Family matters in diabetes prevention
Communication about familial risk of type 2 diabetes

Suzanne van Esch
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ITHAKA

As you set out for Ithaka
hope the voyage is a long one,
full of adventure, full of discovery.
Laistrygonians and Cyclops,
angry Poseidon—don’t be afraid of them:
you’ll never find things like that on your way
as long as you keep your thoughts raised high,
as long as a rare excitement
stirs your spirit and your body.
Laistrygonians and Cyclops,
wild Poseidon—you won’t encounter them
unless you bring them along inside your soul,
unless your soul sets them up in front of you.

Hope the voyage is a long one.
May there be many a summer morning when,
with what pleasure, what joy,
you come into harbours seen for the first time;
may you stop at Phoenician trading stations
to buy fine things,
mother of pearl and coral, amber and ebony,
sensual perfume of every kind—
as many sensual perfumes as you can;
and may you visit many Egyptian cities
to gather stores of knowledge from their scholars.

Keep Ithaka always in your mind.
Arriving there is what you are destined for.
But do not hurry the journey at all.
Better if it lasts for years,
so you are old by the time you reach the island,
wealthy with all you have gained on the way,
not expecting Ithaka to make you rich.

Ithaka gave you the marvellous journey.
Without her you would not have set out.
She has nothing left to give you now.

And if you find her poor, Ithaka won’t have fooled you.
Wise as you will have become, so full of experience,
you will have understood by then what these Ithakas mean.

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Translated by Edmund Keeley and Philip Sherrard
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General introduction
Introduction

Type 2 diabetes (T2D) is a serious chronic disease causing considerable burden on patients as well as health care systems. The increasing prevalence of T2D warrants major efforts regarding the development of preventive strategies targeting populations at high risk. Family history is considered an important risk factor; the chance of developing T2D is two-to-five times higher for people with affected relatives. Family history information can be used to detect persons at risk for T2D, but also to raise awareness about increased susceptibility and motivate individuals to engage in risk-reducing behaviours.

A central question is how to reach persons with a family history of T2D and inform them about preventive options. Currently, public health initiatives and health care professionals make efforts to promote health-protective behaviour in populations at high risk developing T2D. A potential additional targeting strategy might be to ask patients to pass on risk and preventive information in their family. To promote and facilitate family communication about increased susceptibility to diabetes, however, insight is needed in the complex process family risk disclosure.

The main objective of this thesis is to provide insight in the current and potential use of communication about familial risk of T2D to promote health-protective behaviour in families where T2D is (highly) prevalent. In six sub-studies, we set out to explore this question from three perspectives: 1) online public health communications, the point of view of 2) patients with T2D, and 3) health care professionals.

Diabetes Mellitus

Diabetes mellitus is a potentially life-threatening disorder characterised by chronically elevated blood glucose levels (hyperglycaemia). In order to achieve and maintain good glycaemic control, adherence to insulin or oral medication treatment and a healthy lifestyle (physical exercise, healthy nutrition, smoking cessation and weight loss if necessary) is essential. Consequently, diabetes treatment requires a high degree of self-management by the patient, necessary to prevent diabetes-related complications, cardiovascular morbidity and mortality (American Diabetes Association, 2011; Nathan, 1993). This personal responsibility in diabetes care, as well as physical impediments, constitute high (emotional) burden in patients (Maes et al., 1996; Roglic et al., 2005).

Two main types of diabetes can be distinguished. Type 1 diabetes (also known as ‘insulin-dependent’, or ‘juvenile-onset’ diabetes) results from an autoimmune mediated destruction of insulin-producing beta cells in the pancreas and often is diagnosed early in life (American Diabetes Association, 2007). Type 2 diabetes (or ‘non-insulin-dependent’, ‘adult-onset’ diabetes) results from a decreased ability to transduce the insulin signal. Type 2 diabetes, to which this thesis is limited, is mostly diagnosed after the age of 40, usually has a gradual onset and accounts for 90-95% of all cases of diabetes (American Diabetes Association, 2007).
The diabetes epidemic

Nowadays, diabetes is affecting about 366 million people worldwide and is expected to rise to 552 million by 2030 (Herman & Zimmet, 2012; Whiting et al., 2011). Specifically in (newly) industrialised countries with high carbohydrate diets and sedentary lifestyle, T2D prevalence is rapidly increasing, with escalating societal and economic costs as a consequence (American Diabetes Association, 2008; Johnson et al., 2006; Williams et al., 2002; Zimmet et al., 2001). In the Netherlands, over 800,000 people suffer from diabetes and it has been predicted that in 2025 around 1.3 million people (8% of the population) will be diagnosed (Baan et al., 2009).

Risk factors and the inheritable character of type 2 diabetes

T2D is best described as a multi factorial disease, which means disease onset is triggered by the interaction of multiple genes and environmental factors (Lyssenko et al., 2008b; Rathmann et al., 2011). Risk factors include increasing age, lifestyle-related factors as obesity, unhealthy diet and physical inactivity, insulin resistance, family history and ethnicity (American Diabetes Association, 2007). Epidemiological research convincingly demonstrates that T2D is highly prevalent in some families and a positive family history predicts the development of T2D, even after adjustment for common risk factors (Arslanian et al., 2005; Hemminki et al., 2010; Meigs et al., 2000). The chance of developing diabetes is two-to-five times higher for people with a family history of the disease (Annis et al., 2005; Valdez et al., 2007). Twin studies have been used to assess the extent to which familial aggregation of disease can be accounted for by inherited genetic factors (Barroso, 2005). Indeed, the concordance rates for impaired glucose tolerance and T2D are consistently higher in monozygotic than in dizygotic twin pairs (Kaprio et al., 1992; Poulsen et al., 1999). With the introduction of Genome Wide Association Studies, knowledge about diabetes susceptibility genes has been accumulating in an impressive manner. Currently, nearly 40 gene variants have been found to raise or lower the risk of T2D (Frayling et al., 2007; McCarthy & Zeggini, 2009; Saxena et al., 2012; Voight et al., 2010).

Still, no genes have yet been identified with moderate or major effect on the disease, so DNA testing for susceptibility genes in clinical practice is not yet warranted (Herder & Roden, 2010). Thus, although the sequencing of the human genome has provided tools to gain a better understanding of the role of genes in the development of disease, the distinction between genetic and environmental factors is not easily made. Social inheritance, due to certain lifestyles in families, may also result in familial clustering (van ’t Riet et al., 2010). Studies concluded that familial risk of T2D is the result of shared environmental, cultural and behavioural factors and multiple (hitherto unknown) genes (Lyssenko et al., 2008b; Meigs et al., 2008; Vassy et al., 2011). An overview of increased risk based on family history is presented in Box 1.
Other evidence of genetic predisposition may arise from comparing groups with different ethnic backgrounds. For instance, in urbanised regions throughout the world, people from South-Asian descent are known to be at highly increased risk developing T2D (Gupta et al., 2011; Jenum et al., 2005; Lee et al., 2011; Ramachandran et al., 2010; Unwin et al., 2009). Recently, susceptibility genes have been identified in South-Asian populations (Kooner et al., 2011; Tsai et al., 2010; Yamauchi et al., 2010).

In the Netherlands, most South-Asian inhabitants are immigrants from Surinam, a former Dutch colony in South-America. This group has a Hindustani cultural background and a six-to-ten time higher T2D prevalence than the Dutch host population (Middelkoop et al., 1999) (see Box 2). Primary prevention targeted at this population is of urgent priority, since patients with South-Asian ancestry suffer disproportionately from the disease considering severe complications, high morbidity and mortality rates (Bathula et al., 2010; Gholap et al., 2011).

**Box 1. Increased diabetes risk based on family history**

<table>
<thead>
<tr>
<th>Family history</th>
<th>Adjusted OR</th>
<th>95% CI</th>
<th>Study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parents and/or siblings</td>
<td>3.95</td>
<td>3.25-4.79</td>
<td>Annis et al., 2005</td>
</tr>
<tr>
<td>One relative</td>
<td>3.05</td>
<td>2.44-3.82</td>
<td>2005</td>
</tr>
<tr>
<td>Two relatives</td>
<td>5.14</td>
<td>3.81-6.91</td>
<td></td>
</tr>
<tr>
<td>Three or more relatives</td>
<td>14.83</td>
<td>10.95-20.08</td>
<td></td>
</tr>
<tr>
<td>One parent</td>
<td>3.04</td>
<td>2.34-3.94</td>
<td></td>
</tr>
<tr>
<td>Both parents</td>
<td>6.95</td>
<td>4.69-10.29</td>
<td></td>
</tr>
<tr>
<td>At least one sibling</td>
<td>3.52</td>
<td>2.94-4.21</td>
<td></td>
</tr>
<tr>
<td>Moderate familial risk</td>
<td>2.3</td>
<td>-</td>
<td>Valdez et al., 2007</td>
</tr>
<tr>
<td>High familial risk</td>
<td>5.5</td>
<td>-</td>
<td>2007</td>
</tr>
<tr>
<td>Maternal diabetes</td>
<td>2.7</td>
<td>2.0-3.7</td>
<td>Meigs et al., 2000</td>
</tr>
<tr>
<td>Paternal diabetes</td>
<td>1.7</td>
<td>1.2-2.4</td>
<td></td>
</tr>
<tr>
<td>Bilineal diabetes</td>
<td>5.2</td>
<td>2.6-10.5</td>
<td></td>
</tr>
<tr>
<td>Maternal diabetes and an age of onset &lt;50 years</td>
<td>9.7</td>
<td>4.3-22.0</td>
<td></td>
</tr>
</tbody>
</table>

Concordance rates range from

- Dizygotic twin pairs: 0.10 to 0.43 (Barroso, 2005)
- Monozygotic twin pairs: 0.20 to 0.91

* Adjusted for relevant risk factors as gender, age, race/ethnicity, Body Mass Index

1 One first-degree and one second-degree relative, or one first-degree relative, or two second-degree relatives from the same maternal or paternal line

2 Two first-degree relatives or one first-degree and two second-degree relatives
Box 2. Diabetes prevalence in the Netherlands; populations of Dutch and Surinamese South-Asian origin

<table>
<thead>
<tr>
<th>Study</th>
<th>Surinamese-Hindustan population (originally from South-Asian)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dutch host population</td>
<td>% Men % Women % Total</td>
</tr>
<tr>
<td>&gt; 20 years ¹</td>
<td>4.0 3.6 3.8</td>
</tr>
<tr>
<td>35-74 years ¹</td>
<td>1.0 5.0 3.0</td>
</tr>
<tr>
<td>40-75 years ²</td>
<td>5.1 4.5 4.8</td>
</tr>
<tr>
<td>18-70 years ³</td>
<td>- - 6.0</td>
</tr>
<tr>
<td>³ Diabetes diagnosed after physical examination (Ujcic-Voortman et al., 2009; Weijers et al., 1998)</td>
<td></td>
</tr>
<tr>
<td>² Diabetes diagnosed by general practitioners (Kriegsman et al., 2003)</td>
<td></td>
</tr>
<tr>
<td>³ Self reported diabetes (Dijkshoorn et al., 2003; Middelkoop et al., 1999)</td>
<td></td>
</tr>
</tbody>
</table>

Type 2 diabetes prevention

Diabetes prevention programmes have demonstrated that lifestyle modifications (healthy diet, increased physical activity) or pharmacological interventions can significantly decrease the incidence of T2D (Gillies et al., 2007; Kinmonth et al., 2008; Knowler et al., 2009; Lindstrom et al., 2006; Saaristo et al., 2010). Prevention programmes appeared to be effective in persons at risk due to family history (Barwell et al., 2008; Brekke et al., 2005; Uusitupa et al., 2011; Williams et al., 2004; Yamaoka & Tango, 2005), as well as in persons with South-Asian ethnic background (Hsu et al., 2012; Pan et al., 1997; Ramachandran et al., 2006; Viswanathan et al., 1997; Wing et al., 1998). Now, scientific proof that people may delay or prevent the onset of T2D needs to be translated into understandable messages that appeal individuals at high risk and include concrete healthy lifestyle recommendations. Health care professionals are challenged to find new tools and strategies to detect, inform and particularly motivate individuals at high risk.

Public health initiatives

Globally, clinical and public health initiatives are generated to assist in reducing the burden of diabetes in the population. For example, the International Diabetes Federation (IDF) aims at increasing public awareness about diabetes and its complications. In their ‘Global strategic plan to raise awareness of diabetes’, the IDF defined target audiences, developed specific communication messages and listed strategies that are applicable at local, national, regional or international level (International Diabetes Federation, 2003). Through the worldwide network of the IDF, national diabetes organizations (member associations) are stimulated to inform
groups at high risk about diabetes risk factors and preventive options. Interestingly, amongst key players involved in diabetes, such as health care decision makers and medical professionals, the IDF defined people with diabetes as target audience to spread risk and preventive messages in their families.

In the Netherlands, the national government has defined highly ambitious goals in the Prevention Memo 2006, aiming at reducing the incidence of diabetes and its complications (Dutch Ministry of Health, 2006). Following this, the Dutch Diabetes Federation (Nederlandse Diabetes Federatie; NDF) formulated a National Diabetes Action Programme, (Nationaal Actieplan Diabetes; NAD) which will operate until 2013 (Dutch Diabetes Federation, 2009). The NDF launched a campaign to inform the public about risk factors for T2D and preventive options using diverse mass media channels, including an informative website. In this campaign, specific groups at high risk were targeted, including ethnic minority groups and individuals with a family history. On the website, a special portal for professionals was accessible, providing audiovisual and written information, including a validated diabetes risk test in different languages (Alssema et al., 2008).

In addition, inspired by the grant application of our research project, the Dutch Diabetes Foundation chose ‘diabetes and the family’ as central theme in their mass media campaigns from 2007-2010. In consecutive years, the aim was to raise awareness of familial susceptibility to T2D and preventive options, to urge patients to discuss diabetes risk in their family and to bring the ‘National Diabetes Inheritance Test’ to the attention of the public.

The role of medical professionals regarding diabetes prevention in high-risk families

In most countries, the use of opportunistic targeted-screening in patients at risk for diabetes is recommended (American Diabetes Association, 2011). The Dutch College of General Practitioners (Nederlands Huisartsen Genootschap; NHG) adopted this recommendation: the Practice Guideline for diabetes treatment describes that three-yearly testing to detect (pre)diabetes and assess risk for future T2D in asymptomatic people should be considered in adults aged >45 years with one or more risk factors (BMI ≥27 kg/m², first-degree relative with diabetes, being from Moroccan or Turkish descent, having a history of gestational diabetes, having hypertension, Impaired Fasting Glucose, Impaired Glucose Tolerance, or cardiovascular disease). In addition, screening is recommended above the age of 35 years in Surinamese people with South-Asian ancestry (Bouma et al., 2006).

Although primary care professionals generally recognize family history as an important element in the risk stratification process, family history information seems to be under-used in routine practice (Berg et al., 2009). Research has indicated that having a family history seems to be positively associated with risk awareness and risk-reducing
behaviours in relatives of patients with T2D (Acheson et al., 2010; Baptiste-Roberts et al., 2007; Dorman et al., 2012; Hariri et al., 2006), suggesting it could be utilized to motivate relatives to engage in risk-reducing behaviours (Claassen et al., 2010a). Indeed, targeted diabetes education seemed to increase the recognition of diabetes risk, screening possibilities, perceived personal control and the need of healthy behaviour in persons with a family history of T2D (Chang et al., 2011; Pierce et al., 2000; Pijl et al., 2009b; Qureshi & Kai, 2008; Ruffin et al., 2011; Whitford et al., 2009a; Zlot et al., 2009). Yet, directly targeting and informing people about increased familial susceptibility to T2D is not current in clinical practice (Heideman et al., 2011a). Studies indicated that physicians informed fewer than half of patients with a positive family history about familial risk and the importance of preventive behaviour (Chang et al., 2011; Qureshi & Kai, 2008).

The patient as ‘messenger’ in the family

For health care professionals it is difficult to reach individuals with a family history of diabetes. Opportunities of communication with healthy relatives of T2D patients are limited, as they do not visit their physician regularly. Directly targeting persons with a family history also seems complicated, as the extent of family history collected and systematically registered varies widely (Berg et al., 2009; Wilson et al., 2009). Therefore, an approach that might be worthwhile to explore is the patient-mediated method of cascading, as is used in screening for familial hypercholesterolemia (Hallowell et al., 2011). This means that healthy relatives are reached via the index patient, who informs them about increased familial susceptibility to the disease and preventive options. Patients diagnosed with familial hypercholesterolemia seem to prefer a patient-mediated approach more than a direct targeting approach, as they consider it less threatening for relatives (Hallowell et al., 2011).

Research has already indicated that patients with T2D seem willing to disseminate risk messages in their family (Bonomo et al., 2005; Gnanalingham & Manns, 1997; Nishigaki et al., 2009; Whitford et al., 2009b). Offspring appears receptive to be informed about reducing their diabetes risk via the family system (Esch et al., 2009; Pierce et al., 2000; Whitford et al., 2009a). However, clearly emerging from research in the field of genetic screening is the complexity of the process of family risk disclose (Forrest et al., 2003; Wilson et al., 2004). Explorative studies already found that pre-existing personal and familial characteristics of patients with T2D, as well as their perceptions of family risk, knowledge about diabetes risk factors, outcome expectancies, self-efficacy and worries appeared to be predictors of their intentions to disseminate diabetes risk messages in their family (Bonomo et al., 2005; Gnanalingham & Manns, 1997; Nishigaki et al., 2009; Whitford et al., 2009b).

Further understanding is needed to facilitate the use of a patient-mediated approach in diabetes prevention. As patients learn ways of being ill, how to cope with their illness and how to communicate about health problems within a context
of societal, familial and cultural rules (Baumann, 2003; Kleinman et al., 1978), variation in the usability of a family-oriented approach across patients, families and ethnic boundaries may be expected. Multigenerational legacy, the emotional impact of witnessing diabetes in the family and features of the course of the disease, shape relatives’ health beliefs and understanding of familial risk (Scollan-Koliopoulos et al., 2005; Walter & Emery, 2005). It remains unknown, however, whether patients’ beliefs about, for instance, the cause and controllability of their own disease influence ideas about their relatives’ vulnerability to diabetes. Based on the mental contents underlying a person’s own health risk appraisal (Cameron, 2008; Kaptein et al., 2007; Leventhal et al., 2003), one may expect that the experience of patients with having diabetes will be important in the conceptualising of perceptions of susceptibility, preventability and controllability of diabetes in relatives.

In addition, as was mentioned, ethnic variability may be expected. The question is whether a family-oriented intervention would be feasible approaching high-risk groups in the Netherlands, in particular the Surinamese South-Asian population with extremely high diabetes prevalence (Middelkoop et al., 1999). It is known that health-care delivery in South-Asian populations is challenging (Hawthorne et al., 2008; Khunti et al., 2008). On the other hand, given the strong familial aggregation of diabetes in South-Asian families (Viswanathan et al., 1996), a family-oriented prevention strategy would seem legitimate (Ramachandran et al., 2006).

Patients’ response to health threats in relatives; an explanatory model

In our study, we applied the Common-Sense Model (CSM) of self-regulation of health and illness (Cameron, 2003; Leventhal et al., 2003) for further examination of the decisional process of patients with T2D whether or not to inform relatives about increased familial diabetes risk. The CSM delineates that patients create their own ‘models’ or representations of their illness: from direct personal experiences, information from significant others as parents and doctors, social and mass medial communication, a person develops ideas and expectations about illness and health-threatening conditions (Leventhal et al., 1997; Weinman & Petrie, 1997). Research convincingly demonstrated that a person’s illness representations can be ordered into logical themes or dimensions: illness identity, timeline beliefs, consequences, controllability, emotional representation, illness coherence and causal beliefs (Hagger & Orbell, 2003; Moss-Morris et al., 2002).

Research in which the CSM framework is used has mainly focused on illness representations of patients and their influence on coping, recovery and adaptation to the illness (Hagger & Orbell, 2003). However, recently, the concept of illness representations has been investigated in relation to risk perceptions, disease-related worries and preventive behaviour in individuals at increased risk developing a disease
(e.g., (Cameron, 2008; Claassen et al., 2010b; Kaptein et al., 2007; van Oostrom et al., 2007). In line with that, we may assume that the experience of patients with having diabetes also may underpin their perceptions of diabetes threat in relatives (see Figure 1, association A).

Subsequently, the CSM proposes that illness representations guide risk-related cognitions about the illness threat (e.g., risk judgements, control beliefs) and emotional appraisal (e.g., distress, anxiety, worries) which, in turn, will give rise to coping procedures for controlling health threats (Cameron, 2003; Leventhal et al., 2003). These parallel systems of cognitive and emotional information processing may exert distinctive influences on protective health behaviours in different situations (Cameron & Reeve, 2006).

Research, particularly carried out in the field of (breast)cancer susceptibility, has reported considerable variability in the effect of perceived risk, worries and control beliefs on cancer protective behaviours (Cameron & Reeve, 2006; Consedine et al., 2004). Some study findings suggest that worries and fear often influence behaviours independently of the influence of risk beliefs (McCaul et al., 1996; Moser et al., 2007). Others describe situations in which worry and fear predict behavioural outcome, whereas risk judgments do not (Cameron & Diefenbach, 2001; Diefenbach et al., 1999).

In the only diabetes-related study in which worries were measured (Whitford et al., 2009b), patients’ concern was found an important cue to inform relatives about increased diabetes risk. At present, little is known about the interplay

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**Figure 1.** The Common-Sense Model of the self-regulation of health threats (Cameron, 2003; Leventhal et al., 2003) adjusted for the decisional process of patients with type 2 diabetes whether or not to inform relatives about increased familial diabetes risk and preventive options.
between cognitive risk appraisal (e.g., risk perceptions, perceived illness control) and emotional evaluation (e.g., distress, anxiety, worries) in patients’ decisional process of familial diabetes risk disclosure (see Figure 1, association B).

Research questions

The studies in this thesis aim to explore current and potential use of communication about familial risk of T2D to promote health-protective behaviour in families where T2D is (highly) prevalent from three perspectives.

Public health communication

To start, as consciousness and interest in familial susceptibility to T2D are considered significant factors in the process of family risk disclosure, the public availability of and need for information about diabetes, inheritance and prevention will be explored.

1. Is information about familial susceptibility to diabetes and preventive options publicly available and does the public call for this information?
   a. What information about diabetes and inheritance do renowned diabetes organizations provide on the Internet?
   b. What information do people need about the role of inheritance in diabetes?

Patients with type 2 diabetes

We choose the patient as focus of interest in our studies. In addition to what is known from earlier studies (Nishigaki et al., 2009; Whitford et al., 2009b), facilitating and impeding factors of the disclosure of familial diabetes risk by patients with T2D will be explored within the framework of the Common-Sense Model (Cameron, 2003; Leventhal et al., 2003). Subsequently, the possibility of a patient-mediated targeting strategy in diabetes prevention according to Dutch patients with T2D, of which a considerable amount is from Surinamese South-Asian descent, will be investigated.

2. What factors influence intentions of patients to disseminate information about diabetes risk and preventive options within the family?
   a. How do cognitive, emotional and familial aspects influence the decisional process of patients whether or not to disseminate diabetes risk- and preventive information in their family?
   b. To what extent are personal illness representations of patients related to their perceptions of diabetes threat in family members?

3. Is it possible to use family communication as a strategy in Dutch diabetes prevention, specifically targeting families at high risk with Surinamese South-Asian ancestry?
Health care professionals

Practice implications will be considered by reflecting on the insights from above mentioned studies with (diabetes) health professionals within the perspective of current and future use of family history and family communication as additional strategy in diabetes prevention.

4. What are Dutch health care professionals’ attitudes and practices regarding the utilisation of family history in diabetes prevention?

Aim of the study project

The study project that is described in this thesis was financed by the Dutch Diabetes Foundation (Diabetes Fonds) as part of their research programme entitled ‘The patient’s voice’ (Stem van de Patiënt). This programme emphasizes the desire that the projects would anticipate on the wishes and needs of people with diabetes and would lead to results that were practically useful to patients and their environment.

In our project, we conducted three qualitative and three quantitative studies. Findings may provide useful insights contributing to the design of public and clinical communications and patient education programmes that utilize family history and family communication to promote health-protective behaviour in families where T2D is (highly) prevalent.

Outline of this thesis

The chapters of this thesis are based on papers that have been published or submitted for publication. All sub-studies presented are explorative and observational in nature. In two introductory, qualitative studies we evaluated the public availability of and need for information about diabetes, inheritance and prevention. In Chapter 2, an international comparison of online information about diabetes and inheritance provided by renowned diabetes organizations is presented. The study described in Chapter 3 aimed at exploring the need for (additional and/or specific) information about the role of inheritance in diabetes of visitors of the website of the National Genetic Research and Information Centre (‘Erfocentrum’ in Dutch).

To address the second and third research objectives, a cross-sectional, observational study was conducted among 546 patients diagnosed with T2D, receiving treatment in primary- or secondary care. In Chapter 4 we aim to get insight into the complexity of the decisional process of patients whether or not to discuss familial susceptibility to T2D in their family. Cognitive, emotional and familial aspects are being explored and further insight is obtained regarding the interplay between the family risk perceptions of patients, worries and control beliefs regarding diabetes prevention, and their intentions to inform relatives about diabetes risk and preventive possibilities. Subsequently, Chapter 5 describes to what extent
personal illness representations of patients are related to their family risk perceptions, worries about relatives developing T2D, and beliefs with regard to the possibilities of diabetes prevention. In both Chapter 4 and 5, the Common-Sense Model of self-regulation of health and illness (Cameron, 2003; Leventhal et al., 2003) was used as theoretical framework. The study in Chapter 6 investigates the possibility of utilising family communication as a diabetes prevention strategy, specifically targeting families at high risk with Surinamese South-Asian ancestry in the Netherlands.

Next, to reflect on the findings as described in previous chapters, interviews were conducted with medical professionals in primary- and secondary care. Chapter 7 describes the ideas and opinions of health care providers in primary and secondary care on current or future uptake of family history and family communication in diabetes prevention. The general discussion, in Chapter 8, summarizes and reflects on the main findings. Methodological considerations are addressed as well as practice implications and further research in this field.
Type 2 diabetes and inheritance: what information do diabetes organizations provide on the Internet?

S.C.M. van Esch
M.C. Cornel
F.J. Snoek

Diabetic Medicine 2006; 23:1233-1238
Abstract

Aims The worldwide epidemic of type 2 diabetes necessitates preventive actions. Providing information to high-risk populations is key. In an international comparison of websites, we aimed to investigate the presence and quality of information provided by diabetes organizations on inheritance of type 2 diabetes and the benefits of a healthy lifestyle targeted at those with a family history or belonging to a specific ethnic population.

Methods All websites included in the International Diabetes Federation member list in English, German, French, Dutch, Spanish, Portuguese, Swedish, Norwegian, Finnish, Danish, and Japanese were included for assessment. Using qualitative content analysis, we reviewed 34 websites that provided health-related information on diabetes.

Results Most websites mention family history as a risk factor. However, an explanation of the interaction of lifestyle factors and increased genetic susceptibility is lacking. Ethnicity is mentioned in only half of the sites describing risk factors. Although most websites do provide information on the importance of a healthy lifestyle, they do not address specific high-risk groups. Only two websites encourage type 2 diabetic patients to inform family members of the familial character of diabetes.

Conclusions Information on inheritance of type 2 diabetes and prevention specifically targeted at high-risk groups on the Internet by diabetes organizations is often of poor quality or indeed is lacking. Efforts should be made to disseminate information on heredity of type 2 diabetes and preventive options to the general public and high-risk populations.
Introduction

With the rapidly increasing number of type 2 diabetic patients worldwide (Narayan et al., 2003; Steinbrook, 2006; Zimmet et al., 2005), it is necessary to take preventive actions (Sherwin et al., 2004). In addition to the known risk factors for type 2 diabetes (T2D), such as older age, obesity and lack of physical activity (American Diabetes Association, 2003, American Diabetes Association, 2004), evidence has been found for an ethnic susceptibility (Abate & Chandalia, 2003; Hsu et al., 2012; Jafar et al., 2003; Jenum et al., 2005) and genetic factors in the pathogenesis of T2D (Busch & Hegele, 2001; Froguel & Vaxillaire, 2003; Grant et al., 2006; Klupa et al., 2000; McCarthy, 2003; Reynisdottir et al., 2003). Accordingly, screening for a family history of T2D is an effective method to detect people at increased risk of developing diabetes (Annis et al., 2005; Arslanian et al., 2005; Harrison et al., 2003; Pierce et al., 1995).

Patients, as well as family members, seem to be aware of ‘some’ increased risk, but generally underestimate the actual risk percentage and apparently have little knowledge of primary prevention (Adriaanse et al., 2003; Farmer et al., 1999; Forsyth & Goetsch, 1997; Gnanalingham & Manns, 1997; Pierce et al., 2001; Pierce et al., 1999). Scientific proof that people (especially those at increased risk) may delay or prevent the onset of T2D (Curtis & Wilson, 2005; Davies et al., 2004; Knowler et al., 2002; Sherwin et al., 2004; Tuomilehto et al., 2001) needs to be translated into an understandable message which includes concrete healthy lifestyle recommendations. In this context, primary prevention campaigns should aim at providing understandable information regarding the interplay of genetic, environmental and behavioural factors in the aetiology of T2D (Newell, 2004; Pozzilli, 2005). The World Wide Web may offer a unique opportunity to disseminate this information on a large scale (Berland et al., 2001; Eysenbach et al., 2002; Murray et al., 2003; Thakurdesai et al., 2004).

In this study, we set out to explore what information on inheritance, T2D and primary prevention is provided on the Internet by renowned diabetes organizations [i.e. associated International Diabetes Federation (IDF) members], whether this information is targeted at high-risk groups based on family history and/or ethnicity, and to what extent type 2 diabetic patients are urged to notify relatives on their increased susceptibility.

Research design and method

Numerous websites offer information on T2D and the quality is known to vary widely (Gimenez-Perez et al., 2005; Seidman et al., 2003b; Thakurdesai et al., 2004). In this study, we decided to assess websites of renowned, national diabetes patient organizations all over the world. The sampling frame consisted of all associated member organizations of the IDF (n=182) with a URL [uniform resource locators (global address of resources on the World Wide Web)] available on the IDF website.
(http://www.idf.org) in September 2005 \((n=67)\). We included three more URLs of associated IDF member organizations (Spain, USA and Guyana), because we knew these organizations did have a website although they were not mentioned in the IDF list. Four websites of non-IDF member organizations were added in order to obtain an overview of diabetes information in those specific language regions (see ‘Data collection’, step 4). In addition, the websites of the IDF and the World Health Organization (WHO) were added to gain insight into information provided by worldwide health organizations. The final group consisted of 76 websites (see Table 1).

