

# **Adherence to oral hypoglycaemic agents among type-2 diabetes patients of Turkish descent**

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***Chapter 1:***  
***General introduction***

## Overview

Treatment with oral hypoglycaemic agents (OHA) is the backbone of type 2 diabetes mellitus (T2DM) treatment and aims at the reduction of blood glucose levels, the prevention of diabetes-related complications and the improvement of patients' quality of life. In order to reach these goals, medication adherence, defined as 'the process by which patients take their medications as prescribed'<sup>1</sup>, is essential.

This dissertation explores the factors influencing adherence to OHA in one of the largest ethnic minorities in Western Europe, i.e.: patients of Turkish descent. Furthermore, T2DM is frequently treated in primary care, so we focus on the perspectives of general practitioners (GPs) and community pharmacists (PHs) on promoting adherence to OHA in this population.

This general introduction consists of two parts. In the first section, we provide an argumentation for our focus on adherence to OHA among T2DM patients of Turkish descent and describe the contextual background. We start with a description of the physiological mechanism of T2DM and its causes and consequences; focus on diabetes treatment and pharmacological treatment with OHA in specific; to continue with a short overview of prevalence rates of T2DM and diabetes related complications in ethnic minorities in general and people of Turkish descent in particular. In the first section we also describe important background characteristics of Belgian health and diabetes care and of the population of Turkish descent living in Belgium. We conclude this section with a short overview of factors influencing adherence to OHA found in White or mainly White study populations.

The second section of this general introduction consists of a systematic literature review on factors influencing adherence to OHA in several non-White ethnic groups. We performed this study in order to obtain insights that could guide our own studies on adherence to OHA among T2DM patients of Turkish descent. In this systematic literature review we

summarize the available evidence, evaluate the methodological pitfalls in existing research and provide recommendations for future research on adherence to OHA in ethnic minorities



*Section 1:*  
*Argumentation and contextual background*  
*for studying adherence to OHA*  
*among T2DM patients of Turkish descent*

## 1.1 Diabetes and diabetes-related complications

T2DM is a metabolic disorder characterized by hyperglycemia, resulting from a combination of relative insulin deficiency and insulin resistance. Genetic susceptibility in combination with environmental factors (such as obesity, nutrition and physical activity) causes this disease. T2DM is the most common type of diabetes affecting 85-95% of all diabetes mellitus patients <sup>2</sup>. Because the capacity for insulin secretion of the pancreas decreases slowly, patients can have blood glucose levels rising above the normal range (hyperglycemia) for a long period of time before experiencing any symptoms. Many T2DM-patients also suffer from hyperlipidemia, hypertension and obesity, a combination referred to as ‘insulin resistance syndrome’ <sup>3</sup>.

For decades, plasma glucose criteria (the fasting plasma glucose level or the 2h-value in the oral glucose tolerance test) were used to diagnose diabetes. Since 2009 the percentage of glycosylated haemoglobin, HbA1c, is recommended. HbA1c expresses the mean blood glucose level of the preceding 6-8 weeks. Individuals with a HbA1c > 6.5% (48 mmol/mol) are diagnosed with diabetes <sup>4</sup>. Prolonged hyperglycemia increases the risk of microvascular complications like neuropathy, nephropathy and retinopathy <sup>4</sup>. T2DM is one of the main causes of severely limited eye sight and blindness, non-traumatic amputations and kidney failure <sup>4</sup>. Furthermore, T2DM is associated with a two-fold increased risk of cardiovascular disease which is the major cause of mortality in this patient group <sup>4;5</sup>. The burden of these microvascular and macrovascular complications threatens patients’ quality of life and leads to high costs for health care systems <sup>6;7</sup>. Next to these long-term complications, acute hypoglycaemia and hyperglycaemia pose serious threats for patients’ health and well-being.

## 1.2 Diabetes treatment

Normalizing blood glucose levels is the primary treatment goal. For most diabetes patients, the goal is a HbA1c value  $\leq 7\%$  (53 mmol/mol) <sup>4</sup>. Intensive glycaemic control reduces the risk of microvascular complications and may reduce the risk of macrovascular complications for certain groups of T2DM-patients <sup>8-16</sup>.

Diabetes treatment consists of several components of which lifestyle adaptation and pharmacological treatment demand the most of patients' self-care capacities. Lifestyle adaptation includes adopting a low-carbohydrate diet and performing regular physical activity in order to lose weight and reduce the blood glucose level <sup>4</sup>.

When life style changes are no longer sufficient to lower HbA1c-levels, T2DM-patients will start treatment with oral hypoglycaemic agents (OHA). In general, HbA1c will decrease by about 0.5 to 1.5% with monotherapy, depending on the agent used and the baseline HbA1c level <sup>17</sup>. An overview of the different oral hypoglycaemic agents can be found in addendum 1. Guidelines recommend metformin as the first choice for most T2DM-patients because of its efficacy and safety <sup>4;17-19</sup>. When diabetes progresses, a second or third OHA with a different mechanism of action can be added <sup>4;17-19</sup>. Insulin treatment may be necessary for many T2DM-patients, often in combination with OHA <sup>4;17-19</sup>. In treating diabetes, the frequent occurrence of severe hypoglycaemic episodes has to be limited because this can threaten patients' cognitive functioning <sup>20;21</sup>

“To have diabetes is like having a full-time occupation”. This quotation from a patient interview <sup>22</sup> clearly expresses the challenges diabetes treatment poses. Patients are confronted with numerous demands: following advice on physical activity and diet; self monitoring of blood glucose; consulting their GP, diabetes specialist, dietician, diabetes educator and ophthalmologist; examining their feet and taking medication as prescribed. Effective self-care

presupposes acquiring sufficient knowledge about diabetes and its treatment, mastering technical skills (monitoring of blood glucose, injecting insulin), correctly interpreting symptoms and bodily reactions (e.g. blood glucose levels), adopting and maintaining a healthy life style and coping with the emotional demands of a life-threatening, chronic disease. Adherence to diabetes treatment is influenced by a multitude of factors related to the disease itself, characteristics of the treatment, patients' knowledge and emotional well-being, life circumstances, socio-economic factors, cultural factors or characteristics of diabetes care and health care systems <sup>23-28</sup>. Treatment adherence is not a static or unchangeable patient characteristic; living with diabetes is a learning experience and patients will often shift on a continuum from strict adherence to nonadherence while striving to find a balance between treatment adherence and quality of life <sup>29</sup>.

Patients' perspectives on diabetes and adherence to diabetes treatment can come into conflict with health care professionals' perspectives <sup>29;30</sup>. In clinical encounters the health care professional's 'incorporated' biomedical point of view may lead to a strong emphasis on clinical test values (HbA1c) in order to interpret and classify a patient's behaviour as 'adherent' or nonadherent' <sup>30</sup>. From a patient's point of view, periodic nonadherence may be a valuable strategy to find a balance between 'controlling the disease' and the demands put by his or her particular social, cultural and economic life circumstances <sup>29;30</sup>. 'Being in control of a disease' may be very different from 'being in control of living with a disease'. This conflict between two different perspectives may, at worst, damage the patient-health care provider relationship and/or lead to treatment decisions which may be unnecessary <sup>30</sup>.

Consequently, during the last decades there have been pleas for adopting a patient-centred perspective in clinical encounters and for moving from a more traditional compliance model towards a concordance model in which the decision power is shared between the health care provider and the patient <sup>31</sup>. However, this not only means the health care provider must

adopt a supportive and open-minded attitude towards the patient but that the patient has to be able to acquire sufficient knowledge about the disease, to acquire the necessary treatment skills and has to be self-confident enough to openly discuss treatment decisions with health care providers <sup>29</sup>. Described as above, the concordance model may be a suitable approach for well educated patients who have gained sufficient experience in living with the disease. However, for patients from a low socio-economic background, patients with a low level of health literacy or patients who are confronted with a multitude of problems a concordance based approach may be less helpful <sup>32</sup>. Moreover, as illustrated in studies with diabetes patients of Turkish and Pakistani descent, culturally shaped expectations about health care professional's roles can be in conflict with the concordance model <sup>33;34</sup>. Although exploring a patient's perspective is important the adoption of a concordance based approach in clinical encounters may not always be suitable.

### **1.3 The prevalence of diabetes and diabetes-related complications**

The prevalence of DM is rising worldwide. According to the International Diabetes Federation (IDF), in 2012 371 million people or 8.3% of the world population suffered from diabetes, a number expected to rise to 552 million in 2030 <sup>2</sup>. The prevalence of diabetes is rising in every country with rates > 20% in several countries in the Middle-East <sup>2</sup>. In Europe the prevalence of diabetes is estimated at 6.7% <sup>2</sup>. Geographical variation in T2DM prevalence is probably due to genetic, behavioural, and environmental factors <sup>3</sup>.

In high-income countries non-White ethnic minorities suffer disproportionately more from diabetes. In the US, for instance, higher diabetes rates are found among non-Hispanic blacks, Asian-Americans, Native Americans and Hispanics compared to non-Hispanic Whites <sup>35;36</sup>, although these differences may partly be due to socio-economic factors <sup>37;38</sup>. In ethnic

groups other than non-Hispanic Whites the onset of T2DM occurs, on average, at an earlier age<sup>3</sup>. In general, diabetes related complications are also more common in non-White ethnic groups in the US<sup>7;35;36;39;40</sup>. In Europe higher prevalence rates are reported, among others, in immigrants from Iraq, North Africa, South Asia, Syria, Turkey and Middle Eastern countries living in Sweden<sup>41;42</sup>, in ethnic minorities from Sri Lanka, Vietnam, Turkey and Pakistan living in Norway<sup>43</sup>, in Lebanese and Turkish migrants in Denmark<sup>44</sup>, in Turkish and Moroccan minorities in the Netherlands<sup>45-47</sup>, Belgium<sup>48</sup> and Germany<sup>49</sup> or in Pakistani and Bangladeshi in the UK<sup>50</sup>. Also, ethnic differences in HbA1c-values, blood pressure, certain diabetes related complications and diabetes related mortality have been reported in Europe<sup>40;45;51;52</sup>. However, the lack of available data sources of high quality in Europe hinders comparison and forms a barrier to targeting public health interventions<sup>53</sup>. Explanations for ethnic differences in the prevalence of diabetes and diabetes related complications are sought in genetic and bio-physiological factors<sup>54</sup> and environmental factors like changes in dietary patterns, the adoption of a more sedentary lifestyle or socio-economic differences between ethnic groups<sup>38;39;55;56</sup>.

In Europe, especially in Western-Europe, Turks are one of the largest ethnic minorities coming from outside the European Union (EU-28)<sup>57</sup>. As mentioned above, the prevalence of T2DM is higher among Turkish migrants and their descendants compared with the indigenous population<sup>58</sup>. Most studies reporting prevalence rates rely on self-report but the few using objective measures or national health databases confirm these results<sup>44;58</sup>. In Belgium the longitudinal Health Survey Interview is the only source available for estimating prevalence rates of diabetes among people of Turkish descent. In the age group 35-74 years, self-reported diabetes is higher among men of Turkish descent (5.8%) compared to Belgian men (5.0%). Among women of Turkish descent self-reported prevalence rates are the quadruple (18.7%) of

those of Belgian women (4.3%)<sup>48</sup>. For men, differences are explained by life style factors and educational level, in women these ethnic differences remain after controlling for these factors<sup>48</sup>. Diabetes also occurs, on average, at a younger age among people of Turkish descent compared to Belgians<sup>48</sup>. Results from the recent TURDEP-II study estimated diabetes prevalence in Turkey at 16.5% with observed, statistically significant differences between rural (15.5%) and urban areas (17.0%) and between men (16.0%) and women (17.2%)<sup>59</sup>. The differences in diabetes prevalence between migrants in Belgium and the Turkish population and the less pronounced gender differences in Turkey may be due to the self-report measure used in Belgium, age differences between these two populations, the rapidly rising diabetes prevalence rate in Turkey and the less pronounced gender difference in life style in the population in Turkey.

#### **1.4 Characteristics of Belgian health care and diabetes care**

In order to interpret results of our studies on adherence to OHA among T2DM patients of Turkish descent and on perspectives of GPs and PHs on promoting medication adherence in this population, we provide the reader with a short description of some essential characteristics of health care and diabetes care in Belgium.

The Belgian health care system is characterized by compulsory health insurance and solidarity, therapeutic freedom for physicians, freedom of choice for patients and remuneration (mainly) based on fee-for-service payments<sup>60</sup>. Patients pay on average 20% of the total health care expenditures<sup>60</sup>. Several policy measures guarantee the financial accessibility of health care for patients from lower socio-economic backgrounds and the chronically ill<sup>60;61</sup>. Pharmaceuticals for serious and long-term illnesses, including

antidiabetics, are provided for free. Despite these policy measures there is a clear socio-economic gradient in the postponing of health care out of financial reasons (i.e. people occupying lower socio-economic positions show a higher risk for postponing health care out of financial reasons)<sup>62</sup>. Moreover, for people with chronic diseases health care expenditures can still lead to financial problems or poverty<sup>63</sup>. Furthermore, Belgian health policy pays only limited attention to the needs of patients from ethnic minorities<sup>64,65</sup>. Data on ethnic background and health, for instance, are not routinely connected, making it difficult to accurately assess health care needs of ethnic minorities<sup>64,65</sup>. Another example is the limited availability of professional interpreters and intercultural mediators in primary care<sup>64-66</sup>.

General practices and pharmacies are geographically widespread. For every 1200 patients there is one GP, for every 2000 patients there is one community pharmacy<sup>60</sup>. Only a small minority of general practitioners and pharmacists has foreign origins. The vast majority of GPs works in solo practices or small group practices, most often without the assistance of nurses or other health care providers<sup>60</sup>. A small minority is employed in multidisciplinary community health centres which are often located in deprived city areas. PHs are either self-employed or work as an employee in larger chains of pharmacies. Recent legislation on pharmaceutical care changed the remuneration system and assigned more responsibilities in the care for patients with chronic diseases to PHs. The majority of patients always visits the same general practice and the same community pharmacy<sup>60</sup>.

Many T2DM patients are mainly treated in primary care. For patients (starting) on insulin multidisciplinary care pathways were implemented in Belgian health care in 2009. Care pathways aim to promote cooperation between the diabetes care providers in primary care (GP, dietician) and secondary care (specialist) while offering additional services (diabetes education, reimbursement of materials for self-measurement of blood glucose, ...) to

diabetes patients at low costs<sup>60</sup>. By the end of 2011 diabetes care pathways had been implemented for approximately 22.000 patients<sup>67</sup>. PHs play, up till now, a minor role within these diabetes care pathways.

For many patients with T2DM (whether a care pathway is implemented or not) it is the GP who coordinates the provision of diabetes care and functions as the patient's main diabetes care provider. As described above, changes in legislation that implemented pharmaceutical care in Belgium in 2009 extended the role of PHs to e.g. providing patient education on medicines and promoting medication adherence. In diabetes care several interventions by or involving pharmacists have shown to improve patients' medication adherence and health outcomes<sup>68-74</sup>.

The two recent evolutions described above imply that both GPs and PHs play an important role in promoting medication adherence among T2DM patients. However, the stimuli for cooperation between diabetes care providers are limited to patients (starting) on insulin while PHs are hardly involved in the diabetes care pathways. Moreover, the lack of a structurally embedded cooperation between GPs and PHs and of possibilities to mutually exchange information in an efficient way (e.g. through web-based databases with electronic patient files) may hinder cooperation between GPs and PHs in promoting medication adherence.

### **1.5 Characteristics of people of Turkish descent living in Belgium**

Approximately 5 % of the Belgian population originates from non-EU countries. Non-EU immigration increased by leaps and bounds in the 1960's and early 70's when low skilled labour force for the Belgian industry fell short. Agreements with Turkey and Morocco resulted in a large immigration of guest workers and their families. Turks mainly came from

rural areas of central Anatolian provinces. The economic crisis in the 1970's resulted in a more restrictive migration policy but family reunion and family formation still lead to a relatively large immigration from Turkey. Migrants from the same region in Turkey usually moved to the same region of destination in Belgium. After 1980 the number of political refugees rose because the Turkish military government persecuted members of Kurdish organisations and the political left <sup>75-77</sup>. Estimating the total number of people of Turkish descent living in Belgium is very difficult because many of them obtained the Belgian nationality by naturalization or birth in Belgium. Data on the previous nationality are usually not available for research. The most reliable figures for Flanders estimate the number of people of Turkish descent at approximately 112.000 or 1.8% of the Flemish population in 2011, but the authors warn this is an underestimation <sup>78</sup>. Figures for Brussels or Wallonia are not available but, based on what we know about the geographical distribution (see below), we can assume that the total number of people of Turkish descent living in Belgium lies between 200.000 and 225.000.

Most of the Turkish first generation migrants stayed in Belgium, slightly more than half of them reside in the Dutch-speaking northern region (mainly in the cities Ghent and Antwerp and in the coalmine region in Limburg) <sup>77</sup>. Today, a large part of the Turkish migrants and their descendants form an economically underprivileged population characterised by a low educational level, a high level of unemployment and a very high poverty rate <sup>62;76;79;80</sup>. In general, knowledge of Dutch among the first generation is limited with high levels of illiteracy, especially among women. This first generation forms a rather separated community, living in the same neighbourhoods with communal life centred around Turkish shops, cafés and mosques. On average, Turkish migrants are ethnically more conservative and less secularized than the indigenous population. Among first generation

migrants traditional gender roles are widely accepted resulting in women's low participation rates in public life, especially outside the own community<sup>81</sup>.

The Belgian Health Interview Survey provides useful information on health and access to health care, although the two largest non-EU immigrant groups, Turks and Moroccans, are often pooled. Compared with the Belgian population Turks and Moroccans on average report worse general health, worse mental health and higher rates of diabetes. They have a more sedentary lifestyle and higher rates of overweight (BMI > 25) and obesity (BMI > 30). Alcohol consumption is much lower but the number of (daily) smokers is higher. Similar to the Belgian population the vast majority of Turkish and Moroccan patients always visits the same general practitioner but their use of preventive health care services is lower. Approximately one third of the Turkish and Moroccan patients thinks their health care expenditures are too high and 15% postpones health care out of financial reasons<sup>82</sup>.

Since depression is a known risk factor for medication nonadherence (see table 1.1 under heading 1.6) it is useful to have a closer look at the mental health of people of Turkish descent. Rates of depression, anxiety and general psychological distress are higher compared to the Belgian population<sup>83</sup>, a finding confirmed for the Turkish population in the Netherlands<sup>84;85</sup>. For Turks in Belgium being female heightens the risks for depression, anxiety and general psychological distress while a tendency for higher risks is observed among first generation migrants<sup>83</sup>. Again, studies from the Netherlands confirmed these findings<sup>84;85</sup>. A Dutch study on the prevalence of depression among diabetes patients treated in secondary care found higher rates of depression among T2DM patients of Turkish descent<sup>86</sup>. However, this association between ethnicity and emotional distress in patients with diabetes could not be confirmed in a representative sample of the Amsterdam population<sup>87</sup>.

In conclusion, T2DM patients of Turkish descent living in Belgium are, in general, characterized by a low socio-economic position, a low educational level accompanied by a

high rate of illiteracy among women, limited knowledge of Dutch, the acceptance of traditional gender roles, a high prevalence of diabetes and of mental health problems.

## **1.6 Medication adherence**

Medication adherence is defined as: ‘the process by which patients take their medications as prescribed’<sup>1</sup>. Three components of medication adherence should be distinguished: initiation, implementation and discontinuation. Medication nonadherence can occur when patients do not or do not timely initiate their pharmacological treatment, when patients do not optimally take the number of prescribed doses within the prescribed timing intervals or when patients discontinue their therapy too early. Adherence should be distinguished from persistence which measures the time interval between initiation and the last dose taken<sup>1</sup>. Studies on adherence to OHA found that patients took, on average, between 60-85% of the prescribed dose of OHA<sup>88</sup>. Adherence to OHA can be influenced by a multitude of medication-related, patient-related or health care-related factors<sup>26;89-94</sup>. In Table 1.1 we summarize insights on factors influencing medication adherence (OHA and/or insulin) from four reviews, each of which mainly included studies among Whites<sup>27;89;91;92</sup>.

Table 1.1: Factors influencing adherence to OHA and/or insulin

<b>Medication-related factors</b>
Regimen complexity: <ul style="list-style-type: none"> <li>○ Number of daily intakes of OHA</li> <li>○ Number of daily intakes of medicines for all chronic diseases</li> </ul> Adverse effects Agent tolerability Drug– drug interactions
<b>Patient related factors</b>
Medication beliefs: <ul style="list-style-type: none"> <li>○ Patients’ perceptions of the potential benefits of adherence</li> <li>○ Patients’ concerns about medication</li> </ul> Illness beliefs. Mental health: <ul style="list-style-type: none"> <li>○ Stress</li> <li>○ Depression</li> </ul> Self-efficacy Alcohol abuse Social support
<b>Health care related factors</b>
Provider-patient relationship: <ul style="list-style-type: none"> <li>○ effective physician–patient communication regarding treatment regimens</li> <li>○ patient-provider trust</li> </ul> Medication costs / health insurance.
<i>This summary is based on the reviews by Rubin et al., Gellad et al., Odegard et al. and the World Health Organization referred to above.</i>

Adherence to OHA is often suboptimal, with lower adherence rates found in ethnic minorities living in high-income countries<sup>95-97</sup>. Factors influencing adherence to OHA may also be different and may be partly attributable to culturally shaped ideas about illness and medicines or to values and norms characteristic for the patient’s cultural and religious background<sup>98-101</sup>. Barnes et al., for instance, found that medication nonadherence in Tongan T2DM patients was associated with the belief that diabetes was caused by external factors like environmental pollution, God's will and poor medical care in the past. Pakistani and Bangladeshi T2DM patients living in the UK may adjust their intake of OHA according to their perception of Western medicines as ‘strong’, the perceived association between traditional diets and medicines or during Ramadan fasting<sup>99</sup>. In Pakistani living in Norway, Ramadan fasting and language proficiency influenced medication adherence<sup>100</sup>. In Korean immigrants living in the US adherence to OHA can be influenced by the idea that long-term

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use of antidiabetics can have a detrimental effect on health, perceived as ‘a balance between yin and yang’, and by cultural norms guiding physician-patient communication <sup>101</sup>.

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*Section 2:*  
*Systematic literature review*  
*on adherence to OHA*  
*among T2DM patients*  
*of non-White ethnic minorities*

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*Factors associated with medication adherence to oral hypoglycaemic agents in different ethnic groups suffering from type 2 diabetes : a systematic literature review and suggestions for further research.*

**Abstract**

**Aims:** To synthesize knowledge regarding the different factors that may influence adherence to oral hypoglycaemic agents (OHAs) in different ethnic groups through a systematic review of the literature.

