The life and times of a diabetic:

Multiple perspectives on the experiences of subjective wellbeing of persons diagnosed with diabetes mellitus in the Netherlands

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Abstract

This study explores and describes the experiences of subjective wellbeing by people diagnosed with type 1 or type 2 diabetes mellitus and their significant other. Emphasis was placed on the relationship between subjective wellbeing and the self-management of diabetes which is influenced by the concepts coping, health literacy, and social support. By gaining a better understanding of how to reduce the risk of short-term and long-term complications from the experiences of people diagnosed with diabetes, negative consequences for the individuals as well as the costs of health care services may be reduced. This is a qualitative study and data was collected through the method of in-depth interviews with 16 participants throughout the Netherlands of which nine are diagnosed with T2DM, two are diagnosed with T1DM, and five are significant others. The process of data analysis was guided through the use of Atlas.ti. In this study, the participants evaluated their subjective wellbeing, as a whole, positively with diabetes posing as an obstacle which can be overcome through adequate self-management behaviours. Positive influences of self-management include receiving positive social support, and good communication with and access to health care professionals. Negative influences include overprotection from significant other, negative stereotyping, and low critical health literacy skills. Despite their own knowledge and beliefs, the participants relied heavily on external influences for their self-management. In addition, the duration of diabetes affected negatively the subjective wellbeing of the participants. No differences in subjective wellbeing were observed according to age, type of diabetes, and type of medication.

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1. Introduction

The topic of this study is the subjective wellbeing of people diagnosed with diabetes in the Netherlands from the perspective of the diabetic as well as their significant other. This chapter will provide an overview of the biological and epidemiological background of diabetes in the Netherlands. In addition, the societal and scientific relevance of the topic will be given as well as the objective and research questions guiding this study.

1.1 Background diabetes

Diabetes is a metabolism disorder preventing the body from adequately absorbing energy from food. It deregulates the body's glucose (= sugar) levels by the absolute or relative deficiency of insulin production (DeCoster & Cummings, 2004). The hormone insulin, which is produced by beta cells in the Islets of Langerhans in the pancreas, is necessary to absorb the glucose from the blood and to transport it to the cells of the body. Without insulin or the correct use of insulin, glucose will build up in the blood without reaching the cells causing various complications to the body (Janssen & van Avendonk, 2009).

There are two main types of diabetes which can be distinguished: type 1 diabetes mellitus (10% of all diabetic cases) and type 2 diabetes mellitus (90% of all diabetic cases). The former is characterised by an absolute insulin deficiency and the onset of the disease is predominately found among people below the age of thirty creating nicknames such as juvenile diabetes and childhood diabetes. Type 1 diabetes mellitus (T1DM) is an autoimmune disease wherein the body has destroyed the insulin-producing beta cells in the pancreas. Therefore, persons with this type of diabetes are dependent on daily insulin injections in order to survive. The risk factors for T1DM remain uncertain and do not include lifestyle behaviours, excess weight or health status. The effects of the autoimmune disease are irreversible. Type 2 diabetes mellitus (T2DM) is characterised by a progressive insulin resistance in which the body is unable to produce sufficient and/or effectively use its own insulin to reduce blood glucose levels. Risk factors for T2DM are genetic vulnerability, obesity/overweight, physical inactivity, ethnicity, and increased age. The onset of T2DM is typically found among older adults; however, due to changes in the lifestyles of persons below the age of thirty, more people of that age group are being diagnosed with T2DM. In some cases, the effects of T2DM can be reversed with exercise, weight loss and health dietary intake (Janssen & van Avendonk, 2009; Kreugel, 2010; Wagner & Tennen, 2007).

In 2011, roughly 801,000 people in the Netherlands were registered with diabetes mellitus at their general practitioner. The prevalence rate of diabetes in that same year is 48.5 per 1,000 men and 47.7 per 1,000 women. In addition, 87,000 new cases of diabetes were diagnosed in 2011. Since 2000, there has been an influx in the number of people diagnosed with either type 1 or type 2 diabetes mellitus; the number of men with diabetes has doubled and the number of women with diabetes had

increased with 65%. In 2007, the cost of diabetes care was estimated at 1 billion Euros of which one third is a result of complications caused by diabetes. This expenditure accounts for 1.4% of the total costs of the Dutch health services (RIVM, 2013).

Diabetes is a chronic disease with a high demand in self-management, restructuring of daily activities, and a high burden of medication intake. By maintaining stabilised glucose levels, the risk is reduced of the occurrence of both short-term and long-term complications. The former includes hypoglycaemia, in which the blood glucose levels are too low, hyperglycaemia, in which the blood glucose levels are too high, and ketoacidosis, in which the body can be acidified due to insufficient insulin which results in a reaction from the body to use fats which, in turn, will create toxic fat acid (Janssen & van Avendonk, 2009; Kreugel, 2010). Long-term complications of diabetes can include damage to the retina, to the kidneys or to the nerve system, and cardiovascular diseases. In extreme cases, diabetes can result in kidney failure, heart attacks, having a stroke, blindness, and lower extremity amputation (DeCoster & Cummings, 2004; Janssen & van Avendonk, 2009; Wagner & Tennen, 2007). Having diabetes requires a high level of self-management such as maintaining the blood glucose levels at a stable level in order to reduce the type and severity of complications (Brewer-Lowry et al., 2010). As a consequence, diabetics can face high stress levels as well as emotional challenges which can affect their subjective wellbeing (DeCoster & Cummings, 2004).

All in all, the treatment of diabetes is highly demanding with no guarantee of avoiding complications. People diagnosed with diabetes are expected to have a considerable amount of knowledge, skills, and are expected to adjust their life styles according to the treatment. Consequently, diabetes has a significant effect on a person's daily routines as well as their subjective wellbeing (Brewer-Lowry et al., 2010; Cleaver & Pallourios, 1994; DeCoster & Cummings, 2004; Schur et al, 1999; Wagner & Tennen, 2007). By gaining a better understanding of the experiences of the self-management of the disease, the subjective wellbeing of people diagnosed with diabetes might be improved. Support may be provided for those having difficulties with their self-management through the identification of sources of information. Notwithstanding, by gaining a better understanding of how to reduce the risk of short-term and long-term complications from the experiences of people diagnosed with diabetes, negative consequences for the individuals as well as the costs of health care services may be reduced.

1.2 Objective & Research Questions

The objective of this research was to gain a better understanding of the experiences of people diagnosed with type 1 or type 2 diabetes mellitus and their subjective wellbeing. The objective was explored from two perspectives; that of the diabetic and of their significant other. Emphasis was placed on the relationship between subjective wellbeing and the self-management of diabetes. In order to gain an understanding of the issues and life experiences of people diagnosed with diabetes from multiple perspectives, a qualitative study was conducted. This study on the subjective wellbeing of

people diagnosed with diabetes will be described and explored through the following research question:

What are the experiences of subjective wellbeing in relation to self-management by people diagnosed with type 1 or type 2 diabetes mellitus and by their significant other in the Netherlands?

Guiding the main research question, the following sub questions were formulated regarding the concepts coping, health literacy and social support:

- What are the experiences of coping after being diagnosed with diabetes by the diabetics and their significant other?
- What are the experiences of persons diagnosed with diabetes and their significant other of coping in relation to the self-management of diabetes?
- What are the experiences of health literacy by people diagnosed with diabetes and their significant other?
- How do people diagnosed with diabetes and their significant other perceive the quality of their health literacy in relation to the self-management of their disease?
- What are the experiences of the social support by persons diagnosed with diabetes and their significant other?
- How do people diagnosed with diabetes and their significant other perceive the influence of social support in relation to the self-management of diabetes?
- How do persons diagnosed with diabetes and their significant other experience subjective wellbeing in relation to their perceived level of self-management?

1.3 Outline thesis

A description of the applied theory and current literature on the used concepts will be given in the next chapter, 'Theoretical framework'. At the end of the second chapter, the conceptual model which guided this study will be given. In the third chapter, 'Data & Methods', the methods of data collection and analysis will be described as well as an overview of the participants included in this study. In addition, the paradigm and ethical considerations will be discussed. In the fourth chapter, 'Results', the main outcomes will be described based on the concepts identified in the second chapter. The chapter 'Discussion' will consist of interpreting and ascribing meaning of the results through the use of the theoretical framework. The thesis will conclude with an overview of the implications and significance of the study and recommendations for future research in the chapter 'Conclusion'.

2. Theoretical framework

The current study on the subjective wellbeing of people diagnosed with type 1 or 2 diabetes mellitus was guided by the concepts self-management, coping, health literacy, social support, and subjective wellbeing. These concepts will be explained in this chapter including the conceptual model illustrating the theoretical framework of this study.

2.1 Self-management

Living with type 1 or 2 diabetes mellitus requires a high level of self-management which can be defined as "*the individual's means to keep the disease and its effects under control*" (Clark et al., 2001, p. 772). Type 2 diabetes mellitus (T2DM) has a gradual onset and combined with the broadness of the symptoms, such as fatigue, thirst, and frequently having to pee, results often in a late diagnosis of diabetes and, consequently, an increased risk of complications. Type 1 diabetes mellitus (T1DM) is experienced more acute due to the absolute insulin deficiency in the body. Therefore, the initial treatment between the two types is different. After being diagnosed with T2DM, people are firstly advised to restructure their lifestyles through frequent physical exercise and healthier dietary intake. If these adjustments are not sufficient or are not feasible, tablets will be provided to reduce their blood glucose levels. However, if glucose levels remain high, the diabetic will need to include insulin injections or a combination of injections and tablets in their daily routine. People diagnosed with T1DM are immediately insulin-dependent and are required to inject insulin on a daily basis (Kreugel, 2010).

The treatment of both types of diabetes relies heavily on the self-management of the disease through dietary intake, exercise regimen, medication use, and the monitoring of glucose levels. Through these self-management behaviours, the risk of short-term and long-term complications is reduced (Brewer-Lowry et al., 2010). Hence, the adequacy of self-management influences the health of an individual significantly (Mathew et al., 2012). In order to effectively manage diabetes, there are certain barriers which a person must overcome: time constraints, lack of knowledge, limited social support from spouse and family, inadequate financial and material resources, limited coping skills, and poor patient-provider relationships (Nagelkerk et al., 2006).

On a daily basis, decisions by individuals are made regarding the self-management of their disease based on their own knowledge, beliefs, attitudes, resources, and support systems (Nagelkerk et al., 2006). Subsequently, the self-management of diabetes is a behaviour which is influenced by a person's **self-efficacy** which can be characterised as the belief "*to manage their own functioning and to exercise control over events that affect their lives*" (Benight & Bandura, 2004, p. 1131). Self-efficacy has been linked to self-management due to the development of constructive behaviours which may lead, in turn, to better disease control, a lower risk of complications, and improved health (Hill-

Briggs, 2003). This concept of self-efficacy is a component of the social cognitive theory by Bandura (1991) regarding health behaviour. In this study, a further adaptation of the social cognitive theory will be utilised, namely the model of disease management proposed by Clark et al. (2001). This model focuses on the control of a chronic disease through **intrapersonal influences**, including knowledge, attitudes, feelings and beliefs, and **external influences**, including role models, technical advice and service, social support, and money and material resources. According to this model, self-management of a chronic disease is a result from reciprocal relationships between observing, judging, and reacting to attain personal health goals which evolves in self-regulatory processes. The motivation of the individual will increase as the perceived saliency of the goal is greater as well as the likelihood of achievement (Brewer-Lowry et al., 2010; Clark et al., 2001). Specifically, the self-management goals for people living with diabetes can include weight loss, more physical activity, precise glucose monitoring at home, foot care, and the understanding of medication.

According to Brewer-Lowry et al. (2010), there are four types of resources people with diabetes avail to manage the disease: (1) **self-care**, which is based on an individual's own knowledge, beliefs, and financial and material resources, (2) **informal support**, through the help of family and friends to provide material as well as emotional support, (3) **formal services**, which are services which are paid for such as transportation and home care, and (4) **medical care**, which supplies information, medication, diagnosis and treatment. Complications within one of these resources can affect both immediate and long-term outcomes in the multiple areas of self-management (Mathew et al., 2012).

Within this study, the four resources to manage diabetes which were identified by Brewer-Lowry et al. (2010) are translated to three concepts, namely coping skills, social support, and health literacy. Self-care is influenced by a person's ability to cope with the situation and their belief in their self-efficacy. Informal support is given by the person's family and friends which is conceptualised in this study as social support. Medical care and formal services are conceptualised in this study as health literacy which is the ability to access and understand the information concerning the treatment of diabetes. These concepts will be discussed more extensively in the in the following subchapters.

2.2 Coping

Due to the adjustment of daily routines and activities, coping with diabetes is very different compared to other chronic illnesses or disabilities. The treatment of diabetes is often seen as a burden due to the alteration in daily activities which typically intensifies with time; at first, treatment may suffice with adjusted dietary patterns which may develop to oral agents which, eventually, may develop to insulin injections or an insulin pump (Wagner & Tennen, 2007). Many people with diabetes consider themselves responsible for their health and self-management of their disease resulting in a high psychological burden (Wulsin et al., 1987). People may face frustration or even a 'diabetes burnout' when treatment goals are not achieved. Furthermore, there is the fear of short-term and long-term

complications among people diagnosed with diabetes (Wagner & Tennen, 2007). These stress levels in relation to the health of a person diagnosed with diabetes may lead to a vicious cycle in which stress affects a person's ability of self-management, influencing the control of the glucose levels, resulting in a worse state of health and an accumulation of stress (Peyrot & McMurry, 1992). Moreover, due to the diversity of the complications of diabetes, people are continuously challenged to cope with various threats to their health (Karlsen & Bru, 2002). Therefore, the process of coping is intrinsically linked with the self-management of diabetes and will be further explored in this study.