**Inclusion criteria**

All websites from the sampling frame in English, German, French, Dutch, Spanish, Portuguese, Swedish, Norwegian, Finnish, Danish, and Japanese that provide health information on T2D were selected. The language criterion was practical, as the researchers were competent reading these languages or knew colleagues who could. Eighteen websites had to be excluded. Three URLs led to a dead link, meaning the websites not being operational. After a first analysis, 21 websites appeared not to give health information about T2D. A total of 34 websites were included for content analysis in further detail (see Table 1).

**Data collection**

Changes in the content of websites necessitate rapid collection of data. Following McMillan’s recommendation to use month’s timeframe (McMillan, 2000), all websites were analysed in September 2005. The context unit for coding included all pages on a website, as well as links leading to attached documents, information

<table>
<thead>
<tr>
<th>Regions</th>
<th>Africa</th>
<th>Eastern Mediterranean &amp; Middle East</th>
<th>Europe</th>
<th>North America</th>
<th>South and Central America</th>
<th>South East Asia</th>
<th>Western Pacific</th>
<th>World wide</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total URL sampling frame</td>
<td>3</td>
<td>1</td>
<td>40</td>
<td>7</td>
<td>13</td>
<td>1</td>
<td>9</td>
<td>2</td>
<td>76</td>
</tr>
<tr>
<td>URLs not operational or excluded by language</td>
<td>0</td>
<td>-1</td>
<td>-16</td>
<td>0</td>
<td>-1</td>
<td>0</td>
<td>-3</td>
<td>0</td>
<td>-21</td>
</tr>
<tr>
<td>URLs not providing health information</td>
<td>-1</td>
<td>0</td>
<td>-8</td>
<td>-2</td>
<td>-6</td>
<td>-1</td>
<td>-3</td>
<td>0</td>
<td>-21</td>
</tr>
<tr>
<td>Total URLs analysed</td>
<td>2</td>
<td>0</td>
<td>16</td>
<td>5</td>
<td>6</td>
<td>0</td>
<td>3</td>
<td>2</td>
<td>34</td>
</tr>
</tbody>
</table>
leaflets, journals, articles, or magazines published by the diabetes organization.

Data were collected in four steps: (i) starting at the homepage (defined as the first/introduction page), we searched for a direct navigation button possibly leading to information about inheritance and primary prevention of T2D. This could be a button such as ‘what is diabetes?’, ‘are you at risk?’ or ‘how to prevent diabetes?’; (ii) next, we searched for information throughout the whole website, including the links mentioned above; (iii) if an internal search engine was available, we searched the site using the keywords: ‘genetic’, ‘inheritance’, ‘hereditary’, and ‘prevention’ (translated in the language of the website); (iv) when the first three steps did not provide any information, we searched for external links to websites providing health-related diabetes information. In four cases, we added the URLs of these websites (referenced by the German-, French-, Spanish-, and Japanese-associated IDF members) to the sample frame. The added websites were reassessed following the steps above.

Assessment of websites

The websites were analysed using a standardized assessment form designed for this study. The content analysis was based on four questions, which resemble the four communication messages for target audiences developed by the IDF to raise awareness of diabetes worldwide (International Diabetes Federation, 2003). (i) Is information on T2D and inheritance provided and, if yes, is inheritance only briefly mentioned or explained in more detail?; (ii) is family history of T2D mentioned as a risk factor and are specific ethnic populations indicated as high-risk groups?; (iii) is preventive information provided and, if yes, to what degree does it refer to risk information or target audiences and, secondly, is a translation into concrete behavioural recommendations made?; (iv) are patients urged to inform relatives about their increased risk of developing T2D?

Based on the findings of a preliminary study, coding categories were designed regarding the accuracy and comprehensiveness of the information provided. In addition, coding categories were formulated concerning the search strategy. Information easily found by using a direct link or navigation button on the homepage, e.g., ‘what is diabetes’, ‘who is at risk’, or ‘how to prevent diabetes’, and a direct reference or link to these sections, was categorized as ‘direct link’. Information difficult to locate, found after intensive search, or by using the internal search engine, was categorized as ‘no direct link’.

All reviewers were familiar with diabetes and/or genetics from a professional point of view. They received the exact URL and the standardized assessment form, including a detailed coding scheme and an explanation of the steps that should be taken. Websites in English, German, and Dutch were analysed twice by one author (SvE). Native speakers assessed sites in Swedish, Norwegian, Finnish, Danish, and Japanese once. Websites in French, Spanish and Portuguese were analysed by native speakers
once, and re-analysed by one author with knowledge of these languages (SvE). All re-analyses took place within 2 weeks. Reviewers in native languages were instructed to search the website until no additional information could be found, following the steps described in ‘Data collection’. A time restriction of 1 h per website was indicated, but no reviewer mentioned a shortage of time. In four cases, the first author contacted the reviewers in native languages for clarification of their assessment.

As the World Wide Web is a fast-moving medium, every relevant text fragment was copied so discrepancies as a result of eventual changes in content could be checked with the copies in the archive (Koehler, 1999). Data were entered in SPSS 11.0 (SAS Institute, Cary, NC, USA), frequencies and cross tabulations were computed.

Results

Of 34 websites retrieved, 30 (88%) provided some information on diabetes and inheritance and four websites (12%) did not. Three websites (9%) mentioned family history in a list of risk factors, without further explanation or comments on genetics or inheritance. Sixteen websites (47%) provided brief information (in one or two sentences), such as ‘type 2 diabetes is likely to have a genetic basis’, ‘heredity plays a role in diabetes’, or ‘type 2 diabetes tends to run in families’. Five websites (15%) provided basic information explaining the interaction of environmental factors and genes in the development of T2D, for instance ‘A genetic predisposition, being overweight and a lack of exercise contribute to the onset of type 2 diabetes. Several genes are linked to type 2 diabetes. Scientists believe that the combination of several genes causes the disease. The challenge is to understand and identify the mechanisms at work and all the possible combinations that trigger type 2 diabetes’. Six websites (18%) gave detailed information, including risk percentages, depending on the relation of the affected family member.

On 19 websites (56%), this information was easily found via a direct link; on eight websites (24%), information was difficult to locate (see Table 2).

Of the 30 websites, which provided some information on inheritance, most (n=28; 82%) translated this information in ‘family history’ as a risk factor. Ethnic background as a risk factor was mentioned in half of the cases (n=17). In eight of those 17 websites, this information was not specific (mentioning only ‘certain ethnic groups’, ‘non-Caucasian’, or ‘some groups of immigrants’) or indicated high-risk groups of little relevance to that specific region (e.g., ‘Indians living in Asia and Afro-Americans’ mentioned in Luxembourg, and ‘Asia, Africa and the Pacific Ocean area, Pima Indians in USA’ mentioned in Sweden; see Table 3).

Ten websites (29%) offered a risk test, consisting of body mass index calculation and questions to be answered by yes/no, on the basis of a personalized risk profile for T2D is calculated. All risk tests included family history. Interestingly, only three risk tests (Diabetes UK, Canadian Diabetes Association, and Diabetes New Zealand)
asked about ethnicity (see Table 3). As to informing family members about their risk of developing diabetes, only two websites (Canadian Diabetes Association and Diabetes New Zealand; 6%) made patients aware of the importance of informing family members about their increased susceptibility, but there were no specific guidelines provided on what information should be conveyed, how and to whom (see Table 3). Fourteen websites (42%) provided a discussion forum. On only the French and the Irish websites was inheritance a topic people discussed.

We found seven websites (21%) that did not provide any information on prevention of T2D. Twelve websites (35%) provided brief information on primary prevention (for example, by stating ‘a healthy lifestyle can prevent type 2 diabetes’). On seven of these websites (21%), information was found easily using direct links; on five websites (15%), no direct links were provided. Fifteen websites (44%) did translate preventive information into concrete recommendations for behaviour change, mostly found via direct links (n=11; 32%). In four cases (12%), a more intensive search was required (see Table 4).

Table 2. Websites providing information on type 2 diabetes and inheritance

<table>
<thead>
<tr>
<th>Accessibility of information</th>
<th>No information on inheritance (%)</th>
<th>Family history only mentioned in list of risk factors (%)</th>
<th>Brief information on inheritance (%)</th>
<th>Explaining genes and environment (%)</th>
<th>Detailed information with risk percentages (%)</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No information</td>
<td>4 (11.8)</td>
<td>3 (8.8)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>7 (20.6)</td>
</tr>
<tr>
<td>Information provided by</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A direct link</td>
<td>-</td>
<td>-</td>
<td>10 (29.4)</td>
<td>3 (8.8)</td>
<td>6 (17.6)</td>
<td>19 (55.9)</td>
</tr>
<tr>
<td>No direct link</td>
<td>-</td>
<td>-</td>
<td>6 (17.6)</td>
<td>2 (5.9)</td>
<td>-</td>
<td>8 (23.5)</td>
</tr>
<tr>
<td>Total (%)</td>
<td>4 (11.8)</td>
<td>3 (8.8)</td>
<td>16 (47.1)</td>
<td>5 (14.7)</td>
<td>6 (17.6)</td>
<td>34 (100)</td>
</tr>
</tbody>
</table>

Table 3. Websites providing information regarding risk factors and addressing target audiences

<table>
<thead>
<tr>
<th>Websites providing information regarding:</th>
<th>n (% of total)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family history mentioned as risk factor</td>
<td>28 (82.4)</td>
</tr>
<tr>
<td>Ethnicity mentioned as risk factor</td>
<td></td>
</tr>
<tr>
<td>Specified and relevant for region</td>
<td>9 (26.5)</td>
</tr>
<tr>
<td>Not specified</td>
<td>8 (23.5)</td>
</tr>
<tr>
<td>A Risk test</td>
<td></td>
</tr>
<tr>
<td>Including family history</td>
<td>7 (20.6)</td>
</tr>
<tr>
<td>Including family history and ethnicity</td>
<td>3 (8.8)</td>
</tr>
<tr>
<td>Uprising patients to inform relatives on increased susceptibility</td>
<td>2 (5.9)</td>
</tr>
</tbody>
</table>
Information on primary prevention varied as to the degree to which it referred to risk information (described elsewhere) or target audiences. Eight websites (24%) provided information on primary prevention, but no reference was made to risk factors or high-risk groups. In 13 cases (38%), risk- and preventive information were provided in succession on the same page, or there was a direct link, but no explicit reference was made. Six websites (18%) directly addressed preventive information at high-risk groups and urged them to take action, for example ‘you have to take extra care and consult a physician, when type 2 diabetes runs in the family’ (see Table 4).

**Discussion**

This is, to our knowledge, the first review of information on inheritance, diabetes and primary prevention provided by diabetes associations on the Internet. Although most websites do provide some information on the familial character of diabetes, ethnicity as a risk factor is given little mention. In two-thirds of the websites examined, information on inheritance is missing or very brief; in almost 25% of the websites, information on inheritance is hard to find. With the emerging evidence regarding genetics of diabetes, it would seem important to explain the multifactorial aetiology to both patients and relatives (Newell, 2004; Pozzilli, 2005). Translating this complex interaction in a clear way is a challenge, particularly as Ponder et al. (1996) have indicated that older as well as younger people appear to have difficulty understanding the concept of ‘genetics’ in relation with diabetes.

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**Table 4. Websites providing information on primary prevention**

<table>
<thead>
<tr>
<th>Assessment of preventive information and accessibility</th>
<th>No information on primary prevention (%)</th>
<th>No reference between preventive and risk information (%)</th>
<th>Risk and preventive information presented at same page (%)</th>
<th>Preventive information directly addressing high-risk groups (%)</th>
<th>Total (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>No information</td>
<td>7 (20.6)</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>7 (20.6)</td>
</tr>
<tr>
<td>Briefly mentioned</td>
<td></td>
<td>4 (11.8)</td>
<td>2 (5.9)</td>
<td>1 (2.9)</td>
<td>7 (20.6)</td>
</tr>
<tr>
<td>Direct link</td>
<td></td>
<td>3 (8.8)</td>
<td>2 (5.9)</td>
<td>-</td>
<td>5 (14.7)</td>
</tr>
<tr>
<td>No direct link</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mentioned and translated into concrete behaviour</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Direct link</td>
<td></td>
<td></td>
<td>7 (20.6)</td>
<td>4 (11.8)</td>
<td>11 (32.4)</td>
</tr>
<tr>
<td>No direct link</td>
<td></td>
<td></td>
<td>1 (2.9)</td>
<td>2 (5.9)</td>
<td>4 (11.8)</td>
</tr>
<tr>
<td>Total (%)</td>
<td>7 (20.6)</td>
<td>8 (23.5)</td>
<td>13 (38.3)</td>
<td>6 (17.6)</td>
<td>34 (100)</td>
</tr>
</tbody>
</table>
We found that only 44% of the websites provide preventive information including healthy lifestyle recommendations. In addition, only a few websites (18%) target their information directly to relatives of type 2 diabetic patients and/or certain ethnic populations. This would imply that, in most of the cases, people have to combine risk information (‘do I belong to a high-risk group?’) and preventive information (‘is this preventive information especially relevant for me?’) themselves. Generally, our findings suggest that a few websites provide high qualitative information on both inheritance, as well as primary prevention. Websites offering detailed information on inheritance more often provide extensive preventive information along with concrete behaviour change recommendations.

Despite the IDF recommendation (International Diabetes Federation, 2003), only two websites took up the challenge of stimulating patients to inform relatives about their increased susceptibility. Clearly, the issue of raising awareness among family members deserves more attention. The fact that inheritance was found to be a topic on only two discussion panels may be explained by a lack of knowledge about or interest in inheritance.

Although we did not assess website information on readability in this study, we are concerned with the fact adults with low literacy face problems searching health information on the Internet. Most health websites require at least a high-school reading proficiency (Birru et al., 2004). Indeed, evidence suggests that mainly younger, Caucasian people, with higher education, higher income, and who live in metropolitan areas seem to benefit from information provided on the Internet (Fogel, 2003; United States General Accounting Office, 2001). Online health information providers therefore need to ensure that their written material is pitched at a level appropriate to the intended lay audience (Boulos, 2005). Health education providers should also consider other means of primary prevention strategies and delivering health information in addition to the Internet.

We are aware of some limitations of our methodology. First, the selection of websites was limited by choice of languages, as a result of which Eastern European countries, including Russia, are missing. Asia, Eastern Mediterranean, and Africa are underrepresented. According to the IDF list, 37% of all associated members (n=182) do have a website. In reality, 61% of the European member organizations administer a website; 42% in Western Pacific; 36% in South and Central America; 23% in North America; 17% in South East Asia; 14% in Africa; and 7% in Eastern Mediterranean and Middle Eastern countries (n=1; however, that one is not operational). Further efforts should be made to stimulate web-based projects in these regions.

Another limitation may be the bias involved in coding websites of varying lengths. Some websites were reasonably large and/or complex and thus difficult to access. We cannot exclude the possibility that a continued search (particularly in linked documents) could have resulted in some additional information we did not retrieve. However, we doubt that people searching the Internet for information on inheritance and diabetes would actually find this information.
Our review of international websites suggests there is an urgent need to further improve the information provided on the Internet with regard to inheritance and prevention in T2D. One way of achieving this would be through the development of guidelines on the quality and content of diabetes-related websites (Seidman et al., 2003a, 2003b).

We experienced the Internet as a fast-changing medium. When preparing this study in March 2005, several websites were assessed in a pilot study. By September 2005, a substantial number of websites had updated and improved their information on inheritance and primary prevention. However, this information should be accessed preferably through a direct button on the homepage/first page of the website. For most websites, this will probably require an architectural adjustment of the website. Given the importance of the topic, this would seem an effort worthwhile.
“I am pregnant and my husband has diabetes. Is there a risk for my child?”
A qualitative study of questions asked by email about the role of genetic susceptibility to diabetes

S.C.M. van Esch
M.C. Cornel
F.J. Snoek

BMC Public Health 2010 10:688
Abstract

**Background** Diabetes Mellitus is a global health problem. Scientific knowledge on the genetics of diabetes is expanding and is more and more utilised in clinical practice and primary prevention strategies. Health consumers have become increasingly interested in genetic information. In the Netherlands, the National Genetic Research and Information Centre provides online information about the genetics of diabetes and thereby offers website visitors the opportunity to ask a question per email. The current study aims at exploring people’s need of (additional) information about the role of inheritance in diabetes. Results may help to tailor existing clinical and public (online) genetic information to the needs of an increasing population at risk for diabetes.

**Methods** A database with emailed questions about diabetes and inheritance (n=172) is used in a secondary content analysis. Questions are posted in 2005-2009 via a website providing information about more than 600 inheritable disorders, including all diabetes subtypes. Queries submitted were classified by contents as well as persons’ demographic profiles.

**Results** Questions were received by diabetes patients (49%), relatives (30%) and partners (21%). Questioners were relatively young (54.8% <30 years) and predominantly female (83%). Most queries related to type 1 diabetes and concerned topics related to (future) pregnancy and family planning. Questioners mainly asked for risk estimation, but also clarifying information (about genetics of diabetes in general) and advice (mostly related to family planning) was requested. Preventive advice to reduce own diabetes risk was hardly sought.

**Conclusions** Genetic information on diabetes provided by professionals or public health initiatives should address patients, as well as relatives and partners. In particular, women are receptive to genetic information; they worry about the diabetes related health of (future) offspring. It seems important that information on the contribution of genetics to type 1 diabetes is more readily available. Considering the high prevalence of type 2 diabetes with strong evidence for a genetic predisposition, more effort seems needed to promote awareness around familial clustering and primary prevention.
Background

Diabetes Mellitus (a group of disorders characterised by abnormal high blood glucose levels) is a growing health problem (Unwin et al., 2009). In the last decade, scientific knowledge on the genetics of diabetes is expanding and has resulted in clinical application of genetic testing in the case of Maturity-Onset Diabetes of the Young (MODY) and Maternally Inherited Diabetes and Deafness (MIDD) (Pearson, 2008). The understanding of genetic variation predisposing to type 1 diabetes (T1D) (Erlich et al., 2008), Latent Autoimmune Diabetes in Adults (LADA) (Hosszuetal. et al., 2003)), type 2 diabetes (T2D) (Frayling, 2007)), and gestational diabetes (GD) (Robitaille & Grant, 2008)) is evolving. In the case of T2D and GD, family history is used as a marker for genetic susceptibility and a potential risk stratification tool in preventive activities (Claassen et al., 2010a; Hariri et al., 2006; Harrison et al., 2003).

Health consumers have become increasingly interested in genetic information (Dutta et al., 2010; Taylor et al., 2001). This increasing interest is coupled with a growing trend in consumer uses of the Internet for health-related purposes. Statistics reveal that eight in ten American internet users (approximately 113 million adults) searched online for health information in 2006 (Fox, 2006). In the Netherlands, about 93% of the population has access to Internet. Of all inhabitants using the Internet, 54% looked for information about health and medicines at least once in three months in 2009 (Netherland’s National Statistics Agency, 2009).

While consumers recognize great potential in the Internet for health communication on human genetics (Bernhardt et al., 2002), health professionals and genetic experts acknowledge that the translation of genomic information will be a challenge (McBride et al., 2010). Information has to be adjusted to the (genetic) literacy levels of target audiences (Lea et al., 2010) and has to serve the public’s genetic information needs (Scheuner et al., 2008). Since the growing popularity of Internet use, indeed there are a lot of studies evaluating genetic web content (van Esch et al., 2006; Shepperd et al., 2006), readability (Boulos, 2005), and effect on behavioural outcomes (Dutta et al., 2010). In addition, the current study was designed to get insight into the public’s interest, perceptions and information need about the genetics of diabetes.

In the Netherlands, the National Genetic Research and Information Centre provides online information about the genetics of diabetes (all subtypes). Thereby, the Centre offers website visitors the opportunity to ask a question per email. We used this database with emailed questions to gain insight into people’s need of (additional) information about the role of inheritance in diabetes. After all, depending on whether or not visitors read the provided information, the emailed questions reflect their information needs, unaddressed issues, areas of uncertainty or difficult to understand concepts.

Our research interest is in developing a profile of questioners, as well as the discovery of themes and tendencies in the emailed questions. Findings from this
study will contribute to better understanding of specific information needs of online consumers about genetics and diabetes. The results may help to tailor existing clinical and public (online) health information to the needs of an increasing population at risk for diabetes (Collins et al., 2003; Khoury, 2003).

Methods

Data source
The National Genetic Research and Information Centre in the Netherlands provides online information about more than 600 inheritable disorders, including all diabetes subtypes (http://www.erfelijkheid.nl/zena/diabe.php). Web statistics indicate that the general number of website visitors is reaching 2.2 million per year. Almost 9,000 visitors searched specifically for information on ‘diabetes and inheritance’ in 2009.

For each diabetes subtype, information about the pathophysiology, diagnosis, treatment, prevalence, and genetics is provided. Multifactorial-, monogenetic-, or mitochondrial inheritance is explained, and risk estimations are given for first- and second-degree relatives of T1D, T2D, and MIDD patients. Links to other informative websites are given. Apart from reading the information on the website, visitors are offered the possibility to submit a question per e-mail. Three staff members, who are all educated in genetics and inheritance, answer the questions within three days. This helpdesk team refers to professionals in the field (e.g., clinical genetic centres, diabetes specialists or general practitioners) in case they are unable to answer the question. When posting a question on the website, visitors are invited to disclose information (optional) about their gender, age, and whether their interest is personal or professional, for the purpose of evaluation.

Since January 2005, the National Genetic Research and Information Centre has systematically registered personal queries from website visitors. This database with emailed questions is designed for administrative purposes, as well as monitoring the quality of the web content. For the current study, the Centre handed over data concerning ‘diabetes and inheritance’ to the researchers and consented with the research objectives and methods. In view of the observational and non-invasive nature, this study is not subject to the Dutch Medical Research Involving Human Subjects Act. The researchers followed the rules defined in the Dutch Code of Conduct for Medical Research, in which a specific code for adequate secondary use of data is defined.

Study sample
Data were derived from a sample of 265 e-mailed questions related to diabetes and inheritance (administered between January 2005 and November 2009). The National Genetic Research and Information Centre assigned an identification number (#) to each
email. The researchers received the emails without name and email address, to protect confidentiality of participants. A list with identification numbers and corresponding information about questioners’ gender, age, and personal versus professional interest was enclosed.

It is not possible to ask informed consent of participants in secondary analyses, and we therefore excluded all questioners (n=11) that opted not to provide any personal information. In addition, two exclusion criteria were applied. Fifty-eight e-mails did not relate to genetics and inheritance, but concerned diabetes (treatment) in general. Secondly, in this study we were primarily interested in (additional) information needs of ‘private’ health consumers, aiming at tailoring (online) information about diabetes and genetics. Thirty-eight questions were asked by students and health care professionals, and therefore were excluded from the sample. From the 158 e-mails left, fourteen contained two questions. In total, 172 queries were included in this study.

Data analysis

In this study, we used secondary content analysis. The advantage associated with secondary data analysis is its convenience and cost-effectiveness (Szabo & Strang, 1997). We adopted an iterative and inductive approach which is argued to be applicable in computer-mediated convenience samples (Herring, 2010). Two researchers (SvE and research assistant) double-coded all email questions using qualitative data indexing software (Kwalitan 5.0 (Peters & Wester, 1994)). Emerging themes and tendencies were identified and categorised; ambiguities were resolved and categories were reduced to major themes in discussion with two senior researchers and re-reading the emails (Miles & Huberman, 1994).

After qualitative classification, data were quantified in order to develop participants’ profile (by age, gender and family status) and observe the distribution of coding labels within the emerged categories (‘type of diabetes inquired’, ‘topics inquired’, ‘expressed worries’, and ‘type of information requested’). Illustrative quotes are presented as summaries of the questions’ quintessence, paraphrasing the original Dutch formulation as much as possible (however, sometimes with minor alteration to respect subjects’ confidentiality). Participants’ identification number (#), gender, age in years, and family status are included after each quote to help the reader identify the backgrounds of its source.

Results

Questioners’ profile and type of diabetes inquired

As shown in Table 1, it appeared that most people asking questions via the website were relatively young; sixty-eight persons (54.8%) were ≤30 years. Mainly women inquired the role of inheritance in diabetes (n=131; 82.7%). Nearly half of the
questions were asked by diabetes patients \((n=77; 48.9\%)\); almost one third by relatives \((n=47; 29.6\%)\) and the remaining by partners of diabetes patients \((n=34; 21.5\%)\).

Most questions concerned T1D \((n=59; 37.3\%)\). Relatively few questions referred to T2D \((n=15; 9.5\%)\) and GD \((n=13; 8.2\%)\). Thirteen participants inquired about T1D as well as T2D \((8.2\%)\), since they seemed confused about the presence of both diabetes subtypes in their family. A T1D patient for example asked: “I am pregnant. Both my parents have type 2 diabetes. Is my baby at increased risk for type 1 or type 2 diabetes?” \([#3129\text{ Female, 27y, Patient}]\). Other types of diabetes, such as MODY, MIDD or LADA, were rarely inquired \((n=8; 5.0\%)\).

Notably, in forty-four questions \((27.9\%)\) the type of diabetes was not specified, for example: “Has diabetes in men consequences for offspring?” \([#2097\text{ Female, 31y, Partner}]\), or “I have diabetes. My partner’s father and grandfather also have diabetes. We are thinking about having children. Is diabetes inheritable and if yes, what is the diabetes risk of our children?” \([#2088\text{ Female, 18y, Patient}]\). Additionally, slightly more than half of the questions \((n=86; 54.6\%)\) did not contain well-defined family information, for instance: “Five persons in my family have diabetes. Does this have to do with inheritance?” \([#3104\text{ Female, 65y, Relative}]\).

**Table 1.** Questioners’ profile, type of diabetes inquired and information provided about family history \((n=158)\)

| Questioners’ and questions’ characteristics | N (%)
<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td><strong>Age in years</strong></td>
<td></td>
</tr>
<tr>
<td>&lt; 20</td>
<td>19 (12.1)</td>
</tr>
<tr>
<td>21-30</td>
<td>67 (42.7)</td>
</tr>
<tr>
<td>31-40</td>
<td>40 (25.0)</td>
</tr>
<tr>
<td>&gt; 41</td>
<td>32 (20.2)</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>131 (82.7)</td>
</tr>
<tr>
<td>Male</td>
<td>27 (17.3)</td>
</tr>
<tr>
<td><strong>Family status</strong></td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>77 (48.9)</td>
</tr>
<tr>
<td>Relative</td>
<td>47 (29.6)</td>
</tr>
<tr>
<td>Partner</td>
<td>34 (21.5)</td>
</tr>
<tr>
<td><strong>Type of diabetes inquired</strong></td>
<td></td>
</tr>
<tr>
<td>Type 1 diabetes</td>
<td>59 (37.3)</td>
</tr>
<tr>
<td>Type 2 diabetes</td>
<td>15 (9.5)</td>
</tr>
<tr>
<td>Type 1 and type 2 diabetes</td>
<td>13 (8.2)</td>
</tr>
<tr>
<td>Gestational diabetes</td>
<td>13 (8.2)</td>
</tr>
<tr>
<td>MODY/MIDD/LADA</td>
<td>8 (5.0)</td>
</tr>
<tr>
<td>Diabetes insipidus*</td>
<td>6 (3.8)</td>
</tr>
<tr>
<td>Diabetes type not specified</td>
<td>44 (27.9)</td>
</tr>
<tr>
<td><strong>Question lacks well-defined information about family history</strong></td>
<td>86 (54.6)</td>
</tr>
</tbody>
</table>

* Although the name is rather similar, diabetes insipidus is a different clinical entity (left out of the scope of this paper).
Topics that people inquire about

Table 2 displays the topics of interest. Eighty-four participants (48.8%) inquired about genetics and inheritance in relation to reproduction. More than half of these questions specifically referred to a (future) pregnancy.

Evidently, the period of pregnancy brings up worries about consequences for the questioners’ health as well as the health of the foetus, for instance: “I am 13 weeks pregnant and have type 1 diabetes. My blood glucose levels are very unstable. I am worried about my health and possible consequences for my baby.” [#5012 Female, 30y, Patient], or in case of GD: “I have gestational diabetes. What are the risks for the baby during pregnancy and what is the risk for the child later in life?” [#0014 Female, 26y, Patient]. Even regarding to late onset T2D people seem to be worried: “I am six weeks pregnant. My husband is a type 2 diabetes patient. Is there a risk for my child?” [#1048 Female, 31y, Partner]. The preconception phase was mostly inquired by T1D patients: “I have so many questions. I have type 1 diabetes and want to get pregnant. Is that possible? What are the risks for me, the pregnancy and the baby?” [#3131 Female, 36y, Patient]. Besides pregnancy, ‘family planning’ was often explicitly mentioned as a reason for asking the question. A few questioners were in serious doubt about having offspring, because of the (sometimes high) prevalence of diabetes in their family. As one patient stated: “Three persons in my family, including myself, have type 1 diabetes. A fourth family member is diagnosed with LADA. What is the chance my future children will develop diabetes? I don’t know whether I want to have children, if they would be at really high risk.” [#5055 Female, 24y, Patient].

More than one third of the e-mails (n=64; 37.2%) concerned the genetics of diabetes ‘in general’. Most questioners inquired about the role of inheritance in their

<table>
<thead>
<tr>
<th>Topics inquired</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Genetics and inheritance in relation to reproduction</td>
<td>84 (48.8)</td>
</tr>
<tr>
<td>Genetics and inheritance in general</td>
<td>64 (37.2)</td>
</tr>
<tr>
<td>(New) technologies: genetic testing, gene therapy</td>
<td>24 (14.0)</td>
</tr>
<tr>
<td>Expressed worries</td>
<td></td>
</tr>
<tr>
<td>Worries about offspring’s diabetes risk</td>
<td>78 (45.3)</td>
</tr>
<tr>
<td>Worries about own diabetes (risk)</td>
<td>58 (33.7)</td>
</tr>
<tr>
<td>Not explicitly mentioned</td>
<td>36 (20.9)</td>
</tr>
<tr>
<td>Type of information requested</td>
<td></td>
</tr>
<tr>
<td>Risk estimation</td>
<td>69 (40.1)</td>
</tr>
<tr>
<td>Asking for an explanation/clarification/verification</td>
<td>42 (24.4)</td>
</tr>
<tr>
<td>Looking for advice</td>
<td>38 (22.1)</td>
</tr>
<tr>
<td>Asking (specified) information</td>
<td>23 (13.4)</td>
</tr>
</tbody>
</table>
family, for instance: “Two of my kids have type 1 diabetes. Both my parents have type 2 diabetes. Since type 2 diabetes is not inheritable, why do my children have type 1 diabetes?” [#1025 Female, 28y, Relative]. Some people are specifically interested in genes: “I have type 1 diabetes, celiac disease and epilepsy. Which gene defects are causing these diseases? Are these genes related?” [#1018 Male, 30y, Patient].

