetes self-management

Diabetes self-management relates to the skills an individual need to make appropriate choices in regard to their disease.

Heisler et al. claims that diabetes management requires close teamwork between the health care providers and the patients. While the health care providers are in charge of prescribing medicines, tests and provide counseling, the patients are the ones who have to sustain often-complicated medication, diet, and exercise regimens, through a set of skilled behaviors called self-management (Heisler et al., 2003, p. 893).

We find diabetes self-management to be a useful term to reference the skills needed to make a personal effort to treat one's disease. Self-management is thus central to non-communicable diseases where the patient lifestyle needs to be modified and "managed" in accordance with the "recipe" that will cure the body.

Thus, providing diabetes-care to a person with diabetes involves medical guidance, as well as building and strengthening the patients self-management abilities.

2.1.7 Summary and afterthought

The main takeaway of the diabetes-section of this chapter, is that diabetes is no simple disease. There are several aspects to why we get diabetes, that includes both genetic, social and cultural factors. Diabetes type 2 is simultaneously a clinical phenomenon and a social phenomenon, making the treatment of the disease multifaceted.

Most importantly, the disease requires a large effort on part of the patient. It is not so much about being cured by medicine or doctors, as it is about curing oneself through diabetes self-management strategies involving exercise and modified diet.

The ability to manage a lifestyle change depends on resources and the living conditions of the patients. In the next section the living conditions in South-Africa and Mitchells Plain will be presented.

2.2 South Africa

2.2.1 General introduction

South Africa is the southernmost country in Africa and has a population of close to 56 million people. The country is among the most influential and most developed countries in Africa. It's characterized by a multi-ethnic society, with a wide variety of cultures and religions. The country has 11 official languages, where English is most used in public life, together with Afrikaans and Xhosa (Tibane, South Africa, & Government Communications and Information System, 2017).

From being a country where most of the people were hunter and farmers (before 1500), South Africa has experienced occupation, colonization and several wars (1500-1989). It has a complicated history, where the disruptive apartheid politics, from 1948 to 1994, still affects demographics, government, housing and income among the citizens of South Africa today. The gap between rich and poor is increasing, and today South Africa is the country in the world with the largest income inequality. Several of the social welfare services are privatized, including water and electricity. A large scale of poor households spend roughly 34% of their total household expenditure on food (Statistics South Africa, n.d.)

Since 1994, South Africa has been a parliamentary republic, with nine provinces. One of these is The Western Cape, where this research has been conducted.

In South Africa, this includes the so-called townships and informal settlements. The townships, and especially the informal settlements, has a larger amount of poor households and problematic access to water, sanitation and electricity (Mahajan, 2014, p. 2). During the apartheid, townships were created to people with non-white skin color, and split into black or colored areas. After apartheid ended, many families continued to live in these townships. In South Africa, we can still see areas where the inhabitants have very similar socio-economical background and share the same language and culture (Mahajan, 2014). Mitchells Plain used to be a colored township, and many of the people living there today will identify themselves as colored (Department of Provincial and Local Governnment (DPLG) & Business Trust, 2007).

Obesity and diabetes in South Africa

South Africa has big challenges with obesity and diseases connected to obesity. In low-resource areas, like Mitchells Plain, this is a particularly big problem (Kruger, Puoane, Senekal, & Merwe, 2005). Some of the factors that contribute to the high prevalence of obesity in South Africa are related to changes in the food consumption. Eating habits has changed from being low fat and rich in fiber, to a higher food intake of meat, dairy products high in fat, saturated fats, and more refined foods, such as fast food. In addition, we see that consumption of food and drinks rich in sugar and fat has increased (Kruger et al., 2005).

2.2.2 Mitchells Plain Sub-district

In this section, we will give an overview of the socio-economic conditions in Mitchells Plain. We will start with a short background, before we describe some of the challenges related to income, crime and overcrowded households.

Mitchells Plain is a former township, created in the 1970s as part of the apartheid governments plans to house and segregate "colored" people. Mitchells Plain is located about 30 km outside the city center and was planned as a segregated suburb removed from the “white” areas of Cape Town, and isolated from the “black” and “Indian” communities. The township was made for middle-income families, and the houses in Mitchells Plain was built to accommodate 250 000 people in the 1970s. While apartheid has ended, 90% of the residents still belonging to the colored community (Statistics South Africa, n.d.). Since the 1970s, the township has grown to house over 310 000 residents. The majority of the households (58%) house four people or more, and 22% are informal settlements. One third of the households have only one or two rooms, and many of the residents must manage this overcrowding (Department of Provincial and Local Governnment (DPLG) & Business Trust, 2007). Most households have access to electricity, source of water and toilet facilities (Statistics South Africa, n.d.).

Many of Mitchells Plains residents face challenges with their economic situation. According to the Western Cape Government, 63% of the households in the area of Mitchells Plain and Khayelitsha (neighboring area) fall within the "low income" bracket, meaning that these households earn from zero to a little over 50 000 ZAR annually which is 4166 ZAR per month (equal to approximately 4015 USD and 335 USD respectively). Further, 16.5% of the inhabitants have no income, and only 43% of the working age population are employed (Western Cape Government, 2016).

The lack of job opportunities are linked to the lack of skills. Few people have access to higher education, and 40% of the people between ages 5-24 do not attend school. A stated reason for why so many leave school and education are related to work or look for work (Department of Provincial and Local Governnment (DPLG) & Business Trust, 2007).

Crime and safety issues are a challenge in the area, and drug trade and drug abuse are a severe problem accompanied by an increasingly high level of gang activity. (Department of Provincial and Local Governnment (DPLG) & Business Trust, 2007).

2.2.3 Diabetes in Mitchells Plain

The total population in the Mitchells Plain Community Health Clinic (Mitchells Plain CHC) drainage area is about 700,000 people in total. In the population served by Mitchells Plain CHC, the prevalence of Diabetes Type 2 in people over 40 is estimated to be 28.2%. However, most people living with Type 2 are thought to be undiagnosed. The clinic manages approximately 14,000 people with diabetes. Of these 99% are diagnosed with diabetes type 2 (David, 2017, Personal communication).

Erasmus et al. did a study in Cape Town between 2008 and 2009 which showed that the prevalence of diabetes type 2 has increased hugely in the colored community the last years to 28.2% from 7.1% in 1999 (Erasmus et al., 2012).

2.3 Existing Technology for diabetes

It has been shown that technology has great potential in motivating and helping people to achieve a healthier lifestyle. Text-message systems and mHealth are examples of technologies that aim to improve the reach of the health service providers (Watterson, Walsh, & Madeka, 2015). For example, text-message client reminders and behavior change communications have shown a 15% increase in individuals attending Ante-Natal Care (Watterson et al., 2015).

Technology for lifestyle

Examples of technologies directed at people with diabetes include applications for smartphones that motivate and help managing an exercise regime, a diet or remind the patient to take medicine (Vervloet et al., 2012). Another example of more sophisticated diabetes technologies incorporate glucose-level tests, and automatic insulin regulation (Feldman, Brazg, Schwartz, & Weinstein, 2003; Harris, Hood, & Mulvaney, 2012). Yet another example is the Dia:Clock, a wearable technology that helps the user recognize when their body has a low glucose level (Thorseng, 2017).

Technology for blood glucose control

A lot of the technologies are designed to help users better control blood glucose levels. For example, an app where the user can give input on food intake and record blood glucose levels, and get feedback on how she can adjust for a more optimized blood sugar level (Waki et al., 2014). Other tools are designed to give knowledge to the user, by providing basic information about how to balance food and blood-glucose-levels, like many of the self-management games described in Lieberman (2012).

All in all, many of these technologies aim to support the patient in diabetes-self-management, supporting them to organize and better control their disease. However, much of the available technology that is aimed at tackling diabetes is designed for a high-income country context, where education and literacy levels, and financial and technological resources are high. This means that the design examples we generally see are financially out of reach and illiteracy can be a barrier for access and use. Regarding the increasing prevalence of diabetes in low and middle-income countries, there will be an increasing need to help people make positive lifestyle changes (Ajay & Prabhakaran, 2011; Zimmet, Magliano, Herman, & Shaw, 2014). Further, there is a need to design helpful technologies to aid people with diabetes in all social classes.

3 Conceptual framework

In this chapter, we present the framework of theories and concepts that guide our research. We use these theories and concepts to aid our approach to research, analysis, and design.

To guide our approach to researching diabetes and lifestyle change, we use the concept of *Wicked Problems* by Rittel and Webber (1973). There are many facets to wicked problems, but the central point is that a wicked problem has many causes and can be seen as symptoms of other problems. Diabetes type 2 is rapidly increasing due to changing lifestyles, which in turn are caused by changes in economy, globalization, availability of new types of food, changes in activity levels and transportation and much more. Thus, providing good design-suggestions for people with diabetes type 2 is dependent on understanding the problem we are facing. We use the concept of wicked problems to guide our approach to researching diabetes in a social context. In *chapter 8 - Discussion*, we will revisit and discuss the concept of wicked problems in light of our research.

To help us understand how people in Mitchells Plain are affected by and struggle with diabetes, we use the *Capability Approach* by Amartya Sen (1999). The capability approach is used to look at the factors that either enable or hinder the capabilities people have to achieve a goal they have reason to value – such as being healthy. Our analysis, in *chapter 6* is based on the capability approach.

To inform the way we create an appropriate design, we use the theory of *Plans and Situated Action* by Lucy Suchman (1987). The theory is helpful in guiding how we design helpful tools that incorporate the curative approach to diabetes care, while at the same time taking the context in to account. In *chapter 8 – Discussion*, we discuss this theory in light of our design suggestions.

This chapter is structured as follows. First, we present the concept of wicked problems, and how it relates to diabetes. Next, we introduce the capability approach. Finally we present the theory of plans and situated action.

3.1 Wicked Problems

In section 2.1, we discussed diabetes as an epidemic and explained some of the characteristics of type 2 diabetes. Partly, the goal of that chapter was to show the complexity of the disease to illustrate the amount of information a patient needs to take in. We argue that the diabetes epidemic is a wicked problem because its many causes are so intertwined and conditioned by a varied set of factors that are ill-defined, which in turn makes it a difficult problem to solve. Approaching the diabetes epidemic as a wicked problem allows us to form an appropriate strategy to design solutions.

In this chapter, we will start by defining wicked problems, before we describe how this has affected the way we approach problem-solving with design, and explicitly explain in what ways we see the diabetes epidemic as a wicked problem.

3.1.1 Definition

A wicked problem can be defined as such:

> *"A wicked problem has innumerable causes, is tough to describe, and doesn't have a right answer." (Camillus, 2008, p. 1)*

Rittel and Webber (1973) coined the concept of wicked problems, and describe ten properties that distinguish wicked problems from ordinary problems. The point is not to claim that other problems are not hard, but rather to say that ordinary (but hard) problems can be defined, analyzed and solved in a linear fashion. Rittel and Webber argue that most problems that have been solved by scientists and engineers are ordinary problems, with a clear goal, which in turn makes it obvious when it has been solved (Rittel & Webber, 1973). Examples of ordinary problems are the tasks of building a bridge, creating a vaccine or solving an equation. The missions are clear and solutions easy to verify; the problem is solved when a river can be crossed safely, a disease can be cured or when the equation adds up. In contrast, wicked problems are difficult to define and delineate precisely because its causes, and facets are intertwined and unclear. Wicked problems don't have the clarifying traits and orderly set of factors that allow us to neatly calculate and define the problem statement, or to make clear when a problem has permanently been solved (Rittel & Webber, 1973).

According to Camillus, a wicked problem usually has at least 4-5 of the ten characteristics they have identified (2008, p. 2). The ten characteristics are summarized in Camillus's article "Strategy as a Wicked Problem" (2008, p. 3) and reproduced in the table below:

1. **There is no definitive formulation of a wicked problem.**
It's not possible to write a well-defined statement of the problem, as can be done with an ordinary problem.

2. **Wicked problems have no stopping rule.**
"You can tell when you've reached a solution with an ordinary problem. With a wicked problem, the search for solutions never stops."

3. **Solutions to wicked problems are not true or false, but good or bad**
"Ordinary problems have solutions that can be objectively evaluated as right or wrong. Choosing a solution to a wicked problem is largely a matter of judgment."

4. There is no immediate and no ultimate test of a solution to a wicked problem
"It's possible to determine right away if a solution to an ordinary problem is working. But solutions to wicked problems generate unexpected consequences over time, making it difficult to measure their effectiveness."

5. Every solution to a wicked problem is a "one-shot" operation; because there is no opportunity to learn by trial and error, every attempt counts significantly
"Solutions to ordinary problems can be easily tried and abandoned. With wicked problems, every implemented solution has consequences that cannot be undone."

6. **Wicked problems do not have an exhaustively describable set of potential solutions, nor is there a well-described set of permissible operations that may be incorporated into the plan**
"Ordinary problems come with a limited set of potential solutions, by contrast

7. **Every wicked problem is essentially unique**
"An ordinary problem belongs to a class of similar problems that are all solved in the same way. A wicked problem is substantially without precedent; experience does not help you address it."

8. **Every wicked problem can be considered to be a symptom of another problem**
"While an ordinary problem is self-contained, a wicked problem is entwined with other problems. However, those problems don't have one root cause."

9. **The existence of a discrepancy representing a wicked problem can be explained in numerous ways**
"A wicked problem involves many stakeholders, who all will have different ideas about what the problem really is and what its causes are."

10. **The planner has no right to be wrong**
"Problem solvers dealing with a wicked issue are held liable for the consequences of any actions they take, because those actions will have such a large impact and are hard to justify."

Table 1 – The ten characteristics of wicked problems (Camillus, 2008).

3.1.2 Framing diabetes as a Wicked Problem

There are several of the characteristics from the table above that fits with our understanding of the diabetes epidemic. Below, we highlight the four most fitting ones.

There is no definitive formulation of a wicked problem.

First, we take a look at the notion that there is no definitive formulation of a wicked problem. The reasons why so many people are struggling with diabetes type 2 may appear straight forward. It is connected with changing lifestyles. However, the reasons lifestyles are changing are many. As such, formulating a clear problem statement, that delineates the reasons for the increase diabetes type 2 is not a clear-cut task. In the article "Wicked Problems in Design Thinking" Buchanan (1992) points out that the traditional, linear, step-by-step design models doesn't hold up in real life because "problems addressed by designers do not, in actual practice, yield to any linear analysis and synthesis yet proposed". Hence, the task of defining and delineating a social problem is in itself wicked (Buchanan, 1992) .

Every wicked problem can be considered to be a symptom of another problem

While an ordinary problem is self-contained, a wicked problem is entwined with other problems, and those problems do not have one single root cause (Camillus, 2008). For example, rising levels of diabetes is connected with rising levels of obesity. Rising levels of obesity connected to lower levels of activity, and changes in dietary habits. Dietary habits can be connected to the globalization of food-culture. The globalization of food-culture renders food-knowledge that are passed down from generations before to be outdated. The list goes on and on, and similar arguments can be used with activity levels; we have changed our primary mode of transport, where urbanization and a decline in manual labor causes fewer of us to be active during the day. The point is that the problem of increased levels of diabetes type 2 is interconnected with many other problems.

Solving wicked problems

The final two points we highlight are the points that state "wicked problems do not have exhaustively describable set of potential solutions" and "solutions to wicked problems are not true or false, but good or bad".

In terms of finding a solution to a wicked problem, there will always be several possible angles or points of entry to solve the problem, precisely because there are many possible "root-causes" whose impact is interconnected and difficult to measure. We see the two points above as fitting in our case, because there are many types pf potential interventions that can target several or fewer of the root causes, and that to a various degree can contribute to a solution. For example, on a state level, policies such as a high tax on sugar and fat can contribute to making healthy food cheaper. Improving education levels, and curriculum about food and nutrition can increase awareness and so on. On individual level, solutions that aim to increase the diabetes-patients knowledge about diabetes, or solutions that make it easier for them to track their blood-sugar levels are two different approaches that target different aspects of managing diabetes. These interventions cannot be seen as true or false in the sense that they either solved or didn't solve the problem, however, if successfully implemented they can (hopefully) be seen as contributing to bettering the problem.

Solving wicked problems is thus just as much about understanding the problem area in its complexity, as it is about providing solutions. The task of finding one single comprehensive solution that covers all the root-causes can be impossible. However, understanding the type of problem we are faced with can help us form an appropriate strategy to generating helpful interventions. We discuss this in the next section.

3.1.3 Approach to solving wicked problems:

In forming our strategy to approach our wicked problem, we lean on available research on the matter. Stolterman (2008) reflects on the "recommended" approaches to tackle wicked problems. In line with the preceding discussion, he emphasizes the importance of understanding the whole picture, claiming that:

> *"you cannot reduce design complexity by limiting yourself to those things that you have the time or resources to handle or those things that you have sufficient knowledge and information about (Stolterman, 2008, p. 59).*

Further, he claims that attempts to reduce or control design complexity can lead to highly time- and energy-consuming approaches (Stolterman, 2008, p. 57). This is because the nature of the problems - as discussed above - makes it difficult to cover all aspects. In turn, the design approaches themselves become too complex. Instead, Stolterman proposes to stop seeing complexity as something to sort out and overcome, but rather to see it as an asset that can lead to rich experiences and foster creativity. Building on a range of authors, he argues that:

> *"…the only way to keep that richness is for the designer to be fully immersed in the context of the case and to make sense of that context based on an understanding of the particular situation, and then to create an appropriate approach for the specific design task at hand" (Stolterman, 2008, p. 58).*

In discussing the design-approach to tackling wicked problems, we are then adviced to use our knowledge of design-methods not as a recipe or guide to follow strictly, but to see them as preparations for action, and using our design judgement when creating a strategy as the research moves along (Stolterman, 2008).

While Stolterman offers advice on a more philosophical level, Polaine, Reason and Løvlie offers a more concrete advice. In their article about service design, a chapter is dedicated to designing for social problems, and they define social problems as wicked problems (Polaine, Reason, & Løvlie, 2013, p. 186). They argue that social problems, and typically the provision of health services, don't have a defined customer and seller who is in it for profit. The goal of a service, such as a health care service, can only be understood by getting the perspectives of various stakeholders, to understand their needs, and their relationships (Polaine et al., 2013, p. 186). This is backed by Camillus (2008) in his paper on wicked problem-solving:

> *" the simplest techniques are often the best. Involve stakeholders, document opinions, and communicate. […]The aim should be to create a shared understanding of the problem and foster a joint commitment to possible ways of resolving it." (Camillus, 2008, p. 4)*

When facing a wicked problem, such as the one we are researching, we have focused on not cherry-picking a comfortable delineation of the problem area, or to choose a context-of-intervention that seems manageable. In practice, that has meant going into the fieldwork with an open mind. We have been actively seeking to include the views of various stakeholders, and to expand our understanding of the complex problem area. When deciding on an appropriate context-of-intervention, it has been informed by the environmental context, the needs of the patients, the needs of the health workers and the social context.

In sum, we take away four main points from the "wicked problem and design-litterature" that have guided our approach to "solving" wicked problems: (1) Keep the complexity by immersing ourselves in the context, (2) use our design-methods to be prepared for action, not guided in action, (3) involve multiple stakeholders.

3.2 Capability Approach

In this thesis, the *Capability Approach* by Amartya Sen is used as a lens to sort out and make sense of our data.

The central argument in the book *Development as Freedom*, by Amartya Sen, is that the international community needs to stop viewing development as something that can be measured in income or commodities. Instead, development should be measured according to the freedom people have to choose the lives they have reason to value. The concepts we use from the capability approach allows us to analyze the barriers for people in Mitchells Plain to achieve a diabetes-friendly lifestyle.

In this chapter, we will introduce the capability approach. It contains different concepts that we have used to analyze and get an overview of our data. Still, the capability approach is a comprehensive development theory that contains many aspects which we are not able to cover in this thesis. We have chosen to focus on the concepts that we use in our analysis: Functionings, capabilities and conversion factors. These concepts helps us address what people are able to do and be, and to reflect upon the phenomna of «having diabetes in Mitchells Plain» from a patient perspective.

The philosophy behind the capability approach

Amartya Sen sees development as providing individuals with the possibility to pursue choices they value (Sen, 1999). The capability approach puts the human in the center, and argue that development should not be measured by objective targets, such as poverty levels or education levels, but on whether the individuals have the *capabilities* to pursue the lives they value. This perspective puts its emphasis on the freedom to choose, rather than the achieved outcomes an individual experience (Robeyns, 2005, p. 96).

For example, a person should have the capability to be well-nourished (have access to food, income to buy nourishing foods, etc). However, if the person finds value in a religion, and believes that fasting is part of practicing that religion, the person should have the opportunity to do so. Thereof the freedom to choose. In other words, the capability to achieve the function of "being well-nourished" should be available for the person. If the individual is prohibited from having the capability to be well-nourished, or to practice his religion, the person would be deemed *capability-deprived* according to Amartya Sen (Mukherjee, 2016; Sen, 1999).

3.2.1 Explaining the capability approach

Here capability approach is explained through the terms, *capability, functionings* and *conversion factors.*

Functionings and capabilities

There are different things a person can value doing or being, for example working, resting, being respected, being healthy, being part of a community. These are called *functionings* (Robeyns, 2005, p. 95). A functioning is something that can be achieved, and the sum of the valuable functionings a person achieves contribute to give life value (Robeyns, 2005, p. 95).

In Sens framework *capabilities* refer to the set of valuable functionings an individual has effective access to. It has a broader focus than that of functionings because capabilities highlight the freedom to exercise choice in regard to the functionings he wishes to achieve. The freedom to choose endows the person with the 'freedom to lead one type of life or another'(Sen, 1999, p. 40). Thus, functionings are states of being and doing that an individual has reason to value, and capabilities decide if a person has effective access to achieve any given functioning.

Part of Sen's critique is of the intrinsic value that is given to resources such as money or technology. He argues that it does not make sense to measure development according to the number of people with access to, for instance, mobile phones or bikes. Instead, Sen emphasizes the importance of distinguishing between a resource, and capabilities and functionings on the other hand (Robeyns, 2005, p. 98).

One example is the value of having resource in form of a bicycle. In the capability approach, a bicycle is not valuable to us because of the bike in itself. The bike does not hold intrinsic value, but the value is derived from its potential to help us achieve the functioning of mobility. As such, a resource function as means to achieve a functioning. In turn, the capability to convert a resource, and use it as a means to achieve a functioning is influenced by *conversion factors* (Robeyns, 2005, p. 99).

To illustrate, a cooking book with diabetes-friendly recipes can be a good resource to achieve the functioning of having a diabetes-friendly diet. However, for the book to be valuable for a person, the person must be able to convert the resource into a valuable function. The person must be able to read, have access to an environment for cooking the recipes, have enough money to afford the groceries in the recipes and the recipes must not contradict their religious beliefs.

In figure 2 below, we illustrate the relation between resources, conversion factors, capabilities and achieved functionings. In the figure, we see that the potential of converting the neighborhood park in to the achieved functioning of "doing exercise" first depends on the three conversion factors, and secondly depends on the individual choice to do so.

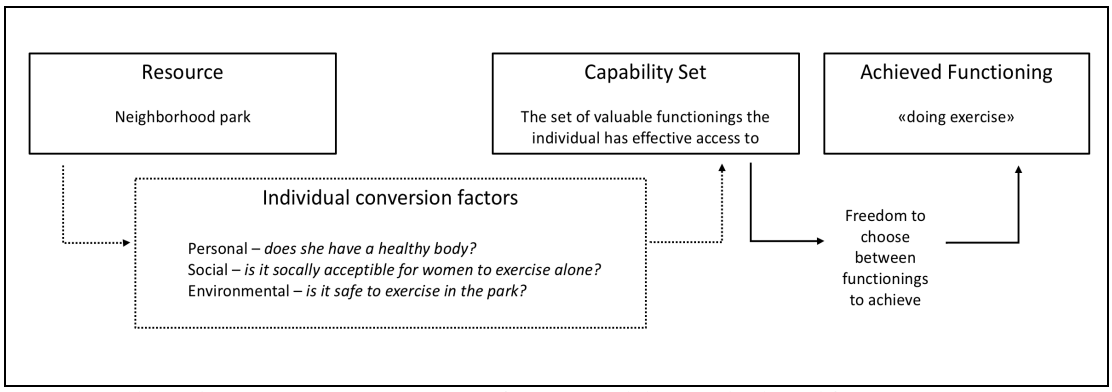

Figure 2 - Relation between resources, conversion factors, capabilities and achieved functionings

Conversion factors

Conversion factors are important because they highlight the factors that constrain the capability achievement of individuals *(Nambiar, 2013)*. Sen divide conversion factors into three groups: Personal, social and environmental.

The *personal* conversion factor regards individual characteristics like gender, literacy, intelligence, disabilities, knowledge etc. If a person has never learned how to ride a bike, this would function as a barrier use the resource of a bicycle to increase mobility. Similarly, having an amputated leg, or impaired sight renders the bike a useless resource (Robeyns, 2005, p. 99). The *social* conversion factor regards conditions influenced by norms, policies, cultural issues, gender roles, power and hierarchies, etc. For example, if women are not allowed to ride bicycles, social norms would influence her use of the resources (Robeyns, 2005, p. 99). The *environmental* conversion factor regards circumstances afforded by the immediate environemt. Examples are infrastructure, geographical, housing, access to clean water etc. If there are no roads for bicycling, or no safe places to store the bike, the environment function as a barrier to utilize it as a resource to achieve mobility(Robeyns, 2005, p. 99).

The conversion factors help us understand how resources and services can be accessed, and potentially be helpful for the person, but different factors influence how able the person is to utilize this potential (Mukherjee, 2016).

3.2.2 Capabilitiy approach in ICT research

Richard Heeks (2006, 2010) argue that ICT (Information And Communication Technology) research has a tendency to put too much emphasis on the value of technology in itself, and calls for an increased focus on whether or not people actually derive value from implementing technology. Andersson, Grönlund and Wicander supports this notion, and argue that the capability approach has promising traits as a tool to evaluate the potential impact of an ICT intervention (2012).

3.2.3 Our use of the Capability Framework

The capability approach represents an (at the time) novel approach to development and has been extensively used in the context of human development. Here 'poverty' is understood as deprivation in the capability to live a good life, and 'development' is understood as capability expansion. It is a comprehensive approach meant to shape how we understand and measure development, and the concept of "freedom" is essential in this approach.