**Methods:** Thirteen databases were searched and 1201 articles were screened by 2 authors independently from each other. Different quantitative study designs were included if the study population included at least 1 ethnic group other than white people, medication adherence was a dependent variable, and a clear description was given of the method used to measure medication adherence.

**Results:** Demographic, disease-related and treatment-related, socioeconomic and cultural factors are associated with medication adherence in the populations that were studied. However, to synthesize results, the number of studies is too small and the included studies differ too much with respect to their study designs and the ethnic groups that were studied. We discuss several methodological challenges with respect to measuring medication adherence, measuring ethnicity and study designs that need to be resolved to make future studies comparable. We propose methodological improvements for future research.

**Conclusion:** Although medication adherence is an essential part of the diabetic regimen, little is known about the association between ethnicity and medication adherence and the underlying factors that could explain this association. More research is needed in which important methodological challenges will have to be faced.

**Key Words:** adherence; ethnicity; type 2 diabetes; review, methodology

## **Introduction**

Non-white ethnic groups living in developed countries suffer disproportionately more from type 2 DM. [1-3]. It is presently assumed that this is caused by changes in nutrition and the adoption of a more sedentary lifestyle on the one hand and genetic predisposition on the other [4,5]. Additionally, ethnic disparities in diabetes complications are found and can partly be explained by poorer glycemic control [6].

In the general population adherence to the diabetic regimen is influenced by a complex configuration of factors, such as availability and transparency of information, social support, healthy lifestyle attitudes, personal health beliefs, patient-provider relationship, body awareness [7], self-efficacy and feelings of depression [8-9]. Therapy related factors (eg, complexity of treatment, side-effects, interaction effects, multiple drugs use) [10-12] and disease-related factors (eg, course of the disease and comorbidity) [7, 13] can be obstacles for appropriate self-care. Finally, cultural background can influence attitudes and beliefs towards health and medical treatment [14,15] just as socioeconomic background determines the access to health care and the availability of material, social, and psychological resources to deal with disease [13]. Although patients may balance the perceived advantages and disadvantages of medication-taking [16] these insights are rarely incorporated in study designs. A better understanding of this strategic non-adherence, which should be distinguished from non-deliberate behaviour (eg forgetting), seems necessary to support patients in their medication taking.

Limited research is done on ethnic differences in medication adherence to oral hypoglycaemic agents (OHAs). The majority of these comparative studies finds lower rates of medication adherence among some non-White ethnic groups living in developed countries [17-28].

## **Methods**

### *Objectives*

Because of the preponderance of type 2 DM in non-White ethnic groups, studying factors that explain medication adherence in different ethnic groups is important. Initially we wanted to review studies on medication adherence among Turks with type 2 DM living in Europe. However, after performing searches with high sensitivity and consulting researchers in different countries we were not able to identify any studies. Broadening the scope of our searches to non-European countries and other ethnic groups showed that the evidence in this field is scarce.

Thus, using a methodology based on existing guidelines[29-32], we decided to perform a systematic literature review with 2 objectives [29]: (1) show the lack of evidence in this field, and (2) synthesize the available evidence for ethnic groups that can be studied. OHA is focused upon because of their central role in the medication regimen [33]. Our research question is, which factors influence medication adherence in different ethnic groups?

### *Search strategy*

In step one the Cochrane Library and the Center for Reviews and Dissemination databases were searched for existing systematic reviews in November 2008, repeated in February 2010. In step two, a systematic literature search in Pubmed, Cochrane, Web of Science, CSA, OVID SP, and FRANCIS (in English, French, and German) was conducted in January 2009.

In both steps a combination of the following search terms was used: ‘medication’, ‘hypoglycaemic agents’ (MESH), ‘pharmaceutical preparations’ (MESH), ‘adherence’,

'compliance', 'concordance', 'treatment refusal' (MESH), 'patient compliance' (MESH), 'diabetes', 'diabetes mellitus' (MESH), 'ethnicity', 'ethnic,' 'ethnic group(s)', 'culture' (MESH), 'ethnology' (MESH), 'minority groups' (MESH), 'migrant', 'migrant group(s)', 'migration and immigration' (MESH), or their translations in the title, topic, and abstract. All databases were searched from their starting years until January 2009, and alerts were installed. The first step did not lead to any published systematic reviews or meta-analysis. In the second step a total of 13 databases yielded 1201 publications which appeared to relate to the topic. Titles and abstracts were screened using the inclusion criteria by 2 authors (BP, sociologist and IVT, pharmacist) independently from each other. On disagreement, full text articles were screened and consensus was reached in discussions, in which one or more co-authors could be involved. References of the selected articles were checked for potentially relevant studies.

#### *Inclusion criteria*

Articles were included in this review if: (1) the study population included type 2 diabetic patients of at least 1 ethnic group other than white people, using OHA (without or in combination with insulin); (2) adherence to OHA was at least one of the dependent variable(s); (3) a clear description of the measurement of medication adherence was presented (pill counts, reliable and validated questionnaires, prescription refill rate, electronic monitoring).

Excluded were: studies on type 1 DM, studies in which medication adherence was an independent variable and clinical studies reporting effects of certain drugs. Study types excluded were clinical case reports and qualitative research (insights from the latter were used in the Discussion section). Letters, commentaries and editorials were also excluded.

## **Data extraction and quality assesment**

Our data extraction sheet was based on examples from the methodological literature on systematic reviews [29-32] and pilot-tested on 3 randomly chosen included studies. After the pilot test, extra items were added: definition and measurement of ethnicity, and comments by the reviewer about this item. The final data extraction sheet included items concerning first author, year of publication, title, country, setting, time, objective(s), research hypothesis, study type, sample selection method, inclusion and exclusion criteria, sample size (total and per racial/ethnic group), racial/ethnic composition, nonresponse, demographic and socioeconomic characteristics, definition and measurement of race/ethnicity, drug type, independent variables included, measurement of independent variables, definition and measurement of medication adherence, categorization criteria for levels of adherence, adherence rates, statistical techniques, conclusions, limitations reported, comments from study authors. The first 2 authors extracted data for each included study independently from each other. Results were discussed.

Our quality assessment tool was based on existing guidelines and quality appraisal tools [29,31,34]. We adapted existing tools because the included studies are observational studies with a cross-sectional design. Other adaptations made pertain to specific problems in studies on ethnicity and medication adherence. Questions were formulated for each of the following domains: research objective, appropriateness of the research design, sample selection, measurement of variables, data collection, confounding variables, statistical analysis, interpretation of results. Special attention was given to the definition and measurement of ethnicity and medication adherence. The first 2 authors of this review assessed the quality of each included study independently from each other. Results were discussed.

For each eligible study we summarized data regarding study design, setting and study population, drug regimen, measurement of adherence, measurement of ethnicity, independent variables, conclusions (Table1). For studies of different drug regimens, eg, antihyperglycaemics and antihypertensives, only data for antihyperglycaemics were extracted.

*A note on the labelling of populations*

Although some included studies use the word *race*, we prefer the term *ethnicity* because this review focussed on health behaviour (see Discussion). In our description of study results ethnic categories are put between quotation marks, because of problems with the delineation of ethnic categories and assignment methods used in studies on ethnic groups (see Discussion). For the included studies we used labels provided by the authors of the original studies.

Table 1. Overview of the included studies<sup>1</sup>.

First Author, Publication Year & Reference Number	Setting & Study Population	Drug Regimen	Measurement of Adherence	Measurement of Ethnicity	Independent Variables /Conditions	Main Results
Aikens, 2009 <sup>51</sup>	USA age inclusion criterion not specified African American (n = 468) or Others (n = 335)	OHA + insulin Insulin	1 survey item cost-related underuse 1 survey item non-cost-related underuse	Self-report: assignment procedure is not reported	Age, gender, ethnicity, educational level household income, monthly out-of-pocket medication costs No. of medical conditions, no. of prescribed medications, prescribed insulin Medication beliefs (BMO) Satisfaction with medication information (SIMS) Health literacy	Concerns about medications are associated with cost-related and non-cost-related underuse Ethnicity, age, satisfaction with medication information, high medication costs, the number of medical conditions and health literacy are associated with concerns about antihyperglycaemic medications
Barnes, 2004 <sup>25</sup>	New Zealand age > 18 Tongan (n = 43) or European (n = 39) decent	Not specified	MARS, two extra items added	Self-report: assignment procedure is not reported	Age, ethnicity unemployment due to health, financial compensation due to diabetes duration of diabetes, hospital admissions, most recent HbA1c (clinic records) illness beliefs: IPQ-R (2 extra items added), medication beliefs: BMQ 'need' and 'concern' subscales	Illness perceptions and medication beliefs associated with medication adherence

<p>Bean, 2007<sup>26</sup></p> <p>New Zealand age &gt; 18 European (n = 80), South-Asian (n = 86), Pacific Islanders (n = 87)</p> <p>OHA OHA + insulin Insulin</p> <p>SDSCA medication subscale, one extra item added</p> <p>Self-report: assignment procedure is not reported</p> <p>Age, gender, educational level, marital status, born in New-Zealand, number of years lived in New-Zealand duration of diabetes, insulin treatment illness perceptions (BIPQ) self-efficacy (MDQ)</p> <p>In all 3 ethnic groups medication self-efficacy influences medication self-care. In Pacific-Islanders diabetes duration, perceptions of consequences and of acute versus chronic nature also influenced medication self-care</p>
<p>Hill-Briggs, 2005<sup>47</sup></p> <p>USA age: 35-75 years African American (n = 181)</p> <p>OHA Insulin</p> <p>MARS, one extra item added</p> <p>Clinical records: self-report in the past, assignment procedure is not reported</p> <p>Age; gender education; income; health insurance duration of diabetes; number of medications depressive symptoms (CES-D) total health self-rating medication-related beliefs (Diabetes Health Belief Scale: 2 items) Perception of personal blood glucose level</p> <p>Age and personal blood glucose levels associated with medication adherence</p>
<p>Kuo, 2003<sup>48</sup></p> <p>USA age ≥ 65 Mexican American (n = 908)</p> <p>OHA OHA + insulin Insulin</p> <p>Inconsistency in medication use: self-reported and controlled by interviewer at respondents home</p> <p>Information in unavailable source</p> <p>Age (2 groups 65-74 and &gt;74), gender, marital status, years of formal education, household income, language medical insurance status (Medicare yes/no), supplemental health insurance (Medicaid yes/no; private/health maintenance organization [HMO] yes/no) Medication type activity of daily living (ADL), instrumental ADL (IADL) cognitive function (MMSE), and depressive symptoms (CES-D)</p> <p>Age and insurance type associated with medication adherence</p>

<p>USA age inclusion criterion not specified n in total = 20685: Japanese, Chinese, Whites, Hawaiians, Filipinos, Koreans, n per ethnic group not specified</p> <p>Lee, 2005<sup>33</sup></p>	<p>Sulfonylurea, metformin, thiazolidinedione, <math>\alpha</math>-glycosidase inhibitors (with or without insulin)</p> <p>Administrative database: retrospective analysis average days of adherence per year</p> <p>Administrative database: ethnicity was self-reported in earlier surveys, 17 categories, more than 1 category could be chosen</p> <p>Age, sex, ethnicity island of residence morbidity level, year of treatment, type of drug type of coverage</p> <p>Drug class, age, ethnicity, island of residence, insurance type and morbidity level associated with adherence</p>
<p>USA age &gt; 30 Asian/Pacific Islander (n =75), African American (n= 100), Hispanic (n = 165), white/non-Hispanic (n = 51)</p> <p>Sarkar, 2006<sup>49</sup></p>	<p>SDSCA medication subscale</p> <p>OHA</p> <p>Self-report: 7 broad categories (3 were omitted from analysis)</p> <p>Sex, income, age, language, ethnicity</p> <p>self-efficacy: 8 items 4-point Likert scale diabetes-specific and general health domains; health literacy: s-TOFHLA duration of diabetes, complications, medical regimen</p> <p>No association of self-efficacy with medication adherence</p>
<p>USA Medicaid insured patients age: 18 – 64 Black (n = 617), White (n = 358)</p> <p>Sclar, 1999<sup>30</sup></p>	<p>Administrative database: retrospective analysis Mean total number of days supply of sulfonlylurea obtained over the 12-month study period</p> <p>Second generation sulfonlylurea (new starters)</p> <p>Administrative database: assignment procedure is not reported</p> <p>Ethnicity, age, gender</p> <p>Ethnicity, age and gender associated with medication adherence</p>

Shenolikar, 2006 <sup>29</sup>	<p>USA</p> <p>Medicaid insured patients age ≥18</p> <p>African-American (n=1527), Whites (n=1128), others (n=514)</p>	<p>Metformine, Sulfonylureas, Thiazolidinediones (new starters)</p>	<p>Administrative database: retrospective analysis Med-Total</p>	<p>Administrative database: ethnicity was self-reported on enrollment in Medicaid</p>	<p>Race, age, gender propensity for healthcare utilization</p> <p>Drug class, total number of medications consumed, number of comorbidities</p>	<p>Drug class and ethnicity associated with medication adherence</p>
Shenolikar, 2006 <sup>32</sup>	<p>USA</p> <p>Medicaid insured patients age ≥18</p> <p>African American (n=539), all others (White, Asian, Native American, Pacific Islander, Other, n=534)</p>	<p>Pioglitazone (TZD) new starters</p>	<p>Administrative database: retrospective analysis Med-Total</p>	<p>Administrative database: ethnicity was self-reported on enrollment in Medicaid</p>	<p>Race, age, gender prescription utilization</p>	<p>Total number of prescriptions associated with medication adherence.</p>
Venter, 1991 <sup>50</sup>	<p>South African Blacks (n = 68)</p>	<p>Metformin Chlorpropamide both drugs</p>	<p>Urine samples observed by clinician</p>	<p>No clear information reported. Presumably skin colour:</p>	<p>Age, sex height, BMI received (for all diseases), time since last dose, frequency of administration</p>	<p>No statistically significant associations between independent variables and medication adherence were found.</p>

<p>USA age ≥ 18 White (n = 374), African- American (n = 201), Latino (n = 133), Asian (n = 63), Native American (n = 15)</p>	<p>At baseline: MARS Administrative database: Med-Out, Comply = 1 - Med-Out</p>	<p>Self-report: 5 broad categories, assignment procedure is not reported.</p>	<p>Age, gender, race, marital status employment status physical and mental health status: RAND SF-36, number of daily doses, insulin, second generation sulfonylurea, number of concurrent medications number of days spent in hospital, new users Severity of comorbid medical conditions: chronic disease score Interaction with healthcare providers: continuity and satisfaction</p>	<p>Age, self reported level of medication-taking compliance at baseline, treatment complexity, the use of second-generation sulfonylureas, perception of general health and being a newly treated patient associated with medication adherence</p>
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Figures of associations are not reported in this table because of the large methodological differences between the included studies (see Discussion section).

## **Results**

### *Search Results*

A total of 1201 titles was initially identified. After exclusion on the basis of title and abstract 32 studies remained. Full-text articles were read by the first 2 authors independently of each other. After discussion consensus was reached on 12 studies that fitted the inclusion criteria. The 20 other studies were excluded because the focus was on adherence in general, adherence to other elements of the diabetic regimen, on quality of care (n=6), on perceptions of diabetes or its treatment (n=4), medication adherence to OHA was not used as a dependent variable (n =6), study populations consisted of a mix of people with type 1 and type 2 DM (n =1 ), the majority of the participants used insulin (n=1), mean medication adherence for drugs of different therapeutic classes was the dependent variable (n = 1), or the focus was on prescription of OHA and adherence was not reported (n = 1). For most cases there was little or no disagreement between the first two authors. For 1 article that seemed eligible, the full text could not be retrieved.

Included studies varied strongly in regard to ethnic groups and drugs studied, measures used for medication adherence and ethnicity, socioeconomic and sociodemographic sample profiles, and variables included in the study (Table 1). This limited amount of evidence and the heterogeneity of the included studies made the synthesis of results very difficult. We provided a narrative review ordered by the kind of factors found to be of influence. Synthesising results by ethnic groups proved to be impossible because of the diversity and the often unclear delineation of study populations.

*Factors associated with medication adherence in different ethnic groups*

Three studies reported a direct association between ethnicity and medication adherence [22,23,26]. In Hawaii, 'Filipino ethnicity' was identified as a risk marker for poorer medication adherence [26,35], while Sclar et al reported that 'Blacks' were less adherent to second-generation sulfonylureas [23], and Shenolikar et al reported lower adherence rates among 'African Americans' [22]. These studies correctly interpreted ethnicity as a risk marker, not as a risk factor, and the need for further research to explain this association was mentioned [22,23,26,35].

*Demographic factors*

The influence of age on medication adherence seemed to be consistent in different ethnic groups (Table 1). Older age was associated with better medication adherence but adherence rates declined for the oldest [19,22-26,36-38]. Only 1 study found no significant association in a small sample of 'Blacks' [39], and Barnes et al did not report on possible associations with demographic variables [18]. Marital status was included in only 3 studies and did not influence medication adherence among 'Europeans, South Asians and Pacific Islanders', 'Mexican Americans', 'Whites, African-Americans, Latinos, Asians, and Native Americans' [19,24,37]. Only two studies showed an association between gender and medication adherence: in 'Europeans and Pacific Islanders' and in 'Blacks and Whites' [19,23]. Aikens et al investigated the influence of several variables on medication beliefs (concerns and necessity) and in a second step the impact of medication beliefs on adherence. Only concerns about antihyperglycaemics influenced adherence. Demographic variables influencing these concerns were younger age and African-American ethnicity [40].

*Socioeconomic factors*

Five studies included measures of income and/or insurance status [26,36-38,40]. Adherence rates for low-income ‘African Americans’ and ‘Asian/Pacific Islanders, African Americans, Hispanics, White/nonHispanics’ were not associated with income level [36,38]. However, for ‘African Americans and Others’ living in an economically distressed region, the level of monthly out-of-pocket costs was correlated with concerns about antihyperglycaemics, which in turn were negatively associated with medication adherence [40]. Insurance type or lack of insurance that covered drug expenses contributed to explaining nonadherence for ‘Japanese, Chinese, Whites, Hawaiians, Filipinos, Koreans’, and ‘Mexican Americans’ [26,37]. Educational level showed a negative association with medication adherence for ‘South Asians’ [19].

*Socio-psychological factors*

Only 3 articles discussed depressive symptoms or the respondent’s perception of his own mental health [24,36,37]. While there was no association with medication adherence for ‘African Americans’, ‘Whites, African Americans, Latinos, Asians, Native Americans’, and ‘Mexican Americans’, other studies indicated that mental health might be an important factor influencing self-care and diabetes control in different ethnic groups [8,9,41-43].

Self-efficacy influenced medication adherence in ‘Europeans, South Asians, and Pacific Islanders’ [19]. In the only other study that included self-efficacy, the lack of a statistically significant association between self-efficacy and medication adherence could be explained by the use of a crude self-report measure for medication adherence [38].

*Disease and treatment-related factors*

Relatively few studies included a variety of disease-related and treatment-related factors. Patients' subjective rating of their general health was inversely related to medication adherence for 'Whites, African Americans, Latinos, Asians, and Native Americans' but this finding was not confirmed for low-income 'African Americans' [24,36]. In middle-class 'Whites, African Americans, Latinos, Asians, and Native Americans' the dosage of antidiabetic drugs and being a newly treated patient had an inverse relationship to adherence while the use of second generation sulfonylureas stimulated adherence [24]. Drug class was also an important factor for 'Japanese, Chinese, Whites, Hawaiians, Filipinos, Koreans', and 'Whites, African Americans, and Others' with adherence rates being the highest for the sulfonylureas [22,26]. A lower adherence rate was reported for 'Pacific Islanders' with a longer history of diabetes [19], but in 2 other studies there was no association between diabetes duration and medication adherence [24,36], and Barnes et al did not report on this possible association [18]. The number of medications used for all diseases did not influence adherence to OHA in 'African Americans' and 'Whites, African Americans and Others' but was associated with adherence to pioglitazone in 'African Americans and Others'[22,25,36]. The number of medical conditions showed a positive association with being concerned about antihyperglycaemics in 'African Americans and Others' [40].

*Cultural factors*

Factors shaped by culture, such as beliefs about health, illness, and medications are rarely included in study designs. Four studies investigated the impact of illness and medication beliefs [18,19,36,40]. Barnes et al found that lower adherence in patients of

‘Tongan or European decent’ was associated with beliefs that environmental pollution, God’s will, or poor medical care in the past were causes of diabetes and with the beliefs that diabetes has a cyclical course and serious consequences. Patients from ‘Tongan decent’ held these beliefs more widely [18]. Beliefs that diabetes has a shorter timeline and fewer consequences have a positive association with medication self-care in ‘Pacific-Islanders’ [19]. However, Hill-Briggs found no statistically significant association between adherence and beliefs concerning the necessity of medication in low-income ‘African-Americans’ [36]. Finally, concerns about antihyperglycaemics but not perceptions of their necessity led to higher risk of medication underuse [40].

#### *Other factors*

Dissatisfaction with information about medications and having a low level of health literacy heightened the chance of being concerned about antihyperglycaemics in ‘African Americans and Others’ [40]. Social support was not included in the research design of any of these studies, and only 1 study included indicators on the patient-provider relationship but found no association with medication adherence [24].

## Discussion

The available research provides an unclear picture of medication adherence to OHA in different ethnic groups. While the retrieved 12 studies focussed on a wide range of ethnic groups in different countries, societal living conditions, socioeconomic positions, access to high-quality health care, and acculturation (the process in which values, attitudes, and habits are shaped through contacts between cultures) may be very different for the ethnic groups that were studied. The lack of knowledge concerning medication adherence among non-White ethnic groups in Europe is surprising; we only found 1 qualitative study on British Pakistani and British Indian subjects [44]. Consequently, more research is needed in which important methodological challenges will have to be faced. In this section we focus on 3 major problems that prevent us from synthesizing results of available research. Table 3 provides suggestions for researchers studying medication adherence in different ethnic groups.

### *The concepts of race and ethnicity in medical research*

The use of *race* and *ethnicity* as variables in medical research has been extensively discussed [35,45-50]. Research should aim at understanding and resolving differences and inequities while avoiding racial/ethnic stereotyping [35,48,50]. This implies providing an argument for the inclusion of race/ethnicity, including a wide range of potentially confounding factors, and interpreting associations without stepping in the pitfall of ‘naturalistic explanations’ [35,48,50].

Both concepts are often wrongly used as synonyms. Race refers to biological differences, notwithstanding that genetic variability within races is higher than between races [48-50], while “ethnicity” refers to one or more shared characteristics (eg. language, religion, ancestry) which create a sense of group identity. In research on health-related behaviours,

such as medication adherence, it is ethically and scientifically more sound to use the concept of ethnicity [50,51]. Moreover, providing a definition of these concepts is necessary to clarify which indicators are chosen. None of the studies included in this review defined the concepts of race/ethnicity nor offered arguments for the choice of indicators (Table 2).