A small amount of e-mails (n=24; 14.0%) concerned queries about (new) technologies such as genetic testing, genetic therapy and progresses in the scientific field, for example: “Which medical centre in the Netherlands performs genetic tests for MODY? Which qualifications for testing are required?” [#3105 Male, 35y, Patient]. A questioner with high expectations asked: “I have type 2 diabetes. When will gene therapy be available?” [#1039 Male, 28y, Patient].

Expressed worries
It appeared that almost half of the queries received (n=78; 45.3%) were related to worries about (future) offspring’s diabetes risk. One third (n=58; 33.7%) referred to the questioner’s own diabetes related health or diabetes risk. Noteworthy, some people inquiring offspring’s diabetes risk seem not worried or even aware of their own possibly increased diabetes risk, for instance: “My partner has type 1 diabetes. My father, and possibly my mother-in-law, had type 2 diabetes. What is the chance my child will develop type 1 diabetes?” [#4027 Female, 36y, Partner]. Or: “My uncle has diabetes. Is it possible this disease is inheritable for my future child?” [#1040 Female, 25y, Relative]. Not all questioners did explicitly express worries in their e-mail.

Type of information requested
Table 2 summarizes the type of information that website visitors requested. Most e-mail questions (n=69; 40.1%) pertained a request for (personalised) risk information. On the website, risk estimations for first- and second-degree relatives of T1D, T2D, and MIDD patients are described. In theory, questions as: “My partner has type 1 diabetes. What is the risk my future child will develop diabetes?” [#0106 Female, 29y, Partner] could be answered by reading this information. Evidently, in families with complex family history (different types of diabetes and/or diabetes running through several generations), the provided risk information might be difficult to apply. For instance, “A relative of mine has type 1 diabetes. In my wife’s family type 1 as well as type 2 diabetes is prevalent. Is it possible to estimate whether my children are at increased risk for type 1 or type 2 diabetes?” [#3154 Male, 28y, Relative].

In almost one quarter of the e-mails (n=42; 24.4%), the questioner requested an explanation, clarification or verification. For example, people inquired about the (genetic) co-occurrence of different types of diabetes in their family: “Are gestational diabetes and diabetes insipidus genetically related?” [3134 Female, 46y, Relative]. Some wanted to verify or validate information or ideas: “I have type 1 diabetes. My father, my aunt and
grandmother also have type 1 diabetes. I was told it’s a coincidence. Is that true?” [#2079 Female, 25y, Patient], or “I have type 1 diabetes. Several family members have type 2 diabetes. Is it possible I inherited my diabetes?” [#2066 Female, 16y, Patient].

Thirty-eight participants (22.1%) expressed a wish to obtain preventive and/or therapeutic advice, with regard to either one’s own health or the diabetes related health of offspring. For example, “We are thinking about a pregnancy. My partner has type 1 diabetes. In my family, some relatives have type 2 diabetes. What precautionary measures do we have to take to get a healthy baby?” [#1016 Female, 29y, Partner]. Preventive advice to reduce own T2D risk was hardly sought. As regards, only three questioners referred to the multifactorial aetiology of T2D: “My father has type 2 diabetes. How can we prevent developing diabetes?” [#0012 Female, 40y, Relative].

Finally, in some e-mails (n=23; 13.4%) people included a clear request for specific information, as a MODY patient stated: “I am looking for information. My son and I are diagnosed with MODY, caused by a heterozygote mutation.” [#3138 Female, 30y, Patient]. Or a patient was interested in scientific progresses: “How far are developments in the field of stem cell transplantation or other possible solutions to cure type 1 diabetes?” [#5016 Male, 41y, Patient].

**Information need**

To get a clearer view of questioners’ information needs, we combined the topics they inquired about with the type of information they requested. It appeared that questioners inquiring about genetics in relation to reproduction most of the time were in need of risk information (n=40; 47.7%) or advice (n=30; 35.8%). The majority of queries concerning genetics and inheritance of diabetes in general also contained a need for risk information (n=28; 43.8%) and in almost an equal number of cases a request for explanation or verification (n=26; 40.6%). People submitting an e-mail about (new) technologies in the genetic field mostly demanded specified information (n=14; 58.3%) (see Table 3).

<table>
<thead>
<tr>
<th>Type of information requested</th>
<th>Reproduction (n=84)</th>
<th>Genetics in general (n=64)</th>
<th>(New) technologies (n=24)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk estimation</td>
<td>47.7</td>
<td>43.8</td>
<td>4.2</td>
</tr>
<tr>
<td>Explanation/ verification</td>
<td>15.5</td>
<td>40.6</td>
<td>12.5</td>
</tr>
<tr>
<td>Advice</td>
<td>35.8</td>
<td>3.1</td>
<td>25.0</td>
</tr>
<tr>
<td>(Specific) information</td>
<td>0.0</td>
<td>12.5</td>
<td>58.3</td>
</tr>
</tbody>
</table>

* Data are percentages
Discussion

Based on e-mails received by the Dutch National Genetic Research and Information Centre, it appears that people in need of (additional) online information about diabetes and inheritance are relatively young and predominantly female. This is in line with previous research indicating that younger Internet users and women are most likely to search for online genetic information (Bernhardt et al., 2004; Eriksson-Backa, 2003). Yet, the online population is expanding and becoming more representative in terms of race, age, income, and educational attainment (Fox & Rainie, 2000; Ybarra & Suman, 2008). Interestingly our data suggest that besides patients with diabetes, relatives and partners seem interested in the topic of inheritance. This is in contrast to earlier reports in the field of oncology where partners and relatives are described as potential ‘blockers’ of genetic information in families (Koehly et al., 2009). This difference at least may be partly related to the disease at stake and warrants further investigation.

Although only accounting for 5-10% of the overall prevalence of diabetes, most questions concerned T1D. Apparently, T1D is assumed to be genetic, probably because of its juvenile onset. More interest could be expected regarding the genetic subtypes of diabetes, MODY and MIDD, although they are rare and treated in specialty clinics where genetic information may be readily available (Pearson, 2008). Considering the high prevalence of T2D (~90% of all diagnosed cases) and GD (2-5% of all pregnancies, with higher prevalence in some ethnic/racial groups (Hunt & Schuller, 2007)), the role of heredity in these subtypes appears to be under appreciated. Possibly, the information need is low due to underestimation of the seriousness of the condition (Lamont et al., 2002) or limited awareness about the role of genetics and shared environment in the aetiology (Adriaanse et al., 2003; Kemple et al., 2005). Recent trends indicating a growing awareness of family risk and worries about the development of T2D in offspring (Whitford et al., 2009a, , 2009b) is not reflected in our results yet. Possibly, people found genetic information about T2D, GD or MODY/MIDD/LADA subtypes on other websites than the one we studied. Research however reveals that most online health information seekers start their session at a search engine (Fox, 2006) and using Google, the first (and almost only) hit when searching for ‘diabetes and inheritance’ in Dutch refers to the website of the National Genetic Research and Information Centre. Moreover, we found earlier that information on diabetes and inheritance provided by websites of renowned diabetes organizations is generally poor or lacking (van Esch et al., 2006).

Finally, data reveal that the majority of queries concern topics related to (future) pregnancy and family planning. This finding is in line with the relatively young age of questioners and overrepresentation of women in our study. It is known that the phase of reproduction generates an active search for genetic information (Eriksson-Backa, 2003; Larsson, 2009). Women have been found to search for genetic information,
because they worry about the health of their (future) offspring (d’Agincourt-Canning, 2001). These results resemble our finding that in most queries worries about the diabetes related health of (future) offspring were expressed.

**Strengths and limitations**

A strength of this study is that data were collected from a registry of people’s search for information in a ‘natural’ setting as opposed to exploring beliefs and knowledge on genetics in a (high-risk) clinical setting or in general public using questionnaires (Morren et al., 2007). We were able to explore questions based on individual perceptions and interests, described in people’s own words.

However by utilising secondary data analysis, we were unable to further expand our understanding by posing additional questions for example related to the amount of visitors actually reading the information provided on the website, the degree of understanding, and perceived utility of the expert answers received (Szabo & Strang, 1997). On the other hand, it appeared that the available 172 queries generated a study sample that was rich enough to emerge categories reflecting interesting themes and tendencies to describe.

We are aware that people submitting e-mail questions via the Internet may represent a selective group (in our study: young, predominantly female Internet users) and we cannot exclude selection bias. In addition, the study’s generalizability is limited due to its reliance on questions gathered by only one web based supplier of genetic information. It would be interesting to expand our study using other interactive websites and other countries to provide insight in other settings and cultures.

**Practical implications**

In earlier research, it appeared that physicians are the preferred first source of health information for 50% of Americans. Yet only 11% report their physician as the first line of inquiry, as compared with 49% who report that the Internet is their first source (Hesse et al., 2005). Consequently, the delivery of genetic information on diabetes is important in clinical practice as well as in (web based) public health initiatives.

Diabetes professionals might adjust their information after discussing clients’ information needs, family situation and risk perceptions. It is important to notice that some recipients will be in need of personalised risk information, while others prefer clarifying information or advice. Public health initiatives, including web-based strategies, can add to the health education of people about genetic backgrounds of common diseases, and provide general risk information as well as preventive messages. In addition, information on scientific progress and new technologies in the field of genetics may fulfil the need of a small, but highly interested public.

In addition of public information, individuals may wish to receive personalised (risk) information or advice. Utilising an email approach often requires more detailed
information from the person than currently provided. As an alternative, clinicians and public health providers could compile a list of frequently asked questions (and answers) about diabetes and inheritance and incorporate it into (web based) diabetes family education.

**Conclusion**

Utilising genetic information requires a well-considered strategy. Our study suggests that patients, in particular women, but also relatives and partners, are in need of information on the genetics of diabetes. Preventive advice to reduce own diabetes risk was hardly sought. Considering the high prevalence of T2D and GD, more effort seems needed to explain the multifactorial aetiology (and with it, the risk of familial clustering). Opportunities to delay or prevent T2D and GD onset by adopting a healthy lifestyle (Horton, 1991; Kinmonth et al., 2008) should be emphasized. To optimise health behaviour, these efforts should take public perceptions about inherited predisposition and primary prevention into account (Pijl et al., 2009a; Senior et al., 1999). Findings from this study underscore the importance of further exploring the genetic information needs of people with diabetes of all types. At least it seems important that information on the contribution of genetics to T1D is more readily available.
Patients’ intentions to inform relatives about type 2 diabetes risk: the role of worry in the process of family risk disclosure

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Abstract

Aims Patients with type 2 diabetes may play a role as intermediary between medical professionals and at-risk relatives to promote diabetes prevention in their family. This study aimed to further our understanding of factors that influence the decisional process of familial risk disclosure in patients with diabetes.

Methods In a cross-sectional study, patients with type 2 diabetes (n=546) filled in a questionnaire assessing family risk perception, worry, personal beliefs regarding diabetes prevention, diabetes-related family communication, intention and perceived ability to inform relatives about familial risk of diabetes. Data were analysed using hierarchical logistic regression and multiple mediation analyses.

Results Sixty percent of the patients were willing to inform their relatives about familial diabetes risk; 61% reported high family risk perception and 41% had positive control beliefs with regard to preventive options in relatives. A majority (69%) did not express serious concern about relatives developing diabetes. Worry about relatives, knowing what to tell, whom to notify, and communication about diabetes in general appeared to facilitate family risk disclosure. Unexpectedly, high family risk perception in itself did not significantly increase patients’ intentions to inform relatives; rather, risk perception appeared to exert an indirect effect through worry and beliefs about diabetes prevention.

Conclusions Worry in patients with diabetes appears to be a key factor in the process of family risk disclosure. When professionals guide their patients in this process, they should not only provide risk information, but also address worry and emphasize opportunities for diabetes prevention.
Introduction

Diabetes prevention programmes convincingly demonstrated that lifestyle modifications or pharmacological interventions can significantly decrease the incidence of type 2 diabetes (T2D) in high-risk populations (Yamaoka & Tango, 2005). Therefore, health care professionals are challenged to find new strategies to detect and motivate individuals at high risk. Family history is recognized as an important stratification tool (Lyssenko et al., 2008b), and having a family history of diabetes seems to be positively associated with risk awareness and risk-reducing behaviours in relatives of patients with T2D (Baptiste-Roberts et al., 2007; Chang et al., 2011). Yet, lifestyle interventions specifically aiming at prevention of T2D in people with a family history seem to be scarce (Heideman et al., 2011a).

Utilizing patients as messengers in the family, as, for example, in cascade screening (Herman et al., 2009), could be an effective strategy to reach healthy individuals with a family history of diabetes. Research has already indicated that adult offspring of patients with diabetes generally seems receptive to being informed via the family system about reducing their diabetes risk (van Esch et al., 2009; Pierce et al., 2000; Whitford et al., 2009a). The majority of patients (ranging from 55 to 100%) recognize the necessity of disseminating risk and preventive messages in their family (van Esch et al., 2012b; Gnanalingham & Manns, 1997; Nishigaki et al., 2009; Whitford et al., 2009b). However, the number of participants that actually inform their relatives appears to be lower (ranging from 49 to 65%) (Gnanalingham & Manns, 1997; Nishigaki et al., 2009; Nishigaki et al., 2011; Whitford et al., 2009b). At this point, the question is: what health care professionals can do to guide patients in the process of family risk disclosure?

Earlier studies found that pre-existing personal and familial characteristics, as well as family risk perception, knowledge about diabetes risk factors, outcome expectancies and self-efficacy, appeared to be predictors of patients’ intentions to disseminate risk messages in their family (Gnanalingham & Manns, 1997; Nishigaki et al., 2009; Whitford et al., 2009b). Generally, risk perception is recognized as a key motivator of risk-reducing behaviours (Weinstein, 1993). However, it has been observed that aspects other than perceived risk need to be explored to help target efforts in the primary prevention of diabetes (Hivert et al., 2009). In the only study in which worries were measured (Whitford et al., 2009b), patients’ concerns about relatives were found an important cue to action. Research carried out in the area of cancer control behaviours has reported considerable variability in the observed relationships of perceived risk, worry and control beliefs with cancer protective behaviours (Cameron & Reeve, 2006; Consedine et al., 2004). These interrelationships remain unexplored in the field of familial diabetes risk disclosure.

Therefore, in the current study, we first explored the influence of patients’ family risk perceptions, worry, personal beliefs about diabetes prevention, self-efficacy and diabetes-related family communication on their willingness to inform relatives.
Next, based on the Common-Sense Model of self-regulation of health and illness (Cameron, 2003; Leventhal et al., 2003), we set out to gain further understanding of how reasoned cognitions (i.e. family risk perception and control beliefs about diabetes prevention) and emotional appraisal (i.e. worry about relatives developing diabetes) are interrelated and associated with patients’ intentions to discuss familial diabetes risk. In addition to the importance of understanding the underlying mechanisms by which psychosocial factors influence health protective behaviours, findings may facilitate the development of targeted family-based diabetes prevention programmes.

Patients and Methods

Data were collected within the context of a larger cross-sectional study on family history and T2D, which was conducted in the Netherlands in 2007. Registered patients with T2D (aged >18 years) in four primary care practices and the diabetes outpatient clinics of the VU University Medical Center and the Haaglanden Medical Center were invited by their physician to participate in the study (n=1312). Patients who were not eligible because of severe medical and/or emotional burden were excluded by the physicians beforehand. All participants gave informed consent and the VU University Medical Center Ethics Committee approved the study.

Measures

Self-reported socio-demographics and diabetes-related characteristics were collected, including age, gender, domestic situation, education and ethnicity. Participants were identified as non-Dutch if at least one parent was born outside the Netherlands (definition Statistics Netherland). Family history of T2D in first- and/or second-degree relatives was assessed, as well as treatment in primary or secondary care, diabetes duration, received medical therapy and diabetes complications.

As in disorders with a multifactorial aetiology, the increased risk is not only present in first-degree, but also in second-degree relatives (Scheuner et al., 1997; Valdez et al., 2007). Family risk perception and worry about relatives was explored with regard to offspring as well as other relatives (including siblings, grandchildren, aunts/uncles and nieces/nephews). Measurements were based on previous studies (Nishigaki et al., 2009; Pierce et al., 1999; Whitford et al., 2009b) (see Table 2 for exact wording of questions). Assuming that communication in social settings is often not restricted to first-degree relatives, participants (only those with living relatives) were asked whether diabetes in general is a topic that is discussed with first-degree as well as second-degree relatives. Answers were provided on a four-point Likert scale.

Control beliefs of patients were assessed by asking ‘do you think there is anything your relatives can do to delay or prevent developing diabetes?’ (no/don’t know/yes). Statements were provided to enquire about patients’ intentions to inform relatives
and perceived self-efficacy (i.e. ‘knowing what to tell’, ‘who to notify’ and ‘how to inform relatives’). Response options were agree/disagree/don’t know.

Data analysis
Analyses were performed using SPSS version 16.0 (SPSS Inc., Chicago, IL, USA). Chi-square tests and an independent Student’s t-test were calculated in non-response analysis. The outcome variable was dichotomized to compare patients who were willing to inform relatives (yes=1) with those who were not, or had not yet decided (no/don’t know=0). Logistic regression analysis (backwards elimination) was conducted to identify demographic and diabetes-related variables that were significantly associated with the outcome variable. Next, hierarchically grouped subsets of variables were entered in the model, controlling for relevant covariates. The probability level for statistical significance was set at $P \leq 0.05$ (two-tailed) for all statistical analyses.

As risk perception is seen as an important cue to action (Leventhal et al., 2003; Weinstein, 1993), and a key variable in health-promoting campaigns (O’Neill et al., 2009), we set out to explore the possibility of family risk perception exerting an indirect effect on patients’ intentions to inform relatives through worry and personal beliefs about diabetes prevention. Multiple mediation analysis was performed using a SPSS macro, allowing for simultaneous mediation by two variables (i.e. worry and control beliefs) and controlling for covariates (Preacher & Hayes, 2008). This procedure is recommended over the widely used causal-steps approach, because it has higher power while maintaining reasonable control over the Type I error rate (Hayes, 2009). The analysis produced traditional direct effects ($a, b, c$ and $c'$ paths, see Figure 1); however, Preacher and Hayes emphasize the direction and size of the indirect effects (Preacher & Hayes, 2008). Bootstrapping (a non-parametric re-sampling procedure that does not impose the assumption of normality of the sampling distribution) was used to examine specific indirect effects of each putative mediator ($a_1b_1$ and $a_2b_2$ paths) and the total indirect effect of the mediators as a set ($a_1b_1+a_2b_2$ path, see Figure 1).

Results
Of 1312 patients invited, 546 (41.6%) filled in the questionnaire. Table 1 shows the background characteristics of the participants. The majority of the study sample (60.3%; $n=298$) expressed their intention to talk about diabetes risk and primary prevention in their family. Other participants did not intend to do so (18.2%; $n=90$) or answered ‘don’t know’ (21.5%; $n=106$). Most participants indicated knowing what to tell (76.6%; $n=379$), who to notify (74.4%; $n=369$) and how to inform their relatives (72.5%; $n=358$).

Table 2 shows that more than half of the participants (60.9%; $n=286$) thought it was (very) likely that offspring and/or other relatives would develop T2D. However, only approximately one third (31.4%; $n=142$) expressed serious concern about that. Less than
### Table 1. Socio-demographic and diabetes-related characteristics of responders and non-responders (n=1312).

<table>
<thead>
<tr>
<th></th>
<th>Responders (n=546)</th>
<th>Non-responders (n=766)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n</td>
<td>%</td>
</tr>
<tr>
<td><strong>Socio-demographic characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean age ± SD*</td>
<td>63.6 ± 11.7 years</td>
<td>60.1 ± 13.3 years</td>
</tr>
<tr>
<td>Female</td>
<td>274</td>
<td>50.2</td>
</tr>
<tr>
<td>Living with partner and/or offspring</td>
<td>350</td>
<td>66.0</td>
</tr>
<tr>
<td>Low educational achievement †</td>
<td>336</td>
<td>64.4</td>
</tr>
<tr>
<td>Dutch ethnic background ‡</td>
<td>311</td>
<td>57.6</td>
</tr>
<tr>
<td><strong>Diabetes-related characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Treatment in primary care</td>
<td>286</td>
<td>52.4</td>
</tr>
<tr>
<td>Family history in first and/or second-degree relatives</td>
<td>391</td>
<td>71.6</td>
</tr>
<tr>
<td>Diabetes duration &lt; 10 years</td>
<td>356</td>
<td>65.6</td>
</tr>
<tr>
<td>Treatment with oral medication §</td>
<td>334</td>
<td>61.6</td>
</tr>
<tr>
<td>Reporting diabetes complications ¶</td>
<td>289</td>
<td>54.0</td>
</tr>
</tbody>
</table>

* Statistically significant difference between responders and non-responders; P<0.001.
† No education, primary school and lower vocational/trade education.
‡ Almost one third (29.1%; n=157) had at least one parent with Surinamese South-Asian background; 7.2% had at least one parent from another Western country (n=39); 6.1% had non-Western ancestry (n=33).
§ As opposed to insulin treatment.
¶ Self-reported complications included retinopathy, neuropathy and nephropathy and co-morbid cardiovascular problems.

Half of the participants (41.4%; n=216) had positive beliefs regarding the possibility of relatives delaying or preventing diabetes onset. The majority (79.9%; n=388) indicated that they discuss their diabetes with first- and/or second-degree relatives ‘sometimes/often’.

**Factors that influence patients’ intentions to inform relatives**

From all background variables, only higher education (OR 1.8; 95% CI 1.2-2.7) and non-Dutch descent (OR 1.7; 95% CI 1.1-2.4) appeared to be related with a more positive intention towards disclosure of family risk. In Table 3, the outcomes of a stepwise logistic regression analysis, adjusted for education and ethnicity, are presented. No significant relation between family risk perception and patients’ intentions to inform relatives was found (OR 1.0; 95% CI 0.6-1.7). However, worry (OR 2.1; 95% CI 1.1-3.7) and personal control beliefs (OR 1.6; 95% CI 1.0-2.7) appeared to be positively associated with the outcome variable. As would be expected, by adding diabetes-related family communication to the model, it was learned that patients showed greater intention to disseminate risk and preventive information when diabetes is regularly discussed with relatives (OR 2.5; 95% CI 1.4-4.4). Yet patients’ worries
Table 2. Descriptive statistics with regard to patients’ family risk perceptions, worries about relatives’ health, control beliefs regarding diabetes prevention and diabetes-related family communication

<table>
<thead>
<tr>
<th>Family risk perception§</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I think it is (very) likely that offspring and/or other relatives † will develop Type 2 diabetes”</td>
<td>286</td>
<td>60.9</td>
</tr>
<tr>
<td>“I think it is not (very) likely that offspring and other relatives † will develop Type 2 diabetes”</td>
<td>184</td>
<td>39.1</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Worry about relatives developing diabetes§</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I have no/little worries about my offspring and other relatives † developing Type 2 diabetes”</td>
<td>310</td>
<td>68.6</td>
</tr>
<tr>
<td>“I have (quite) a lot of worries about my offspring and/or other relatives † developing type 2 diabetes”</td>
<td>142</td>
<td>31.4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Personal control beliefs regarding diabetes prevention</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>“Do you think there is anything your relatives can do to delay or prevent developing diabetes?”</td>
<td>216</td>
<td>1.1</td>
</tr>
<tr>
<td>No</td>
<td>86</td>
<td>16.3</td>
</tr>
<tr>
<td>Don’t know</td>
<td>224</td>
<td>42.64</td>
</tr>
<tr>
<td>Yes</td>
<td>98</td>
<td>20.2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Pre-existing family communication about type 2 diabetes‡</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I never/rarely discuss my diabetes with first- and second-degree relatives”</td>
<td>98</td>
<td>20.2</td>
</tr>
<tr>
<td>“I sometimes/often discuss my diabetes with first- and/or second-degree relatives”</td>
<td>388</td>
<td>79.9</td>
</tr>
</tbody>
</table>

§ The questions about patients’ family risk perceptions and worries about relatives were combined for offspring and other relatives.
† Other relatives include siblings, grandchildren, aunts/uncles and nieces/nephews.
‡ The question about family communication about diabetes was combined for first- and second-degree family members.

remained a significant determinant (OR 2.0; 95% CI 1.1-3.8). The final step reveals that knowing what to tell (OR 3.2; 95% CI 1.6-6.4), who to notify (OR 2.5; 95% CI 1.3-4.9) and being worried about relatives’ health (OR 2.4; 95% CI 1.3-4.7) facilitated patients’ intention to inform relatives most strongly. Family communication about diabetes in general (OR 1.9; 95% CI 1.0-3.6) also remained a predisposing factor.

Exploring putative indirect effects

As higher risk perception appeared not to be significantly associated with the intention to inform relatives, the possibility of an indirect association between family risk perception and the outcome variable through patients’ worries and personal beliefs about diabetes prevention was explored (see Figure 1). Findings indicated that increased risk perception led to elevated levels of worry (a₁ path; β=0.28, P<0.001), which in turn led to greater intention to inform relatives (b₁ path; β =0.65, P <0.01). A trend was found towards higher risk perception leading to more negative beliefs about diabetes prevention (a₂ path; β =-0.07, P=0.11). Positive control beliefs
Table 3. Hierarchical logistic regression analysis for variables predicting patients' intentions to inform relatives, controlling for background variables§

<table>
<thead>
<tr>
<th>Predictor variable</th>
<th>Intention to inform relatives</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Step 1</td>
</tr>
<tr>
<td></td>
<td>β (SE)</td>
</tr>
<tr>
<td>Constant</td>
<td>0.009 (0.233)</td>
</tr>
<tr>
<td>Family risk perception</td>
<td>0.014 (0.263)</td>
</tr>
<tr>
<td>Worry</td>
<td>0.720* (0.302)</td>
</tr>
<tr>
<td>Control beliefs</td>
<td>0.496* (0.239)</td>
</tr>
<tr>
<td>Diabetes-related family</td>
<td>0.898** (0.301)</td>
</tr>
<tr>
<td>communication</td>
<td></td>
</tr>
<tr>
<td>Knowing what to tell</td>
<td></td>
</tr>
<tr>
<td>Knowing who to notify</td>
<td></td>
</tr>
<tr>
<td>Knowing how to inform</td>
<td></td>
</tr>
</tbody>
</table>

* P<0.05  ** P<0.01  *** P<0.001

§ Controls are education and ethnicity (omitted from the table). Data were analysed list wise, resulting in a sample size of n=341.
increased patients’ intentions to talk with their relatives ($b_2$ path; $\beta = 0.33$, $P < 0.05$). According to the procedure of Preacher and Hayes (Preacher & Hayes, 2008), family risk perception exerted a positive indirect effect on the intention to inform relatives through worry ($a_1b_1$ path; point estimate $= 0.19$, BCa 95% CI 0.06 to 0.33). Personal beliefs in diabetes prevention, however, showed only a trend towards a negative indirect effect ($a_2b_2$ path; point estimate $= -0.02$, BCa 95% CI -0.08 to 0.00). The relationship between patients’ family risk perceptions and their intentions to inform their relatives about T2D risk was positively mediated through worry and control beliefs as a set ($a_1b_1 + a_2b_2$ path; point estimate $= 0.17$, BCa 95% CI 0.03 to 0.31). It seemed that opposite signed direct effects of worry and control beliefs with family risk perception slightly attenuated the total indirect effect.

Figure 1. Graphic representation of the multiple mediation model (Preacher & Hayes, 2008). Estimates are shown of the total (without putative mediators) and direct (with putative mediators) effects of family risk perception on patients’ intentions to inform relatives, as well as the indirect effect through worry about relatives and personal beliefs about diabetes prevention, while controlling for education and ethnicity. The bootstrap method was used, calculating 10000 sample boots. Data were analysed list wise, resulting in a sample size of $n=386$. Direct effects are represented with standardized regression coefficients ($\beta$) and $P$-values. Indirect effects are represented by point estimates (boot $\beta$) and a Bias Corrected and accelerated 95% Confidence Interval (BCa 95% CI).
Discussion

In this study, we explored factors that are associated with the willingness of patients with T2D to serve as a health educator in the family. In line with earlier studies, more than half of the participants intended to inform their relatives about increased diabetes risk (Gnanalingham & Manns, 1997; Nishigaki et al., 2009; Whitford et al., 2009b). Worry about relatives’ health, knowing what to tell, whom to notify and family communication about diabetes in general appeared to be important predisposing factors of family risk disclosure. Interestingly, high family risk perception was not significantly associated with patients’ intentions to inform relatives. Rather, risk perception appeared to have an indirect effect on the intention to talk with relatives through worries about relatives’ health and personal beliefs about diabetes prevention, in which worry had the largest specific indirect effect. These findings underscore the complexity of patients’ decisional processes to engage in actions to protect their family members’ health.

Although our results underline the importance of addressing patients’ worries, interventions also need to address risk perceptions. After all, promoting health-protective behaviour cannot successfully target worries alone, because worries cannot be permanently altered without changing risk cognitions that elicit this affective response (Cameron, 2003). Education on the possibilities of diabetes prevention is clearly needed, given our finding that more than half of the participants did not have positive beliefs about preventive options. Patients’ understanding of risk factors and primary prevention should be assessed to inform the development and implementation of educational programmes. In addition, to optimize acceptance of provided risk and preventive information and increase message effects, patient’s perceptions of, for instance, the seriousness and controllability of their condition, should be taken into account (Rimer & Kreuter, 2006).

Our research was strengthened by the fact that the study population resembled the population with T2D in the Netherlands (van Dam et al., 1991). Ethnic backgrounds of the participants were mixed, representing minority groups with high T2D prevalence (Middelkoop et al., 1999; Weijers et al., 1998). In an earlier study, we reported on cultural variation in patients’ risk perceptions, worries and family communication (Heideman et al., 2011a). In this study, we adjusted for ethnicity. Future (qualitative) research should explore the role of culture in the context of family risk disclosure, because it may have implications for the delivery and construction of educational messages targeting different high-risk families.