After being diagnosed with a chronic disease, such as diabetes, people try to adjust to living in the new situation. This process of alteration starts with the **appraisal** of the situation in two steps. The first step is primary appraisal, which is the identification of the perceived threat to a person's wellbeing. This is followed by secondary appraisal, in which potential responses to the threat are formed (Carver et al., 1989; Kleinke, 2007; Lazarus & Folkman, 1984; Moos & Schaefer, 1993). After the process of appraisal, **coping** is initiated which can be defined as cognitive and/or behavioural attempts to manage and tolerate stressful life events and daily hassles that are appraised as being inherently stressful or harmful to an individual which has the potential to become a physical, emotional, and psychological burden (Carver et al., 1989; Duangdao & Roesch, 2008; Kleinke, 2007; Livneh & Martz, 2007). In this definition, coping is perceived as a process taking place over time involving a certain amount of effort and planning with either a positive or a negative outcome (Kleinke, 2007).

Various coping strategies have been identified by previous studies, such as emotion-focused and problem-focus coping (Lazarus & Folkman, 1984), and avoidance coping and approach coping (Duangdao & Roesch, 2008; Karlsen et al., 2004). However, the framework proposed by Moos & Schaefer (1993) was applied in this study as it incorporates both the focus of coping as well as the different methods for coping into one framework. According to this framework, there are four types of coping strategies: (1) **cognitive approach coping**, in which the individual tries to make a logical analysis of the situation by focusing on one aspect at a time and gaining a positive reappraisal of the situation, (2) **behavioural approach coping**, in which the individual actively seeks guidance and support and tries to deal immediately with the situation or its aftermath, (3) **cognitive avoidance coping**, in which the individual denies the seriousness of the situation or accepts the situation as imperative, and (4) **behavioural avoidance coping**, in which the individual seeks activities which distract from or replace the situation creating alternative sources of satisfaction (Chronister & Chan, 2007; Moos & Schaefer, 1993). Furthermore, it has been discovered that the choice of coping strategy relies on the perceived self-control of the situation, i.e., a person is more likely to utilise a problem-focused strategy when he or she feels that something can be done about the problem (Chronister & Chan, 2007; Kleinke, 2007).

Despite the relevancy of the relationship between coping and diabetes self-management, only a few studies have been conducted on coping experiences by adults diagnosed with either type 1 or type

2 diabetes mellitus (Duangdao & Roesch, 2008; Karlsen & Bru, 2002; Wagner & Tennen, 2007). Many of them have tried to quantify and categorise the ways in which people cope with a change in their health situation (e.g. DeCoster & Cummings, 2004; Hesselink et al., 2004; Jonker et al., 2009; Karlsen & Bru, 2002; Karlsen et al., 2004). However, coping is considered as a dynamic and complex process; many people combine coping strategies to adequately overcome situations making it more difficult to identify and categorise the utilised strategies (Chronister & Chan, 2007; Kleinke, 2007). Moreover, many studies have ignored the influence of positive emotions which may affect how an individual may cope with a disease (Wagner & Tennen, 2007). Furthermore, many studies disregard the role of the social context in which a person copes with the disease. Each individual lives within its own environment shaping the beliefs and values which may influence their perception of living with diabetes (Wagner & Tennen, 2007). Therefore, the process of coping, in relation to self-management, may be better understood from the perspectives of people diagnosed with diabetes.

2.3 Health literacy

Due to the high demands in self-management of their disease, great educational requirements are placed on people diagnosed with type 1 or type 2 diabetes mellitus. In addition, the level of education is of influence on people's acceptance of their diagnosis as well as their understanding of required behavioural changes (Williams et al., 1998). This section will go more in-depth as to the effects of the level of health literacy may have on the self-management behaviours of diabetes.

Health literacy consists of the ability to function effectively in the health care environment through cognitive and social skills which motivate individuals to gain access to, understand, and use information to maintain good health (Al Sayah et al., 2012; Ishikawa et al., 2008; Nath, 2007; Sorensen et al., 2012). Health literacy skills can be categorised into three groups: (1) **functional skills**, which is required to function in daily situations including the ability to read and understand written text, locate and interpret information in documents, and write or complete forms, (2) **interactive skills**, which refers to being able to communicate about health-related information, and (3) **critical skills**, wherein the individual is able to analyse the available information critically and is able to make appropriate health decisions (Al Sayah et al., 2012; Eichler et al., 2009; Nutbeam, 2008; Sorensen et al., 2012). According to previous research, health literacy is "*a stronger predictor of health status than is socioeconomic status, age, or ethnic background*" (Nath, 2007, p. 44). Moreover, research indicates that poor health literacy is independently associated with poor self-rated health as well as a higher demand for health services (Schillinger et al., 2002).

The treatment of diabetes consists of extensive self-care education and management which is further complicated by relying on printed educational material and verbal instructions (White et al., 2010). Adequate health literacy skills are required as the self-management of diabetes can be complex, e.g. interpreting blood glucose levels (Al Sayah et al., 2012; Boren, 2009). Therefore, a high

level of health literacy is associated with improved adherence to treatment resulting in a higher self-rated health (Ishikawa et al., 2008). Lower levels of health literacy among people with type 2 diabetes mellitus have been associated with poor glycaemic control (Schillinger et al., 2002; Williams et al., 1998), lower access to health care (Sudore et al., 2006), lower medication refill adherence (Gazmararian et al., 2006), and higher rates of retinopathy (Schillinger et al., 2002). Consequently, health literacy was a central concept of this study.

2.4 Social support

Social support can influence physical and emotional health of an individual directly or through a buffering effect. With regards to diabetes, social support has been acknowledged as a successful contributor to the management of the disease. Individuals can be supported with the daily management of diabetes, the management of other life stressors or receive emotional support from their social environment (Auslander & Corn, 1996; Ford et al., 1998a; Karlsen et al., 2004; Schiøtz et al., 2012). Through social support, individuals diagnosed with diabetes may experience less diabetes-related emotional distress and assume more health-promoting self-management behaviours (Schiøtz et al., 2012). Furthermore, a person with diabetes monitors their glucose levels and administers medication in social settings which may alter family and social routines. Support in conducting self-management tasks can be provided by family and friends who may help overcoming these social barriers (Rosland et al., 2008). As a result, social support has been identified as an important concept influencing the self-management of diabetes.

Social support is defined by McDowell and Newell as "*the availability of people whom the individual trusts, on whom he can rely, and who make him feel cared for and valued as a person*" (in Westaway et al., 2005, p. 74). In the available literature, five functions of support from the social environment can be distinguished: (1) **emotional support** through empathy, admiration, respect or love, (2) **instrumental support** through practical ways (e.g. money, labour, time), (3) **informational support** through the provision of advice, suggestions or information, (4) **appraisal support** through self-evaluation, and (5) **social companionship** through spending time with others (Ford et al., 1998a; Gleeson-Kreig et al., 2002; Westaway et al., 2005). Notwithstanding the previous defined functions, an important underlying factor of social support is how it is perceived by the individual regarding the nature and the quality of the interaction. Social support has to be desired, perceived as appropriate in nature, and has to have an adequate length of time to be a positive influence. This is influenced by characteristics of the support recipient as well as the provider. Factors which determine the effect of social support on health are satisfaction with social support received, the size of the network and the perceived availability of the social support. In general, social support is perceived by many as a positive influence. However, it may have negative effects in the form of creating dependency or allowing for criticism (Ford et al., 1998a; Gleeson-Kreig et al., 2002).

Several studies indicated the influence the significant other may have on the health behaviours of people diagnosed with diabetes (Hagedoorn et al., 2006; Jacobs, 1998; Rosland et al., 2008; Schokker, 2010; Schokker et al., 2011). In a study by Schokker (2010) on intrapersonal factors for psychosocial outcomes in diabetes, three ways of providing support by the significant other were identified: (1) **active engagement**, which is positive support behaviour through the use of constructive problem-solving methods, such as enquiring about medication, (2) **protective buffering**, which is hiding one's concerns and from preventing the significant other from worrying about the illness, and (3) **overprotection**, in which the significant other excessively helps the diabetic. In this study, a positive association was found between active engagement by the significant other and low distress levels of the diabetic. On the other hand, protective buffering and overprotection were considered negative influences on the self-management behaviours of persons diagnosed with diabetes.

Studies conducted on the type of influence social support has in relation to diabetes have been contradictory. Positive accounts of social support has been found in relation to general health and wellbeing (Westaway et al., 2005), increased health-promoting behaviours (Schiøtz et al., 2012), better self-care (Rosland et al., 2008; Skinner & Hampson, 1998), improved treatment adherence (Garay-Sevilla et al., 1995), and improved psychosocial adaptation (White et al., 1992). As a contrast, negative social support has been associated with poorer metabolic control and the offer of more help than desired was received as obstructive (Gleeson-Kreig et al., 2002; Hagedoorn et al., 2006; Schokker et al., 2011). However, these previous studies have largely focused on structural aspects of support and less on the extent of social support provided to people diagnosed with diabetes. Therefore, in this study, the concept of social support from the social environment as well as the significant other had a central place.

2.5 Subjective wellbeing

A central concept in this study was the perceived subjective wellbeing of people diagnosed with type 1 or type 2 diabetes mellitus. According to Diener (2000), **subjective wellbeing** (SWB) refers to how people evaluate their lives. This can either be done **affectively**, through the experience of positive or negative emotions, moods and feelings, or **cognitively**, through the evaluation of certain experiences or life as a whole as satisfactory. For example, people generally have a good subjective wellbeing when they have more satisfaction with life, feel more positive emotions, participate in interesting activities, and experience few pains or illnesses. Apart from evaluating their whole lives, people tend to evaluate certain domains of their lives resulting in a further categorisation of SWB: life satisfaction (overall evaluation of one's life), satisfaction with important domains (e.g., marriage, social life, work), and high levels of positive affect and low levels of negative affect through the experience of (un)pleasant feelings, emotions, and moods (Diener, 2000).

A framework which is often applied to describe how ill health influences a person's wellbeing is the **Social Production Function (SPF)** theory by Lindenberg. According to the SPF theory, psychological wellbeing is achieved through the optimisation of the universal needs physical wellbeing and social wellbeing. **Physical wellbeing** is achieved by fulfilling the goals activation/stimulation, external comfort, and internal comfort, through, e.g. a pleasant and safe environment or the absence of hunger, thirst and pain. For the fulfilment of the need **social wellbeing**, the instrumental goals are status, behavioural confirmation, and affection, through e.g. caring relationships and the confirmation of a person's behaviour by others (Ormel et al., 1997; Steverink & Lindenberg, 2006).
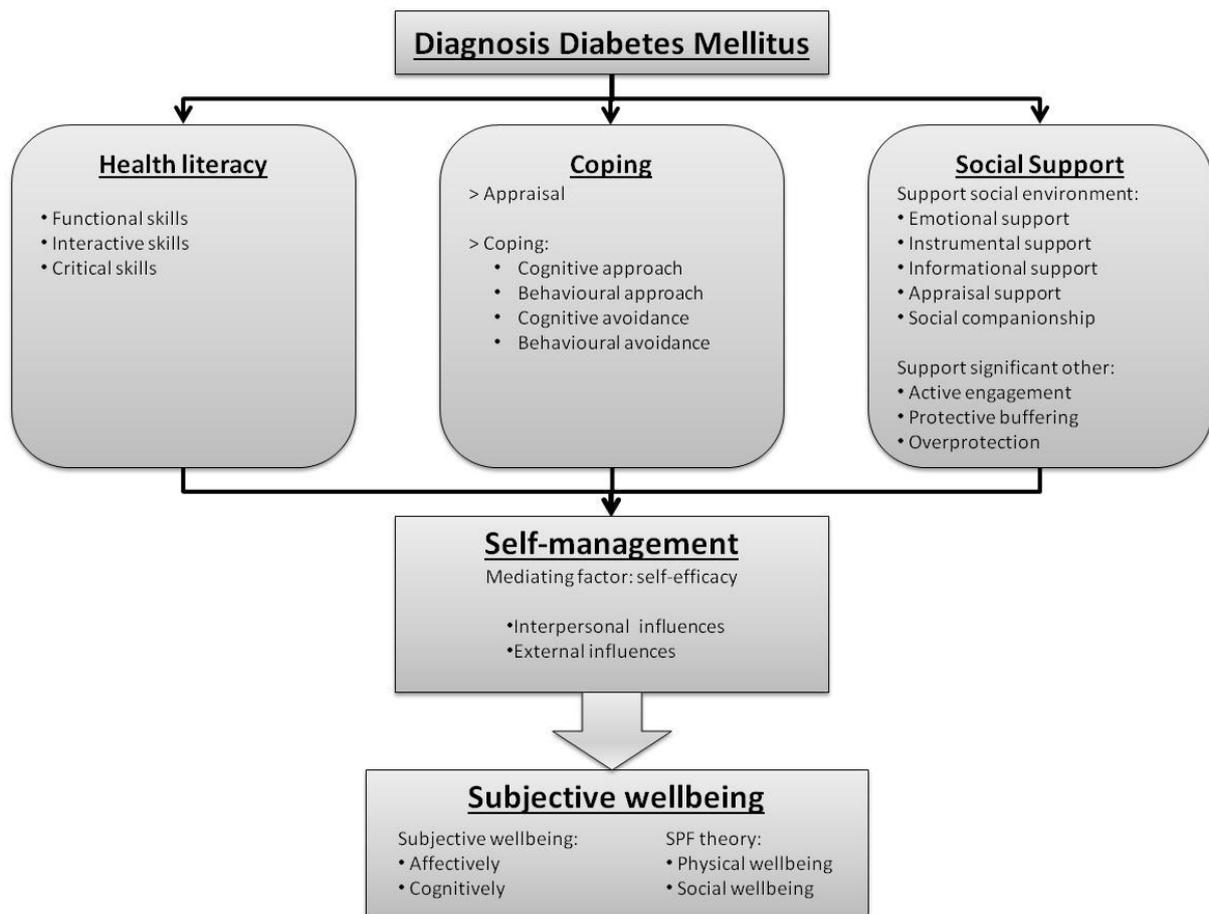
Studies have shown that people diagnosed with diabetes report lower psychological wellbeing compared to people with no reported disease (Brown et al., 2000; Markowitz et al., 2011; Misra & Lager, 2008; Naess et al., 2005; Rubin & Peyrot, 1999). In a quantitative study by Karlsen et al. (2002) among adults diagnosed with diabetes type 1 and type 2 in Norway, the difference in self-reported psychological wellbeing was researched and the association with disease-related strains. Their results suggest that people diagnosed with type 2 diabetes mellitus have a lower self-reported psychological wellbeing as well as people who are younger. However, the latter is in contradiction to the findings by Eiser et al. (2001) where age does not play a role in the psychosocial wellbeing among people with diabetes. In addition, Karlsen et al. (2002) discovered that the duration of the disease has no influence on the psychosocial wellbeing. In their review of scientific literature, (Rubin & Peyrot, 1999) discovered that better glycaemic control is associated with better quality of life for people diagnosed with diabetes.