There is a lack of consensus regarding racial/ethnic labels in medical research. Broad labels (eg Asians or Whites) comprise a range of ethnically diverse subpopulations and may create a false impression of within-group homogeneity [35,45,50]. Thus, it is scientifically more sound to employ specific labels that may include the research hypothesis or the assessment method [50,52-54]. When broader categories are used this should be supported with sound arguments and, where possible, a detailed description of the subpopulations should be provided. As is shown in Table 2, almost all studies fail to provide a clear description of the categories. Several studies even aggregate broad categories into an encompassing one labelled Others.

Several methods are available to assign people to ethnic categories: the use of administrative data (eg, country of birth), assessment by a third party (eg, by skin colour), or self-report. There is a general consensus that the latter is probably the best way to measure ethnicity [50,51], especially when a combination of indicators is used [55], despite the fact that self-identification may change over time under the influence of social and historical circumstances. Yet, whatever method is employed, a rationale for its use should be stated and the method reported in detail [35,47,50]. All of the included studies fell short in providing a clear description of the method and the criteria (Table 2).

Assigning an explanatory role to race/ethnicity without measuring potentially confounding factors may lead to misleading conclusions [46,50,51]. Several authors pointed out that socioeconomic, psychological, and cultural factors may explain differences otherwise attributed to race/ethnicity [35,46,50], and in a small but interesting study, Walsh showed the

value of uncovering factors hidden behind race/ethnicity [56]. Most of the included studies avoided this use of race/ethnicity as a proxy measure by including potentially confounding factors or by focussing on the importance of certain factors (eg, medication beliefs). The direct measurement of cultural factors, however, was neglected in most studies [22-26,37-39]. Studies relying on existing databases failed to include a range of confounding variables but most authors suggested that further research is necessary to explain the association between ethnicity and medication adherence [22,23,26].

Despite the existence of journal guidelines on the use of ethnicity and race, recent reviews show that the problems mentioned above are rather common in medical research [57-61].

Table 2. Descriptions of terminology used and rationale for use in race/ethnicities categories, assignment procedures, and use of ethnicity/race as proxy for unmeasured variables.

Study	Sound Rationale for Studying Ethnicity	Terminology Used/Definition & Rationale	Clear Description of Ethnic/Racial Categories & Rationale for Categories	Clear Description of Assignment Procedure	Avoidance of Use of Ethnicity/Race as Proxy for Unmeasured Variables
Aikens, 2009 <sup>51</sup>	No clear rationale for the inclusion of the variable race	Race/Ethnicity: no definition/no rationale offered	2 broad categories (African American vs Others). No rationale offered.	Self-reported ethnicity but no further information provided.	Yes, inclusion of wide range of variables
Barnes, 2004 <sup>25</sup>	Ethnic differences in morbidity and mortality	Ethnicity: no definition/no rationale offered	At least 1 broad category (European vs Tongan). No rationale offered.	Self-reported ethnicity but no further information provided.	Yes, focus on medication and illness beliefs
Bean, 2007 <sup>26</sup>	Ethnic differences in morbidity and mortality	Ethnicity: no definition/no rationale offered	Subcategories of 2 out of 3 broad categories reported. No rationale offered.	Self-reported ethnicity but no further information provided.	Yes, inclusion of wide range of variables Separate analysis for each ethnic group
Hill-Briggs, 2005 <sup>47</sup>	Ethnic differences in morbidity, mortality and medication adherence	Ethnicity: no definition / no rationale offered	1 broad category. No rationale offered.	African American ancestry by self-report, no further information provided.	One ethnic group is studied
Kuo, 2003 <sup>48</sup>	Ethnic differences in morbidity and mortality	Ethnicity: no definition/no rationale offered	Unsure, unavailable source	Unsure, unavailable source	One ethnic group is studied
Lee, 2005 <sup>33</sup>	Ethnic differences in morbidity and mortality	Race/Ethnicity: no definition/no rationale offered	17 ethnic categories. Chosen for their consistency with state health surveillance program.	Self-reported ethnicity. Procedure for 'mixed ethnicity' explained.	No, several potentially confounding variables known from previous research are not included
Sarkar, 2006 <sup>49</sup>	Ethnic differences in morbidity and mortality	Race/Ethnicity: no definition / no rationale offered	4 broad categories. No rationale offered	Self-reported ethnicity but no further information provided.	Yes, inclusion of wide range of variables

Sclar, 1999 <sup>30</sup>	No clear rationale for the inclusion of the variable race	Race: no definition/no rationale offered	2 broad categories. No rationale offered.	No information provided.	No, several potentially confounding variables known from previous research are not included
Shenolikar, 2006 <sup>29</sup>	Ethnic differences in morbidity, mortality and medication adherence	Race: no definition/no rationale offered	3 broad categories are used; no definition/no rationale offered.	Self-report at enrolment in Medicaid, no further information reported	No, several potentially confounding variables known from previous research are not included
Shenolikar, 2006 <sup>32</sup>	Ethnic differences in morbidity, mortality and medication adherence	Race: no definition/no rationale offered	2 broad categories (African American vs Others). No rationale offered.	Self-report at enrolment in Medicaid, no further information reported	No, several potentially confounding variables known from previous research are not included
Venter, 1991 <sup>50</sup>	No clear rationale for the inclusion of the variable race	Neither race or ethnicity were used.	1 broad category. No rationale offered.	No information provided.	One ethnic group is studied
Venturini, 1999 <sup>31</sup>	No clear rationale for the inclusion of the variable race	Race: no definition / no rationale offered	5 broad categories are used; no definition/no rationale offered. Reduction to dummy variable in analysis.	Self-reported ethnicity but no further information provided.	Yes, inclusion of wide range of variables

*Definition and measurement of medication adherence*

None of the included studies explicitly defined medication adherence but the study authors all understood it as ‘the extent to which a patient takes the prescribed number of medications’. Another facet of medication adherence, the time at which medication doses should be taken, was not studied.

In assessing medication adherence there is no gold standard in the categorization of patients as adherent or nonadherent, nor in the measurement methods used. Measurements of adherence can be divided in direct and indirect methods [62]. Direct measures involve the detection of a chemical in a body fluid, and are considered accurate. However, these methods can be costly, uncomfortable, and accuracy depends upon the drug’s pharmacokinetic and pharmacodynamic variability. One included study using direct measurement warned that compliance to chlorpropamide might be overestimated [39].

Indirect methods include self-report, pill counts, prescription refill records, and electronic monitoring. Self-report questionnaires are cheap, easy to use, and have been validated in different study populations. But they tend to overestimate adherence because of the social desirability of answers and the difficulties respondents experience in remembering their actual behaviour. When using these instruments in different ethnic groups cultural habits or other population characteristics often call for not just a translation but a rephrasing of the questions used. Six of the studies in this review used self-report measures like the Medication Adherence Scale (MARS) [63,17,36], the medication subscale of the Summary of Diabetes Self Care Activities (SDSCA)[19,38] or survey questions developed by the researchers [37,40] but there was no uniformity in the use of the scale nor in the categorization of respondents (Table 1).

Retrospective analyses relying on existing databases are able to give a rather accurate picture provided that these data are reliable. One should also keep in mind that obtaining medication does not provide information on the actual medication-taking behaviour. Assessment of adherence should also take into account shifts in medication regimen, hospitalisation periods, and medically supervised temporary adjustments (eg, for religious reasons during a period of fasting). A variety of measures has been developed to calculate refill adherence using administrative data [64,65]. The included studies that focus on refill adherence use different measures and calculation methods [22-26]. (Table 1)

Researchers should present an extensive rationale for their choice of measures, calculation methods, and classification procedures (Table 3). The use of a range of direct and indirect measurement methods and the differences between studies that used similar measurement methods makes it difficult to compare adherence rates (Table 1). The choice of measurements should depend on the reliability, validity, sensitivity/specificity, and nonreactivity of available methods but evidence is scarce. However, there is no agreement on the accord of adherence rates obtained by different measurement methods [24,66,67,68].

### *Study designs*

The study designs of the included studies differed with respect to their central research questions and hence with respect to the included variables. Some studies investigated the importance of one or more theoretical variables; for example, medication beliefs [18,19], illness beliefs [18,19], self-efficacy [19,38], or health literacy [38]. The choice of potentially confounding independent variables was based on insights from a wide range of previous studies, mainly in white populations, with different theoretical foci. Other studies included

also based their choice of variables on insights from a wide range of previous studies. The choice of variables partly depends on the researchers' theoretical foci.

Whether the outcome of interest is medication adherence or a range of self-care activities may also influence the choice of the included independent variables. Studies based on administrative databases are only able to include a limited number of variables [22,23,25,26]. Consequently, synthesizing results was difficult because the choice of included variables varied according to the central research question, the outcome of interest, the range of previous studies consulted, and the availability of variables in administrative databases.

Although testing insights from previous quantitative studies among white people is useful this approach runs the risk of providing a partial picture of medication adherence in other ethnic groups. In a review of research on compliance, Vermeire et al showed that during the past 3 decades patients' perspectives often were neglected and 'despite continuing efforts, no substantial new insights have arisen from quantitative studies' [62]. Using results of qualitative research that explores patients' perspectives on (medication) adherence in specific ethnic groups can lead to a fuller understanding. The study conducted by Lawton et al. on perceptions and experiences of taking OHA among British Pakistani and British Indian individuals is a good example of qualitative research that may inform the choice of variables for quantitative research [44]. This study showed the potential importance of British Pakistanis' and British Indians' medication beliefs, their perceptions of the effects of dietary habits, and their perceptions of healthcare professionals on the use of OHA. Qualitative studies may provide new insights or point to commonalities between white people and other ethnic groups, thereby negating prejudices that otherwise could have influenced the design of quantitative studies [14,15,69-72]. A promising, rather new pathway is the practice of 'meta-synthesis of qualitative research' [73]. A good example is the synthesis of qualitative research on resisting medicines by Pound et al, which shows the importance of concerns about

medications in a range of study populations [16]. More attention should be given to the results of qualitative research in different ethnic groups because this could lead to a more informed choice of variables in quantitative research. The involvement of members of the ethnic groups under study in the design phase could also help to assure a better informed choice of variables.

The study carried out by Bean et al is the only comparative study in which separate analyses were performed for each ethnic group [19]. This resulted in insights into medication adherence and other self-care activities that were specific for each ethnic group (although the same factor may be of influence in each ethnic group). Other comparative studies used race/ethnicity as a dichotomised control variable [22-26,38,40]. Finding an association with medication adherence means there is a statistically significant difference for mean medication adherence between ethnic groups after controlling for other included variables [46]. This association can be explained by variables not included in the design and should not be interpreted in causal terms. The procedure used by Bean et al is more fruitful when the goal of the research is the discovery of influencing factors that could be targeted in interventions.

Other problems encountered in synthesising results of these studies pertained to small and/or homogenous samples [18,36,39], the use of imprecise indicators for complex constructs (eg socioeconomic status) which can downplay their influence [18,19,37], the diversity of drugs under study, inclusion criteria that limited generalisation of results [18,22-25,36], the diversity of measurement instruments used for concepts such as medication beliefs [18,36,40], and measurement errors due to the translation of questionnaires [18]. In some studies the lack of testing univariate associations in multivariate analysis hinders the interpretation of results [18,36,39].

Table 3. Suggestions for researchers studying medication adherence in different ethnic groups.

*Measuring ethnicity*

- Explain the reasons for the inclusion of ethnicity as a variable.
- Define the concept of ethnicity.
- Explain the choice of indicators derived from the definition of the concept.
- Explain the measurement instruments and procedures.
- Explain the procedure to assign people to an ethnic group.
- Try to delineate each ethnic group in such a way that ethnic within-group heterogeneity is minimised.
- When a clear delineation is not possible or not suitable for the overall research objective: explain the composition of the broader ethnic categories.
- Use labels that clearly describe the ethnic groups (these labels may contain elements of a central research hypothesis or a description of the measurement procedure).
- Include as many potentially influencing factors as possible to avoid the use of ethnicity as a proxy for unmeasured variables.
- Interpret the results in the light of the limitations of the measurement and assignment procedures.
- Avoid causal interpretations of associations between ethnicity and medication adherence and formulate hypotheses for further research.
- Be careful with the generalisation of results when broad ethnic categories are used.

*Measuring medication adherence*

- Define medication adherence.
- Explain the choice of indicators derived from the definition of the concept.
- Provide arguments for the choice of measurement instrument(s).
- Describe the measurement instrument(s) and procedure(s).
- Provide arguments for any adjustment made to measurement instrument(s).
- In the case of self-report measures provide evidence for the methodological properties of the measurement instrument in the ethnic groups under study.
- Describe the criteria to categorize patients into different levels of adherence.
- Describe the calculation procedures used to categorize patients.
- Consider the use of multiple methods of adherence assessment so that they can be compared.
- Interpret the results in the light of the limitations of the measurement and assignment procedures.

*Study designs*

- Use insights from qualitative research (or meta-synthesis of qualitative research) to inform the inclusion of variables in quantitative research.
- Involve members of the ethnic groups under study in the phases of designing, conducting and analysing.
- Do not limit the choice of variables to the ones included in research on Whites.
- Provide a clear argumentation for the included variables.
- Describe the analysis techniques in the light of the research question. Consider reporting results that may not be of direct relevance to your research question (eg, a remaining association between ethnicity and adherence when the focus is on the influence of one variable).
- Consider separate analyses for each ethnic group.
- Maximize sample sizes.
- Explain the procedures for the 'translation' of questionnaires and measurement scales
- Provide evidence for the methodological properties of measurement scales in the ethnic groups under study.
- Use a refined set of indicators for complex constructs.

*Significance of the review*

Medication management is an important part of diabetes treatment. Only a small number of studies have explored the association of ethnicity and medication adherence. Further research is required to understand the reasons for differences in medication adherence in well-defined ethnic groups. The main methodological challenges in this field are discussed and suggestions for further research are made. Identifying these differences leads to designing strategies for improving medication adherence and assists in improving patients' glycaemic control and reducing healthcare costs.

*Limitations of the review*

A first limitation is the small number of studies retrieved despite the fact that a large number of databases was searched with broadly defined queries. However, we did not include any grey literature or unpublished studies. Secondly, it is very difficult to compare results of the existing studies due to the great diversity of settings, study designs, measurements of adherence, drugs, and ethnic populations.

**Conclusion**

There is a great lack of research on medication adherence to OHA in several non-White ethnic groups. Synthesising results requires a larger number of studies, a better informed inclusion of variables in study designs, and more uniformity in measurements of ethnicity and adherence. Authors should also describe in detail the populations under study and the methodological choices that were made. Medication adherence is an essential part of

the diabetic regimen for every person with diabetes. In today's multiethnic world more efforts should be made to understand medication adherence in several ethnic groups. Purposeful interventions based on this understanding are an important step towards equitable diabetes care for everyone.

**Declaration of Competing Interests**

Nothing to declare.

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***Chapter 2:***  
***Aims***

***Study aims.***

Our systematic review showed limited insights are available on adherence to OHA among patients belonging to ethnic minorities. For some ethnic minorities culturally shaped illness and medication beliefs may influence adherence to OHA. Furthermore, no studies are available on adherence rates to OHA and factors influencing adherence to OHA among T2DM-patients of Turkish descent in Europe.

In our evaluation of the studies included in our systematic review we pointed out several methodological pitfalls. One of the most important is the fact that inclusion of covariates in these quantitative studies was not based on insights of exploratory qualitative research. When questionnaire designs are based on insights from previous studies in mainly White populations, studies run the risk of providing a partial picture of factors influencing adherence to OHA. In turn, interventions based on insights from these studies may have only a limited impact on adherence to OHA in ethnic minorities. Another important limitation of some of the included studies was the use of self-report to measure medication adherence.

In the general introduction we also pointed out the importance of exploring patients' perspectives and the possible conflicts that can arise between patients' and health care providers' perspectives on adherence.

The aims of this dissertation are fourfold: 1) to explore the factors influencing adherence to OHA among patients of Turkish descent; 2) to assess the participation of DM patients of Turkish descent at Ramadan fasting, the impact of Ramadan fasting on adherence to OHA and/or insulin, the extent to which patients receive advice from health care workers on Ramadan fasting and adherence to OHA and/or insulin; 3) to explore perspectives of GPs and PHs on factors influencing adherence to OHA and barriers to promoting adherence to

OHA in T2DM patients of Turkish descent and 4) to integrate insights from aims 1 and 3 into a quantitative, cross-sectional study that, using an objective measure of medication adherence, explores the factors influencing adherence to OHA among patients of Turkish descent on a larger scale and provides an estimate of the nonadherence rate to OHA in this population.

*Aim 1: To explore the factors influencing adherence to OHA among patients of Turkish descent.*

First we conducted an explorative, qualitative study using in-depth interviews with T2DM-patients of Turkish descent. Qualitative research is able to explore in great detail patients' perspectives on health, treatment and the health care received in small, carefully selected samples. The results of this qualitative study are reported in Chapter 3.

*Aim 2: To assess the participation of DM patients of Turkish descent at Ramadan fasting, the impact of Ramadan fasting on adherence to OHA and insulin and the extent to which these patients receive advice from professional health care workers on Ramadan fasting and adherence to OHA and insulin.*

The vast majority of DM-patients of Turkish descent living in Belgium are Muslims. From the interview study (chapter 3) we learned that some patients adjust the intake of OHA during Ramadan fasting without consulting their health care providers. Therefore we conducted a cross-sectional study among T1DM and T2DM patients of Turkish descent to assess participation in Ramadan fasting, adherence rates to OHA and insulin during Ramadan fasting and advice received from health care providers on diabetes and Ramadan fasting. The results of this study are reported in chapter 4.

*Aim 3: To explore perspectives of GPs and PHs on factors influencing adherence to OHA, and on barriers to promoting adherence to OHA in T2DM patients of Turkish descent.*

As described in the general introduction T2DM is frequently treated in primary care. Consequently, GPs and PHs are diabetes care providers who play a central role in promoting adherence to OHA. In order to do so they must have an accurate picture of factors influencing adherence to OHA in T2DM patients of Turkish descent. Our description of important population characteristics and of the organisation of diabetes care, provided in the general introduction, also indicates several potential barriers to promoting adherence to OHA in this population.

Therefore we conducted a qualitative study with GPs and PHs, using focus groups, to describe views of Belgian GPs and PHs on factors influencing adherence to OHA in T2DM patients of Turkish descent, to understand the barriers they encounter in promoting adherence to OHA and to describe solutions deemed necessary by GPs and PHs to overcome these barriers. Results of this study are reported in chapter 5.

*Aim 4: To conduct a quantitative, cross-sectional study that, using an objective measure of medication adherence, explores the factors influencing adherence to OHA among patients of Turkish descent on a larger scale and provides an estimate of the nonadherence rate to OHA in this population.*

The results from the qualitative study (chapter 3) lay the foundation for the questionnaire used in our quantitative, cross-sectional study. This study, reported in chapter 6, aimed to identify and to assess the relative importance of factors influencing adherence to OHA in a representative sample of T2DM patients of Turkish descent. Furthermore, our

## Chapter 2

cross-sectional study provides an estimate of the nonadherence rate to OHA in this population, using an objective measure of medication adherence.

In the final chapter we formulate our general conclusions and discuss the implications for practice and future research.



***Chapter 3:***  
***Qualitative study among***  
***patients of Turkish descent with T2DM***

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***Understanding medication adherence among patients of Turkish descent with type 2 diabetes: a qualitative study.***

**Abstract**

**Objective.** To explore perspectives of Turkish migrants with type 2 diabetes mellitus (T2DM) on adherence to oral hypoglycaemic agents (OHA).

**Design.** In-depth interviews with 21 T2DM patients of Turkish descent recruited from primary care and community sources in Ghent, Belgium, using a theoretical sampling procedure. Analysis was guided by a grounded theory approach, using Nvivo 8.

**Results.** Respondents reported a multitude of barriers and facilitators of adherence to OHA. Some of these barriers are distinctive for T2DM patients of Turkish descent. Respondents' causal beliefs about stress and the Belgian climate often led to nonadherence during less stressful periods, like summer holidays in Turkey. Some respondents adjusted their medication use to food intake or during Ramadan fasting. Concerns about OHA were the main reason for the widespread use of herbal medicine in this sample. The religious framework used to interpret diabetes led, in combination with feelings of depression, to nonadherence while to other respondents it facilitated medication adherence. A potential gender effect with respect to the self-management of OHA was observed. Non-distinctive factors include: beliefs about OHA, polypharmacy, beliefs about the course of diabetes, forgetfulness, the perception of the doctor's medical expertise, feelings of depression and social support.

**Conclusion.** Health care providers should explore in detail and regularly patients' perspectives on illness beliefs, medication beliefs and their trust in doctors' medical expertise as this will provide useful starting points for promoting medication adherence. Whenever possible health care workers should engage with their patients in therapeutic alliances.

**Keywords:** type 2 diabetes; medication adherence; immigrant; Turkish ethnic minority; oral hypoglycaemic agents; qualitative research

## **Understanding medication adherence among patients of Turkish descent with type 2 diabetes: a qualitative study.**

### **Introduction**

Type 2 diabetes mellitus (T2DM) is a major global health problem associated with substantial morbidity and mortality, as well as an economic burden (IDF 2011). Migrants and ethnic minorities residing in developed countries suffer disproportionately more from T2DM and diabetes complications, the latter can partly be attributed to poorer glycaemic control (Carter, Pugh, and Monterrosa 1996; Dagogo-Jack 2003). Adherence to hypoglycaemic medication is a key factor to good glycaemic control (Asche 2011). However, adherence to oral hypoglycaemic agents (OHA) is generally poor (Cramer 2004). To improve medication adherence, guidelines recommend a patient centred approach (Nunes et al. 2009; Wens et al. 2005). A better understanding of how patients perceive treatment provides important insights for promoting medication adherence. However, research investigating patient views on adherence to OHA in ethnic minorities is limited (Peeters et al. 2011).

A focus on ethnicity is relevant because ethnic differences are observed in disease prevalence, health-related behaviours, perspectives on health and medicines and access to health care. Following Bhopal, we define ethnicity as ‘the social group a person belongs to, identifies with or is identified with by others based on cultural and other factors including language, diet, religion, ancestry and physical features.’ (Bhopal 2004, 441) To accurately interpret results a detailed description of the ethnic group under study, in this case ‘people of Turkish descent living in Belgium’, is provided in box 1. Relevant characteristics of health and diabetes care in Belgium are presented in box 2.

The aim of this qualitative study is to explore perspectives of people of Turkish descent with T2DM on taking OHA. We focus on one aspect of medication adherence, taking the prescribed number of OHA, because this is the most important aspect from a clinical point of view. In Western Europe Turks form one of the largest ethnic groups from outside the European Union (Eurostat 2012; Uitewaal et al. 2004; Wets 2006). Among people of Turkish descent in Belgium, Germany and the Netherlands, prevalence of diabetes is 2 to 3 times higher compared to the indigenous population (Uitewaal et al. 2004; Vandenheede and Deboosere 2009). Insights obtained from this study can inform interventions to promote adherence to OHA among these patients.