However, potential selection bias because of low response rate warrants consideration; those who participated may have stronger family bonding than patients who chose not to participate. Secondly, to enable comparison of results with earlier research (Nishigaki et al., 2009; Pierce et al., 1999; Whitford et al., 2009b), similar one-item questions about family risk perception and worry were used in this
study. Future studies should use multiple item measures to corroborate the reliability and validity of these constructs and our study findings. Finally, it is important to notice that causality cannot be proven in a cross-sectional study design. Results of the multiple mediation analysis reflect correlations between variables. Causal patterns as presented in Figure 1, however, were based on the Common-Sense Model of self-regulation of health and illness (Cameron, 2003; Leventhal et al., 2003), in which risk perception, worry and control beliefs precede (the intention towards) health protective behaviour. However, we have to take into account that the Common-Sense Model is described as a dynamic processing system, in which risk perception, emotional responses and behaviour are interrelated and evolve over time.

In summary, we can conclude that patients with T2D are generally willing to inform their relatives, and the intention to do so is partly driven by worry. This raises the question how to best utilize patients as messengers and the need for education material and support. The results of this study clearly point to the need for professionals to provide risk information, but also address worry and emphasize opportunities for diabetes prevention.
Illness representations of type 2 diabetes patients are associated with perceptions of diabetes threat in relatives

S.C.M. van Esch
M.D. Nijkamp
M.C. Cornel
F.J. Snoek

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Abstract

In the fight against the type 2 diabetes (T2D) epidemic, patients might be asked to discuss familial susceptibility to T2D in their family. Illness representations of patients (N=546) were assessed to explore their impact on perceived T2D threat in relatives. Reporting high T2D burden, emotional impact and perceiving T2D as an inheritable disease seemed to increase patients’ family risk perception and worries about relatives’ future health. Patients with coherent illness understanding reported positive beliefs regarding T2D prevention in relatives. Findings may give direction in how illness representations may be used to guide patients in the process of family risk disclosure.
Introduction

Type 2 diabetes (T2D) is a chronic progressive disorder and an increasing health problem in many countries because of explosively rising prevalence (Herman & Zimmet, 2012). Increased susceptibility to T2D is associated with hereditary factors and unhealthy lifestyle: the chance of developing T2D is two to five times higher for people with close relatives diagnosed with the disease (Valdez et al., 2007). Diabetes treatment requires a high degree of self-management, which implies healthy eating, being active, monitoring of blood glucose and taking medication. These behaviours occur largely within the family setting, which make patients a role model in their family (Scollan-Koliopoulos et al., 2005).

In the fight against the diabetes epidemic, it seems worthwhile to explore whether patients could play a more active role in the prevention of T2D in their family. Professionals could ask patients to inform their relatives about familial susceptibility to T2D and preventive options, as in patient-mediated cascade screening for familial hypercholesterolemia (Hallowell et al., 2011). Research already indicated that adult offspring of patients seems receptive to be informed about reducing their T2D risk via the family system (Pierce et al., 2000; Whitford et al., 2009a) and the majority of patients recognise the necessity of disseminating risk- and preventive messages in the family (van Esch et al., 2012a; Nishigaki et al., 2009; Whitford et al., 2009b). The question is, however, whether a patient-mediated strategy targeting persons with a family history will be applicable in T2D prevention. When patients are asked to pass on information about familial susceptibility to T2D, it seems important to understand if and to what extent their beliefs about, for instance, the cause and controllability of their own disease influence ideas about the vulnerability to T2D in their relatives.

A useful framework for identifying patients’ perceptions about their illness is the Common-Sense Model (CSM; Leventhal et al., 2003). The CSM proposes that patients create their own models or representations of their illness. These illness representations (IRs) guide risk-related cognitions about the illness threat (e.g., risk judgements, control beliefs) and emotional appraisal (e.g., distress, anxiety, worry), which, in turn, will give rise to coping procedures for controlling health threats (Cameron, 2003; Leventhal et al., 2003). Research convincingly demonstrated that IRs could be ordered into five logical themes or dimensions: illness identity, timeline beliefs, consequences, controllability and causal beliefs (Hagger & Orbell, 2003).

Understanding IRs of patients with diabetes already has proven to be useful in, for instance, managing diabetes outcomes, quality of life and self-care behaviour (Mc Sharry et al., 2011; Paschalides et al., 2004; Searle et al., 2007b). Recently, studies reinforce the importance of understanding IRs in a social and familial context (Quiles Marcos et al., 2009; Searle et al., 2007a; White et al., 2009; August & Sorkin, 2011) and there has been a growing interest in IRs of individuals at
increased (familial) risk developing a disease (e.g., Cameron, 2008; Claassen et al., 2010b; Figueiras, 2007; Kaptein et al., 2007). This is the first study, to the best of our knowledge, that uses the CSM framework to explore IRs in relation to risk estimations and affective appraisal that do not concern a person’s own health, but rather involve health risks in close relatives.

In our former study, patients’ perceptions of T2D risk in relatives, their worries about relatives developing the disease and their beliefs with regard to the possibility of T2D prevention in relatives appeared to be important factors that influenced intentions of patients to pass on risk and preventive information in their family (van Esch et al., 2012a). In the current study, we set out to explore whether and to what extent patients’ IRs are related to these three determinants in family risk disclosure. Findings may give direction in how personal beliefs of patients with T2D may be used to guide and potentially improve the process of disclosure of familial T2D risk. Based on the mental contents underlying a person’s own health risk appraisals (Cameron, 2008; Kaptein et al., 2007; Shibayama et al., 2011), we hypothesize that attributions that may tell something about feelings of little control and perceived seriousness and severity of the disease will be associated with perceptions of greater T2D risk in relatives. IRs that are indicative for high diabetes burden (e.g., daily consequences and emotional representations) seem likely to be associated with elevated levels of concern about relatives developing T2D. Beliefs that one can take actions to prevent diabetes are assumed to interact with risk estimates and beliefs regarding T2D prevention.

Method

The study used a cross-sectional survey design. Data were collected within the context of a larger study on family history and T2D prevention, which was conducted at primary and secondary care practices in the Netherlands in the period 2007-2011. The VU University Medical Center Ethics Committee granted ethical approval.

Participants

Registered patients with T2D (aged >18 years) in four primary care practices and the diabetes outpatient clinics of the VU University Medical Center and the Haaglanden Medical Center were invited by their physician to participate in the study (N=1312). The physicians excluded patients who were not eligible because of severe medical and/or emotional burden beforehand. Eligible patients received a study invitation letter from their physician. Once written informed consent was obtained, the participants were provided with a self-report questionnaire per mail.
Measures

Self-reported socio-demographics included age, gender, domestic situation, educational achievement and ethnic background. Patients were identified as non-Dutch when at least one parent was born outside the Netherlands (Statistics Netherlands; http://www.cbs.nl). Additionally, participants reported on the following diabetes-related characteristics: family history of T2D in first-degree and/or second-degree relatives, diabetes duration, treatment setting (primary versus secondary care), medical treatment and presence of diabetes complications.

Illness representations

IRs were assessed using the Dutch version of the Illness Perception Questionnaire Revised (IPQ-R) (Moss-Morris et al., 2002), which is retrievable from www.uib.no/ipq/. The IPQ-R scales have been tested in a variety of patients, including T2D and have been found to have adequate test-retest reliability and internal validity (Moss-Morris et al., 2002; Skinner et al., 2003).

The IPQ-R measures participants’ IRs over nine dimensions. The illness identity scale provides a list of 14 general symptoms; patients indicated whether they experience these symptoms and whether they believe these symptoms are related to their diabetes. The timeline subscale measures the perceived duration of the illness (acute-chronic; six items) and the extent of illness variability, fluctuations and unpredictability (timeline-cyclic; four items). Consequences are measured by the perceived impact of T2D on patients’ life (six items). The control subscale assesses perceived efficacy in controlling the illness (personal control; six items, treatment control; five items). The illness coherence subscale measures the extent to which patients have coherent illness understanding (five items) and emotional representations refer to perceived emotional states associated with the illness (six items). Finally, causal representations were assessed with a list of potential factors responsible for diabetes occurrence (i.e. heredity, diet or eating habits, chance or bad luck). As items relevant to the causes of the illness are allowed to be inserted into the questionnaire, two possible causes (‘lacking exercise’ and ‘fate’) were added to the original 18 causes from the IPQ-R (Moss-Morris et al., 2002). Responses were given on a 5-point Likert scale ranging from 1 'strongly disagree' to 5 'strongly agree'.

Outcome measurements

Based on the CSM framework (Leventhal et al., 2003), cognitive (family risk perception and control beliefs regarding T2D prevention) and affective (worries about relatives developing T2D) risk appraisals of patients with T2D were used as indicators of perceived illness threat in relatives. Patients were asked “How likely do you think it is that your child(ren) will get T2D?”. As in disorders with a multifactorial aetiology, the increased risk is present in first-degree and second-degree relatives (Scheuner et al., 1997; Valdez et al., 2007), the same question was
asked with regard to other relatives (siblings, grandchildren, aunts/uncles and nieces/nephews). Answers were provided on a four point Likert scale, ranging from 1=not very likely to 4=very likely. Emotional appraisal was measured in a similar way: “Do you worry that your child(ren)/other relatives might get T2D?” Answers ranged from 1=not at all to 4=a lot. To measure control beliefs with regard to diabetes prevention, patients were asked: “Is there anything your relatives can do to delay or prevent developing T2D?” Response options were no/don’t know/yes.

**Data analysis**

Analyses were performed using SPSS version 16.0. Chi-square tests and an independent Student’s t-test were used in non-response analyses. The probability level for statistical significance was set at ≤ 0.05 (two-tailed). Internal consistency of the IPQ-R subscales was established by calculating Cronbach’s alpha coefficients. The identity scale score was calculated by dividing the sum of yes-rated symptoms related to T2D by the number of items provided. Higher scores indicated a stronger belief that the experienced symptoms are part of patient’s illness. Means and standard deviations were calculated on the other IPQ-R subscales, with higher scores denoting greater endorsement of the given construct. One-sample t-tests were used to compare mean scores with the neutral value (not disagree/not agree=3). The 20 items pertaining to the perceived cause of T2D were analysed as separate items and not as scale scores, because descriptive information was considered more informative than items clustered in subscales. Percentages of endorsement of a causal item were computed through dichotomisation (scores 1, 2 and 3 were coded into 0=not endorsed, and scores 4 and 5 into 1=endorsed).

Outcome variables were dichotomized and variables measuring family risk perceptions and worries about relatives were combined for offspring and other relatives. Outcome categories were successively: “I think it is not (very) likely that offspring **and** other relatives will develop T2D”=0 and “I think it is (very) likely that offspring **and/or** other relatives will develop T2D”=1. “I have no/little worries about offspring **and other relatives developing T2D**”=0 and “I have (quite) a lot of worries about offspring **and/or other relatives developing T2D**”=1. “I don’t think that, or I don’t know whether there is anything my relatives can do to delay or prevent T2D onset”=0 and “I do think there is something my relatives can do to delay or prevent T2D onset”=1.

Associations between socio-demographic and diabetes-related variables and the outcome variables were calculated using multiple logistic regression analyses (backward elimination). To assess associations between separate IRs and the outcome variables, a series of univariate logistic regression analyses was conducted adjusting for relevant covariates (i.e. age and family history for family risk perceptions; age and ethnic backgrounds for worries about relatives; educational achievement and diabetes complications for beliefs about T2D prevention). Collinearity diagnostics
were examined (Stevens, 2009). To control for potentially type I errors due to multiple comparisons (i.e. finding a relationship when in fact no relationship exists) a conservative significance value of p<0.01 was applied.

Results

Of 1312 patients invited, 546 (41.6%) filled in the questionnaire. There were no differences in gender ($\chi^2(1)=1.036, p=0.312$) nor treatment setting (primary versus secondary care) ($\chi^2(1)=0.081, p=0.780$) between responders and non-responders. Non-responders, however, were a little younger than responders (t=-5.044; p<0.001; 95% CI between -2.1 and -4.9 years). Table 1 shows the background characteristics of the study sample.

Perceived diabetes threat in relatives

More than half of the patients (60.9%; n=286) thought it was (very) likely that offspring and/or other relatives would develop T2D. About one third of all patients (31.4%; n=142) expressed serious worries about relatives that might develop T2D. Multivariate regression analyses revealed that, generally, patients with a family history of T2D perceived higher T2D risk in their relatives and a non-Dutch background appeared to predispose for worries about relatives developing T2D. Younger patients perceived higher T2D risk in their relatives and expressed more concern about their relatives’ health as compared to the older participants (see Table 2).

Less than half of the study sample (41.4%; n=216) had positive beliefs regarding possibilities to delay or prevent T2D onset in their relatives. Higher education appeared to be associated with more positive control beliefs, whereas patients with diabetes-related complications (indicative for severe diabetes burden) were less confident that relatives would be able to postpone or prevent T2D onset. Noticeably, gender, patients’ domestic situation, T2D duration, medical treatment and treatment setting were not related to outcome variables. Multicollinearity between independent variables could not be demonstrated.

Illness representations

Patients reported an average of three illness symptoms ($M=3.16; SD=3.08$) and related one symptom to their diabetes ($M=0.99; SD=1.90$). Most frequently listed symptoms were fatigue (22%; n=121), sore eyes (14%; n=77), and stiff joints (10%; n=52).

The internal consistency of the IPQ-R subscales was acceptable or good (Cronbach’s alpha >0.7 or >0.8), except for personal and treatment control it was questionable ($\alpha=0.66$ and $\alpha=0.58$ respectively) (George & Mallery, 2003). In comparison to the neutral value of each subscale, patients had strongly held beliefs about the chronicity of their disease (timeline-acute/chronic; $M=4.00, SD=0.74$), effectiveness of controlling T2D
Table 1. Participants’ socio-demographic and diabetes-related characteristics (N=546)

<table>
<thead>
<tr>
<th>Socio-demographic characteristics</th>
<th>n</th>
<th>%</th>
</tr>
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<tbody>
<tr>
<td><strong>Age (mean ± sd)</strong></td>
<td>63.6 ± 11.7</td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>272</td>
<td>49.8</td>
</tr>
<tr>
<td>Female</td>
<td>274</td>
<td>50.2</td>
</tr>
<tr>
<td><strong>Domestic situation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living alone</td>
<td>180</td>
<td>34.0</td>
</tr>
<tr>
<td>Cohabitation with partner and/or offspring</td>
<td>350</td>
<td>66.0</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low (no education, primary school, lower vocational/trade education)</td>
<td>336</td>
<td>64.4</td>
</tr>
<tr>
<td>High (secondary or tertiary school, bachelor- or master degree)</td>
<td>186</td>
<td>35.6</td>
</tr>
<tr>
<td><strong>Ethnic background</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dutch</td>
<td>311</td>
<td>57.6</td>
</tr>
<tr>
<td>Surinamese South-Asian</td>
<td>157</td>
<td>29.1</td>
</tr>
<tr>
<td>Other (non-)Western countries</td>
<td>72</td>
<td>13.3</td>
</tr>
<tr>
<td><strong>Diabetes related characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family history of diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No family history</td>
<td>155</td>
<td>28.4</td>
</tr>
<tr>
<td>First-degree or second-degree relatives</td>
<td>189</td>
<td>34.6</td>
</tr>
<tr>
<td>First-degree and second-degree relatives</td>
<td>202</td>
<td>37.0</td>
</tr>
<tr>
<td><strong>Diabetes duration</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 5 years</td>
<td>241</td>
<td>44.4</td>
</tr>
<tr>
<td>5-10 years</td>
<td>115</td>
<td>21.2</td>
</tr>
<tr>
<td>&gt; 10 years</td>
<td>187</td>
<td>34.5</td>
</tr>
<tr>
<td><strong>Treatment setting</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Primary care</td>
<td>285</td>
<td>52.2</td>
</tr>
<tr>
<td>Secondary care</td>
<td>261</td>
<td>47.8</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet and/or tablets</td>
<td>334</td>
<td>61.6</td>
</tr>
<tr>
<td>Insulin</td>
<td>208</td>
<td>38.4</td>
</tr>
<tr>
<td><strong>Diabetes complications†</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>289</td>
<td>54.0</td>
</tr>
<tr>
<td>No</td>
<td>246</td>
<td>46.0</td>
</tr>
</tbody>
</table>

† Self-reported complications included retinopathy, neuropathy, and nephropathy and co-morbid cardiovascular problems.
Table 2. Patients’ characteristics associated with patients’ family risk perceptions, worries about relatives developing T2D and control beliefs with regard to diabetes prevention

<table>
<thead>
<tr>
<th>Patient characteristics</th>
<th>Family risk perceptions $^a$</th>
<th>Worries about relatives $^a$</th>
<th>Beliefs T2D prevention $^a$</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B (SE) OR 95% CI</td>
<td>B (SE) OR 95% CI</td>
<td>B (SE) OR 95% CI</td>
</tr>
<tr>
<td>Age</td>
<td>-.03 (.01)** 0.97 0.958-1.00</td>
<td>-.05 (.01)** 0.96 0.94-0.98</td>
<td>- - - - - - - - - - - - - -</td>
</tr>
<tr>
<td>Educational achievement</td>
<td>- - - - - - - - - - - - - -</td>
<td>- - - - - - - - - - - - - -</td>
<td>- - - - - - - - - - - - - -</td>
</tr>
<tr>
<td>Ethnic background $^f$</td>
<td>- - - - 1.31 (.24)** 3.72 2.34-5.89</td>
<td>- - - - - - - - - - - - - -</td>
<td>.58 (.19)** 1.79 1.23-2.60</td>
</tr>
<tr>
<td>Family history of diabetes $^f$</td>
<td>1.23 (.24)** 3.41 2.14-5.45</td>
<td>- - - - - - - - - - - - - -</td>
<td>- - - - - - - - - - - - - -</td>
</tr>
<tr>
<td>Diabetes complications</td>
<td>- - - - - - - - - - - - - -</td>
<td>- - - - - - - - - - - - - -</td>
<td>-.48 (.19)** 0.62 0.43-0.89</td>
</tr>
</tbody>
</table>

**p<.01   *** p<.001

Table 2 shows outcomes from multivariate logistic regression analyses. Only statistically significant relations (p<.01) are presented.

$^a$ Non-Dutch descent compared to Dutch descent.

$^f$ Positive family history compared to no family history of diabetes.

$p$ Perceived diabetes risk in relatives: “I think it is not (very) likely that offspring and/or other relatives will develop T2D”=0, “I think it is (very) likely that offspring and/or other relatives will develop T2D”=1.

$^g$ Patients’ worries about relatives’ health: “I have no/little worries about offspring and/or other relatives developing T2D”=0, “I have (quite) a lot of worries about offspring and/or other relatives developing T2D”=1.

$^h$ Perceived possibility of T2D prevention in relatives: “I don’t think that, or I don’t know whether there is anything my relatives can do to delay or prevent T2D onset”=0, “I do think there is something my relatives can do to delay or prevent T2D onset”=1.
by own behaviour ($M=3.60, \text{SD}=0.58$) and by medical treatment ($M=3.67, \text{SD}=0.56$). They reported a rather good understanding of their disease (illness coherence; $M=3.48, \text{SD}=0.73$) (all p<.001). Moreover, patients did not perceive their disease as unpredictable (timeline-cyclic; $M=2.74, \text{SD}=0.91$), they did not report major consequences ($M=2.84, \text{SD}=0.77$) and emotional impact ($M=2.49, \text{SD}=0.80$) (all p<.001).

Causal attributions seemed to be in accordance with the multifactorial aetiology of T2D. The top-ten of most endorsed causes were: heredity (61.3%; $n=314$), ageing (49.4%; $n=253$), diet or eating habits (44.5%; $n=220$), stress (40.4%; $n=205$), lack of exercise (37.4%; $n=187$), chance or bad luck (36.7%; $n=182$), fate (29.7%; $n=148$), my own behaviour (25.3%; $n=125$), family problems or worries (22.9%; $n=115$) and altered immunity (21.6%; $n=107$).

Illness representations and perceived diabetes threat in relatives

Univariate regression analyses revealed that reporting more diabetes symptoms, perceiving one’s own diabetes as variable and unpredictable (high scores on timeline-cyclic), experiencing high emotional burden and attributing T2D to inheritance was associated with higher T2D family risk perceptions and more worries about relatives developing T2D. In addition, reporting serious daily consequences and attributing T2D to fate also seemed to increase patients’ concern about relatives’ health. Patients with coherent IRs and patients reporting diabetes symptoms and high levels of personal and treatment control expressed positive attitudes towards T2D prevention in relatives (see Table 3).

Causal factors that showed the strongest association with positive beliefs regarding T2D prevention in relatives were attribution to diet/eating habits and lacking exercise. Attribution to stress/worry and one’s own behaviour also were positively associated with control beliefs. Attribution to chance/bad luck appeared to be negatively associated with beliefs about T2D prevention in relatives. Multicollinearity between independent variables could not be demonstrated.

Discussion

This study aimed to understand how IRs of patients with T2D are related to perceptions of diabetes threat in their relatives. It appeared that perceiving diabetes as a serious or unpredictable disease was related to higher family risk perceptions and worries about relatives developing T2D. Experiencing serious daily consequences and high emotional impact were most strongly associated with elevated levels of concern. As hypothesized, patients with coherent IRs and high levels of personal and treatment control expressed positive attitudes towards T2D prevention in relatives.
Table 3. Univariate relations between patients' scores on IPQ-R with family risk perceptions, worries about relatives developing T2D and control beliefs with regard to diabetes prevention

<table>
<thead>
<tr>
<th>IPQ-R subscales</th>
<th>Family risk perceptions§</th>
<th>Worries about relatives#</th>
<th>Beliefs T2D prevention¥</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B (SE) OR 95% CI</td>
<td>B (SE) OR 95% CI</td>
<td>B (SE) OR 95% CI</td>
</tr>
<tr>
<td>Identity</td>
<td>.17 (.06)** 1.19 1.05-1.35</td>
<td>.17 (.06)** 1.18 1.06-1.32</td>
<td>.17 (.05)** 1.19 1.06-1.29</td>
</tr>
<tr>
<td>Timeline acute-chronic</td>
<td>- - - -</td>
<td>- - - -</td>
<td>- - - -</td>
</tr>
<tr>
<td>Timeline cyclic</td>
<td>.38 (.12)** 1.46 1.16-1.84</td>
<td>.57 (.14)** 1.78 1.35-2.34</td>
<td>- - - -</td>
</tr>
<tr>
<td>Consequences</td>
<td>- - - - .76 (.16)** 2.14 1.55-2.95</td>
<td>- - - -</td>
<td>- - - -</td>
</tr>
<tr>
<td>Personal control</td>
<td>- - - -</td>
<td>- - - - .81 (.19)** 2.26 1.57-3.24</td>
<td>- - - -</td>
</tr>
<tr>
<td>Treatment control</td>
<td>- - - -</td>
<td>- - - - .56 (.18)** 1.76 1.23-2.50</td>
<td>- - - -</td>
</tr>
<tr>
<td>Illness coherence</td>
<td>- - - -</td>
<td>- - - - .65 (.14)** 1.91 1.44-2.52</td>
<td>- - - -</td>
</tr>
<tr>
<td>Emotional representation</td>
<td>.38 (.14)** 1.46 1.11-1.92</td>
<td>.84 (.16)** 2.32 1.69-3.20</td>
<td>- - - -</td>
</tr>
</tbody>
</table>

Causal attribution items

| Heredity- runs in the family | 1.01 (.23)*** 2.73 1.73-4.32 | .76 (.25)** 2.14 1.30-3.33 | - - - - |
| Diet or eating habits       | - - - - | - - - - | .91 (.20)** 2.50 1.69-3.68 |
| Stress or worry             | - - - - | - - - - | .53 (.20)** 1.70 1.16-2.49 |
| Lacking exercise            | - - - - | - - - - | .75 (.20)** 2.11 1.43-3.13 |
| Chance or bad luck          | - - - - | - - - - | -.79 (.21)** 0.45 0.30-0.68 |
| Fate                        | - - - - | .69 (.25)** 1.98 1.23-3.21 | - - - - |
| My own behaviour            | - - - - | - - - - | .64 (.22)** 1.89 1.23-2.90 |

**p<.01  *** p<.001

Table 3 shows outcomes from univariate logistic regression analyses. Only statistically significant relations (p<.01) are presented.

§ Perceived diabetes risk in relatives adjusted for age and family history.

# Patients' worries about relatives' health adjusted for age and ethnic background.

¥ Perceived possibility of T2D prevention in relatives adjusted for educational achievement and diabetes complications.
Interestingly, older patients seemed to perceive their relatives as less vulnerable to T2D and they were less concerned about the fact that relatives could develop T2D. Earlier studies suggest that the elderly minimize health risk (Leventhal & Crouch, 1997). Being of non-Dutch descent was found to be related to (a lot of) worries about relatives’ health, as was reported in earlier research (van Esch et al., 2012b). It would be interesting to explore ethnic variability in IRs in relation to patients’ family risk appraisal in further detail, as differences in IRs may be assumed between ethnic populations (Grewal et al., 2010).

Pertaining to the idea of stimulating family communication about T2D in high-risk families, assessment of IRs may help professionals to identify patients who are assumed to be most successful as messenger in their family. For instance, reporting positive control beliefs was associated with higher education and causal attributions that are in accordance with current medical opinions (American Diabetes Association, 2007). This may suggest that these patients seem able to deliver accurate risk messages in their family. In contrast, patients suffering from diabetes complications and attributing their diabetes to chance/bad luck were less confident that relatives would be able to postpone or prevent T2D onset. Addressing unhelpful beliefs, for instance, with regard to causal attribution and the controllability of T2D (onset) seem important targets when guiding patients in the process of family. Eliciting the patient’s perspective will optimize the acceptance of information that could correct patients’ cognitions (Phillips et al., 2012).

Strengths of the study include the relatively large study sample (\(n=546\)) that resembled the population of patients with T2D in the Netherlands with regard to socio-demographic and diabetes-related characteristics (van Dam et al., 1991; Middelkoop et al., 1999; Weijers et al., 1998). However, we cannot rule out selection bias because of low response rate (42%). Participants were a little older than non-responders, which may have led to underestimation of family risk perceptions and reported worries. After all, older patients seemed to have lower risk perceptions and reported less concern about their relatives. Nevertheless, our results with regard to perceived familial risk and positive beliefs regarding T2D prevention are in line with earlier findings (Nishigaki et al., 2007; Pierce et al., 1999; Whitford et al., 2009b). Yet, the number of participants expressing worries about their relatives’ health seems rather low in our study (Pierce et al., 1999; Whitford et al., 2009b). IRs were consistent with recent literature on T2D (Mc Sharry et al., 2011; Paschalides et al., 2004; Searle et al., 2007b). Diabetes symptom perception was rather low, but could be explained by the use of a generic version of the identity scale. It would be worthwhile to complement the generic symptoms of the identity scale by diabetes-specific symptoms in future studies.

To enable comparison with earlier studies (Nishigaki et al., 2007; Pierce et al., 1999; Whitford et al., 2009b), we used single-item measures to assess family risk perceptions of patients, worries and control beliefs. In future research, we would
suggest to use multi-item measures to increase the reliability and validity of the measured constructs (Cameron & Reeve, 2006; Cameron et al., 2009). Moreover, one should take into account that causality cannot be proven in a cross-sectional study design. Results in this study reflect correlations between variables. Suggested causal patterns between IRs and the outcome variables are based on theoretical constructs of the CSM (Leventhal et al., 2003).

Finally, besides socio-demographic and diabetes-related characteristics, IRs have been analysed as the only ‘predictor’ variables. To unravel underlying mechanisms of patients’ perceptions of diabetes threat in their relatives, potential overlapping constructs and confounders, such as dispositional personality traits (e.g., neuroticism, optimism) and mental health (e.g., depression, anxiety disorder), should be included in the analyses (Lawson et al., 2010).

Nevertheless, we may conclude that IRs, as delineated by the CSM framework (Leventhal et al., 2003), could be helpful in understanding patients’ appraisal of T2D threat in their family. Findings may have practical implications related to the design of family-based diabetes prevention programmes and the way in which health messages could be tailored to the needs of individual patients.
Family communication as strategy in diabetes prevention; an observational study in families with Dutch and Surinamese South-Asian ancestry

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M.C. Cornel
P.H.L.M. Geelhoed-Duijvestijn
F.J. Snoek

Patient Education and Counseling 2012; 87:23-29
Abstract

Objective To explore the possibility of utilising family communication as a diabetes prevention strategy, specifically targeting high-risk families with South-Asian ancestry in the Netherlands.

Methods In a cross-sectional study, type 2 diabetes patients from Dutch ($n=311$) and Surinamese South-Asian ($n=157$) origin filled in a questionnaire assessing socio-demographic characteristics, beliefs and concerns about familial diabetes risk, primary prevention and diabetes-related family communication.

Results Discussing diabetes is regarded acceptable in most families. Especially Surinamese South-Asian patients (68%) seemed motivated to convey risk messages to their relatives; they reported higher risk perceptions and expressed more concern than Dutch patients. While 40% in both groups thought relatives are able to prevent developing diabetes, 46% in Dutch and 33% in Surinamese South-Asian patients were unsure.

Conclusion Promoting family communication appears a feasible strategy in diabetes prevention in high-risk (Surinamese South-Asian) families. Health care providers should address concern of patients and emphasize opportunities for prevention.

Practice Implications Findings favour training of clinicians in utilising a family approach as prevention strategy. Patients (particularly Surinamese South-Asians) are in need of professional help in the process of family risk disclosure. (Online) educational tools should be made available at which patients can refer their relatives.
Introduction

Type 2 diabetes (T2D) is a serious chronic disease and has become a global health problem (Unwin et al., 2009). In the Netherlands, it has been predicted that around 1.3 million people (8% of the population) will be diagnosed with T2D in 2025 (Baan et al., 2009), prompting the Dutch Government to define a National Diabetes Action Plan targeting at prevention of T2D, early diagnosis and lifestyle interventions for high-risk groups (2004). For that, identifying effective strategies is of key importance.

One relatively new idea in diabetes prevention is to make use of patients as health educators in the family. After all, family history is an important predictor of diabetes risk (Lyssenko et al., 2008a) and intervening in high-risk families is thought to be practical and (cost-)effective compared with population screening (Hariri et al., 2006; Uusitupa et al., 2011). Studies suggest that communicating familial diabetes risk increases family members’ perception of personal risk (Pierce et al., 2000; Whitford et al., 2009a). So far, behavioural outcomes have received limited attention; one European study reports a slight increase in relatives’ healthy behaviour after disclosure of familial risk (Nishigaki et al., 2008; Pijl et al., 2009b), whereas a study in Japan indicated that parental advice seemed not to facilitate offspring’s preventive behaviour (Nishigaki et al., 2008; Pijl et al., 2009b). Yet, offspring appears receptive to be informed via the family system about reducing their T2D risk (Pierce et al., 2000; Whitford et al., 2009a) and patients do seem willing to disseminate risk messages in the family (Gnanalingham & Manns, 1997; Nishigaki et al., 2009; Whitford et al., 2009b).

