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Chapter 1 - General introduction.

This thesis reports on six studies that were conducted to get a better understanding of the influence of emotional factors on self-care behaviors and on self-management support for type 2 diabetes. Furthermore, the thesis is set out to uncover the feasibility of online and web-based solutions for supporting patient centeredness and self-management for people with type 2 diabetes. The current chapter gives a short introduction on type 2 diabetes, risk factors, consequences, global impact, treatment, and online treatment and support solutions. At the end of this introductory chapter, the aims of this thesis and an outline of its consecutive chapters are provided.

Diabetes mellitus

Diabetes mellitus is a metabolic disease characterized by abnormally increased blood glucose levels, defined by a fasting plasma glucose of 7 mmol/L or higher or a non-fasting plasma glucose of 11,1 mmol/L or higher.¹ Increased blood glucose levels are caused by a shortage or absence of insulin, and/or a decreased sensitivity to insulin. When beta cells in the pancreas are unable to produce insulin, this causes a shortage or absence of circulating insulin. An acute onset with a total lack of circulating insulin is defined as having type 1 diabetes (T1DM). When the production of insulin slowly declines, and/or the cells of the body are developing a resistance towards insulin and beta cell insulin production cannot keep pace, it is defined as having type 2 diabetes (T2DM).² Type 2 diabetes is the primary focus of this thesis.

Risk factors for developing type 2 diabetes

The most important factors associated with an increased risk of developing type 2 diabetes are older age, being overweight, and a sedentary lifestyle. Moreover, research has shown that people who have first degree family members with type 2 diabetes are more susceptible of developing type 2 diabetes themselves.³ This could either be due to genetic predisposition or to the fact that families generally share eating and physical activity behaviors.

Lifestyle factors such as a failure to exercise and poor eating habits, add to being overweight and having an increased waist circumference, all which increase the chance of developing type 2 diabetes.^{4,5} Increased body fat mass is associated with increased insulin resistance, which will result in high blood glucose levels, even when insulin levels are still comparatively high due to the inability of beta-cells to continue a sufficiently high insulin production to maintain euglycemia. Chronic high glucose levels will then add to the fray, since under such conditions “glucose toxicity” will result into even more severe insulin resistance.^{1,2}

Consequences of type 2 diabetes

In type 2 diabetes, beta cell dysfunction and insulin resistance lead to an abnormal increase of blood glucose levels. Glucose lowering medication will therefore be initiated in order to try to lower blood glucose concentrations to levels approaching non-diabetic levels as much as possible. The use of some medications may even lead to a decrease of blood glucose levels below normal. Such low blood glucose levels, or hypoglycemia, can ultimately lead to short-term consequences such as losing consciousness and even death. High blood glucose levels, or hyperglycemia, can lead to long-term consequences in the form of diabetes related complications. These complications can be divided into macro vascular complications (accelerated atherosclerosis and cardiovascular problems) and micro vascular complications (specifically; retinopathy, nephropathy, and neuropathy).⁶ Macro vascular complications are primarily related to insulin resistance, hypertension, and lipid

metabolism disorders, and can eventually lead to myocardial and cerebral infarction. Micro vascular complications are primarily related to hyperglycemia and the regulation of blood glucose levels, and can eventually lead to poor eye sight, blindness, end-stage renal disease, and amputation of limbs.⁷ Furthermore, people with diabetes have a lower life expectancy than people without the disease.⁸ Consequently, having type 2 diabetes has large implications on the life of patients, as well as on health care systems, and on the world economy in general.⁹

For people with type 2 diabetes, hypoglycemia is less common, and the long-term consequences of prolonged hyperglycemia are more common and relevant. However, hyperglycemia is less noticeable and has little short-term impact compared to hypoglycemia. Most common symptoms of hyperglycemia are; being thirsty, having to urinate more frequently, feeling tired, losing weight without reason, and blurry eyesight.¹⁰ Therefore, quite often people with type 2 diabetes initially do not notice much negative effect of their disease. Becoming aware of hyperglycemia, and understanding the severity of the consequences of hyperglycemia for the patient, is therefore challenging. Additionally, because the complications of type 2 diabetes to a large degree develop in long term, newly diagnosed patients do not feel disease burden, and perceive the severity of the disease as low.¹¹

Global impact of diabetes

Worldwide, there were approximately 387 million people (8.3%) known with diabetes in 2014. It is estimated that this number will rise with 9.8 million newly diagnosed patients each year, towards 592 million in 2035.¹² Of all the people diagnosed with diabetes, 90% has type 2 diabetes. These large numbers of diagnosed people have a big impact on the health care systems, especially when complications develop, and therefore have a big impact on the global economy.¹³ This raises the necessity of strategies that can help lower the burden of developing diabetes, on patients, on costs, and on the health care services.