In his book *Development as Freedom,* Amartya Sen spends the first two chapters mapping out the concepts and building blocks that the approach builds on (that of capabilities, functionings, agency and conversion factors). The remaining chapters are spent making the case for abolishing "un-freedoms" such as poverty, famine and lack of political freedom while framing these as things that constrain peoples' general capabilities. These concepts are discussed in the vast part of his book (chapters 3-12), where Sen goes through the concepts that are needed to be "in place" for the individuals to achieve freedom. The themes that are covered are (1) political freedoms (democracy), (2) economic facilities (3) social opportunities, (4) transparency guarantees and (5) Protective security. The discussions on these themes are high-level, with a primary goal of shifting the reader's view of development to that of viewing it as "freedom."

Hence, "Development as Freedom" provides us with 1) a set of concepts that constitute the building blocks of the capability approach; and 2a) a reframing of development as having freedom to live the lives people value, and 2b) an outline of the overarching structures that need to be in place **not** to inhibit those freedoms.

While acknowledging that the capability approach primarily is a development theory, and this is not a development thesis, we find parts of his framework useful to understand the barriers that prohibits people in Mitchells Plain from living a diabetes-

friendly lifestyle. We will not examine the bigger overarching themes (point 2a and 2b above) that Amartya Sens discusses in *Development as Freedom*, but instead use the building blocks of the capability approach to examine the aspects of a person's capabilities to achieve the functioning of living a diabetes-friendly lifestyle.

We believe the capability approach can be useful to analyze the barriers people face, through the three conversion factors, in achieving diabetes-self management in Mitchells Plain.

3.3 Plans and situated action

In the previous section we explained how we will use concepts from the capability approach as an analytic lens to understand how the patients can achieve a diabetes friendly lifestyle. In this chapter, we present the concept of "plans and situated action", and the way we intend to let it inform our designs.

Lucy Suchmans book *Plans and situated actions: the problem of human-machine communication* (1987) is an "analytic critique of the then-dominated paradigm for modelling human behavior in AI" (Dourish, 2004, p. 70). The critique points out that technology was seemingly designed with a notion that humans act according to pre-formulated plans, in a context where the features are stable objective phenomena. This is referred to as "the planning model". The planning model is based on the belief that people act according to pre-formulated plans, and it presents features of the world - and of our interaction with it - as stable, objective phenomena, that enables the relatively unproblematic execution of a plan formed around these objective phenomena (Dourish, 2001, p. 72).

Suchman, however, argue that most plans are reconstructed retrospectively when someone is forced to give an account of an action. Thus, the retrospective reconstruction of plans "systematically ignore the necessary *ad hocness* of situated action in favor of an account of the action as in accord with the plan"(Suchman, 1987, p. 5). To offer an example: a person who is about to ride a bike do not formulate a plan to first get on the bike, then push down on the pedal with the left leg first and the right leg second. In any case, the plan becomes apparent through the retrospective reconstruction of it, when someone perhaps asks: "how do you ride a bike?". Further, the ad-hoc response to regain balance - if the bike hits the curb - is typically left out in the reconstruction of the plan.

As such, Suchman points out that human beings rarely formulate a plan to conduct their actions. Instead, Suchman proposes to see actions as performed in ad hoc responses to the features of the setting in which they arise. Thus presenting her argument that actions are not planned: they are situated.

The result of prescribing to the set of thought that bisects "the planning model" is that technology is designed for a context-less use-context. Meaning, that the design assumes that the context won't influence the use of the object or resource. The "plan" that is inscribed in to the technology is based on the assumption that every move and contingency can be predicted. As such, the plan becomes a straight-jacket.

In Suchmans alternative view, the plan should function as a resource for action. Instead of the plan being a prescribed recipe to follow precisely, the plan is there to guide and help, while allowing the users to respond to the context.

In this thesis, we draw parallels between "the planning model" and the curative perspective (presented in section 2.1.5 - managing diabetes). Based on Lucy Suchmans theory, we aim to use the "plan" on how to cure the body, as a guide to action. By this, we mean that the designs will not contain an in-flexible step-by-step guide to good health. Rather, the designs will contain context-appropriate suggestions that are informed by the plan. This is discussed further in section 8.3.

3.4 What the theories help us with

In sum, the theories guide us through the research. The theory of wicked problems helps us form proper strategies to research diabetes, the capability approach help us analyze the barriers to achieving diabetes self-management in Mitchells plain, and plans and situated action guide the way we make use of the curative plan as a resource for action.

4 Methodology

In this chapter we outline the methodological approach we have undertaken, and the methods we have used during our fieldwork.

4.1 An interpretive approach

The basis for this study has been the problem of managing diabetes in Mitchells Plain. For our research approach, this has meant that we sought to understand the complex realities faced by people in Mitchells Plain with diabetes type 2, who struggle to achieve a lifestyle change.

The philosophical grounding for this thesis is the interpretive paradigm, as we believe that contributing with valuable knowledge about social phenomena can only happen through trying to uncover the meanings these stakeholders ascribe to the phenomena connected to having and managing diabetes type 2 (Klein & Myers, 1999). This approach is suitable for studies where the research question to be answered must be seen in a larger social context (Klein & Myers, 1999). When it comes to researching a lifestyle disease such as diabetes, there are many stakeholders involved. Stakeholders include the patients, their families, the health providers, the government, the local grocery suppliers and the community as a whole. This means that there exists many views on the issues with diabetes type 2, who are all part of the larger context.

Walsham argue that through interpretive research, our theories concerning reality are ways of making sense of the world, and that shared meanings are a form of intersubjectivity rather than objectivity (Walsham, 2006, p. 320). We ascribe to this notion, and in our research, we strive to understand the stakeholders and their context and build an intersubjective understanding together with the participants in the study of these phenomena. We elaborate on this below.

In order to understand the realities of people living with diabetes in Mitchells Plain, we have - through this research - worked with understanding and explaining diabetes in Mitchells Plain as a social phenomenon. Our attempt to understand this phenomenon, has materialized through trying to understand the meanings that people assign to them. Hence, in our work with understanding the phenomena we had to involve ourselves by talking, listening, and interpret together with the stakeholders. This means that we are using our own interpretations and involvement when we learn and present our study. Being two researchers who come from a vastly

different context than the one we have conducted our research in, we have attempted to be mindful about the ways our interpretations are shaped in the research context. We find that the anthropologist Clifford Geertz put it in good words:

> *What we call our data are really our own construction of other people's constructions of what they and their compatriots are up to. (Geertz, 1973, p. 9)*

We take this as a reminder to make sure that our interpretations are based on a shared understanding with the informants. This is how we view intersubjectivity: that our research is not meant to uncover an "objective truth" but that the "reality-for-us" can be understood by forming a shared understanding (Walsham, 1995).

4.2 Case Study

The goal of this research has been to understand the wicked problem from its many sides by being fully immersed in the context of the case, and to create a shared understanding of the problem by involving a multitude of stakeholder-perspectives. Based on this research goal we have chosen to conduct an interpretive case study. Two fieldworks have been completed for this study. These fieldworks have been instrumental in our endeavor to understand more about the people, the city, country, the health system, the disease, the culture, and all the factors that sums up this particular context.

Based on our research interest, ethnography could also have been a viable option. However, we deemed the ethnographic approach to be less suitable due to the length of the fieldwork and the challenge of gaining access to the community. Understanding the patient perspective through ethnography would require that we became part of the Mitchells Plain community. That we lived and gained an understanding of the lives of a diabetes patient in Mitchells Plain by experiencing them ourselves. Doing participatory observation in this context would require a lot more time and involve a higher personal risk due to the environmental factors in Mitchells Plain.

While ethnography usually focus more on creating an in depth understanding of a group or culture, choosing a case study approach gave us better opportunity to focus on the phenomenon of having and managing diabetes in Mitchells Plain from its many perspectives. Thus, one advantage of doing a case study has been the opportunity to delineate and focus on a specific context. Our motivation for choosing to do a case study is aligned with the definition Flyvbjerg (2011) provides:

> *"If you choose to do a case study, you are therefore not so much making a methodological choice, as a choice of what is to be studied" (Flyvbjerg, 2011, p. 301).*

In this thesis we want to gain knowledge about the general phenomenon "what it is like to have and manage diabetes in a resource poor setting". We do this by focusing on diabetes management in Mitchells Plain, attempting to highlight the challenge from many perspectives. Flyvbjerg notes that case studies focus on the relation of the case to the context, and claims that "the drawing of boundaries for the individual unit of study decides what gets to count as case, and what becomes context for the case"(Flyvbjerg, 2011, p. 301). In our case we focus on the immediate experience with having and managing diabetes. Thus, the patient perspective and the perspectives of the local health providers, represented by Mitchells Plain CHC and Arisen Women are all part of the case. However, as the patients are the ones we are trying to help, their perspectives receive the most attention in this thesis. Further, the Mitchells Plain community and culture provides the context for the case.

Stake (2005) distinguishes between *instrumental* and *intrinsic* case studies. *Instrumental case studies* are used when the case provide insight into a general issue. By this, we mean that the case can teach us something about a phenomenon, and can be interesting to other similar cases. In contrast, an *intrinsic case study* is undertaken because the case is interesting in itself and is considered a unique phenomenon.

We believe that researching this particular case, can increase our knowledge about diabetes management in other resource poor settings. For this reason, we define our study as an interpretive instrumental case study. The findings we discover through this research can contribute to comparison, falsification or the development of concepts and theories through further research.

Interpretative case studies are useful for understanding social situations through so-called thick descriptions (Geertz, 1973; Walsham, 1995, 2006). Thich descriptions are descriptions of human behavior where the explanations of behavior and context are presented in a way that allows outsiders to add meaning to what is described. This is what we have attempted to do with our empirical chapter.

4.3 Data collection

In this section we introduce our fieldwork, the different sources of data collected, and the methods we have utilized. We have used several different methods which lets us look at the phenomenon from various perspectives.

4.3.1 Fieldwork in Cape Town

Data collection for this research has been collected through two separate field trips to Cape Town. The first, a three-week preliminary field trip was instrumental in shaping the research focus of this thesis, and the second was a ten-week main fieldwork where most of our empirical data stems from.

The initial field trip was carried out as part of an exchange between the University of Oslo and the University of Western Cape. It lasted for three weeks in January 2017. The goal was to explore the health challenges Cape Town was faced with and to shape the research focus of this thesis. Our initial meetings with the Department of Health in Cape Town revealed a big challenge with lifestyle diseases, and we were put in contact with a health clinic in Mitchells Plain. During our meetings with staff at Mitchells Plain Community Health Clinic (Mitchells Plain CHC), interest was expressed from Dr. Neal David, the family physician at Mitchells Plain CHC in working with us. For that reason, Mitchells Plain was chosen as the research setting for our study. The staff told us about the significant challenges with chronic diseases in the area, especially diabetes type 2.

In October 2017 we went back to Cape Town, and stayed for a little over 10 weeks, as we conducted the field work for this study. Our main focus have been that of understanding the realities of people living with diabetes type 2 in Mitchells Plain. For this reason our most important data sources have been our interviews and interactions with diabetes patients. Further, to understand the context, we have conducted observations, participated in meetings at Mitchells Plain CHC, had interviews and informal conversations with experts, other researchers, and conducted a focus group, a design workshop, and read documents about diabetes. Our data sources are relayed in table 2 below.

Most of the empirical data is collected at Mitchells Plain CHC, at Arisen Womens offices in Mitchells Plain, or in the homes of people living in Mitchells Plain. Interviews with other stakeholders, such as diabetes researchers and representatives of Cape Town Department of Health was primarily held in their respective offices around the city.

Activities undertaken during main fieldwork		
Source of data collection	**Method**	**Frequency**
Diabetes patients Mitchells Plain	Interview	9 patients - one each
Home visit to diabetes patient	Observation	2 patients - one each
Diabetes patients Mitchells Plain	Focus group	9 patients – once
CHWs at Mitchells Plain	Focus group	2 CHWs* - once
CHWs at Arisen Women	Group interview	25 Women – once
Arisen Women	Workshop	25 Women – once
Mitchells Plain CHC	Observation	Twice a week
MP family physician	Meeting and informal interview	Two times
Arisen Women Project Lead	Meeting and informal interview	Two times
Department of health	Meeting and interview	Three times
Mitchells Plain COPC-meetings	Participation in meetings	Three times
2 Diabetes Researchers SA MRC	Interview	One interview
2 Diabetes Researchers UWC	Interview	One interview
UCT researchers	Interview	One interview
Expert in Behaviour Change and UX in Health	Interviews	Two interviews
Clinical UX association	Interview	One interview

Table 2 - List of stakeholders
** Community health workers*

4.3.2 Participants

During our fieldwork we performed several interviews and focus groups. The participants were mainly women diagnosed with diabetes type 2. The reason for this was that the women were more eager to sign up for interviews and focus groups than the men. We interviewed three men early on, however the men provided fewer insights in to the way cooking and lifestyle was organized, due to traditional gender roles, where women are more responsible in the households. Thus, women became our primary source of insight in to the way diabetes is managed in the household and daily life.

We decided that having focus groups with only women could be beneficial when it came to the freedom of discussion. The women were age 40+ and several of them were mothers and grandmothers. Participants in our study were given vouches to the local grocery store of between 60 and 100 ZAR (ca 5-8 USD), depending on the time spent.

We utilized a mix of opportunistic and convenience sampling of participants to our study. A criterion was that they either had diabetes themselves, or could provide significant insights to the phenomenon. Creswell and Creswell notes that during a fieldwork, the researcher rely on their judgment to select participants for the study, based on their research questions (Creswell & Creswell, 2007, pp. 127–128).

Due to safety- and access- related issues in Mitchells Plain, we recruited participants to the study from the Mitchells Plain chronic disease club. This happened at Mitchells Plain CHC. As we later came in to contact with Arisen Women through the community oriented primary care-pilot (COPC) we were provided access to members of the community in a way we couldn't from the clinic. Thus, allowing us to get a better perspective on life in Mitchells Plain.

4.3.3 Methods for data collection

The data collection methods have been qualitative. Qualitative research are developed to enable researchers understand people, and the social and cultural context within which they live (Myers & Avison, 2002). Crang and Cook elaborate on the choice of data collection methods during fieldwork, and states that the methods are mixed and matched according to the questions, but also according to the different opportunities that came up in the field (2007, p. 128). This description of choice of methods fits our experience from the fieldwork. We planned to conduct interviews and focus groups, but other data collection methods like informal conversations and participating in

meetings with the COPC-project were situations that "came up" in the field. In this chapter we will describe some of the data collections we have conducted.

4.3.3.1 Interviews

Interviews were our primary method of data collection in the beginning of our fieldwork, in order to identify and describe the challenges experienced by diabetes patients and develop design solutions to address some of the challenges they faced. The interviews with the patients were held at Mitchells Plain CHC where we had rooms at our disposal. To understand the context of their daily life, we wanted to conduct interviews in the homes of patients. However, this was difficult to achieve due to safety reasons. At the end of our fieldwork we got the opportunity to visit two patients in their homes.

Walsham writes about the importance of interviews in interpretive research. Interviews gives the researcher a source to gain insight in how the informant interpreters actions and events (Walsham, 1995, p. 78). The interviews gave us room to understand the individual, and talk about personal topics and opinions. We used semi-structured interviews, to assure that we covered some of the main topics we were curious about, but at the same time have the freedom to divert from the guide if the users brought up interesting topics that we have not thought of, or if we wanted them to elaborate on anything during the conversation.

Immediately after each interview, we wrote a short summary and discussed our experiences. All interviews conducted with the patients were recorded and transcribed to guide our analysis and to clear up misunderstandings. Sometimes the participants would mention names of dishes or products that we later could search for information about. If there were local references we didn't understand, we consulted our local contact at the University of Western Cape. The interviews with the patients were held at Mitchells Plain CHC where we had a private room to our disposal during our visits.

Figure 3 - Picutre of Ingrid in the room we conducted interviews in, at Mitchells Plain CHC

4.3.3.2 Focus groups

The advantage of conducting focus groups, is the opportunity to gather a broad range of opinions in a cost-effective manner. Additionally, there is the opportunity to better understand what are community issues and what are individual issues (Lazar, Feng, & Hochheiser, 2010), for example with managing and having diabetes. Two focus groups were organized to foster more discussion and get a better feeling of the community issues that arise with having diabetes type 2. One focus group was held with diabetes patients from Mitchells Plain, and one was held with two CHWs. This provided insight into the dynamics when patients talked to each other and we got a sense of the overall consensus around different types of topics. This might also serve as a weakness with focus groups, as individual differences may be lost, however we experienced that the participants were very open and sharing. They often disagreed and were unafraid to correct the others if someone made a claim they didn't identify with.

The goal of the focus groups was two-folded. Firstly, we wanted to gather the abovementioned broad range of opinions. Secondly, we wanted to get a better sense of the informants' understanding of diabetes by letting them explain to us and each other their strategies and knowledge about diabetes. During our interviews we experienced that several of our informants felt uncomfortable or perhaps embarrassed about his or her lack of knowledge. In the focus group, however, the atmosphere was relaxed. The participants were open and willingly shared their understanding of diabetes, diet and exercise, as well as positive and negative experiences with having diabetes. A photo from the focus group can be seen in figure 4 below.

We initially had planned to only conduct a patient-oriented focus group. However, as we recruited for the above-mentioned focus group, interest was expressed from a group of CHWs from Mitchells Plain CHC to participate. To avoid the group size becoming too large, we opted to have a separate focus group with CHWs. During recruitin, they indicated that they had diabetes (most likely because they thought they had to have diabetes to be allowed to participate), however when arriving it turned out that they simply wanted to learn more about the disease.

Both focus groups started with a discussion about the participants experiences with diabetes and ended with a session on diabetes-diet were the participants could ask questions. The focus groups were held at the board room in Mitchells Plain CHC, recorded and transcribed.

Figure 4 - Picture from the focus group with diabetes patients

4.3.3.3 Pictures

Crang and Cook writes about the potential of using photographs as a visual method. Photographs taken in the field can complement field notes, increase memory. Further it can supplement descriptions, and work as a reminder for what first seemed initially strange, but became familiar, or reveal things that one did not see or put attention to at the time the picture was taken (2007, pp. 106–107). We took pictures throughout the research process to document, look at the context and to supplement our field notes.

We did not take pictures of participants except from situations where we deemed it valuable to either document the process, like the focus groups, or to reflect upon later

in the research process. We took great concern in not showing faces, so they would not be identified, and we collected informed consent before taking any pictures. We also took photos at the home visit to remember and document the particular research setting. In these two situations the informants gave verbal consent prior to the photo being taken.

We wished we could have taken more photos of the research setting, but chose not to do so due to safety issues. Mitchells Plain is an area where we could have been exposed to serious criminal events if we did not take precautions. We were advised to not expose our cameras or valuables, and we only took pictures when we felt comfortable and safe. Below is a photograph of the view from Arisen Women's offices.

Figure 5 - photo taken out the window in from Arisen Women's offices

4.3.3.4 Workshops

One of the last methods we used in the fieldwork was a workshop with Arisen Women. The goal with the workshop was two-fold. First, we wanted to hear how their opinions about challenges with diabetes patients. Second, we wanted to hear their opinions and ideas for how Arisen Women could contribute in meeting the diabetes challenge, by listen to their ideas around solutions and interventions. The outcome of the workshop was several presentations, made by the CHWs at Arisen Women, of challenges, suggestions and solutions. These have functioned as inspiration and to help us guide our design.

We were inspired by the *sprint* method from Knapp, Zeratsky, & Kowitz (2016) when we planned the workshop. We used the method "work alone together". This method is made to improve problem solving by giving individuals room to think and work out solutions individually, before presenting it to the group, and further building og and re-working the ideas together with the group (Knapp, Zeratsky, & Kowitz, 2016).

On our workshop, the smaller groups worked on their ideas and picked one to present for whole group. We did this to foster a discussion if someone would not agree or had inputs. The method also left us a stack with papers where both the individual ideas and the group-ideas had been written down. As this workshop was our last meeting with Arisen Women, we found this valuable to bring back to Norway and use for further inspiration. The two photos below show the group discussions from the workshops.

Figure 6 - photos from the workshop with CHWs from Arisen Women. Faces are shown with permission.

4.3.3.5 Observations

An important part of doing the fieldwork is being there, doing the same things as others, and hearing what people talk and care about (Crang & Cook, 2007). As we conducted a fieldwork over 10 weeks, and spent much of our time in Mitchells Plain, we have extensive amounts of hours of informal observations. By this, we mean that we found ourselves in situations that made impressions on us, and that we discussed and described in our field notes and with other stakeholders. Apart from this, we only had a few planned observation sessions that we conducted at Mitchells Plain CHC. Here, we took notes and made drawings of different sites in a notebook. These observations made it easier to remember locations and actions and has been useful when we have reflected and interpreted during the analysis.

During the fieldwork, we also participated in several of the meetings with the COPC-pilot project group at Mitchells plain CHC. Since we were writing about the diabetes challenges, the family physician at Mitchells Plain CHC thought it would be useful for us to participate. In the initial meetings, we did not interrupt the meetings unless someone asked for our opinions, but sat at the same table and took notes about what was being said. In the later stage of the fieldwork, we contributed with a presentation of our findings thus far and had a more participatory role. During the fieldwork we participated in three meetings.

4.3.3.6 Documents

During the time at Mitchells Plain CHC, we gathered different types of written information like diabetes-pamphlets and information sheets and brochures regarding diabetes that are given to the patients. We found it interesting to look closer at the content and compare it. We used the documents as part of our interpretation on challenges with lifestyle-advice that are given to the patients.

4.4 Data analysis

In this section, we will elaborate on how we have analyzed our data throughout this research process. In chapter 6, we use the capability theory to help us understand the empirical data, in addition, applying theory to empirical data has helped us understand more about the theory. In this section, we describe our process of analysing as a *hermeneutic approach* to describe how we in addition has interpreted and understood data throughout the process.

We understand the essence of hermeneutics to be the hermeneutic circle. The hermeneutic circle is the process of trying to understand the "whole" by alternating between analyzing the parts, looking at the whole, and revisiting the parts (Myers, 1997). This process of looking closer at the many data sources, and trying to make sense of them separately, while continuously attempting to let them inform our understanding of the whole has been instrumental for the way we have worked with understanding diabetes as a wicked problem, both before, during, and after our fieldwork.

Traditionally, hermeneutic analysis has primarily been concerned with understanding the meaning of a text, or a text-analogue (Myers, 1997). We have based our analysis on the transcriptions from our workshops, interviews and focus groups, in addition to the fieldnotes from the field work. While the fieldnotes describe how we interpreted an occasion or situation in the moment we wrote it down, we find the term *headnotes* useful to describe how our process of thoughts about the situation evolves through time. Sanjek (1990) conceptualized headnotes like this:

> *"the field-notes stay the same, written down on paper, but the headnotes continue to evolve and change as they did during the time in the field" (Sanjek, 1990, p. 93)*

Our understanding of the case and the context has evolved throughout the research process, especially aided by our internal discussions during the fieldwork about the things we experienced. The way we interpret a phenomenon will therefore not always be reflected in what we have written.

In our empirical chapter (chapter 5) we have sought to ensure that our interpretation represents the views of our informants. We do this by letting the story unfold through the quotes and words our informants used to describe their realities. By doing so we ensure that the voice and views of the informants are not lost to our own interpretation.

4.5 Design approach

Before our main fieldwork, we had planned to conduct a user-cent red design-process (UCD-process), such as the one described in figure 7 below. In a UCD-process, the designer put the user (of the potential technology) in the center of attention, letting the user's needs, goals and preferences guide the design. The aim of the designer is therefore to research what the needs, goals and preferences are, and how a design can

be created to meet these needs (Abras, Maloney-Krichmar, & Preece, 2004; Dabbs et al., 2009).

Figure 7 represents one example of a UCD-process model. The steps in the model are meant to be conducted in iterations, through a process of gaining insight, analysis, design and prototyping, and evaluation of the design. A core aspect to UCD is for the continued involvement of the users and stakeholders in every phase of the design (Saffer, 2010). The three colors in the figure represent our vision of the six steps in the mode, divided in to three phases:

Phase 1- Green - Gain insight and establish requirements.

Phase 2 - Yellow - Designing alternatives and prototype.

Phase 3 – Blue - Evaluate.

Our vision for the ten-week fieldwork was to get through all three phases, before returning to Norway. However, we started getting in to the context, we realized that the problem we were facing was very complex, and that it would be misleading to propose design solutions before we better understood the wicked problem of having and managing diabetes.

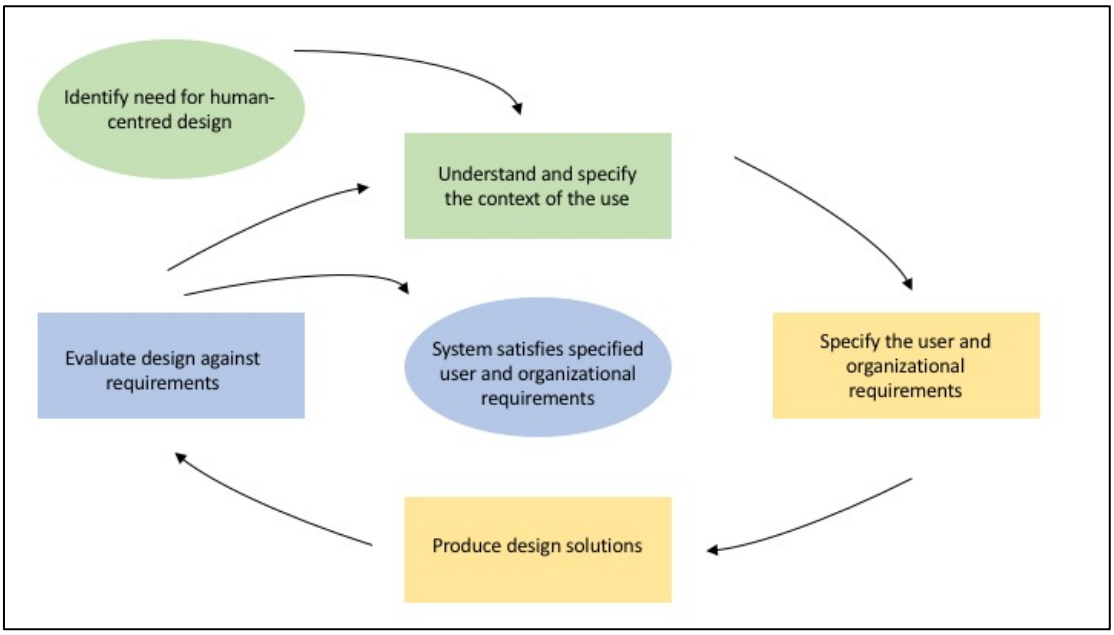

Figure 7 - This illustration is based on the ISO 13407 standard (Pagliari, 2007) for human-centered design processes for interactive system

While the plan was to follow all three phases of an iterative design process, we ended up with using our entire fieldwork to understand the problem area, thus focusing on the first phase (green), and partly the first step of the second phase (yellow). The primary part of the second phase has been conducted after the fieldwork, through a process of analysis and ideation. This is the work we present in this thesis.