**Box 1: Turks in Belgium.**

Approximately 5 percent of the Belgian population originates from non-EU countries. Non-EU immigration increased by leaps and bounds in the 1960's and early 70's when low skilled labour force for the Belgian industry fell short. Agreements with Turkey and Morocco resulted in a large immigration of guest workers and their families. Turks mainly came from rural areas of central Anatolian provinces. The economic crisis in the 1970's resulted in a more restrictive migration policy but family reunion and family formation still lead to a relatively large immigration from Turkey. Migrants from the same region in Turkey usually moved to the same region of destination in Belgium. After 1980 the number of political refugees rose because the Turkish military government persecuted members of Kurdish organisations and the political left (Levrau 2011;Martiniello et al. 2010;Wets 2006). In this study Kurds were excluded.

Most of the Turkish first generation migrants stayed in Belgium, more than half of them reside in the Dutch-speaking northern region (mainly in the cities Ghent and Antwerp and in the coalmine region in Limburg) (Wets 2006). Today, a large part of the Turkish migrants and their descendants form an economically underprivileged population characterised by a low educational level, a high level of unemployment and a very high poverty rate (Dierckx et al. 2012;Djait, Boussé, and Herremans 2011;Martiniello, Rea, Timmerman, and Wets 2010). In general, knowledge of Dutch among the first generation is limited with high levels of illiteracy, especially among women. This first generation forms a rather separated community, living in the same neighbourhoods with communal life centred around Turkish shops, cafés and mosques. On average, Turkish migrants are ethnically more conservative and less secularized than the indigenous population. Among first generation migrants traditional gender roles are widely accepted resulting in women's low participation rates in public life, especially outside the own community (Vancluysen, Van Craen, and Ackaert 2009).

The Belgian Health Interview Survey provides useful information on health and access to health care although the two largest non-EU immigrant groups, Turks and Moroccans, are often pooled. Compared with the Belgian population Turks and Moroccans on average report worse general health, worse mental health and higher rates of diabetes. They have a more sedentary lifestyle and higher rates of overweight (BMI > 25) and obesity (BMI > 30). Alcohol consumption is much lower but the number of (daily) smokers is higher. Similar to the Belgian population the vast majority of Turkish and Moroccan patients always visits the same general practitioner but their use of preventive health care services is lower (Levecque, Lodewijckx, and van den Eeden 2006).

Since depression is a known risk factor for medication nonadherence it is useful to have a closer look at the mental health of people of Turkish descent. Rates of depression, anxiety and general psychological distress are higher compared to the Belgian population (Levecque, Lodewyckx, and Bracke 2009), a finding confirmed for the Turkish population in the Netherlands (De Wit et al. 2008, van der Wurff et al. 2004). For Turks in Belgium being female heightened the risks for depression, anxiety and general psychological distress while a tendency for higher risks was observed among first generation migrants (Levecque, Lodewyckx, and Bracke 2009). Again, studies from the Netherlands confirmed these findings (De Wit et al. 2008, van der Wurff et al. 2004). A Dutch study on co morbid depression among diabetes patients treated in secondary care found higher rates of depression among T2DM patients of Turkish descent (Pouwer et al. 2010, 27:217-224). However, this association between ethnicity and emotional distress in patients with diabetes could not be confirmed in a representative sample of the Amsterdam population (Pouwer et al. 2013, 30:E25-E31).

Box 2: Essential features of health care and diabetes care in Belgium.

The Belgian health care system is characterized by compulsory health insurance and solidarity, therapeutic freedom for physicians, freedom of choice for patients and remuneration (mainly) based on fee-for-service payments. Patients pay on average 20% of the total health care expenditures. Several policy measures guarantee the financial accessibility of health care for patients from lower socio-economic backgrounds and the chronically ill (Gerkens and Merkur 2010:1-266).

General practices and pharmacies are geographically widespread. For every 1200 patients there is one GP, for every 2000 patients there is one community pharmacy. Only a very small minority of general practitioners and pharmacists has foreign origins. The vast majority of general practitioners works in solo practices or small group practices, most often without the assistance of nurses or other health care providers. The majority of patients always visits the same general practice and the same community pharmacy (Gerkens and Merkur 2010:1-266).

Pharmaceuticals for serious and long-term illnesses, including antidiabetics, are provided for free. The general practitioner is the main diabetes care provider. For patients (starting) on insulin care trajectories were implemented in Belgian health care. These initiatives aim to promote cooperation between the different diabetes care providers (GP, specialist, dietician, ...) while offering additional services (diabetes education, reimbursement of materials for self-measurement of blood glucose, ...) to diabetes patient at low costs. Patients not on insulin pay more for the use of these additional services (Gerkens and Merkur 2010:1-266).

In summary, health care and diabetes care in Belgium shows no significant financial barriers.

Box 3: Glossary of medical terms.

**Type 2 diabetes mellitus (T2DM)** is a chronic metabolic disorder characterized by hyperglycaemia and associated with a relative deficiency of insulin production, along with a reduced response of the target tissues to insulin.

**Hyperglycaemia** refers to abnormally raised levels of glucose in the blood. Chronic hyperglycaemia can damage blood vessels and organs, leading to serious, sometimes life-threatening, complications.

**Hypoglycaemia** refers to abnormally lowered levels of glucose in the blood. Hypoglycaemia most often occurs as a complication of the treatment of diabetes mellitus with insulin or oral hypoglycaemic agents.

**Haemoglobin A1c (HbA1c)** is created by the association of glucose with haemoglobin in the blood. HbA1c is a measure for the average blood glucose level during the past 2 to 3 months. Patients are diagnosed with diabetes when this average blood glucose level exceeds 6.5% or 47.5 mmol/mol. Evidence shows that the HbA1c-level is linked to the progression of microvascular complications in type-2 diabetes.

**Glycaemic control** refers to the average blood glucose level expressed in the HbA1c-level. For nonpregnant adult diabetes patients good glycaemic control is defined as a HbA1c-level < 7.0% or 52 mmol/mol.

**Oral hypoglycaemic agents (OHA)** are orally administered drugs that lower blood glucose levels.

## Methods

### *Design and setting*

This in-depth interview study was conducted in Ghent, Belgium, where approximately 9 % of the inhabitants are of Turkish descent. The ethical committee of Ghent University Hospital approved the study; informed consent was obtained from all respondents.

### *Recruitment and sample*

T2DM patients of Turkish descent aged  $\geq 18$  years and using OHA were eligible for participation. We recruited potential respondents with the aid of general practitioners, community pharmacists, imams and volunteers of Turkish descent.

We used a theoretical sampling procedure which involves concurrent data collection and analysis (Strauss and Corbin 1990). Potential respondents completed a questionnaire detailing sociodemographic characteristics, diabetes duration, medication regimen, comorbidity and adherence to OHA (using a validated self-report measure) (Morisky, Green, and Levine 1986). First we purposively recruited 6 respondents, maximizing diversity with regard to these characteristics. The findings from these cases led to new selection criteria that were assessed in a new questionnaire: illness beliefs, medication beliefs and relationships with health care professionals. Remaining and newly recruited potential respondents completed this second questionnaire. In the second sampling phase, we purposively looked for deviant cases that could contradict developing insights. For example, a question emerging during data analysis was whether the as positive perceived emotional aspects of the doctor-

patient relationship had a more important impact than the perception of the doctor's medical expertise. This led to the selection of cases who perceived the emotional aspects as positive while their trust in the doctor's medical expertise was low. Analysing cases recruited in the second sampling phase did not lead to new selection criteria. Sampling was continued until data saturation was reached. Out of the pool of 48 potential respondents 21 patients were included.

### *Interviews*

A topics list (Table 1) was developed based on systematic literature reviews, pilot interviews and advice from health care professionals of Turkish descent (Cramer 2004; Peeters et. al. 2011). We recorded patients' current and past hypoglycaemic medication as well as all other chronic medications. The most recent glycated haemoglobin value (HbA1c) was retrieved from the respondents' general practitioners.

One interview was conducted by GY (community pharmacist of Turkish descent) and 20 interviews were done by BP (sociologist experienced in qualitative interviewing). BP has knowledge of Turkish and is familiar with common habits among Turks. The interviews were performed in Dutch (n=1) or Turkish (n=20), according to the respondent's preference. During the Turkish interviews, BP was assisted by a professional translator (n=13) or a Master of Pharmaceutical Sciences student of Turkish descent (ZD) (n=6). The translators, ZD and GY received training in qualitative interviewing techniques. Translators were instructed to translate questions and answers literally and complete. Prior to the interview no relations existed between interviewers and respondents, or translators and respondents. All interviews were audio-taped, fully transcribed in Turkish by students of Turkish descent and

translated into Dutch by another translator than the one present during the interview. During the transcription and translation process students and interpreters checked and double-checked the quality of the interpretations. This quality control showed that interpretations were of high quality and had no influence on content or course of the interviews. Interviews took place at the respondents' home. All but 2 interviews consisted of 2 to 4 conversations and averaged 3 hours in total. Spreading the interviews over time contributed to building a relationship based on trust and allowed us to check and clarify information provided in previous conversations.

Table 1. Topics list.

**History of diabetes:** diagnosis; symptoms; emotional impact of diagnosis; knowledge and information at time of diagnosis; social support.

**Diabetes beliefs:** beliefs about causes, nature and consequences; impact of diabetes on identity and daily life; information on/ impact of/ treatment of complications; beliefs about/ impact of co morbidities.

**Medication adherence:** medication history; intentional and unintentional nonadherence; barriers and facilitators; impact on identity and daily life; use of complementary and alternative medicine (CAM); medication use during Ramadan / holidays in Turkey.

**Medication beliefs:** necessity; concerns; short and long term effects; adverse effects; knowledge of/ information on hypoglycaemic medication.

**Lifestyle changes:** treatment history; knowledge of/ information on lifestyle changes; barriers and facilitators.

**Social support:** information gathering; medication use; lifestyle changes; emotional support.

**Relationships with general practitioner, endocrinologist and pharmacist:** history; contact frequency; information gathering; communication barriers / facilitators; decision power; emotional aspects; expectations.

### *Analysis*

Analysis was guided by a grounded theory approach (Strauss and Corbin 1990) and undertaken by BP (sociologist), IVT (pharmacist), and ZD (pharmacist). Bringing different professional perspectives to the data proved fruitful to obtain a complete, detailed picture of

respondents' accounts. NVivo 8 was used to manage, code and analyze the data. Interview transcripts were read and coded repeatedly by the researchers independently from each other. Codes reflected interview questions and themes emerging from the data. In a first phase codes were descriptive 'indexes', functioning as signposts to interesting bits of data. Each researcher described the (throughout this process changing) meaning of codes that were developed. Descriptive codes, their meaning and coded excerpts of data were then compared between researchers in order to reach agreement on the meanings of codes. When relationships between codes became clear these were grouped under broader categories and hierarchical and non-hierarchical relationships were defined. New data often led to new codes or to the refining and redefinition of existing codes, categories and relationships. This iterative process of indexing, coding, categorizing and discussions between researchers was repeated several times. Throughout this process coding queries and coding comparison queries, tools available in Nvivo 8, were used to assess intra-rater consistency and inter-rater reliability. Consensus on preliminary and final results was reached in discussions with all authors.

We analyzed each respondent's experience of taking OHA in great detail. By constantly comparing across cases, thereby paying close attention to deviant cases, we developed a detailed insight in respondents' common and divergent experiences. This resulted in a classification of respondents according to recurrent patterns of interdependent factors influencing medication adherence.

In Tables 3 - 6, supporting quotations are tagged with codes (e.g. R09M: respondent 9, man).

## **Results**

Table 2 summarizes participants' characteristics.

Table 2. Sample characteristics (n = 21).

	N° of patients
<b>Age</b>	
30 – 39 y	2
40 – 49 y	7
50 – 59 y	6
60 – 69 y	6
<b>Sex</b>	
Men	9
Women	12
<b>First generation immigrant</b>	21
Age ≥ 18 y at migration	16
Age < 18 y at migration	5
<b>Duration of residency in Belgium</b>	
1 – 5 y	3
6 – 10 y	3
11 – 20 y	4
> 20 y	11
<b>Educational level</b>	
None	6
Only primary education	10
Secondary education until 15 y	2
Secondary education until 18 y	2
Tertiary education	1
<b>Knowledge of Dutch language</b>	
None – basic	16
Moderate	4
Fluent	1
<b>Religion: Muslim</b>	21
Practising	19
Non-practising	2
<b>Diabetes duration</b>	
0 – 4 y	5
5 – 9 y	9
10 – 14 y	2
≥ 15 y	5
<b>Hypoglycaemic medication</b>	
Oral hypoglycaemic agent (OHA) alone	13
OHA + insulin	8
<b>Type of OHA used</b>	
Metformin	16
Metformin + sulphonylurea	3
Metformin + repaglinide	2
<b>Number of pills/day</b>	
1 – 5 pills/day	11
6 – 10 pills/day	6
≥ 11 pills/day	4
<b>Treated with antidepressants</b>	4
<b>Most recent HbA1c at the time of interview</b>	
≤53 mmol/mol (7%)	3
>53 mmol/mol (7%)	18

*Beliefs about diabetes*

The majority of respondents reported their doctors had never provided information about the causes. Most of them had incorrect ideas (Table 3, Q1). Only three respondents referred to dietary habits in the past. Respondents mostly reported causes beyond their control: heredity, the Belgian climate (i.e. weather and temperature) and, most mentioned, stress. Almost all believed diabetes started during stressful periods (Table 3, Q2). This causal belief about stress was reinforced by the perception that stress influenced their blood glucose levels and/or diabetes symptoms.

Most respondents stated their diabetes was Allah’s will. This either contributed to fatalism (i.e. the perception that someone is not responsible for an undesirable situation and is unable to change it) among respondents who suffered from depression, or it was an additional facilitator for coping with diabetes and its treatment (Table 3, Q3).

At the time of the interviews all respondents realized diabetes is a chronic disease. However, two women who had previously suffered from gestational diabetes had been convinced at the time of diagnosis that also T2DM is an acute disease.

Table 3. Supporting quotations: beliefs about diabetes

Incorrect ideas about the causes of diabetes <i>Q1.</i> ‘Sugar disease, what is it in fact? Doesn’t your throat work properly then? The throat doesn’t make the sugar melt anymore?’ (R33M, suffering from diabetes for more than 10 years)
Stress as cause of diabetes <i>Q2.</i> ‘My son had an accident. He died and I was very sad. That’s when I got sugar.’ (R18F)
Diabetes is Allah’s will, religion as a facilitator for medication and treatment adherence <i>Q3.</i> ‘Of course I accept it (his diabetes). Because Allah gave it to me. My faith makes it easier to deal with it.’ (R02M)

*Beliefs about OHA*

Most respondents could not tell in which way their medicines influence their condition and reported that medication was not an important topic during consultations. One respondent for instance was not even aware of the fact that he took two OHA, although having them prescribed for 3 years (Table 4, Q4). His lack of knowledge led to concerns about and nonadherence to his OHA.

All respondents weighed perceived advantages and disadvantages of the lifelong taking of OHA. Advantages encompassed perceived short- and long-term benefits, often confirmed by perceived improvements of blood glucose levels and/or physical well-being. Perceived disadvantages included short- and long-term inefficacy, perceived adverse effects and beliefs that long-lasting use is detrimental or addictive (Table 4, Q5).

Because of cultural habits and concerns about OHA half of our respondents used herbal medicine; however, concerns about disadvantages, perceived inefficacy, costs and inconvenience of use often led to a cessation (Table 4, Q6).

Table 4. Supporting quotations: beliefs about OHA

Limited provision of information about OHA <i>Q4.</i> 'I only found out 5 to 10 days ago that both of these are sugar pills.' (R38M)
Perceived long-term disadvantages of taking OHA <i>Q5.</i> 'Why would I take it? You get addicted to it. And because you always use it, it no longer has any effect on your body.' (R04F)
The use of herbal medicine <i>Q6.</i> 'I serve as a guinea pig for pills. Which pills have side effects and which ones haven't, I know that. They (family members) told me that karabaş would be good. My son has brought these herbs from Turkey. I boiled and drank them but it didn't help. It was expensive.' (R32F)

*Patient-health care provider relationship*

In Belgium, mainly the general practitioner (GP) is responsible for diabetes treatment. Most respondents trusted their GP's advice; a few used a second medical opinion, physical experiences or blood glucose measurements to assess their GP's medical expertise (Table 5, Q7). Doctor-patient communication was negatively influenced by some patients' perspectives of the doctor's medical expertise (Table 5, Q8).

For most respondents the doctor-patient relationship could be characterized as hierarchical: decision power rested with the doctor while the patient passively followed advice. Only a few respondents actively gathered information and claimed part of the decision power, while GPs explored their perspectives and negotiated decisions.

Some respondents visited a Turkish speaking GP but most relied on the aid of Dutch speaking family members. Language barriers hindered doctor-patient communication (Table 5, Q9).

Respondents regarded the pharmacist as a dispenser of medications and did not recognize his expertise. Language barriers and the fact that, in some cases, family members obtained the medication hindered pharmacist-patient interaction.

Table 5. Supporting quotations: patient-health care provider relationship

Assessment of the GP's medical expertise
Q7. 'Like 2 months ago I felt good and decided to test my sugar. It was 220. I said to myself, wow if it's like this when I feel good, what (would it be) when I feel worse? So that's why I have to take it (OHA) every day, like my doctor used to say.' (R13F who used to be sceptical about metformin)
A lack of trust in GP's medical expertise negatively influences doctor-patient communication.
Q8. 'I don't think it's a doctor (her GP) who has a lot of expertise. (...) I let him prescribe me my medication but apart from that I never consult him. (...) I don't ask any questions at all. He writes the prescriptions and hands them to me.' (R18F who rarely consults her GP)
Language barriers
Q9. 'I did (want to ask for more information) but I don't know the language.' (R36M)

### *Adherence to OHA: barriers and facilitators*

Only few of the respondents reported to be fully adherent to their OHA treatment. Respondents reported a multitude of barriers which led to intentional and/or unintentional nonadherence (Table 6).

Forgetfulness, due to broken routines or problems demanding the patient's attention, was often mentioned (Table 6, Q10 and Q11). The asymptomatic nature of the disease was also cited as reason for forgetfulness (Table 6, Q12). Most respondents had developed strategies to fit drug taking into their daily routines, e.g. keeping the medication in the same place or using help by family members.

Causal beliefs about stress and the Belgian climate influenced some respondents' medication adherence. They reported temporarily stopping or reducing OHA during holidays in Turkey (Table 6, Q13 and Q14).

Non-awareness of the chronic nature of diabetes also led to nonadherence. Two women with previous gestational diabetes had been nonadherent after being diagnosed with T2DM (Table 6, Q15).

A few respondents took less medication because of their beliefs about OHA. To some the perceived disadvantages outweighed advantages. Perceived disadvantages could be long-term (Table 4, Q5) or short-term (Table 6, Q16).

Respondents' concerns about taking many pills also led to intentional nonadherence (Table 6, Q17). Communication with health care providers about concerns was rare, however an open communication can improve medication adherence (Table 6, Q18).

A lack of trust in the medical expertise of the GP contributed to nonadherence among some respondents. For instance, a nonadherent respondent, who perceived his OHA as ineffective and whose expectations about the consultations were not met, distrusted his GP's advice (Table 6, Q19).

Some respondents described they adjusted their use of OHA to their food intake. When having a healthy meal they deliberately skipped a dose. Whenever having an unhealthy meal, they took an extra dose (Table 6, Q20).

Mental problems showed to be important barriers for medication adherence. Feelings of depression or powerlessness, caused by unsettling life events and the impact of diabetes, hindered medication adherence (Table 6, Q21). Co-morbidities or old age caused memory problems leading to unintentional nonadherence.

Facilitators of OHA adherence were: beliefs about diabetes, beliefs about OHA, trust in the GP's medical expertise and social support.

Awareness of the chronic nature of diabetes and its complications stimulated OHA adherence (Table 6, Q24). For some respondents perceived benefits of OHA outweighed perceived disadvantages (Table 6, Q25 and Q26). Others, being concerned about OHA or the number of pills prescribed, still were adherent because they put a lot of trust in the GP's advice (Table 6, Q27). Trust in the GP's medical expertise countered the potential negative

influence of other factors among many of our respondents. Social support, provided by family members or health care professionals, stimulated adherence (Table 6, Q28 and Q29).

Religion did not play a univocal role. To some respondents it was a facilitator (Table 3, Q3) but for respondents with depression religiosity led to fatalism and medication nonadherence (Table 6, Q22). Religious rules were important for most respondents. During the month Ramadan Muslims fast from sunset to dawn. Although the Koran dispenses the chronically ill several respondents participated. Some respondents adjusted their OHA intake without medical consultation (Table 6, Q23).

Table 6. Supporting quotations: barriers and facilitators of adherence to OHA.

<i>Barriers<sup>a</sup></i>
<p>Forgetfulness (due to broken routines or the asymptotic nature of diabetes)</p> <p><i>Q10.</i> ‘When I’m home I never forget them. But when I’m somewhere else this happens.’ (R09M)</p> <p><i>Q11.</i> ‘Because I didn’t have this habit, I forgot them. It also had to do with the irregular working hours.’ (R11M)</p> <p><i>Q12.</i> ‘Some days I forget I have diabetes. I’m not constantly thinking: I have diabetes, I have diabetes. On those days I often forget to take my medicines.’ (R13F)</p>
<p>Impact of causal beliefs about diabetes (stress, Belgian climate) on medication adherence</p> <p><i>Q13.</i> ‘In Turkey the weather is much better. Once a year I go to Turkey for 5 to 6 weeks. Sometimes I don’t inject (the insulin) at noon although I eat and drink a lot. Because I have no worries my sugar (blood sugar level) is very low.’ (R30M)</p> <p><i>Q14.</i> ‘In Turkey I don’t take it (his OHA) at all. I sometimes measure my sugar and it is always lower than (when I am) over here.’ (R40M)</p>
<p>Non-awareness of the chronic nature of diabetes</p> <p><i>Q15.</i> I: ‘Why didn’t you take your medication back then?’</p> <p>R04F: ‘I thought it (T2DM) would pass. It was just the beginning, I couldn’t know.’</p> <p>I: ‘Back then you didn’t know that diabetes would last for the rest of your life?’</p> <p>R04F: ‘I didn’t know that at all.’</p>
<p>Concerns about OHA</p> <p><i>Q16.</i> ‘When I feel my sugar is high I take 1,5 (pills). The doctor says I should take 3 (a day). But it has an effect on my stomach and other things.’ (R31F)</p>

## Polypharmacy

*Q17.* ‘Because I took a lot of pills, I took less (OHA). I wanted to try it because I was bit worried.’ (R32F)

*Q18.* ‘I started with three diabetes pills. But I also used other pills and I thought it was too much. I went back to the doctor and told him three is too much, it would damage the kidneys. And since I follow my diet now I take two pills.’ (R09M discussed his concerns with his GP and they jointly decided to reduce the intake of OHA on the condition that he followed the dietary advice).