The question now is whether a family-based intervention would be feasible approaching high-risk groups in the Netherlands, in particular the Surinamese South-Asian population. Similar to other native and migrant Asian populations living in urban areas (Barnett et al., 2006; Lee et al., 2011), the prevalence of T2D in people from Surinamese South-Asian descent is extremely high (a four-to-six fold increased risk compared to originally Dutch people (Middelkoop et al., 1999)). Given the strong familial aggregation of T2D in South-Asian families (Viswanathan et al., 1996), a family approach as prevention strategy targeting this high-risk group would seem legitimate (Ramachandran et al., 2006). However, it is known that health-care delivery in South-Asian populations is challenging and education should take cultural and socio-economic factors into account (Hawthorne et al., 2008; Khunti et al., 2008). Indeed, determinants of patients’ disclosure of family risk, including family risk perceptions, worries about relatives’ health and knowledge about diabetes risk factors (Gnanalingham & Manns, 1997; Nishigaki et al., 2009; Whitford et al., 2009b), can significantly vary between different cultures (Pierce et al., 1999; Whitford & Al-Sabbagh, 2010).

Considering the high prevalence of T2D, familial clustering and high morbidity and mortality rates in South-Asian populations (Bathula et al., 2010), we might assume relative high family risk perceptions and concern about relatives developing T2D. This may urge patients to disclose T2D risk information to relatives. On the other hand,
experiences with severe and highly prevalent T2D in the family may negatively affect control beliefs with regard to diabetes prevention. Moreover, the South-Asian culture is sometimes described as fatalistic, attributing illness to fate or the will of a higher power (Davison et al., 1992; Dickinson & Bhatt, 1994), making it less likely that patients take responsibility for health-promoting actions. Yet, the South-Asian culture, known for its collectivism and strong family cohesion (Sinha et al., 2001), may be particularly suited for a family-based approach. However, it remains unknown whether T2D is a topic in everyday communication in these high-risk families.

In this observational study, we aimed at exploring possible facilitating and impeding factors in utilising family communication as a strategy in primary prevention of diabetes, specifically targeting the high-risk Surinamese South-Asian community in the Netherlands. We compared family risk perceptions, concerns and control beliefs with regard to diabetes prevention in patients with a Dutch and Surinamese South-Asian ethnic background. In addition, we explored everyday familial communication about T2D, as well as intentions and perceived ability of patients to play a messengers’ role in the family. Results may help to decide whether promoting family risk communication is a feasible strategy in diabetes prevention and inform the development and implementation of educational programs.

Methods

Study design and recruitment of participants

Data were collected within the context of a larger cross-sectional study on family history and diabetes. Registered type 2 diabetes patients (aged >18 years) were recruited from four primary care practices (in Amsterdam and Haarlem), the diabetes outpatient clinics of the VU University medical center (VUmc, Amsterdam) and the Haaglanden Medical Center (HMC, The Hague). Participating physicians were asked to exclude patients who were not eligible due to severe medical and/or emotional burden; the remaining patients (N=1312) received an invitation letter together with information about the study. Once written informed consent was obtained, participants were mailed a self-report questionnaire to be returned in a pre-stamped envelope. A postal reminder followed four weeks later. The VUmc Ethics Committee granted ethical approval.

Patients with South-Asian ancestry in the Netherlands

In the Netherlands, most South-Asian inhabitants are immigrants from Surinam, a former Dutch colony in South-America. About a century ago, their ancestors came from South-Asia to Surinam to work as contract labourers. After the independence of Surinam in 1975, a large cohort of Surinamese South-Asian people settled in the Dutch governmental city The Hague. This group has a Hindustani cultural background and a six-to-ten times higher T2D prevalence than general Dutch
population (Middelkoop et al., 1999). In this study, participants with Surinamese South-Asian ethnic background (further referred to as ‘Surinamese patients’) were recruited from the HMC in The Hague. This Center provides culturally adapted diabetes care (involving secondary as well as primary care treatment) targeting Surinamese patients. The majority of the Surinamese population is fluent in Dutch since it is the national language in Surinam.

**Measurements**

**Socio-demographics and diabetes-related characteristics**

Socio-demographics were self-reported, including age, gender, marital status, having offspring, domestic situation, educational achievement and ethnicity. Participants were identified as ‘Dutch’ in case both parents were born in the Netherlands (according to the definition used by Statistics Netherlands). All participants recruited in the HMC were known to be from Surinamese South-Asian descent.

Diabetes-related background data were self-reported, including family history of T2D in first-degree and/or second-degree relatives, diabetes duration (less or more than ten years), treatment (diet, tablets, insulin), diabetes complications (diabetes causing problems with eyes, feet/or kidneys) and co-morbid cardiovascular problems.

**Worries, family risk perceptions and belief in primary prevention**

Using a single item question (based on previous studies (Pierce et al., 1999; Whitford et al., 2009b)), participants were asked whether they worried about offspring developing T2D. The same question was asked with regard to other relatives (including siblings, grandchildren, aunts/uncles and nieces/nephews). Answers were provided on a four point Likert scale, ranging from ‘not at all’ to ‘a lot’. Similarly, participants were asked to estimate the likelihood of children and other relatives developing T2D. Responses ranged from ‘not very likely’ to ‘very likely’. Finally, participants were asked whether they thought there is anything that relatives can do to delay or prevent getting T2D. Response options were ‘yes’, ‘no’ or ‘don’t know’. See Table 2 for exact wording of questions.

**Family communication**

Participants were asked whether T2D is a topic that is discussed in everyday communication with, respectively, first-degree and second-degree relatives. Both questions were answered on a four point Likert scale, ranging from ‘never’ to ‘often’. Subsequently, participants were provided with six statements (based on Mesters et al., 1997); used as single item questions), to assess their ideas about ‘openness’ in the communication (items a–d) and familial emotional support (items e–f) (see Table 3). Answers were provided on a five point Likert scale ranging from ‘strongly agree’ to ‘strongly disagree’.

To examine ideas of patients about serving as a ‘messenger’ in the family, a question was developed asking participants whether they intended to talk about diabetes risk and primary prevention in their family. Additionally, four single item statements were provided
to explore the perceived ability of patients to inform relatives. Response options were 'agree', 'disagree' or 'don’t know'. See Table 4 for exact wording of questions.

**Statistical analyses**

The statistical package SPSS v16.0 (SPSS Inc., Chicago, IL, USA) was used for statistical analyses. Socio demographic and diabetes-related characteristics of Dutch and Surinamese patients were analyzed using exact tests for categorical variables and Student’s *t*-tests for normally distributed continuous variables. Crude percentages were tabulated to evaluate the number of participants reporting (quite) a lot of worries about relatives’ health, high family risk perceptions, positive control beliefs and diabetes-related family communication (representing the main outcome variables). Then (since assumptions for parametric tests were not met), the method of (multinomial/ordinal) logistic regression analysis was used to assess the relative influence of ethnic backgrounds (Dutch versus Surinamese) on (dichotomized, three-part categorical and ordinal) outcome variables, controlling for age, domestic situation (which is highly correlated with having a partner) and education. Differences in family history, diabetes duration and complications were not adjusted for, since higher reports on these variables are typical for the Surinamese population (Bathula et al., 2010). The probability level for statistical significance was set at ≤ 0.05 (two-tailed).

**Results**

**Response and non-response**

In the HMC in The Hague, 361 Surinamese patients were identified as fulfilling the inclusion criteria and were invited to participate in the study; 157 responded (response rate 43.5%). From 951 patients recruited in general practices and the VUmc, 383 patients returned a completed questionnaire (response rate 40.3%). Data from 72 patients in this group were excluded, since their ethnic backgrounds (originating from (non-)Western countries) were too diverse to permit any valid comparisons. This left 311 participants in the Dutch study population.

Non-respondent analyses revealed that Surinamese patients who chose not to participate did not differ in age and gender from participating Surinamese patients. Dutch non-participants were younger than participating Dutch patients (*t* = -4.735; *p* <.001).

**Participants’ characteristics**

Socio demographic and diabetes related characteristics are presented in Table 1. Dutch participants were statistically significant older than the Surinamese patients (67.5 vs. 58.1 yrs; *t* =8.913; *p* <.001). The male/female distribution was equal in both study groups. Dutch patients were more likely to be married/having a partner
Table 1. Socio-demographic and diabetes-related characteristics of Dutch (n=311) and Surinamese T2D patients (n=157)

<table>
<thead>
<tr>
<th></th>
<th>Dutch patients</th>
<th>Surinamese patients</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Socio demographic characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean age ± SD ***</td>
<td>67.5 ± 10.5</td>
<td>58.1 ± 11.1</td>
</tr>
<tr>
<td>Female</td>
<td>148 (47.6)</td>
<td>89 (56.7)</td>
</tr>
<tr>
<td><strong>Family situation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/with partner ***</td>
<td>209 (67.4)</td>
<td>76 (48.7)</td>
</tr>
<tr>
<td>Having offspring</td>
<td>255 (82.3)</td>
<td>129 (84.9)</td>
</tr>
<tr>
<td>**Domestic situation ***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living alone</td>
<td>103 (33.3)</td>
<td>61 (40.4)</td>
</tr>
<tr>
<td>Cohabitation with partner</td>
<td>171 (55.3)</td>
<td>42 (27.8)</td>
</tr>
<tr>
<td>Living with offspring (and partner)</td>
<td>35 (11.3)</td>
<td>48 (31.8)</td>
</tr>
<tr>
<td>Low education **</td>
<td>188 (61.6)</td>
<td>108 (72.5)</td>
</tr>
<tr>
<td><strong>Diabetes related characteristics</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family history of diabetes **</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No family history</td>
<td>106 (34.1)</td>
<td>22 (14.0)</td>
</tr>
<tr>
<td>First-degree or second-degree relatives</td>
<td>107 (34.4)</td>
<td>52 (33.1)</td>
</tr>
<tr>
<td>First-degree and second-degree relatives</td>
<td>98 (31.5)</td>
<td>83 (52.9)</td>
</tr>
<tr>
<td>Diabetes duration &gt;10 years ***</td>
<td>91 (29.4)</td>
<td>77 (49.7)</td>
</tr>
<tr>
<td><strong>Treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diet and/or tablets</td>
<td>195 (63.1)</td>
<td>85 (54.5)</td>
</tr>
<tr>
<td>Insulin</td>
<td>114 (36.9)</td>
<td>71 (45.5)</td>
</tr>
<tr>
<td>**Diabetes complications† ***</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>199 (64.0)</td>
<td>74 (47.1)</td>
</tr>
<tr>
<td>One</td>
<td>86 (27.7)</td>
<td>45 (28.7)</td>
</tr>
<tr>
<td>Two or more</td>
<td>26 (8.4)</td>
<td>38 (24.2)</td>
</tr>
<tr>
<td><strong>Co-morbid cardiovascular problems</strong></td>
<td>80 (26.1)</td>
<td>41 (26.8)</td>
</tr>
</tbody>
</table>

Data are n (%) unless otherwise indicated.
* P-value obtained using t-tests and exact tests, significance is denoted by * p<0.05, ** p<0.01, *** p<0.001.
# Low education (no education, primary school and lower vocational/trade education) as compared to moderate or high educational achievement (secondary-, or tertiary school, bachelor- or master degree).
† Self-reported complications included retinopathy, neuropathy and nephropathy.

(χ²=15.279; p<.001) and the majority of both study groups reported having offspring. Asking about participants’ domestic situation, Dutch participants appeared to cohabit more often with a partner whereas Surinamese offspring seemed to live more often with their parents (χ²=41.552; p<.001). Dutch participants more often finished secondary or higher education (χ²=5.188; p=.023).

Surinamese participants reported more frequently a family history of diabetes, especially in first-degree and second-degree relatives (χ²=27.720; p=.001). Despite their younger age, more Surinamese patients were diagnosed with T2D more than ten years ago (χ²=18.494; p<.001). There were no differences in diabetes treatment between the ethnic groups. Surinamese patients more often reported two or more
diabetes-related complications ($X^2=24.269; p<.001$). In both groups, about a quarter reported co-morbid cardiovascular problems.

**Worries, family risk perceptions and belief in primary prevention**

As shown in Table 2, 14% ($n=33$) of the Dutch participants tended to worry (quite) a lot about their offspring developing T2D and 6% ($n=17$) expressed their worries about other relatives. Surinamese patients seemed to be more worrisome. Almost half of them (48%, $n=61$) expressed (quite) a lot concern regarding to their offspring’s health and 30% ($n=46$) worried about other relatives. Adjusted analyses revealed that the proportion of Dutch patients reporting ‘no’ or ‘little’ worries about the diabetes-related health of offspring and other relatives is higher compared to Surinamese patients with little concern (both $p<.001$).

In the Dutch population, 39% ($n=90$) thought T2D onset is (highly) probable in offspring, compared to 58% ($n=71$) in the Surinamese population. High-risk estimations for other relatives are reported by 39% ($n=114$) of the Dutch and 62% ($n=93$) of the Surinamese patients. Differences between both ethnic groups are confirmed in adjusted analyses, showing a higher number of Dutch patients indicating diabetes onset is not (very) likely in offspring ($p<.01$) or other relatives ($p<.01$) compared to the Surinamese patients.

When asked about the possibilities of primary prevention, 42% of the Dutch ($n=122$) and 44% ($n=68$) of the Surinamese participants were inclined to believe relatives might be able to postpone or prevent T2D onset. Interestingly, a relatively large number of participants was unsure about diabetes prevention (46% in Dutch and 33% in Surinamese patients). Differences between Dutch and Surinamese patients were not statistically significant, after controlling for age, domestic situation and education.

**Family communication**

The majority of the Dutch patients (60%; $n=166$) reported to talk at least ‘sometimes’ with their first-degree relatives about T2D, whereas 44% ($n=105$) had conversations with second-degree relatives. Surinamese patients seemed not to differentiate between first-degree or second-degree relatives; 78% ($n=114$) discussed T2D with first-degree and 74% ($n=95$) with second-degree relatives. Adjusted analyses revealed that conversations about T2D are more common in Surinamese families relative to Dutch families (first-degree relatives, $p<.05$; second-degree relatives, $p<.001$). Notably, 18% of the Dutch ($n=57$) and 6% of the Surinamese patients ($n=10$) reported that T2D is never discussed within the family (see Table 2).
Table 2. Patients’ concern about relatives developing type 2 diabetes, family risk perceptions, belief in primary prevention and family communication about diabetes; comparison between Dutch (n=311) and Surinamese (n=157) patients

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
<th>Dutch patients</th>
<th>Surinamese patients</th>
<th>Adjusted p-value</th>
<th>Odds ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you worry that your child(ren) might get T2D? (^\text{i)})</td>
<td>Not at all/a little (Quite) a lot</td>
<td>212 (86.5)</td>
<td>66 (52.0)</td>
<td>&lt;.001</td>
<td>4.6 (2.5–8.2)</td>
</tr>
<tr>
<td>Do you worry that other relatives might get T2D? (^\text{ii)})</td>
<td>Not at all/a little (Quite) a lot</td>
<td>284 (94.4)</td>
<td>107 (69.9)</td>
<td>&lt;.001</td>
<td>5.5 (2.7–11.0)</td>
</tr>
<tr>
<td>How likely do you think it is that your child(ren) will get T2D? (^\text{i)})</td>
<td>Not (very) likely (Very) likely</td>
<td>142 (61.2)</td>
<td>52 (42.3)</td>
<td>.002</td>
<td>2.3 (1.4–3.9)</td>
</tr>
<tr>
<td>How likely do you think it is that other relatives will get T2D? (^\text{ii)})</td>
<td>Not (very) likely (Very) likely</td>
<td>179 (61.1)</td>
<td>56 (37.6)</td>
<td>.001</td>
<td>2.3 (1.4–3.7)</td>
</tr>
<tr>
<td>Do you think there is anything that your relatives can do to delay or prevent getting T2D?</td>
<td>Yes</td>
<td>122 (41.2)</td>
<td>68 (44.4)</td>
<td>.114*</td>
<td>0.6 (0.3–1.1)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>38 (12.8)</td>
<td>35 (22.9)</td>
<td>.186*</td>
<td>1.4 (0.8–2.3)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>136 (45.9)</td>
<td>60 (32.7)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you discuss T2D with first-degree relatives?</td>
<td>Never/rarely</td>
<td>113 (40.5)</td>
<td>33 (22.4)</td>
<td>.022</td>
<td>1.8 (1.1-2.9)</td>
</tr>
<tr>
<td></td>
<td>Sometimes/often</td>
<td>166 (59.5)</td>
<td>114 (77.6)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you discuss T2D with second-degree relatives?</td>
<td>Never/rarely</td>
<td>133 (55.9)</td>
<td>33 (25.8)</td>
<td>&lt;.001</td>
<td>3.4 (2.0-5.9)</td>
</tr>
<tr>
<td></td>
<td>Sometimes/often</td>
<td>105 (44.1)</td>
<td>95 (74.2)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\(^{1}\) Data are n (%) and represent crude values.
\(^{i)}\) Only subjects with children were asked this question.
\(^{ii)}\) “Other relatives” includes siblings, grandchildren, aunts/uncles and nieces/nephews.
\(^{\$}\) The method of logistic regression analysis was used to explore the association between outcome variables and ethnic backgrounds (Dutch versus Surinamese), controlling for age, domestic situation and education. Presented outcomes do not correspond with the observed (crude) values.
\(^{\#}\) Multinomial logistic regression analysis was used with ‘yes’ as reference category.

As represented in Table 3, slightly more than half of the Dutch patients (55%; n=164) and a smaller proportion of Surinamese patients (39%; n=57) indicated that they talk as little as possible about their diabetes, not wanting to upset their family. Adjusted analysis revealed that Dutch patients tend to refrain more often from talking with relatives (p<.01). On the other hand, most patients in both groups indicated that their relatives don’t seem to mind talking about T2D and that few relatives tend to be disturbed by such conversations. In general, responses referring to ‘openness to discuss T2D in the family’ (items a-d) show a trend towards more openness in Surinamese families. On the other hand, as far as familial emotional support is concerned (items e-f), Dutch patients reported less often that family members want to hear positive stories (p<.01).
Finally, from Table 4 it can be read that the majority of participants (55%; \( n = 156 \) in Dutch and 68%; \( n = 98 \) in Surinamese patients) expressed the intention to inform family members about familial diabetes risk and primary prevention. The difference between both ethnic groups is confirmed in adjusted analyses (\( p < .05 \)). Around seventy-five percent in both study populations indicated to know ‘what to tell’, ‘how to tell’ and ‘whom to inform’. Dutch patients reported having less problems deciding which relatives to inform (\( p < .05 \)). Notably, almost twice as much Surinamese participants (68%; \( n = 98 \)) indicated that patients should receive professional help in the process of familial risk disclosure (\( p < .001 \)).
Discussion and Conclusion

Discussion

The results of this study confirm the potential of utilising family communication as strategy in diabetes prevention, targeting high-risk families in the Netherlands. In line with common health behaviour theories (Weinstein, 1993), family risk perceptions of patients were identified as a motivator to inform relatives about their diabetes risk in earlier research (Gnanalingham & Manns, 1997; Nishigaki et al., 2009; Whitford et al., 2009b). In our study, it appeared that Surinamese patients had significantly higher family risk perceptions than Dutch patients. This finding was in line with our expectations and might be explained by the higher prevalence and generally less favourable clinical T2D profile in this population (Bathula et al., 2010). However, a recent study showed that families in Bahrain do not consider themselves more susceptible to diabetes than families in Ireland, despite a higher prevalence of T2D in Bahrain (Whitford & Al-

Table 4. Willingness and perceived ability of patients to serve as a ‘messenger in the family’; comparison between Dutch (n=311) and Surinamese (n=157) type 2 diabetes patients

<table>
<thead>
<tr>
<th>Statements</th>
<th>Response</th>
<th>Dutch patients</th>
<th>Surinamese patients</th>
<th>Adjusted p-value</th>
<th>Odds ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I intend to inform my relatives about potential familial diabetes risk and possibilities of primary prevention”</td>
<td>Agree</td>
<td>156 (55.3)</td>
<td>98 (68.1)</td>
<td>.012</td>
<td>2.3 (1.2-4.5)</td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td>65 (23.0)</td>
<td>15 (10.4)</td>
<td>.526</td>
<td>1.2 (0.7-2.1)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>61 (21.6)</td>
<td>31 (21.5)</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>“I know what to tell my relatives”</td>
<td>Agree</td>
<td>221 (78.6)</td>
<td>109 (75.7)</td>
<td>.201</td>
<td>0.7 (0.2-1.3)</td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td>18 (6.4)</td>
<td>13 (9.0)</td>
<td>.817</td>
<td>0.9 (0.5-1.7)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>42 (14.9)</td>
<td>22 (15.3)</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>“I know how to inform my relatives”</td>
<td>Agree</td>
<td>211 (75.4)</td>
<td>101 (70.1)</td>
<td>.297</td>
<td>0.7 (0.3-1.4)</td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td>25 (8.9)</td>
<td>18 (12.5)</td>
<td>.689</td>
<td>0.9 (0.5-1.6)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>44 (15.7)</td>
<td>25 (17.4)</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>“I know which relatives to inform”</td>
<td>Agree</td>
<td>215 (76.8)</td>
<td>103 (70.5)</td>
<td>.049</td>
<td>0.4 (0.2-0.9)</td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td>14 (5.0)</td>
<td>16 (11.0)</td>
<td>.924</td>
<td>1.0 (0.6-1.8)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>51 (18.2)</td>
<td>27 (18.5)</td>
<td>.</td>
<td></td>
</tr>
<tr>
<td>“Patients should receive professional help when informing their relatives”</td>
<td>Agree</td>
<td>107 (38.2)</td>
<td>98 (67.6)</td>
<td>&lt;.001</td>
<td>4.6 (2.4-8.7)</td>
</tr>
<tr>
<td></td>
<td>Disagree</td>
<td>83 (29.6)</td>
<td>17 (11.7)</td>
<td>.001</td>
<td>2.7 (1.5-4.6)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>90 (32.1)</td>
<td>30 (20.7)</td>
<td>.</td>
<td></td>
</tr>
</tbody>
</table>

1 Data are n (%) and represent crude values.
$ The method of multinomial logistic regression analysis was used to explore the association between the willingness and perceived ability to function as a ‘messenger in the family’ and ethnic backgrounds (Dutch versus Surinamese), controlling for age, domestic situation and education. Reference category was ‘agree’. Presented outcomes do not correspond with the observed (crude) values.
Sabbagh, 2010). Therefore, explanations from a cultural perspective also might be plausible, arguing that Asian people in general perceive themselves as more vulnerable to diseases than Western people (Heine & Lehman, 1995).

In addition, Surinamese patients expressed more concern about their relatives than the Dutch patients. Especially the number of Surinamese patients being worried about the wider family (including second-degree relatives) is noticeable, which could be related to the fact that South-Asian families often consist of more members (grandparents, siblings and aunts/uncles) than just the nuclear family (parents and children) (Sue, 1998). A growing body of research indicates that disease-related worries and anxiety also play a motivational role in promoting health behaviours (Cameron, 2003). Indeed, worrisome diabetes patients appeared to be most willing to disseminate risk messages in their family in earlier research (Whitford et al., 2009b).

In contrast to what could be expected (Davison et al., 1992; Dickinson & Bhatt, 1994; Grewal et al., 2010), Surinamese patients did not express more fatalistic beliefs than Dutch patients. About forty percent of both study populations in our study was inclined to believe that relatives might be able to postpone or prevent T2D onset. A similar percentage on positive control beliefs was reported a decade ago (Pierce et al., 1999). Notably, a large group of Dutch (46%) and Surinamese patients (33%) reported that they were unsure about the possibilities to prevent or delay T2D onset in relatives.

With regard to family communication, results indicated that T2D is discussed in everyday conversations in most families. More than half of the Dutch participants and almost seventy percent of the Surinamese participants expressed their willingness to educate relatives about increased T2D risk and primary prevention. These percentages are in line with earlier research (Nishigaki et al., 2009; Whitford et al., 2009b). Open and supportive communication among family members seems to be of crucial importance in applying a family approach in diabetes prevention (Wiseman et al., 2010). As we expected, considering the strong family bonding in Surinamese families (Sinha et al., 2001), our findings suggest a trend towards more ‘openness’ in discussing T2D in Surinamese families. However, Dutch patients more often reported familial emotional support.

Finally, participants were positive about their ability to disseminate risk- and preventive messages in the family. Around three-quarter of all patients indicated they are well informed about T2D risk and prevention, knowing “what to tell, how to tell and whom to inform”. However, the content and accuracy of risk- and preventive messages that patients disseminate in their families remains unknown.

Strengths and limitations
Our study was strengthened by the fact that participants in both study populations speak Dutch, limiting linguistic problems and facilitating comparison. We also
included large enough samples of Dutch and Surinamese patients to correct for socio demographic differences between the groups. However, the study was limited by a relatively low response rate and we cannot rule out selection bias; participants may be more enthusiastic about engaging with their families than non-responders. Low response rates have also been reported in previous research about family communication (Whitford et al., 2009b). Non-response analyses in our study revealed that 18% (n=27) of the reported reasons for not participating in the study referred to ‘lack of family contact’, ‘being the only diabetes patient in the family’, or ‘not wanting to bother relatives’. Besides, over reporting of diabetes-related communication in the Surinamese sample should be taken into account, since social desirability is known in populations with Asian background (Zane & Yeh, 2002).

The study’s generalizability with regard to other South-Asian populations might be limited. Our study population represents a specific sub group of South-Asian people, migrated via the former Dutch colony Surinam. Unfortunately, we do not have data on participants being first-degree or second-generation migrants. Future research should explore whether other populations from South-Asian descent show similar opportunities in utilising family communication as prevention strategy.

Conclusion
Our results did not reveal specific barriers targeting high-risk Surinamese families; in fact, Surinamese patients reported higher risk perceptions, expressed more concern about relatives than the Dutch patients and seemed highly motivated to communicate with their family. Around forty percent, in both the Dutch and the Surinamese population, had positive control beliefs with regard to diabetes prevention.

Clearly, knowledge is essential to facilitate the delivery of accurate messages in the family. To enhance the effect of family-based interventions, patients should be educated about increased familial risk and the effectiveness of lifestyle modification on diminishing T2D risk. After all, a large group of Dutch as well as Surinamese patients seemed not to know whether T2D prevention is possible in relatives.

Providing family risk information may arouse (new) concern in patients about their relatives' health. In fact, a significant number of Surinamese patients was already worried about their relatives developing T2D. Professionals should address these concerns and reassure patients. On the other hand, as suggested by Whitford and colleagues, emphasizing worries in patients may lead to increased discussion of T2D risk within families (Whitford et al., 2009b). It is known that some fear arousal is necessary to trigger protective actions; however, arousing fear may be counterproductive when people do not perceive themselves able to engage in risk reducing actions (Witte & Allen, 2000). Therefore, emphasizing possibilities of T2D prevention in this process is essential, as well as providing recommendations about how, when and which relatives to inform.
Finally, we must not overlook the fact that in some families T2D is never discussed and patients might resent being a health messenger in their family. Stimulating diabetes related communication is obviously not appropriate in those families.

**Practice Implications**

Clinicians should be trained in utilising a family approach as primary prevention strategy and learn to coach patients to carry out a messengers’ role in the family. The majority of Surinamese patients explicitly demanded professional help in the process of family risk disclosure. Indeed, patients’ needs and the challenge of integrating the inheritable character of common diseases into the regular practice of medicine have been indicated before (Scheuner et al., 2008).

To optimize acceptance of information about T2D risk and prevention in the Surinamese population, cultural adaptation might be needed. After all, culturally sensitive, enhanced interventions appeared most effective when targeting South-Asian populations (Bellary et al., 2008). In the Netherlands, a family approach may fit in targeted interventions that take the Surinamese traditions into account (Middelkoop et al., 2001). As for content, it is important to be aware of assumptions of patients with regard to etiological recognition of T2D. After all, illness beliefs with regard to causal attributions and personal control appeared to be different between South-Asian and Caucasian populations (Bean et al., 2007; Macaden & Clarke, 2006), which may affect ideas about T2D susceptibility and prevention (Heine & Lehman, 1995; Råberg Kjøllesdal et al., 2011).

Finally, as long as the content of risk- and preventive messages delivered by patients is unknown, (online) information should be made available at which patients can refer family members who are interested in their T2D risk and possibilities of prevention (van Esch et al., 2010). Subsequently, health professionals should be accessible to advice those relatives motivated to engage in preventive activities.
Health care providers’ perspective on using family history in the prevention of type 2 diabetes: a qualitative study including different disciplines

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W.H. Heideman
W. Cleijne
M.C. Cornel
F.J. Snoek

Submitted
Abstract

Background Family history (FH) is considered an important factor to detect individuals at increased risk developing type 2 diabetes (T2D). Moreover, FH information could be used to personalise risk messages, which are assumed to increase risk-reducing behaviours. In this study, we aimed to explore Dutch health care professionals’ attitudes regarding current or future uptake of a more extensive use of FH information and the family system in diabetes prevention.

Methods Semi-structured interviews were conducted with a purposive sample of nineteen health care professionals, including general practitioners, practice nurses, diabetes specialists and diabetes nurses. The use of FH information in preventive consultations was explored, as well as the usability of a direct versus patient-mediated targeting strategy to reach persons with a FH of T2D. Three researchers analysed the interview transcripts separately.

Results Dutch health care professionals expressed positive attitudes with regard to using FH to promote and motivate health-protective behaviour. Directly targeting and educating patients known to have a FH of T2D was desirable for most primary care professionals, but not considered feasible. Findings indicated that FH information was not systematically gathered and Electronic Medical Records were not equipped to retrieve persons with T2D running in their family. The idea of asking patients to pass on risk and preventive information was new to all interviewees, but was considered an acceptable strategy to reach persons with a FH of diabetes. Nevertheless, practical barriers with regard to time, expertise and financial reimbursement were mentioned.