To improve subjective wellbeing, it is important to understand the influence of being diagnosed with diabetes as well as the influence of the self-management of the disease. By gaining a deeper understanding of these issues, self-management of diabetes can be improved.

2.6 Conceptual model

Following the literature review and the identification of relevant theories, a conceptual model was developed based on the identified concepts which guided this study (see figure 1). Based on the literature, it was hypothesised that being diagnosed with type 1 or type 2 diabetes mellitus influences a person's subjective wellbeing. An important influence on subjective wellbeing is the self-management of diabetes. However, this effect of self-management is mediated by the ability to cope with the change in health situation, the level of health literacy, and feelings of support from the social environment. The conceptual model will be approached from two different perspectives, namely the perspective of the person diagnosed with diabetes and the perspective of their significant other. The outcomes of this study will be based on the experiences of both parties.

Figure 1 Conceptual model

Diagnosis Diabetes Mellitus

Health literacy

• Functional skills
• Interactive skills
• Critical skills

Coping

> Appraisal

> Coping:
  • Cognitive approach
  • Behavioural approach
  • Cognitive avoidance
  • Behavioural avoidance

Social Support

Support social environment:
• Emotional support
• Instrumental support
• Informational support
• Appraisal support
• Social companionship

Support significant other:
• Active engagement
• Protective buffering
• Overprotection

Self-management
Mediating factor: self-efficacy

•Interpersonal influences
•External influences

Subjective wellbeing

Subjective wellbeing: SPF theory:
• Affectively   • Physical wellbeing
• Cognitively   • Social wellbeing

3. Data & Methods

This was a study on the experience of living with type 1 or type 2 diabetes mellitus in the social context. In this chapter, a description will be given of the paradigm in which the study is situated, the applied methods, the participants and how they were recruited, the process of data collection, the analysis of the data, and the ethical considerations of this study.

3.1 Interpretive paradigm

This study is situated in the interpretive paradigm which emphasises the understanding of experiences from an *emic* perspective or the 'inside' perspective. Within this paradigm, the subjectivity of the participants is highly valued for the social actions of the individual is analysed in the context in which the individual lives. The emphasis of this study is on the meaning people attach to their experiences and social interactions, i.e. it is "*an inductive approach concerned with understanding an individual's personal account of a particular experience or phenomenon, rather than trying to find causal explanations for events or produce objective 'facts'*" (Clarke, 2009, p. 37). At the centre of this study lies the understanding of the experienced reality of people as a social construction of social, cultural, historical, and personal contexts (Clarke, 2009; Hennink et al., 2011).

The study describes the experiences of living with type 1 or type 2 diabetes mellitus from the perspective of the participants. Moreover, the study aims at gaining new insights in the experiences of subjective wellbeing. Throughout this study, an emphasis is placed on the understanding of the experiences of people diagnosed with either type 1 or type 2 diabetes mellitus and their significant other from their perspective by using the *Verstehen* approach. This approach is characterised by describing their experiences in the participant's own words and in their own specific context. No participant is the same and each person is unique with their own story to tell. The aim of this study is to understand the subjective meaning people diagnosed with diabetes give to their experiences (Hennink et al., 2011). This was acknowledged in the development of the interview guide by including only open-ended questions and allowing room during the interviews for the story of the participants themselves. In the analysis of the data, room was left for the inclusion of the words and phrases the participants used and citations are included in the results to maintain the context of their experiences.

3.2 Data collection methods

To optimise the inclusion of the subjectivity of the experiences of the participants with diabetes, in-depth interviews (IDIs) was chosen as the method of data collection. Through IDIs, a better understanding was gained of the experiences of the interviewee through the use of their own words and allowing space for them to tell their stories at their own pace as well as in their own chronological order. IDIs allow for a flexible approach wherein a central place is given to the understanding of the

individual's experiences and meanings while at the same time maintaining an awareness of the contextual factors surrounding the interview. The interviewee leads the conversation while the interviewer merely facilitates it (Clarke, 2009).

The advantage of conducting in-depth interviews (IDIs) is that it allows for the collection of data which is personal and based on people's own experiences situated in their own contexts. Additionally, it allows for interaction between the participant and the researcher creating more depth in the information provided. Furthermore, IDIs are suitable for sensitive topics, such as health, feelings, emotions, and subjective wellbeing. The disadvantages of IDIs include a significant amount of time collecting, processing and analysing the data. In addition, due to the nature of qualitative research, the researcher will have influenced the data collection, process and analysis through her own interpretations based on her personal background. This will be further elaborated in paragraph 3.6.

3.3 The process of data collection

For this study, two separate interview guides were created for the person diagnosed with diabetes and their significant other. The interview guide for the person diagnosed with diabetes was based on a thorough review of the literature and focused on the following themes: the experience of being diagnosed with diabetes, social support, the influence of diabetes on their daily activities, their comprehension of the treatment of diabetes, and their subjective wellbeing. The interview guide for the significant other contained similar themes, however, it focused on the experiences of the significant other and their relationship with the person diagnosed with diabetes. To allow the participants to express their experiences in their own words, the interviews included open questions such as 'How did you feel when you were told that you have diabetes? What is the influence of diabetes on your daily activities? By whom do you feel supported? How do you experience the treatment of diabetes?' Probes were used to facilitate the discussion of their experiences. To include all the relevant experiences from the perspective of the participant, at the end of each interview the participants were asked whether they wanted to add something to the interview which was not discussed previously.

After the construction of the interview guides, a pilot interview was conducted with a participant who is diagnosed with type 1 diabetes mellitus. During the interview, the most important aspects were discussed, including the experience of living with the disease in daily circumstances as well as how the person perceived his societal and social functioning. Aspects, such as coping with the disease, the understanding of treatment and recent trends in diabetes, and the role of the social environment were discussed. However, questions regarding the fears and emotions concerning the further discourse of the disease were rephrased to gain more in-depth information for there appeared to be a misunderstanding due to the choice of words. The final interview guides which were used in this study are included in the appendix.

The process of interviewing took place in the homes of the participants throughout the Netherlands. The participants were sent an information letter beforehand explaining the content of the study and of the interview. Rapport was easily established with most of the participants due to familiarity with a contact person of the researcher's social network (further details on participant recruitment in paragraph 3.4). If rapport proved to be more challenging, the researcher would first explain her personal motivation for conducting the research before commencing the interview. Due to the fact that the interviews took place in the participant's homes, family members were often present in the room or were close by. However, the researcher did not feel that they interfered with the interview and only asked the partner to leave the room because they were going to be interviewed separately at a later stage. All interviews were tape recorded and a verbal consent was asked before the start of the interview. The interviews lasted between 40-90 minutes and were transcribed verbatim.

3.4 Participants

The participants were recruited through the social network of the researcher as well as through health care services. The inclusion criteria were Dutch adults who were diagnosed with either type 1 or type 2 diabetes mellitus and were residing in the Netherlands. Social media sites, such as the Diabetes Forum (www.diabetesforum.nl) and the Facebook of the Diabetesvereniging Nederland, were used for participant recruitment. An attempt was made to include the patients of the rehabilitation clinic Beatrixoord in this study. However, this was denied due to fear of overloading their patients and their consideration that the patients were not a representative sample of the diabetes population of the Netherlands. Apart from approaching the rehabilitation clinic, posters were distributed among the diabetes clinics in the hospitals and general practitioners offices in Groningen. In addition, the researcher visited a physiotherapist who worked with people diagnosed with diabetes in Haren. Despite these efforts, no participants were recruited through these means and only through the social network of the researcher which allowed for a snowballing effect. After each interview, the researcher would ask whether the participant knew anyone else who had diabetes and might be willing to participate in the study. An advantage of this snowballing technique that the people with diabetes are easily identified and rapport is more easily established. A disadvantage is the time it consumes for this effect to take place as well as the danger of all the recruited participants to be from the same social network. However, this effect was diminished by using multiple entry points throughout the Netherlands as well as from different age groups.

A total of eleven persons participated in this study of which nine were diagnosed with type 2 diabetes mellitus (T2DM) and two were diagnosed with type 1 diabetes mellitus (T1DM). Five males and six females participated in this study with an age ranging from 26 years to 75 years. Two participants used insulin pumps as their mode of medication while three participants used insulin injections, and six used tablets. The participants lived throughout the Netherlands and were not

confined to a specific geographic area. The period of the diagnosed diabetes ranged from 6 months to 34 years.

Table 1 Basic characteristics of the participants with diabetes

Participants	Gender	Age	Type of Diabetes	Medication type	Period of diabetes
1	Male	60	1	Insulin pump	28 years
2	Male	53	2	Insulin pump	16 years
3	Female	75	2	Tablets	5 years
4	Male	50	2	Tablets	12 years
5	Female	53	2	Insulin injections	7 years
6	Female	62	2	Tablets	4 years
7	Female	46	2	Tablets	4 years
8	Male	48	2	Tablets	6 months
9	Female	66	2	Tablets	9 years
10	Female	70	2	Insulin injections	34 years
11	Male	26	1	Insulin injections	1 year

Besides the persons diagnosed with diabetes, five interviews were conducted with significant others. The reason for interviewing this group was to describe the experiences of being diagnosed with and the influence diabetes has on a person's subjective wellbeing from the perspective of the social context. People from the social environment can provide a different experience and perspective on the concepts used in this study. Notwithstanding the alteration in the lives of the diabetic, the lives of the significant other changes as well. They may need to alter their dietary patterns, daily schedules, and cope with short-term complications (Jacobs, 1998). All participants in this study were middle-aged (44-63 years) of which four were females and one male. Four participants were a partner of the participants diagnosed with diabetes. However, one mother of an eight year old diabetic was included in this study to shed light on the difficulties faced when being diagnosed with type 1 diabetes mellitus at a younger age.

Table 2 Basic characteristics of significant others

Participants	Gender	Age in years	Relationship diabetic	Medication type diabetic	Period of diabetes
1	Female	53	Married	Insulin pump	16 years
2	Female	47	Married	Tablets	12 years
3	Female	54	Married	Tablets	6 months
4	Male	63	Married	Insulin injections	34 years
5	Female	44	Parent	Insulin pump	4 years

The aim of this study was an exploration of the experiences of subjective wellbeing from multiple perspectives. Through the inclusion of participants of different age groups and different ranges of the duration of diabetes, the researcher collected richness in the experiences from persons diagnosed with diabetes and their significant other. Saturation point was achieved through the variety in gender, age, type of medication, and duration of diabetes. Consequently, the results of this study provide a diversified insight into the experience of being diagnosed with diabetes in the Netherlands.

3.5 Data analysis

The data analysis was a continuous process throughout the study, commencing after the conducting of the interviews through the writing down of key themes which came up during the interviews by the researcher. This process was continued in the transcribing of the interviews by maintaining a field dairy in which the researcher kept notes on important themes emerging from the interviews. These notes provided a guideline for the construction of the results and discussion chapter. The final part of the analysis was conducted by analysing the transcripts using the computer programme Atlas.ti.