## Lack of trust in the GP’s medical expertise

*Q19.* R38M: ‘The GP doesn’t examine you. She asks questions, you talk, she prescribes and says that I should continue with these pills (his as ineffective perceived OHA).’

I: ‘Did you mention these concerns about your diabetes pills to your doctor?’

R38M: ‘I did explain it but the doctor doesn’t listen and says I should continue taking them. (...). Our GP doesn’t know much.’

## Adjustment of OHA to food intake

*Q20.* ‘When I eat a lot or when I eat fatty foods then I take more. When I eat lettuce or other healthy things I only take one or two (a day).’ (R33M)

## Mental problems

*Q21.* I: ‘You just mentioned that your diabetes pills are stronger than your other pills. What do you mean by that?’

R31F (who is treated with antidepressants): ‘Because you have to take them more often. She (the doctor) says I should take them 3 times. But I think 2 will be enough. Maybe it’s not enough but I’m tired of it (of taking care of her diabetes).’

## Religiosity in combination with psychological problems

*Q22.* ‘There is nothing you can do about it. I’m religious, everything comes from Allah. So there is nothing you can do about it.’ (R24M, treated with antidepressants and nonadherent to OHA)

## Adjustment of OHA during Ramadan fasting

*Q23.* I: ‘But you have to take three pills (OHA) a day?’

R27M: ‘I take one at sun dawn and one at sunset.’

I: ‘Does your doctor know?’

R27M: ‘I decide this myself.’

<i>Facilitators</i>
<p>Awareness of the chronic nature of diabetes and diabetes complications</p> <p><i>Q24.</i> ‘I know sugar disease will not go away. I also know someone who has sugar and his foot is amputated. That frightened me. If you want it or not, as long as you live you have to take care of it.’ (R36M)</p>
<p>Perceived benefits of OHA</p> <p><i>Q25.</i> ‘When my mouth is dry and I take the pills it gets better within 30 minutes.’ (R27M)</p> <p><i>Q26.</i> ‘I started injecting this (insulin) and I quit the pills. But because I quit the pills my sugar was very high. I see this because I regularly measure my sugar and it was always high. If I take my pills my sugar stabilises.’ (R32F)</p>
<p>Trust in the GP’s advice</p> <p><i>Q27.</i> ‘I think it has (long-term) adverse effects. But since the doctor says I should use it (OHA), that it’s good for me, I use it. If it wouldn’t be good, he wouldn’t give it to me.’ (R02F)</p>
<p>Social support</p> <p><i>Q28.</i> I: ‘Back then (during her depression) you also had diabetes. Could you take care of it?’  R26F: ‘No, I couldn’t. I don’t know what I have done. (...) And now I easily forget things. For instance yesterday at 4 pm I realized I forgot my injection (of insulin). It’s not normal. (...) When I travel to Turkey my daughter is always with me. She takes care of my insulin and my pills.’</p> <p><i>Q29.</i> ‘I feel I’m getting support from my GP, also emotionally and psychologically. It’s the way she says things, the way she handles things. (...) For instance when it (blood sugar level) dropped to 121 or when I lost weight she showed she was really happy for me.’ (R28F)</p>
<p>Religiosity</p> <p>See Table 3, Q3.</p>

<sup>a</sup>: Socio-economic barriers were not mentioned in interviews since hypoglaecemic agents are free of charge and patients’ costs for medical consultations are low in the Belgian health care system.

Medication adherence is a dynamic process influenced by a multitude of interdependent factors. Several respondents reported changes in their adherence to OHA during the course of their illness. Most reported improved medication adherence due to their own illness experiences (e.g. hypoglycaemia), information obtained from community members (e.g. seeing a person with diabetes whose leg was amputated) or health care professionals (e.g. improved knowledge through participation in diabetes education sessions). Others reported a multitude of problems (e.g. in the family, other health problems, ...) that pushed diabetes and adherence to OHA to the background and, in some cases, led to poor mental health. Reducing or temporarily stopping the intake of OHA was reported when respondents used herbal medicine.

Detailed cross-case comparisons allowed us to uncover patterns of interdependent factors leading to (non)adherence. Based on the detailed interview information 15 respondents were classified as adherent (taking > 80% of OHA). These were subdivided into two groups depending on how active their role was in their medication management. 'Active adherers' played an active role in the management of their OHA and in the information gathering process, resulting in better knowledge and critical appraisal of their doctor's medical expertise. Their doctor-patient relationship is cooperative: patients claimed part of the decision power while doctors explored patients' views and negotiated decisions. Some adjusted their OHA taking in particular situations (e.g. during fasting or holidays in Turkey) but did this in concordance with their doctor's advice. 'Passive adherers' were more concerned about OHA and more often had misleading diabetes beliefs. The potentially negative impact of these beliefs was countered by their almost blind confidence in their doctor's expertise. Their doctor-patient relationship was hierarchical: decision power rested with the doctor while the patient followed advice without questioning it.

A mixture of intentional and unintentional nonadherence was observed among three respondents. All three reported being confronted with a multitude of other problems and felt overpowered by their diabetes. Feelings of stress and depression led to a fatalistic attitude which, in combination with concerns about OHA, explained their nonadherence, that was not discussed with their GP. Three male, nonadherent respondents, in which intentional nonadherence predominated, were classified as 'active nonadherers'. Two young blue-collar workers regarded diabetes as incompatible with their self-concept, had doubts about the necessity and efficacy of OHA's and experienced no diabetes-related complications or symptoms. One older respondent minimized the importance of diabetes and showed a profound distrust of OHA's and his GP's medical expertise.

The differences in the patterns of interdependent factors point out a potential gender effect. All but two male respondents, whether adherent or nonadherent, adopted an active role in the management of OHA. One adherent, recently immigrated respondent consulted Dutch-speaking health care workers and adopted a passive role because of the language barrier. A second male respondent suffered from depression and was classified as a 'passive nonadherer'. Women took on a passive role, the only clear exception being a highly educated respondent, fluent in Dutch, who was classified as an 'active adherer'.

## **Discussion**

In this qualitative study we explored patient perspectives on adherence to OHA among Turkish migrants with T2DM. Factors influencing adherence to OHA similar to results found in other ethnic groups include: beliefs about OHA, polypharmacy, beliefs about the course of diabetes, forgetfulness, the perception of the doctor's medical expertise, mental health and

social support (Gonzalez et al. 2008; Peeters et. al. 2011; Rubin 2005; Vermeire et al. 2007; WHO 2003). Compared to research in other ethnic groups the most distinctive findings identified were: the causal beliefs about stress and climate, the religious framework of interpretation, the adjustment of medication to food intake or during Ramadan fasting, the use of herbal medicine and the potential gender effect in the patterns of influencing factors (Peeters et. al. 2011; Rubin 2005).

Beliefs that stress or the Belgian climate are causes of diabetes were widespread in this sample. These causal beliefs, which may be linked to respondents' low educational level, induced medication nonadherence in particular circumstances (e.g. holidays in Turkey). Turkish first generation migrants (the majority of the people with T2DM) usually spend 3 to 6 months a year in Turkey; several of them reduce or temporarily stop their use of hypoglaecemic agents because of these causal beliefs. Studies among Turkish Berliners and other ethnic groups mention stress as a causal belief but did not assess its impact on medication adherence (Greenhalgh, Helman, and Chowdhury 1998; Guell 2011; Mercado-Martinez and Ramos-Herrera 2002). This study showed that specific causal beliefs can have a circumstantial but clinically important impact on medication adherence.

Almost all respondents used a religious framework to interpret their disease but their common statement "diabetes is Allah's will" did not influence medication adherence in a univocal way. It depended on the presence of feelings of depression whether this religious framework led to nonadherence or whether it stimulated adherence. People who suffered from depression were more likely to be nonadherent, a finding confirmed in religious and secularized populations (Gonzalez et. al. 2008; WHO 2003). But among Turkish people, as in other ethnic groups, religion can also be a stimulating factor for adherence (Hunt, Arar, and Akana 2000). This finding is in contrast with the common belief among Belgian health care

providers that religiosity leads to fatalism and nonadherence in this population (Peeters et al., forthcoming).

Respondents sometimes adjusted their OHA to food intake or during Ramadan fasting, mostly without discussing this with their doctor. These adjustments are potentially dangerous without proper medical supervision (Salti et al. 2004).

A study among patients with diabetes in Turkey shows the widespread use of complementary and alternative medicine, a practice rarely discussed with health care professionals (Küçükgüçlü et al. 2010). Concerns about OHA was the main reason for almost half of our respondents who had used herbal medicine. Health care providers should be aware of these practices.

An important question is whether these distinctive findings may be explained by factors underlying 'ethnicity'. Ethnic differences in health, health-related behaviour and access to health care are often (partly) explained by taking into account the (generally low) socio-economic position of ethnic minorities (Bhopal 2007). Among people of Turkish descent living in Belgium poverty rates are very high (Dierckx et al. 2012; van Robaeys 2007). However, in our study, poverty did not have a direct impact on medication adherence. Although several respondents experienced socio-economic difficulties, medication costs were not identified as a barrier. As described in box 2 antidiabetics are provided for free in Belgium; in other health care systems costs may hinder medication adherence (Rubin 2005). Poverty not only has a material dimension but should be defined as 'a network of social exclusions that extends itself to several domains of life' (Dierckx et al. 2012; Vranken et al. 2008). Limited material and immaterial (e.g. educational level, social network, ...) resources confront the poor with the gap between their life and generally accepted patterns of life in society. Socio-economic deprivation can induce feelings of stress and lead to poor mental

health, especially when accompanied by experiences of ethnic discrimination (Missinne and Bracke 2012). Poverty may thus be one possible explanation for the effect of stress and depression on medication adherence. The observed ‘fatalism’ among our respondents is one possible way in which poor respond to the challenges they are confronted with. This ‘fatalism’ is not necessarily attributable to religiosity.

Another possible explanation for the association between stress and depression on the one hand and medication adherence on the other may be found in the process of acculturation. Turkish migrants coming from rural, culturally traditional areas are confronted with a western, urban culture. In discussing their causal beliefs some respondents referred to the stress induced by living and raising a family in a different culture. Most first generation migrants live in rather closed communities. This may make them more vulnerable to stress and depression when confronted with cultural conflicts, especially when they feel discriminated (Missinne and Bracke 2012). Women might be more vulnerable since their life is centred around the family and they tend to have less contacts outside the Turkish community.

The process of acculturation may also influence medication adherence through its effect on illness and medication beliefs or access to health care. For instance, culturally shaped illness and medication beliefs of Vietnamese patients in the US or British Pakistani and British Indian patients are reported to be barriers for adherence to OHA (Lawton et al. 2005; Mull, Nguyen, and Mull 2001). In this sample however we found no clear indications of culturally shaped differences in medication beliefs. Western medicine was not considered as ‘stronger’ (Lawton et al. 2005) or as ‘disturbing the balance between hot and cold in the body’ (Mull, Nguyen, and Mull 2001). On the contrary, most respondents perceived no differences with OHA prescribed in Turkey or put more trust in medicines obtained in Belgium. Concerns about long-term detrimental effects of OHA led to nonadherence and use

of herbal medicine but these concerns are also observed in majority populations (Gherman et al. 2011) and thus should not be considered as an ‘ethnic difference’.

With respect to access to health care no impact of the cultural background could be detected. Most of our respondents were living in Belgium for a long time and were familiar with the health care system. Others recently moved to Belgium for reasons of ‘family reunion’ and received help from family members in contacts with the health care system. Migration histories of our respondents reflect those of Turkish migrants in general (see box 1). Moreover, studies in Belgium show no relevant differences in the use of health care (e.g. contact frequency with GPs) for people of Turkish descent (Levecque, Lodewijckx, and van den Eeden 2006). But, as shown in our results, language barriers and the low educational level remain important barriers to providing diabetes education.

Next to adjusting OHA during Ramadan fasting, the most distinctive way in which cultural background may influence medication adherence is through the pathway of culturally shaped traditional gender roles. Based on observed differences in the patterns of interdependent factors we hypothesise that women of Turkish descent adopt a more passive role towards their medication management and in contacts with health care providers. This finding is relevant for health care providers since communication processes may need to be adapted. Explanations for this are the very low educational level, high rates of illiteracy and limited language proficiency on the one hand and the acceptance of traditional gender roles by first generation migrants on the other hand (Vancluysen, Van Craen, and Ackaert 2009). Women’s more passive role might lead to gender differences in knowledge but whether this results in different adherence rates remains a question.

*Strengths and limitations*

The main strength of this qualitative study is that it provides a detailed exploration of the interdependent factors influencing medication adherence for an ethnic group not yet studied. Qualitative methods allowed us to show more clearly how the effect of a particular factor depends on the effects of other factors: concerns about medication for instance may not lead to nonadherence when trust in the doctor's medical expertise is high.

The small sample size does not allow generalization. The use of qualitative methods in this study informed our choice of variables included in a quantitative study that will assess whether these results apply to the population of Turkish people with T2DM in Belgium.

Although generalization is not the goal of qualitative research, the question remains whether these insights are transferable to other European countries with large Turkish communities. Transferability depends on the similarity between contexts and populations (Seale 2000). There are great similarities between European countries regarding migration history and several important characteristics of people of Turkish descent (educational level, socio-economic position, integration in host country) (Wets 2006). These results may thus, up to a certain extent, be applicable to members of other Turkish migrant communities but not to people of Turkish descent with different characteristics (e.g. women of the second and third generation, highly educated people, people coming from urban areas in Turkey). Moreover, health care contexts can be very different with respect to financial and geographical accessibility, organisation of care, availability of interpretation services, ... . Transferability always remains an empirical issue but insights from this study can inform empirical work in other settings.

Recruiting respondents with the aid of health care workers and community members can cause a selection bias. We avoided this by, firstly, recruiting patients with limited contact

with general practitioners and pharmacists through members of the Turkish community, and, secondly, instructing all recruiters not to select patients based on other criteria than those provided by the researchers. By using questionnaires based on literature and insights from the data-analysis 21 actual respondents were selected out of 48 potential respondents. This use of a theoretical sampling procedure led to a well informed inclusion of respondents and contributed to the reliability of the results.

Spreading the interviews over time (all but 2 interviews consisted of 2 to 4 conversations) allowed us to check insights obtained from the preliminary analysis of the earlier conversations and thus contributed to the reliability of results. The use of interpreters is a potential pitfall but since a thorough quality control showed no substantial impact we believe that this had no effect on our results. Reliability of results was further guaranteed by involving three researchers (with different backgrounds) in the process of coding and analysing the data and by discussing (preliminary) results with all authors.

### *Implications for clinical practice*

Health care professionals should address several factors that impact medication adherence. Improving knowledge on diabetes and hypoglycaemic medication is necessary but insufficient. Exploring in detail patients' perspectives on diabetes, medicines and their trust in doctors' medical expertise will provide useful starting points for promoting medication adherence. Whenever possible health care workers should engage with their patients in therapeutic alliances.

## **Conclusion**

This study highlighted a multitude of barriers and facilitators to medication adherence in one of the largest non-EU ethnic minorities in Western-Europe. Some important barriers of adherence to OHA were distinctive for people of Turkish descent and can have a clinically important impact. The religious framework commonly used to interpret health did not have a univocal impact on medication adherence. Health care providers should be more aware of common and distinctive factors influencing medication adherence in this aging population and explore patients' perspectives as a starting point for promoting adherence.

## **Key Messages**

- Distinctive factors influencing adherence to OHA among people of Turkish descent are the causal beliefs about stress and climate, the adjustment of OHA to food intake and during Ramadan fasting, the widespread use of herbal medicine, the potential gender difference in patterns of influencing factors.
- Religion can be a barrier or a facilitator to medication adherence depending on the psychological profile of the patient.
- Health care workers should be aware of influencing factors, explore patients' perspectives and engage in therapeutic alliances whenever possible.

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## ***Chapter 4:***

# ***Ramadan fasting and diabetes***

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**Ramadan fasting and diabetes: an observational study among Turkish migrants in Belgium.**

**Abstract.**

**Aims:** To investigate (i) Ramadan participation, (ii) provision of Ramadan-related advice by healthcare providers (iii) medication use during Ramadan fasting among Turkish migrants with diabetes in Belgium.

**Methods:** This pilot observational study was conducted among a convenience sample of 52 Turkish migrants with diabetes in Belgium. Two questionnaires collected information on socio-demographic characteristics, diabetes-related characteristics, current hypoglycaemic medication with dosing regimen, participation in the past Ramadan, reasons for (non-) participation, use of hypoglycaemic medication during the past Ramadan, advice from their healthcare providers about fasting during Ramadan and follow-up of this advice.

**Results:** Sixteen patients (31%) had fasted during the past Ramadan. Main reason for Ramadan participation was reinforcement of faith (12/15), while the main reason for non-participation was having diabetes (34/36). About 56% of the study population had received recommendations from their healthcare provider(s) about fasting and diabetes during Ramadan. The most commonly provided advice was not to participate in Ramadan, followed by modification of drug therapy. Only 3 patients ignored the advice of their health professionals. In addition, only 60% of those who actually fasted received recommendations about intake of diabetes medication during the ramadan. Most fasters continued their medication dose unchanged (87% of OHA users and 80% of the insulin users).

**Conclusions:** This pilot study found a low prevalence of Ramadan fasting among Turkish migrants with diabetes in Belgium. We also found that provision of advice by healthcare providers could be improved. Larger scale studies are warranted to confirm these findings.

**Keywords:** Ramadan, fasting, medication adherence, Belgium, Turks.

## Introduction

Muslims who fast during Ramadan must abstain from food and drink from dawn to sunset for about 30 days. Although the Koran exempts chronically ill from fasting, many Muslims with diabetes still wish to fast. A large study conducted in 13 Muslim countries on 12,243 individuals with diabetes - the EPIDIAR study - showed that 79% of type 2 and 43% of type 1 diabetes patients actually fast during Ramadan [1].

During the past decades, the number of Muslims living in Western Europe has steadily grown due to immigration from Muslim-majority areas such as the Arab region and Turkey [2,3]. However, literature on Ramadan fasting among Muslim migrants with diabetes living in Western countries is limited. An interview study of patients' and general practitioners' (GPs) attitudes towards Ramadan fasting in France found that Muslim patients consider Ramadan participation important, and revealed a large cross-cultural gap between GPs and their patients [4]. Another study, conducted among 27 Arab Americans with type 2 diabetes, found suboptimal diabetes management during Ramadan fasting [5].

This pilot observational study was conducted among a convenience sample of Turkish migrants with diabetes in Belgium. Our specific research questions were: i) what is the proportion of patients who fast during Ramadan, and what are their motives to (not) participate in Ramadan?, (ii) do they receive recommendations from their healthcare providers about Ramadan participation, and (iii) how do those who actually fast use their diabetes medication during Ramadan?

## **Methods**

### *Study design*

This observational study was carried out from June 2010 till October 2010 in Ghent, Belgium's third largest city where approximately 10 % of the inhabitants are of Turkish descent. Approval for the study was granted by the Ethics Committee of Ghent University Hospital, and all patients gave written informed consent.

### *Patients*

Recruiting ethnic minorities can be difficult, therefore we used several recruitment sources [6]. We recruited patients from general practices and community pharmacies having a large proportion of Turkish patients, and from the Department of Endocrinology and Diabetology of Ghent University Hospital. In addition, we used face to face recruitment via volunteers from the local Turkish community to access housebound patients and patients with limited contact with health services. Patients were eligible for participation when fulfilling the following inclusion criteria: (i) aged 18 years or older, (ii) born in Turkey or have at least one parent born in Turkey, (iii) reported to be Muslim, and (iv) using oral hypoglycaemic agents (OHA) and/or insulin in treatment of type 1 or type 2 diabetes. We asked recruiters to record background characteristics of patients who refused to participate and the patients' reasons for refusal.

*Data collection*

Patients who agreed to participate completed two self-administered questionnaires. The first questionnaire was given to the participants 7 to 1 week(s) before the start of Ramadan, while the second was given immediately after the end of Ramadan. Patients were asked to complete them and post them back to the research centre. Those who did not initially return the questionnaires were reminded by telephone. Respondents could complete the questionnaires in the language of their choice (Dutch or Turkish; the Turkish version was obtained via back-translation). For illiterate patients, questions contained in the questionnaires were read out by the investigators or by any literate person easily accessible to them.

The first questionnaire collected information on socio-demographic characteristics, diabetes-related characteristics, and current hypoglycaemic medication with dosing regimen. The GP of each patient was requested to provide the patient's most recent HbA1c. The second questionnaire included questions on participation in the past Ramadan, reasons for (non-) participation, use of hypoglycaemic medication during the past Ramadan, advice from their healthcare providers about fasting during Ramadan and follow-up of this advice.

## **Results**

Sixty-six patients completed the first questionnaire. Fourteen of them did not return the second questionnaire, resulting in a final sample of 52 patients. Socio-demographic and diabetes-related characteristics of patients who did not return the second questionnaire did not differ significantly from patients who did, except for gender (more women among those who did not return the second questionnaire; Fisher's exact test,  $p < 0.05$ ).

### *Sample description*

The socio-demographic and diabetes-related characteristics of the participants are shown in Table 1. Approximately 60% of the sample was female. About three quarters had a low educational level and was unemployed. Half of the study population was treated with OHA alone, and half used insulin (alone or in association with OHA). Thirty-seven percent had at least one Turkish speaking healthcare provider. The HbA1c level was good ( $\text{HbA1c} < 7\%$ ,  $< 53 \text{mmol/mol}$ ) in one third of the respondents, and insufficient ( $\text{HbA1c} > 8\%$ ,  $> 64 \text{mmol/mol}$ ) in another third.

Table 1: Sample characteristics.

	N = 52
Sex	
Female	32 (62)
Male	20 (38)
Age, yrs	52.5 (26-82)
BMI, kg/m <sup>2</sup>	31.3 (22-55)
Education	
No high school degree	39 (77 <sup>#</sup> )
High school degree	8 (16 <sup>#</sup> )
Higher education*	4 (8 <sup>#</sup> )
Employed	13 (26 <sup>#</sup> )
Years living in Belgium	
0-10	4 (8 <sup>#</sup> )
11-20	3 (6 <sup>#</sup> )
21-30	8 (16 <sup>#</sup> )
>30	36 (71 <sup>#</sup> )
Knowledge of Dutch language	
None - basic	33 (65 <sup>#</sup> )
Moderate	3 (6 <sup>#</sup> )
Fluent	15 (29 <sup>#</sup> )
Diabetes	
Type 1	3 (6)
Type 2	31 (60)
Unknown to patient	18 (35)
Diabetes duration, yrs	10.9 (1-27)
HbA1c	
<7%, <53mmol/mol	15 (35 <sup>‡</sup> )
7-8%, 53mmol/mol – 64mmol/mol	14 (33 <sup>‡</sup> )
>8%, >64mmol/mol	14 (33 <sup>‡</sup> )
Self-monitoring of blood glucose	30 (58)
Hypoglycaemic medication	
OHA alone	26 (50)
OHA + insulin	15 (29)
Insulin alone	11 (21)

Data are presented as n (%) or mean (range).