If we had even more time, our goal would have been to continue the iterative process, especially focusing on evaluating the designs with the users (people with diabetes) and the other stakeholders in Cape Town and Mitchells Plain.

Even though we did not follow the entire process, we find it useful to reflect on how the UCD-approach has influenced our research. Our focus on understanding the patients' and other stakeholders needs in relation to our research questions was heavily influenced by the philosophy behind user-centered design: namely to put the users experiences and needs at the center of attention.

4.6 Ethical considerations

There are several ethical considerations we have had to consider when we conducted this research. Here, we will briefly go through some of the most important ethical considerations for this project.

4.6.1 Permission

To conduct research in South Africa, research permission is needed. The process of getting research approach is extensive and involves writing a detailed description of the planned fieldwork, and writing a thorough research proposal. First, ethical clearance from the University of Western Cape was obtained before our research proposal was considered for approval by the Western Cape Government through the National Health Research Database (NHRD). The process started in April 2017 and permission was granted August 2017. Additionally, the study has been approved by Mitchells Plain Community Health Centre before commencement of the study.

4.6.2 Risks

Diabetes and lifestyle changes may be a sensitive topic, thus there are risks attached in interviewing patients. The participants may become distressed during discussions about their diagnosis and about how they have attempted to make lifestyle changes. Before we conducted any interviews, we made preparations for the potential

situations that could occur during an interview. At Mitchells plain CHC we were had contact with available staff or health workers that we could refer participants to should they experience any form of distress. This recognition also influenced how we talked about the disease and potential end-stage complications from diabetes with the participants. Trying to be mindful, and sensitive to their circumstances. We did not experience any situations where patients became distressed.

4.6.3 Participant Information Sheets

Participant information sheets was provided to all participants. The information sheet was available in English, and we also went through it verbally, in case any of the patients had challenges with eyesight or literacy. The participant information sheet contains the title of the research, its purpose, a description of the research process, what being a study participant will involve and a request for them to consider being a participant in the study. It assures them that participation is voluntary and deciding not to participate will not have any negative consequences for their care. It also informs them that even if they elect to participate, they are free to withdraw from the study at any stage, without any negative consequences.

4.6.4 Consent

Written consent was sought and provided by the participants' by signing the consent form to show that they have agreed to participate. Separate consent forms were provided for the interviews and the focus groups. We collected consents form from all participants.

4.6.5 Confidentiality and anonymity

Confidentiality and anonymity is ensured by not using names or showing faces of the participants. An exception has been made for the CHWs at Arisen Women, whose faces are shown in our photos.

4.6.6 Being white in Mitchells Plain

As we described in section 2.2 *South Africa*, the "contours" of the apartheid regime is still visible. The different areas of Cape Town have quite distinct racial profiles still, and many of our informants used race to explain differences in culture and habits. In fact, coming to Cape Town our first time, we were both surprised at how common it

was to bring up race in explanations and discussions. Throughout our fieldwork we experienced almost daily people bring up their or others' race as an explanatory factor.

During the fieldwork it therefore became natural for us to reflect upon our skin color. Being white made us stand out quite distinctively in Mitchells Plain. During our visits to the clinic, many of the patients took us automatically for being doctors, even though our clothing was deliberately casual. We were pleasantly surprised in the beginning of how welcome we were made to feel at the clinic in Mitchells Plain, both by the patients and the staff, and we were surprised at how eager people were to participate in our study and give up their time to be with us. The fact that we are white might have influenced the perceptions people had of us, and the opportunities we were afforded during the fieldwork.

4.6.7 Answering questions about diabetes

Both the CHWs at Arisen Women and the patient-informants had many questions about diabetes. Several of the patients expressed that their motivation to participate was to learn and get advice.

In the beginning, we found it difficult to know how to act in the situations where patients asked us for advice. We approached the dilemma by discussing it with the family physician at Mitchells Plain. His opinion was that it was better that we share our knowledge with the patients and CHWs who had questions, as we were in a position where we knew more about the disease than the patients and the CHWs we interacted with.

We have spent many hours researching diabetes type 2 and have discussed our understanding of diabetes with doctors and diabetes researchers, to confirm our knowledge is correct.

When sharing our knowledge, we were careful not to give harmful advice. We were extra careful when a patient used insulin-injections. In such cases, the insulin dosages have to be calculated to match the food intake and energy expenditure. For that reason, intensive exercise can pose a risk of experiencing hypoglycemia, if the insulin dosages aren't calculated correctly. Generally, we focused on giving information about how the disease affects the body, and why amputations and ulcers occur, as well as safety advice about diet. The diet advice was directed at guiding their understanding of complex and fast-acting carbohydrates, and clearing up misconceptions, in addition to explaining the value of eating less fat and sugar.

5 Empirical Findings

In chapter 4 we presented our research approach, methods, and fieldwork in a chronological order. The goal of our fieldwork was to investigate how individuals living in Mitchells Plain with diabetes relate to and think reflect about the disease, and in turn, how those reflections materialize in to strategies to manage a lifestyle change. In order to "untangle the knot" that is the wicked problem of managing the diabetes epidemic, we have sought to include the perspectives of multiple stakeholders: health providers, health strategists, health researchers, NGOs, and most importantly individuals living with diabetes type 2. The aim of this chapter is to convey the big-pictured, but multifaceted views on managing diabetes in Mitchells Plain. Our goal in this chapter is to convey the multifaceted views on managing diabetes, while not attempting to hash out every connection and contingency related to managing diabetes in Mitchells Plain.

Although it is straightforward to provide a detailed account of the activities we undertook during our fieldwork, a coherent and structured description can not only be challenging but also counterproductive when dealing with wicked problems. This counter-productiveness is described in the reflections of John Law on how to present messy phenomena in social science:

> *"[…] simple clear descriptions don't work if what they are describing is not itself very coherent. The very attempt to be clear simply increases the mess" (Law, 2004, p. 2)*

In the context of Law (2004), the attempt to simplify and categorize neatly might lead to loss of information and a skewed view of the wickedness of problem. Although, we aim to describe our empirical findings in a way that is easy to follow for our readers, simplifying and delineate phenomena that in reality affect and bleed in to each other might undermine the complex reality of managing diabetes in Mitchells Plain.

For this reason, we have chosen to tell the story from its many-sided, by taking a comprehensive approach to the way we present our empirical findings. Our approach aligns with Flyvbjerg's views that learning from a wide range of detailed case experience can move a practitioner from a rule-based novice to an expert. In order for this thesis to have a learning value, we aim to present our data in such a manner that the reader can take our findings and build on them. Aligning with Flyvbjerg in attempting to:

> *"tell the story in its diversity allowing the story to unfold from the many-sided, complex and sometimes conflicting stories that the actors in the case have told [us]". (Flyvbjerg, 2006, p. 238)*

On the one hand, portraying our empirical data in a too categorized and "clear cut" way would undermine the wickedness of the problem, yet - on the other - having no categories or themes to rely on would make the text incoherent and not least impractical for others to learn from. Thus, in an attempt to balance the line between "incoherent mess" and "counterproductive order" we relay our empirical findings through three sections: 5.1) *Diabetes management in Mitchells Plain*, where we reveal the struggles on diabetes management afforded to us by spending time at Mitchells Plain CHC and through interviews, 5.2) *Arisen Women*, where we present the NGO of community health workers that are part of the COPC-pilot in Mitchells Plain, and finally 5.3) *Patient perspective*, where we emphasize the patient experience in its diversity.

The focus of this thesis is the patients and their experiences. For this reason, the patient perspective makes up the bigger part of the chapter 5. Further, the perspectives afforded by the staff at Mitchells Plain CHC and Arisen Women serve as an introduction of themselves and of the community of Mitchells Plain.

Furthermore, the patient perspective in section 5.3 is divided into subsections, each representing reoccurring themes from the patient perspective on lifestyle and diabetes. Therefore, some of the themes in the subsections may overlap, as often reality does. Insights in to the patients' food culture, priorities, views on a good life, knowledge about diabetes and motivation to make changes will be revealed as the chapter progress.

We impose some level of order in section 5.3 by trying to highlight three areas of inquiry:

- *Why do so many people get diabetes?*
- *In what way does the patients understand **why** lifestyle must change?*
- *In what way does the patients understand **what** will make their lifestyles more diabetes-friendly?*

5.1 Mitchells Plain

During our preliminary-fieldwork in Cape Town, our first introduction to Mitchells Plain happened at the Mitchells Plain Community Health Clinic (Mitchells Plain CHC), where we were met by the family physician at the clinic, and a doctor working with diabetes. They explained the high prevalence of diabetes in the area in this way:

Family physician: *"[The factors in the area that lead to a high diabetes prevalence] are all interwoven, but people have very unhealthy lifestyles. And, unhealthy lifestyles that are aggravated by stress. The area has a very high incident of crime, drug addiction, a lot of our patients are elderly, and has children or grandchildren. Most of the children or grandchildren are addicted to drugs, in one form or another, so it is tremendous stress in the households. And most people that are diabetic try to stretch their money to feed themselves, so they are eating food that are cheap calories. And cheap calories are high in carbohydrates and has a long shelf-life. You might get a bag of mielie-meal to last you the whole month – you know maize-meal."*

Doctor: *"-There are households that don't drink water. When they eat they take their meals with soda."*

Family physician: *"-Yea cool drinks! Cool drinks are, there is a whole range of companies that make it. […] It's not only the big companies like Coca Cola and Fanta. There is a whole industry here, Jive, Double O […] and they produce this toxic stuff – high sugar. And people here grow up on this. Kids grow up on this. And we know that they get sugar addicted. There is also a culture of eating junk food. There are more fast food outlets in Mitchells Plain per capita than in any other area in Cape Town, because they make a lot of money. They are the busiest [here].*

"And so, there is many many factors – there is genetic factors as well. There is a high population of people of Cape Malay and Indonesian decent, and those people have been eating diabetogenic diet for hundreds of years. Very fatty and carbohydrate rich diets, that have now literally adjusted the genepool. Patients are born now with a genetic pre-disposition to become diabetic."

"[…] We obviously have type 1 diabetics in our community as well, but in this community, the epidemic we are talking about here is type 2 diabetes, that emerge because of all these historical, cultural, socio-politcal and economic factors."

-Excerpt from our first meeting with Mitchells Plain CHC (Jan, 2017).

This was our first introduction to Mitchells Plain, and throughout our main fieldwork we would get many of these notions confirmed by other members of the Mitchells Plain community. The excerpt provides a brief introduction to the community of Mitchells Plain, and can be useful to understand the magnitude of factors that together create a difficult environment to be healthy in.

5.1.1 Diabetes management at Mitchells Plain CHC

During the above-mentioned meeting, it was established that Mitchells Plain CHC are seeking ways to better provide health care to their community. The current situation is very pressed. Mitchells Plain CHC is the only community clinic serving the greater Mitchells Plain, and about 700,000 people appertain to the clinic.

This high number causes the clinic to be burdened with long lines. For drop-ins and new cases, there is a queue-system where the patient gets a number and are sorted according to the degree of urgency. The family physician at the clinic estimated that the doctors could maximum spend 8 minutes per patient to make it through all the daily visitors.

There are many chronic patients, who have to come in often to renew their prescription. Recent years Mitchells Plain CHC reorganized their routines to address the waiting times, and the family physician noted that the previous waiting time could have been up to 13 hours:

> *"Before implementing the system, patients would typically arrive before 05:00 and leave after 18:00, sometimes without their medication." (People's Post Mitchells Plain, 2016, p. 1)*

This new system is called the *chronic club* where they assist the patients who have diabetes and hypertension, in a back-to-back process. Approximately 14.000 of the patients in the Mitchells Plain Chronic Club have diabetes. Of these 14.000, 99% are diagnosed with diabetes type 2 (Personal Communication, Family Physician, 2017).

In the chronic club, the patients come in at scheduled appointments every 6 months, with intakes at 07:00, 09:00 and 11:00 every day. Each intake receives approximately 200 patients through a process of taking new blood tests, seeing a nurse or doctor, and picking up the prescription for the next 6 months. The chronic club system has brought waiting times down from up to 13 hours, to an average on 2 hours.

Two hours is a definite improvement compared to spending thirteen hours at the clinic. However, this waiting time is for the chronic patients who are on a stable treatment regimen. For people who feel sick or need a consultation, the alternative is the drop-in system. Here, queues are still long even though the implementation of the chronic club has lifted some of the burden on the lines for the pharmacy. In addition, the queue system requires the patient to arrive early enough to be seen. A staff at Mitchells Plain CHC indicated that if you come after 09:00, it is likely you won't be seen by a doctor that day. As a result, people show up as early as 04:00 and sacrifice full days of work to tend to their health. The unpredictability and long waiting times function as a barrier for people to show up to the clinic when they start to feel sick. As a result, many people wait until they really cannot postpone a visit any more, leading to a later diagnosis than desirable. A community health worker noted:

> *"[The patients] have to wait there for hours, so they sometimes don't even want to go. Because remember they don't have the money and they have to eat at a certain point. So, [they] take nothing with and wait for hours. So, some choose to just not go."*

In the population which appertains to the CHC, the prevalence of diabetes type 2 in people over 40 is estimated to be 28.2%. However, most people living with Type 2 are thought to be undiagnosed. The family physician at the clinic put it this way:

> *"Patients who are in the clinic are the lucky ones. They are diagnosed, they are on treatment, they got a chance. The biggest need is in the community. The number of patients who are undiagnosed are high, and we also know that our capacity to absorb those patients are extremely limited" (Family Physician, Mitchells Plain)*

In our discussions with the family physician and other staff at Mitchells Plain CHC, the limited capacity to prevent the diabetes epidemic, is described as one of the biggest challenges they face. Organizing health care through *Community Oriented Primary Care* (COPC) is a way of bringing the health care closer to the communities. During a meeting for the COPC-pilot project in Mitchells Plain, a fitting analogy was presented together with the illustration presented in figure 8 below:

In order for *Team Health* to win over *Team Epidemic*, Team Health has to be able to score some goals as well. The burden of disease in Mitchells Plain restricts Mitchells Plain CHC to – currently - only being able to play defense. People in the community are getting sick without properly understanding the causes. In other cases, illnesses and symptoms progress too far before the patient turns up at the clinic. The clinic in turn has no capacity to reach the community such that disease is detected at an early stage. Teaming up with local community health workers (CHWs) through the COPC-program allows Team Health to finally score some goals, by catching diseases earlier and do preventive work.

Team Health vs Team Disease

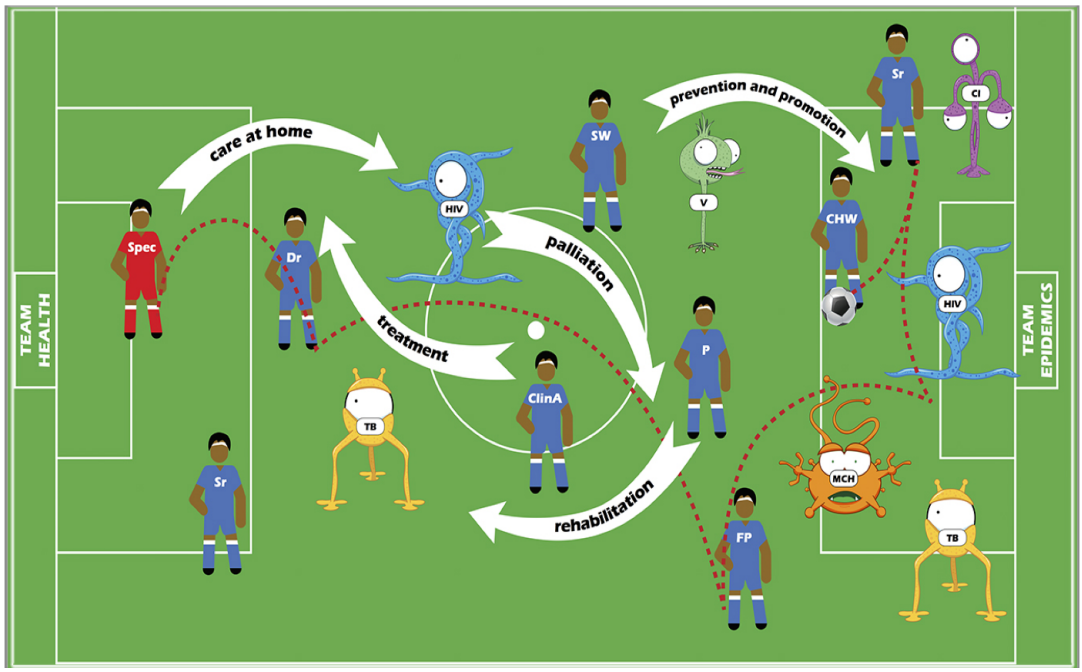

Figure 8 - Illustration of the analogy presented about the fight against disease

5.1.2 Community Oriented Primary Care (COPC)

There are four process steps to organizing and implementing COPC, where community involvement is critical to each step (Nutting & Connor, 1984):

1) Define the community of interest

2) Identify the health problem

3) Develop and implement interventions

4) Conduct ongoing evaluation

This is further carried out through a continuous process. The essence here, is to be aware of the health issues the defined community face, and to implement tailored interventions that target the specific community.(Mullan & Epstein, 2002)

The COPC pilot project in Mitchells Plain was introduced in October 2017. The aim of the project is to involve and cooperate with the community in order to create a better health service. In the COPC-pilot-project, Mitchells Plain CHC teamed up with a local organization called Arisen Women that consist of community health workers (CHWs). Together, they will promote health and preventative interventions at the household and community level.

The task of bringing the health care closer to the communities is done by having the CHWs go from household to household. Each CHW is given responsibility of 200 households, of which the cares at Arisen Women will assess the health status of each family member in the household.

In the long term, the COPC-project can be part of restructuring of the health service in Mitchells Plain, with decentralize the service, and release capacity on the health clinic.

> *The aim of the project is to change the focus of health services – from only reacting when people become ill enough to come for care, to proactively looking at a whole community and addressing the most important challenges,a together with residents and -organisations (family physician, Mitchells Plain CHC).*

5.2 Arisen Women

5.2.1 Introduction

Arisen women are the Non-Governmental Organization (NGO) that collaborates with Mitchells Plain CHC through the COPC-pilot mentioned above. They established in 2002, and are based in Mitchells Plain.

The organization model is based on having volunteers from the local society that work for a small economic support, they are called carers but are referred to as Community Health Workers (CHWs) in this thesis. The CHWs in turn get relevant experience with health work, by supporting the people in their community. During the time at Arisen Women, the CHW will be trained in both theoretical and practical experience with nursing care. Some of the carers use this experience to continue on to further education in health.

Today, there are 153 CHWs working for Arisen Women. They are organized in different groups which focus on different work tasks. During our main fieldwork we followed one such group at a home visit to a diabetes patient. Four days a week they do home-based nursing care. Thursdays, the CHWs meet at Arisen Women's office to share knowledge and get training and education from experienced nurses and organizations.

Arisen Women is an established organization in Mitchells Plain. The CHWs already has responsibility to follow up patients and help them with various health-related tasks. With the COPC this structure is becoming more streamlined.

5.2.2 Needs and wishes

During our fieldwork, we spent some time with Arisen Women. We attended some of their Thursday-meetings, conducted a group-interview, individual interviews, a workshop and joined them on home-visits.

In the group-interview we discussed diabetes and the knowledge that is needed to provide good advice. During this discussion, the CHWs had many questions for us, and expressed a wish to build more knowledge and experience to provide better care for their patients. They wanted to educate themselves so that they could educate others. They also expressed that they wanted other health workers to come and teach

the patients: "*they won't listen to us*". They were worried that they sometimes were giving the wrong information to the patients because they themselves were unable to into details. They wanted to learn more about diabetes, about symptoms on diabetes, and also knowledge about diet.

When we discussed the role of sugar in their community, many were surprised at how unhealthy it is. They expressed a wish to give more information to the community, for example in churches, or in schools. They want to teach the children about healthy food habits. One CHW put it like this:

> *"Education is careers first, patient second, and then the whole family."*

5.2.3 Some praise

Even though the CHWs sometimes wish they had even more knowledge, and authority facing the patients, the women we met at Arisen Women are very engaged in being a positive force in their community. They are themselves part of the community and are often just as resource poor or resourceful as their neighbors. While there is a small economic grant provided for their work, it is not enough to count as a full income. The work they do consist of going from door to door in the different areas of Mitchells Plain often with a planned schedule for patients to see, and defying the high crime levels to do so.

During our main fieldwork, a group of CHWs had been caught in the crossfire of a drug-related gang shooting. The CHWs managed to get in to a house in the area, and when the shots died down, they were determined to finish their route. During the next couple of weeks, four more shootings occurred in the streets of Mitchells Plain - that they knew of. Within only two weeks after the incident Arisen Women had worked out an escape-plan with identified "safe-houses" or churches on every street, that they could hide in if need. This story expresses some of the engagement the CHWs have for continuing to work for their community, even in extreme conditions

5.3 Patient perspective

In relaying the patient perspective we build on the quotes from our focus groups, workshops and interviews. The quotes represent the words and phrases people in Mitchells Plain used. In some cases, the quotes are re-written for the sake of coherence and clarity. For instance, interruptions are edited out where they don't serve a purpose. As mentioned in the introduction of the chapter, we relay the patient perspective by going through the three questions:

- *Why do so many people get diabetes?*
- *In what way does the patients understand **why** lifestyle must change?*
- *In what way does the patients understand **what** will make their lifestyles more diabetes-friendly?*

Why do so many people get diabetes type 2?

Backdrop

In subsection 2.2.2 we introduced Mitchells Plain and some of its main characteristics. The main takeaways from that introduction is the high prevalence of poverty, and crime rates. Especially the prevalence of drugs (mainly *Tic* - crystal meth) has disrupted many families. Many of our informants were adult women who often had a large responsibility in taking care of their families. In many cases that responsibility included her grandchildren in addition to her own kids. In effect, many households contain several generations. These factors serve as the backdrop of circumstances people in Mitchells Plain have to deal with and can be useful to keep in mind while following the rest of the empirical findings.

In the next sections, we will tell some of the stories and findings from the fieldwork. We start with looking closer at one of the many aspects that affects the high prevalence of diabetes in Mitchells Plain. We do not claim to answer the question of why people get diabetes, but we try to shed light on some of the factors that contribute to it.

«Us colored people eat the good stuff»

During our time in Mitchells Plain it became apparent that the food culture was a very important source of life quality. During many our interviews, the informants reminisced about the food they used to eat before getting diabetes:

> *"I tell my kids I cannot do it anymore because I am diabetic, so you can't eat it. It is a change for them also. I used to eat samosa - you know, and pies, and ... All that stuff I make it myself but now I'm diabetic I cannot do it anymore. [Pause] I can do it, but we are not allowed to eat that."*

People were also keen on showing us and sharing their local food with us. When having tasted a curry at one of our gatherings with Arisen Women, one of the Community Health Workers (CHWs) described the food in the area in this way:

> *"The accany is meat with potatoes and just rice. It is just rice. We will have that if it is a party, or just cook it because we like it, but we like tasty food with lots of spice, lots of salts, so it is hard for a diabetic person to not eat the way we eat. -Try to eat it! It will make you understand. Samosas is with lots of oil, made with onion and deep fried." (CHW Arisen Women, interview)*

The same CHW explained to us how "everything" in Mitchells Plain is an excuse to gather around food. In these explanations offered by several of our informants, it was explained that there was a common food culture in Mitchells Plain, by saying things like "us colored people eat the good stuff". It was notable that few people referred to what he or she personally liked, but used this classification of "us colored people" or "we eat" the samosas and the curries. This indicates that food is an important identity marker in Mitchells Plain.

«We have sugar on everything»

Sweets, sugar and desserts also play a big role in Mitchells Plain diet. This was highlighted by many of our informants. By the family physician at Mitchells Plain it was explained that sugar became more accessible towards the end of the apartheid era, and that it became a small source of luxury in an otherwise tough daily life.

Several informants told us about how "we have sugar on everything, even the vegetables" the explanation offered was that it would taste bitter otherwise. Similarly, when we turned down sugar in our coffees we got the reaction:

> *"Hah! You Norwegians like the bitter stuff!" (CHW, Arisen Women)*

The CHWs at Arisen Women explained to us how cool-drinks (soda) is commonly consumed several times a day, and that most of their patients was reluctant to cut down on their intake. This was apparent from our interviews and focus groups as well:

> *"Oh lord, don't take me away from coke! Haha!" (Patient, workshop)*

> *"I can't control myself with cool-drinks, because my son is with me at the moment, and he buys it. I bought two Jives on Saturday, and from the one bottle I had two glasses." (Patient, workshop)*

Generally, it was apparent that the opportunity to treat oneself with a piece of cake, chocolate or sweets was highly valued. In one focus group, a participant explained how she sometimes indulged herself with a candy they called sour plum:

> *"It is a sweet [thing], I like it. I am not supposed to eat it, but it taste so salty and sweet. I call it the sour plum sweet. It is a tiny fruit in it. I was so greedy, so I bought me a whole pack - a 50 rand packet. I ate it all! It was 50 rand for a 100!" (patient, workshop)*

Such revelations were met with both awe and support by the other participants. Most of the ladies in the focus group had examples of their own about things they craved. In one interview, the informant told us how chocolate used to be part of her break from a hectic life, and that she lacked alternatives that fulfilled her:

> *"At the end of the day what about me? I used to have some chocolate with my 'me-time', but now I cannot buy chocolate, because I am diabetic, so what must I eat now? A carrot?" (patient, interview)*

All in all, sugar, sweets, chips, candies are central in everyday life. Things that are not sweet are explicitly seen as bitter. The thought of not giving candies to their children when they can afford it seemed a foreign thought. In fact, when we told them about the tradition we grew up with – the concept of only giving candy to children in Norway on Saturdays, we were met with big eyes and muffled laughs.