Conclusions Evidence showing the (cost-)effectiveness of family-oriented strategies in the prevention of T2D could stimulate health care professionals in primary as well as secondary care to use FH information, the family system and family communication to promote health-protective behaviour. Besides increasing skills and expertise in professionals, more insight is needed in cultural aspects regarding the disclosure of family risk, the effect of low health literacy and negative modelling in families at high risk developing T2D.
Background

Type 2 diabetes (T2D) is a serious chronic disease causing considerable burden on patients as well as health care systems (American Diabetes Association, 2008). The rapidly increasing prevalence of T2D warrants major efforts to explore effective tools and strategies to detect, inform and motivate individuals at high risk to engage in preventive actions (Herman & Zimmet, 2012).

T2D is best described as a multi factorial disease, which means disease onset is triggered by the interaction of multiple genes and environmental factors (Lyssenko et al., 2008b). Research has convincingly demonstrated that T2D is highly prevalent in some families and a positive family history predicts the development of T2D, even after adjustment for common risk factors (Arslanian et al., 2005; Hemminki et al., 2010; Meigs et al., 2000). Consequently, a family history (FH) of T2D is seen as a valuable tool in preventive activities (Guttmacher et al., 2004). FH information can help to detect persons at increased risk developing T2D: the chance of developing diabetes is two-to-five times higher for people with a FH of the disease (Annis et al., 2005; Valdez et al., 2007). Moreover, evidence suggests that preventive messages tailored to a person’s FH can increase risk awareness and risk-reducing behaviours (Chang et al., 2011; Qureshi & Kai, 2008; Ruffin et al., 2011). Yet, lifestyle interventions specifically aiming at prevention of T2D in people with a FH seem to be scarce (Heideman et al., 2011a).

In most Western countries, the use of opportunistic screening targeting patients at risk for T2D is encouraged (American Diabetes Association, 2011). In combination with other risk factors, FH is recognized as an important element in the risk stratification procedure. Directly targeting and educating people known to have T2D running in their family, however, is not current in clinical practice (Chang et al., 2011; Qureshi & Kai, 2008). At present, there is an increasing need for structured preventive activities linked to primary care (Assendelft et al., 2012). A targeting approach that might be worthwhile to explore in this context is patient-mediated cascading, as is used in screening for familial hypercholesterolemia (Hallowell et al., 2011). This means that relatives are reached via the index patient, who informs them about increased familial susceptibility to a disease and the preventive options. Indeed, research already has indicated that the majority of patients with T2D seemed willing to disseminate risk and preventive information in their family (van Esch et al., 2012b; Whitford et al., 2009b) and adult offspring generally seemed receptive to be informed about reducing their diabetes risk via the family system (Whitford et al., 2009a).

In this study, semi-structured interviews with Dutch health care professionals were conducted to investigate opinions, attitudes and practices with regard to the current and future use of FH in preventive consultations. Ideas with regarding two potential strategies to reach persons with T2D running in their family were
explored: 1) directly targeting patients known to have a FH of T2D and 2) a patient-mediated approach, asking patients with T2D to pass on risk information in their family. Although preventive activities usually are carried out in primary health care, we also considered opinions of secondary care professionals of relevance in this study. Patients receiving diabetes treatment in secondary care visit outpatient clinics regularly, which might provide opportunities to discuss the familial character of the disease. Findings may provide insight in the uptake of FH as a tool in T2D prevention and the conditions that are needed to apply a family-oriented approach in routine care.

Methods

Design and participants

Between February and April 2010, two researchers (SvE and WH) conducted nineteen semi-structured interviews with Dutch health care professionals. A purposive sampling strategy was used, aiming to achieve maximum variation in the characteristics of the included affiliations and professionals. General practices were recruited via the regional network of the Academic General Practice of the VU University Medical Center. Six practices in three cities in the urban area of Amsterdam were willing to participate. Interviews were conducted with five general practitioners (GPs) and six practice nurses (PNs). The term ‘general practice’ is commonly used in the Dutch health care system and is considered synonymous to ‘family medicine’ and ‘family practice’.

Diabetes specialists (DSs) and diabetes nurses (DNs) in secondary care were approached via contacts of the authors in four outpatient diabetes clinics in Amsterdam. Interviews were conducted with five DSs and three DNs. The study sample included professionals of both sexes and varying years of clinical experience, affiliations varied in size and characteristics of patient populations (see Table 1). All interviewees gave informed consent prior to the interview. The VU University Medical Center Ethics Committee approved the study.

Interview guide

The interviews were semi-structured and based on a topic guide that was pilot tested in two interviews. In the first part of the interview, interviewees were asked to describe current practice with regard to the use of (opportunistic) screening for T2D, assessment and registration of FH and structured education targeting patients at risk developing T2D. Individual opinions with regard to bringing up FH as a topic of conversation in preventive consultations were explored. Next, two potential strategies to reach relatives of T2D patients were discussed: 1) directly targeting
### Table 1. Characteristics of the interview sample

<table>
<thead>
<tr>
<th>General Practice</th>
<th>Professionals' identification number</th>
<th>Gender</th>
<th>Years of clinical experience</th>
<th>Characteristics patient population¹</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>GP1, PN1</td>
<td>Female,Female</td>
<td>16-20</td>
<td>Average SES</td>
</tr>
<tr>
<td>2</td>
<td>GP2, PN2</td>
<td>Male,Female</td>
<td>6-10</td>
<td>Low SES</td>
</tr>
<tr>
<td>3</td>
<td>GP3¹, PN3¹</td>
<td>Female,Female</td>
<td>21-25</td>
<td>Average/high SES</td>
</tr>
<tr>
<td>4</td>
<td>GP4, PN4&amp;5²</td>
<td>Male,Female</td>
<td>&gt; 30</td>
<td>Low SES</td>
</tr>
<tr>
<td>5</td>
<td>GP5, PN4&amp;5²</td>
<td>Male,Female</td>
<td>&gt; 30</td>
<td>Low SES</td>
</tr>
<tr>
<td>6</td>
<td>PN6a³, PN6b³</td>
<td>Female</td>
<td>0-5</td>
<td>Low/average SES</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Outpatient clinic</th>
<th>Professionals' identification number</th>
<th>Gender</th>
<th>Years of clinical experience</th>
<th>Characteristics patient population¹</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>DS1, DN1</td>
<td>Male,Female</td>
<td>6-10</td>
<td>Average/high SES</td>
</tr>
<tr>
<td>2</td>
<td>DS2, DN2</td>
<td>Male,Male</td>
<td>11-15</td>
<td>Low SES</td>
</tr>
<tr>
<td>3</td>
<td>DS3a, DS3b, DN3</td>
<td>Male,Male</td>
<td>21-25</td>
<td>Low SES</td>
</tr>
<tr>
<td>4</td>
<td>DS4</td>
<td>Female</td>
<td>0-6</td>
<td>Low SES</td>
</tr>
</tbody>
</table>

GP=General practitioners, PN=Practice Nurses, DS=Diabetes Specialists, DN=Diabetes Nurses

¹ Professionals were asked to define their patient population according to socioeconomic status (SES), age distribution, and ethnic backgrounds.

¹¹ GP3 and PN3 were interviewed at the same time

² PN4&5 worked in both general practice 4 and 5

³ PN6a and PN6b were interviewed at the same time

Health care providers’ perspective on family-oriented diabetes prevention

Considerable flexibility during the interviews allowed interviewees to discuss and elaborate on issues that were most important to them. Each interview lasted about half an hour and took place in the participants’ work environment.
### Table 2. Topic list used in semi-structured interviews

#### Introduction
With the increasing incidence, primary prevention of type 2 diabetes is of key importance. Clinical and public health efforts are generated to assist in reducing the burden of diabetes in the population. In this interview, we aim to explore the current and future uptake of proactive patient education about familial susceptibility to type 2 diabetes.

#### A. Mapping current practice
- Are patients at risk developing type 2 diabetes systematically screened in this general practice?*
  - In case of opportunistic screening: which risk factors are assessed?
  - Can you describe the practical implications of the screening process
- Is family history of type 2 diabetes systematically assessed (if yes, how registered)?
- Is education about risk factors and preventive options systematically offered when patients are at risk developing type 2 diabetes (but not yet diagnosed)?*
  - Which risk factors are emphasized?
  - To which extent is family history discussed?

#### B. exploring Perceptions and attitudes
- What is your opinion about using family history as a topic of conversation to promote health protective behaviour?*
  - Do you use family history to personalize preventive messages?
  - Do you think it is effective (e.g., with regard to promote healthy behaviour)?
- What is your opinion about proactively targeting patients with a family history of type 2 diabetes to educate them about preventive options?*
  - What will be the potential effect (e.g., patient empowerment/responsibility/privacy)?
  - Do you think it is feasible?
- What is your opinion about asking patients to deliver diabetes risk and preventive messages in their family? Elaborate on:
  - Patients’ willingness
  - Potential effect on relatives
  - Feasibility
  - Familial and/or cultural aspects
- What would be needed to implement a family-oriented approach in diabetes prevention?
- Are you familiar with the information that is provided by mass media campaigns and websites aiming to raise public awareness about familial susceptibility to type 2 diabetes?
  - Do you use this information and/or refer patients to these websites?

* Topic only discussed with primary care professionals

### Data analysis
All interviews were digitally recorded, transcribed verbatim (WC) and checked for errors (SvE and WH). Qualitative data indexing software (ATLAS.ti 5.2) was used for data coding and retrieval. The transcripts were analysed using thematic content-analytical techniques. Main codes were established for the core questions in the interview guide; sub-codes were inductively formulated to identify emerging sub-themes. Two investigators (SvE and WC, or WH and WC) independently coded each transcript. Ambiguities in the final code-lists were discussed until consensus was
reached. Subsequently, (sub-)codes were grouped in thematic matrices and similarities, variations and patterns amongst the professional groups were summarized. Main findings were discussed with all members of the study group. The quotations that follow were chosen to reflect a range of both consensual and dissenting views.

Results

Mapping current practice

All included GPs work in accordance with the Dutch guideline for diabetes treatment, which include opportunistic screening for T2D (Bouma et al., 2006). One GP participated in a trial to implement the screening protocol for cardio-metabolic prevention, targeting all patients >55 years old (Assendelft et al., 2012; Dekker et al., 2011). All interviewees perceive FH as important factor in the risk stratification procedure. However, according to the interviewees in primary care, the assessment of FH is not standardized; a person’s FH of diabetes is inquired the moment it is thought to be of relevance. In diabetes outpatient clinics, FH is systematically assessed during the first consultation. Both in primary and secondary care, FH information is registered in electronic medical records (EMRs), but not with a retrievable code. When patients are diagnosed with (pre)diabetes, they are regularly monitored and receive education about T2D risk factors and lifestyle modifications to prevent diabetes complications (secondary prevention).

Using family history information in preventive actions

Data revealed that the extent to which the multifactorial aetiology of T2D is explained varied between professionals: ‘It depends on the patient, whether (s)he is interested. But I try to explain that some people are more at risk than others.’ [GP4]. Some GPs and NPs do not emphasize the role of FH as a risk factor, as it is not a factor that can be controlled: ‘We think monitoring weight and blood glucose levels in this population is most effective. We don’t emphasize family history.’ [GP3] ‘Understanding the balance between food consumption and energy expenditure, that’s what counts.’ [GP5].

None of the interviewees used FH information to promote health-protective behaviour. The clarification of what FH could mean to a person seemed to be minimal. Professionals could not bring up absolute or relative risk estimates of developing T2D in persons with a FH. Nevertheless, they agreed that personal perceptions about diabetes running in the family could be discussed more thoroughly and knowledge about familial susceptibility to diabetes could be improved: ‘There is a lot of ignorance. […] People don’t recognize diabetes symptoms, despite the –sometimes high– diabetes prevalence in their family.’ [GP4]. The idea of using FH information to motivate risk-reducing behaviour was new to all interviewees, but it was
acknowledged that for some relatives, personalized risk messages could be a cue to action: ‘I think, targeting family members could be effective. However, I think you should reach them in a neutral and thoughtful manner. People don’t want you to interfere with their personal life too much.’ [GP2].

However, in practices with many patients from ethnic minority groups, cultural and linguistic barriers were mentioned. GPs and PNs do not expect benefits from illuminating the familial character of T2D in ethnic minority groups because of differences in perceived controllability with regard to health and illness, causal attributions, generational conflicts and low literacy: ‘The illness burden of first generation migrants might not impress the younger generations. These youngsters do not identify with their parents as far as health-related issues are concerned.’ [GP5].

Nevertheless, all primary care professionals reported to be interested in new strategies and tools to inform people about the importance of a healthy lifestyle. Interestingly, with exception of one PN, none of the interviewees had paid attention to or used the information provided by renowned Dutch health organizations. Between 2009 and 2013, diverse mass medial campaigns and an informative website were launched (Dutch Diabetes Federation, 2009), providing a diabetes risk test that generates personalized preventive information (Alssema et al., 2012).

**Directly targeting patients at familial risk developing type 2 diabetes**

Most GPs and PNs indicated that directly targeting and educating populations at risk, including persons with a FH, would be desirable and worthwhile: ‘We plan to set up more preventive activities targeting patients with an extensive family history of cardiovascular disease and type 2 diabetes.’ [GP4]. However, they foresee practical problems; lack of time, finance and organizational barriers were reported: ‘What we need is a continuing approach. Our PNs are trained to provide patient education and motivate patients in the process of behaviour change. […] We could organize and facilitate a structured programme, on condition that financial resources are available.’ [GP2]. Most importantly, however, directly targeting patients with a FH is not possible because EMRs are not equipped to retrieve persons with a FH: ‘The most important barrier is to identify and reach patients with an extensive family history.’ [PN6b].

**Asking patients to pass on risk and preventive messages in their family**

The idea of asking patients to inform relatives about familial susceptibility to T2D appeared to be new to all interviewees. During the interviews, the professionals became more and more interested in this potential approach to reach relatives at risk: ‘When you think about prevention, you have to reach as much people as possible. I do not
disapprove this kind of targeting approach.' [PN4&5]. Interviewees referred to patients who bring up inheritance and concern about the future health of their relatives themselves. They commended on the possibility of contacting otherwise unreachable healthy individuals and thought that a specific group of patients seems willing to disseminate information in their family: ‘Patients who adequately handle their disease will be motivated to participate. Other patients are into denial and/or struggling with their disease. You can’t ask these patients to deliver diabetes risk messages in their family.’ [PN6a].

However, for some GPs it was difficult to think about targeting a population that does not necessarily include their own patients: ‘I think it is difficult to manage, sometimes I ask about relatives, but most relatives are not registered as a patient in our practice.’ [GP1]. Moreover, besides a lack of time during their consultations, they indicated that they would need expertise and skills to guide and educate patients who are willing to serve as a messenger in their family.

**Family-based diabetes prevention in secondary care**

Most interviewees in secondary care do not think they should have an active role in the primary prevention of T2D, however, they are open to the idea of informing patients and their relatives about familial susceptibility to T2D: ‘Indeed, we talk about family history. When patients or relatives ask about it, I inform them about the importance of a healthy lifestyle and advice relatives to consult their GP for a yearly check-up.’ [DS2]. One DS realized that in other situations, they have a more active role with regard to prevention in families at high risk developing a disease: ‘We always inform patients about familial susceptibility in case of monogenetic disorders. The problem with T2D is its multifactorial aetiology; the message is not clear and more difficult to explain.’ [DS1].

One DN thinks every health care professional should be concerned about a population at risk, but emphasized that there are little opportunities to act upon that in secondary care. Other professionals were interested in the idea of initiating conversations in families at risk: ‘I think patients can tell from their own experience what it’s like to have the disease […] Most of my patients have adult offspring. That would be a good target population.’ [DS4]. They emphasized the importance of repeating health-protective messages: ‘Repetition is important in health education. […] It seems a good idea that people hear the same message over and over again: from public health communications, in general practice, from dieticians and from us.’ [DS1]. Another professional, however, stated that a patient-mediated targeting approach is not appropriate in secondary care: ‘Some patients in secondary care are quite sick. You can’t ask them to inform their relatives.’ [DN2].

**Perceived barriers regarding a patient-mediated targeting approach**

Notwithstanding the interest and enthusiasm of most interviewees, some questioned the feasibility and benefits of a patient-mediated approach in diabetes prevention: ‘Patients don’t want to deliver bad news and relatives don’t want to receive such messages.’
They doubted whether patients will be able to pass on accurate messages and whether relatives will be alarmed: ‘Will the messages be delivered? To be honest, considering our patient population, I suppose a substantial amount will not.’ [PN4&5]. As T2D is a lifestyle related disease, many patients would not fulfil a role model with regard to health behaviour: ‘I think the most important factor is how patients experience and cope with their disease and how visible it is for relatives.’ [PN1]. Interestingly, nurses (PNs and DNs) seemed to be more hesitative than medical professionals (GPs and DSs).

Different professionals mentioned strong family bonding in ethnic minority families as a potential advantageous factor: ‘Family tights seems to be stronger in immigrant families.’ [DS3]. However, according to other professionals, asking non-Dutch patients to pass on information seems not feasible: ‘It’s the other way around. Those children are used to translate during consultations and provide their parents with health information. They won’t listen to their parents and will search for information themselves when they need it.’ [GP5]. Moreover, according to the interviewees, the younger generation in general would not be admissible to risk messages via the family system: ‘I question whether it’s effective. Younger offspring is not concerned with future health risks.’ [GP1] ‘Do children listen to their parents? […] I think a person will be interested the moment (s)he is confronted with the problem.’ [DS3a].

Discussion

Findings in this study indicated that, although interviewees were unacquainted with, they did not decline the idea of discussing a person’s understanding of familial risk in order to promote and motivate health-protective behaviour. Nonetheless, some professionals questioned the effectiveness of illuminating FH, especially with regard to patients of non-Dutch descent and younger generations. Targeted diabetes education, however, seems to increase the recognition of diabetes risk, screening possibilities, perceived personal control and the need of healthy behaviour in persons with a FH of T2D (Chang et al., 2011; Pijl et al., 2009; Qureshi & Kai, 2008; Ruffin et al., 2011; Zlot et al., 2009).

Relatives, who were informed via the family system, perceived themselves at increased risk developing diabetes (Pierce et al., 2000; Whitford et al., 2009). Professionals are right stating that the effect of using FH in preventive communications targeting specific populations remains unknown (Chang et al., 2011; Qureshi & Kai, 2008; Ruffin et al., 2011). Earlier research, however, has indicated that in families with different ethnic backgrounds (e.g., South-Asian, Middle-Eastern), family communication about T2D is not a taboo and patients seem willing to pass on risk and preventive information in their family (Esch et al., 2012; Whitford & Al-Sabbagh, 2010).

Generally, the study findings lend support for the adoption of direct as well as indirect strategies targeting persons with T2D running in their family. Both methods seem effective in other disease areas (Hallowell et al., 2011). In Dutch primary care
practice, an active and personal invitation of the GP increased the screening uptake of participants for a lifestyle intervention on T2D risk reduction (Assendelft et al., 2012; Vermunt et al., 2010). According to some interviewees, however, proactively targeting individuals with a FH was not considered feasible. Besides practical barriers with regard to time, expertise and financial reimbursement, they indicated that FH is not systematically gathered and EMRs are not equipped to retrieve persons with a FH. These findings are in line with what was declared in the US National Institutes of Health (NIH) statement on 'Family history and improving health' (Berg et al., 2009). In the future, the development of tools to collect standardized FH that are compatible with EMRs may solve this problem (Valdez et al., 2010). In the Netherlands, the implementation of proactive disease prevention linked to primary care may create opportunities to initiate conversations about FH more systematically (Assendelft et al., 2012; Dekker et al., 2011). A lifestyle intervention that uses FH to motivate relatives of T2D patients to maintain good health is currently being evaluated (Heideman et al., 2011b).

The idea of asking patients to pass on risk information was new to all interviewees, but was considered an acceptable strategy to reach persons with a FH. Nevertheless, quite a lot of professionals (especially nurses) were sceptical about the potential benefits of such a strategy. They doubted whether patients would be able to deliver accurate messages in their family. Research already has demonstrated that it would be advisable to provide patients with written information when they are asked to deliver risk and preventive messages in their family. Written information about familial hypercholesterolemia reduced patients’ hesitation and appeared to be helpful in the disclosure of family risk. In another study, information packages served as a cue to action for relatives and legitimated them to ask for a medical check-up (van den Nieuwenhoff et al., 2006).

A study in Japan has indicated that booklets with information about T2D risk and prevention, which were handed over by patients, worked effectively on attitudes and preventive behaviours in relatives. Yet, the reliability of patients as information deliverers appeared to be limited (Nishigaki et al., 2011). This latter finding underlines the doubts that some interviewees expressed in our study. Professionals’ concern that patients may fulfil a negative role model in their family was also indicated as a barrier in the disclosure of family risk by patients themselves (Whitford et al., 2009b). Nevertheless, patients diagnosed with familial hypercholesterolemia seem to prefer a patient-mediated approach more than a direct targeting approach, as they consider it less threatening for relatives (Hallowell et al., 2011).

Limitations
In this study, data were collected from a maximum variation sample of diabetes care professionals in the Netherlands, representing most important disciplines in primary
and secondary diabetes care. Interviews were conducted in an urbanised area, though there are no indications that this may limit the study’s generalizability to all diabetes professionals in the Netherlands. The Dutch health care system, however, might restrict generalizability to an international context.

Next, it should be noticed that the idea of asking patients to inform relatives about familial susceptibility to T2D was new to all interviewees. It would be interesting to explore opinions of professionals who have considered these issues more thoroughly, as (in)directly targeting relatives of index patients may raise ethical questions (Hallowell et al., 2011). In addition, more insight is needed in cultural aspects regarding the disclosure of family risk, the effect of low health literacy and negative modelling in families at risk when utilizing a family-oriented approach in diabetes prevention.

Conclusions
The results of this study suggest that health care professionals in primary, as well as secondary care are open to the idea of using FH in preventive activities. To start, professionals could be stimulated to use the (online) information that is made available by national public health initiatives to inform populations at risk developing T2D, including persons with a FH of the disease (Federation, 2003). In Dutch primary care, the future implementation of a protocol for proactive prevention of non-communicable diseases (Assendelft et al., 2012; Dekker et al., 2011) might provide opportunities to systematically discuss patients’ interpretation of familial susceptibility to a disease and potential effects on health-related behaviour.

Importantly, however, for professionals to adopt family-oriented strategies in the prevention of T2D, convincing evidence is needed regarding the (cost-)effectiveness. Subsequently, professionals (especially nurses) should be educated on how to use FH information, the family system and family communication to promote health-protective activities.
General discussion and conclusions
Type 2 diabetes (T2D) is a serious chronic disease and has become a global health problem (Herman & Zimmet, 2012). In the Netherlands, around 1.3 million people (8% of the population) will be diagnosed with diabetes in 2025 (Baan et al., 2009). In response to that, the Dutch Government has defined highly ambitious goals aiming at reducing the incidence of T2D (Dutch Ministry of Health, 2006). Clinical and public health efforts are made to inform the Dutch public about risk factors for T2D and preventive options.

Research has demonstrated that the family matters, is of importance, in diabetes prevention. A family history of T2D can help to detect persons at increased risk (Valdez et al., 2007), but can also raise the level of awareness about the role of shared genes and environments in families and the need for risk-reducing behaviours (Chang et al., 2011; Pijl et al., 2009b; Qureshi & Kai, 2008; Ruffin et al., 2011; Zlot et al., 2009). The main objective of this thesis is to provide insight in the current and potential use of communication about familial risk of T2D to promote health-protective behaviour in families where T2D is (highly) prevalent. Six sub-studies were presented, in which we set out to explore this question from three perspectives: 1) online public health communications, the point of view of 2) patients with T2D, and 3) health care professionals.

This final chapter summarizes and reflects on the main findings of this thesis. The methodology that was applied in the studies, practice implications and future research will be discussed. To conclude, five key messages are formulated.

Reflection on the main findings

Public health communication

The public availability of information about familial susceptibility to diabetes

More than a decade ago, patients with T2D and their family members seemed to be aware of ‘some’ increased familial susceptibility, but generally underestimated the actual risk percentage and had little knowledge of primary prevention (Adriaanse et al., 2003; Farmer et al., 1999; Forsyth & Goetsch, 1997; Gnanalingham & Manns, 1997; Kemple et al., 2005; Pierce et al., 2001; Pierce et al., 1999). Findings from our study (described in Chapter 2) underline that T2D risk and prevention were of little interest before 2005. Information on the familial character of diabetes provided by renowned diabetes organizations on their websites appeared to be very brief and hard to find. Less than half of the websites provided preventive information that included healthy lifestyle recommendations.

Recent research, however, indicate a growing awareness of family risk and worries about the development of T2D in persons with a family history (Hariri et al., 2006; Nishigaki et al., 2008; Whitford et al., 2009a). After 2005, various (inter)national public health initiatives to promote risk-reducing behaviour were launched and (online) risk assessment tools that include family history of T2D are flourishing.
(Alssema et al., 2012; Holmberg et al., 2011; O’Neill et al., 2009; Orlando et al., 2011; Yoon et al., 2009). Even direct-to-consumer genetic tests for diabetes are available on the Internet (van El & Cornel, 2011). We may assume that the (online) availability of information about diabetes risk factors and preventive options has increased in recent years. The quality of the current (online) information, however, has to be confirmed in further research.

Public need for information on diabetes and inheritance

People are increasingly searching for online information about diabetes (Thakurdesai et al., 2004) and genetics (Taylor et al., 2001). When searching the Internet for information about ‘diabetes and inheritance’ in Dutch (diabetes en erfelijkheid), at least until 2005, Google’s first hit directed to the website of the Dutch National Genetic Research and Information Centre (Erfocentrum.nl). This not-for-profit organization provides online information about inheritable diseases, including all diabetes subtypes and offers visitors the opportunity to ask questions by email.

Using content analysis, we investigated emailed questions of website visitors (Chapter 3). Findings could prove helpful in tailoring clinical and public (online) information to the needs of an increasing population at risk for diabetes. For instance, we learned that not only patients, but also relatives and partners should be addressed and provided with information about the inheritable character of T2D. In line with other research, persons seeking for information were relatively young (<30 years) and predominantly female (Powell et al., 2011). Most questioners appeared to be in need of risk information; others were looking for clarifying information about the genetics of diabetes or advice. The genetics of type 1 diabetes, (future) pregnancy and family planning were the most queried topics. Although we observed an increase in emailed queries between 2005 and 2009, the number of questions asked about T2D and inheritance remained relatively low. In line with that, health care professionals also indicated that patients rarely ask questions about the inheritable character of T2D (Chapter 7). Nor could professionals recall patients referring to or asking questions about the information about diabetes risk and prevention that was provided by mass media campaigns of the Dutch National Action Programme (NAD) (Dutch Diabetes Federation, 2009) and the Dutch Diabetes Foundation. This seemingly lack of (public) interest seems at odds with the increasing awareness of familial risk and worries about the development of T2D in persons with a family history (Hariri et al., 2006; Nishigaki et al., 2008; Whitford et al., 2009a).

The patients’ perspective

Patients as messenger in the family

In line with earlier research (Nishigaki et al., 2009; Whitford et al., 2009b), sixty per cent of the patients in our study sample was willing to disclose familial diabetes risk (Chapter 4). Discussing T2D in everyday communication appeared to be acceptable
in 80% of the families. Moreover, communication about T2D with family members seems to be open and supportive in most of the participants’ families (Chapter 6), which is considered of crucial importance in applying a family approach in diabetes prevention (Wiseman et al., 2010).

Patients appeared to be positive about their ability to disseminate risk and preventive messages in their family. Around three-quarter of all patients indicated they are well informed about diabetes risk and prevention, knowing “what to tell, how to tell and whom to inform”. According to these findings, asking patients to pass on risk and preventive information in their families seems to be a feasible strategy targeting high-risk relatives of patients with T2D. However, one must not overlook the fact that in approximately 20% of the families, T2D is never discussed and 40% of the patients resent being a health messenger in the family (Chapter 4). Stimulating diabetes-related communication seems not be appropriate in these families.

**Worry seems to be an important determinant in the process of family risk disclosure**

It appeared that a majority of the participants in our study (61%) considered the development of T2D (very) likely in their first-degree and/or second-degree relatives. Less than half of the patients (41%) reported positive beliefs regarding the possibility of their relatives to prevent or postpone T2D onset (Chapter 4, 5). Similar percentages were reported in earlier research (Pierce et al., 1999; Whitford et al., 2009b). Worry about the future health of relatives appeared to be an important motivator of patients’ willingness to serve as a health educator in their family, as was also reported by Whitford et al. (2009). In addition, perceived self-efficacy of patients (Schwarzer & Fuchs, 1996), expressed in knowing what to tell, whom to notify and the presence of everyday conversations about diabetes, appeared to be predisposing factors regarding family risk disclosure (Chapter 4).

Interestingly, family risk perceptions of patients appeared not to have a direct effect on their intentions to inform relatives, rather perceived risk exerts an indirect effect through worries about relatives’ health and personal beliefs about T2D prevention (Chapter 4). Research carried out in the area of cancer control behaviours has reported considerable variability in the observed relationships of perceived risk, worries and control beliefs with cancer protective behaviours (Cameron & Reeve, 2006; Consedine et al., 2004). There are studies reporting situations in which worries and fear predict breast cancer screening behaviours, whereas risk judgments do not (Cameron & Diefenbach, 2001; Diefenbach et al., 1999). Also in the area of influenza vaccination, anticipated worry and regret were stronger predictors of vaccination than perceived risk (Chapman & Coups, 2006).

Research from clinical, physiological and (subfields of) psychology demonstrated that emotional reactions and cognitive evaluations typically work in concert to guide reasoning and decision making. However, emotional reactions to risky situations sometimes diverge from cognitive evaluations and, when they do, emotional reactions
may drive behaviour. In other words, feelings may be more than just an important input into decision-making under uncertainty; they may be necessary and, to a large degree, mediate the connection between cognitive evaluations of risk and risk-related behaviour (Loewenstein et al., 2001). In line with that, a hypothesis described in cancer-related research suggests that if the effectiveness of a health-protective action is unknown or modest, then cognitive risk appraisals may be only weakly associated with the use of that action, whereas emotional appraisal may motivate behaviour due to hopes that it might provide some protection (Cameron, 2003).

**Personal illness representations of patients underpin perceived diabetes threat in relatives**

Asking patients to pass on risk and preventive information puts them within an active role to discuss familial diabetes threat in their family. It was argued that insight is needed to guide—and potentially improve—patients in the process of disclosure of familial T2D risk (Hallowell et al., 2011). Diverse health behavioural theories describe that people react to the prospect of risk at two levels: they evaluate the risk cognitively and they react to it emotionally. Although the two reactions are interrelated, with cognitive appraisals giving rise to emotions and emotions influencing appraisals, the two types of reactions may have different underlying determinants (Leventhal et al., 2003; Loewenstein et al., 2001; Weinstein, 1993).