Two separate projects in Atlas.ti were created for the data of persons diagnosed with diabetes and for the data of the significant others. The first level of coding was executed by coding the interviews close to the text allowing for the preservation of the context of the participants. Frequent use was made of In Vivo codes as well as Open coding. After the initial analysis, a second level of coding was conducted by creating code families based on the theoretical framework. These code families included self-management, social support, coping, health literacy, and subjective wellbeing. Subsequently, the linked data of the codes were written down in the results chapter.

This process of data analysis can be described as a double hermeneutic whereby "*the participants are trying to make sense of their world, the researcher is trying to make sense of the participants trying to make sense of their world*" (Smith & Osborn, 2008, p. 53). The results of this study include many quotations to maintain the context of the participants' story without imposing any predetermined theory.

3.6 Ethical considerations

Due to the qualitative nature of this study, it is important to reflect on the ethical implications the study will have. The process of data collection and analysis are highly interpretative. Therefore, it is necessary to discuss the positionality and subjectivity of the researcher to minimise misinterpretation.

Positionality refers to how the researcher will portray herself during the collection of data (Hennink et al., 2011). Before the start each in-depth interview, the researcher explained her personal interests in the topic as well as her scientific background. The researcher disclosed her educational level, field of studies, and her personal experiences with diabetes. Through the disclosure of having a father who has been living with type 2 diabetes mellitus for 23 years, rapport was easier established as well as the formation of an equal power relationship between the researcher and the participant.

However, she remained the position of a student as well as a willing listener to personal issues. By recruiting participants through her social network, the researcher was able to establish rapport more easily with the participants. Small talk about their similar acquaintance at the start of the interview helped to establish this. During the interviews, the use of theoretical concepts was avoided through the development of an interview guide phrased in colloquial language. All the interviews were conducted at the homes of the participants creating an atmosphere in which the participant felt more at ease and in control of the situation.

Subjectivity refers to how the characteristics of the researcher may influence the quality and quantity of the information obtained (Hennink et al., 2011). The researcher was aware of differences in age, education, occupation, and health status during the process of data collection. However, by disclosing her family situation, the researcher aimed to gain more in-depth information regarding life with diabetes. At the time of the interview, the participants were living with a chronic disease which may influence various aspects of their lives. Despite this difference in health, the researcher was not aware of the existence of a gap between her and the participants during the interviews. This was prevented by extending the knowledge of the researcher on diabetes and self-care through conducting a thorough literature research and by reflecting the acquired knowledge with people who are living with diabetes. Through this process of acquiring knowledge and reflection, much of the contextual misinterpretation was prevented. Despite these efforts, the researchers own norms and values may still be of influence on the interpretation of the data.

4. Results

The results of this study will be discussed in the order of the conceptual model depicted in chapter 2. Firstly, the experience of being diagnosis with diabetes will be discussed. This will be followed by the coping experiences of this change in health, the participant's access and need for information on diabetes and its management, and the influence of the social environment. Finally, the experiences of self-management and the overall subjective wellbeing will be described.

4.1 Diagnosis diabetes mellitus

Due to the difference in the nature of the disease in type 1 (T1DM) and type 2 diabetes mellitus (T2DM), the onset of the disease is experienced very differently. Firstly, the experiences of the onset and diagnosis of T1DM will be described followed by the experiences of people being diagnosed with T2DM.

The participants that were diagnosed with T1DM described the onset of the diabetes as a sudden phenomenon where, covering a short period of time, they felt the urge to drink in huge quantities, to having frequently use the toilet, and felt, overall, terribly ill. Due to this disruption in their bodies and eating habits, the participants experienced weight loss. One of the participants described the loss of vision at the onset of the disease:

> *"After I graduated I still experienced a lot of thirst and over time I woke up and I couldn't see anything. I couldn't see anything or it was just very blurry. I could just make out where you are sitting but the rest was just a blur. That happened on a Saturday and then in the course of the day it became a lot better so I thought to myself it must have been a phase. I had been drinking the night before so I thought I must have been extremely hung-over. Yeah so the day after I had it again and I thought well I should go and see a doctor. So I went to the GP's office and they immediately referred me to the emergency department. I then had to stay for a week."*
> – Male, 1 year T1DM, age 27 years –

After experiencing these symptoms, all the participants were diagnosed within a week with type 1 diabetes mellitus. Two of the participants were diagnosed at a late age, 26 years and 32 years, which resulted in a vivid memory of the diagnosis. After their blood had been tested on glucose levels, the GP disclosed the disease. The diagnosis was experienced by both participants as a shock and one of the participants described a difficulty comprehending the long-term consequences it will have on his life. However, both participants were glad that their symptoms could be attributed to a disease they had heard of before and knew could be managed effectively.

"Participant: Uh it was in 85 and I uh became really ill in the sense that I uh in a week I lost five kilos, began to drink, and uh I frequently had to go to the toilet. At that time I didn't know what was happening. And uh then at a certain moment I got the idea that what I had must be definitive and isn't something that can be stopped. What it was I did not know but when the GP uh diagnosed me it became immediately clear and uh I had been diagnosed with diabetes.

Interviewer: *Yes... And how did you feel at that moment?*

Participant: *As weak as water. Really I felt dreadful."*

– Male, 28 years T1DM, age 60 years –

According to the mother, the onset of the type 1 diabetes mellitus of her, at that time, 4 year old daughter came quite rapidly. The participant herself was diagnosed with gestational diabetes but she recovered after five years. However, due to this experience and the presence of diabetes in her immediate family, the mother was aware of the symptoms of diabetes which resulted in a rapid diagnosis of T1DM of her daughter minimising the risk of long-term complications.

The participants who were diagnosed with type 2 diabetes mellitus (T2DM) described different experiences of varying acuteness of the symptoms ranging from no noticeable symptoms to blackouts and feelings of unquenchable thirst. Overall, the participants, who were younger and had a more severe loss in the functionality of their pancreas, experienced a more acute onset of T2DM. They experienced an unquenchable thirst over a period of time ranging to several years. However, this urge to drink was not a main concern and it was not until other symptoms, such as strong smelling or dark urine, that the participants went to see a GP. In hindsight, the experience of thirst could be ascribed to the diabetes.

"Participant: And I actually discovered it because I uh began to drink a lot uh in the course of a year and a half two years. It built itself up from first a glass of water by the coffee to uh later uh nine to twelve litres of fluid every day without any problems and then still feel thirsty. And then I had some kind of highly active course at the police academy and eh in the course I had an argument with an instructor because I wanted to drink because I had to drink so bad that I would even kick in a door and that I apparently I seemed convincing enough because we were allowed to drink. Yeah.

Interviewer: *If you wanted to kick in a door?*

Participant: *Yeah that was a situation where we had a physically challenging exercise. That had been going on for hours on a Wednesday night. And uh at one o'clock at night we passed a gymnastics hall and uh I thought that we should have a break there because I really needed to drink some fluids and uh well that ended with a conversation of uh you*

open this door now or otherwise I will kick it shut or uh I will kick it open and then you may throw me off the course. Yeah and eventually he opened the door and we could drink water. Well I think I drank litres of water. Uh that was a course of three weeks and after that time I went to the GP because my urine began to smell in the mornings. At least that's what I thought. And at the GP it eh became clear with one swab that you are a diabetic.
– Male, 16 years T2DM, age 53 years –

Having a member of their immediate family diagnosed with T2DM appeared to have affected the health behaviour of four participants and their own diagnosis of the disease. They regularly checked their glucose levels through the use of their immediate family member's monitors to check for any irregularities. This resulted in an early diagnosis of T2DM even though they hardly experienced any noticeable symptoms. For example, one participant had a father and a daughter diagnosed with diabetes which resulted in her monitoring her glucose levels preventatively:

"My father had diabetes type two. And [daughter] had gestational diabetes. And then the internist told [daughter] that it must run in your family. So she told me. And then I tested my blood twice with her [at her house] while sober. And it was twice too high. And then I went to the GP. By that time I had developed high cholesterol levels. And I think my blood pressure was a bit too high as well. When I went to the GP I told him my sugar is too high, my cholesterol is too high and my blood pressure is too high. What can I do about it? And then he said, "We don't know everything". And then I said and what would you do if had it yourself? "We don't know everything." So then I petulantly asked the question whether there is someone on this world who had the mental capacity to understand it. Well, I was sent to an internist. So then I ended up with the same internist as [daughter]. "And what are your complaints madam?" And then in the meantime they were emailing each other. In the past you received a letter which you could open. So they emailed each other. I said well I would like to know what the GP emailed. "Well that you were slightly moody." I said well that's right. I said well you speak the truth and that may be but he doesn't know what to do with it. "Well", he said, "you have diabetes..." I said I thought so. What can I do about it?"
– Female, 4 years T2DM, age 62 years –

This awareness of the possibility of developing diabetes was shared by another participant. Her mother is a diabetic and the participant as well as her sister regularly checked their glucose levels. When visiting her mother, she decided it was time to check again and discovered that her glucose levels were too high. After visiting her GP about this, she was diagnosed with T2DM.

Notwithstanding feeling tired and lethargic prior to the diagnosis, it was not until after the diagnosis of T2DM that the symptoms were attributed to the diabetes:

> *"Yes 3-4 years ago. Uh I think. Then it started to snowball. It was funny because my GP asked well how do you feel and then I said I feel sometimes lethargic but everyone has that. And then she told me that I had diabetes and then she said you are more than just a bit tired and then I realised sort of well yes I am constantly tired but well because I heard everyone complaining about feeling tired I thought yes well I am no different from them so yes that should be it but afterwards it appeared to be diabetes. "*
> – Female, 4 years T2DM, age 46 years –

Due to the slow onset of the disease, some participants inadvertently discovered their condition. One participant discovered that she was a diabetic while undergoing a medical examination to get her driving license renewed at the age of 70 years. Despite the blood test indicating that her glucose levels were extremely high, the participant hardly noticed the effects of the disease. She had experienced blackouts while conducting heavy work around the farm which were unexplainable at the time but which can now be attributed to T2DM. This accidental discovery of T2DM without any noticeable symptoms was shared by more than one participant. For example, a participant was diagnosed with diabetes after having had a blood test for an infection caused by erysipelas on her legs. Another participant described how she has been struggling with her weight since she was a young due to a thyroid problem. Despite warnings by her GP, she had troubles adhering to her diet. She experienced severe fatigue and when explaining these problems to her GP, he tested her glucose levels which indicated she has T2DM. Due to the slow onset, the participant would have developed the disease several years before the diagnosis.

In general, the onset of T2DM was experienced less drastic compared to T1DM. Similar to T1DM, most of the participants described the urge to drink and to frequently use the toilet. However, contrary to T1DM, this thirst was not experienced severe enough and resulted in a late discovery of T2DM. It could often go undetected for a number of years while the onset and the diagnosis of T1DM elapsed over a few weeks. However, there appeared to be a difference in the variation of the acuteness of the symptoms caused by the age of the participants with T2DM and the relative loss in the functionality of the pancreas. In addition, the genetic character of T2DM created awareness among the participants which may result in an early diagnosis of their condition without any noticeable symptoms. This was also observed in the experience of the mother of a young diabetic who had personal experience with diabetes which allowed her to act quickly to the change in her daughter´s health. All of the other participants with T2DM, who did not experience the classical symptoms of diabetes and went to visit a GP, were either aware of their risk through heredity or stumbled on the disease inadvertently.

4.2 Coping

After being diagnosed with diabetes, people will adjust to living with their new situation through the process of appraisal and coping (Carver et al., 1989; Kleinke, 2007; Lazarus & Folkman, 1984; Moos & Schaefer, 1993). The participants in this study indicated various strategies to cope with the change in their health. Some participants experienced shock upon hearing the diagnosis while to others it did not come as a surprise. This section will cover the various coping experiences based on the theoretical framework starting from appraisal to coping and the identification of the four coping strategies categorised by Moos & Schaefer (1993).

According to the literature, the process of alteration starts with appraisal of the threat to their health and their daily life (Lazarus & Folkman, 1984). For some of the participants, the diagnosis of diabetes did not come as a surprise. Many have immediate family members living with diabetes which created an awareness of the risk it would have on their own health. This allowed for an easier identification of the threat and form potential responses. They had some knowledge regarding the short-term and long-term complications and the self-management of diabetes. For example, one of the significant others explained the process of the diagnosis of her husband's T2DM. She was aware that the mother of her husband was diagnosed with T2DM which allowed her to be watchful about the dietary patterns of her spouse. Despite her awareness and warnings, the husband was still diagnosed with T2DM.