When our informants described the food they liked, and the sweets they craved, they did so with passion, almost daydreaming about those moments when it was consumed. Many of our informants did not know that the food and sweets were harmful.

While most of the informants didn't focus on the details of how tough their lives are, during our one-on-one interviews it became apparent how tired, burdened by responsibility and stressed the informants were. For them, sweets and good food, and the moments that followed, were a small source of comfort, in an otherwise uncomfortable life.

«My children are not going to eat that food»

The culture around food was also explained to make it difficult to make healthy choices during festive times:

> *"When the holidays come up, you eat all the wrong things! You go visit, and people put out the plates with all the luxury stuff, and it is so difficult to say no." (Patient, focusgroup).*

One of the CHW shared thoughts about how difficult it was to stay away from certain food types when all the others at a party could eat it:

> *"If you eat that chocolate, my mouth is going to water for that chocolate, because that is who we are". (CHW, Arisen Women)*

Pressures (and cravings) to eat "the good food" as opposed to "healthy food" was a topic that often came up. One CHW explained how a balanced diet was viewed as something only the person with diabetes needed to eat:

> *"If I make for a diet - a balanced diet - my children is not going to eat that food. Most of them are not going to eat that food, because it is only for one person. [the person with diabetes]" (CHW, Arisen Women)*

In general, such views became apparent through the way people expressed themselves about the dietary changes they had to make. "Good food" and "healthy food" were seen as opposites, and eating "healthy food" was seen as a mandatory act only sick people had to commit to.

«Why go to the gym?»

Similar attitudes were apparent from discussions about exercise. Exercise wasn't a topic that came up unless we asked. It seemed that there was a general disinterest in the concept. One informant explained:

> *"If you try to go to the gym, people say 'Oh, why do you do that?'". (patient, interview)*

While another said:

> *"I heard people say there is a lot of activities with a Diabetic Club, but I must say I'm too lazy, I am too lazy to go" (patient, interview)*

We also discovered that several informants first and foremost connected exercise to the task of preserving healthy feet to avoid complications. Our impression is that most people were unaware of how effective it is to exercise with a certain amount of intensity. Both in order to lose weight, but also as a benefit to increase insulin sensitivity. This became apparent through formulations such as this one:

> *Because I do my exercise […] the doctor says to press my toes up and down. So, I do my exercise because I'm very anxious about my feet. If they amputate my feet I don't know what is going to happen." (patient, interview)*

«People die because of lack of knowledge»

The empirical data we have relayed so far provide some insight in to the prevalent lifestyle in Mitchells Plain. Generally, people who were diagnosed with diabetes knew that they should not eat sweets and "fatty food" as they had been instructed. However, almost no one connect their diets and lifestyles to potential risk of diseases before being diagnosed. We witnessed a lack of understanding about how a different diet could have prevented diabetes, and that their children and family also were at risk of getting diabetes if they didn't change their diets too. While some informants made healthy food for the entire family after being diagnosed with diabetes, several informants reported that they made their healthy food separately while the family still ate the same:

> *"[…] because [the family] like the **nice** food." (patient, interview)*

When the same informant was asked whether or not she was worried that her family members also would get diabetes she said:

> *"No, they know by me, they must be careful themselves. Yes, they are careful, they cook their food. Always with the vegetables." (patient, interview)*

This statement revealed an inconsistency between claiming that the family still ate the "good food" and that the family had changed their diets. We experienced this type of reasoning with several of our informants: that the family was healthy because they could learn from themselves how difficult it is to have diabetes – while at the same time claiming the family didn't want to change their habits just because "mommy has to". This points to a lack of understanding the connection between diet and diabetes.

A lack of understanding also applies to the harmfulness of sugar. In our first meeting with a group of 25 CHWs from Arisen Women, several participants reported that their patients knew little about the effects of sugar. One CHW said that:

> *"People die because of lack of knowledge"*

And also, that her patients would say:

> *"Life is already bitter, therefore I won't eat bitter stuff".*

In what way does the patients understand why lifestyle must change?

In subsection 5.1.1 we described some of the struggles Mitchells Plain CHC face with following up and giving information to the patients. The vast number of patients with chronic diseases contribute to an overburdening of the clinic. These circumstances are known to Mitchells Plain CHC and are part of the reason why the COPC-pilot has been initiated. In this next section, we try to highlight how the lack of knowledge affects the patients in Mitchells plain.

«I wish there was a cure»

We found that a lot of people struggle to understand how big of an impact their diet can have on the disease. Above, we described how the patients didn't really understand the importance of diet before they got a diagnose. However, even when they were diagnosed, the connection between diet, lifestyle and disease remained blurry for most people. Especially, we saw that there was a lack of understanding about how and why diabetes-complications could occur. We interviewed several people who had been forced to amputate one or both legs. When asked if they knew why the amputations had to take place, one informant said:

> *"This one? It was the poison that came to the leg. And this one will also get it [points to the other foot]. [The doctors] say it will move to the second leg. I try to avoid it. I pray and pray and pray. You know. It must not go to the second one. That they must not cut my leg" (patient, interview)*

The way she spoke about it revealed a feeling of powerlessness:

> *"I wish there was a cure - why haven't the doctors found a cure? The poison shouldn't move to the other leg. There should be a cure". (patient, interview)*

When asked about what can be done to bring blood glucose levels down, and to avoid complications the patients had a tendency to focus on adhering to the medicine routine. However, one informant stated that:

> *"It's better to have HIV than sugar-diabetic. With HIV the people just take a pill and live long and are not getting sick every day every night. They can just take a pill and still be beautiful. For us, you must just take the tablets(medicine), but the tablets don't always work. They are supposed to have something that work! It's just something to just help you that moment." (patient, interview)*

This understanding of disease can perhaps be linked to their knowledge of other common diseases, especially communicable diseases. The types of diseases you "get" by accident or the likes (like HIV, viruses, diarrhea etc.) and that you get "cured of". Most of our informants could not explain why they got diabetes, even when they moments before had told us about the diet a diabetic person had to adhere to. The result is that many people continue to have a fuzzy understanding of what a lifestyle change can contribute with for them, even after they are diagnosed.

«Do's and don'ts»

The lack of information can likely be attributed to the mentioned circumstances at the Mitchells Plain CHC, and the lack of reliable information sources that fit the patients' needs. By this we mean that much of the pamphlets and messages the patients receive have a very basic message, outlining only the most basic level of information. Advice is often formulated in terms of simplified lists of *do's and don'ts*, such as "avoid fatty food, sugars and starches" and "eat more fruit and vegetables". However, this can also be confusing because potatoes, grapes and bananas are in both categories. The information that is provided give a general idea of what to do, but leaves it up to the patient to translate the advice in to concrete actions and choices. In contrast to the specific lists with *do's and don'ts*, we found other pamphlets to very simplified, leaving room for misconceptions regarding diet. Two examples are depicted in figure 9 below. To the left, the message is that the patient should eat less, which can have great impact on losing weight, however we find the attached picture to be misleading, as it depicts a plate where the bread fills almost a quarter of the plate. To the right, picture can indicate that the patient can eat white bread, biscuits and chocolate.

Figure 9 - Two examples from diabetes-pamphlets in Mitchells Plain

In addition, the advice rarely seemed to be adapted to the patients' individual circumstances. One person described the advice he got from a dietitian this way:

> *"if you go to a dietitian, they tell you: You must eat that food and that food. But they don't know if you can afford to buy the diet food. Because the diet food is expensive. And as we are pensionist, we have little money. If we are going to buy diet food everyday, there is nothing there for us before the end of the month. We can only live on what we can afford." (patient, interview)*

During our interviews, we discovered that most people had a very basic knowledge about what to eat and not. The informants could list some basic traits of a diabetes-friendly diet, but it was very much focused on the list of things to avoid. The list below contains the most common foods that featured the answers we got:

- No fatty food
- No starches
- No sugar
- No carbonated drinks
- No salt
- No oils
- No spices
- No canned food

Mostly, these rules are correct, but contains some misunderstandings and lacks nuance. Further, the informants seemed to **accept** that this was the diet they should eat without really understanding how it could impact their blood glucose levels.

This was revealed when we asked about their strategies to lower their blood glucose levels, and we mostly received answers that regarded "quick remedies":

> *"I am clever. I use all the remedies. My friend told me, I must buy Diabon. […]*
>
> *-What is it?*
>
> *"That is for your sugar not to, what can I say, to lessen your (..) for diabetic people… it is like a vitamin.[…] Not everyone buys it, because it's expensive. 110 Rand. For the month."*
>
> *-Do you find it worth it?*
>
> *"Yes, with my health concern I am really worried. I'll do anything."*

Diabon is a vitamin supplement. On the package, it claims to be adapted to people with diabetes. It will not affect the blood glucose level directly. Similarly, several informants mentioned the effect of using cinnamon and water to bring down the blood glucose levels:

> *"I got a friend (..) She told me I could drink stick cinnamon, and lemon. So I been taken that since. I was very proud, because I drank that last night and this morning. Then I took my tablets, and when I got here my sugar was 7.7." (patient, interview)*

It was striking that no one mentioned diet or exercise as part of their "strategy" to lower the blood glucose levels. This may be explained by the fact that we often started our conversations with discussing how their lives had changed after being diagnosed, and that by the time we got in to their understanding of blood glucose levels – they perhaps felt we had already been through diet and exercise, and that we now were looking for different answers. However, the quotes represent the general misunderstanding we witnessed throughout our fieldwork. While cinnamon admittedly can positively affect insulin sensitivity, having a glass of water with cinnamon will not be enough to get the blood sugar levels down to 7.7 if other efforts haven't been made. During the focus group, one of the participants seemed surprised of the fact that eating healthy had such an impact on her blood sugar levels:

> *"I just ate the steamed vegetables and drank water and was very healthy and my number was 5-6. So the diet counts very much!" (patient, interview)*

«The doctor is more important»

Diabetes is a complicated disease, and while many diseases are complex, the patients can usually leave the doctor with quite clear instructions on what to do. However, when the consultations are as pressured as they are in Mitchells Plain, the necessary level of detail about diet, exercise, medicine and consequences is almost impossible to communicate.

The family physician at a Community Health Clinic in an area with a similar demographic put it this way:

> *"What I have found with my patients, despite repeated instructions, is that probably at least a half of them haven't seen a dietician. I don't know why.*
>
> *A lot of people say that they didn't know that they should make bookings – they'll sort of look at you surprised. It is seen [by the patients] as more important to see the doctor than to see the dieticians, even though the dietician is probably most important.*
>
> *I think there's a lot of information that is given to patients in a very short pressured consultation […] and if you have to wait half an hour in a queue to make a booking then you're not going to do that."*

So, we see that there is a great amount of confusion and mystery around the concept of diabetes type 2 amongst the people in Mitchells Plain. While many have a general idea of the diet they "should follow", few seem to really understand why it is so important and effective. The important outcome of this is that some patients become demotivated in their attempts at adhering to the "correct diet". Especially since "diet food" it is seen as an opposition to the "good food". In addition, the use of oral medicine for diabetes can also be a confusing factor, as medicine (in their perception) usually "does the job". These views leave the patient little reason to believe he can have any major impact on the disease and blood glucose levels.

In what way does the patients understand what will make their lifestyles more diabetes-friendly

In the previous sections, we have described the ways lack of knowledge has led to an unclear understanding of the potential effect and utility that can be derived from a lifestyle change. In this section, we focus on the concrete outcomes that derive from not knowing enough about diabetes and diet. We see two types of outcomes. First, the lack of knowledge affects the ability to evaluate concrete food options. Second, the lack of knowledge affects the patients ability to create a strategy and assess whether the sum of their efforts are good enough.

"What is healthy?"

In the "do's and don'ts" section above, we highlighted how we perceive the knowledge about diet, exercise and diabetes type 2 to manifest. The very basic, rule-based, stay-away-from-this-and-that knowledge that is prevalent means most people lack the tools to evaluate the advice they get.

During the focus group we conducted with nine diabetic women, we made three lists based on their collective knowledge about diet; one list of healthy food, one of unhealthy food and one list of all the things they were unsure of. The lists are shown in figure 10 below.

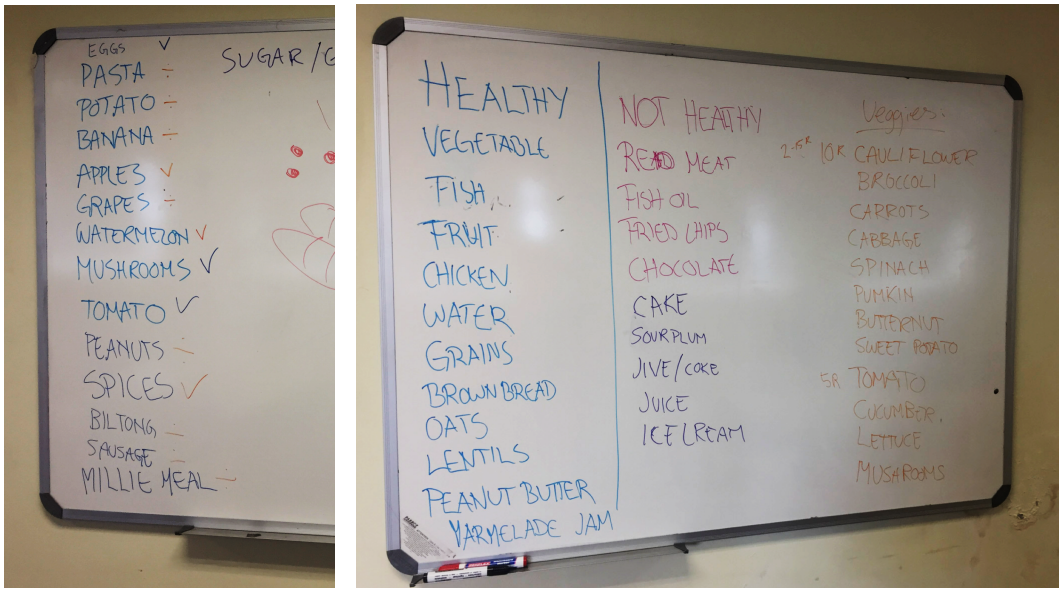

Figure 10 - Photos from the focus group. Lists of foods that the patients described as healthy, unhealthy and that the participants were uncertain of.

In the list of healthy options, *oats* are listed as healthy, however in the shops, there are many variations of flavored and unflavored oats and instant-oats, many of which have a great deal of added sugar. In addition, the instant-oats are processed, so in effect a given package of *oats* can be anywhere on the scale from very *fast-acting carbohydrates* to *complex carbohydrates*. Deciding on what to have for breakfast therefore requires more knowledge than simply knowing that "oats are healthy".

To build on this example, it is widely understood that people with diabetes should stay away from sugar. During a visit to one informants home, we discussed breakfast options, and the informant was very proud to finally having found a breakfast porridge that he didn't "need sugar" on. This was the type of strawberry-flavored Mielie-pap that is a type of maize porridge. It contained 89 grams carbohydrates per 100 grams of serving. These are highly refined products that are cheap, *fast-acting*, and will bring your blood glucose levels quickly up, and quickly down. So, while he no longer added sugar to his porridge, this option was probably worse. Below is a picture of the strawberry-flavored *pap*.

Figure 11 - Picture of strawberry flavored "Pap"

Several such misunderstandings can be found in the examples in figure 10 above.

First, many are given the advice to stay away from salt, as it is a dietary need for people who have hypertension, and hypertension is a common comorbidity connected to diabetes. However, somehow people have broadened this advice to include all spices. Adding to the impression that "diet food" has to be tasteless and a far inferior option to the diet they are used to.

Second, peanut butter and jam were confidently put on the list of healthy foods on the basis of them being made of nuts and fruit. However, similarly to that of oats, the amount of sugar and fat vary from type to type, and either way these products should be consumed with moderation.

Third, very few of our informants had formed a clear conception of what carbohydrates are. Therefore, when discussing types of foods, the most common terms they used was either "sugar" or "starches". We found that when the participants discussed whether a food item was unhealthy or not, an argument for deeming an item unhealthy would be that it tasted sweet. By this type of classification, bitter-tasting foods like beer and dark chocolate is not necessarily seen as unhealthy, and sweet tasting fruits like watermelon and apples are seen as unhealthy.

Other dilemmas concerned foods that are difficult to place, like mushrooms, pastas, potatoes and rice. To understand the differences between concepts like starches and grains can be challenging. A discussion arose in the focus group about brown bread, when a participant suggested that brown bread should be in the healthy-column:

> *Another participant: "not actually – the doctor told me you must not eat brown bread. […] He asked me what kind of brown bread? I said* ***brown bread****, hehe. *mentions types of bread*. He said I must not eat* ***that*** *brown bread, because he mentioned there is too much something – I don't know what … I must just try to keep to the other bread...*
>
> *Others chime in: "but it's too expensive, very difficult. But when you don't have the money buy it – it's difficult". "just eat whatever you get" If someone give you a bread you must just take it"*
>
> *If I must eat white bread I just toast it. Don't know if it helps i just do.*

Discussions about conflicting advice came up frequently during our entire fieldwork. People have been told to eat – and not to eat bananas, that tomatoes are bad due to the acidity, that dark chocolate is good because it is bitter, that fruit juice is good (even

though it often has a as much sugar as sodas), that frozen vegetables isn't good enough (even though it is definitively much better then not affording fresh vegetables) and so much more. The advice comes from doctors who don't have time to get a nuanced message through, as well as from friends and neighbors, and CHWs who sometimes don't have the correct information. The result is that much of the efforts people make are confusing:

> *"As a diabetic I can't eat the curries... They say we must stay away from curries […] Because it is too much acid in the curry, or, I don't know. But when I speak to the doctor they ask you:*
>
> *'What did you eat last night?'*
>
> *I had a little curry*
>
> *[the doctor replied] 'No, you are not supposed to eat curry!'" (Patient, Home visit)*

Here, the advice is to not eat curries, however, a curry can be made to be healthy or less healthy. While curries in Mitchells Plain often lean to the unhealthy side, the focus should have been to discuss ways to make the curries healthier.

"Diet food is expensive"

The financial situation had a huge impact on the households' food routines. Many of the interviewed expressed that this was one of the main challenges with eating healthier:

> *If you go for diabetic food, you are going to spend a lot of money, so money is a problem. Even the rice (...) You get the unpolished brown rice, and that is the healthy rice, but it is too expensive. (Patient, home visit)*

During our focus group, there was expressed that the expensive food constrained the patients eating habits

> *- But it is difficult, because it is what you eat. I eat what is there in the house, I can't go out and eat fresh fruit and veggies. There is no money for that, I must eat what is there. So, it is a little difficult. In order to bring my sugar down I must eat nothing then. Ha-ha.(Patient, focus group)*

Sometimes it seemed like the patients struggled to think differently about how to put together healthy meals on a budget. When CHWs and the family physician at Mitchells Plain CHC explained to us the local food culture, they highlighted that most people build their meals around the meats they could afford. One of our informants confirmed this notion:

> *"Once in the month, only when we get our pension [we do the grocery shopping]. Then one of our sons will come and help us get our money. Then we go buy chicken from the place, there is a chicken place, we go there and buy chicken for a month, and from there we go to the shop. With what is left from our money we shop like small things, groceries, rice, and stuff like that. And then the money is gone."*

Later, when we discussed the option to get proteins from cheaper sources like lentils and beans, the informant objected:

> *"But now-a-days beans are not so cheap anymore. Even lentils is not so cheap anymore. Those days you used to pay like, 2.99 for a pack with lentils, and now Oooh! Almost 20 rand a packet! It's not cheap – it's not cheap anymore."*
>
> *[We ask if it is still cheaper than meat]*
>
> *"Yes, hehe, it is cheaper than meat. Because lentils you can use as meat. (Patient, home visit)*

We experienced differing views on the impact of economy on the opportunity to eat healthy. While several participants said they couldn't afford fruit and vegetables, others focused more on the price of substitute-products (like quinoa for white rice, or "diabetic sugar" for normal sugar):

> *"Vegetables is not the problem. But you can't put sugar in your coffee, you must buy diabetic sugar. You can't afford to buy that, because it is expensive. That's why. To tell the truth I am not living like I must with the diet stuff. You must just eat what is on the table." (Patient, home visit)*

While lack of adherence to a diabetes-friendly diet was often explained with economy, one participant in the focus group told us that she had previously had a very healthy diet and had achieved a low blood glucose level over several months. This, however was several year ago. When we asked why she had stopped eating healthy, she paused to think. During the silence, several of the other participants suggested it was because the diet is too expensive. However, the previously healthy participant refuted the

suggestion, saying that she could just steam her chicken. While not really providing a solid answer for why she stopped eating healthy, it was indicated that the healthy food didn't taste nice enough.

Patient strategy

There are so many facets to the confusing and conflicting knowledge about diabetes and diet in Mitchell's Plain, and we don't have space to go through it all. The types of mix-ups we have discussed thus far lead individuals with diabetes type 2 to make semi-intuitive decisions about what to eat, in the belief (and perhaps hope) that the decision will contribute to lowering the blood glucose levels.

The important takeaway from the discussions we have made above is that people do make efforts, but that the efforts are a bit fragmented, and rarely based on a strategy. What we mean by basing choices on a strategy is that unless an individual is capable of following the "perfect diet" and doing a sufficient amount of exercise, the individual has to use her knowledge to determine what effort is "good enough". When it isn't economically feasible to switch from white rice to quinoa, or from white bread to whole-grain, or from cheap fatty cuts of meat to tenderloin, then compromises have to be made, which requires more knowledge in order to evaluate the better option. In addition, regardless of economic background, festivities make it difficult to completely stay away from sweets and desserts. When an individual happens to deviate from a healthy diet by having a piece of cake, they don't necessarily know if it ruined all the other efforts he has made, or if he has to wait a day, a week or a month until the next time he can indulge in a piece of cake is difficult.

Thus, there is a high level of uncertainty concerning how much impact a deviation actually will have. In the focus group with the diabetes patients, frustration about this was expressed:

> *"For me whatever I eat, will either way push my sugar level up. So, I can just take a piece of cake […] I even ate a cucumber and it pushed my sugar up! "(focus group)*

While there was a lot of uncertainty about the tangible effects of lifestyle change, many of our informants wanted to do what they could to avoid becoming insulin dependent, and avoid end-stage complications. This was especially notable in the cases the patients knew someone who experienced complications. One patient described a

neighbour that had started to inject insuline. Hi described that he wanted to eat healthier, becauase hi would not end up in the same situation:

"I do not want to prick myself" (patient,interview)

While the efforts made by the patients above are a bit scattered and fragmented, most of our informants expressed a wish to slearn more about the disease, diet and what they could do to become healthier. Several informants said they wanted to speak to us because they hoped we could help them. Three of the informants asked if we were there to provide a cure. They were frustrated that their efforts didn't always seem to help.

Those informants who had already experienced complications such as amputations and ulcers expressed regret in not having taken enough action before. And hoped that their contributions to this study could help others. The photo in figure 12 below is from one of our home visits. The patient hoped our research would contribute in helping other diabetes patients avoid late stage complications.

Figure 12 – The patient is about to show us a picture from before he had to amputate. He wanted us to help others avoid late stage complications

6 Analysis

In section 6.1 we provide an updated view on the problem area as we understand it now. Here we present the rationale behind the context of intervention that we design for in this thesis – namely the interplay between the community health workers (CHW) at Arisen Women and the patient. The goal is to provide design-suggestions that can support Arisen Women's work with supporting the patients in becoming healthier.

In this chapter, we will take a closer look at how our empirical findings relate to the opportunity to have a diabetes-friendly lifestyle. In section 6.2 we utilize theoretical concepts derived from the Capability Approach to guide our analysis. The Capability Approach is useful to provide insight about the factors that decide **if** a person can achieve a healthy lifestyle, by looking at how the empirical findings relate to the concept of *capability deprivation*, summarized in subsection 6.2.5.

We find the capability approach useful to understand the factors that can explain part of the reason why people in Mitchells Plain struggle to live a diabetes-friendly life. However, we found that the Capability approach does not provide us with the tools to analyze why some of the patients choose to not prioritize healthy choices, in those situations where it was possible to choose. As we saw in the empirical findings, motivation (lacking or confused) play a big part in the way people organize their lifestyle choices.

For this reason, we expand the framework in section 6.3 by adding the concepts of Reflective and Automatic Motivation to understand how the aspects analyzed in section 6.2 affects the actions people end up taking.

The goal of the analysis is to make clearer what we are attempting to achieve with our design.

6.1 Capability approach to understand the patient perspective

For our analysis of the patient circumstances, we will use the Capabilities approach by Amartya Sen, as a lens to sort out and make sense of our data. Before moving on to the analysis, we will briefly recap the main concepts we utilize.

The central argument in Sens Capability approach is that the international community needs to stop viewing development as something that can be measured in income or commodities. Instead, development should be measured according to the freedom people have to choose the lives they have reason to value.

In explaining this framework, Amartya Sen draws up two central concepts. That of *capabilities*, and that of *functionings*.

- Functionings are the states of "being and doing" of a human being and signify outcomes a person can achieve. An example is "being nourished" as opposed to "having food" and “being mobile” as opposed to “having a bike”.

- Capabilities signify the set of valuable functionings a person has effective access to. In our case we can ask: “does this individual have the capability to choose the functioning of being healthy”. Whether or not the person in fact ***is*** healthy is not the center of attention. The importance lies in the individual freedom a person has to choose the functionings he or she might deem valuable.

This distinction is important, because of the emphasis the Capabilities approach puts on the freedom to choose what life they want to live. The difference between a person who is starving and a person who is fasting lies in the freedom to choose. If the person who is fasting has the capability to choose the functioning of not being hungry, the state of fasting can be seen as an achieved functioning. However, having a lifestyle is not the same as choosing it. If the person who is fasting doesn't have the capability to choose to be full, then Amartya Sen would deem this person to be capability-deprived.

6.1.1 The capability to "live a diabetes-friendly lifestyle"

For this analysis, we define the target functioning as that of having the capability to "live a diabetes-friendly lifestyle". Framing it in this way allows us to address the primary struggle and express the primary goal of our informants, which is to generally feel better and for the disease not to progress in to complications.