The study in Chapter 5 indicated that personal illness representations of patients appeared to be useful in understanding their family risk perceptions, worries and belief in preventive options in relatives. Patients who perceived their diabetes as a serious, unpredictable disease appeared to have higher family risk perceptions and more worries about relatives developing T2D. Reporting serious daily consequences and high emotional impact were most strongly associated with elevated levels of concern. Moreover, patients with coherent illness beliefs and perceiving control over their disease reported positive beliefs about the possibilities for relatives to postpone or prevent diabetes onset, whereas patients attributing to chance/bad luck reported less positive control beliefs. These findings are in line with the mental contents underlying a person’s own health risk appraisal (Cameron, 2008; Kaptein et al., 2007; Leventhal et al., 2003).

**A family-oriented prevention strategy targeting Surinamese-South Asian families**

As described in Chapter 6, patients from Surinamese South-Asian descent expressed a higher motivation to inform their relatives about T2D risk than Dutch patients did. Findings also suggested a trend towards more ‘openness’ in discussing diabetes in Surinamese families. The family bonding seemed to be strong, not only with offspring but also with the wider family (siblings, aunts/uncles and grandparents). According to these results, a patient-mediated prevention strategy targeting at-risk relatives in Surinamese South-Asian families seems justifiable. A recent study among another Surinamese population in the Netherlands confirmed the willingness in this group to talk about diabetes with family members and friends (Kohinor et al., 2011).
Interestingly, it was noticed that Surinamese-South Asian patients expressed higher family risk perceptions and more worries than Dutch patients (Chapter 6). In a multivariate regression analysis, however, ethnic backgrounds as such appeared not to be associated with increased family risk perceptions. Other characteristics, as family history and age, largely explained the variance in familial diabetes risk perceptions instead. Being of non-Dutch descent, on the other hand, appeared to be an independent determinant of patients’ increased worries about relatives developing T2D (Chapter 5). In contrast to what could have been expected based on reported severe diabetes burden (Bathula et al., 2010) and cultural ideas about the role of fate in life (Davison et al., 1992; Dickinson & Bhatt, 1994), Surinamese patients did not express more fatalistic beliefs than Dutch patients did. About forty per cent of both study populations was inclined to believe that relatives might be able to postpone or prevent diabetes onset (Chapter 6).

The interplay between family risk perceptions of patients, their worries and control beliefs in the process of family risk disclosure, as investigated in Chapter 4, was adjusted for ethnic backgrounds. Neither did we differentiate between ethnic groups investigating illness beliefs of patients in relation to perceived diabetes threat in relatives (Chapter 5). Differences in illness beliefs with regard to causal attributions and personal control, however, may be assumed in South-Asian and Caucasian populations (Bean et al., 2007; Macaden & Clarke, 2006). Therefore, the applicability of the study findings (Chapter 4 and 5) in Surinamese South-Asians patients merits further investigation.

Health care professionals’ perspective

Using family history in preventive consultations

In Dutch medical practice, family history information is not structurally used to promote health-protective behaviour. Health care professionals were not aware of the potential positive effect of personalized education on the recognition of diabetes risk, screening possibilities, perceived personal control and the need of healthy behaviour (Chang et al., 2011; Pijl et al., 2009b; Qureshi & Kai, 2008; Ruffin et al., 2011; Zlot et al., 2009). Nevertheless, primary care professionals were open to the idea of using family history in preventive activities, as they were interested in new strategies to promote and motivate health-protective behaviour in patients at risk developing T2D (Chapter 7). Currently, however, proactively targeting individuals with a family history was not considered feasible. Besides practical barriers with regard to time, expertise and financial reimbursement, findings suggest that professionals lack expertise and tools to assess, register and use family history accurately.

The potential of a patient-mediated approach targeting relatives at risk

The idea of asking patients to pass on risk and preventive information was new to all interviewed professionals, but was considered an acceptable strategy to reach persons with a family history of T2D. Nevertheless, quite a lot of professionals in first as
well as secondary care (especially nurses) were not convinced of the benefits of such a targeting strategy (Chapter 7). Targeted diabetes education, however, seems to increase the recognition of diabetes risk, screening possibilities, perceived personal control and the need of healthy behaviour in persons with a family history of T2D (Chang et al., 2011; Pijl et al., 2009; Qureshi & Kai, 2008; Ruffin et al., 2011; Zlot et al., 2009). Relatives, who were informed via the family system, perceived themselves at increased risk developing diabetes (Pierce et al., 2000; Whitford et al., 2009a).

Behavioural outcomes, on the other hand, have received limited attention yet. A study in Japan has indicated that booklets with diabetes risk and preventive information, which were handed over by patients, worked effectively on attitudes and preventive behaviours in relatives, however the reliability of patients as information deliverers appeared to be limited (Nishigaki et al., 2011). This latter observation stresses the importance of professional guidance in the process of family risk disclosure. Professionals are right in stating that more insight is needed in cultural aspects regarding the disclosure of family risk, the effect of low health literacy and negative modelling in families at risk when utilizing a family-oriented approach in diabetes prevention.

Reflection on research methods and theory

Several methods were used to answer the research questions as outlined in the Introduction. All studies in this thesis were observational and explorative in nature. In the interpretation of the main findings, some strengths and limitations of the research methods warrant further consideration.

Qualitative research methods

In the studies reported in Chapter 2, 3 and 7, we used a qualitative study design. Data consisted of, respectively, website information, emailed questions and interview transcripts. In all three studies we conducted thematic content analyses, which is an established social science methodology concerned with thematically analysing qualitative data (Boyatzis, 1998). This means that a priori coding labels were formulated based on the research questions in the study. In addition, new themes were generated inductively from the raw data with constant comparison between researchers. In Chapter 2 and 3, after qualitative classification, data were quantified in order to observe the distribution of coding labels within the emerged categories. In Chapter 7, (sub-)codes were grouped in thematic matrices and similarities, variations and patterns among the professional groups were summarized.

Subjectivity in data collection and analyses

To enlarge the reliability and validity of the study outcomes, data were analysed by representative interpreters with expertise in the field. In each study, two researchers
established the initial code list for fragments and the coding process was exercised. Data were analysed twice by different researchers and checked for inter-coder consensus concerning the assignment of text segments to major themes. Ambiguities were resolved in discussion with the research team, which included two senior researchers and the main results of the study were discussed to receive feedback about the plausibility of the conclusions. However, in qualitative studies, researchers make decisions in the data retrieval and analysing process that may encompass subjective elements. For instance, data collection and analysis in Chapter 2 and Chapter 7 was done by the researchers themselves and, consequently, may have generated researcher bias. Researchers’ knowledge and ideas might contribute to blind spots and disproportional focus on specific elements.

The use of Atlas.ti software (Muhr, 1994) enabled us to make notes about decisions in the analysing process and reflections on the data. In that way, consistency of the data analyses could be verified by examination of the steps taken in the process.

Use of secondary data
In Chapter 3, we conducted content analysis on secondary data. Data from secondary sources have been collected by others and not specifically for the research question at hand. (Hakim, 1982). Our study was strengthened by the fact that data were collected from a registry of people searching for information in a ‘natural’ setting, as opposed to using questionnaires to explore knowledge and information needs on genetics in a (high-risk) clinical setting or in general public. We were able to explore questions based on individual perceptions and interests, described in people’s own words. Because of this unobtrusive data collection, social desirability response bias was reduced considerably (Hakim, 1982). Moreover, the research methods using secondary data are often more easily amenable to replication and to validity and reliability checks than some methods used to collect primary data in social settings (Frankfort-Nachmias & Nachmias, 1996).

A limitation of this method, however, is that we could not exercise any control over the data generation and recording. We were unable to expand our understanding further by posing additional questions, for example, about the amount of visitors actually reading the information provided on the website, the degree of understanding provided information and perceived utility of the expert answers received. This may restrict the quality and depth of the contextual nature of the data (Szabo & Strang, 1997).

Generalization
The selection of 34 websites in Chapter 2 was restricted by choice of languages and limited the study’s generalizability. Furthermore, the Internet is a fast-moving medium and results from a study conducted in 2005 are no longer applicable to the current situation. The generalizability of the findings derived from emailed questions that we explored (Chapter 3) is limited as well, because of its reliance on data gathered by only one web based supplier of genetic information. Noticeably, people submitting questions via the Internet may represent a selective group and we
cannot exclude selection bias. On the other hand, the 172 queries that were available generated a study sample that was rich enough to emerge categories reflecting interesting themes and tendencies to describe.

In the interview study described in Chapter 7, data were collected from a maximum variation sample of diabetes care professionals in the Netherlands, representing most important disciplines in primary and secondary diabetes care. Interviews were conducted in an urbanised area, covering only a small part of the Netherlands. We have no indications that this might limit the study’s generalizability to all diabetes professionals in this country. However, the Dutch health care system might restrict generalizability to an international context.

**Quantitative research methods**

In the studies reported in Chapter 4, 5 and 6, we used a quantitative approach to explore factors that may influence the process of family risk disclosure. These studies relied on data obtained through self-report questionnaires.

**Study design**

It is important to notice that causality cannot be proven in a cross-sectional study design. Results of multivariate logistic regression and multiple mediation analyses reflect correlations between variables. Causal patterns were assumed, based on the Common-Sense Model (CSM) of self-regulation of health and illness (Cameron, 2003; Leventhal et al., 2003), in which risk perceptions, worries and control beliefs precede (the intentions towards) health-protective behaviour. However, we have to take into account that the CSM is described as a dynamic processing system, in which illness representations, behaviour and emotions evolve and change over time (Leventhal et al., 2003). Moreover, a problem with self-report questionnaires is that they may be susceptible to social desirability bias and poor patient recall (King & Bruner, 2000). Indeed, over-reporting of diabetes-related communication in the Surinamese sample should be taken into account, since social desirability is known in populations with Asian background (Zane & Yeh, 2002).

**Participants**

Patient recruitment in primary as well as secondary care resulted in a study sample that resembled the population with T2D in the Netherlands with regard to socio-demographic and diabetes-related characteristics (van Dam et al., 1991). A mixed population was included, representing minority groups in the Netherlands with high diabetes prevalence (Weijers et al., 1998). Because of exceptional high diabetes risk (Middelkoop et al., 1999), the Surinamese South-Asian population was purposefully over-sampled, which may limit the study’s generalizability with regard to other ethnic populations.

Another drawback is that we could not rule out selection bias. The response rate was low at 41%, but not too far from other questionnaire studies (e.g., Whitford et al., 2009b).
On the other hand, the study sample was relatively large. There were no differences between responders and non-responders in gender and treatment in primary- or secondary care. Non-responders, however, were on average five years younger than respondents were. Non-response analyses revealed that only a minority of the reported reasons for not participating in the study referred to ‘lack of family contact’, ‘being the only diabetes patient in the family’, or ‘not wanting to bother relatives’. Another possible source of selection bias is the motivation of the participating patients. Presumably, the study sample consisted of highly motivated patients being more enthusiastic about engaging with their families than non-responders.

Measurement instruments

We used single-item measures to assess patients’ cognitive and emotional appraisal of diabetes threat in their relatives. Although the reliability of a measure may be compromised by single-item measures, we decided to use these measures to enable comparison with earlier studies conducted in the field of diabetes. Indeed, family risk perceptions of patients and beliefs about diabetes prevention are consistent with these studies, although the number of participants expressing worries about their relatives’ health in our study seemed rather low (Nishigaki et al., 2007; Pierce et al., 1999; Whitford et al., 2009b).

Illness representations were assessed using the Dutch version of the Illness Perception Questionnaire Revised (IPQ-R; Moss-Morris et al., 2002), adapted for T2D. The IPQ-R scales have been tested in a variety of patients, including T2D and have been found to have adequate test-retest reliability and internal validity (Moss-Morris et al., 2002; Skinner et al., 2003). The internal consistency of the IPQ-R subscales was acceptable or good (Cronbach’s alpha > .7 or > .8), except for personal and treatment control (α = .66 and α = .58 respectively) (George & Mallery, 2003). The internal reliability of these subscales could not be improved by item reduction. Generally, illness representations in our study sample were consistent with recent literature on T2D, although scores on the identity dimension appeared to be rather low (Paschalides et al., 2004; Searle et al., 2007b).

Implications and recommendations

Some implications and recommendations for public health communications, clinical practice and research follow from the findings described in this research project.

Public health communications should be combined with interpersonal interactions

The World Wide Web may offer a unique opportunity to disseminate diabetes risk and preventive information on a large scale. It seems important that information
on the contribution of genetics to type 1 diabetes, (future) pregnancy and family planning becomes more readily available, as these topics are inquired most of the time. More effort seems needed to promote awareness around familial clustering and primary prevention of T2D (Chapter 3).

Targeted and well-executed mass media communications can have small-to-moderate effects on health knowledge, beliefs and attitudes and are considered an effective initial strategy to raise awareness of health related risks (Noar, 2006). Additional interpersonal interactions, however, are needed to reach low literate groups (Birru et al., 2004), like ethnic minorities and people in low social classes, who are at increased risk developing T2D (Allgot et al., 2003; Everson et al., 2002; King & Rewers, 1993; Mather & Keen, 1985; Rich, 1990). Moreover, face-to-face interactions are required to produce the desired behaviour change (Rimer & Kreuter, 2006; Wanyonyi et al., 2011; Westmaas et al., 2007). Therefore, it seems important that Dutch health care professionals adopt and continue the efforts made in national public health initiatives. Currently, however, only a small minority of the professionals that were interviewed was familiar with mass media campaigns of the Dutch National Action Program (NAD) (Dutch Diabetes Federation, 2009) and the Dutch Diabetes Foundation. None of the professionals, except for one nurse practitioner, paid attention to these public health initiatives nor did they visit or refer patients to the websites (Chapter 7).

**Family matters**

Research has demonstrated that the family matters, is of importance, in diabetes prevention. In the literature, it is demonstrated that family history not only can be used to detect persons at risk developing T2D, but evidence also suggests that preventive messages tailored to a person's FH can increase risk awareness and risk-reducing behaviours (Chang et al., 2011; Qureshi & Kai, 2008; Ruffin et al., 2011). In addition, studies in this thesis shed light on family matters, e.g., family risk perception, family relations and concern about relatives that might influence the usability of a family-oriented approach in the prevention of T2D.

Findings indicated that the family system could be used as an additional strategy to reach and educate persons at risk developing diabetes in Dutch as well as Surinamese South-Asian families. Generally, family communication about diabetes is not a taboo in most families and patients seem willing to pass on risk and preventive information in their family (Chapter 4 and 6). These findings could encourage professionals to initiate conversations about familial susceptibility to T2D in families at high risk.

An active role for patients in the prevention of diabetes in their family requires professional guidance (Hallowell et al., 2011). The results in our study learn that health care professionals should address worries when they guide their patients in the process of disclosure of T2D family risk. Yet, efforts to develop interventions to
promote health-protective behaviour will still require attention to risk cognitions. First, knowledge of risk factors is essential to facilitate the delivery of accurate messages in the family. Secondly, promoting health-protective behaviour cannot successfully target worries alone, because worries cannot be altered permanently without changing the risk cognitions that elicit this affective response (Cameron, 2003). However, arousing fear may be counterproductive when people do not perceive themselves to be able to engage in risk reducing actions and believe that their actions will work in averting or minimizing the threat (Witte & Allen, 2000). Therefore, providing risk information that may generate perceptions of threat always should be combined with information about how to control the threat.

The study in Chapter 5 indicated that personal illness representations of patients appeared to be useful in understanding their family risk perceptions, worries and belief in preventive options. Eliciting the patient’s perspective and illness representations will optimize the acceptance of information that could correct patients’ cognitions (Phillips et al., 2012; Rimer & Kreuter, 2006). Addressing unhelpful beliefs regarding to, for instance, causal attribution and the controllability of T2D (onset) seems most important targets when guiding patients in the process of family risk disclosure. In addition, assessment of illness representations may help professionals to identify patients who are assumed to be most successful as messenger in their family. Findings suggest that patients with positive control beliefs seem able to deliver accurate risk messages in their family as they reported causal factors (like diet/eating habits, lacking exercise, stress/worry and one’s own behaviour) that are in accordance with known risk factors (American Diabetes Association, 2007; Pyykkonen et al., 2010) (Chapter 5). Unfortunately, only less than half of the study population did express positive beliefs about diabetes prevention. Possibilities of T2D prevention in relatives should be emphasized, specifically in low educated patients.

**Ethical considerations**

Systematically approaching relatives of patients affected by an inheritable disease, like in cascade screening, is subject of ethical discussion. Objections include that it undermines the autonomy of relatives. It might be interpreted as an invasion of their privacy, particularly their right ‘not to know’ that they are at risk (de Wert, 2005). Professionals in our study did not report ethical objections targeting patients with a family history of T2D. It was argued that reaching and informing relatives in a neutral and thoughtful manner will give them the opportunity to make informed decisions regarding the uptake of preventive actions. One diabetes specialist in secondary care indicated that, in case of monogenetic disorders, they always inform patients about familial susceptibility to the disease. The only difference, according to this specialist, is the multifactorial aetiology of T2D, which makes the message more difficult to explain (Chapter 7). Noticeably, the idea of asking patients to inform
relatives about familial susceptibility to T2D was new to all interviewees. Opinions of professionals who have considered the idea of utilizing cascade screening in diabetes prevention in more detail should be explored in future research.

A substantial part of the patients (about 40%) was not willing to serve as a messenger in their family (Chapter 4 and 6). Stimulating diabetes-related family communication is not appropriate in those families. Unfortunately, we have no information about the reasons for rejecting disclosure of family risk in our study, besides the finding that diabetes was not a topic of conversation in 20% of the families. In other research, it was argued that patients might struggle between ideas about their duty to inform versus not wanting to upset their family (Forrest et al., 2003). However, there is no evidence that informing individuals about their familial risk might cause psychological harm (Pierce et al., 2000; Pijl et al., 2009b; Qureshi et al., 2001). A recent study indicated that patients diagnosed with familial hypercholesterolemia preferred to be involved in risk disclosure in their family, as they considered a direct targeting approach by professionals more threatening for their relatives (Hallowell et al., 2011).

**Implementation strategies**

The National Diabetes Action Programme (NAD), which was instigated by the Dutch Government (Dutch Ministry of Health, 2006), will operate until 2013 (Dutch Diabetes Federation, 2009). After that, medical professionals will have to continue the activities that were initiated in the past years, aiming at the prevention of T2D. Clinically and practically, however, it seems (cost-)effective to aim at primary prevention of a broader spectrum of multi factorial diseases, like obesity and cardiovascular disease. Family history is a risk factor for many lifestyle-related diseases and can be incorporated into efforts to address many diseases of public health importance.

Currently, family history information seems not actively used to promote health-protective behaviour in Dutch medical practice. Most professionals that were interviewed, however, were interested in discussing the understanding of familial risk in relatives of patients with T2D to motivate them to engage in risk-reducing behaviours (Chapter 7). In the Netherlands, a new Practice Guideline entitled ‘Prevention Visit’ (*het Preventieconsult*) has been developed for the prevention of cardio metabolic diseases in primary care (Assendelft et al., 2012; Dekker et al., 2011). This programmatic prevention protocol might provide opportunities to use family history to personalize health-promoting information. It also appeared that an active and personal approach increased the screening uptake of participants for a lifestyle intervention on T2D risk reduction (Assendelft et al., 2012; Vermunt et al., 2010). Therefore, the use of a family-oriented approach may appear useful as additional strategy to reach the target population. For that, however, professionals should be educated on how to use family history information, the family system and family communication adequately to promote health-protective activities.
When asking patients to deliver risk and preventive messages in their family, it would be advisable to provide them with written information. After all, written information packages about familial hypercholesterolemia reduced patients’ hesitation and appeared to be helpful in the disclosure of family risk. Moreover, the information packages served as a cue to action for relatives and legitimated them to ask for a medical check-up (van den Nieuwenhoff et al., 2006). In addition, a study in Japan has indicated that booklets with diabetes risk and preventive information, which were handed over by patients, worked effectively on attitudes and preventive behaviours in relatives (Nishigaki et al., 2011). When designing preventive activities targeting families at risk from different ethnic backgrounds, it seems inevitable that professionals have to identify cultural and community conventions and work with factors that influence the disclosure of familial susceptibility to diabetes in these populations (Hawthorne et al., 2008).

Next, when persons with a family history of diabetes turn to their physician for advice, preferably, they should be enrolled in preventive programmes. As yet, lifestyle interventions specifically aiming at prevention of T2D in people with a family history are scarce (Heideman et al., 2011a). Currently, however, a lifestyle intervention that uses family history to motivate relatives of T2D patients to maintain good health is being evaluated (Heideman et al., 2011b). A culturally adapted version targeting the migrant population from Turkey in the Netherlands is underway.

**Future directions in research**

Several issues raised in this thesis deserve more attention in further research. Learning from the limitations in our research (Chapter 4, 5 and 6), we would suggest to use multi-item measures to increase the reliability and validity of the measured constructs of family risk perceptions, worries and control beliefs in future research. For instance, multi-item measures of risk-related cognitions and affect are constructed and used in the field of genetic susceptibility (Cameron & Diefenbach, 2001; Cameron & Reeve, 2006; Cameron et al., 2009). Moreover, repeated measures would provide more insight into the dynamic relationships between patients’ cognitive and emotional appraisal of diabetes threat in relatives and the effect on intentions of patients to protect their relatives’ health (Chapter 4).

One of the main topics for further research and debate include the feasibility and the (cost-)effectiveness of direct as well as patient-mediated approaches, targeting persons with a family history of T2D and/or other common multifactorial diseases, like obesity and cardiovascular disease. It should be explored whether utilising family communication as prevention strategy shows similar opportunities in families from different ethnic backgrounds, as was found in Surinamese South-Asian families.

Next, we know too little about the content, process and impact of familial communications about disease risk initiated by index patients. For example, what
factors influence decisions to communicate risk information to some relatives and not to others? How detailed is increased familial risk communicated and how accurate is this information? How does it affect relatives being confronted with risk estimations regarding diseases occurring in their family? Does family communication about diabetes threat encourage or discourage health-protective actions in relatives? Do relatives feel overloaded with risk information and does it lead to avoidance and defensive reactions? What is the best timing to discuss familial susceptibility; shortly after diagnosis, when patients are confronted with increased diabetes burden and/or complications or when special events occur in the family?

More insight is needed into ethical issues, the cultural aspects in family communication, the effect of low health literacy and negative modelling of patients in families at high risk. Finally, medical professionals generally seem to support a more extensive use of family history and family communication, but how can they best be trained to carry out family-oriented strategies in diabetes prevention?

Key messages

The studies presented in this thesis have provided better insight into the usability of family history and family communication to promote health-protective behaviour in families where T2D is (highly) prevalent. Five key messages can be formulated.

1. More effort seems needed to explain the multifactorial aetiology of type 2 diabetes and to promote opportunities to delay or prevent disease onset. Health care professionals should adopt and continue the efforts made in public health initiatives and motivate behaviour change in a growing population at risk developing diabetes, including persons with a family history of T2D.

2. The studies described in the thesis show that family communication about diabetes is not a taboo in most families. Asking patients to pass on risk information might be a potential additional strategy to reach persons in Dutch as well as Surinamese South-Asian families at high diabetes risk. However, outcomes also underscore the complexities colouring the disclosure process, including family-related issues and the personal coping mechanisms of patients.

3. To facilitate the delivery of accurate messages by patients in high-risk families, health care professionals should not only provide risk information, but they also should address patients’ worries and emphasize the possibilities of T2D prevention in relatives. Moreover, to optimize the acceptance of information, (unhelpful) illness representations of patients with diabetes should be discussed.

4. The study’s results underline professionals’ willingness to give family history a more profound role in preventive activities. Outcomes also lend support for the
adoption of direct as well as patient-mediated methods to target persons with a family history. Professionals should be educated on how to use family history information, the family system and family communication adequately.

5. Studies are needed to investigate the feasibility and (cost-)effectiveness of a family-oriented approach in T2D prevention, especially when targeting persons with different ethnic backgrounds and/or low literacy.
Summary & Samenvatting
Family matters in diabetes prevention

Communication about familial risk to type 2 diabetes

Type 2 diabetes (T2D) is a progressive disorder characterised by chronically elevated blood glucose levels (hyperglycaemia). As the diabetes epidemic spreads worldwide, there is a growing need for preventive actions targeting populations at high risk. Family history is considered an important risk factor; the chance of developing T2D is two-to-five times higher for people with affected relatives. Importantly, T2D onset can be delayed or prevented by means of lifestyle modifications, even in persons with a family history.

Research has demonstrated that the family matters, is of importance, in diabetes prevention. A family history of T2D can help to detect persons at increased risk, but can also raise the level of awareness about the role of shared genes and environments in families and the need for risk-reducing behaviours. Studies in this thesis shed light on family matters (e.g., family risk perception, family relations and concern about relatives) that might influence the usability of a family-oriented approach in the prevention of T2D.

The main objective was to provide insight in the current and potential use of communication about familial risk of T2D to promote health-protective behaviour in families where T2D is (highly) prevalent. From the viewpoint of public health initiatives, the online availability of and public need for information about familial susceptibility to diabetes was investigated. Subsequently, personal and familial factors were investigated to further understand the mental constructs that underlie the process of family risk disclosure in patients with T2D. The usability of such a patient-mediated targeting strategy in diabetes prevention was investigated in patients of Dutch as well as Surinamese South-Asian descent, as diabetes prevalence and disease burden is extremely high in the latter group. Finally, opinions of health care professionals were explored with regard to current and future uptake of the use of family history and family communication in diabetes prevention.

Type 2 diabetes and inheritance: what information do diabetes organizations provide on the Internet?

The first study that is described in this thesis (Chapter 2) was conducted in 2005. The aim was to explore what information on inheritance, T2D and primary prevention was provided on websites of renowned diabetes organizations, whether this information was targeted at high-risk groups based on family history and/or
ethnic backgrounds and to what extent patients with T2D were urged to notify relatives on their increased familial susceptibility. Using qualitative content analysis, 34 websites of national diabetes patient organizations (associated member organizations of the International Diabetes Federations; IDF) that provided health-related information on diabetes in English, German, French, Dutch, Spanish, Portuguese, Swedish, Norwegian, Finnish, Danish and Japanese were investigated.

It appeared that most websites mentioned family history as a risk factor. However, the information that was provided was very brief, not explaining the interaction between genes and environment and importantly, it was hard to find on most websites. Ethnicity as a risk factor was mentioned by only half of the included websites; ethnic groups were not specified or when specified sometimes of little relevance to that specific region. Most websites did provide information on the importance of a healthy lifestyle; however, they did not address specific groups at high risk. This would imply that people have to combine risk information (‘do I belong to a group at high risk?’) and preventive information (‘is this preventive information relevant for me?’) themselves. Despite the recommendations of the IDF, only two websites took up the challenge of stimulating patients to inform relatives about their increased susceptibility. No recommendations were made about what information should be conveyed by patients, how and to which relatives. It was concluded that efforts should be made by diabetes organizations to disseminate information on heredity of T2D and preventive options to the general public and populations at high risk.

Questions asked by email about the role of genetic susceptibility to diabetes

In the Netherlands, the National Genetic Research and Information Centre (Erfocentrum) provides online information about more than 600 inheritable disorders, including all diabetes subtypes. Moreover, the website offers visitors the opportunity to ask questions per email. Chapter 3 presents a qualitative study, investigating the need of (additional) information of website visitors about the role of inheritance in diabetes. Using secondary content analysis, 172 emailed questions about diabetes and inheritance, posted in 2005-2009, were investigated. Depending on whether or not visitors did read the provided information, the emailed questions reflect their information needs, unaddressed issues, areas of uncertainty or difficult to understand concepts.

It appeared that visitors utilising the opportunity to ask questions were relatively young and predominantly female. Questioners were diabetes patients, as well as relatives or partners of patients with diabetes. Most queries related to type 1 diabetes and concerned topics related to (future) pregnancy and family planning. Questioners mainly asked for risk estimation, but also clarifying information (about genetics of diabetes in general) and advice (mostly related to family planning) was requested. Preventive advice to reduce own diabetes risk was hardly sought.
It was concluded that information on the contribution of genetics to type 1 diabetes should be more readily available. In addition, considering the high prevalence of type 2 diabetes with strong evidence for a genetic predisposition, more effort seems needed to promote awareness around familial clustering and primary prevention.

**Patients’ intentions to inform relatives about type 2 diabetes risk: the role of worries in the process of family risk disclosure**

The study in Chapter 4 aimed to obtain further understanding of determinants that influence the decisional process of familial risk disclosure in patients with diabetes. In a cross-sectional study, patients with T2D (N=546) filled in a questionnaire assessing family risk perceptions, worries, personal beliefs regarding diabetes prevention, diabetes-related family communication, intentions and perceived ability to inform relatives about familial risk of diabetes. Data were analysed using hierarchical logistic regression and multiple mediation analyses.

Sixty percent of the patients were willing to inform relatives about familial diabetes risk; 61% reported high family risk perceptions, 31% expressed serious concern about relatives developing diabetes and 41% had positive control beliefs with regard to preventive options in relatives. Worries about relatives, knowing what to tell, whom to notify and communication about diabetes in general appeared to facilitate the disclosure of family risk. Unexpectedly, high family risk perception in itself did not significantly increase the intentions of patients to inform relatives; rather, risk perceptions appeared to exert an indirect effect through worries and beliefs about diabetes prevention. Findings in this study underscore the importance of worries as determinant in the process of family risk disclosure. When professionals guide their patients in this process, they should not only provide risk information, but also address worries and emphasize opportunities for diabetes prevention.

**Illness representations of type 2 diabetes patients are associated with perceptions of diabetes risk in their relatives**

The next study (Chapter 5) aimed to identify illness representations of patients with T2D that underlie their cognitive and emotional appraisal of diabetes threat in close relatives. Data were gathered from 546 T2D patients in a cross-sectional design. Measures of illness representations (IPQ-R), perceived diabetes risk in relatives, beliefs regarding diabetes prevention in relatives and worries about relatives developing the disease were assessed using self-report questionnaires. Multiple logistic regression analyses were conducted, adjusting for demographics and diabetes-related characteristics.

Findings indicated that, generally, patients perceived their T2D as a chronic illness that was controllable and they mentioned no serious daily consequences or emotional impact.
Patients, however, who perceived their diabetes as a serious, unpredictable disease appeared to have higher family risk perceptions and more worries about relatives developing T2D. Reporting serious daily consequences and high emotional impact were most strongly associated with elevated levels of concern. Moreover, patients with coherent illness beliefs and perceiving control over their disease reported positive beliefs about the possibilities for relatives to postpone or prevent diabetes onset, whereas patients attributing to chance/bad luck reported less positive control beliefs.