Treatment and self-management of type 2 diabetes

The treatment of type 2 diabetes is focused on improving life style, quitting smoking, losing weight, normalizing blood pressure, improving lipids, and regulating blood glucose levels, and thereby the prevention of future complications.¹⁴ The medication needed for treating type 2 diabetes is either oral medication (e.g. metformin) and/or insulin or GLP-1 injections. Various classes of drugs exist, each with a different mode of action regarding lowering glucose levels.¹⁴ For most people with type 2 diabetes tablets are sufficient to regulate their blood glucose levels. However, when the disease has advanced to a point where their own insulin production falls short, insulin injections are needed. The use of insulin injections is more common for people who have type 2 diabetes for a longer time period.¹⁴

Because insulin resistance can slowly but progressively worsen, it is important that people with type 2 diabetes keep focusing on their life-style and health behavior, more so than the general population.¹⁴ Also, patients need to know how their medication works, and in the case of insulin- use, should be able to adjust their medication accordingly. The Association of American Diabetes Educators (AADE) has defined 7 key self-care behaviors that are important for patients to control their diabetes. These 7 features are: healthy eating, being physically active, monitoring, taking medication, problem solving, reducing risks and healthy coping. Healthy eating and being physically active, can both decrease possible surplus weight and belly

circumference. They can also lower the blood glucose levels. By doing so, patients can reduce the risk of developing future complications.

Managing type 2 diabetes is a difficult task and requires constant attention. Consequently, the treatment of type 2 diabetes calls on patients to take responsibility for their own actions and treatment adherence. Patients basically self-manage their disease. The concept of self-management implies that care should strive to enable and support patients to take control of their chronic disease, the treatment, the physical and the psychological symptoms, by having patients make their own decisions and perform self-chosen actions aimed at improving their health.¹⁵ That being said, self-management is more challenging for some than for others. Performing necessary tasks to manage and maintain a good health requires discipline, knowledge, and perseverance. For patients to change and adapt to a healthy life style requires that they need to understand the risks involved and they should at least have an intention or intrinsic motivation to change their health behaviors.¹⁶ Additionally, emotional status could influence and interfere with the self-care behaviors and consequently negatively influence the diabetes related outcomes.

Emotional consequences of diabetes

Dealing with the daily struggle of diabetes self-care and being constantly reminded of long-term complications, may affect the emotional status of people with type 2 diabetes. It is known that between 10% to 20% of the people with type 2 diabetes are dealing with low emotional well-being and/or high diabetes-related distress.^{17,18} Low emotional well-being is characterized by experiencing low mood, having low energy, feeling tired, being disinterested in daily activities, and having thoughts about death.¹⁹ In addition, it is argued that low emotional well-being and diabetes have underlying mechanisms, in which one disease can enhance the other.^{20,21} However, the causal direction and the true underlying mechanisms between low mood and diabetes are still unknown.²¹ Diabetes-related distress is characterized by feeling fearful when thinking about diabetes, being overwhelmed with the treatment, and worrying about future complications. Consequently this diabetes-related distress is found to have negative influence on glycemic control.^{22,23}

Patient centeredness and patient centered care

For diabetes care, a patient centered approach is advocated by the American Diabetes Association (ADA) and the European Association for the Study of Diabetes (EASD). Patient centered care places the patient in the directive role in the treatment of diabetes, in which the care provider takes on a supportive role. Patient centered care ensures that the preferences, needs and values of the patient are met, and ensures involvement from care provider as well as the patient, and characterized by shared decision making.²⁴ One model that can guide patient centered care is the 5A's behavioral change model from Glasgow et al (2000).²⁵ This model provides a sequential checklist that consists of Assess, Advise, Agree, Assist, & Arrange, which guides the patient centered interaction between care provider and patient.

Diabetes Self-management educational programs

To endorse patient centeredness and support people with type 2 diabetes with their self-care behaviors, self-management educational and support programs have been developed, researched, and implemented into diabetes health care.^{26,27} These self-management educational programs can be delivered individually or as group gatherings with one or two trainers, who inform patients about their disease, and

teaches them the self-management skills required for maintaining a healthy diet, exercise regime, medication adherence and healthy coping.