As we hope to have shown in the background chapter about diabetes, there are several possible treatment-responses to having diabetes type 2:

- Eating a healthy diet
- Less fat
- Less carbs
- Smaller portions
- Doing exercise
- Achieve weight loss (loss of *adipose tissue*)
- Adhering to medicine
- Relieving oneself of stress

While all of the above are important factors, our data reveal a severe confusion about what to eat, and a lack of understanding about the effectiveness (and importance) of exercise to achieve positive results. For the sake of being clear in our analysis, we have therefore chosen to divide the functioning of "living a diabetes-friendly lifestyle" into the two sub-functionings "Eating a healthy diet" and "doing exercise".

6.1.2 The central concepts

When using the capability approach as a lens to understand the capability to live diabetes-friendly in Mitchells Plain, we must first look closer to the building blocks in the framework that concerns conversion factors. We described the relation between conversion factors, capabilities, and functionings in section 3.2.

Conversion factors describe whether a person has the ability to convert a resource, a good or a condition into a functioning. Sen divides conversion factors into three types: *personal*, *social* and *environmental* conversion factors (Sen, 1999). In our analysis, we use conversion factors to explain the connection between our empirical data and what we

find inhibits peoples' capabilities to live diabetes friendly. Below is the figure we presented in subsection 3.2.1

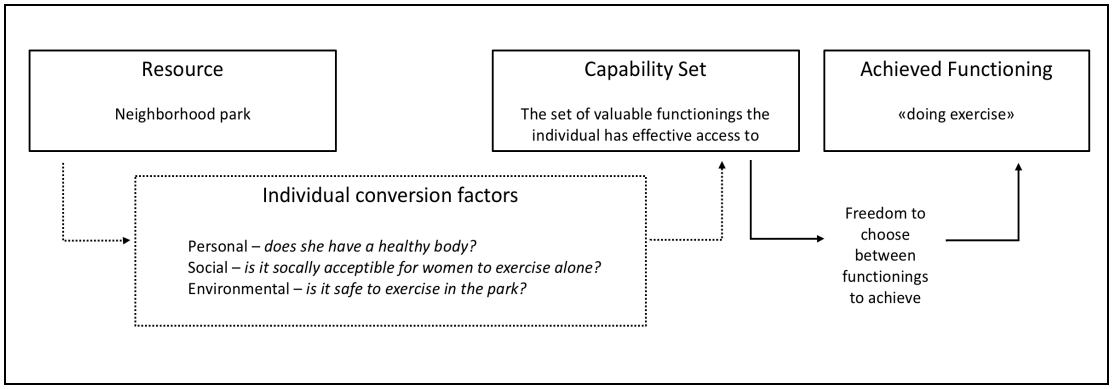

Figure 13 - Relation between resources, conversion factors, capabilities and achieved functionings

6.2 Analysis of the patients' conversion factors in Mitchells Plain

In Table 3 - Description of the conversion factors in Mitchells PlainTable 3 below, we have identified themes and categories from our empirical data, that we have sorted in to each category of a conversion factor.

The table represents a simplified depiction of our data, and does not reveal the complexities in the outcomes, and how the categories are intertwined, but we find it purposeful to give the reader an overview of the factors that affect and restrict individual efforts to become healthier.

In the next few sections, we will present our analysis of the connection between our empirical findings and the way they restrict the opportunity to achieve the functioning of a "diabetes friendly lifestyle". We do this by looking closer at the conversion factors and their relation to the two functionings of "doing exercise" and "eating a healthy diet".

Conversion Factors		
Conversion factor	Empirical finding	Restrictive outcome
1) Social		
Family relations	-Patient often responsible for many family members	Shopping cheap food (usually unhealthy)
Social Structure	-Wish to fit in and belong -People don't judge each other	Positive Support (heaping each other) and negative support (saying it's okay to cheat)
Food Culture	- Considered "weird" to be healthy -Temptations: Sweets, Large portions, -Types of food we eat (linked to economy as well) -Identity: us people eat…, celebrations, "deprive others of their good food"	
2) Personal		
Knowledge	-About diet, diabetes and exercise	Not knowing how to evaluate a good choice, make plans and strategies.
Skills	-Budgeting, Economic planning, -Reading, Taking in information	Difficult to plan economy Difficult to acquire knowledge
Disease complications	-Ulcers and amputations -Energy level	Difficult to exercise Difficult to make active decisions
3) Environmental		
Economy	-Many to feed, lone providers -Healthy food is (sometimes) expensive -Little money	Available income has to go a long way
Sources of Information	-Health facilities – overburdened, little time -Pamphlets not instructive enough -Internet, Libraries -Neighbors	Sources of Information are too unavailable, incomprehensive or unreliable
Safety	-Exercise, buying food	Dependent on help or transport to shop in unsafe area. Restricts possibility to exercise outside.
Accessible food	-Fast Food -Processed food	Few cheap and available options for healthy food on the go
Living conditions	-One floor -Electricity -Cooking facilities	Difficult to exercise at home. Good cooking facilities in homes, but high electricity prices are a barrier.

Table 3 - Description of the conversion factors in Mitchells Plain

6.2.1 Having the capability to exercise

The conversion factors help us see the constraints that hinder the individual in achieving the functioning of "doing exercise". As mentioned in the background chapter on diabetes type 2, exercise is important to lose weight, and to increase insulin sensitivity. Below we will highlight some of the ways the empirical data affect the conversion factors that relate to exercise.

Environmental conversion factors

Within the environmental conversion factors, we see that people in Mitchells Plain often are deprived of suitable facilities to conduct exercise. Here, we see economy, safety, living conditions and sources of information to play a part.

The issue of *safety* contributes to making it difficult for many people to exercise outside. Because of the relatively high crime rate, taking a walk in the community or utilizing the exercise apparatuses that are located in some parks can pose a risk. In addition, the issue of *living conditions* makes it difficult to exercise at home, due to lack of space, and the economic situation makes it difficult to prioritize spending time and money on a commercial gym membership.

To offer some nuance: some people said they were doing activities at home, like walking up and down the stairs, as exercise, and others mentioned activity groups who did exercise together. Others walked a lot for work. We find that there are environmental constraints to conduct exercise, but that they perhaps can be addressed by finding alternative ways to utilize the immediate surroundings.

Personal conversion factors

There are barriers within the personal conversion factors as well. We see that there exists a lack of knowledge about what exercise entails. During our interviews, several of our informants confirmed that they did exercise, however when asked to explain the activities they described exercises primarily aimed at increasing the blood circulation. Doing such exercises are good for practicing proper foot-care, as a means to avoid amputations. However, exercise in the more intense format was not connected to weight loss or increased insulin sensitivity by the patients. So, to state the obvious: not knowing the effect of exercise will typically not lead someone to go for a run. However, we would like to bring some nuance to the picture we just painted. The interviews also revealed that many informants knew they *should* exercise and

provided explanations about why they chose to not conduct exercise anyway; one of the patients said she was "too lazy", another said that it was "considered strange" to go to the gym.

Additionally, an extra complicating factor are experienced when an individual has had a very high blood glucose level over time. Disease complications such as ulcers and amputations, but also exhaustion obviously function as a barrier to complete exercise without special facilitation.

Social conversion factors

A general perception we have is that exercising and actively seeking the gym is seen as a bit peculiar. Several times throughout the fieldwork we hear references such as "my sister is a *healthy person*" and "my daughter in law is in to *that type of stuff*". The social barriers to exercise aren't necessarily the biggest barriers, but there also is little social incentive to exercise. While this is the general perception, one of our informants said her son used to invite her to go to the gym with him. Likely, there are very varying experiences with social support and social discouragement.

Exercise summed up

In sum, the environmental conversion factors together play a part in depriving people in Mitchells Plain of proper facilities to conduct exercise. However, we also saw examples of people who made an effort to work around and defy some of these barriers. Similarly, while many of the patients knew that they "should exercise", they mostly didn't have a tangible idea about why exercise was important other than that the doctor said they should.

In examples of "social conversion factors" in Amartya Sen (1999) the social context either enables or hinders the capability to achieve a functioning. We would not go as far as to say that the social context makes it impossible or very difficult to exercise. However, we see that there is little incentive, and that the social context affects the patients motivation to exercise.

6.2.2 Having the capability to eat a healthy diet

As mentioned in the background chapter, a "diabetes-friendly" diet has great impact on the disease development. Advice about diet has two goals: to avoid products that has a high level of fast-acting carbohydrates (like sugar, and white bread); and to reduce weight (adipose tissue). Through the capability analysis, we will look at the conversion factors that hinder the individual in achieving the functioning of "eating a healthy diet".

Environmental conversion factors

Within the environmental factors, we will start by elaborating on the most prevalent factor: low income. In Mitchells Plain, we see that the low income-level make it difficult for many households to afford healthy ingredients. The economy is stretched thin, due to the often single-income large households, and the fact that healthier food options typically cost more. Especially if the goal is to make the usual dishes healthier, buying quinoa or brown rice instead of white rice; buying leaner cuts of meat; buying fresh fruit and vegetables; and not least buying artificial sweeteners instead of sugar is often out of the question. Thus, achieving a healthier diet on a budget puts more pressure on the skill and knowledge to get nutrition from different sources then before.

Another environmental factor is the accessibility of unhealthy food. This is in large a reference to the high prevalence of fast food in the area. It is highly available, through informal street vendors, as well as in the shops and super markets, and is generally considered a cheap and easy option. Conversely, healthy food is very available in the super markets, but is less available on the street corners and informal vendors. Some CHWs at Arisen Women, suggested that some people do grow their own vegetables on a small plot of soil in their garden, but that it had been a challenge the last couple of years due to the water restrictions throughout the summer.

Personal conversion factors

Again, the knowledge levels serve as an important barrier to achieve a diabetes-friendly life. Knowledge about diabetes manifest as overarching rules that are difficult to operate. We have seen examples where the informants thought they ate something healthy because they didn't need sugar (like the strawberry flavored mielie-meal) and an overall confusion about how to prioritize food options.

In addition, we find that many individuals lack the agency and perhaps confidence to seek out information. There are many possible explanations why. The staff at Mitchells Plain CHC experienced that their patients would be offered information sheets, but that they didn't read them or didn't understand. This can possibly be related to language-barriers and low education levels. Another explanation may relate to the feeling of being a burden, or of being overlooked. Our impression when we talked to members of the Mitchells Plain community was that they felt that the "world wasn't made for them". Many people had had encounters with the health care where their questions were not answered properly, or where the answers didn't help because their financial situation wasn't accounted for. A CHW at Arisen Women suggested that health care personnel didn't care too much about diabetes patients, because "they won't die or anything. They'll just lose a leg".

A final individual characteristic relates to the ability to budget and plan economy. The most common habit was to do the grocery shopping for the month, when the salary or social support came in. When we asked if it was possible to buy groceries more often (to buy fresher food, rather than refined long-shelf-life types of food), the informants usually answered that there wouldn't be any money left. While we didn't go into details about their personal economy, we believe there are several explanations. Their shopping-habits can be attributed to their budgeting skills but can also be of practical reasons. We know that there is high levels of alcoholism and drug abuse in Mitchells Plain. Buying the necessary food for the month can be a way of making sure the basics are covered, and that the money doesn't "disappear". In addition, many of the female informants explained to us how they would spend entire days comparing prices in different shops to get the cheapest deals. As such, shopping more often would require a lot more time. The shopping-habits has implications for their choice of food, creating barriers for buying fresher foods, but also for trying new recipes. If there is a chance a person will end up buying healthier food, but not enough food, the family is in risk of going hungry towards the end of the month.

Social conversion factors

As a result of the social fabric of Mitchells Plain, many households have multiple generations living on a low income. The diabetes friendly food is seen as a necessity only for the sick, and as such, the family culture affects how much money an individual with diabetes feel they can use on themselves. In addition, we heard many examples of informants reporting that their families didn't like the "diet food". Similarly, healthy food was rarely available at social gatherings.

In effect, the family members often continued to eat the food that the patient craved. This has several negative impacts on the patients' motivation: first it leaves the patient to feel tempted often, second it results in a lack of support from the community and family. Here, we see "having support" as being encouraged to make healthy choices and having someone that holds you accountable when you make unnecessarily bad ones. While encouragement and empathy were abundant, the aspects of being held accountable and to be given that extra push or reminder was more absent.

We saw this dynamic clearly in the focus group. Here, the participants felt free to talk about their "successes" with diet and also their "failures". When the participants talked about their difficulties with resisting chocolates or sour plums, the other participants were understanding. We see this as a good thing, but we also see that there is a high level of acceptance that having a healthy diet cannot be achieved. Generally, the patients lack people close to them who tell them that they believe it can be done, and that it will make a difference. To offer some nuance again: we do not claim that everyone in Mitchells Plain lack support, however we see it as part of the challenge.

Eating healthy summed up

The economy is an obvious constraint on the individuals freedom to choose a healthy diet. When the patient cannot simply buy healthier replacements of the ingredients they usually cook with, it requires more knowledge and time to plan and to make adjustments. Additionally, the scope-of-action afforded by the economy varies drastically from household to household, by this we mean that just having 150 rands (ca 12 USD) extra per month can make the difference between only the very bare minimum, and to be able to buy for instance oats instead of mielie-meal. Some households' scope-of-action allows for very little wiggle-room in regard to how they prioritize money, while others have a little more.

Regardless, the low levels of income put pressure on the need for knowledge, and the need to focus on the measures that are less expensive. Instead of focusing on switching from sugar to artificial sweeteners (that are considered very expensive), the available options are to cut out cool-drinks and chocolates, have smaller portions, switch meats for lentils, and utilize other cooking methods such as steaming meat instead of frying it. While these options are available, they are seen as quite big sacrifices for the patients, as they value the "good food". In the end of the empirical chapter, we discussed the confusion around the value of making a lifestyle change.

In sum, we see that there is an interplay between the environmental factor «economy» and the personal factors «knowledge and skills», that exist in a social context that leaves little incentive to make extensive changes.

6.2.3 A closer look at knowledge

So far, we have seen that knowledge has a big impact on the capability to choose a diabetes-friendly lifestyle. Most importantly, knowledge is intertwined with the other categories. Having a narrow financial scope-of-action can be compensated by using knowledge to prioritize differently. Building knowledge about diabetes, diet and exercise can be done through conversations, reading and education. However, the availability of these resources in Mitchells plain is a constraining factor.

Building knowledge is thus connected to the environmental factors of information sources. As we described in the empirical chapter, Mitchells Plain CHC struggle to provide enough education due to several reasons. This leaves the patient with the main responsibility to gain knowledge for diabetes self-management. Drawing on the capability analysis, internet and libraries are resources that could have been an option for some. However, internet-access or mobile-data is a luxury few households can prioritize. In addition, the written sources tend to offer too little nuance (like the pamphlets) or to be expressed in unavailable language, or to give unattainable advice.

If we revisit the philosophy of the capability approach, we also see the contours of something more. The knowledge not only affects whether or not an individual understands what exercise is, or what a diabetes-friendly diet is. It also affects the patients' motivation to prioritize health:

While there were many faults to their understanding and ability to evaluate healthy diet options, most patients had a general idea of what they could do. Admittedly, their impression of a diabetes-friendly diet was rather dull – painting a picture of healthy food as steamed, tasteless chicken and vegetables with no rice, potatoes or spices and no sweets or tasty cool-drinks. As such, their lack of understanding about the connection between diet and the potential complications affects their willingness to prioritize health over immediate enjoyment.

This motivation is additionally influenced by the social conversion factors. From our empirical findings, we sensed a strong wish to be part of the social group. We noticed there was a strong notion of what the Mitchells Plain community objectively constituted as "good food", and the things that "we like to eat". We experienced many

accounts of informants feeling like they had nothing to eat at gatherings and other social settings.

6.2.4 Summing up the capability analysis

Using the capabilities approach to analyze a situation provides us with an explanation of the factors that deprive a person from his capability to choose between functionings he has reason to value. To put this in plainer words, the capability approach lets us identify the hindrances that make it difficult or impossible to live diabetes-friendly. The focus in the capability approach is not on whether people choose that functioning, but whether or not they could if it was what they valued the most.

If we apply the capability approach very literally, an analysis through the framework would thus offer us two possible explanations of why such few people live diabetes-friendly lifestyles in Mitchells Plain:

1. Either, people are deprived of their capabilities to choose the functioning of "living a diabetes-friendly lifestyle"

2. Or, people are not capability-deprived but are rather rationally choosing other functionings that they value more.

We believe there exists a more nuanced view than the either/or conclusion that is offered here. While we believe that capability-deprivation alone cannot explain the low prevalence of diabetes-friendly lifestyles - as we discussed in the previous section - we see that capability deprivation contributes to constraining the *scope-of-action* a person has. By this we mean that the available options of how to respond to having diabetes is limited by economic, safety and information-related factors.

In reference to the second proposed explanation above, we believe that most people's "choice" to not live diabetes-friendly are **not** - in most cases - an active and rational choice that is based on a calculation of what will bring most value. We rather believe that there is a tug-of-war between two competing types of functionings: those that lead to a more diabetes-friendly lifestyle, and those that lead away from this. In our case, the functioning of "having a healthy diet" will in many instances collide with the functionings of "enjoying good food" or "experiencing social belonging" based on the individual perceptions of what these functionings entail. Here, we see that the analysis reveals a lack of motivation to prioritize the long-term goal of having a healthy lifestyle, over the current positive utility derived from the less healthy choices, such as enjoying "good food" or a sour-plum.

So, while the capability approach is useful to provide insight about the factors that decide **if** a person can achieve a given functioning, it does not provide us with the tools to analyze **why** someone prioritizes one functioning over another. By extension, an analysis through the capability approach does not allow us to pinpoint what can be done to make someone prioritize the functioning of "living diabetes-friendly".

The capability approach is built on the intrinsic belief in individual freedom to choose the functionings he finds valuable, regardless of whether or not the consequences objectively can be seen as negative. However, we believe that there are two good reasons why we nevertheless should aim to make people healthy:

1. All of our informants wished they had more "control" over their disease and feared the potential outcomes of late-stage complications (or regretted not having taken action before experiencing complications such as an amputation).

2. The health services and Arisen Women has a mandate to try to keep their community healthy and to battle disease.

However, we will value the views of Amartya Sen in our design proposals, by underlining the importance of arriving at compromises, and allow the patient to make informed considerations of what he or she is willing to give up. This is discussed in depth in section 8.2.

In the next section, we will expand the capability approach by adding elements from a behavior system model that takes motivation into account when explaining how social, environmental and personal factors affect our actions and behavior. Through the expanded framework we will try to explore how this tug-of-war manifests – so that we can create better designs that support the goals people try to achieve.

6.3 Expanding the framework

From the analysis we conducted in section 6.2 above we learned that motivation plays a part in determining the choices people in Mitchells Plain end up making. For this reason, we expand the capability framework to include motivation.

Motivation is a vast topic, and extensive amounts of research has been done on the subject. Examples range from studying the cognitive processes behind motivation, to researching motivation within various domains such as addiction, learning, lifestyle-change and much more. In this thesis, we will not go into detail regarding the many theories involving motivation and human behavior. Instead, we have opted to use the

understanding of motivation as it is presented in the behavior system model (COM-B) developed by Michie, Stralen and West (2011).

However, it is important to be aware of the epistemology that underlies this theory. We understand the field of behavior change as being quite positivistic. As opposed to the focus on the freedom to choose, they operate with setting behavioral targets, and conduct research on how they can create interventions that help people reach those targets. While we find the themes of the behavior theory useful, we have made a deliberate choice not to use the framework in its full extent, to avoid projecting an instrumental view of behavior.

The behavior model we borrow from has been termed COM-B to illustrate how *Behavior* is seen as the result of an individuals' *Capability, Opportunity* and *Motivation* (Michie et al., 2011). Michie et al. claim that in order to perform a specified intended behavior an individual need:

> *"the skills necessary to perform the behavior, a strong intention to perform the behavior, and no environmental constraints that make it impossible to perform the behavior." (Michie et al., 2011, p. 4)*

In addition to the three factors (COM), Michie et al. divide each factor in two categories, allowing for some distinction. With motivation - for instance - they distinguish between the *reflective* and *automatic* processes that motivate action.

Overlap between the *capability approach* and COM-B

We argue that the conversion factors from the capability approach overlap with the COM-B factors *capability* and *opportunity,* and that *motivation* represents the extension of the framework. To make clearer the similarity and difference between the capability approach and the COM-B system, we added figure 14 and 15 below.

In Figure 14, the COM-B model is illustrated, together with the two conceptual distinctions within each category. This figure is adapted from Michie et al. (2011), and shows how the three factors, capability, motivation and opportunity affect behavior. In addition, the arrows attempt to highlight how the capabilities and opportunities can affect motivation.

The overlap between the capability approach, and the COM-B system is illustrated in Figure 15 below. The term "capability" is used differently in the two models, but in both of them "capability" refers - on some level - to the ability a person has to achieve

or do something. For sake of clarity: Amartya Sen's *capability* refers to the sum of the conversion factors, Michie et al.'s *capability* refers to the personal abilities a person has to achieve something. We thus see *capability* in the COM-B model to correspond with the concept of personal conversion factors from the capability approach.

Further, in figure 15, *social opportunities* from COM-B corresponds to social conversion factors, and *physical opportunities* corresponds to environmental conversion factors.

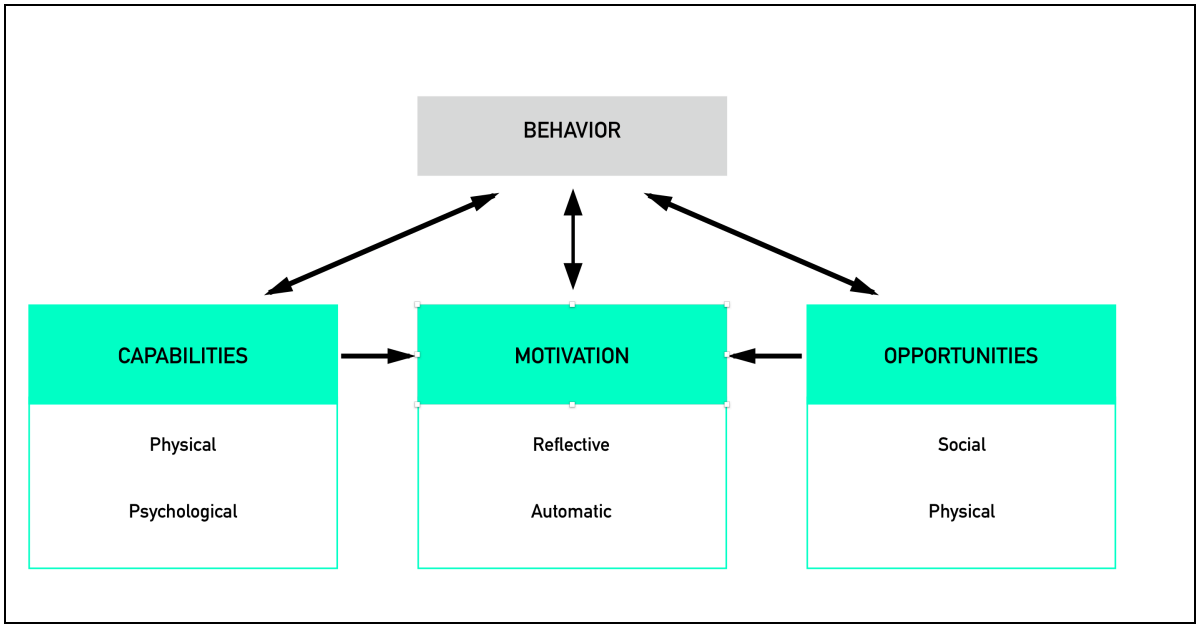

Figure 14 - Adapted version of the COM-B behavior model found in (Michie et al., 2011)

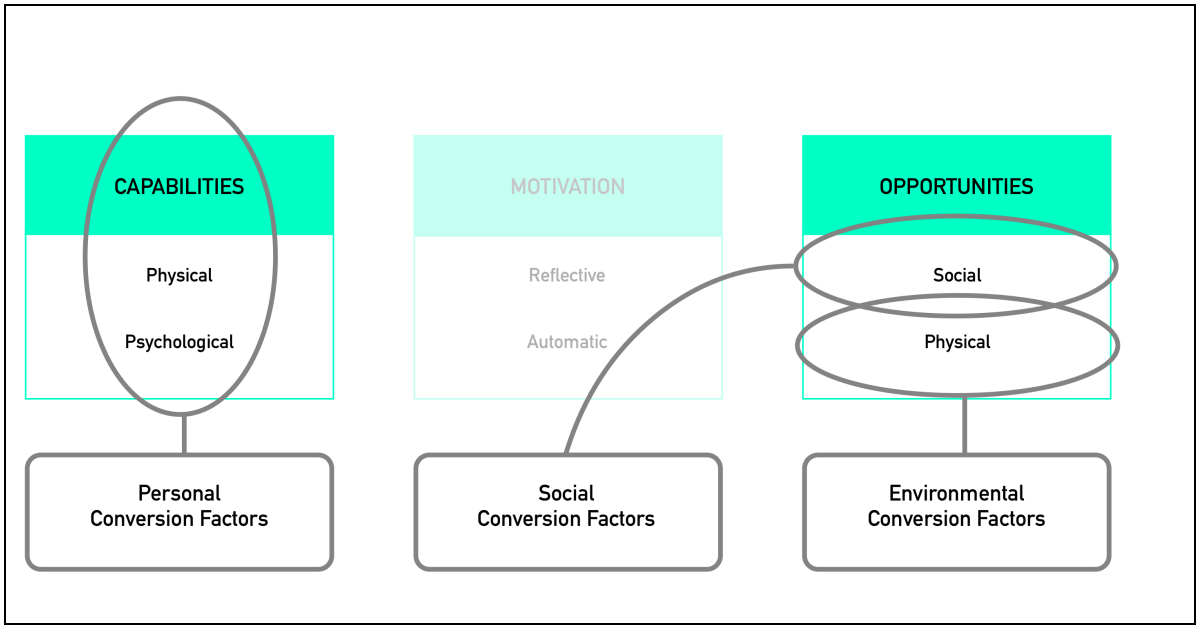

Figure 15 - Overlap between the conversion factors in the capability approach, and the three cateories in the COM-B model

Adding motivation

There are several reasons why we find this framework useful in our thesis. First, the model communicates a similar message to that of the capability approach. Namely, that our scope of action is constrained or enabled by our innate abilities and the opportunities afforded by our immediate social and physical environment. The main difference is that the COM-B model provides us with an opportunity to address motivation, and the interplay between motivation and the barriers identified in the capability approach analysis.