In line with the mental contents underlying a person’s own health risk appraisals, illness representations of patients with T2D may serve as the basis for their cognitive and emotional appraisal of diabetes threat in relatives. When patients are asked to play a more active role in the prevention of diabetes in their family, findings could help medical professionals to address potential unhelpful cognitions with regard to, for instance, causal attribution and the controllability of T2D (onset) and improve the information that patients might communicate with their relatives.

**Family communication as strategy in diabetes prevention; a multi ethnic observational study in families with Dutch and Surinamese South-Asian ancestry**

**Chapter 6** presents the results of a study that explored possible facilitating and impeding factors in utilising family communication as a strategy in primary prevention of diabetes, specifically targeting families with South-Asian ancestry in the Netherlands at high T2D risk. In this study, data from 311 T2D patients from Dutch origin and 157 from Surinamese South-Asian descent were analysed. The results did not reveal specific barriers targeting Surinamese families at high risk. In fact, discussing diabetes is regarded acceptable in most families. Especially Surinamese South-Asian patients (68%) seemed motivated to convey risk messages to their relatives, as compared to 55% in Dutch patients. Surinamese South-Asian patients reported higher risk perceptions and expressed more concern than Dutch patients. While 40% in both groups thought relatives are able to prevent developing diabetes, 46% in Dutch and 33% in Surinamese South-Asian patients were unsure.

Clearly, knowledge is essential to facilitate the delivery of accurate messages in the family. To enhance the effect of family-oriented interventions, patients should be educated about increased familial risk. Thereby, it is important that health care deliverers address concern of patients, emphasize opportunities for prevention and provide recommendations about how, when and which relatives to inform. Finally, we must not overlook the fact that in some families diabetes is never discussed and patients might resent being a health messenger in their family. Stimulating diabetes-related communication would obviously not be appropriate in these families.
Health care providers’ perspective on using family history in the prevention of type 2 diabetes: a qualitative study including different disciplines

Chapter 7 presents the results of a qualitative study among Dutch primary and secondary care professionals. The study aimed to explore attitudes of professionals with regard to current or future uptake of a more extensive use of family history information and the family system in diabetes prevention. After all, family history not only has been recognized as an important risk stratification factor, but also can be used to personalize risk messages to motivate risk-reducing behaviours.

Semi-structured interviews were conducted with a purposive sample of nineteen health care professionals, including general practitioners, practice nurses, diabetes specialists and diabetes nurses. The use of family history in preventive consultations was explored as well as the usability of a direct versus indirect, patients-mediated targeting strategy to reach persons with a family history of T2D. Three researchers analysed interview transcripts separately.

It was found that, generally, Dutch health care professionals expressed positive attitudes with regard to using family history information to promote health-protective behaviour. Directly targeting patients known to have a family history of T2D was desirable for most primary care professionals, but not considered feasible. Practical barriers with regard to time, expertise and financial reimbursement were mentioned. Findings also indicated that family history information was not systematically gathered and electronic medical records were not equipped to retrieve persons with T2D running in their family. The idea of asking patients to pass on risk and preventive information was new to all interviewees, but was considered an acceptable strategy to reach persons with a family history of diabetes. Nevertheless, practical barriers with regard to time, expertise and financial reimbursement were mentioned.

It was concluded that showing evidence on the (cost-)effectiveness of family-oriented strategies in the prevention of T2D could stimulate health care professionals in primary as well as secondary care to use FH information, the family system and family communication to promote health-protective behaviour. Besides increasing skills and expertise in professionals, more insight is needed in cultural aspects regarding the disclosure of family risk, the effect of low health literacy and negative modelling in families at high risk developing T2D.

The final chapter (Chapter 8) summarizes and reflects on the main findings of this thesis. The methodology that was applied in the studies, practice implications and directions in future research are discussed. Five key messages were formulated.

To start, it seems important that health care professionals adopt and continue the efforts made in public health initiatives and motivate behaviour change in a growing population at risk developing diabetes, including persons with a family history of T2D.
The studies described in this thesis show that family communication about diabetes is not a taboo in most families. Asking patients to pass on risk information might be a potential additional strategy to reach persons in Dutch as well as Surinamese South-Asian families at high risk. However, outcomes also underscore the complexities colouring the disclosure process, including family-related issues and personal coping mechanisms of patients. To facilitate the delivery of accurate messages by patients in high-risk families, health care professionals should not only provide risk information, but they also should address patients’ worries and emphasize the possibilities of T2D prevention in relatives. Moreover, to optimize the acceptance of information, (unhelpful) illness representations of patients with T2D should be discussed.

Generally, professionals are willing to give family history a more profound role in preventive activities and outcomes lend support for the adoption of direct as well as patient-mediated methods to target persons with a family history. The future implementation of a programmatic prevention protocol in Dutch primary health care might provide opportunities to discuss a person’s family history more systematically and to use a family-oriented approach as additional strategy to reach the target population. Importantly, however, the feasibility and (cost-)effectiveness of a family-oriented approach in T2D prevention should be demonstrated in further research, especially when targeting persons with different ethnic backgrounds and/or low literacy. In addition, professionals should be educated on how to use family history information, the family system and family communication adequately to promote health-protective activities.
Diabetes preventie in de familie
*Communicatie over familiair risico op diabetes type 2*

Diabetes type 2 (DM2) is de meest voorkomende soort diabetes. De ziekte wordt gekenmerkt door een chronisch verhoogde bloedsuikerspiegel (hyperglykemie) en heeft een progressief verloop. Door de wereldwijde toename van het aantal patiënten met DM2 ontstaat er een groeiende behoefte aan preventieve acties, die zich bij voorkeur richten op groepen met een hoog risico op het krijgen van DM2. Naast bijvoorbeeld ouder worden en een ongezonde leefstijl, is familiegeschiedenis een belangrijke risicofactor. De kans op het ontwikkelen van DM2 is twee tot vijf keer groter voor mensen met een familiegeschiedenis, dan voor mensen waar DM2 niet in de familie voorkomt. Wetenschappelijk onderzoek heeft aangetoond dat het krijgen van DM2 kan worden uitgesteld -of misschien zelfs voorkomen- door gezond eten en voldoende beweging, ook bij mensen met een familiegeschiedenis.

Door de familiegeschiedenis in kaart te brengen kunnen mensen met een verhoogd risico op DM2 opgespoord worden. Bovendien zijn er aanwijzingen dat het bespreken van de familiegeschiedenis mensen bewust kan maken van een mogelijk verhoogd risico op DM2 en de noodzaak van een gezonde leefstijl. Een relatief nieuw idee om mensen met een familiegeschiedenis te bereiken is patiënten te vragen om informatie binnen hun familie te verspreiden over risicofactoren voor DM2 en de mogelijkheden van primaire preventie.

De doelstelling van dit proefschrift was inzicht te krijgen in het huidige en mogelijk toekomstige gebruik van communicatie over familiair risico op DM2, ten einde gezond gedrag te stimuleren in families waar DM2 (zeer) veel voorkomt. Om te beginnen is vanuit het perspectief van de algemene volksgezondheid (‘public health’) de online beschikbaarheid van en de publieke behoefte aan informatie over diabetes en erfelijkheid onderzocht. Vervolgens is gekeken naar persoonlijke en familiegerelateerde factoren die invloed hebben de bereidheid van patiënten om als boodschapper in hun familie op te treden. De mogelijkheid om familiecommunicatie te gebruiken voor de preventie van DM2 is onderzocht in families van Nederlandse en Surinaams-Hindostaanse afkomst. Het is belangrijk laatstgenoemde groep te bereiken met preventieve acties, omdat de prevalentie en ziektelast van DM2 in deze groep erg groot is. Tot slot zijn de ideeën en meningen van artsen en verpleegkundigen met betrekking tot het gebruik van familiegeschiedenis en familiecommunicatie in preventieve consulten in kaart gebracht.
Hoofdstuk 2 beschrijft de analyse van gezondheidsgerelateerde informatie, die in 2005 verstrekt werd op 34 websites van nationale diabetes patiëntenorganisaties in Engels-, Duits-, Frans-, Nederlands-, Spaans-, Portugees-, Zweeds-, Noors-, Fins-, Deens- en Japans-sprekende landen (allen leden van de International Diabetes Federation; IDF). De meeste websites noemden familiegescidenis als risicofactor voor DM2. Echter, de informatie die werd verstrekt was beknopt en het samenspel tussen genetische aanleg en de invloed van omgevingsfactoren werd niet uitgelegd. Etniciteit als risicofactor werd door de helft van de onderzochte websites genoemd. Specifieke groepen met een verhoogd risico werden niet vermeld of waren weinig relevant voor de regio waar de online informatie verstrekt werd.

De meeste websites gaven informatie over het belang van een gezonde leefstijl, maar mensen met een verhoogd risico werden niet direct aangesproken en van advies voorzien. Bezoekers van de websites moesten zelf informatie combineren (‘behoor ik tot een riskogroep’) en ‘doorbladeren’ op de website (‘welke preventieve adviezen zijn relevant voor mij’). Ondanks de aanbevelingen van de IDF bleken slechts twee websites patiënten te stimuleren om familieleden te informeren over hun familieair verhoogde risico op DM2. Er werden daarbij geen aanbevelingen gedaan over wat patiënten zouden moeten vertellen, aan wie en hoe ze dat zouden kunnen vertellen.

Opgelet moet worden dat momenteel de informatievoorziening op de websites van diabetes organisaties waarschijnlijk aanzienlijk verbeterd is. In veel Westerse landen zijn er vanuit een integraal gezondheidsbeleid initiatieven ontplooid en is er op grote schaal aandacht gevraagd voor de groeiende diabetes epidemie, de risicofactoren voor het ontwikkelen van DM2 en het belang van een gezonde leefstijl om de ziekte uit te stellen of te voorkomen.

De informatiebehoefte van mensen die op zoek zijn naar (online) informatie over diabetes en erfelijkheid

In Nederland biedt het Erfocentrum online informatie over meer dan 600 erfelijke aandoeningen, waaronder diabetes subtypen. Bovendien biedt de website bezoekers de mogelijkheid om per e-mail vragen te stellen. In hoofdstuk 3 wordt een kwalitatief onderzoek beschreven naar de behoefte aan (aanvullende) informatie van website bezoekers over de rol van erfelijkheid bij het krijgen van diabetes. Met behulp van secundaire inhoudsanalyse zijn 172 e-mails met vragen over diabetes en erfelijkheid, verstuurd in de periode 2005-2009, onderzocht.

Het bleek dat met name jonge en vrouwelijke bezoekers gebruik maken van de mogelijkheid om vragen te stellen. De helft van de vragenstellers was zelf patiënt, eenderde was een familielid en de overige vragenstellers waren partners van patiënten met diabetes. De meerderheid van de verzoeken om informatie ging over erfelijkheid
van diabetes type 1, voornamelijk gerelateerd aan een (toekomstige) zwangerschap en/of gezinsplanning. In de meeste e-mails werd gevraagd om een risico-inschatting, maar er werd ook om uitleg (genetica en diabetes in het algemeen) en advies (meestal met betrekking tot gezinsplanning) gevraagd. In ongeveer tachtig procent van de e-mails uitten de vraagstellers op één of andere hun zorgen. Er werden weinig vragen gesteld over diabetes type 2 en erfelijkheid. Preventief advies werd nauwelijks gevraagd. De vraag is of deze bevinding erop duidt dat mensen geen vragen hebben over een mogelijk familiale aanleg voor diabetes type 2, dat zij daar überhaupt niet van op de hoogte zijn, of dat zij wel vragen hebben maar de antwoorden niet op de website van het Erfocentrum zoeken. Opgemerkt moet worden dat Google ten tijde van het onderzoek de website van het Erfocentrum als eerste hit toonde wanneer er gezocht werd naar informatie over diabetes (type 2) en erfelijkheid.

De bereidheid van patiënt en familieleden om te lichten over een mogelijker verhoogd risico op diabetes type 2: de rol van zorgen in het proces van familiecommunicatie

De studie die is beschreven in hoofdstuk 4 geeft inzicht in de complexe samenhang van determinanten die van invloed zijn op de intentie van patiënten om gezondheidsrisico’s te communiceren binnen hun familie. De resultaten in dit onderzoek zijn gebaseerd op de gegevens van 546 patiënten met DM2 die de vragenlijst getiteld ‘diabetes en uw familie’ invulden. Over het algemeen was 60% van de patiënten bereid om familieleden over een familair risico op diabetes te informeren, dacht 61% dat het (zeer) waarschijnlijk was dat familieleden DM2 zouden krijgen en toonde 31% zich daar (zeer) bezorgd over. Een minderheid (41%) dacht dat het mogelijk zou zijn voor familieleden om het krijgen van DM2 uit te stellen of te voorkomen. Uit aanvullende analyses bleek dat de intentie van patiënten om familieleden te lichten samenhang met de mate waarin patiënten zich zorgen maakten over hun familieleden. Ook de mate waarin zij zichzelf in staat achten om de boodschap te brengen (d.w.z. weten wat te vertellen en wie in te lichten) en de mate waarin DM2 in het algemeen bespreekbaar was binnen de familie bleken belangrijke motiverende factoren. Een opvallende bevinding was dat een hogere risicopercepie niet direct in relatie stond met een grotere bereidheid om als boodschapper in de familie op te treden. Een mediatie-analyse liet echter zien de risicopercepie van patiënten samenhang vertoond met de zorgen die zij rapporteerden en ideeën over de mogelijkheden van primaire preventie. Een hogere risicopercepie bleek indirect –via zorgen en geloof in preventie– effect te hebben op de intentie van patiënten om informatie in de familie te verspreiden. Het dynamische karakter van dit proces kan echter niet in een cross-sectioneel studiesign onderzocht worden.

De emotionele beoordeling van het risico op DM2 voor familieleden (de zorgen die patiënten zich maken) lijkt de belangrijkste factor te zijn die patiënten
aan kan zetten tot het inlichten van familieleden. Het verstrekken van risico-informatie kan de zorgen van patiënten doen toenemen. Echter, in de literatuur is beschreven dat een hoge mate van zorgen en angst averechts kan werken als mensen geen mogelijkheden zien om het risico het hoofd te bieden. Het benadrukken van handelingsopties voor de preventie van DM2 en het vergroten van het zelfvertrouwen van patiënten om de boodschap over te brengen (weten wat te vertellen, aan wie en op welke manier) zijn daarom van wezenlijk belang in de begeleiding van patiënten tijdens het proces van familiecommunicatie.

Ligt de beleving van de eigen ziekte ten grondslag aan de perceptie van het risico op diabetes type 2 bij familieleden?

In hoofdstuk 5 is gekeken in hoeverre de ideeën en ervaringen van patiënten met hun eigen ziekte invloed hebben op de perceptie van het risico op DM2 bij familieleden. Met behulp van de ‘Illness Perception Questionnaire’ (IPQ-R) zijn bij 546 patiënten met DM2 ziektepercepties in kaart gebracht.

Over het algemeen zien patiënten hun DM2 als een chronische aandoening die beheersbaar is en ze melden geen grote praktische en/of emotionele belemmeringen in het dagelijkse leven. Echter, uit multiple logistische regressieanalyses komt naar voren dat patiënten die hun DM2 wel als ernstige en onvoorspelbare ziekte ervaren, het risico op DM2 bij familieleden hoog inschatten en dat zij zich veel zorgen maken over de toekomstige gezondheid van hun familieleden. Ook patiënten die fysieke belemmeringen en een grote emotionele impact van hun ziekte ervaren, rapporteren dat zij zich (zeer) veel zorgen maken over de mogelijkheid dat familieleden DM2 krijgen. Patiënten die hun ziekte toeschrijven aan toeval of pech hebben vaker negatieve ideeën ten aanzien van de mogelijkheden van primaire preventie. Patiënten daarentegen die aangeven hun ziekte goed te snappen en vinden dat zij controle kunnen uitoefenen op het ziekteverloop, zijn over het algemeen positief over de mogelijkheden van familieleden om invloed uit te oefenen op het wel of niet krijgen van DM2.

Wanneer patiënten gevraagd wordt een actieve rol te spelen bij de preventie van DM2 in hun familie, kan het bespreekbaar maken van de ervaringen en ideeën van patiënten ten aanzien van hun eigen DM2 zorgverleners helpen om patiënten op te sporen die een correcte boodschap in hun familie zouden kunnen verspreiden, of kan aandacht besteed worden aan mogelijke hiaten in kennis en/of onjuiste ideeën van patiënten.

Familiecommunicatie als strategie in de preventie van diabetes type 2 in families van Nederlandse en Surinaams-Hindostaanse afkomst

Hoofdstuk 6 toont de resultaten van een onderzoek naar de mogelijkheid om familiecommunicatie te gebruiken als strategie in de primaire preventie van DM2 in Nederlandse en Surinaams-Hindostaanse families waar DM2 (veelvuldig) voorkomt.
Zoals verwacht op basis van de hoge prevalentie en ziektelast van DM2 binnen de Surinaamse gemeenschap in Nederland, schatten Surinaamse patiënten het risico op DM2 voor familieleden hoger in en rapporteren zij meer zorgen over de diabetesgerelateerde gezondheid van hun familieleden dan Nederlandse patiënten. Er bleek echter geen verschil te zijn in de mate waarin beide groepen patiënten geloven in de mogelijkheden van diabetes preventie. Het bespreken van DM2 blijkt binnen de meeste families geen taboe. Binnen Surinaamse families lijkt er meer openheid te bestaan in het bespreken van diabetes; in vergelijking met Nederlandse patiënten rapporteren Surinaamse patiënten een sterkere familieband met zowel kinderen als andere familieleden (broers/zussen, ooms/tantes, grootouders). Vooral Surinaamse (68%), maar ook Nederlandse (55%) patiënten bleken gemotiveerd om hun familieleden in te lichten over een mogelijk verhoogd risico op DM2.

Op basis van deze bevindingen kan geconcludeerd worden dat familiecommunicatie als strategie gebruikt kan worden om mensen met een verhoogd risico op DM2 op te sporen en te bereiken in een groot deel van Nederlandse en Surinaamse families waar DM2 (veelvuldig) voorkomt.

**Ideeen van Nederlandse zorgverleners over het gebruik van familiegeschiedenis in de preventie van diabetes type 2**

In de studie in hoofdstuk 7 is het draagvlak onder zorgverleners in Nederland geïnventariseerd ten aanzien van het gebruik van familiegeschiedenis en familiecommunicatie als strategie om mensen te bereiken met een verhoogd risico op het krijgen van DM2. Negentien semi-gestructureerde interviews zijn afgenomen onder huisartsen, praktijkondersteuners, diabetes specialisten en diabetesverpleegkundigen.

De geïnterviewde zorgverleners stonden over het algemeen positief tegenover het idee om diabetesgerelateerde familiegeschiedenis met patiënten te bespreken om hen bewust te maken van een mogelijk verhoogd risico op DM2 en te motiveren tot een gezonde leefstijl. Systematisch en direct aanspreken van mensen met DM2 in de familie bleek wenselijk voor veel zorgverleners, maar volgens hen in het huidige zorgsysteem niet haalbaar. Familiegeschiedenis wordt niet structureel uitgevraagd en elektronische patiëntendossiers zijn niet toegerust om patiënten met een familiegeschiedenis te selecteren. Het idee om patiënten te vragen familieleden in te lichten over DM2 risico’s en primaire preventie was nieuw voor alle geïnterviewden. Echter, zorgverleners in zowel de eerste- als de tweedelijnszorg vonden het een aanvaarbare strategie om een risicogroep te bereiken.

De resultaten in deze studie onderstrepen de interesse van zorgverleners om nieuwe strategieën te gebruiken om mensen met een verhoogd risico op DM2 te bereiken en te motiveren tot gedragsverandering. Naast het oplossen van praktische belemmeringen met betrekking tot tijd en financiële vergoeding, zijn vaardigheden en expertise nodig bij de zorgverleners om het gebruik van familiegeschiedenis en familiecommunicatie doelmatig
in te zetten. Maar bovenal moet de (kosten)effectiviteit van familiegeoriënteerde preventiestrategieën op het gebied van DM2 aangetoond worden.

Het laatste hoofdstuk (hoofdstuk 8) vat de bevindingen in het proefschrift samen, reflecteert op de gebruikte onderzoeksmethoden en beschrijft praktische implicaties en vragen die in toekomstig onderzoek aan de orde zouden moeten komen. De belangrijkste bevindingen worden in vijf kernpunten samengevat.

Gezien het snel groeiende aantal mensen met DM2 is het belangrijk om het bewustzijn van een mogelijk verhoogd risico op DM2 te vergroten en risicogroepen te attenderen op het belang van een gezonde leefstijl om het krijgen van diabetes uit te stellen of wellicht zelfs te voorkomen. Zorgverleners zouden meer gebruik kunnen maken van bestaande initiatieven op het gebied van de volksgezondheid; in Nederland hebben diverse voorlichtingscampagnes het risico om DM2 te krijgen en het belang van een gezonde leefstijl onder de aandacht gebracht bij een groot publiek. Informatieve websites zijn beschikbaar en zouden gebruikt kunnen worden in preventieve consulten in de eerstelijnszorg.

Voorts laten de studies in dit proefschrift zien dat communicatie over diabetes geen taboe is de meeste families. Patiënten vragen om risico-informatie in hun familie te verspreiden kan een mogelijke aanvullende strategie zijn om mensen met een verhoogd risico op DM2 te bereiken in zowel Nederlandse als Surinaams-Hindostaanse families. Echter, de resultaten onderstrepen ook de complexiteit van het proces van familiecommunicatie over gezondheidsrisico’s. Zorgverleners zullen rekening moeten houden met omstandigheden in de familie en persoonlijke coping-mechanismen van de patiënt. Het is van belang dat niet alleen risico-informatie verstrekt wordt, maar ook ruimte geboden wordt voor het bespreken van eventuele zorgen van de patiënt. De mogelijkheden voor de preventie van DM2 moeten benadrukt worden, alsook de manier waarop de patiënt de boodschap zou kunnen brengen in de familie (wie inlichten, wat te vertellen en hoe/wanneer dat te doen).

Om de acceptatie van informatie door patiënten te verbeteren doen zorgverleners er goed aan om aan te sluiten bij de ideeën en ervaringen van patiënten met hun ziekte. Op die manier kunnen eventueel onjuiste ideeën worden bijgesteld.

Over het algemeen zijn zorgverleners geïnteresseerd in nieuwe strategieën om mensen met een hoog risico op DM2 te bereiken en hen te attenderen op het belang van een gezonde leefstijl. De toekomstige implementatie van een programmatisch preventieprotocol in de Nederlandse eerstelijnszorg kan de mogelijkheid bieden om de familiegeschiedenis systematischer in kaart te brengen en te bespreken met patiënten. Zorgverleners staan niet negatief tegenover het gebruik van familiecommunicatie als aanvullende strategie om een risicogroep te bereiken. Echter, de haalbaarheid en (kosten-) effectiviteit van een familiegeoriënteerde aanpak in de preventie van DM2 moet worden aangetoond. Daarnaast moeten zorgverleners worden opgeleid in het doelmatig bespreken van familiegeschiedenis en adequaat gebruik van familiecommunicatie.
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Addendum
Woord van dank

As you set out for Ithaka
hope the voyage is a long one,
full of adventure, full of discovery.

En een lange reis was het. Bergen zijn beklommen en dalen overwonnen. En dat ik veel geleerd heb, dat staat vast.

Maar onderzoek doe je niet alleen en een proefschrift schrijven al helemaal niet. Op de eerste plaats ben ik dank verschuldigd aan alle respondenten die de moeite hebben genomen om de (omvangrijke) vragenlijst over diabetes en hun familie in te vullen. Ik waardeer de openhartigheid waarmee patiënten mij een inkijkje hebben gegeven in hun leven met diabetes en de communicatie daarover in hun familie. De deelnemende (huis)artsen ben ik zeer erkentelijk voor het gestelde vertrouwen en hun bereidheid om patiënten uit te nodigen voor het onderzoek. Dank ook aan de huisartsen, praktijkondersteuners, internisten en diabetes verpleegkundigen in Amsterdam, Haarlem en Weesp die bereid waren om aan onze interviewstudie deel te nemen. De terugkoppeling van onderzoeksresultaten aan mensen uit de praktijk heeft het project echt een meerwaarde gegeven.

Ithaka gave you the marvellous journey.
Without her you would not have set out.

Prof. dr. Snoek, beste Frank, als promotor en eerste aanspreekpunt was jij nauw betrokken bij het hele proces. Ik werd min of meer met mijn onderzoeksplan in jouw schoot geworpen. En hoewel het onderwerp niet zonder meer in je onderzoekslijn paste, heb je het met veel interesse opgepakt. Je vermogen om te brainstormen is ongekend en ik vind het mooi om te zien dat je altijd op zoek bent naar de toepasbaarheid van onderzoeksresultaten in de (klinische) praktijk. Dank je dat je je kennis en kunde op het gebied van de psychosociale diabetologie hebt willen delen.

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Professor Henk van der Ploeg, emeritus hoogleraar medische psychologie, jij was het die mij dat laatste zetje gaf om aan een promotieonderzoek te beginnen. Dat het over
Woord van dank

(familie)communicatie zou gaan, was meteen duidelijk. De keuze voor diabetes type 2 was spannend, want een familiebenadering in de preventie van leefstijlgerelateerde aandoeningen was in die tijd vernieuwend.

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and may you visit many Egyptian cities to gather stores of knowledge from their scholars.


Ik wil de leden van de multidisciplinaire projectgroep ‘diabetes, erfelijkheid en perceptie van familiair risico’ (Martina Cornel, Frank Snoek, Jacqueline Dekker, Daniëlle Timmermans, Lidewij Henneman, Liesbeth Claassen, Miranda Pijl, Marcel Adriaanse, Ton Maassen en Leen ’t Hart) danken voor hun deelname aan de brainstormsessies, de feedback, het delen van expertise en de prettige samenwerking.

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may you stop at Phoenician trading stations to buy fine things, mother of pearl and coral, amber and ebony, sensual perfume of every kind—as many sensual perfumes as you can;
Een groot voorrecht van een promovendus is het bezoeken van (buitenlandse) congressen. I would like to thank all (inter)national colleagues for the supportive and stimulating environment they created during the PSAD and BRIDGE meetings. Louise en Celeste van *Artisa Academic & Arts Retreat*, wat een fijne en inspirerende ambiance hebben jullie weten te creëren tijdens mijn schrijfweek in Griekenland! Zo ontzettend welkom op dat moment. Hélène van den Nieuwenhoff, dank voor je tips en literatuursuggesties. Marjan Nijkamp, jij verstaat de manier van motiverende feedback geven. Dank je voor je waardevolle bijdragen aan twee artikelen.

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*Laistrygonians and Cyclops, wild Poseidon—you won’t encounter them unless you bring them along inside your soul, unless your soul sets them up in front of you.*
Hope the voyage is a long one.
May there be many a summer morning when,
with what pleasure, what joy,
you come into harbours seen for the first time;

Better if it lasts for years,
so you are old by the time you reach the island,
wealthy with all you have gained on the way,
not expecting Ithaka to make you rich.

Family matters! Fred en Mieke Reijerse en Maayke, dank voor jullie interesse en steun al die jaren. Bart en Annemarie, Koen en Paula, Ilse en Jeroen, de afgelopen jaren hebben we over en weer kunnen merken waar familiebanden goed voor zijn. Bart, als ‘grote broer’ ben jij altijd mijn lichtend voorbeeld geweest. Koen, vanuit Portugal leef jij mee (een paar dagen voor en ik weet dat je gaat bellen om te vragen of we al geschaatst hebben…). Ilse, het is fijn om jou als zus te hebben. Jij zorgt er vaak voor dat ik de boel weer in perspectief kan zien. Papa en mama, dank voor jullie onvoorwaardelijke steun. Mam, aan jouw dapperheid neem ik een voorbeeld. Pap, jouw bezorgdheid is tekenend; wanneer ik op reis was zat jij er altijd een beetje over in of Joost zich wel zou redden thuis…

Lieve Sophie en Madelon, dit is ‘m dan: mama’s ‘boekje’. Ik heb jullie geduld behoorlijk op de proef gesteld (‘Oh. Zit je weer hier… [lees: in de studeerkamer]’). Zonder het te weten brachten jullie soms mijn twijfel onder woorden (‘Mam, waarom heb je niet gewoon een beroep gekozen?’). Jullie begrip (‘Wij gaan wel met papa zwemmen hier, kan jij lekker rustig werken’) en opbeurende woorden bij tegenslag (‘Ach, hoe maakt het uit…’) waren hartverwarmend.

Keep Ithaka always in your mind.
Arriving there is what you are destined for.
Lieve Joost, eerlijk is eerlijk, jij verdient de meest eervolle vermelding. Van alle ballen die ik hoog probeerde te houden, ving jij er velen op. Zonder jouw hulp en geloof in een goede afloop zou ik dit traject niet tot een goed einde hebben kunnen brengen. Dank je dat je me, vooral de laatste maanden, alle ruimte hebt gegeven om het karwei af te maken. Ik zou zeggen; trek die fles maar open!

Wise as you will have become, so full of experience, you will have understood by then what these Ithakas mean.
About the author

Suzanne van Esch was born on February 1st, 1972 in Bergen op Zoom, the Netherlands. After secondary school at the Gymnasium Juvenaat H. Hart in Bergen op Zoom, she successfully passed the Propadeutics in Psychology at the Radbout University Nijmegen in 1991. In 1996, she graduated in Communication Science at the University of Amsterdam with a major in public health communication and a minor in business communication. During her study, she participated in a research project on drug education for (inter)national policy makers at the Municipal Center in Amsterdam. She also was an active member of the International Student Association AEGEE and the VU University Student Orchestra, where she played the cello.

In 1997, she started working at the department of Medical Psychology of the VU University medical center (VUmc) in Amsterdam as junior researcher on a research project on Post-Traumatic Stress complaints of Dutch military, who served on a peacekeeping operation in Cambodia. After finishing this project in 1998, she started lecturing about patient-physician communication and medical psychology in all phases of the medical curriculum. In 2005, she wrote a grant proposal under the direction of prof. dr. Frank Snoek and prof. dr. Martina Cornel, which resulted in the PhD project that is described in this thesis. Besides working on her PhD project, she obtained a master degree in Health Psychology at the Open University of the Netherlands in 2011 and the VUmc Basic Training Qualification in 2012. Suzanne is married and is the mother of two daughters.
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