> *"I knew his mother had it so you know sort of. And that it's hereditary so uh... yeah... First let it sink in of course that he had it but immediately straightened it out. We had to go together to see the dietician. I said I want to go with you. But I had adjusted his diet immediately myself. Just by asking what do you eat? What do you take with you to work? I sort of knew of course but not completely and what changes needed to be made. Because he is used to or was always used to eat the whole day. And especially at night he wouldn't give his jaws a rest. The whole day he would eat because he had a sweet tooth. And the sweeter the better. And we had told him already be careful your mother is a diabetic. And we had already tested his blood because his mother has a pricker and then he didn't have it. When they discovered it, they said he had it for some time now."*
> – Female, married to a diabetic, age 54 years –

After the process of appraisal, coping is initiated to manage and tolerate being diagnosed with diabetes. The framework proposed by Moos & Schaeffer (1993) identified four possible coping strategies. The first, cognitive approach coping, was utilised by a participant who seemed less worried about the change in health due to the mildness of the symptoms. This resulted in an expectation that their symptoms and the severity of the disease would also be mild. The participant focused on the

aspect of dietary patterns of self-management and adapted his habits accordingly. Through this, he gained a positive reappraisal of the situation:

"Yes I have actually never made a big deal out of it. You can't do anything about it and uh I have never had a hard time because of it. Of course it is getting use to in the beginning. Is it really strange? You have your medication and you need to take them on time. Those sort of things and about food. Thinking about what you eat or how you eat. I had to get used to that. I mean we were never really uh punctual. Oh twelve o'clock dinner. And now a little bit more. I had to get used to that. Then I think oh yeah. So uh but I never had difficulties with it. No not at all."
– Male, 6 months T2DM, age 48 years –

The second strategy, behavioural approach coping, was seen among the persons who experienced acute symptoms of diabetes. Both the participants with T1DM actively sought guidance from physicians and diabetes nurses regarding the use of medication and the prevention of irregular glucose levels. For example, one of the participants explained that through support from health care professionals, he feels lucky and that the situation was handled well:

"The first three months were certainly not easy. But now that I look back I think that I have been very lucky and that I've had a good run. And I can certainly in my mind handle it pretty well. At that time I was really focused on being able to see again. Let it be diabetes, but then I know what's going on. And now I still have that in my mind of yeah, I simply have it. I don't really fuss about it and I will see what the future will bring and I know that it will be worse and at the same time I may be hit by a car and then it's over too. So I look at it pretty positively... But yeah the first three months were no fun."
– Male, 1 year T1DM, age 27 years –

However, despite of the heredity of the disease, one of the participants hoped that by adjusting her dietary patterns she would postpone the development of the disease. This form of cognitive avoidance coping is still present through her notion that by exercising weight loss, her T2DM would eventually lessen or disappear:

"Yes well bummed out. Like oh no, what now? So I asked what if I lose some weight maybe uh but I wasn't overweight that uh well I still lost a lot of weight because of that. And I keep holding on to that."
– Female, 4 years T2DM, age 46 years –

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Behavioural avoidance coping was only experienced by one of the participants who was diagnosed with T1DM 28 years ago. At the moment of diagnosis, the participants experienced feelings of shock and devastation. Currently, he is more depressed about his situation compared to a few years ago. Throughout his life he has pursued many activities and crossed his limits various times resulting in frequent short-term complications. However, after having recovered recently from a burnout, he feels he is limited in his activities which results in feelings of depression:

"I work as a teacher and uh I always have the feeling that uh the diabetes uh yeah... it was like a bolt out of the blue when I got it. I suffer extremely uh despite the fact that I do many things in my day to day life. I have undertaken a lot of things despite the diabetes. But these last few years I have the feeling that it is becoming a lot harder to deal with it. And uh I think so uh it was of course undeniable that it was going to happen at one point but I think it's very unfortunate and disappointing. Uh so I find it harder at the moment than uh say five or ten years ago."
– Male, 28 years T1DM, age 60 years –

The process of coping seemed to vary according to type and severity of the symptoms experienced by the participants. The participants diagnosed with T1DM applied behavioural coping strategies while participants diagnosed with T2DM applied cognitive strategies. In addition, the duration of the diabetes seemed to affect the current emotional wellbeing of the participants; people who have been living with diabetes for a longer period of time seem to become more worried about long-term complications of diabetes. This trend was observed with participants from both types of diabetes.

4.3 Health literacy

As a consequence of the high-demand in self-management of the disease, it is vital for the person diagnosed with either T1DM or T2DM to have a good level of health literacy which is to understand, have access to and utilise the information available to them to function effectively in the health care environment (Nath, 2007; Sorensen et al., 2012). The three categories of health literacy skills will guide the description of the results in this section.

Functional skills are needed to function in daily situations through writing, reading and interpreting information in forms, documents, and text (Nutbeam, 2008). At the moment of diagnosis, the participants were given various sources of information to comprehend and adapt to the health change. All of the participants mentioned being informed by a healthcare professional about the biological change in their bodies, the use of medication and short- and long-term complications of diabetes. Depending on the severity of their condition, the participants were either informed by their GP or internist at the hospital on the treatment plans. All participants indicated that they had sufficient

access to information through written and verbal sources. Examples participants gave were information given to them by the diabetes nurse and their general practitioner verbally or through leaflets and brochures. Only a few participants used the internet as a source of information for they feared the exaggeration of long-term consequences and the unreliability of the information. For example, one of the participants indicated that after being diagnosed with diabetes, he read a lot about diabetes to be able to function in this new health situation. The diabetes nurse provided him with the required information:

> *"Yes just thinking about it a lot uh reading a lot about it and try to get information*
> *everywhere. In that sense, the diabetes nurse is of great importance. Uh yes for the rest*
> *just other information which is available at that moment and I have read a lot and tried to*
> *digest a lot of information."*
> – Male, 16 years T2DM, age 53 years –

However, some participants feel that the information provided to them by health care professionals is difficult to comprehend. The language the health care professionals use is not colloquial which can be a source of confusion and misunderstanding. Contrary, a few participants indicated that they appreciated the high level of information provided to them and felt equal through this form of communication. An example of the communication between the health care professional and the participants is given below in which one of the participants indicated that she often does not understand the information provided by her physician which could lead to difficulties in the self-management of diabetes:

> *"She will easily uh yes very elaborately she will explain it and uh yes. Well sometimes*
> *using physician phrases of which I think uuh can you say it in another language? But uh*
> *if they notice it they will quickly change to uh to your language and explain it better. But*
> *no they are really good and I am really happy that I ended up there."*
> – Female, 4 years T2DM, age 46 years –

According to Nutbeam (2008), interactive skills refer to being able to communicate about health-related information. Most of the participants rely on their health care professionals as a source of information regarding the self-management of diabetes. They indicated having a good relationship with their diabetes nurse which makes them feel comfortable asking for additional information regarding their treatment or self-management behaviours:

> *"Yes I would if I'm at the hospital where there are magazines and I would read them but*
> *most of it I already know and if there is something new [diabetes nurse] will always tell*

me and if I want to know something else. Like we went for example in the morning at five or half past six on holiday with the car and then I would ask her how should I do the morning injection. Then she said you just have a cup of tea in the morning and if you normally inject the insulin at eight or half past nine then you should do it in the car and then you eat a sandwich or a roll straight away you know. So those types of things uh I will ask her. She always asks if I have any questions. That's how you know. A lot of things and that is good. I always get along with her. But I have been seeing her for twenty years."

– Female, 34 years T2DM, age 70 years –

Other participants indicated that the communication with health care professionals can be too theoretical. They feel that the contact is impersonal and that the health care professionals have hardly time for them. This was especially indicated with regards to internists who seem to invest less time in personal contact with the participants compared to the diabetes nurse. Therefore, some participants feel that they can better communicate with the diabetes nurse:

"If I see the internist... when I first arrived at the internist it was actually just standard measuring of weight, blood pressure uh some other standard things and the approach to my problem was very theoretical uh there was not a lot of emotion in it uh no. And with the diabetes nurse you have a more personal contact. There you have the time and space to discuss personal issues. Uh an internist you see twice a year uh you do not hold any value to it. I understand that he must have studied longer for it and that he is the one making the decisions, concerning the treatment. But yeah I uh do not hold much value to it."

– Male, 16 years T2DM, age 53 years –

Some of the participants indicate that the information they receive is sufficient and they feel that they have influence on their treatment plans. Through the openness in asking questions, the level of accessibility to health-related information is considered high.

"Well what's not going that good with the treatment... no if that were the case I would have drawn attention to this. I would not let it come that far because a lot of things would go bad or things would not get enough attention which need it. Uh I consider myself an outspoken patient and that's how they know me. So no."

– Male, 28 years T1DM, age 60 years –

The last category, critical skills, entails the critical analysis of the provided information and make appropriate health decisions (Nutbeam, 2008). The participants indicated a high dependency on health care professionals for decisions regarding the treatment of diabetes. However, some participants indicated an information saturation point regarding the information provided by the dietician. For example, one of the participants indicated that this information saturation resulted in the cancellation of future appointments:

> *"No but well uh at a certain point I was at the old dietician at the hospital. I was with [doctor], "yes, I will send you to the dietician for nutrition advice." Well then you go to the dietician. Yes they indicate new things with food. Well I think I visited [name] regularly for four years, the dietician. And at a certain point I think to myself well I haven't heard anything new in a while. I'm not hearing anything new so I cancelled the appointment and I haven't made a new appointment yet so I haven't seen them, it has been 2.5 years since I was there for the last time."*
> – Male, 12 years T2DM, age 50 years –

All in all, the participants indicated a sufficient comprehension of functional and interactive skills. The participants indicated that they had good communication with the diabetes nurse who is the main source of information. The communication with the internist often seemed to be too theoretical and impersonal which could lead to a threshold in the accessibility of health-related information. The dietician seemed to have an opposite effect; the participants feel that they reach a saturation point and critically assess the frequency of their visits and the information provided. Therefore, comprehension of critical skills seemed to apply only to the information provided by the dietician.

4.4 Social support

The social context in which people live may have a positive or a negative influence on the self-management behaviours and subjective wellbeing of people diagnosed with diabetes. In this section, social support will be categorised as social support received from the social environment as a whole and social support received from the significant other.

Of the five functions of social support from the social environment distinguished in previous studies (e.g. Westaway et al., 2005), emotional support seemed to be the most frequently mentioned by the participants. All of the participants indicated a few people of whom they feel support them in their everyday life. Partners, adult children, siblings and close friends were frequently mentioned in this context. Especially the people who the participants lived with or who were an immediate family member of the participant appeared to play a significant role in emotional support and social

companionship. For example, one of the participants mentioned how he feels not only emotionally supported by his wife and his two adult children but, also, supported through social companionship:

> *"They all know the ins and outs. They will never let me down. Uh from your family members you can sort of expect that. Uh solidarity is sort of a natural attitude. But they know of course how I uh react if something happens and uh if the moment is there they are always there to say do this or that. And uh yes sometimes I really need them. I need them a lot. But then they are always there. So uh but that also goes for people who are a little further from me. They all know now that I have this problem and uh I have never had the idea that I have been avoided because of my problem that I take with me or that they don't understand the situation I am in. And uh I do not suffer because of that."*
> – Male, 28 years T1DM, age 60 years –

Another function of social support which was indicated by the participants was informational support. The participants indicated that their significant other plays a significant role in the signalling of extreme blood glucose levels. The participants would appear to be moody or thirsty which serves as a signal for the significant other. Participants indicated that partners would provide them with food or advising them to check their glucose levels. For example, the significant other may act as a reminder to check the glucose values to prevent short-term complications which not only affect the diabetic but also the rest of the family:

> *"He has to eat regularly and he doesn't always do that. He uh doesn't always think about the effects that certain efforts have on him. And uh yeah he is affected by it and not only him because yeah everyone in the family is affected by his mood swings. So you want to prevent that by reminding him what time it is."*
> – Female, married to a diabetic, age 53 years –

Those who are without a partner are often supported by their siblings or children. The three oldest participants indicated that their family often accompanied them to hospital visits, collect medication for them at the pharmacy, and help make health decisions including medication intake. This form of support can be categorised as instrumental support. No evidence was found of appraisal support among the experiences of the participants.

Schokker (2010) identified three ways of social support by the significant other. In the data collected from the experiences of the participants, active engagement was the most common method of social support. The participants indicated that the significant others actively enquired about medication intake, discussed dietary patterns, and accompanied them on visits to health care professionals. Many of the significant others indicated that they consumed information concerning

diabetes through magazines, the internet and information provided by the health care professionals. An example of active engagement can be found in the following citation in which one of the participants referred to his wife as a watchdog or an advisor who would help out when necessary:

> *"No it is more of a uh support or a walking encyclopaedia or a watchdog on the background. Like have you tested yet? Isn't it about time that you eat something because you haven't eaten in a while? Uh while I'm thinking no I'm feeling alright. But she is a watchdog at the background like hey keep that in mind because I don't want you to have a hypo again because it bothers me too. So uh it is like having a watchdog in the background. Yeah."*
> – Male, 16 years T2DM, age 53 years –

Another role the significant others ascertain is protective buffering in which the significant other hides their concerns to prevent the diabetic worrying about the illness. This behaviour was only seen by the mother of a young diabetic who was concerned with creation of a framework in which her daughter could easily move around in. The participant would have frequent contact with school, parents of friends, and had arrangements made at her workplace to be available for third parties about questions concerning her daughter's wellbeing. The participant and her husband created a safe environment for their daughter in their home by turning it into a children's playground in order for the daughter to feel safe and she is not confronted by her diabetes.

