

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.