The second reason why we add motivation is related to the way people prioritize based on the options available. Our analysis revealed that motivation can play a part in the way people prioritize. The term motivation holds intuitive meaning to most people, as it is used in our daily speech, and we believe it is useful to form a shared meaning of the term, through a framework that isn't too comprehensive to grasp in the scope of this thesis. Here, they define motivation as:

> *"all those brain processes that energize and direct behavior, not just goals and conscious decision-making. It includes habitual processes, motional responding, as well as analytical decision-making. (Michie et al., 2011, p. 4)*

The definition is based on research about addiction as well as the widely cited research of Strack and Deutsch (2009). In their article about reflective and impulsive determinants of social behavior they conclude that:

> *"the notion that humans are rational beings is only part of the truth. We know that behavior is not only determined by its anticipated consequences but also driven by forces outside of rational control." (Strack & Deutsch, 2009, p. 243)*

This definition has informed the distinction between *reflective* and *automatic motivation* and is of great value to acknowledge that the decision-making-processes are not always rational and deliberate.

In their distinction, reflective processes involve evaluations and plans. Reflective motivation (to act) signify the rational and active evaluations of whether or not an action will lead to a goal. Conversely, automatic processes involve emotions, instincts and impulses that arise from the context or innate dispositions (Michie et al., 2011, p. 4). We'd like to offer a few examples to clarify.

Reflective and automatic motivation

Reflective motivation is about the active evaluations of actions that may lead to an anticipated outcome. For example, buying a fridge because of its energy performance rating involves a reflective process of evaluations and plans. Similarly, choosing to go for a run based on its anticipated effect on weight loss, involves reflective motivation. To many people exercise is an activity one undertakes to achieve something else: it has instrumental value to achieve better health.

Conversely, automatic motivation would be when a person chooses to go for a run because they find intrinsic value in the activity itself. Going for a run can feel good to give the head some "alone-time". In this case, the behavior is part of a desire to please ones' immediate needs. Grocery shops often exploit our automatic motivation by placing temptations like chocolates or sweets by the check-out counter. These are attempts to trigger our cravings and let our instincts guide our actions, hopefully (for them) leading to us buying more.

Automatic motivation is thus the behavior we exhibit that is triggered by our habits, cravings and instincts. Whereas reflective motivation is based on our rational considerations of the alternatives, and how they affect our goals.

In the next few sections we will take a look at reflective and automatic motivation in light of our empirical data, and the analysis we conducted in section 6.2 "Analysis of the patients' conversion factors in Mitchells Plain". Here, we highlight the factors that we believe functions as a barrier for reflective and automatic motivation towards achieving a diabetes-friendly lifestyle.

In Table 4 below, we have re-sorted the same themes we presented in table 1 above. Here, we show how they fit into the COM-B categories. Additionally, we have added themes to the category of motivation in the middle column. Again, the table is meant to give a simplified view of the themes we highlight. As we went through the COM-B *capabilities* and *opportunities* in the capability approach analysis (as personal, social and environmental factors), we will focus on motivation in this final part of the analysis.

Behavior Theory:		
Capabilities	Motivation	Opportunities
1) Psychological	3) Reflective	5) Social
World view Knowledge Skills	Apprehension Informed strategy Consequence-understanding	Family relations Social Belonging Food Culture
2) Physical	4) Automatic	6) Physical
Disease complications	Cravings towards sweets and the "good food" Habits for cooking and activity-level	Economy Health Facilities Sources of Information Safety Accessible food

Table 4 - Categories from the empirical findings sorted into the COM-B Behavior Theory System

6.3.1 Reflective motivation

From our empirical data we learned that there was a lack of reflective motivation to achieve a diabetes-friendly lifestyle. By this, we mean that the patients rarely had a tangible goal to motivate their actions, and that they didn't seem be confident about what actions would lead them towards a healthier lifestyle. In our empirical chapter, we highlighted the difficulties the patients had with evaluating dietary options and understanding the value of making a lifestyle change. We see these factors as hindrances in formulating a goal, and a strategy to achieve it. Below we elaborate on those two aspects.

Setting a goal

The way we see it, setting a goal to aid reflective motivation can both be a tangible measurable goal, but also goals that are less defined. There is a difference in setting the goal of getting the blood sugar below a certain number, and having a general motivation or desire to make healthier choices. Regardless, either of these will function as a guide for how the patient evaluates an option or decides on an action. When it comes to diabetes and lifestyle change, motivation can either be fueled by a goal to avoid negative consequences of not making a change; or by a wish to achieve the positive outcomes of having better health; or by both. We have identified four factors that impact the patients ability to formulate a goal:

- Not knowing how likely complications are to occur.
- The feeling of not being able to impact the disease.
- Extra good health is generally not strived for in Mitchells Plain.
- Short-term perspective as opposed to long-term perspective.

The first two points above is interlinked with the lack of knowledge. Many do not know how likely they are to experience complications, as a result of their lack of understanding about the disease. We also see that the use of medicine may contribute to confuse the understanding about what oneself can do to impact the disease. While we have seen that the patients wish to avoid end-stage complications, we also experienced that there was an element of denial or simply that the consequences are too much to comprehend. This related to the next point: the feeling that they cannot impact the disease.

This feeling is impacted by the scope-of-action they have to react to the disease (as based on the capability analysis). As we have discussed previously, not knowing enough about the disease manifests in a clouded view of how much they can impact it, and leaves a feeling that a diabetes-friendly lifestyle is unattainable. Thus, these factors function as barriers to form a strong intention to make a change.

We have also seen that the prospect of being extra healthy is not given the same value in Mitchells Plain culture, as it is in western popular culture, where we experience that fitness often is seen as intrinsically valuable. This can perhaps be attributed to the fact that being thin sometimes is linked with having HIV and being big is linked with having wealth (Bradley & Puoane, 2007). During our fieldwork it became apparent that exercise and health simply wasn't a focus amongst the majority.

Lastly, we were told by several of our informants that it is uncommon to have a long-term perspective. Their lives are unpredictable in so many ways, and usually the focus is to make the next foreseeable weeks manageable. We have argued that a lifestyle change towards a more diabetes-friendly lifestyle is perceived to entail a sacrifice of good food and of the ability to indulge on something good. Further, the utility an individual derives from having good food is yielded immediately, while the utility from making a lifestyle change is both less tangible, and yielded at a much later stage after having made an effort over time. Thus, the short-term planning perspective that prevails in Mitchells Plain makes it difficult to focus on the long-term utility that a lifestyle-change can provide. This was perfectly illustrated in this quote from the empirical chapter:

> *"Life is already bitter, therefore I won't eat bitter stuff".*

Evaluating options to achieve goal

In the previous section we discussed the things that make it difficult to formulate a tangible goal when it comes to becoming healthy. However, while the concept of health and consequences remained vague, people generally have a notion that diet matters and that a low blood glucose level is positive. Additionally, the fear of having to amputate, or to become dependent on insulin seems to be a motivating factor. So, there exists a vague goal of sorts. In this section we look at the factors that make it difficult to utilize reflective processes to work towards that goal. Below we have identified another three factors that function as barriers to reflective motivation:

- Not knowing what will lead to better health (for instance types of food or amount of exercise).

- Evaluating the total sum of efforts - not knowing if deviating from the plan has ruined it all.

- The lack of tools and skills to conduct self-monitoring

Again, the first two points to the challenge of not having enough knowledge. The lacking ability to evaluate options (like oats over mielie-pap) makes a healthy lifestyle difficult in itself. Perhaps more importantly, we found that this lack of knowledge has great impact on the second point: evaluating the total sum of efforts.

In our empirical chapter we presented this quote:

> *"For me whatever I eat, will either way push my sugar level up. So, I can just take a piece of cake […] I even ate a cucumber and it pushed my sugar up!" (Focus group)*

Several others also pointed to this feeling of not knowing what to eat because their blood glucose levels would go up either way. We see this as relating to the total sum of their efforts. The patients will make efforts based on the knowledge they have, and turn down soda and chocolates like they have been told to. However, it is difficult to know how big of an effort is enough, and how much they must sacrifice. This is something we ourselves have spent some time understanding, and there is no one answer. There are many ways to make the blood glucose levels go down. As such, making the breakfasts healthier, or turning down sweets may not be enough to make the blood glucose level go down, of the patient is still gaining weight. The combination of making an effort based on their intuition, and the lack of understanding of how to "balance the scale" of efforts restrains their ability to evaluate the types of health efforts they should make. In addition, the feeling of making an effort, and still seeing the blood glucose levels rise has a discouraging effect, that feeds into the feeling that they cannot impact the disease trajectory.

A tool to help evaluate health efforts is a blood glucose meter. It is used to measure the amount of glucose there is in a drop of blood. However, the meters are expensive and requires some knowledge and skill to use and analyze. The blood glucose levels fluctuate throughout the day, and is affected by meals and energy consumption. Thus, at a given point it can be low (like before breakfast) and after a meal it can be high. In

Mitchells Plain, only patients who are dependent on insulin were equipped with blood glucose meters through the public health care.

Summing up reflective motivation

In sum, knowledge has a big impact on the ability to conduct actions based on a reflective motivation to achieve a diabetes-friendly lifestyle. Their current reflective motivation is manifested mostly by a wish to avoid complications, rather than to achieve good health. However, the motivation is characterized by confusion and discouragement from not having control of one's disease trajectory. Further, we believe the lacking reflective motivation makes it difficult to prioritize health over the automatically fueled processes like eating "good food".

6.3.2 Automatic motivation

Automatic motivation is about acting out of impulses or habits. Here, actions are not based on active evaluations and reflections, but are based on automatic mechanisms that activate behavior. We understand automatic motivation as something that can either coincide with someone's reflective goals, or that can counteract and contradict the goals. In a way, we see the prevailing automatic motivation amongst our informants to counteract the goals of achieving a diabetes-friendly lifestyle. They regard the two concepts of *cravings* and *habits*.

From our empirical data, we found that sugar-addiction, and craving good food play a big part. We learned from several of our informants that they used chocolates and sweets as a way to take a break from their life, and to have some "me-time". Additionally, sugar and candies are relatively inexpensive, and has become part of the everyday life in Mitchells Plain.

In addition, there is a perception of the diabetes-friendly diet that it cannot be as fulfilling as the food they are used to. This perception is fueled by the many misconceptions that take root in the community, and the mixed signals they get regarding diet. As such, there is a lack of automatic motivation to eat healthy food, as it is not seen to stimulate other senses such as taste and texture.

We also see that the dietary choices are largely influenced by habit. Here we reference their shopping and cooking habits. Learning new ways to put together meals and find

affordable ingredients that will saturate the entire family requires a "recalibration" of these habits. To do so, knowledge and guidance is needed.

Summing up:

In the capability analysis we identified a tug-of-war between the functionings of "having a healthy lifestyle" and the functioning of "enjoying good food". We believe this is mirrored in this analysis of reflective and automatic motivation. The prospect of enjoying the perceived "good lifestyle" is largely influenced by the automatic motivation identified above: having "good food" and social gatherings as a main source of enjoyment in an otherwise tough life.

6.4 Results: identified needs to achieve diabetes self-management

Looking back to section 2.1.6 - *achieving diabetes self-management*, self-management was defined as "the skills an individual need to make appropriate choices in regard to their disease." The constrained scope-of-action many people in Mitchells Plain face outs pressure on the need for motivation and individual adaptation of advice. With fewer resources, more knowledge and skill is needed to elicit appropriate responses to managing and treating diabetes. Thus, the people in Mitchells plain need help gaining the skills and knowledge needed to take action based on the individual scope-of-action one has.

The needs we have identified below represent the building blocks we believe the patient needs to achieve diabetes self-management. We have sorted the needs to address respectively reflective motivation, automatic motivation, and some overarching needs. In sum, the points below address the two main goals of our designs: 1) for people with diabetes to get help with managing diabetes based on the individual scope-of-action they have, and 2) to provide support and build motivation to achieve diabetes-self management.

Reflective motivation

- Need to understand value of lifestyle change (goal-setting)
- Need skills and knowledge to evaluate what are healthy options (strategy)
- Need guidance and help to balance the health efforts (avoid discouragement)

Automatic Motivation

- Need healthier options to become more desirable (cravings)
- Need easier ways to make healthy options (habits)

Overarching needs for motivation and support

- The need to be sought out
- The need for individual adaptation
- The need for ownership and confidence

Addressing reflective and automatic motivation:

Reflective	
Goal-setting	Build knowledge about the disease Build confidence that one can impact the disease
Strategy	Build knowledge about healthy food Focus on ability to evaluate options
Avoid discouragement	Provide guidance on health-efforts Give feedback on progress
Automatic	
Cravings	Identify recipes and alternatives that are tasty Clear up the inhibiting misunderstandings
Habits	Provide guidance on healthy routines Identify factors that enable negative automatic motivation

Table 5 - Table of how we address the various needs identified in the analysis

Addressing the overarching needs

The first point under "overarching needs" is a reference to the circumstance as it stands today. The lack of knowledge causes the patient to not know how important a lifestyle change is. As a family physician said it:

> *"A lot of people say that they didn't know that they should make bookings [for a dietician] - they'll sort of look at you surprised."*

We believe there is a lack of agency amongst people with diabetes in Mitchells Plain. Many are confused and are keen to learn, but feel they cannot ask the staff at the clinic. To most of our informants, using internet or libraries to seek out information is not an option. We believe that the greatest success can come from letting the help and information come to the patient, rather than making an apps or personal tool they would have to navigate themselves. This is one of our arguments for utilizing community health workers as a facilitator for building diabetes self-management skills.

In addition, people with diabetes in Mitchells Plain are not a homogenous group; they have different starting points for knowledge; different levels of reflective motivation; different ways automatic motivation manifest; different scope-of-action through their incomes; and different family and support-structures. To achieve a lifestyle-change these factors need to be addressed individually.

Lastly, we have seen that many of the patients feel burdened by carrying the responsibility for their disease alone, and that the social context can make them feel like outsiders.

6.5 Context of intervention

Based on the needs identified above, and the opportunities afforded by the fieldwork, we have chosen to focus on the interplay between community health workers (CHWs) at Arisen Women and the patients. Thus, the aim of our designs is to support the CHWs at Arisen Women in their endeavor to build diabetes self-management capabilities in the patients.

We believe there are several advantages to focusing on supporting CHWs and Arisen Women. First, the CHWs at Arisen Women are part of the community and organized so that they work in their neighborhood. They know and understand the patient's circumstances and will be better equipped to give adapted advice. We also saw that

many of the CHWs had a good relationship with the entire family. Second, we find it positive to utilize the context of the patients' homes. During our fieldwork we found that the home visits were very useful to get a better understanding of the patient's scope-of-action. The task of suggesting solutions could then be rooted in the opportunities afforded by the kitchen appliances they had, and we got a better understanding of the diet when they showed us the kitchen.

At the home visits, we wish to establish a space where the patient can feel free to talk about issues and get support for managing the disease. Another aspect is that the family members often are at home together. A potential positive outcome of this is that the family can learn together, and perhaps that it is easier to foster support and joint commitment to preventing and managing diabetes in the household.

There are some potential challenges to utilizing CHWs. We experienced during our fieldwork that the CHWs had many questions for us about the disease, and that they wish they knew more. The lack of knowledge has implications for the ability to give adapted advice and guide the patient, the ability to convey information about diabetes, diet and exercise in a precise and correct matter. We also experienced that the CHWs expressed that they sometimes felt the patients wouldn't listen to them, perhaps because they were considered equals.

Regardless, we believe these challenges can be worked with. In our designs, we have attempted to suggest ways to organize and convey knowledge about diabetes. While these are crude suggestions, they may provide some guidance. Additionally, the designs function as a resource bank of options the CHWs can utilize in their home visits. Thus, we hope this may provide some structure and integrity to the CHWs, so that they gain some credibility with the more critical patients. Further, Arisen Women have support from the Mitchells Plain CHC through the community oriented primary care (COPC)-network. Thus, from a health management perspective, providing training and education for the CHWs is a contingency for the COPC-strategy of organizing diabetes-care.

6.6 Summary

Through our analysis, we have found that the analysis through the capability framework is useful to understand the scope-of-action people in Mitchells Plain have to achieve a healthy lifestyle. We also found that the capability approach cannot explain alone the reasons why people struggle with diabetes self-management.

By looking at our empirical data, through the lens of personal, social and environmental conversion factors, we learned that lack of knowledge and skills, the social fabric, and the economy play a role in hindering the achievement of a diabetes-friendly lifestyle. However, the capability approach is built on the assumption that people are rational and will choose the lives they value the most. Our empirical data tells us otherwise: namely that people struggle with managing diabetes, and that they regret not having taken action earlier. Therefore, we argue that the assumption of rationality does not account for the tug-of-war that can be experienced between two competing functionings; that of "having a diabetes-friendly lifestyle" and that of "enjoying good food" as perceived by our informants. Based on this, we expand the capability framework to include motivation.

We believe there is a lack of reflective motivation to "have a diabetes-friendly lifestyle", and the automatic motivation of our informants pull them in the opposite direction of the diabetes-friendly lifestyle, towards the functionings of "enjoying good food" or "enjoying social belonging".

Based on this analysis, we focus on creating designs that support the CHWs at Arisen Women in their attempt to build and support diabetes-self management abilities in the patients.

7 Design

In this thesis we have attempted to explore the types of design that can be helpful for people who struggle with diabetes type 2. Further, an important effort has been made to arrive at an appropriate context of intervention, and to make sure we don't target symptoms of - but sources for the wickedness. Thus, the context of intervention we focus on is the interplay between Arisen Women and the individual patients. The goal of our designs is to support the community health workers (CHWs) at Arisen Women in their endeavor to build diabetes self-management capabilities with the patients.

For this thesis the primary aim with the design-proposals is to highlight the value that can be derived from addressing reflective and automatic motivation respectively, however several of the ideas may influence both types of motivation. In addition, we try to communicate how the ideas can be adapted to a local context. Further we have focused on creating examples of how to implement flexibility in the ideas. Both in terms of giving the CHWs options between resources to utilize in their patient-visits, but also to provide examples of designs that can be configured to fit the individuals' needs and goals. Thus, in the design, we have focused on ideas that can be implemented step-by-step, and that address reflective and automatic motivation in different ways.

The design ideas do not represent an exhaustive list of resources or activities that can contribute to the resource bank, neither are they tested and iterated upon with users. They are meant to illustrate the points we make in our analysis by showing how knowledge-building, reflective and automatic motivation can be addressed through design, and how the cultural aspects can be attended to. The examples are meant to illustrate the principles that should guide a design for similar contexts-of-intervention as the one we focus on in this thesis. We hope the design can serve as inspiration for CHWs and other designers to create adaptations for their own contexts, either by switching elements (like using names of local food brands), or as inspiration to create new ideas.

Our design proposals can be seen together as contributing to a "resource bank" of activities and artifacts that community health workers can utilize in their daily work and their home visits. The ideas represent different ways to build and strengthen the patients' diabetes self-management abilities. The ideas can be used together, through various mediums, or separately.

In this chapter we present our approach to designing for knowledge in section 7.1, before we discuss the potential formats our designs can take in 7.2. We present our design suggestions connected to reflective and automatic motivation in sections 7.3 and 7.4, before providing a short reflection about the ideas in section 7.5.

7.1 Designing for knowledge

During our fieldwork we gained much experience with discussing and trying to explain diabetes to members of the Mitchells Plain community. In this section we will present the ways our experiences have influenced our approach to address knowledge. The points below are based on our concrete findings about knowledge from our fieldwork, and have functioned as guidelines we have attempted to follow in our design suggestions.

1) **Use food suggestions that are represented in the local food culture**

   Drawings of a plate with food are often used to illustrate the amount of food one should eat. And the proportions of for instance rice to vegetables etc. However, much of the local food is made in a different way. Curries and pots are mixed, and proportions are less easy to communicate. Thus, a suggestion is to focus on the making of the food, rather than the plate it is on.

2) **Use concrete examples or tools to evaluate food-options**

   The overarching rules can be difficult to evaluate. Looking back to the example with oats, advice should either specify specific types of oats, or provide the patient with tools to know what to look for to determine the nutritional value of an option. The same example regards bread. In Mitchells Plain, many of the options for brown bread is almost as refined as white bread. Rather, looking for bread that have complex carbohydrates, such as wholegrain is the important factor.

3) **Provide alternative "do's" to the "don'ts"**

   Things are unhealthy to a varying degree. Instead of simply saying what not to do, help the patient to find options. Several of our informants didn't realize there were several sources to proteins other than meat. Beans can substitute fatty minced meat, in addition to saving the household some money. If the household cannot afford brown rice, they can alternatively eat less white rice or alternatively, switch some rice for vegetables.

4) **Build on local and cultural habits**

Use their cultural preferences for different food types, dishes and habits. Examples are ways to make dishes like *briyani*, *accani* and local curries and stews healthier. Many people enjoy a cup of tea for breakfast. People should be guided on how to make this habit healthier by guiding the use of sugar or other sweeteners. During our fieldwork we saw examples of a pamphlet that addressed diabetes and Ramadan. These types of adaptations are important and can be used not only for religious groups but cultural factors.

5) **Simplify abstract concepts**

There is great value in understanding the metabolic processes our bodies go through when we eat and how the blood glucose levels react to different types of food. Especially, understanding the difference between complex and fast-acting carbohydrates can provide the patients with a better intuition about the types of food they should aim to consume. However, explaining the mechanisms that happen on the inside of the body can be difficult. Especially considering that many in Mitchells Plain lack proper anatomic understanding due to low levels of education

Thus, the use of illustrations and metaphors can be useful tools to build understanding about metabolic processes. The key-and-lock example we presented in subsections 2.1.1. and 2.1.2 where we explained diabetes, can be illustrated and provide understanding about the relationship between food and glucose, insulin, and the cells that store and use glucose. Abstract terms and concepts can be a barrier to understand the disease and the treatment process.

6) **Accommodate and adjust information based on background, education level, financial situation.**

Acknowledge the individual differences in the scope-of-action to respond to the disease. When someone has many resources in terms of time, money, education, literacy, access to information and support, the task of achieving diabetes self-management can be based on a multitude of actions. The capability to exercise, to cook food from scratch, to use fresh and wholesome groceries are useful responses to getting diabetes type 2, but may be unattainable for others. The scope-of-action in Mitchells Plain is generally much smaller than the one described above, and as such, there is a need for advice that can be comprehended and carried out within said scope.

7.2 Format of the design

The ideas we present here are represented only as sketches. The point is to get across the message we try to convey in our descriptions of the ideas. In practice, we have had a focus on creating ideas that are scalable. By that we mean that the ideas are meant to function as inspiration, and can be used in different types of formats and technologies. For example, the principles and ideas can be used as design for an app, they can be digitalized and presented on TV-screens in peoples home, or they can be presented in a booklet for diabetes patients, or be used in pamphlets and posters.

This being said, there are certain factors we have considered with our context of intervention. As described in our analysis chapter, Mitchells Plain is a crime-ridden area. As the CHWs presence in the community increases with the *community oriented primary care-project*, it is important that they don't walk around in the neighborhood with expensive equipment that can make the CHWs a target for robbery.

In Mitchells Plain many of the inhabitants, though resource poor, has a TV and sometimes an old computer or DVD-player. It is rare to afford internet access, or to use apps, even though some have smart-phones. Thus, when we discuss the concrete ideas, the main format we have envisioned are print-outs on paper, posters, or presentations that can be added to a DVD or USB-stick. These are cheap and flexible formats that is appropriate for the level of access in the area. Many of the ideas can even be drawn together with the patient.

In the future, as technology progress and become cheaper, and access to internet becomes more widely available, the ideas we present can be added to more comprehensive information systems that allow for two-way communication, to be used in apps or websites to be shown on tablets, or to health information systems to capture statistics for strategy and planning. However, the focus of the current design is to show the representations of the ideas, with the more accessible formats in mind.

7.3 Ideas that address reflective motivation

As mentioned in the introduction to this chapter, the ideas that address reflective and automatic motivation may in many cases positively reinforce the both types of motivation.

With reflective motivation, one of the central components are to increase awareness and knowledge to aid the skills the patient has to create a strategy and evaluate options. We believe reflective motivation can play a part in overriding the automatic processes that compete with the reflective goal. For example, having a clearly defined intention of losing weight, and the knowledge and strategy to evaluate actions, can trigger the mechanisms that helps a person resist the urge to have an extra serving or to buy that chocolate.

In this section, the ideas are meant to 1) help the patient formulate an informed goal based on a more thorough understanding of the potential consequences, 2) help the patient gain the knowledge to evaluate health efforts and work according to a strategy to reach his goals, and 3) support the patient and avoid discouragement by giving feedback on progression.

7.3.1 Diabetes knowledge

During our fieldwork we experienced that communicating the many facets of diabetes is difficult without some assisting resources, such as illustrations or videos.

To understand more about diabetes type 2 as a disease, there are two central themes that we believe should be better explained: 1) How blood glucose levels are affected by food consumption and exercise, and 2) how a high blood glucose level affects the body over time.

The first point relates to the mental model people in Mitchells Plain have about food. We experienced that many used characteristics that regarded taste, such as “sweet”, “bitter” and “acidic” to explain the things a person could eat. An increased understanding about types of food, and how the body breaks down and uses food for fuel can lead to increased skills to evaluate healthy options. Also, a better understanding about complex and fast-acting carbohydrates are useful to understand how to evaluate options. In addition, we believe that it is important to show how the body uses energy, so that the patient’s understanding of the total sum of efforts is

increased. Especially, we see that few understand the value of exercise, and that organizing group exercise can a valuable and cheap option to an expensive diabetes-friendly diet. We have found that illustrations and cartoon-style videos are useful to understand better how the body works. Simply knowing that the insulin-resistance is caused by excess fat (*adipose tissue)* can aid and help target the health-efforts an individual undertakes.

The second point relates to the understanding about the consequences of having a high blood glucose level, and to increase awareness about the likeliness that they will occur if one does not take action. Having a high blood glucose level over time may lead the blood vessels in hands and feet to be damaged, which is the reason why even a small cut or bruise can have big consequences. The body can look healthy from the outside, but be damaged on the inside. An example of how this can be illustrated is shown in figure 16 below.