> *"Yes you always have it in the back of your mind even though we do a lot of good things. Even though you can live normally it is constantly in your mind and uh yes you think about it when there are special activities at school, oh how's that going and call the school to ask if they need help or how's it going uh those sort of things. So sometimes you're not busy with it the whole day and sometimes you are busy with it the whole day."*
> – Female, mother to a diabetic, age 44 years –

Overprotection was indicated not only by the significant others but also by the participants diagnosed with diabetes. Significant others would change their own behaviours to make the diabetic feel more at ease. However, this often ended in an adverse effect in which the diabetic would feel guilty for affecting the life of their significant other.

> *"At the beginning I adjusted to it a lot. I just didn't eat foods she couldn't. Yeah. But then at a certain moment I noticed uh then she starts to feel a bit guilty because I'm not doing it... But you need to prevent of course. She mustn't feel guilty about it. So oh well sometimes you follow it more than other times. It depends on the whole situation."*

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– Male, married to a diabetic, age 63 years –

Overprotection from others was often met with feelings of frustration by the participants diagnosed with diabetes. They refused to be pitied on or to be limited in their activities. Many felt there is a stigma attached to diabetes which could result in confrontations with others who misunderstood the self-management of diabetes. For example, a participant explained how her colleagues do not fully comprehend her situation which frustrates her at times:

> *"Well yeah through the fact that my family knows what diabetes is uh yeah they know what to look for. Sometimes they tend to forget but they know what to watch out for and uh yeah it's is nice that you can it is annoying if people don't know what it is and there are always a few who tell you to take this and do that. I notice it at work as well. They say are you allowed to have this? I say I'm allowed to have everything! But it's just not good for me. So then I will say no. Yeah and they are slowly beginning to adjust to it and that they may see me in different moods. That was getting used to in the beginning too."*
> – Female, 4 years T2DM, age 46 years –

The social environment of people diagnosed with diabetes can be a positive influence on their self-management of diabetes and their subjective wellbeing. The participants indicated that they feel supported by their partner, their children and their siblings. They assumed roles such as a watchdog, an advisor, mode of transportation or a pair of extra ears during visits to the hospital. Participants often did not realise their low or high glucose levels were until their different behaviour was indicated by a member of their social environment. These results support four functions of support from the social environment with the exception of appraisal support. The three ways of the provision of support by the significant other categorised by Schokker (2010) were identified in the experiences by the participants. Furthermore, overprotection was experienced negatively as well as the lack of understanding from their social environment which was met with frustration and feelings of limitation in the pursuit of activities.

4.5 Self-management

As indicated by the existing literature, the management of diabetes is dependent on the involvement of the individual through self–management. The treatment of diabetes relies heavily on the self-management of the disease through dietary intake, exercise regimen, medication use, and the monitoring of glucose levels which reduces the risk of short-term and long-term complications (Brewer-Lowry et al., 2010). Self-management behaviour is influenced by intrapersonal and external factors which are mediated by a person's belief in their self-efficacy (Clarke et al., 2001). This section

will describe the experiences of self-management regarding dietary and exercise patterns, medication use and the monitoring of glucose levels based on the concept of self-efficacy, and the categorisation of intrapersonal and external influences.

An important influence in the self-management behaviours of people diagnosed with diabetes is the belief in their self-efficacy (Bandura, 1991). The participants indicated that they are purposefully eating at regular times to stabilise and gain control over their glucose levels. Some started including a breakfast in their daily eating patterns while others focus more on eating at the same time each day. They felt that they were in control of this aspect in their lives and actively pursued regularity in the time periods between their meals. For example, one of the participants explained that she would first take care of herself with regards to dietary patterns to prevent short-term complications despite being in a social environment:

> *"Uuh well through eating regularly. And if you're away than I sometimes need to go to my work and then I think how should I do it during lunch. Of course we will go later or sometimes I will eat on my own something and then I won't eat with the rest later but sometimes I will eat in the morning later so the rest can move to a later time as well but then you have to think how you are going to work that out. I can never skip a meal like I used to do before I can't do that anymore. I need to uh you know if someone doesn't have lunch or doesn't have breakfast, they will have brunch. Yeah I can't do that. For me I have to have something in the morning and then a regular lunch. So those are things to keep in mind and that is something where you need to think about and if the rest doesn't want to eat than the rest won't eat in the morning."*
> – Female, 4 years T2DM, age 46 years –

This need to take control of their new health situation seemed to affect not only the dietary patterns but also medication intake by the participants. For example, one of the participants experienced frequent irregularities in his glucose levels resulting in the attainment of a sensor which constantly monitors his blood levels. Participants using tablets are less concerned with the monitoring of their glucose level and prefer to go by feeling. Those who use insulin injections seem to feel the need to be more in control of their blood levels and monitor them on a daily basis. Consequently, the participants always measure their glucose levels before administering insulin.

Through this constant monitoring, the participants feel that they have to be conscious about the activities they perform, their food intake, and incorporate this in their medication use. All of the participants indicated that they feel solely responsible for the management of their disease. Before they leave their homes, they check that they have brought products containing high levels of sugar and have brought their medication with them. If they conduct activities with others, they made sure

that their own needs come first regarding food and physical exercise. One of the participants who is unmarried and childless emphasised the need to be prepared and to maintain in control of the diabetes:

> *"Well I am unmarried so I have yeah have to bear in mind the diabetes on your own. If you fall somewhere, you can't have that. No."*
> – Female, 9 years T2DM, age 66 years –

Intrapersonal influences include knowledge, attitudes, feelings and beliefs (Clark et al., 2001). Throughout the attainment of self-management behaviours, the participants described being confronted with changes in their attitudes and beliefs. At the moment of the diagnosis, some of the participants feared a huge change in their dietary intake with the omission of sugar. However, after consulting their dietician, the participants soon discovered that the biggest change in their diet is a change in patterns instead of intake. For example, one of the participants feared that she wasn't able to consume biscuits and sweets but realised that she was with moderation:

> *"And when I heard I had diabetes I first had a scare like oh no you can't have anything anymore. No biscuits. No sweets. And then your life becomes limited you know like uh yeah that image you had of the old days that you can't have anything and wasn't allowed to use anything. And then a whole new world opens up when I visited the dietician and she said well yes you can use this once in a while and you can sometimes have a biscuit. Yeah you don't have to uh close yourself off of sugar and sorts because the sugar you consume can never cause high sugar levels. Yeah a certain amount but as I hear what you eat well you sometimes have these outburst where you eat more like on parties or something like that. Then you know that that is the cause of the high levels and that is not so much of a problem. Well I was a little relieved."*
> – Female, 7 years T2DM, age 53 years –

This inclusion of sugar in the diets of people diagnosed with diabetes has not always been the case. Previously, diabetics were not allowed to consume any products containing sugar. However, with the change in medication and diet, diabetics are allowed to consume sugar but have to think more about what they consume. This change in dietary intake is an extra source of concern for the participants. They find it hard to find the limit to their eating habits:

> *"Yeah and I when I got diabetes I wasn't allowed to have any sugar and that was very difficult. On the one hand it was very easy because you didn't take any sugar and now you are allowed to have sugar and well it is a lot harder. Where do you draw the line? I have a sweet tooth I know that. Wish I didn't."*

– Female, 34 years T2DM, age 70 years –

According to Clark et al. (2001), external influences include role models, technical advice and service, social support, and money and material resources. Technical advice was sought for the use of medication. Forms of medication used by the participants in this study include tablets, insulin injections and insulin pumps. The participants who were using tablets indicated that they had no problems taking medication. They made sure that their medication was administered at the appropriate times. The participants in this group hardly suffered from low glucose levels due to the low dosage of insulin. Those who are on their maximum dosage feared the switch to insulin injections. Some believed that they would be seen as a junkie or feared the pain that would accompany the injection in the stomach:

"At a certain time my physician wanted me to start injections and then I thought before my fortieth I don't want to live my life like a junky. It is strange but that was the picture I had. Well eventually around my fortieth I uh started using insulin and yeah it made my life a lot easier. You become more regulated but not that much. There were a lot of hiccups and in my average values there a lot uh between the eleven and thirteen/fourteen. That was relatively high. But I felt more comfortable with it. It is of course disputable because the body adjusts to it because yeah it is a fragile game."
– Male, 16 years T2DM, age 53 years –

Participants who inject themselves with insulin or had an insulin pump had more experience with hypo or hyper attacks. Moreover, they were less concerned with dietary intake for they can adjust their dosage accordingly. Through the use of insulin, the participants felt they were more in control of their glucose levels. However, upon calculating the correct dosage, many factors had to be taken into account which could potentially be a cause of low glucose levels, such as stress, excitement, and hot weather. An example of the latter was given by one of the participants:

"I do have a uh steady or a steady pattern I am of course not in the but I try to eat on time and sometimes it will be an hour later but like with a birthday we will eat a little bit later but yeah I have more snacks so it's not really an issue. Only when it's really hot I find it uh yes you will more easily get a hypo. Yes because you inject and pff because of the heat you will absorb the insulin much quicker. I find that sometimes a bit difficult."
– Female, 34 years T2DM, age 70 years –

Through medication and dietary patterns, the participants stabilise the glucose levels in their blood. The experiences of short-term complications appeared to be similar among the participants. If the

glucose levels are too high and the participants experience hypertension, the participants feel a loss of energy, lethargic, lightheaded, start sweating, and have an unquenchable thirst with a result of frequent toilet visits. However, the participants seems to be more affected by the other extreme, hypotension, wherein the participants slow down, are captured in an activity, feel dizzy, are cramping, feel shivers, feel cold, start sweating, or even have complete blackouts. Often, the participants preferred to risk having high glucose levels in order to prevent hypotension and, therefore, administered less insulin. One of the participants described his hypotension experience as follows:

"At night I experience most of the hypos uh I get hypos at night between four and half past four. Apparently. I don't notice them myself. I don't feel them coming. But my wife notices it and she wakes up because apparently I start to scream at a high pitch uh a really annoying high pitch scream uh I will cramp up like I am having an epileptic seizure. I bite my tongue so half of the bed is covered in blood uh yeah I lie there all tense and if I've had a hype like that my wife will first give me a capsule in my mouth but my swallowing reflex is almost paralysed. Then she has the time to prepare the emergence injection and she administers it and after about five or ten minutes I will come around. But I can't work that day. I will have the feeling as if I've had an iron band strapped around my head that has only been tightened. Mega headache. Muscles are aching because of the cramping. Like I had run a marathon. Uh... Yeah and then I just feel worn down. Really the whole day all I can do is just lie on the couch. Here and there drinking a cup of coffee and doing as little activity as possible. After a day like that I will be alright again but no those are certainly not the nicest days of the year."
– Male, 16 years T2DM, age 53 years –

All the participants with diabetes felt solely responsible for the management of diabetes. They believed in their self-efficacy to manage their dietary patterns, monitor their glucose levels and control their medication intake. However, concerning medication dosage and treatment plans, the participants relied on health care professionals. Furthermore, there was a difference in the experience of self-management according to medication type. The biggest change for the participants taking tablets was regularity in their dietary intake and consuming more healthy produce and fewer products with a high sugar contents. This group hardly suffered from extreme blood sugar levels. Participants who utilise insulin syringes are more flexible concerning their dietary intake through the possibility to alter their insulin dosage if required. However, they are faced with more irregularities in their glucose levels, thus, having a higher risk of short-term complications. In order to prevent the frequency of these short-term complications, some participants utilise an insulin pump which, also, monitors their glucose levels more consistently. Intrapersonal influences on the self-management behaviours were changing attitudes and the reliability on one's own knowledge. External influences consisted, mainly, out of

social support from the immediate family and close friends, and technical advice and service by health care professionals.

4.6 Subjective wellbeing

Subjective wellbeing refers to how people either affectively or cognitively evaluate their lives (Diener, 2000). A framework to assess the psychological wellbeing of a person is the Social Production Function (SPF) theory in which wellbeing is divided in physical and social wellbeing (Ormel et al., 1997). This section will describe the experiences of the participants regarding the influence of diabetes on their subjective wellbeing according to the framework of the SPF theory. In the conclusion of this section, the experiences of the participants will be linked to the definition of subjective wellbeing by Diener (2000).

According to the SPF theory, physical wellbeing plays a significant role in the psychological wellbeing of the individual (Ormel et al., 1997; Steverink & Lindenberg, 2006). The participants indicated the importance of physical and mental activities and not to feel limited by their diabetes to pursue these activities. Some participants indicated that despite their diabetes, they can actively pursue hobbies, such as sports, and a career, such as physically challenging roles in the police force. For example, when asked what she thought constitutes wellbeing, a participant answered that freedom is one of the most important aspects of wellbeing:

> *"Yes and that you have freedom. That you are happy to do things that you want to do. Yes I think that is important to have the freedom to do the things you want to do. And that you are not limited by one or the other. And I don't think that I am being limited by my diabetes form uh the things that I want to do, I can do them."*
> – Female, 7 years T2DM, age 53 years –

When discussing their physical wellbeing, many of the participants focused on the long-term consequences diabetes may have on their lives. None of the participants were currently experiencing any of these complications which resulted in an overall, positive evaluation of their wellbeing. Furthermore, it appeared that all of the participants using tablets and, as a result, hardly experience any short-term complications, feel that diabetes barely has an influence on their subjective wellbeing. For example, one of the participants experienced no noticeable effects of diabetes on her physical wellbeing but she was aware of the long-term complications it may have:

> *"Barely. Because I hardly have any complaints about it but it can cause a lot. Hmm. And at the moment I am not really bothered by it. Not that I know of."*
> – Female, 5 years T2DM, age 75 years –

Most of the participants diagnosed with diabetes indicated that diabetes has no influence on their physical wellbeing. However, the participants who experienced short-term complications more frequently experienced the effects of diabetes on their physical wellbeing more strongly. This was predominately described by participants who utilise insulin as opposed to tablets.