A known self-management education program is the Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) program which was developed in the United Kingdom. DESMOND has patient empowerment as core principle, and is theoretically well founded in which it is based on Leventhal's common sense theory, the dual process theory, and the social learning theory. DESMOND has been proven (cost)effective for newly diagnosed type 2 diabetes patients at least up to 12 months.²⁸⁻³⁰

Another diabetes self-management educational program is the Dutch Proactive Interdisciplinary Self-Management Training (PRISMA) which was developed in the Netherlands, and based on the DESMOND program.³¹ Similar self-management programs that have focused on diabetes self-care behaviors, have demonstrated subsequent improvements in diet behavior, glycemic control, and to a lesser extent emotional well-being and diabetes-related distress.^{26,27,32} However, self-management programs are not vaccines and do not work forever.³³ The effect of self-management programs slowly decline, and need additional refreshments for it to stay effective over time.

Web-based diabetes self-management support

To further endorse a patient centered approach and diabetes self-management support, online and web-based solutions have been made available for people with type 2 diabetes. In studies, these online solutions have shown to be just as effective for improving patients' knowledge, behavior change, and outcome variables, as face-to-face solutions.³⁴ The advantages of online and web-based solutions, is that they can support larger groups of people at the same time. The patients do not have to travel and they can use the course or program at the time and moment when they see fit. A disadvantage of online and web-based solutions is that it is easier for people to close the web-browser, and that there is little caretaker incentive to keep on going. Additionally using online or web-based solutions requires the patients to be knowledgeable in technique. Also, an online program is more susceptible to software errors and downtime.³⁵

Web-based solutions can be distinguished into telecare, telehealth and other types of online self-management support. Telecare is the definition for a web-based system, linked to devices with which patients self-monitor their blood glucose, and receive feedback and advice from their care provider.³⁶ Telehealth can be defined as online platforms with which the patient can obtain personal medical outcome measurements, health information, and communication with the care provider.^{37,38} These telehealth systems can also be described as Personal Health Records (PHR).³⁹

One known personal health record is the Dutch 'e-Vita - interactive care platform'. e-Vita was developed by the Foundation Care Within Reach, which was founded by Philips and Achmea (Dutch health care insurance company). The foundation has the objective to facilitate the development and creation of remote health care solutions for people with a chronic disease. The goal of Care Within Reach is; 1) to create a more patient centered approach in health care, 2) reduce the workloads of care providers, and 3) eventually reduce health care costs.

Next to the telehealth and telecare systems, online self-management education programs are also available for supporting people with their diabetes self-management. Where telehealth systems act as extensions of the health care system,

online self-management programs act as diabetes educational programs. Like group based diabetes self-management education courses, web-based self-management courses have shown to be effective in improving diabetes outcomes.⁴⁰ A recently developed online self-management program is the Dutch PRISMA-Online. PRISMA-Online distinguishes itself from the other online-self-management programs, by supporting the group-based PRISMA program and focusing on behavioral maintenance. The online program has been pilot tested and is ready for redesign and testing for effectiveness.

Aim of this thesis

The aim of this thesis is to get more insight into the treatment for people with type 2 diabetes, where the interconnection between self-management behaviors, emotional well-being and diabetes-related distress are considered. Additionally, alternative ways of self-management education and support, in the form of online programs, are evaluated.

Main themes throughout this thesis are 1) the influence of emotional factors on self-care behaviors and self-care effectiveness. 2) The development, testing, implementation, and use of online and web-based care programs for supporting people with type 2 diabetes.

The main questions that this thesis is trying to answer are:

- What is the influence of emotional status, such as emotional well-being and diabetes-related distress, on the self-care behaviors, and on the effectiveness of self-management education?
- Are online and web-based solutions capable of endorsing patient centeredness and successful in supporting diabetes self-management in routine primary care setting?

Thesis outline

Several studies have been conducted to answer the two research questions. An outline of each chapter is described below. introduction on type 2 diabetes, its impact, and its treatment possibilities.

Chapter 2 proposes and tests a model in which emotional factors and behavioral factors have a direct and indirect effect on glycemic control.

In chapter 3 it is studied if emotional well-being of participants of a group based face-to-face self-management program, influences the possible outcomes of the program.

In chapter 4 the specific behavioral change techniques needed for a success web-based self-management program for people with type 2 diabetes are uncovered.

Chapter 5 describes the development of a web-based self-management support program for people with type 2 diabetes that will be integrated in a patient web-portal, and a study protocol of a randomized controlled trial in which the unknown effect of coaching will be investigated.

Chapter 6 describes the results of the performed randomized controlled trial within the self-management support program.

Chapter 7 describes the development and feasibility of an online addition focused on behavioral maintenance, to an existing group based self-management course, PRISMA.

Chapter 8 provides a discussion and conclusion covering all the chapters.