OHA: oral hypoglycaemic agents.

\* Succeeded any type of higher education (college or university).

<sup>#</sup> Percentage calculated on n=51, since 1 participant did not complete this item.

<sup>‡</sup> Percentage calculated on n=43, since HbA1c could not be retrieved for 9 participants.

*Participation in Ramadan*

Almost 80% of our sample (40/51; total n is 51 since 1 participant did not complete this item) considered participation in Ramadan as (very) important (rating on a 5-point Likert scale). Most patients (46/52; 89%) were aware of the exemption from fasting for chronically ill. Sixteen patients (31%) had fasted at least 15 days during the past Ramadan. Eleven of them were treated with OHA alone (11/16; 69%), 4 with a combination of OHA plus insulin (4/16; 25%) and 1 with insulin alone (1/16; 6%). Half of Ramadan participants performed self-measurements of blood glucose (8/16). Main reasons for participation in Ramadan were: reinforcement of faith (12/15), feeling mentally and physically fit enough to participate (8/15) and obligation of fasting by Koran (7/15) [total n is 15, since 1 participant did not complete this item; respondents could indicate more than one reason]. Main reasons for non-participation in Ramadan were: having diabetes (34/36), the treating physician advised against participation (20/36) and exemption from fasting by Koran (14/36).

*Recommendations from healthcare providers*

About 56% of the study population (29/52) had received recommendations from their healthcare provider(s) about fasting and diabetes during Ramadan (general practitioner: 26/29, endocrinologist: 12/29, community pharmacist: 5/29). The most commonly provided recommendation was not to participate in Ramadan, followed by modification of drug therapy. Only 3 patients ignored the advice of their health professionals, all others followed it.

Ten of the 16 patients who actually fasted during Ramadan were advised by a health professional about the use of OHA or insulin during fasting, while 6/16 did not receive advice.

#### *Medication use during Ramadan*

The OHA dose remained unchanged in most Ramadan participants (13 out of the 15 OHA users), while a reduced dosis was seen in one individual and completely stopped in another individual. With respect to timing of OHA intake, all patients took their doses at suhur (i.e. the meal before dawn) and at iftar (i.e. the meal after sunset). Those who normally also take a dose at mid-day (n=5) did this during Ramadan at iftar (3/5), at suhur (1/5) or at night (i.e. during an extra meal eaten between iftar and suhur) (1/5). Four out of the 5 insulin users did not change their insulin dose during Ramadan, while one used a reduced dosage. Self-reported adherence to diabetes medication during Ramadan, defined as following the (modified) regimen prescribed by the doctor, was very high: 14/16 reported intake of OHA and/or insulin as prescribed on every day of Ramadan fasting.

## **Discussion**

This observational survey of Ramadan fasting among Turkish migrants with diabetes in Belgium found that only 30% actually fasted. This percentage is considerably lower than that observed among migrants in France (51%) and among Muslims in Muslim countries (76%) [4,1].

Another relevant finding is that only slightly more than half was informed by a healthcare provider about Ramadan fasting and diabetes. This percentage is similar to that observed in previous studies [1,4]. In addition, only 60% of those who actually fasted received recommendations about intake of diabetes medication during the fasting period. Most fasters continued their medication dose unchanged (87% of OHA users and 80% of the insulin users), which is slightly more than in the EPIDIAR study (75% of OHA users and 64% of insulin users). These findings suggest that health workers should pay more attention to informing their Muslim diabetes patients about medication use during the Ramadan. A patient's decision to fast should be made after consultation with health professionals about the possible risks of fasting for their individual health. Patients who decide to fast should undergo pre-Ramadan assessment and receive Ramadan-focused structured education [7]. Especially community pharmacists could play a more active and prominent role in increasing awareness among patients, as they have the opportunity (i.e. pharmacists are one of the most highly accessible members of the primary healthcare team and have regular contact with their chronic patients) and their current level of advice provision shows room for improvement (i.e. only a minority of our participants received Ramadan-related advice from their pharmacist). Specific Ramadan education for Muslim patients with diabetes can be integrated in community health interventions in areas with a considerable proportion of inhabitants from Muslim countries.

The main limitation of this study is the small number of participants. Our initial aim was to enroll 100 patients, however recruitment showed to be more difficult than expected. It is known that ethnic minority patients are a hard to reach group for survey research [8]. Therefore we combined different recruitment sources. However, during the recruitment period we found that many eligible patients were not in Belgium because they spend summer in Turkey (Ramadan 2010 fell in the summer months). This may have caused a selection bias: Muslims with diabetes who did not want to fast during the Ramadan month may have stayed in Belgium; which may explain the low percentage of participation in Ramadan in this study. Another limitation: is that we do not have data on the refusal rate. Although we asked the recruiters to record this, only a limited number of recruiters carried this out.

In conclusion, this pilot study found a low prevalence of Ramadan fasting among Turkish migrants with diabetes in Belgium. We also found that provision of advice by healthcare providers could be improved. Larger scale studies are warranted to confirm these findings.

**Declaration of Competing Interests:** Nothing to declare.

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***Chapter 5:***  
***Qualitative study among***  
***general practitioners and***  
***community pharmacists***

Submitted as:

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**Perspectives of general practitioners and community pharmacists on barriers to promoting medication adherence among Turkish migrants with type-2 diabetes.**

**Aims.** To explore perspectives of general practitioners (GPs) and community pharmacists (PHs) on barriers to promoting medication adherence among type-2 diabetes mellitus (T2DM) patients of Turkish descent.

**Methods.** Qualitative study in which focus groups with a purposive sample of GPs (n=18) and PHs (n=16) were used. A thematic analysis, using Nvivo 9, was performed.

**Results.** GPs and PHs have a rather accurate picture of the influencing factors but report a multitude of barriers to promoting medication adherence. At the patient level the low educational level, language discordance, lack of continuity of care, cultural habits, the influence of the community on patients' beliefs and expectations about consultations are identified. Lack of time and the lack of a structured exchange of information between GPs and PHs are barriers at the provider level.

**Conclusions.** In order to optimize diabetes care for T2DM patients of Turkish descent GPs and PHs need access to means to overcome language barriers and training in cultural competencies and skills to promote behavioural change. Patients should be stimulated to always visit the same GP and PH. Barriers to a closer cooperation between GPs and PHs should also be levelled in order to promote medication adherence.

**Keywords:** type 2 diabetes; medication adherence; health care provider; general practitioner; community pharmacist; immigrant; Turkish ethnic minority; oral hypoglycaemic agents; qualitative research

## **Perspectives of general practitioners and community pharmacists on barriers to promoting medication adherence among Turkish migrants with type-2 diabetes.**

### **Introduction**

Adherence to oral hypoglycaemic agents (OHA) and insulin is essential to achieve glycaemic target values and prevent diabetes complications <sup>1</sup>. Health care providers can have an important impact on medication adherence and clinical outcomes by influencing patients' perspectives on diabetes and antidiabetics <sup>2;3</sup>. Characteristics of the patient-health care provider relationship (e.g. trust, communication style, patient centeredness, language concordance) are important predictors of medication adherence and clinical outcomes <sup>4-9</sup>. Patients' perspectives on medication adherence in diabetes are widely studied <sup>10</sup>. In order to develop effective interventions, understanding health care providers' perspectives on barriers to promoting medication adherence is also important. Research on providers' perspectives however is scarce and does not focus on experiences with patients from different cultural backgrounds <sup>11</sup>.

Taking into account that European health care systems are confronted with ageing migrant and ethnic minority populations <sup>12</sup>, and with a growing sense of the economic and clinical impact of nonadherence <sup>1;13</sup>, focussing on adherence improvement in ethnic minorities seems appropriate. Turks are one of the largest ethnic minorities in Western-Europe. The prevalence of type 2 diabetes mellitus (T2DM) is 2 to 3 times higher in the Turkish ethnic minority compared to the indigenous population <sup>14;15</sup>. In this study we explore perspectives of Belgian general practitioners (GP) and community pharmacists (PH) on promoting

medication adherence in patients of Turkish descent with T2DM (Table 1 provides information on the role of GP and PH in diabetes care). The aims of this study are:

1. to describe views of Belgian GPs and PHs on factors influencing medication adherence in T2DM patients of Turkish descent,
2. to understand the barriers they encounter in promoting medication adherence,
3. to describe solutions deemed necessary by GPs and PHs to overcome these barriers.

Table 1. Diabetes care within the Belgian health care system.

The Belgian health care system is characterized by compulsory health insurance, patients' freedom of choice between providers, and remuneration mainly based on fee-for-service payments. Patients' out-of-pocket costs are relatively low and several policy measures ensure the accessibility for patients from lower socio-economic backgrounds. Although health care in Belgium is of high-quality and highly accessible, its organisation is not well accustomed to needs of the growing number of patients with chronic diseases. Cooperation within primary care and between primary, secondary and tertiary care can be further optimized.

In Belgium the GP is the main diabetes care provider. Ninety-five percent of all patients always consult the same GP. Most GPs are self-employed and work within the fee-for-service remuneration system. A minority works in multidisciplinary community health centres which are mostly located in deprived city areas with ethnically diverse populations. Community health centres operate outside the fee-for-service remuneration system, for patients consultations with a GP are free. Community pharmacies are highly accessible, with one pharmacy for every 2000 patients. PHs are either self-employed or work as an employee in larger chains of pharmacies. Recent legislation on pharmaceutical care changed the remuneration system and assigned more responsibilities in the care for patients with chronic diseases to PHs. The majority of patients with chronic diseases always obtain their medication from the same pharmacy.

## Methods

We used purposive sampling to recruit PHs and GPs experienced in treating T2DM patients of Turkish descent<sup>16</sup>. Recruitment was done in Ghent, Belgium, where approximately 9% of the inhabitants are of Turkish descent. We invited all GPs and PHs working in districts with a large proportion of people of Turkish descent and maximized diversity with respect to gender, years of professional experience and knowledge of Turkish. We held 4 focus groups

with 16 PHs (4 per focus group) and 3 focus groups with 18 GPs (4-7 per group). PHs and GPs were interviewed separately since, in the Belgian context, there is no structurally embedded cooperation between the two professions. Mixed groups might have hindered participants to formulate their thoughts.

A topics list was prepared based on the available literature, conversations with GPs and PHs and interviews with patients of Turkish descent with T2DM (Table 2). BP, a sociologist experienced in conducting focus groups, moderated all focus groups. IVT, a pharmacist, observed non-verbal interaction and summarized the discussion on a clipboard. During breaks and after the focus groups, moderator and observer had a debriefing on the process and content of the focus groups.

The focus groups were audio recorded and fully transcribed. A thematic analysis was performed by BP and IVT independently from each other<sup>17</sup>. Nvivo 9 was used to manage, code and analyze the data. Codes reflected interview questions and themes emerging from the data. In a first phase codes were descriptive 'indexes', functioning as signposts to interesting bits of data. Each researcher described the (throughout this process changing) meaning of codes that were developed. Descriptive codes, their meaning and coded excerpts of data were then compared between researchers in order to reach agreement on the meanings of codes. When relationships between codes became clear these were grouped under broader categories and hierarchical and non-hierarchical relationships were defined. New data often led to new codes or to the refining and redefinition of existing codes, categories and relationships. This iterative process of indexing, coding, categorizing and discussions between researchers was repeated several times. Throughout this process coding queries and coding comparison queries, tools available in Nvivo 9, were used to assess intra-rater consistency and inter-rater reliability. Preliminary results and questions for further analysis were discussed with all authors.

Table 2. Topics list.

<i>Theme 1: Factors influencing medication adherence</i>
Question 1: Please think of good and bad examples from your practice. Which factors according to you influence medication adherence?
Question 2: Are there other influencing factors than the ones listed? Which are in your opinion the most important factors?
Question 3: Two quotations on medication adherence and its influencing factors from interviews with Turkish people with diabetes were distributed. GPs and pharmacists were asked to react on these patient perspectives.
<i>Theme 2: Improving diabetes care for patients of Turkish descent</i>
Question 1: Which of the influencing factors listed can you tackle as GP / PH?
Question 2: Describe your role in diabetes care. What facilitates the up-take of this role? What hinders the up-take? Which other health care providers play an important role in diabetes care?
Question 3: Which changes are necessary to improve diabetes care for people of Turkish descent?

**Results**

For the background characteristics of the sample see Table 3. Supporting quotations (Q) can be found in Table 4.

Table 3. GPs' and PHs' characteristics.

	<i>General Practitioners N = 18</i>	<i>Community Pharmacists N = 16</i>
Gender		
Female	6 (33%)	12 (75%)
Professional experience		
≤ 9 years	8 (45%)	0 (0%)
10-19 years	4 (22%)	9 (56%)
20-29 years	4 (22%)	6 (38%)
≥ 30 years	2 (11%)	1 (6%)
Knowledge of Turkish (self-reported)		
None	10 (56%)	5 (31%)
Basic	2 (11%)	3 (19%)
Moderate	0 (0%)	5 (31%)
Good	4 (22%)	2 (13%)
Very good	2 (11%)	1 (6%)
Practice		
Community health centre	14 (78%)	
Solo or small group practice	4 (22%)	

*Perceptions of factors influencing medication adherence.*

A wide range of factors were mentioned by GPs and PHs. Most factors were mentioned by both professional groups although GPs tended to pay more attention to psychological and religious factors. The most important factor according to GPs and PHs was the lack of knowledge about diabetes and hypoglycaemic medication leading to misleading beliefs and nonadherence. Understanding patients' illness beliefs and the cultural context in which these are shaped was considered important (Table 4, Q 1-4). Depression was also considered to be an important risk factor for nonadherence, although, in the perspectives of GPs and PHs, the social support provided by strong family ties and the closed communities can possibly counter this effect (Table 4, Q 5-6). The apathy or fatalism observed in some patients was attributed to religiosity by most GPs, PHs rarely mentioned religiosity. Only a few GPs took a more balanced point of view and saw the multitude of problems members of ethnic minorities can be confronted with as a cause of this attitude (Table 4, Q 7-8). Some GPs reported that religious and cultural habits can also have an impact on dietary habits and consequently on medication adherence (Table 4, Q 9). A facilitating factor for medication adherence, reported by GPs and PHs, was the authority attributed to professional health care workers (Table 4, Q 10). Although hypoglycaemic agents are free of charge, PHs and GPs working in a fee-for-service system mentioned financial barriers because low-income patients sometimes postpone consultations because of the cost (Table 4, Q 11). New policies encouraging generic prescribing were also mentioned as a factor that can lead to medication errors and nonadherence in this low-educated population (Table 4, Q 12-13).

*Barriers to promote medication adherence in Turkish patients with T2DM.*

Barriers related to patients' characteristics.

Barriers specific to T2DM patients of Turkish descent, most mentioned by both GPs and PHs, are the low educational level, the high rates of illiteracy and language discordance. These barriers hinder the exploration of patients' perspectives, the provision of diabetes education and the use of practical aids to ensure medication adherence (Table 4, Q 14-16). Most T2DM patients of Turkish descent are retired and spend several months a year in Turkey. This lack of continuity of care was reported to lead to medication problems and pose a potential threat to medication adherence (Table 4, Q 17). Patients are mainly first generation migrants who live in rather closed communities with specific cultural habits and religious demands. In general non-Muslim GPs and PHs found it hard to deal with cultural habits and religious demands that endanger medication adherence. Almost all claimed they're not entitled to tackle religious and cultural barriers (Table 4, Q 18). Culturally shaped gender roles can form a barrier to communication and ensuring medication adherence. A few female PHs reported male first generation migrants are sometimes less willing to accept their advice (Table 4, Q 19). Communication with first generation women can be difficult when male family members function as spokesman (Table 4, Q 20). Closed communities and strong family ties were reported to provide resources for social support which, according to our respondents, outnumber those available among their Belgian patients. On the other hand the influence of ideas about diabetes treatment present in the community can counterbalance diabetes education, according to GPs and PHs (Table 4, Q 21). According to some GPs, patients of Turkish descent sometimes hold expectations about consultations that hinder the exploration of patients' perspectives and the provision of diabetes education (Table 4, Q 22-

23). Confronted with this multitude of barriers, feelings of frustration were rather common among participating GPs and PHs, especially when they considered cultural influences to be important (Table 4, Q 24-25).

#### Barriers related to the provision of diabetes care.

Although the importance of understanding patients' illness and medication beliefs was recognized by the participants, only a few GPs reported actively exploring these perceptions (Table 4, Q 26). Next to educational and language barriers the lack of time complicates this process (Table 4, Q 27). Furthermore, the trust necessary for this exploration of perspectives has to grow over time (Table 4, Q 28). Some respondents reported a certain reluctance to discuss medication adherence out of fear to damage the patient-provider relationship or to arouse concerns about OHAs (Table 4, Q 29-30). Both professions regret the lack of structured, interprofessional exchange of information, which even prevents them from making reliable assessments of a patient's medication adherence (Table 4, Q 31-32).

#### *Potential strategies to tackle barriers.*

Suggestions from PHs and GPs to improve diabetes care for people of Turkish descent can be divided into practical solutions and proposals to stimulate cooperation between GPs and PHs. The latter are extendable to other groups of patients with chronic diseases.

To overcome the language barrier both groups suggest a range of initiatives from the use of professional interpreters or educational materials in Turkish to education provided by health care workers of Turkish descent (Table 4, Q 33-35). GPs and PHs all considered information as the most important way to tackle nonadherence. Because of the high rates of

illiteracy among patients of Turkish descent practical aids like reminder charts (with pictures) and pill organizers were suggested. Text message reminders were also considered helpful to prevent unintentional nonadherence. However, PHs also pointed out the time-consuming character of reminder charts and pill organizers and suggested that text message reminders may be regarded as too commercial (Table 4, Q 36-37).

Stimulating patients to always visit the same general practices and pharmacies is seen as an essential condition to stimulate information exchange between GPs and PHs and to obtain reliable assessments of medication adherence (Table 4, Q 38-39). The wish for a closer cooperation between GPs and PHs was expressed by most participants. Most GPs thought PHs can play an important role in patient education about medicines, in preventing medication errors and in assessing and/or stimulating adherence (Table 4, Q 40-41). However, time constraints and the lack of a structurally embedded cooperation in daily practice were seen as obstacles to improving cooperation.

**Table 4. Supporting quotations.**

<i>Perceptions of factors influencing medication adherence</i>
<p>Patients' illness and medication beliefs</p> <p><i>Q 1.</i> GP09: 'I try to explain it (diabetes) real slow. And I try to put myself in the patient's position, how he looks at things because it's amazing what kind of theories people have about diabetes. If you can't correct them you don't get them to follow the treatment.'</p> <p><i>Q 2.</i> GP05: 'How do they experience diabetes, which place does it occupy in their lives, how important is it... To me that is often a big mystery and of course it differs from person to person but I do think cultural differences matter.'</p> <p><i>Q 3.</i> PH02: 'Sometimes they take them (OHA) when they think it's necessary. They expect the pills will cure them but they don't feel an effect so that's why some think it's not important.'</p> <p><i>Q 4.</i> GP04: 'They sometimes just stop taking their medicines without telling you. They don't feel the effects, they don't see a difference whether they take them or not.'</p>

<p>Depression and social support</p> <p><i>Q 5.</i> GP01: ‘Some people have a lot of other problems which makes them depressed, apathetic.’</p> <p><i>Q 6.</i> PH04: ‘They’re well supported. What is positive in the Turkish community is that they live in large families. There is always someone who takes the responsibility to help with the medication.’</p>
<p>Religiosity</p> <p><i>Q 7.</i> GP04: ‘This religion, I think it often leads to fatalism. They say this disease has been given to me by Allah and I can’t change it. They have resigned their selves to their faith.’</p> <p><i>Q 8.</i> GP01: ‘I think people who are part of a religious community interpret everything from a religious point of view. But this apathy you see among some patients, I think they have too much problems, they’re deep down in the dumps.’</p>
<p>Impact of religious and cultural habits on dietary habits and medication adherence</p> <p><i>Q 9.</i> GP03: ‘What strikes me very much is that the older patients, they sleep long, so they only eat 2 meals a day. You can tell them to take 3 pills a day but they won’t do it. They pray at 6 am and they go back to sleep.’</p>
<p>Authority attributed to professional health care workers</p> <p><i>Q10.</i> ‘GP03: ‘You get a lot of authority from patients and you can use that to motivate them and to give them advice. I’m still shocked sometimes by how well some of them listen. (...) We do not have to underestimate our position as GP.’</p>
<p>Financial barriers</p> <p><i>Q11.</i> GP16: ‘When I ask ‘did you take your pills?’ they answer they were out of pills and didn’t get to visit me. I’ve been seeing this for years, the third week of the month is the calmest. When they receive their pension they’re back.’</p>
<p>Generic prescribing</p> <p><i>Q 12.</i> GP 16: ‘I’m not an advocate of prescribing generics, it leads to so many errors.’ GP18: ‘Yes, and then they come from the hospital and they have changed it again, no thanks.’</p> <p><i>Q 13.</i> PH 14: ‘Like with generic drugs. One time they prescribe a generic, the next time they don’t. These people don’t understand it. They take the same medicine twice or they feel bad and stop taking it. And you can’t explain it to them.’</p>

**Table 4. Supporting quotations (continued).**

<i>Barriers to promote medication adherence</i>
<i>Barriers related to patients' characteristics.</i>
<p>Low educational level, illiteracy and language discordance</p> <p><i>Q 14.</i> GP08: 'There was a language problem with this woman and she didn't understand her disease. She was diagnosed with diabetes and she didn't take her medication anymore. She didn't understand diabetes is for the rest of her life and she asked herself why should I take it, I don't feel sick.'</p> <p><i>Q 15.</i> PH08: 'The most important factors are the language problems and the low educational level. They don't realize how important their medicines are.'</p> <p><i>Q 16.</i> GP17: 'It's not that they don't want to, they just don't understand. They haven't been to school, most of them. (...) I did try it with these medication schemes. (...) But they don't follow it, they can't read.'</p>
<p>Lack of continuity of care</p> <p><i>Q 17.</i> GP05: 'The continuity of care is another issue. Because they stay in Turkey for a long time this continuity is difficult.'</p>
<p>Religious and cultural barriers</p> <p><i>Q 18.</i> GP07: 'I think it's difficult to talk about these things not being a Muslim. To use religion to motivate patients, I think they would have difficulties accepting that.'</p>
<p>Culturally shaped gender roles</p> <p><i>Q 19.</i> PH11: 'We're with 4 women in our pharmacy and we once had a male intern. It was incredible how the Turkish men looked up to this student. He knew it all. We were twice his age, had more experience and had done so much for these patients but they were going to ask him for advice.'</p> <p><i>Q 20.</i> GP17 (Turkish-speaking): 'This first generation, they're low educated, the women are illiterate and depend upon their husband. They have an inferior position in the household. I've seen it so many times, when I visit them it's the husband or the son who does the talking.'</p>

<p>Ideas about diabetes treatment present in the community</p> <p><i>Q 21.</i> GP17: ‘We can tell them and tell them again but once they’re back in their home environment it gets lost. I once had this patient with diabetes, a grandfather, and he told me that next time he would go to Turkey on holiday he would use Turkish honey to cure his diabetes. I told him not to do it and I asked his son and daughter to tell him the same thing. After the holiday I ask them if they told their father not to do it and they say they didn’t dare to. So this old chieftain has this idea and the children don’t dare to object.’</p>
<p>Expectations about consultations</p> <p><i>Q 22.</i> GP15: ‘I have the impression they look at us as some kind of consumer good. I need something, I don’t feel very well, I go to a doctor, he gives me back my health and that’s it.’</p> <p><i>Q 23.</i> GP10: ‘If you’re talking about the relationship with health care providers, well, the expectations from these patients are very technical. If you send a Turkish patient to a diabeteseducator they don’t want to go. They prefer to go to a specialist, something technical, labs and other magical things.’</p>
<p>Feelings of frustration among GPs and PHs</p> <p><i>Q 24.</i> GP17: ‘I have no illusions. What we tell and repeat 2-3 times gets lost for a great deal when they are back in their own world.’</p> <p><i>Q 25.</i> PH09: ‘They are very much on their own, they live in a cocoon, very protected. (...) I sometimes have the feeling that we are beating our heads against a brick wall.’ PH10: ‘I have that feeling all the time.’</p>
<p><i>Barriers related to the provision of diabetes care</i></p>
<p>Exploring patients’ perceptions and lack of time</p> <p><i>Q 26.</i> GP09: ‘First I usually ask ‘what does diabetes mean to you?’, ‘how do you look at it?’ and as long as I have the feeling they don’t understand what it is, it is pointless to stress the importance of daily medication intake.’</p> <p><i>Q 27.</i> GP15: ‘We have to tell so much. You don’t have the time so you don’t pay attention to it.’</p> <p><i>Q 28.</i> GP03: ‘I try to ask if they succeeded in following the treatment. (...). I try to listen to their story, I try to understand. But sometimes it’s difficult because they’re low educated, and you have to know them some time, they have to trust you.’</p>

Reluctance to discuss medication adherence

*Q 29.* PH13: 'I had this young man with diabetes who didn't take his medication. I tried to explain the consequences but he just said he didn't have the time to listen. I have Turkish families that won't come to me because I have been too direct.'