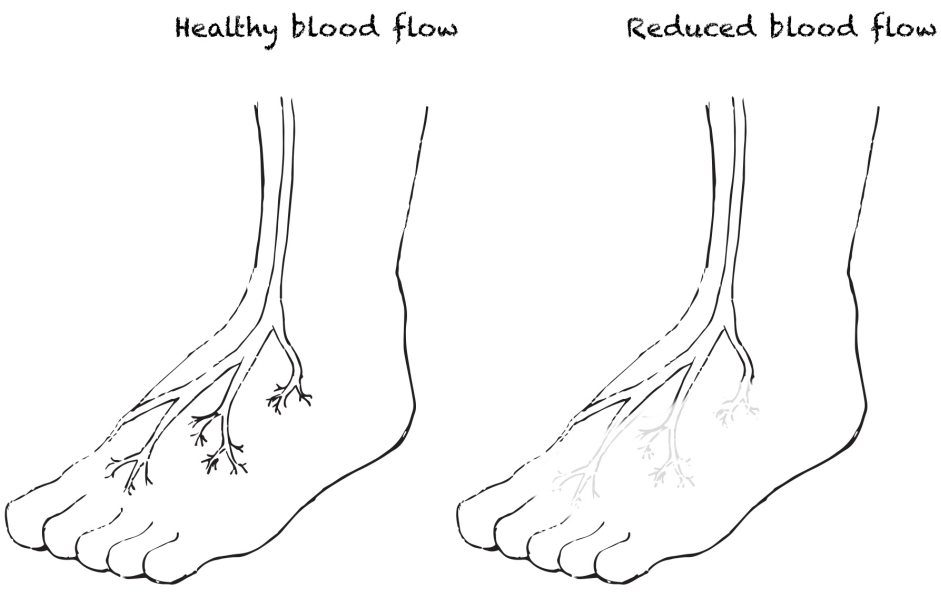

Figure 16 - Illustration of one common end-stage complcaiton from having high blood glucose levels over time

7.3.2 Hierarchical ranking of different types of food

The illustrations below are attempts at addressing the confusion surrounding diabetes and diet. Here, we attempt to give the patient an overview of different diabetes-friendly groceries. The foods that are represented in the poster should mirror what the typical diet in the local food culture contains and take into consideration the financial situation.

This idea is based on our experience from the fieldwork with the misconceptions regarding different types of food and the lack of knowledge of the types of food that was safe to eat. Especially, we found the existing pamphlets that was available in the clinics to focus much more on the things that the patient could not eat, than to provide tangible options. In the illustration below, we try to provide the patient with alternatives that are safe to eat, and to offer some nuance to the things they should eat less of.

The poster with the hierarchic ranking of food types is meant to contribute to increasing knowledge of safe food that one can eat. This overview can stimulate to create more healthy dishes - the patient can be inspired to compose meals based on the safe groceries. The illustrations can be used to aid discussion between the CHW and the patients, or can be hung in a strategic place, for instance in the kitchen.

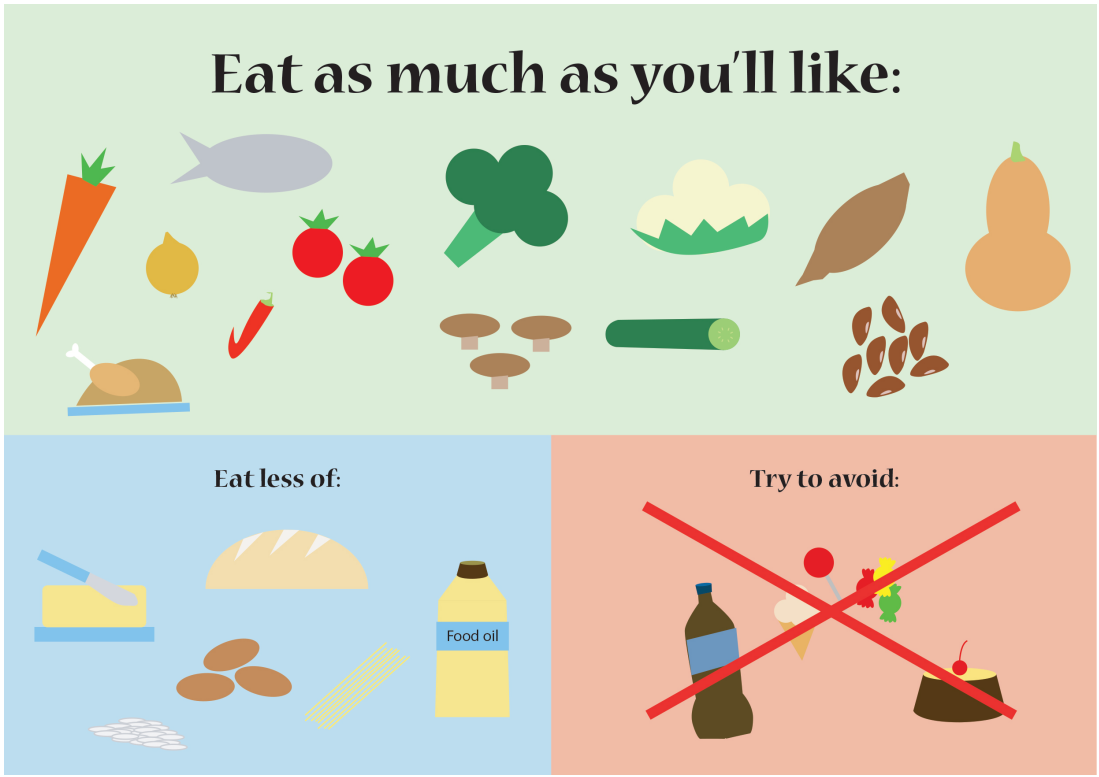

Figure 17- Illustration of a poster to aid understanding of a diabetes-friendly diet

7.3.3 "Kitchen Activity"

During our fieldwork we had good experiences with discussing with the patients in the context of their homes. Especially, when discussing dietary options, it was useful to use the products and groceries they had at hand as a starting point to suggest options.

Thus, the activity we have named "kitchen activity" is an activity Arisen Women can use at home visits, together with the patient and her family. The goal is to create a shared space for understanding, and to make it easier to address specifics, rather than only talking in general terms.

In the kitchen, the CHW will have the opportunity to see kitchen facilities, equipment, and get a sense of how the patient makes food and her eating habits. When looking at groceries, and ask about dishes and meals, the CHW can give information adjusted to the patient existing food habits and living condition. With the groceries as props, the CHW can also provide tips considering how one can make a healthy meal (with what's available). The patient can be taught about nutritional content for different types of food, and address existing healthy eating habits. We found that many people didn't know that they could look for the carbohydrate level at the back of the packages as a means to evaluate options. This activity provides a good opportunity to clear up some misunderstandings about carbohydrates and learn some skills they can utilize during grocery shopping. Based on the kitchen activity, the CHWs can adjust advice to be more situated to current habits, and the financial situation.

Potential outcomes of this activity:

- The CHW gets to know the patient, and her food habits.
- Address possible misunderstandings about food nutrition or health effects.
- Demonstrate healthy meals and food preparations with tools and equipment that is available for the patient.
- Give feedback on grocery options, and use groceries at hand to talk about diet.
- Give the patient the opportunity to ask about specific groceries, meals, and food preparations.
- Create a space for knowledge sharing and to address specifics.
- Being in someone's home create the opportunity for a shared experience with the family, and can build support around the patient.

7.3.4 Feedback sessions

In our analysis we identified the need to avoid discouragement. This need was based on our finding that people were discouraged to discover that their blood glucose levels continued to rise, even though they made an effort to change. The patients only get the average blood glucose tested when they renew their prescriptions at the clinic. This can be as seldom as every six months. In an attempt to give more structure to the health efforts made by the patients, we suggest a combination of shared goal-setting and feedback sessions.

The goal of involving the patient in a shared-goal setting is for the patient to feel ownership towards the efforts he has to make, whilst being assured by the CHW that the effort will make an impact. In the figure 18 below, the graph can be used as a visual representation of the blood glucose levels week by week. And can be printed or be drawn on paper. It can help the map their health efforts to outcomes in the blood glucose levels. This can be combined with self-monitoring techniques such as writing weekly summaries, or food and exercise diaries to understand the things that impact blood glucose levels. These are techniques that in themselves may contribute to increased awareness.

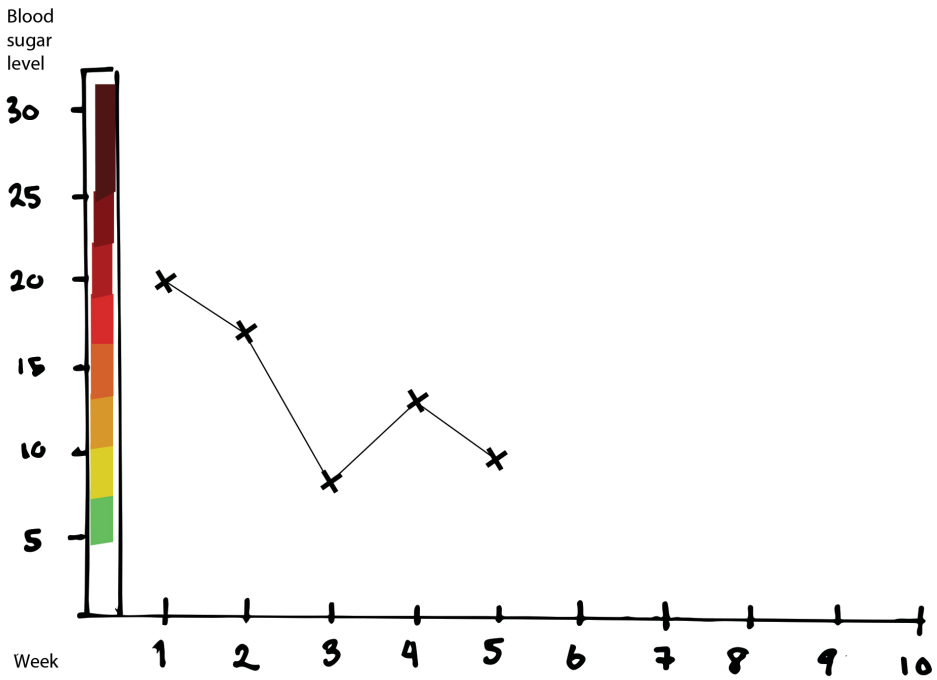

Figure 18 – Graph to monitor blood glucose level week by week

7.3.5 Sharing stories and experiences from other patients

Our experience from the field is that many of the patients either did not understand how severely the disease can harm the body, or that they did not want to realize or think about the consequences. However, we talked to several patients who took action because they had family members or a neighbor who had become insulin-dependent or who struggled with end-stage complications. In our talks they were afraid to end up experiencing the same struggles. Thus, we see that learning from others can be a motivating factor. Based on this, one motivation for providing the opportunity to share stories and experiences between patients is to achieve a consequence orientation and to provide a reality check.

Additionally, we believe there can be great value in also sharing positive experiences from people who have made progress. We wish to highlight the success-stories, and believe they can motivate others in a similar situation, and build confidence that a healthier lifestyle can be achieved, even in the circumstances they face.

The experiences, stories and advice can be shared through the CHWs at Arisen Women. They can both take the form of letter, or perhaps even made in to videos. To tell the story of another person who lives with complications can be a powerful tool to make the patient realize their potential future, and to strengthen the faith in his abilities to affect it.

7.4 Ideas that address automatic motivation

While building knowledge is instrumental to achieving the skills needed to make decisions based on reflective motivation, we believe it is valuable to provide support for the patient that does not entail a focus on knowledge. In this section we address automatic motivation by trying to make it easier to make the right choices, regardless of knowledge-level.

There are two aspects of automatic motivation we identified in the analysis, that we address in this section. The concept of *habits* and *cravings*. We address habits by focusing on ideas that have an element of *enablement* in them. Reflective motivation and knowledge-building would try to alter negative habits by "re-calibrating" them. Conversely, ideas based on automatic motivation attempts to provide alternatives that enable the patient to take positive action, without much effort.

There are three ways we address cravings. First, we try to address their cravings by providing healthy food alternatives that are closer to their preferences. This is based

on the misconceptions we discovered of what a diabetes-friendly diet entail. Second, we try to address their cravings by making it more difficult to act on them. Third, we address cravings by trying to address fat and sugar-addiction.

7.4.1 "Mitchells Plain Cook Book for a healthy life style"

The idea of a cook book is to suggest recipes that are diabetes friendly, but are also representative of the dishes that are found in the local food culture, with recipes that are affordable. We believe such a cook book can address habits, by making it easier to plan meals, and by influencing the overall cooking habits. Here, nuance can be offered to the "don't-eat-this-rules" by guiding the use of oil in cooking and providing healthier methods for preparation.

Further, having access to tasty and healthy recipes can address cravings by narrowing the gap between their perception of what is "good food" and what is "diabetes-friendly- food". The cook book should provide replacements for sweeteners to tea and breakfast porridges. For instance, baked sweet potato with cinnamon can provide some of the sweet taste in a healthier way.

The book can contain healthy recipes, the estimated cost of a dish, estimated time and especially alternatives to expensive ingredients, such as replacing meat with lentils.

A possible execution of the cook book can be to involve the community and Arisen Women with experimenting to make traditional food healthier and contribute with recipes to the book. This crowdsourcing can both save costs, and meet the requirement with affordable, traditional meals. In addition, participation in community projects can be rewarding in itself, and that it can be a good experience to have been part of creating the book.

7.4.2 Grocery lists

In this idea the goal is to address the habits regarding grocery shopping and meal choices. The idea is to provide shopping lists, with price calculations that are based on a low food-budget. Here, the lists should provide specific options for breakfast, lunch, dinner and snacks. By specific, we mean not just "oats" but list the concrete alternatives that are better, such as original oats rather than the one-minute oats that are refined. The grocery lists can be included in the above-mentioned cook book.

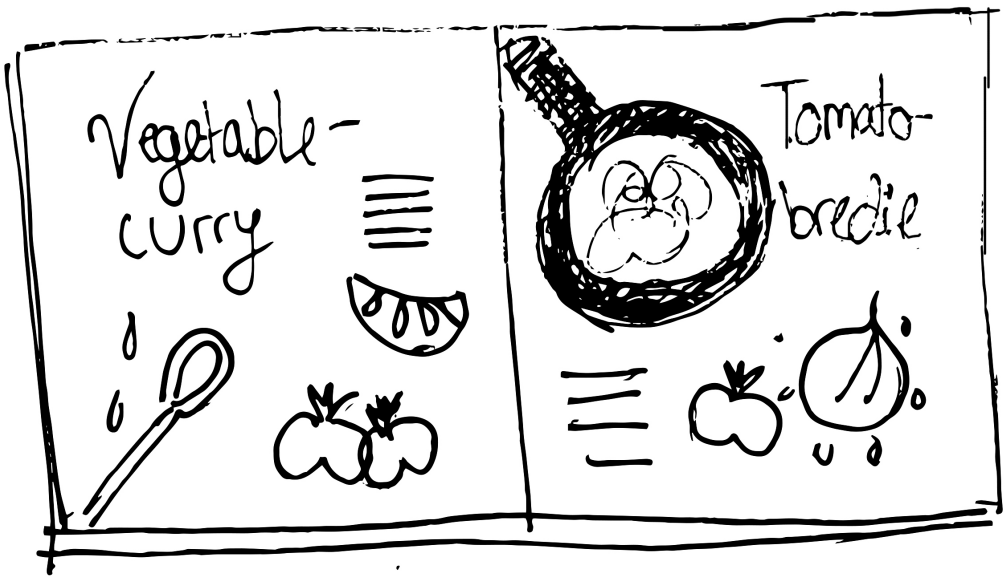

Figure 19 - Illustration of a cook book

7.4.3 "Kitchen re-organizing"

This activity is meant to provide strategies to tackle food cravings. Here we try to address the patients' cravings by making it more difficult to act on them. The idea is based on the effect of hiding away the foods and groceries that may offer temptation, to not trigger the craving. Physically arranging hinders so that the sweet stuff is hard to get, can provide a pause that allows the reflective processes to kick in.

A CHW and the patient can go through the kitchen and re-organize some of the foods and groceries, and place unhealthy choices in places where it is more difficult to reach and see. This activity can be combined with the "kitchen activity" from the reflective section. This is a great opportunity to identify the habits and typical pitfalls that makes it difficult for the patient to make healthy choices. For example, if the family members buy food that is bad for the person with diabetes, provide a shelf or drawer that is less accessible for them to store these options.

The activity can also be used to discuss storage options to keep vegetables fresher for longer. Similar activities can be undertaken to identify exercise opportunities.

7.4.4 Sugar addiction program

From the empirical findings we learned that many experience a craving for the *sweet stuff*. We also know that sugar can have a negative impact on the disease. The prospect of cutting out something the body very badly craves can be daunting if the individual does not know that the feeling of cravings will pass.

Giving the patient a program to cut down on sugar can be effective to help her with reflecting upon the addiction and give her strategies to avoid and say no to sugar. It can be valuable for the patient to learn about how the body reacts when reducing sugar consumption, and that it will require discipline to fight the craving for sugar.

To assist the patient in cutting down on sugar, the patient can create a sort of "punch card" to monitor progress. In figure 20 we show how a patient for instance can allow himself five cool-drinks, sweets or desserts per week, and cross of in one box when he allows himself a treat. This can help bring awareness and self-monitoring to address the cravings. These goals should be made based on the current sugar-consumption.

The illustration in figure 21 can function as an assisting tool for the sugar-addiction-program. The illustration shows how much sugar different items of drink contain, represented in spoons of sugar. This might make it easier for the patient, to determine the amount of sugar he consumes during the day. Similarly, if the patients prefer a spoon of sugar in the tea for breakfast, they can be reminded to choose water for lunch. This idea can simultaneously strengthen the understanding of how much sugar different foods and beverages contain.

Figure 20 – Illustration of a "punch card" for monitoring sugar consumption

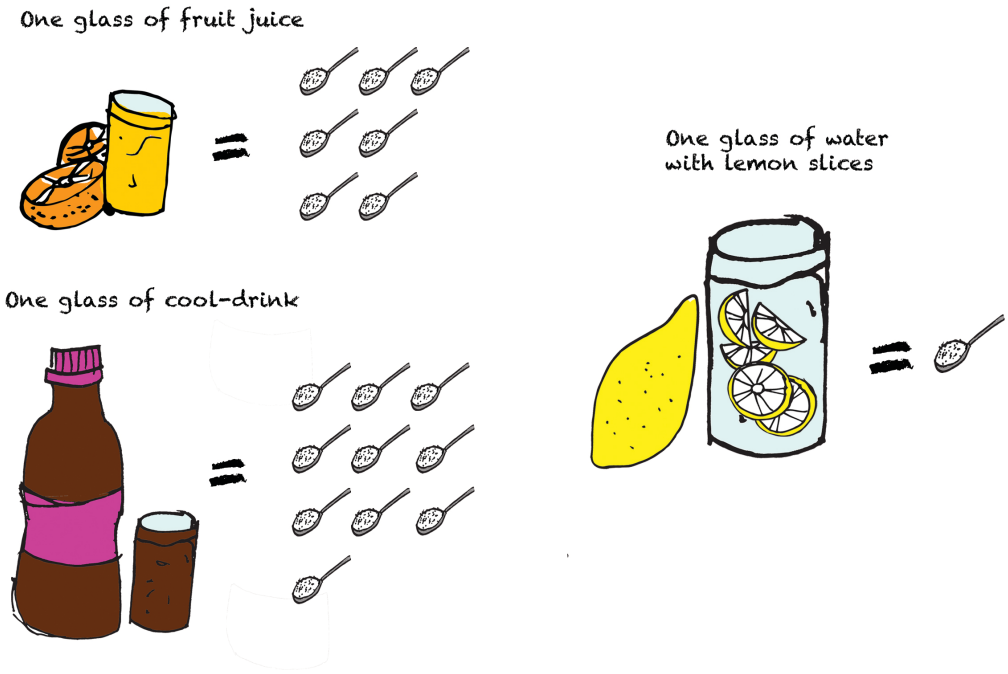

Figure 21 - Illustration of sugar content in different items

7.5 Summary

The aim with the ideas presented in this chapter, was to exemplify how the principles of flexibility and local adaptation can be implemented in practice, and how the ideas can address reflective and automatic motivation. By addressing both reflective and automatic motivation through separate activities and resources, we provide the CHW flexibility to configure their response to the individual needs of the patients.

This design proposals should not be regarded as definite solutions to solve the wicked problem of having diabetes. Rather, the "resource bank" contains examples of how the needs we have identified can be met in practice, and is meant for inspiration to others.

8 Discussion: creating a design

Löwgren and Stolterman (2004) propose three levels of design ideas, that we interpret as three levels of concretization: the vision, the operative image, and the specification. We find these three levels useful to frame discussions in this chapter.

The vision is not a solution or specification. It should, however, be thought of as a "first organizing principle that helps the designer to structure the initial attempts to respond to the situation at hand" (Löwgren & Stolterman, 2004, p. 18).

The *operative image* has the function of bridging the gap between the abstract and elusive vision and the concrete and complex situation (Löwgren & Stolterman, 2004, p. 19). The third level is that of *specification*, where the ideas take a concrete form.

In our case, the design *vision* is aligned with our research interest: It can be defined as the attempt to increase life quality of people having diabetes in Mitchells Plain, by increasing their self-management capabilities. To us, there is not a clear delineation between the *vision, operative image* and *specification* levels of our ideas. However, we take the *operative image* to signify the design concretizations that have emerged through our analysis and ideations in chapter 6 and 7.

In chapter 7 we presented the *specifications* of our ideas through the design proposals. In this chapter, we discuss and present the thoughts and reasonings behind our operative image, and the ways our operative image is rooted in the theories we have used in this thesis.

Chapter structure

First, we take a closer look at the impact of viewing diabetes as a wicked problem on the design in section 8.1. In section 8.2 we discuss the way we approach the task of promoting health in our designs. We do this by comparing the perceived quality-of-life of being 1) completely healthy but having a comprehensive treatment plan, to that of 2) having a less comprehensive treatment plan, but experiencing some or severe complications from diabetes. Further, in section 8.3 we discuss how the theory about plans and situated action has guided the way we designed the "resource bank" for the CHWs at Arisen Women. This discussion highlights how we approach the task of designing an appropriate tool that function as a *resource for* action to support CHWs with managing diabetes.

8.1 Designing for wickedness

The goal of our research has been to create an appropriate design that will help patients in Mitchells Plain achieve their goals. The process of design has been influenced by the UCD tradition presented in section 4.5, and our understanding of diabetes as a wicked problem. Thus, as mentioned before, the task of defining the problem is a big part of creating design solutions for wicked problems.

At the outset of our main fieldwork, the problem areas we first wanted to learn more about was:

1. What is difficult for the patients
2. What is difficult for the health care providers
3. The influence of the environmental and social aspects in Mitchells Plain
4. Analyze how these are interrelated and affect each other.

Just a couple of weeks in to the fieldwork we began to see the contours of how some of these problem areas manifested. For instance, at the clinic, the vast number of patients and the lack of time made it difficult for the clinic workers to provide quality health care to everyone. For the patients, the lack of knowledge and poor economy were restraining factors. Their uncertainty about the effects of a lifestyle change was apparent from the beginning.

While we understood that knowledge was an important aspect, and that economy was restraining, the task of asking: "what can we do, then?" revealed the wickedness of having and managing diabetes. There was no apparent context of intervention that revealed itself merely by identifying some of the issues with having and managing diabetes. For instance, we felt that a knowledge lift would have to occur amongst people with diabetes, but we felt that pamphlets and written material wouldn't do the job, based on the feedback from patients and CHWs. Additionally, trying to provide education through an app or website 1) wouldn't be sought out by the patients and 2) required technological resources and literacy skills that often were inaccessible to the patients. In effect, while we knew some of the things we wanted to achieve, we were unsure of how to achieve them, given the circumstances.

While our initial plan was to follow a UCD process where we would have time to prototype and do some evaluations during our 10-week long fieldwork, much of the time was spent on finding a context of intervention and exploring that. Thus, the

research phase related to designing for wickedness had three distinct parts. First, try to understand the problem. Second, identify a meaningful context of intervention. Third, specify the user and organizational requirements for that context.

Recognizing diabetes as a wicked problem helped us adapt our research strategy to respect the complexity, rather than trying to reduce it. In effect, we aligned our strategy with the views of Eric Stolterman who claim that:

> *"you cannot reduce design complexity by limiting yourself to those things that you have the time or resources to handle or those things that you have sufficient knowledge and information about.(Stolterman, 2008, p. 59)*

Our focus on the search for a meaningful context of intervention eventually lead us to focusing on designing tools that would help CHWs to support the patients, rather than designing tools directly aimed at the patient. The involvement of human resources in building up the diabetes self-management capabilities in people solves many of the needs we identified in section 6.4.

Thus, designing for the wicked problem of managing diabetes in Mitchells Plain entails a thorough research phase that respects the complexity of the problem. Additionally, recognizing diabetes as a wicked problem helped us understand the heterogeneity of the different (but similar) needs of the patients in Mitchells Plain. Our aim to design tools that allow flexibility and individual adaptation is a result of this realization. In Section 8.3 this is discussed further, by framing our design suggestions as a "resource in action" based on Lucy Suchmans framework of *plans and situated actoin*.

Our designs focus on one specific context of intervention, namely that of the interplay between the CHW and the patient. As a result of the wickedness, we would like to stress that we don't view the problem as being solved, nor do we know if our design is the most effective one. This is a result of the wickedness. That solutions aren't right or wrong, but good or bad. If it was possible to create one single comprehensive solution, it would not be wicked.

In our designs, we have chosen to focus on how we can help the patient in the social and environmental context they find themselves in. However, a takeaway from the empirical findings- and analysis chapters is that there are many initiatives that may contribute to alleviating various aspects of the problem. For instance, initiatives that make healthy diet options cheaper and more available through sugar-taxes or social support programs. Improving knowledge levels through a bigger focus on lifestyle

diseases in the education, and so on. There are many options for solutions that in various degree directly or indirectly contributes to bettering the conditions for diabetes self-management.