Social wellbeing appeared to be an important aspect of the wellbeing of the participants and was the main focus in their description of their experiences of subjective wellbeing. The participants diagnosed with diabetes mentioned the importance of family and friends for affection and emotional support. Furthermore, the participants valued being accepted in certain social groups. For example, a mother of a young diabetic described that, despite the burden of self-management of diabetes and the presence of short-term complications, the wellbeing of her daughter was not compromised by the diabetes. She is still able to function socially through support from her parents and others in her social environment:

> *"... you're always thinking about it and especially if you need to take care of your daughter and especially when she was just diagnosed as a diabetic as a four year old you can't take care of yourself and you need to take over. So it's had a lot of impact for her but it's like what do I put in my mouth, what do I need to check uh that is basically the daily things but if you look at wellbeing is has no impact. Uh she plays sport a lot. She does everything she wants to do uh but you notice for example that she prefers to do things at home because at home there is less pressure than when she's with others because with others she needs to do it on her own and she has to think a lot more about it while here the parents will take over and at school it's just her."*
> – Female, mother to a diabetic, age 44 years –

Regardless being diagnosed with diabetes, the participants diagnosed with diabetes felt that their social and societal functioning was not decreased. Some participants felt that functioning properly within their social environment is the key to their wellbeing. Diabetes is experienced as a handicap in this functioning but is an obstacle which can be overcome. Through social involvement, the participants feel that their social wellbeing may be affected by diabetes but is not controlled by it. For example, one of the participants indicated that controlling diabetes is important in social and societal functioning:

> *"Uh well what I think is important in life is that uh I uh and uh can function in society as I want and uh socially can function as I want. And uh diabetes can pose a great handicap to achieve this but I feel that I can control it relatively well at the moment."*
> – Male, 28 years T1DM, age 60 years –

The level of self-management seemed to be of influence on the overall wellbeing of people diagnosed with diabetes. This appeared to be stronger among people with T1DM or those using insulin injections with T2DM. They suffer from more short-term complications of diabetes and are, thus, more confronted with their condition. Through the higher frequency of short-term complications, more discomfort is experienced by the participants.

Due to this change in health, the participants felt the perceptions of themselves change accordingly. Some of the participants were confronted with the transition of feeling healthy to someone who has an illness. They were labeled as diabetic or a patient even though they still felt healthy and unchanged which affected their psychological wellbeing. For example, a participant explained the transition from feeling healthy to becoming a patient. The participant talked about the need to accept this change in abilities and freedom in order to live with diabetes:

> *"Uh yeah you feel healthy but from that moment on you become suddenly a patient. I thought in the beginning well diabetes patient, illness, medicine or a tablet or an injection and that's it you're rid of it. But that isn't the case. But I realised that then, and uh from that moment on diabetes rules your whole daily schedule. Your whole life. And that I had never realised it at first that it could have such a huge impact. As well as the capacity to accept that you're a diabetic, you had to keep in mind certain things and that you can't do certain things anymore and uh that is difficult at times."*
> – Male, 16 years T2DM, age 53 years –

Some of the participants diagnosed with diabetes valued having close relationships with family and friends, good health and a good financial situation. Most of the participants focused on various components of their lives such as social functioning or physical health. Some participants indicated that by living with diabetes, they regarded their lives more healthy compared to before the diagnosis. This is a result of improved dietary patterns, increased physical exercise, loss of body weight, less consummation of alcoholic beverages and not smoking.

Overall, the participants evaluated their subjective wellbeing as a whole positive. They all experienced hardly any effects of the diabetes on their wellbeing. However, when discussing certain aspects of their lives, diabetes appeared to have a substantial impact on their social wellbeing, through changes in their status and identity, as well as their physical wellbeing, in the participation of activities and the severity of short-term complications. The negative influence diabetes may have on their subjective wellbeing was predominately described by people who have been diagnosed with diabetes for a longer period of time. Diabetes can become a handicap in social functioning but, through good self-management, can be controlled.

5. Discussion

The objective of this research was to gain a better understanding of the experiences of people diagnosed with type 1 or type 2 diabetes mellitus and their subjective wellbeing from the perspective of the diabetic and their significant other. The focus was on the self-management of diabetes in relation to the subjective wellbeing. A qualitative study was conducted to explore and describe the experiences of living with type 1 or type 2 diabetes mellitus in the Netherlands. The concepts used to guide this study were coping, health literacy and social support. The results of these concepts will be separately discussed in this chapter and will be linked to the existing knowledge generated through a literature review described in the second chapter Theoretical Framework. This will be followed with a discussion on the concept of subjective wellbeing among people diagnosed with diabetes and their significant other.

Coping. The experiences described by the participants in this study appeared to include multiple behaviours in their coping process, including seeking social support and actively searching information to comprehend the change in their health. This is in support of an existing critique on the identified coping strategies by Moos & Schaefer (1993) in which people diagnosed with a chronic disease often combine various coping strategies. Consequently, difficulties can appear in the identification and distinguishing of the coping strategies and, consequently, the different effects it may have on the subjective wellbeing of the individual (Chronister & Chan, 2007; Kleinke, 2007). Furthermore, the results of this study indicate that the intrinsic process of coping seemingly varied according to type and severity of the symptoms experienced by the participants. The presence of diabetes in their immediate family as well as mildness or acuteness of the onset of diabetes would often lead to the coping strategies cognitive approach coping or cognitive avoidance coping. An additional trend was observed over time in which people who have been living with diabetes for a longer period of time appear to become increasingly concerned with the long-term complications of diabetes. This trend was observed with participants from both types of diabetes. This continuing process of coping was, to the best of my knowledge, hardly illustrated in current literature.

Health literacy. In this study, the participants indicated that the information gathered was primarily through verbal communication by visiting health care professionals, such as a diabetes nurse and a general practitioner. The participants relied heavily on the health care professionals indicating that their interactive skills are adequate while their critical skills may be lacking. Furthermore, after the diagnosis, few participants actively sought information on their own feeling that they had reached a saturation point. In addition, this feeling of saturation appeared among the information provided by the dietician which resulted in a cease to the visits. This trend is seen in current literature in which a distinction is made between basic health literacy, consisting of functional and interactive skills, and advanced health literacy, consisting of critical skills (Nutbeam, 2008). Among the participants in this study there seemed to be no relationship between poor glycaemic control and low health literacy as

opposed to results from previous studies by Schillinger et al. (2002) and Williams et al. (1998). Rather, the participants who were faced with fluctuating glucose levels seemed to supplement their knowledge with other sources, including support groups and articles in medical journals.

Social support. The participants in this study indicated that they perceived the support from their social environment positively in relation to their self-management and their subjective wellbeing. This is in agreement with the existing literature, in which social support is identified as an influence on physical and emotional health of an individual as well as on the adequacy of self-management of diabetes directly or through a buffering effect (Ford et al., 1998b). The participants indicated that they felt supported by their partner, their children and their siblings through assumed social roles, such as a watchdog, an advisor, transportation or a pair of extra ears during visits to the hospital. These experiences are in accordance with four of the functions of social support, with the exception being appraisal support (Ford et al., 1998a; Gleeson-Kreig et al., 2002; Westaway et al., 2005). The significant others in this study felt the need to support the diabetic through the adaptation of their own and that of the diabetic's dietary patterns, urge the diabetic to check their glucose levels, administer medication in extreme short-term complications, and through the creation of a safe environment for the diabetic. These results are in support of the three identified support strategies identified by Schokker (2010). However, in this study, overprotection through the adaptation of their own dietary patterns and behaviours resulted in feelings of guilt and resentment from the diabetics. This negative effect on feelings and emotions of the diabetic caused by overprotection from the significant other was different from the identified negative effects by previous studies which focused on the neglect of self-management behaviours (Schokker, 2010). Moreover, the participants of this study indicated the creation of dependency for some participants relied on their partners regarding alterations in their dietary patterns and on health care professionals for advice on medication use. This is, partially, in support of the existing literature which indicated dependency as negative effects of social support as well as the allowance of criticism (Ford et al., 1998a; Gleeson-Kreig et al., 2002). However, the latter was not identified in the experiences of the participants. Another trend was observed among the participants in which a lack of understanding from the social environment was met with frustration by the diabetic as well as the significant other. Diabetics appeared to be faced with the stigma of not being allowed to consume sugar which resulted in feelings of limitation in their diet and activities by the social environment. Consequently, this trend negatively influences the wellbeing of the person with diabetes. This trend was not discussed, to the best of my knowledge, in current literature.

Self-management. All the participants indicated that they felt responsible and in control of the self-management of diabetes. An important concept which can be linked to this is self-efficacy which is the belief of a person in their own functioning and their ability to exercise control over events that affect their life (Benight & Bandura, 2004). Through this belief, the participants in this study indicated that they felt in control of their dietary and medication intake patterns despite pressures from the social environment. They felt comfortable adjusting their daily schedules to comply to

medication patterns and consumed food when they felt necessary. Consequently, this study is in support of the development of constructive behaviours to manage one's diabetes through self-efficacy as was indicated by the study by Hill-Briggs (2003). In the results, the main difference in the experience of self-management was found among different types of medication; participants taking tablets experienced more changes in their dietary intake and exercise regimen while participants who utilise insulin injections are faced with more irregularities in their glucose levels, thus, having a higher risk of short-term complications. This difference in experiences caused differences in the need for social support and the type of technical advice from health care professionals. This differs from previous studies in which differences were primarily discovered between T1DM and T2DM and not between medication types (Eiser et al., 2001). As was indicated by the literature (Brewer-Lowry et al., 2010; Clark et al., 2001), the participants focused in their self-management on goals of which the perceived saliency and the likelihood of achievement is great. For example, the participants focused on adjusting their food intake to maintain stable glucose levels as opposed to adjusting their medication intake. Furthermore, in this study, the participants indicated the use of self-care, through basing their health decisions on their own knowledge and beliefs, informal support, through emotional support from family and friends, and medical care, through support from health care professionals and medication usage. There was a high dependency on the latter source and no indication of the use of formal services. This is contrary to findings by Mathew et al. (2012) in which they discovered that complications in one of these resources can affect the frequency of short- and long-term complications in multiple areas of self-management.

Subjective wellbeing. The participants in this study perceived their overall wellbeing positively. When asked how they perceived their wellbeing, the participants focused on being able to function successfully in social as well as in societal settings. They experienced no differences in their roles within social groups or in the level of affection received from their families and friends. However, the participants indicated a change in identity through the transition of a person who is healthy to a person who has a chronic disease. This process of labelling appeared to a have a negative effect on the participants' wellbeing. Another important aspect of subjective wellbeing was the ability to pursue their own goals and activities without feelings of constraints. These aspects, indicated by the participants, can be linked to the concepts physical and social wellbeing of the social production function theory (Ormel et al., 1997; Steverink & Lindenberg, 2006). However, a greater emphasis was placed on social wellbeing by the participants. In addition, the feeling of freedom and the change in identity are not incorporated in the SPF theory. Among the participants there appeared to be no difference in age in the positive appraisal of subjective wellbeing. However, as the duration of the diabetes increased, the participants felt the effects of the diabetes increase on their subjective wellbeing through the intensification of short-term complications. The effect of the duration of diabetes was experienced by both types of diabetes. This is in contrast to the study by Karlsen et al. (2002) wherein differences were found in age and type of diabetes. However, the study by Eiser et al.

(2001) does support the effect of duration of diabetes on subjective wellbeing as was experienced by the participants in this study. Moreover, due to the diagnosis of diabetes and the need for self-management, the participants indicated that they feel healthier prior to the diagnosis due to changes in their dietary patterns, body weight, and lifestyles. This change in healthier lifestyles is hardly discussed, to the best of my knowledge, in current studies.

6. Conclusion

The objective of this study was to gain a better understanding of the experiences of subjective wellbeing of people diagnosed with type 1 or type 2 diabetes mellitus in the Netherlands. The study was guided by the research question '*How do Dutch adults diagnosed with type 1 or type 2 diabetes mellitus perceive their subjective wellbeing in relation to the self-management of diabetes in the Netherlands?*' In this section, the implications and the significance of this study will be discussed as well as the recommendations for future research.