*Q 30.* I: 'Do you ask if they trust their antidiabetics?' PH04: 'We could ask this, but we don't. I never thought about asking whether they trust their medication.' PH03: 'I think that would be a strange question. It would arouse suspicion if you would ask that.' PH01: 'It creates the impression that you don't trust it yourself.'

Lack of structured exchange of information

*Q 31.* GP14: 'Medication, I don't know, we're not able to assess that. I don't know if someone always takes his medication. We don't know that.'

*Q 32.* PH07: 'I'm thinking about a Turkish female patient. The one time she visits the GP, the other the specialist. And the problem is that the number of pills a day is never indicated on the prescriptions. So you can't assess whether she is adherent.'

**Table 4. Supporting quotations (continued).**

<i>Potential strategies to tackle barriers</i>	
Means to overcome the language barrier	<p><i>Q 33.</i> PH12: ‘A brochure with information about the disease, the treatment, the consequences. With pictures and in their own language.’ PH13: ‘That does exist but we don’t have it and we don’t have the time to look for it.’</p> <p><i>Q 34.</i> GP12: ‘What would improve the situation is that we would be able to call an interpreter (professional) because I think a consultation with an interpreter involved would make a big difference.’</p> <p><i>Q 35.</i> PH11: ‘I had a patient who had consulted a diabetes educator that could communicate in Turkish. Well, than you can work with a patient.’</p>
Reminder charts and pill organizers	<p><i>Q 36.</i> PH03: ‘I sometimes make these reminder charts, a paper with the pills glued on, for illiterate patients. But then when something changes (in the medication regimen)... And it’s very time consuming.’</p> <p><i>Q 37.</i> PH05: ‘I think people would interpret this (text message reminders) as a message to buy their next box. They could think of us as being very commercial.’</p>
Stimulating patients to visit the same general practices and pharmacies	<p><i>Q 38.</i> PH02: ‘You can see this (the patients’ level of medication adherence) in your computer. (...) We could ask them how they take their medication, whether they have adverse effects. When necessary call the GP or hand the patient a letter for the GP. (...) We should also try to stimulate patients to always visit the same GP and the same pharmacy.’</p> <p><i>Q 39.</i> PH11: ‘The good patients always visit the same pharmacy, but the bad ones...’ PH10: ‘They shop around.’ PH11: ‘They shop around, yes. And the bad ones create problems to us. The good ones have children who look after them, they visit the same GP, we can work with them. But the other ones, we do not have any idea of their medication adherence. Then you give up. We cannot give them pharmaceutical care if we don’t know anything’</p>
Closer cooperation between GPs and PHs	<p><i>Q 40.</i> GP04: ‘We don’t make optimal use of the pharmacist in our health care system. They could do some of our tasks, we have too many consultations for practical medication issues.’</p> <p><i>Q 41.</i> GP10: ‘The pharmacist should control our prescriptions on the one hand and on the other hand inform us about how many boxes of pills patients take.’</p>

## Discussion

Medication adherence is an important topic deservedly drawing increasing scientific attention. Perspectives of health care providers on promoting medication adherence are rarely studied, especially with regard to ethnic minorities. This is the first study exploring perspectives of GPs and PHs on promoting medication adherence among one of the largest ethnic minorities in Western Europe.

GPs and, to a lesser extent, PHs identified most obstacles to medication adherence found in an earlier interview study with T2DM patients of Turkish descent<sup>18</sup>. However, there are some notable differences. A factor reported by patients, but not mentioned by GPs and PHs, was the influence of causal beliefs about stress and the Belgian climate on medication adherence. This might be due to the fact that the exploration of illness perceptions was reported by only a few GPs. Nevertheless, it has been reported that a better understanding of these perceptions can lead to improved self-care among T2DM patients<sup>19</sup>. From the perspectives of GPs, religion was often seen a cause of fatalism and hence nonadherence. However, our earlier interview study showed that religious beliefs can also contribute to medication adherence in people of Turkish descent<sup>18</sup>, while other studies show its' beneficial impact on the self-management of diabetes<sup>20,21</sup>. The widespread use of herbal medicine among Turkish T2DM patients, observed in the interviews and in a study in Turkey, was hardly recognized by our respondents<sup>18,22</sup>. Participating GPs and PHs rarely explored patients' medication beliefs although the impact of medication beliefs on adherence has been shown in several studies<sup>23-25</sup>.

Although most GPs and PHs had a good picture of the influencing factors, they reported a multitude of barriers to promoting medication adherence among their T2DM patients of Turkish descent.

The low educational level and language barrier were mentioned as the most important barriers at the patient level. Overcoming language barriers is essential because language concordance improves health outcomes in patients with diabetes <sup>4;5</sup>. Language barriers also impede patient-centred communication while higher levels of patient-centred communication have shown to improve medication adherence and glycaemic control in multi-ethnic populations <sup>26;27</sup>. Overcoming these barriers is difficult because the availability of professional interpreters in Belgian primary care is limited <sup>28</sup>. Consequently most GPs and PHs were forced to use informal interpreters, mostly family members, who make more clinically important translation errors <sup>29;30</sup>.

Cultural differences, like culturally shaped gender and family roles, also complicated communication in diabetes care. Ideas about diabetes treatment present in the Turkish community sometimes undermine advice provided by health care professionals. Several studies confirm these challenges in treating patients from different cultural backgrounds <sup>31;32</sup>. Despite the lack of high-quality evaluation studies there is some evidence that higher levels of cultural competency of health care workers may lead to improved health outcomes in general and improved glycaemic control among T2DM patients <sup>33;34</sup>. Therefore, training cultural competencies seems an important challenge in educating health care providers working in societies with aging populations from different ethnic backgrounds.

Confronted with a multitude of cultural and other barriers feelings of frustration were common. Wens et. al. reported a similar finding in their study of GPs' perceptions on adherence among Belgian T2DM patients<sup>11</sup>. We agree with their suggestions that health care providers should view diabetes care as a shared patient-provider responsibility and need training in skills to promote behavioural change.

Ensuring medication adherence can also be hindered by a lack of continuity of care, due to long stays in Turkey or the postponing of consultations because of financial barriers. Maintaining policy measures that guarantee the financial accessibility of primary care is important, especially since the poverty rate among people of Turkish descent is very high<sup>35</sup>.

GPs and PHs stressed the importance of patients' knowledge about diabetes and antidiabetics to improve medication adherence. However, a review by Glazier et. al. showed that the least effective interventions in socially disadvantaged populations focus on diabetes knowledge. To improve self-care and clinical outcomes interventions need to be culturally tailored, involve community members, require a high number of contacts over a long period of time, provide individualised feedback and make use of behavioural methods. Studies included in this review show that improvements in clinical outcomes obtained in these interventions may justify their higher cost<sup>36</sup>.

Both professions expressed the wish for closer cooperation. Nowadays, in Belgium, existing multidisciplinary care networks are limited to patients (starting) on insulin and may be too loosely structured. Pilot projects, extended to broader groups of patients with diabetes, showed closer cooperation between health care providers improved patients' health outcomes<sup>37</sup>. The assessment of medication adherence might also improve with the electronic exchange

of patient records, being implemented in the Belgian health care system<sup>38</sup>. An important condition however is stimulating patients to visit the same health care providers. Efforts to promote cooperation between health care providers should be maintained.

### *Strengths and limitations*

Studies on health care providers' perspectives on promoting medication adherence in ethnic minorities are scarce. With this study we contribute to the field of knowledge by exploring perspectives of Belgian GPs and PHs on promoting medication adherence among patients of Turkish descent.

Focus groups proved to be a fruitful method to explore the diversity in experiences and perspectives. The wide variety of gender, years of professional experience and knowledge of Turkish of the recruited GPs and PHs guaranteed the richness of the data. Dynamic discussions in each group showed GPs and PHs were highly concerned about providing optimal diabetes care to patients of Turkish descent.

Some important limitations of this study have to be mentioned. Because of differences in the health care system or the characteristics of the Turkish communities these experiences and views of health care providers might not be transferable to other West-European countries with large numbers of T2DM patients of Turkish descent. However, these results may contribute to the further exploration of this topic in other settings.

Although participants showed a wide diversity in background characteristics, most participating GPs worked in community health centres which may have caused a potential bias. However, the Turkish community is concentrated in deprived city areas where community health centres reside. Most patients of Turkish descent visit these centres because of their financial accessibility and multidisciplinary character. Moreover, although the work

setting differed we found considerable similarity in the reported problems and suggested solutions. Some important results, e.g. the need for better cooperation in diabetes care, were also found in another study among Belgian GPs working in small practices <sup>11</sup>.

In conclusion, although Belgian GPs and PHs held rather accurate views of factors influencing medication adherence, they are confronted with a multitude of barriers at the patient and organizational level and often lack the means to level these barriers. In order to provide adequate care to these socio-economically vulnerable, ethnic minority patients providers need access to educational materials in Turkish and/or professional interpreters. Training health care providers in cultural competencies and skills to promote behavioural change is also necessary in societies confronted with ageing ethnic minority groups. Stimulating information exchange and cooperation between health care providers can improve diabetes care and clinical outcomes. In multi-ethnic societies with aging populations a chronic care based model of health care can be more appropriate to stimulate cooperation between providers and to enhance patients' self care and clinical outcomes.

#### **Ethics approval, funding and conflicts of interest**

The ethical committee of Ghent University Hospital approved the study; informed consent was obtained from all respondents. No funding. No conflicts of interest to declare.

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***Chapter 6:***  
***Adherence to OHA,***  
***a cross-sectional study.***

Article in preparation:

Peeters, B., Van Tongelen, I., Mehuys, E., Lapauw, B., Ruige, J., Remon, J. P., Boussery, K.  
Medication adherence in European ethnic minorities: an explorative, cross-sectional study  
among type-2 diabetes patients of Turkish descent.

**Medication adherence in European ethnic minorities: an explorative, cross-sectional study among type-2 diabetes patients of Turkish descent.**

**Aims.** People of Turkish descent form a large ethnic minority in Europe, suffering disproportionately more from type-2 diabetes melitus (T2DM). This cross-sectional study aims to 1) estimate the adherence rate to oral hypoglycaemic agents (OHA) in T2DM patients of Turkish descent and 2) validate findings from a qualitative study on factors influencing adherence to OHA in a representative sample of T2DM patients of Turkish descent living in Belgium.

**Methods.** Data were collected in Belgium, using a wide variety of recruitment channels to obtain a representative sample. The questionnaire was based on a previous qualitative study and on literature reviews. Multiple logistic regression analyses, using SPSS 21.0, were performed to identify factors associated with nonadherence to OHA.

**Results.** A total of 197 patients were included. A large majority of the total sample spent at least one month in Turkey. Of this group 27% reported reducing or temporarily stopping the intake of OHA during their stay in Turkey. A subsample of 143 patients for whom the medication possession ratio (MPR) could be calculated were included in the multiple logistic regression analysis. Approximately 40 % of T2DM patients of Turkish descent were nonadherent (MPR<80%) to OHA. Logistic regression analysis showed nonadherence to OHA was explained by the employment status, living situation, the type of OHA regimen, forgetfulness and the trust put in the GP as diabetes care provider.

**Conclusions.** This cross-sectional study found a low adherence rate to OHA among T2DM patients of Turkish descent. Adherence can even be lower during stays in Turkey. Life circumstances, the type of OHA regimen, forgetfulness and trust in the GP influenced adherence to OHA. These risk factors should be taken into account by health care providers in order to stimulate adherence and improve glycaemic control in this low-educated ethnic minority.

**Keywords:** type 2 diabetes; medication adherence; ethnicity; immigrant; Turkish ethnic minority; oral hypoglycaemic agents; cross-sectional study

## **Medication adherence in European ethnic minorities: an explorative, cross-sectional study among type-2 diabetes patients of Turkish descent.**

### **Introduction**

Health care systems in Western-Europe are confronted with aging ethnic minorities, immigrated during periods of economic prosperity in the 1960's and 70's. Turks form one of the largest minorities from outside the EU-28<sup>1</sup>. First-generation migrants met the industry's need for low-skilled labour, most of their descendants still occupy low socio-economic positions<sup>2:3</sup>. Among people of Turkish descent prevalence of type-2 diabetes mellitus (T2DM) is 2 to 3 times higher compared with the indigenous population<sup>4:5</sup>.

Medication adherence is essential to prevent diabetes related morbidity and mortality<sup>6-8</sup>. The association of medication adherence with glycaemic control has been demonstrated in several cross-sectional and longitudinal studies<sup>9:10</sup>. A study among low-income T2DM-patients showed that interventions to improve medication adherence can have a substantial, beneficial effect on glycaemic control<sup>11</sup>. However, little is known on factors influencing medication adherence in ethnic minorities, especially among those living in Europe<sup>12</sup>.

In our previous qualitative study we used in-depth interviews to explore patient perspectives on adherence to oral hypoglycaemic agents (OHA) among Turkish migrants with T2DM<sup>13</sup>. Factors potentially influencing adherence to OHA in that small sample (n=21) included: beliefs about OHA, polypharmacy, beliefs about the course of diabetes, causal beliefs about stress and climate, forgetfulness, the perception of the doctor's medical expertise, mental health and social support, the religious framework of interpretation, the adjustment of medication to food intake and the use of herbal medicine. We also noted a potential gender effect in the patterns of influencing factors<sup>13</sup>.

With this quantitative study we aim to 1) provide an estimate of the adherence rate to OHA in T2DM patients of Turkish descent and 2) validate the findings from our qualitative study in a representative sample of T2DM patients of Turkish descent living in Belgium.

## **Research design and methods**

### **Methods**

#### *Design and setting*

Data were collected in Belgium between February and October 2012. The ethical committee of Ghent University Hospital approved the study; written informed consent was obtained from all respondents.

Respondents were interviewed by Turkish-speaking students, trained by the research team. Most structured interviews took place at the respondents' homes, some in private consultation rooms in a general practice or outpatient clinic. Confidentiality was explicitly guaranteed (e.g. by assuring their general practitioner (GP) would not see respondents' answers) in order to avoid social desirability.

#### *Recruitment and sample*

To obtain a representative sample we used a wide variety of recruitment channels: mosques and other organisations in the Turkish community, general practices, community pharmacies and the diabetes outpatient clinic of Ghent University Hospital. Patients of Turkish descent (i.e. born in Turkey or having at least one parent born in Turkey) aged 18 years or older, diagnosed with type 2 diabetes and treated with OHA for at least 12 months (regardless of the use of insulin) were eligible for inclusion. Recruiters were asked to record background characteristics of patients who refused to participate and the patients' reasons for refusal. Because of the study's exploratory character a priori sample size calculation could not be performed. The aim was to include 200 respondents.

#### *Questionnaire development and measures*

The questionnaire was developed by a panel of medical doctors, pharmacists and a sociologist. Inclusion of variables was based on our previous qualitative study and on literature reviews<sup>12-14</sup>. Panel members chose between available validated measurement scales

based on psychometric properties and practicability in this low educated population. When necessary items were rephrased to refer explicitly to diabetes and diabetes pills.

A pilot version of the questionnaire was back translated by two professional translators. The Turkish version was then corrected by the research team and a third professional interpreter. This pilot questionnaire was tested with 10 T2DM-patients of Turkish descent. Based on this test minor adjustments were made (e.g. rephrasing of some of the negatively phrased scale items for comprehensibility).

### *Adherence to OHA*

Medication adherence is defined as: ‘the process by which patients take their medications as prescribed’<sup>15</sup>. Nonadherence occurs when patients do not (timely) initiate their pharmacological treatment, when patients do not take the number of prescribed doses within prescribed timing intervals or when patients discontinue their therapy too early. In this study we focus on the intake of the number of prescribed doses because this is the most relevant aspect of adherence to OHA from a clinical point of view. Three measures were used to assess adherence to OHA: two self-report scales and the patients’ medication history obtained from pharmacy databases.

To stimulate respondents’ honesty, a statement that forgetting or deliberately not taking diabetes pills is normal, preceded the self-report instruments. The first instrument was an item asking how many diabetes pills respondents missed for each of the last 7 days, preceded by recall questions about situations in which pills are likely to be missed. When respondents missed pills they answered questions on intentional and unintentional nonadherence. Furthermore, based on the results of our interview study, we assessed whether respondents reduced or stopped their intake of OHA during their stays in Turkey<sup>13</sup>.

The second self-report measure was an adapted version of the 8-item Morisky Medication Adherence Scale (MMAS)<sup>16</sup>. In order to maximize variability we followed the recommendation in Al-Qazaz’s validation study and replaced ‘yes/no’ answers by a 6-point Likert scale (‘always’ to ‘never’, scored 0-5)<sup>17</sup>. Because the MMAS measures barriers to adherence we deleted two items providing a quantitative assessment: “Over the past two weeks, were there any days when you did not take your pills?” and “Did you take your pills yesterday?”. Responses on six remaining items were summed (0-30), higher scores indicate fewer barriers.

The third measure is the medication possession ratio (MPR), calculated for respondents who always obtained their OHA from the same pharmacy. The MPR was calculated as the number of days for which OHA were obtained divided by the number of days in the time period<sup>18</sup>. The mean number of days for which the MPR was calculated was 624 (range: 180-853). A detailed description of the calculation method can be found in the methodological addendum. Patients were classified as nonadherent when the MPR<80%. This 80% limit is widely accepted in the literature although there are, to our knowledge, no clinical arguments to use this or any other limit for adherence to OHA.

*Covariates*

An overview of all covariates and the measurement scales used is given in Table 1.

Table 1: Independent variables included in the survey.

<b>Demographic and socio-economic variables</b>
Age; sex; educational level; country of birth; duration of stay in Belgium; profession; marital status; living alone / living together; knowledge of Dutch.
<b>Clinical variables (self-reported)</b>
BMI; smoking status; presence of the following diabetes-related complications and co morbidities: high blood pressure (hypertension), high cholesterol level (hypercholesterolemia), cardiovascular disease, numb feeling or tingling in the limbs (neuropathy), kidney problems (nephropathy), eye problems (retinopathy), slow healing foot wounds (diabetic foot), depression, other chronic diseases; number of diabetes-related complications; number of chronic diseases; oral medicines prescribed for diabetes and other chronic diseases: names, prescribed number of pills a day; prescribed number of diabetes pills a day; total number of prescribed pills a day; diabetes duration; diabetes type; presence of diabetes in family / social environment; diet therapy; duration of treatment with OHA; duration of insulin treatment (if applicable); use of complementary and alternative medicine (CAM) for diabetes; self-monitoring of blood glucose (SMBG); presence of side-effects of OHA; hospitalisation during the last 2 years
<b>Clinical variables (data obtained from patient’s GP)</b>
HbA1c; treatment for depression during the last 2 years; diagnose of: retinopathy, nephropathy, neuropathy, macro vascular complications; changes in the OHA dosing regimen.
<b>Contact with health care providers</b>
Treated by: specialist, dietician, diabeteseducator; entitled to treatment within the diabetes care trajectory; contact frequency with community pharmacist during the last 3 months
<b>Adherence to diet and exercise</b>
Summary of Diabetes Self-Care Activities (SDSCA): diet subscale (4 items, examples were adapted to Turkish food habits) and exercise subscale (2 items) <sup>19</sup> . Itme scores indicate the number of days during the past week (0-7 days) on which the respondent adhered to diet/exercise. The mean of item 1 and 2 and the mean of item 3 and 4 are calculated to obtain the SDSCA General Diet subscale score and the SDSCA Specific Diet subscale score; the mean of item 5 and 6 is calculated to obtain the SDSCA Exercise subscale score. SDSCA showed good psychometric properties in a validation study among Turkish type-2 diabetes patients <sup>20</sup> .
<b>Illness perceptions</b>
<i>Brief Illness Perceptions Questionnaire (B-IPQ)</i> : 9 items, each for a different dimension of patients’ illness perceptions <sup>21</sup> . Eight items are scored on a scale from 0 to 10, higher scores indicate higher agreement. The last item is an open question asking respondents to give (at most) three perceived causes (in order of importance) of their diabetes.
<b>Beliefs about OHA</b>
<i>Beliefs about Medicines Questionnaire (BMQ)</i> : The BMQ-Specific subscale was used to measure patients’ concerns (5 items) and patients’ beliefs about the necessity (5 items) of OHA <sup>22</sup> . Items are scored on a 5-point Likert scale and summed to obtain scores for the BMQ-Necessities, the BMQ-Concerns and a total score measuring the difference between the BMQ-Necessities and the BMQ-Concerns.
<b>Coping with diabetes-related stress</b>
<i>Brief Cope / Emotional Approach Coping scale (EAC)</i> : 12 items from the Brief Cope and 2 items from the EAC <sup>23,24</sup> . The introduction and scale items were rephrased to refer explicitly to diabetes-related stress. Each item, measured on a 5-point Likert scale (from never to always), indicates a different coping strategy, with higher scores indicating a more frequent use.