8.2 How healthy is healthy enough?

As we mentioned in section 2.1 the treatment of diabetes type 2 is not only medicinal but entails that the patient modifies his lifestyle. The ability to do so in a "correct" manner is referred to as diabetes self-management, indicating that the patient is capable of contributing to his own recovery. As designers, we believe that part of our job is to increase life quality. As such, our design proposals in chapter 7 aims to increase life quality through building the capacity to self-manage the recovery from diabetes. This invites a discussion about the ways in which we tackle the task of promoting health, through our designs.

8.2.1 Quality of Life

The outcomes of diabetes care can be anywhere on a scale from achieving 'perfect health', to 'milder complications', to 'severe end-stage complications' and even 'death', depending on the intensity of treatment (Huang, Brown, Ewigman, Foley, & Meltzer, 2007). These outcomes are referred to as *utilities* in a study conducted by Huang et al. In this study, the research objective was to investigate the perceived quality-of-life for people with diabetes type 2 by comparing the intensity of treatment with a range of *utilities*. They found that end-stage complications have the greatest perceived burden on quality of life; however, they also found that comprehensive diabetes treatments have significant negative quality-of-life effects. (Huang et al., 2007)

This highlights that while becoming healthier is a goal to avoid end-stage complications, the comprehensiveness of the treatment plan can become a bigger burden on quality-of-life than the more manageable symptoms of diabetes. Further, the study points out that the patients' willingness to adopt the proposed care-regime is likely to be determined, in part, by the patients perceptions of the relative quality-of-life effects of complications and treatments. (Huang et al., 2007, p. 2)

This is correlates with our findings in Mitchells Plain. As we discussed in the subsection "patient strategy" under section 5.3, the people in Mitchells Plain value their current lifestyle and are daunted by the prospect of having to give it up. A dilemma for the patients seemed to be: "how much must I sacrifice to achieve 'good

enough' health?". The main motivation to achieve better health was mostly driven by the desire to avoid complications and to avoid becoming insulin dependent. As such, the patients' goals are not necessarily to have perfect health, but to achieve better life quality by avoiding the worst end-stage complications.

8.2.2 Shared decision making and goal-setting

Huang et al. notes that the perception of life quality is not homogenous amongst people with diabetes type 2 and highlights the importance of incorporating a shared decision-making approach into everyday diabetes care. Shared decision-making is not only important to value the patients quality-of-life, but research also show that when the patient is actively involved in setting health goals, they are more likely to be achieved. (Huang et al., 2007) This notion is supported by Heisler et al. (2003) who suggests that involving the patient in goal-setting increases their confidence in their ability to complete these activities (Heisler et al., 2003, p. 893).

We ascribe to the notion that there is great value to be found from finding solutions together with the patients. During the course of the fieldwork, a recurring remark by the patients was that they were given advice they couldn't follow. Further they felt that the health care providers didn't understand or respect their financial situation. Health advice can thus be seen as objectively good or bad from a curative perspective, but the value of the advice comes from the likeliness that the patient will and can follow them.

In the empirical chapter we described a situation from one of our home-visits. The patient was proud to have found a breakfast option he didn't need sugar on, but it turned out that the option was a strawberry-flavored mielie-pap porridge with 89 grams fast-acting carbohydrates per 100 grams. Towards the end of our visit we went answered questions about diabetes, about diet, we made lists and explained diabetes using drawings for the informant to keep. The patient had throughout the visit referenced economy as a limiting factor. However, when we were working together to find better options for a filling breakfast, the informant seemed happy to invest a little extra in un-processed oats – as a replacement of the mielie-pap. We discussed using apples as sweeteners instead of sugar, and the fact that un-processed oats takes longer time to break down, so that the informant would likely feel full for longer. To us it became evident that the way to address the many constraining factors with economy, safety and food preferences was to provide advice that was within limit for the patient to conduct, and to let the patient choose the degree of commitment.

We believe there are two good reasons for focusing on patient-involvement and an inclusive process of goal-setting:

The first reason is a reference to the discussion above, and regards the argument of autonomy and the capability to choose the lives one wants to lead. The quality-of-life is a subjective perception, that needs to be taken in to account. Our aim is not to make every individual in Mitchells Plain "perfectly healthy", but they should have the opportunity to become so. However, we see that people are unaware of the likeliness that complications occur, and that the informants who have had to amputate a limb experience a deep sense of regret of not having taken action earlier. Thus, the process of shared goal-setting should be accompanied by helping the patient be aware of the potential outcomes of a treatment regime.

The second reason relates to the fact that some of the members of the Mitchells Plain community live in rather extreme conditions, both socially and economically. Knowing if a dietary advice is economically feasible to an individual can be difficult without working together with that person to find solutions. During our focus group with nine ladies with diabetes, they would sometimes offer advice based on their own experiences and routines. Several times, the reactions from the other participants was that they could never afford to follow that advice. While Mitchells Plain overall is a poor area, there are differences in the economic scope-of-action people have to change their diet. Finding solutions for a person with very few economic resources might entail giving different advice compared to the advice that can be given to someone with a slightly better economy. After all, if the only advice a person gets, are advice that would make the diet too expensive to feed the family, the individual is left without actionable and feasible advice.

8.2.3 Health and our designs

The goal of the designs we propose in chapter 7 is that they help people in Mitchells Plain to manage their diseases and avoid late-stage complications by building their self-management capacities. We propose doing so through a collaborative process between the patient and health personnel, such as CHWs. Thus, in this discussion, we are heavily aligned with that of the capability approach, where we give weight to the freedom to choose. We believe that the patient should have the freedom to choose not to sacrifice "everything" he values to have a healthy body. Our stance in the matter of "how healthy is healthy enough" is thus that the CHWs should have the tools to help the patient become as healthy as the patient wishes, given that the patient is provided with sufficient understanding of the potential risks of complications.

We would like to add that CHWs still have the mandate to try to make people healthy. This regard both the patients' capacities to understand the likeliness and severity of end-stage complications, but also is a reference to the negative perception the patients have of "diet food". We saw that the lack of knowledge manifested as a very strict understanding of a diabetes-friendly diet, where the list mostly said "don't eat this". By increased knowledge and learning a few skills and exchanging advice the transition to a more diabetes-friendly lifestyle will perhaps not be perceived as negatively as it currently is.

In our design suggestions, we have focused on creating resources and activities that can be used as tools to build understanding of the disease and the potential consequences. These are focused mostly on "Reflective Motivation". In addition, the design ideas that address "Automatic Motivation" aim to build tools that will reduce the negative impact of a health intervention on the quality-of-life. An example of this is providing healthy options for the cravings they have, such as using fruit as sweeteners, and provide cooking methods that provide tasty food using spices, instead of the large amounts of fat and salt.

In the next section we discuss how we have let the concept of "resource in action" guide the way we design tools for the CHWs.

8.3 Resources to provide health care, and achieve individual adaptation

The discussion in the previous section was inspired by the capability approach, and the freedom to choose "how healthy is healthy enough". In this section, we will discuss how we make use of the *curative approach* (discussed in section 2.1.5]) as a resource to guide action, rather than as a plan to be carried out.

This discussion highlight how the designs can strengthen the CHWs to better respond and adapt their health care efforts to the individual patients.

8.3.1 Resource in action

This discussion is based on the theories of Lucy Suchman, and her critique of using the "planning model" to design technology. This critique was brought forth because the "plan" fails to anticipate all the aspects that make up the context (Suchman, 1987). As such, when something occurs that lead the user to deviate from the "plan" that is inscribed in to the technology, the technology offers little or no support.

Lucy Suchman argues instead to acknowledge that all actions are situated (Suchman, 1987). Meaning, human actions occur as ad-hoc responses to the actions of others and to the contingencies of particular situations. Based on this, plans should be viewed as a resource to guide situated action, rather than a recipe to be executed.

In this thesis, we draw parallels between the planning model and the curative approach to diabetes care. Our argument is that there is an inscribed "plan" in much of the literature and resources that are made to help people live diabetes-friendly. This rigid "plan" takes the *curative approach* to diabetes care, and is made as a recipe to cure the body. In such resources, the focus is on the "best practice" of diet, exercise and medicine to make the body healthy.

However, the "plan" to make the body healthy must be carried out and conducted in the context of someone's life, and the ability to carry out the ideal steps to cure the body depends on a person's capability to do so (as discussed in the analysis in chapter 6). Thus, the plan is made for the body, and not as a resource for the situated action.

In Mitchells Plain, this was clearly manifested in people's perception of what a diabetes-friendly diet entail. The plan that was inscribed in the available diet advice instructed patients to avoid fatty food, avoid sugar and avoid most things they perceived as good food. However, when it was time to put together meals within

social and economic context they reside in, the "plan" did not support their ability to achieve a diabetes-friendly diet.

Based on this, we argue that there is a need to move away from designing resources and tools that have a rigid plan inscribed to them. We use Lucy Suchmans theories about plans and situated actions to guide the way we make use of the "plan" that is the *curative perspective*, in our designs. To us, the goal is to let the plan function as a resource to guide action. By this we mean that the activities and resources we have designed in chapter 7 are all informed by the "plan" to make the body healthy. Together, the ideas pull in the same direction. The aim is to make it easier either to know what to do through increased knowledge, or to make it easier to make healthy choices through enablement.

Thus, the tools and activities do not make up steps to be followed, nor are there inscribed objective goals that normatively decide how healthy a patient should be. Rather, the designs function as a bank of resources to draw on and that give the CHW a range of options of how to address a situation, based on the needs she identifies in an individual. An important part of our design suggestion is to give the CHW the "power" to respond to the situations by giving her the choice to use the tools or resources she finds best suited for the individual patient. The CHW can use these tool and resource to educate, support and motivate the individual, based on what she believe suits the individuals needs given their specific situation.

9 Conclusions

This thesis has presented a research process aimed at contributing to knowledge about how people with diabetes type 2 in resource poor settings can be supported by design interventions. Throughout the thesis, we explore the two research questions:

1. *"What are the needs of people living with diabetes type 2 in Mitchells Plain, and what are the design implications of these needs?"*

2. *"How can tools be designed to support community health workers with managing diabetes?"*

We will reflect upon these research questions below.

We have found that there is a lack of knowledge, that inhibits the capability of people in Mitchells Plain to achieve sufficient diabetes self-management skills. Further, we found that the individuals have a limited scope-of-action to respond to having diabetes, especially restrained by low income, but also by social factors and unsafety. This limited scope-of-action creates the need for even more adapted advice and strategies to create diabetes management strategies that account for the limited resources the patients have. Further, the overburdening of the local public health clinic causes many people with diabetes to lack proper understanding of the importance of making a lifestyle change as part of the treatment of the disease. This leads many of the patients to make fragmented and demotivated attempts at following the set of health-advice they have been given.

By looking at how reflective and automatic motivation manifested in Mitchells Plain , we found that people lack reflective motivation due to lack of knowledge, and due to lack of understanding of the potential consequences of having high blood glucose levels over time. With automatic motivation, we found that the food culture and social fabric of Mitchells Plain deeply affected the cravings and dietary habits of the patients: they lack an automatic motivation to exercise and follow a diabetes-friendly diet, due to their comfort with pre-existing lifestyle, and their negative perception of a diabetes-friendly lifestyle.

Throughout this thesis we have discovered that the people living in Mitchells Plain need support with strengthening their diabetes self-management skills. And that this entails addressing knowledge and motivation by utilizing local community health workers (CHWs). For CHWs to be able to support patients in achieving diabetes self-management, they must have resources to help them facilitate education and support.

These tools need to be designed so they can be adapted to the local context, and to allow individual adaptation to meet the patients scope-of-action. To ensure that the support can be individually adapted, we have used the theory of plans and situated action, by Lucy Suchman () to guide how we have designed the ideas to function as a resource for action. Thus, allowing the CHWs to draw on the resources they see most fit, in the situation they find themselves in with the patient.

Building on the concepts of reflective and automatic motivation, we have proposed a design that address these, by building knowledge, creating awareness of the consequences of having high blood glucose levels, and through helping the patients manage their cravings and habits. Thus, our design suggestions serve as examples of the types of resources we believe can help the patients. The takeaways from our designs, however, is the ideas they are built on.

9.1 Contributions

We have two types of contributions in this thesis. The first is the contribution to practice. We provide a way to organize health care, by addressing reflective and automatic motivation through a set of ideas that are flexible and can be recreated and adapted to a local context by CHWs, designers and health care providers in other places.

The second contribution is to theory. The capability approach provides us with an analytic lens that allow us to identify some barriers to achieve a diabetes-friendly lifestyle, however the approach doesn't account for motivation. The approach is built on the assumption of people as rational beings, as such it is assumed that as long as people have the freedom to choose the functionings they wish to achieve, they will choose the functioning they find the most valuable. However, we argue that this assumption of rationality undermines the fact that people can wish to achieve two competing functionings simultaneously, and that there isn't necessarily a rational choice behind the functioning that in the and is achieved. In the case of this thesis, this tug-of-war represents the desire to have a diabetes-friendly life while at the same time having the desire to enjoy the fruits of the current lifestyle.

On the basis of this, we provide an expansion to the capability framework by including the aspect of reflective and automatic motivation to help us understand how this tug-of-war manifests and can be addressed through design.

References

Abras, C., Maloney-Krichmar, D., & Preece, J. (2004). User-centered design. *Bainbridge, W. Encyclopedia of Human-Computer Interaction. Thousand Oaks: Sage Publications*, *37*(4), 445–456.

Ajay, V. S., & Prabhakaran, D. (2011). The scope of cell phones in diabetes management in developing country health care settings. *Journal of Diabetes Science and Technology*, *5*(3), 778–783.

Andersson, A., Grönlund, Å., & Wicander, G. (2012). Development as freedom – how the Capability Approach can be used in ICT4D research and practice. *Information Technology for Development*, *18*(1), 1–4. https://doi.org/10.1080/02681102.2011.632076

Borghouts, L. B., & Keizer, H. A. (2000). Exercise and Insulin Sensitivity: A Review. *International Journal of Sports Medicine*, *21*(1), 1–12. https://doi.org/10.1055/s-2000-8847

Bradley, H. A., & Puoane, T. (2007). Prevention of hypertension and diabetes in an urban setting in South Africa: participatory action research with community health workers, 49–54.

Buchanan, R. (1992). Wicked Problems in Design Thinking. *Design Issues*, *8*(2), 5. https://doi.org/10.2307/1511637

Camillus, J. C. (2008). Strategy as a wicked problem. *Harvard Business Review*, *86*(5), 0–10.

Chen, L., Magliano, D. J., & Zimmet, P. Z. (2012). The worldwide epidemiology of type 2 diabetes mellitus—present and future perspectives. *Nature Reviews Endocrinology*, *8*(4), 228–236.

Crang, M., & Cook, I. (2007). *Doing ethnographies*. Sage.

Creswell, J. W., & Creswell, J. W. (2007). *Qualitative inquiry & research design: choosing among five approaches* (2nd ed). Thousand Oaks: Sage Publications.

Dabbs, A. D. V., Myers, B. A., Mc Curry, K. R., Dunbar-Jacob, J., Hawkins, R. P., Begey, A., & Dew, M. A. (2009). User-Centered Design and Interactive Health Technologies for Patients. *Computers, Informatics, Nursing: CIN*, *27*(3), 175. https://doi.org/10.1097/NCN.0b013e31819f7c7c

Department of Provincial and Local Governnment (DPLG) & Business Trust. (2007). *Mitchells Plain Nodal Economic Development Profile*. Retrieved from http://www.btrust.org.za/library/assets/uploads/documents/5_CIPPN_Mitchells%20Plain%20narrative.pdf

Dourish, P. (2001). *Where the action is: the foundations of embodied interaction*. Cambridge, Mass: MIT Press.

Dourish, P. (2004). *Where the Action Is: The Foundations of Embodied Interaction* (New Ed edition). Cambridge, Mass.: The MIT Press.

Erasmus, R. T., Soita, D. J., Hassan, M. S., Blanco-Blanco, E., Vergotine, Z., Kengne, A. P., & Matsha, T. E. (2012). High prevalence of diabetes mellitus and metabolic syndrome in a South African coloured population: Baseline data of a study in Bellville, Cape Town. *SAMJ: South African Medical Journal*, *102*(11), 841–844.

Family Physician, M.-C. (2017, December 6). From Mitchells Plain CHC - Email about Diabetes in Mitchells Plain.

Feldman, B., Brazg, R., Schwartz, S., & Weinstein, R. (2003). A continuous glucose sensor based on Wired Enzyme^{TM} technology-Results from a 3-day trial in patients with type 1 diabetes. *Diabetes Technology & Therapeutics*, *5*(5), 769–779.

Flyvbjerg, B. (2006). Five Misunderstandings About Case-Study Research. *Qualitative Inquiry*, *12*(2), 219–245. https://doi.org/10.1177/1077800405284363

Flyvbjerg, B. (2011). Chapter 17 - Case Study. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE Handbook of Qualitative Research* (4th ed., pp. 301–316). London: SAGE Publications. Retrieved from https://uk.sagepub.com/en-gb/eur/node/52625/print

Geertz, C. (1973). *The interpretation of cultures* (Vol. 5019). Basic books.

Harris, M., Hood, K., & Mulvaney, S. (2012). Pumpers, skypers, surfers and texters: technology to improve the management of diabetes in teenagers. *Diabetes, Obesity and Metabolism*, *14*(11), 967–972.

Harvey, R. A., & Ferrier, D. R. (2011). Diabetes Mellitus. In *Biochemistry* (5th ed., pp. 337–348). Lippincott Williams & Wilkins.

Heeks, R. (2006). Health information systems: Failure, success and improvisation. *International Journal of Medical Informatics*, *75*(2), 125–137.

Heeks, R. (2010). Do information and communication technologies (ICTs) contribute to development? *Journal of International Development*, *22*(5), 625–640. https://doi.org/10.1002/jid.1716

Heisler, M., Vijan, S., Anderson, R. M., Ubel, P. A., Bernstein, S. J., & Hofer, T. P. (2003). When Do Patients and Their Physicians Agree on Diabetes Treatment Goals and Strategies, and What Difference Does It Make? *Journal of General Internal Medicine*, *18*(11), 893–902. https://doi.org/10.1046/j.1525-1497.2003.21132.x

Huang, E. S., Brown, S. E. S., Ewigman, B. G., Foley, E. C., & Meltzer, D. O. (2007). Patient Perceptions of Quality of Life With Diabetes-Related Complications and Treatments. *Diabetes Care*, *30*(10), 2478–2483. https://doi.org/10.2337/dc07-0499.

International Diabetes Federation. (2017). *IDF Diabetes Atlas 8th edition* (p. 150). International Diabetes Federation. Retrieved from http://diabetesatlas.org/resources/2017-atlas.html

Klein, H. K., & Myers, M. D. (1999). A Set of Principles for Conducting and Evaluating Interpretive Field Studies in Information Systems. *MIS Quarterly*, *23*(1), 67–93. https://doi.org/10.2307/249410

Knapp, J., Zeratsky, J., & Kowitz, B. (2016). *Sprint: How to Solve Big Problems and Test New Ideas in Just Five Days*. Bantam Press (2012).

Koplan, J. P., Bond, T. C., Merson, M. H., Reddy, K. S., Rodriguez, M. H., Sewankambo, N. K., & Wasserheit, J. N. (2009). Towards a common definition of global health. *The Lancet*, *373*(9679), 1993–1995. https://doi.org/10.1016/S0140-6736(09)60332-9

Kruger, H. S., Puoane, T., Senekal, M., & Merwe, M.-T. van der. (2005). Obesity in South Africa: challenges for government and health professionals. *Public Health Nutrition*, *8*(5), 491–500. https://doi.org/10.1079/PHN2005785

Law, J. (2004). *After method: Mess in social science research*. Routledge.

Lazar, J., Feng, J. H., & Hochheiser, H. (2010). *Research methods in human-computer interaction*. John Wiley & Sons.

Lieberman, D. A. (2012). *Video games for diabetes self-management: examples and design strategies*. SAGE Publications. Retrieved from http://journals.sagepub.com/doi/abs/10.1177/193229681200600410

Löwgren, J., & Stolterman, E. (2004). *Thoughtful interaction design: a design perspective on information technology*. Cambridge, Mass: MIT Press.

Mahajan, S. (Ed.). (2014). *Economics of South African Townships: Special Focus on Diepsloot*. The World Bank. https://doi.org/10.1596/978-1-4648-0301-7

Medicine, I. of. (1988). *The Future of Public Health*. https://doi.org/10.17226/1091

Michie, S., Stralen, M. M. van, & West, R. (2011). The behaviour change wheel: A new method for characterising and designing behaviour change interventions. *Implementation Science*, *6*(1), 42. https://doi.org/10.1186/1748-5908-6-42

Mukherjee, A. (2016). Empowerment: The invisible element in ICT4D projects? The case of public health information systems in India and Kenya.

Mullan, F., & Epstein, L. (2002). Community-Oriented Primary Care: New Relevance in a Changing World. *American Journal of Public Health*, *92*(11), 1748–1755. https://doi.org/10.2105/AJPH.92.11.1748

Myers, M. D. (1997). Qualitative research in information systems. *Management Information Systems Quarterly*, *21*(2), 241–242.

Myers, M. D., & Avison, D. (2002). *Qualitative research in information systems: a reader*. Sage.

Nambiar, S. (2013). Capabilities, conversion factors and institutions. *Progress in Development Studies*, *13*(3), 221–230. https://doi.org/10.1177/1464993413486547

Nutting, P. A., & Connor, E. (1984). *Community Oriented Primary Care: A Practical Assessment* (Vol. 1). National Academies.

Pagliari, C. (2007). Design and evaluation in eHealth: challenges and implications for an interdisciplinary field. *Journal of Medical Internet Research*, *9*(2), e15. https://doi.org/10.2196/jmir.9.2.e15

People's Post Mitchells Plain. (2016, November 15). People's Post Mitchell's Plain - 2016 11 15. Retrieved April 24, 2018, from https://issuu.com/thepeoplespost/docs/peoplespostmm_20161115

Polaine, A., Reason, B., & Løvlie, L. (2013). *Service Design: From Insight to Implementation*. Rosenfeld Media. Retrieved from www.rosenfeldmedia.com

Rittel, H. W., & Webber, M. M. (1973). Dilemmas in a general theory of planning. *Policy Sciences*, *4*(2), 155–169.

Robeyns, I. (2005). The Capability Approach: a theoretical survey. *Journal of Human Development*, *6*(1), 93–117. https://doi.org/10.1080/146498805200034266

Saffer, D. (2010). *Designing for Interaction: Creating Innovative Applications and Devices*. New Riders.

Sanjek, R. (1990). *Fieldnotes: The Makings of Anthropology*. Cornell University Press.

Sen, A. (1999). *Development as freedom*. Oxford: Oxford University Press.

South Africa - urbanization 2006-2016 | Statistic. (2018). Retrieved May 2, 2018, from https://www.statista.com/statistics/455931/urbanization-in-south-africa/

Stake, R. E. (2005). Chapter 17 - Qualitative case studies. In N. Denzin & Y. Lincoln (Eds.), *The Sage Handbook of Qualitative Research* (pp. 443–466).

Statistics South Africa. (n.d.). Statistics South Africa [Statistics South Africa]. Retrieved April 28, 2018, from http://www.statssa.gov.za/?page_id=4286

Stolterman, E. (2008). The Nature of Design Practice and Implications for Interaction Design Research. *International Journal of Design; Taipei*, *2*(1), 55–65.

Strack, F., & Deutsch, R. (2009). Reflective and Impulsive Determinants of Social Behavior, 28.

Suchman, L. A. (1987). *Plans and Situated Actions: The Problem of Human-machine Communication*. New York, NY, USA: Cambridge University Press.

Thorseng, A. A. (2017). *Building patient-centred health information infrastructures*. University of Oslo, Faculty of Mathematics and Natural Sciences, Department of Informatics, Oslo.

Tibane, E., South Africa, & Government Communications and Information System. (2017). *Pocket guide to South Africa, 2016/17* (Fourteenth (14th)). Pretoria: Government Communications (GCIS). Retrieved from https://www.gcis.gov.za/pocket-guide-south-africa-201617

Vervloet, M., van Dijk, L., Santen-Reestman, J., Van Vlijmen, B., Van Wingerden, P., Bouvy, M. L., & de Bakker, D. H. (2012). SMS reminders improve adherence to oral medication in type 2 diabetes patients who are real time electronically monitored. *International Journal of Medical Informatics*, *81*(9), 594–604. https://doi.org/10.1016/j.ijmedinf.2012.05.005

Waki, K., Fujita, H., Uchimura, Y., Omae, K., Aramaki, E., Kato, S., … Ohe, K. (2014). DialBetics: A Novel Smartphone-based Self-management Support System for Type 2 Diabetes Patients. *Journal of Diabetes Science and Technology*, *8*(2), 209–215. https://doi.org/10.1177/1932296814526495

Walsham, G. (1995). Interpretive case studies in IS research: nature and method. *European Journal of Information Systems*, *4*(2), 74.

Walsham, G. (2006). Doing interpretive research. *European Journal of Information Systems*, *15*(3), 320–330. https://doi.org/10.1057/palgrave.ejis.3000589

Watterson, J., Walsh, J., & Madeka, I. (2015). Using mHealth to Improve Usage of Antenatal Care, Postnatal Care, and Immunization: A Systematic Review of the Literature. *Biomed Res Int*, *153402*.

Western Cape Government. (2016). SEP Socio-economic profile. City of Cape Town 2016. Western Cape Government. Retrieved from https://www.westerncape.gov.za/assets/departments/treasury/Documents/Socio-economic-profiles/2016/City-of-Cape-Town/city_of_cape_town_2016_socio-economic_profile_sep-lg.pdf

Winslow, C.-E. A. (1920). The Untilled Fields of Public Health. *Science*, *51*(1306), 183–191. https://doi.org/10.1126/science.51.1306.23

World Health Organization. (n.d.). WHO | Diabetes mellitus. Retrieved April 28, 2018, from http://www.who.int/mediacentre/factsheets/fs138/en/

Worthview. (2017, December 16). A Guide on Normal Blood Sugar Level and How to Maintain it. Retrieved April 23, 2018, from http://www.worthview.com/guide-normal-blood-sugar-level-maintain/

Zimmet, P. Z., Magliano, D. J., Herman, W. H., & Shaw, J. E. (2014). Diabetes: a 21st century challenge. *The Lancet Diabetes & Endocrinology*, *2*(1), 56–64. https://doi.org/10.1016/S2213-8587(13)70112-8