Based on the existing literature, it was hypothesised that the subjective wellbeing of an individual is affected by the diagnosed of type 1 or type 2 diabetes mellitus. However, this affect is mediated by self-management behaviours which, in turn, is affected by the concepts coping, health literacy, and social support. The hypothesis was explored through two perspectives, namely by the person diagnosed with diabetes and by their significant other. The diagnosis of diabetes differed among the participants according to type of diabetes, age, and the relative loss in functionality of the pancreas. The coping strategies used to adapt to this change in health appeared to differ between severity of the symptoms of the diabetes wherein people with noticeable symptoms utilising behavioural coping strategies. The participants appeared to comprehend sufficient functional and interactive health literacy skills but lacked in their critical skills through a heavy dependency on the provision of information by health care professionals. Social support was, on the whole, experienced positively with behaviours supporting the self-management behaviours of the person diagnosed with diabetes. However, negative feelings and emotions were generated through overprotection and stigma. All in all, the participants felt solely responsible for their self-management behaviours in which they focused on goals which had a high likelihood of achievement. Despite their own knowledge and beliefs, the participants relied heavily on external influences, with a significant role played by health care professionals. Overall, the participants evaluated their subjective wellbeing positively with diabetes posing as an obstacle which can be overcome through adequate self-management behaviours.

As a result of this study, positive and negative influences on the subjective wellbeing of people diagnosed with diabetes can be clarified and utilised in guiding people newly diagnosed with diabetes. In addition, the identification of these obstacles may help people who have already been diagnosed with diabetes in their self-management behaviours. Through this exploration on the subjective wellbeing, the dependency on health care professionals for information regarding their treatment and medication was discovered. Therefore, health care professionals are able to use this information in their communication with people diagnosed with diabetes. The participants valued their opinions and are heavily dependent on them for the provision of information. However, the participants valued having personal contact with the health care professionals wherein the diabetes nurse plays a significant role. Through utilising personal contact, the participants feel that the accessibility is greater

which, in turn, may lead to improved self-management behaviours. Therefore, personal contact with the health care professional is greatly emphasised by this study.

This study on the subjective wellbeing of people diagnosed with diabetes in the Netherlands contributed to the existing literature through the emphasis of the social context in which the persons live and how diabetes may influence certain aspects of a person's subjective wellbeing. Recommendations for future research is a further exploration by academic researchers on social wellbeing and the influence of social support on the overall wellbeing of people diagnosed with diabetes. Current studies primarily focus on the physical alterations caused by diabetes while this study discovered that the subjective wellbeing is heavily influenced by the social wellbeing of the individual. Furthermore, the concepts health literacy and social support can be further explored through the use of quantitative methods in their relationship to the self-management of diabetes. As a result of this exploration, the different effects of the categories of the concepts can be distinguished and implemented to the self-management behaviours of people with diabetes. However, the concept of coping needs to be further re-defined as there were complications in the identification of the categories. The participants utilised various coping strategies to cope with the change in health. Through this refinement, a tool can be created for the identification of negative influences on a person's self-management behaviours and subjective wellbeing. Consequently, measures can be taken to prevent these influences and improve the subjective wellbeing of people diagnosed with diabetes in the Netherlands. Through this improved understanding of the subjective wellbeing of people diagnosed with diabetes, adequate policies can be designed to help improve their wellbeing as well as prevent certain healthcare costs generated from complications concerning diabetes.

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Appendix I: Interview Guides

Interview vragen - Diabeet

Introductie
Mijn naam is Amanda en ik ben een master student van de Rijksuniversiteit Groningen. Het onderwerp van mijn onderzoek is het welbevinden van mensen met diabetes type 2. Voor mijn onderzoek zal ik mensen interviewen om een beter beeld te krijgen wat de ervaringen zijn van het leven met diabetes. Het gaat vooral om uw verhalen en ervaringen dus er zijn geen goede of foute antwoorden.

Alles wat er nu gezegd wordt zal alleen worden gebruikt in mijn onderzoek en zal niet worden gedeeld met mensen buiten dit project om. De medewerkers van het project zijn mijn begeleider en mijzelf. In het onderzoek zal er gebruik worden gemaakt van pseudoniemen zodat alles vertrouwelijk blijft. Even voor de duidelijkheid, heb ik uw toestemming voor het houden van dit interview? Is het goed als ik het gesprek opneem zodat ik beter kan letten op het gesprek en dat er minder fouten in de interpretatie kunnen komen? Hoe wilt u geadresseerd worden in dit gesprek? Heeft u nog vragen voor we beginnen?

Inleidende vragen

1. Kunt u me kort iets over uzelf vertellen?
   Probes: leeftijd, getrouwd/weduwe, familie, gezondheid, religie, opleiding, etniciteit, werk

2. Wat doet u gedurende een normale dag?
   Probes: activiteiten, werk, hobby's/vrijetijdsbesteding

Vragen over sociale omgeving
Ik zou u nu graag wat willen vragen over uw sociale omgeving.

3. Wie zijn de mensen die belangrijk voor u zijn?
   Probes: familie, vrienden, buren, waarom zijn ze belangrijk?

4. Door wie voelt u zich gesteund?
   Probes: Hoe? Mentaal? Emotioneel? Fysiek? Praktisch? Informatief?

Vragen over diabetes en coping
U heeft me net iets verteld over uw sociale omgeving, ik zou nu graag verder willen gaan met hoe u om gaat met diabetes.

5. Hoe heeft u te horen gekregen dat u diabetes heeft?
   Probes: Aanwezige klachten? Wanneer?

6. Hoe voelde u zich toen u te horen kreeg dat u diabetes heeft?
   Probes: Emotioneel? Fysiek? Steun gezocht? Afleiding gezocht?

7. Hoe voelt u zich nu?
   Probes: Emotioneel? Fysiek? In hoeverre heeft u het geaccepteerd? Ontwikkeling?

8. Wat is de invloed van diabetes op uw dagelijkse bezigheden?
   Probes: eten & drinken, beweging, medicatie inname, werk

9. In hoeverre zou uw leven er anders uitzien als u geen diabetes zou hebben?
   Probes: eten & drinken, beweging, medicatie inname, werk

10. Zijn uw sociale contacten veranderd sinds het hebben van diabetes?
    Probes: Wat is er veranderd? Waarom? Hoe ervaart u dit?

Vragen over gezondheidsvaardigheden (HL)
Ik zou nu graag iets meer willen weten over de informatie en de behandeling van diabetes.

11. Wat vindt u van de <u>gesproken</u> informatie over diabetes, zoals een bezoek aan de huisarts?
    Probes: Informatie bron? Zelf gezocht? Kwaliteit? Verbeteringen? Medicatie?

12. Wat vindt u van de <u>geschreven</u> informatie over diabetes, zoals leest u ook over diabetes?
    Probes: Informatie bron? Zelf gezocht? Kwaliteit? Verbeteringen? Medicatie?

13. Hoe ervaart u de behandeling van diabetes?
    Probes: Mediatie gebruik, dieet, fysieke activiteiten, symptomen en complicaties, bloedsuiker in de gaten houden, wat gaat goed, wat minder,

Vragen over welzijn en levenskwaliteit
Zojuist heeft u me verteld over de behandeling van diabetes, ik zou graag nu meer willen weten van de invloed van diabetes op uw leef plezier.

14. Wat vindt u belangrijk in het leven?
    Probes: (mentale) gezondheid, sociale relaties, activiteiten, leef plezier, welbevinden

15. Wat is de invloed van diabetes op uw welzijn?
    Probes: sociale relaties, gezondheid, mentaal, leef plezier

16. Hoe ervaart u de ontwikkeling van diabetes tot nu toe?
    Probes: Emotioneel? Fysiek? Sociaal? Angsten? Stress?

Slotvragen

17. Als een kennis van u te horen zou krijgen dat hij of zij diabetes heeft, wat zijn de tips die u mee zou geven?

18. Is er nog iets wat u graag zou willen toevoegen aan dit interview wat we nog niet besproken hebben?

19. Wat vond u van het interview?

Heel erg bedankt voor uw tijd en dat u mee heeft gedaan in mijn onderzoek.

Naast uw ervaringen ben ik ook erg benieuwd naar de ervaringen van uw sociale omgeving. U gaf aan dat <persoon> erg belangrijk voor u is met het geven van steun. Zou ik hem/haar mogen interviewen over zijn ervaringen?
Wilt u nog op de hoogte blijven van de resultaten uit dit onderzoek?

Interview vragen – Belangrijke persoon

Introductie

Mijn naam is Amanda en ik ben een master student van de Rijksuniversiteit Groningen. Het onderwerp van mijn onderzoek is het welbevinden van mensen met diabetes type 2 en de ervaringen van de partner. Voor mijn onderzoek zal ik mensen interviewen om een beter beeld te krijgen wat de ervaringen zijn van het leven met een partner met diabetes. Het gaat vooral om uw verhalen en ervaringen dus er zijn geen goede of foute antwoorden.

Alles wat er nu gezegd wordt zal alleen worden gebruikt in mijn onderzoek en zal niet worden gedeeld met mensen buiten dit project om. De medewerkers van het project zijn mijn begeleider en mijzelf. Uw naam zal nergens worden genoteerd zodat alles vertrouwelijk blijft. Even voor de duidelijkheid, heb ik uw toestemming voor het houden van dit interview? Is het goed als ik het gesprek opneem zodat ik beter kan letten op het gesprek en dat er minder fouten in de interpretatie kunnen komen? Hoe wilt u geadresseerd worden in dit gesprek? Heeft u nog vragen voor we beginnen?

Inleidende vragen

20. Kunt u me kort iets over uzelf vertellen?
    Probes: leeftijd, getrouwd/weduwe, familie, gezondheid, religie, opleiding, etniciteit, werk

21. Hoe lang kent u al <persoon>?
    Probes: Hoe hebben jullie elkaar leren kennen? Hoe vaak zien jullie elkaar?

Vragen over sociale omgeving
Ik zou u nu graag wat willen vragen over uw sociale omgeving.

22. Wie zijn de mensen die belangrijk voor u zijn?
    Probes: familie, vrienden, buren, en voor <persoon>?

23. Door wie voelt u zich gesteund?
    Probes: Hoe? Mentaal? Emotioneel? Fysiek? Praktisch? Informatief?

Vragen over diabetes en coping
U heeft me net iets verteld over uw sociale omgeving, ik zou nu graag verder willen gaan met hoe u om gaat met het ondersteunen van iemand met diabetes.

24. Hoe voelde u zich toen u te horen kreeg dat <persoon> diabetes heeft?
    Probes: Emotioneel? Fysiek? Steun gezocht? Afleiding gezocht? Angsten?

25. Hoe voelt u zich nu?
    Probes: Emotioneel? Fysiek? Hoe heeft u het geaccepteerd? Ontwikkeling?

26. Hoe voelde <persoon> zich toen hij/zij te horen kreeg dat hij/zij diabetes heeft?
    Probes: Emotioneel? Fysiek? Steun gezocht? Afleiding gezocht?

27. Hoe voelt <persoon> zich nu?
    Probes: Emotioneel? Fysiek? In hoeverre heeft hij/zij het geaccepteerd? Ontwikkeling?

28. Wat is de invloed van het leven met een persoon met diabetes op uw dagelijkse bezigheden?
    Probes: Eten & drinken, beweging, medicatie inname, werk

29. In hoeverre zou uw leven er anders uitzien als <persoon> geen diabetes zou hebben?
    Probes: eten & drinken, beweging, medicatie inname, werk

30. Zijn de sociale contacten veranderd sinds uw partner diabetes heeft?
    Probes: Wat is er veranderd? Waarom? Hoe ervaart u dit? En voor <persoon>?

Vragen over gezondheidsvaardigheden (HL)
Ik zou nu graag iets meer willen weten over de informatie en de behandeling van diabetes.

31. In hoeverre bent u betrokken bij de behandeling van de diabetes van <persoon>?
    Probes: Mee naar afspraken, medicatie inname, eten & drinken, bloedsuiker controle

32. Hoe gaat <persoon> om met de behandeling van diabetes?
    Probes: Mediatie gebruik, frequentie intenist/huisarts bezoek, wat gaat goed, wat minder

33. Wat vindt u van de geschreven informatie over diabetes?
    Probes: Informatie bron? Zelf gezocht? Kwaliteit? Verbeteringen? Medicatie?

34. Wat vindt u van de gesproken informatie over diabetes?
    Probes: Informatie bron? Zelf gezocht? Kwaliteit? Verbeteringen? Medicatie?

Vragen over welzijn en levenskwaliteit
Zojuist heeft u me verteld over de behandeling van diabetes, ik zou graag nu meer willen weten van de invloed van diabetes op uw leef plezier en die van <persoon>.

35. Wat is de invloed van diabetes van uw partner op uw leefplezier?
    Probes: sociale relaties, gezondheid, emotioneel, dagelijkse bezigheden

36. Wat is de invloed van diabetes op het leef plezier van <persoon>?
    Probes: sociale relaties, gezondheid, emotioneel, dagelijkse bezigheden

37. Hoe ervaart u de ontwikkeling van diabetes tot nu toe?
    Probes: Emotioneel? Fysiek? Sociaal? Wat verwacht u voor de toekomst?

Slotvragen

38. Als een kennis van u te horen zou krijgen dat zijn/haar partner diabetes heeft, wat zijn de tips die u mee zou geven?

39. Is er nog iets wat u graag zou willen toevoegen aan dit interview wat we nog niet besproken hebben?

Heel erg bedankt voor uw tijd en dat u mee heeft gedaan in mijn onderzoek.
Wilt u nog op de hoogte blijven van de resultaten uit dit onderzoek?