Diabetes knowledge
Most existing scales were too long and/or too complicated to use in this population. We compiled a diabetes knowledge scale, based on items from existing scales. From a total of 10 items, three measured knowledge of diabetes medicines, two items each measured knowledge about diet and exercise and three items measured knowledge about causes and consequences. Patients responded 'yes', 'no' or 'I don't know' to indicate whether they thought a statement was correct or not. Correct answers received a score of 1, scores can be summed to obtain a total score and subscale scores.
Satisfaction with information about OHA
<i>Satisfaction with Information about Medicines Questionnaire (SIMS)</i> <sup>25</sup> . Items irrelevant to OHA or to this population were deleted, retaining 5 items from the Action and Usage subscale and 4 from the Potential Problems of medication subscale. The answers 'I received too much/too little/no information' receive a score of 0, 'I received enough information / I needed no information' a score of 1. Because no arguments are given for this scoring we also used an alternative scoring system in which 'too much' is scored with 1 <sup>25</sup> . Item scores can be summed to obtain a total score and subscale scores.
Depression and Anxiety
<i>Patient Health Questionnaire for Depression and Anxiety (PHQ-4)</i> : the short form of the Patient Health Questionnaire for Depression and Anxiety (PHQ-4) uses validated 2-item scales to measure anxiety and depression <sup>26</sup> . The response scale consists of 4 categories measuring how frequent patients experienced feelings of anxiety and depression during the last two weeks (scored 0-3). Higher scores reflect higher risks for anxiety and depression. An item asking whether respondents at the time of the survey suffered from depression. A second item asking whether respondents were treated for depression (consultations and/or medicines) during the two years preceding the survey. A composite measure indicating whether respondents were treated for depression during the 2 years preceding the survey according to self-report and/or GPs' data.
Social support
<i>Multidimensional Diabetes Questionnaire (MDQ) / Diabetes Distress Scale (DDS)</i> : Three items from the MDQ (measuring instrumental support for adherence to diet, OHA and exercise) and two items from the DDS (measuring emotional support) <sup>27,28</sup> . Items were positively rephrased. The 7 scale categories (scores 0-6) range from 'totally disagree' to 'totally agree' with higher scores indicating perceptions of stronger social support.
Expectations about treatment outcomes
<i>Multidimensional Diabetes Questionnaire (MDQ)</i> : The MDQ Outcome Expectancies subscale measures patients' expectations about treatment outcomes <sup>27</sup> . Answers range from 'not at all important' to 'very important' (scores 0-5).
Trust in GP
The <i>Wake Forest Trust in Physician Scale</i> was used to assess respondents' trust in their GP as diabetes care provider <sup>29</sup> . One item on trust in the GP's prescription of medicines, part of the original pool of items used by the scale developers, was added. An item on general trust in the GP was deleted. Answers are scored on a 5-point Likert scale (1-5) and can be summed to obtain a total score (10-50). Higher scores indicate higher levels of trust in the GP as diabetes care provider.
GP-patient relationship
Frequency of contact during last 3 months; duration; recommend GP to family and friends; satisfaction; second opinion because of not being satisfied with the GP's provision of diabetes care; GP's knowledge of Turkish.

### Statistical analysis.

Data are presented as means (standard deviations) or percentages (sample sizes). Pearson  $\chi^2$  test, Fisher exact test (categorical data) or independent samples t-test (continuous variables) were used to compare differences between adherers (MPR $\geq$ 80%) and nonadherers (MPR<80%) and between the subsample with MPR (MPR sample) and the subsample without MPR (No MPR sample).

Internal consistency (Cronbach  $\alpha$ ), non-parametric measures of association and ROC-analysis, using the MPR as golden standard, were conducted to assess the psychometric properties of the two self-report scales for medication adherence.

Internal consistency (Cronbach  $\alpha$ ) and, when possible, criterion validity (parametric or non-parametric measures of association) of the different measurement scales for covariates were

assessed in this sample. A short, general overview of these results can be found in the methodological addendum.

A series of multiple logistic regression analyses, using SPSS 21.0, was performed according to recommendations in the literature<sup>30-32</sup>. The aim was to identify factors associated with nonadherence to OHA (MPR<80%). We used a stepwise forward selection procedure with backward elimination following Sun et al.'s recommendation to 'set the p-value from 0.15 to 0.25 for entering variables and from 0.10 to 0.15 for deleting variables'<sup>33</sup>. The obtained preliminary model was compared to a model built with the stepwise backward elimination method. Alternative models were assessed by deleting and adding variables based on the Wald statistic and their theoretical relevance. Theoretically plausible interaction effects were added to the preliminary model. Because of the small number of observations dividing the data set into a model-building and a validation data set was not possible. A more detailed description can be found in the methodological addendum.

Initially, analysis was performed on the subsample with MPR (for an argumentation see the results section). Because listwise deletion of missing values can lead to biased parameter estimates and loss of statistical power, we repeated the multiple logistic regression with multiple imputations for missing values in order to validate results<sup>34</sup> (see methodological addendum for a detailed description). Logistic regression models and parameter estimates from the imputed data sets were compared with the model and the parameter estimates from the original data set.

Clinical relevance of medication adherence was assessed using multiple logistic regression with patients having a HbA1c  $\leq 7\%$  (53mmol/mol) as dependent variable and adherence to OHA, adherence to diet, adherence to exercise, diabetes duration and age as independent variables. Multiple linear regression was used to assess the impact of a 10% decrease in adherence to OHA on HbA1c.

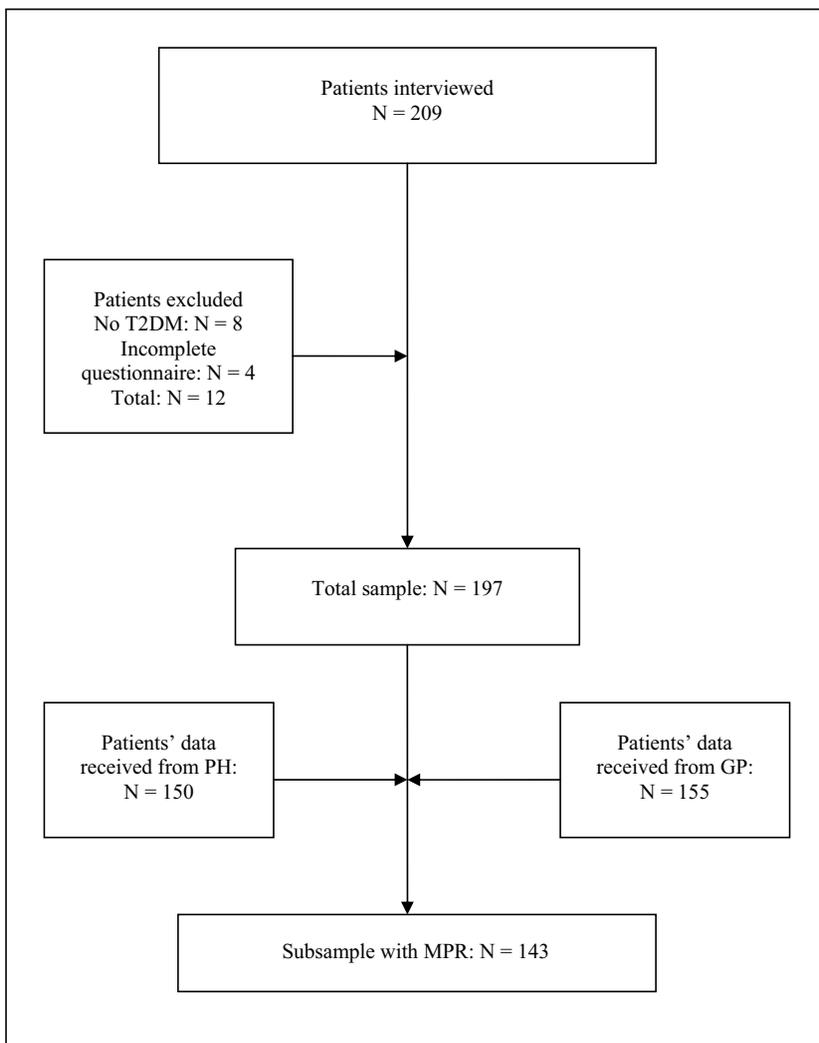
## **Results**

### ***Sample***

We included 197 patients in this study, for 143 of them (76.2%) we were able to calculate the MPR (see Figure 1). Reasons for not being able to calculate the MPR were missing data from the patient's GP or PH, or the fact that patients obtained their OHA from several pharmacies. Compared to patients with MPR, patients without MPR were less likely to be married (59%

versus 78%,  $p=0.007$ ), had a shorter duration of stay in Belgium (26 years versus 33 years,  $p=0.003$ ), were more likely to be treated with metformin as only OHA (i.e. regardless of insulin use) (78% versus 52%,  $p=0.001$ ), used a smaller number of diabetes pills (mean: 2.7 versus 3.1,  $p=0.043$ ) and reported more barriers to adherence to OHA (mean MMAS total scores: 26.52 in the MPR sample versus 24.13 in the No MPR sample,  $p=0.006$ ). For all other characteristics no statistically significant differences could be detected between patients with MPR and patients without MPR (data not shown).

Figure 1: Size of total sample and MPR subsample.



***Psychometric properties of the self-report measures for adherence to OHA.***

Self-report measures of adherence to OHA proved to be unreliable in this sample, Although internal consistency of MMAS was good and both self-report measures show a moderate but statistically significant correlation with MPR in the expected direction, the ROC-analyses clearly show both measures are not able to correctly classify patients as nonadherent (Table 2). Therefore we reported adherence rates for the MPR sample, and performed bivariate analyses (Tables 3-4) and multiple logistic regression (Table 5) with the MPR subsample. We included the MMAS-item and total scores in the pool of covariates for the logistic regression because the MMAS, often wrongly used as a quantitative assessment of medication adherence, measures different kinds of barriers to medication adherence.

Table 2: Psychometric properties of self-report instruments of medication adherence.

	Correlation with MPR	ROC-analysis (positive state value = MPR<80%)	Internal consistency
'how many diabetes pills were missed on each of the preceding 7 days'	Spearman $\rho = -0.233$ ; $p < .010$	AUC = 0.590 (95% CI=0.495-0.685, $p = .065$ )	N.A.
MMAS	Spearman $\rho = 0.296$ ; $p < .001$	AUC = 0.361 (95% CI=0.269-0.453; $p = .004$ )	Cronbach $\alpha = 0.77$

N.A. = not applicable.

***Medication adherence.***

Only 5.6% of the MPR sample ( $n=143$ ) reported missing more than 20% of the prescribed number of diabetes pills during the last 7 days (9.3% in the No MPR sample,  $n=54$ ,  $p=0.410$ ). Results from the MMAS (Table 4) showed that respondents with MPR, on average, report few barriers to medication adherence. Results from pharmacy databases are in contrast with these high levels of self-reported medication adherence. 43.7% of patients (95% CI: 35.3%-52.1%) obtained less than 80% of the prescribed dose of OHA, the mean MPR is 81.9% (95% CI: 76.4%-87.4%, median: 83.4%, range: 15.9%-166.7%).

A large majority of the total sample of 197 respondents (86%,  $n=168$ ) spent at least one holiday ( $> 1$  month) in Turkey during the last two years. Of this group 27% ( $n=45$ ) reported reducing or temporarily stopping the intake of OHA during their stay in Turkey.

***Factors associated with adherence to OHA: bivariate analysis.***

Demographic, socio-economic, clinical and treatment-related characteristics of the MPR subsample (n=143) are shown in Table 3, p-values indicate statistical significance of differences between adherers and nonadherers. Approximately two thirds of the sample were women; the educational level was very low. Self-reported physical health in the sample was low. Prevalence of depression was between 33% and 40%, according to self-report and/or GP's data. Mean diabetes duration was approximately 10 years. Less than 30% of the patients had a HbA1c  $\leq$  7% (53 mmol/mol). Four out of 5 patients did not know which type of DM they have.

Nonadherers were on average 5 years younger and stayed 5 years less in Belgium than adherers. Of the 7 patients born in Belgium, 6 were nonadherent. Compared to patients without employment, a larger proportion of employed patients was nonadherent (7.4% versus 27.4%). A smaller proportion of nonadherers was treated by their current GP for more than 5 years (63% versus 79%). 37% of nonadherers received diabetes care from their current GP for more than 5 years compared to 60% of adherers. Other factors showed a trend towards statistical significance ( $p \leq 0.10$ ). A majority of the patients who live alone are adherent to OHA ( $p=0.051$ ). A larger proportion of nonadherers reported suffering from hypertension ( $p=0.098$ ); no other differences in comorbidities, according to self-report or GP's data, were detected. The mean HbA1c-value was 0.5% (6 mmol/mol) higher in nonadherers ( $p=0.067$ ) and a smaller proportion of nonadherers reached the goal of HbA1c  $\leq$  7% (53 mmol/mol) ( $p=0.068$ ). Approximately 60% of nonadherers were treated with metformin as only OHA compared to 46% of adherers ( $p=0.064$ ). A larger proportion of adherers had family members with DM ( $p=0.055$ ).

Table 3: Demographic, socio-economic, clinical and treatment-related characteristics of adherent and nonadherent patients.

	Sample with MPR (N=143)	MPR ≥ 80% (N=81)	MPR < 80% (N=62)	p-value
Sex: female	67.1% (96)	70.4% (57)	62.9% (39)	0.346
Country of birth: Turkey	95.1% (136)	98.8% (80)	90.3% (56)	<b>0.037</b>
Duration of stay in Belgium (years) <sup>a</sup>	33.0 (11.4)	34.9 (10.7)	30.3 (11.8)	<b>0.017</b>
Age (years) <sup>b</sup>	56.2 (11.3)	58.5 (10.8)	53.2 (11.4)	<b>0.005</b>
Educational level				0.375
At most secondary education until 15y	76.2% (109)	79.0% (64)	72.6% (45)	
Secondary until 18y or Tertiary education	23.8% (34)	21.0% (17)	27.4% (17)	
Employed	16.1% (23)	7.4% (6)	27.4% (17)	<b>0.001</b>
Language concordance GP-patient <sup>c</sup>	57.5% (69)	61.4% (43)	52.0% (26)	0.303
Married	78.3% (112)	76.5% (62)	80.6% (50)	0.555
Living alone	8.4% (12)	12.3% (10)	3.2% (2)	<u>0.051</u>
Language concordance GP-patient <sup>c</sup>	57.5% (69)	61.4% (43)	52.0% (26)	0.303
BMI (kg/m <sup>2</sup> )	32.9 (6.0)	32.2 (5.9)	33.8 (6.0)	0.119
Smoker <sup>b</sup>	21.8% (31)	21.0% (17)	23.0% (14)	0.779
Self-reported diabetes-related complications/other co morbidities:				
high blood pressure	65.0% (93)	59.3% (48)	72.6% (45)	<u>0.098</u>
high cholesterol level	70.6% (101)	71.6% (58)	69.4% (43)	0.770
cardiovascular disease	38.5% (55)	43.2% (35)	32.3% (20)	0.182
numb feeling/tingling in limbs	56.6% (81)	55.6% (45)	58.1% (36)	0.764
kidney problems	15.4% (22)	14.8% (12)	16.1% (10)	0.829
eye problems	63.3% (91)	61.7% (50)	66.1% (41)	0.558
slow healing foot wounds	20.3% (29)	21.0% (17)	19.4% (12)	0.810
depression	32.9% (47)	35.8% (29)	29.0% (18)	0.393
other chronic diseases	42.0% (60)	42.0% (34)	41.9% (26)	0.996
Self-reported number of diabetes-related complications and other co morbidities	4.2 (2.2)	4.1 (2.2)	4.3 (2.0)	0.633
Data from GP:				
depression (last 2 years) <sup>d</sup>	16.0% (19)	17.9% (12)	13.5% (7)	0.511
retinopathy <sup>e</sup>	8.5% (10)	8.8% (6)	8.2% (4)	0.900
nephropathy <sup>e</sup>	21.4% (25)	19.1% (13)	24.5% (12)	0.484
neuropathy <sup>e</sup>	12.0% (14)	10.3% (7)	14.3% (7)	0.512
macro vascular complications <sup>f</sup>	23.1% (27)	26.5% (18)	18.4% (9)	0.305
Depression by self-report and/or data GP <sup>b</sup>	39.4% (56)	41.3% (33)	37.1% (23)	0.615
HbA1c <sup>f</sup>	8.1 (1.4)	7.9 (1.4)	8.4 (1.4)	<u>0.067</u>
HbA1c ≤ 7.0%	27.0% (30)	33.9% (21)	18.4% (9)	<u>0.068</u>
HbA1c > 7.0%	73.0% (81)	66.1% (41)	81.6% (40)	
Type of diabetes unknown to patient	79.7% (114)	77.8% (63)	82.3% (51)	0.509
Diabetes duration (years)	10.6 (7.7)	11.3 (8.0)	9.7 (7.3)	0.222
Treated with insulin	37.1% (53)	39.5% (32)	33.9% (21)	0.498
Duration of treatment (years) with:				
OHA	9.7 (7.0)	9.8 (6.7)	9.5 (7.4)	0.804
Insulin <sup>g</sup>	7.5 (6.6)	6.7 (5.5)	8.7 (8.1)	0.288
Self-reported side-effects of OHA <sup>h</sup>	17.7% (25)	21.3% (17)	13.1% (8)	0.210
Treated with metformin as only OHA	52.4% (75)	45.7% (37)	61.3% (38)	<u>0.064</u>

Table 3 (continued): Demographic, socio-economic, clinical and treatment-related characteristics of adherent and nonadherent patients.

Prescribed n diabetes pills/day	3.1 (1.4)	3.2 (1.5)	3.0 (1.2)	0.516
Total n prescribed pills/day	7.3 (3.7)	7.5 (3.5)	7.0 (4.1)	0.529
Use of CAM for diabetes	19.6% (28)	18.5% (15)	21.0% (13)	0.715
Self-monitoring of blood glucose	53.1% (76)	49.4% (40)	58.1% (36)	0.303
Diet therapy	69.9% (100)	66.7% (54)	74.2% (46)	0.331
Presence of diabetes in:				
Family <sup>b</sup>	23.9% (34)	30.0% (24)	16.1% (10)	<u>0.055</u>
Social environment <sup>b</sup>	27.5% (39)	26.3% (21)	29.0% (18)	0.713
% (n) of patients who:				
○ are treated by their GP for > 5 years <sup>b</sup>	71.8% (102)	78.8% (63)	62.9% (39)	<b>0.037</b>
○ suffer for > 5 years from T2DM and are treated by their GP for > 5 years <sup>b</sup>	50.0% (71)	60.0% (48)	37.1% (23)	<b>0.007</b>
Data are presented as percentage (number) or mean (standard deviation). P-value: <b>bold</b> = p < 0.05, <u>underlined</u> = p < 0.10. Reduced sample size due to missing data: <sup>a</sup> Sample with MPR N = 140; <sup>b</sup> Sample with MPR N = 142; <sup>c</sup> Sample with MPR N = 120; <sup>d</sup> Sample with MPR N = 119; <sup>e</sup> Sample with MPR N = 111; <sup>f</sup> Sample with MPR N = 117; <sup>g</sup> Sample with MPR N = 53; <sup>h</sup> Sample with MPR N = 141. GP = general practitioner, CAM = complementary and alternative medicine.				

Table 4 shows scale scores, subscale scores and item scores with  $p < 0.30$  (included in the model-building covariates set for logistic regression) of patients' beliefs and behaviors for the MPR sample. Adherence to diet and exercise was low. Three out of four patients perceived stress as a cause of T2DM, slightly more than half of them believed their lifestyle had caused diabetes. Beliefs about the necessities of OHA outweighed the concerns patients had about OHA. Knowledge about diabetes was moderate. Satisfaction with the information received about OHA was low, especially with the information about potential problems (side effects and what to do when they occur, interactions with other medicines, what to do when a dose is forgotten). Mean scores for the PHQ-4 and its subscales were rather high, indicating a potentially large proportion of patients experiencing anxiety and/or depression. On average, patients experienced moderate social support in adhering to diet, exercise and medication and moderate emotional support. Outcome expectancies were high which indicates patients believed it's important to adhere to the diabetic regimen (diet, exercise and medication). The mean score for trust in the GP as diabetes care provider was high.

Statistical significant differences between adherers and nonadherers were found for several MMAS mean item scores and the mean total score, meaning nonadherers reported slightly more barriers to medication adherence. The barrier 'forgetting to take OHA' showed the biggest difference between adherers and nonadherers. Nonadherers were slightly more concerned about their diabetes and about the long-term effects of OHA. When confronted

with diabetes-related stress, nonadherers responded they accepted the situation slightly more frequently than adherers did. The mean diabetes knowledge score was slightly higher for nonadherers. Perceived emotional support was stronger among nonadherers. Trends towards statistically significant differences were detected for two mean MMAS-item scores ('stopping to take diabetes pills because of feeling worse when taking them' and 'finding it difficult to take diabetes pills everyday'), and knowledge of diabetes medicines, causes and consequences of diabetes. The majority of patients who put insufficient trust in their GP as diabetes care provider were nonadherent ( $p=0.078$ ).

Table 4: Behavior and beliefs of adherers and nonadherers.

	Sample with MPR (N=143)	MPR ≥ 80% (N=81)	MPR < 80% (N=62)	p-value
<i>SDSCA: Summary of Diabetes Self Care Activities.<sup>a</sup></i>				
SDSCA General Diet	2.39 (2.74)	2.35 (2.76)	2.44 (2.73)	0.841
SDSCA Specific Diet	3.57 (1.66)	3.71 (1.81)	3.38 (1.42)	0.284
SDSCA Exercise	3.41 (2.21)	3.46 (2.13)	3.34 (2.32)	0.740
<i>MMAS: Barriers to medication adherence.<sup>b</sup></i>				
Do you sometimes forget to take your diabetes pills?	4.23 (0.99)	4.47 (0.84)	3.92 (1.10)	<b>0.001</b>
Have you ever cut back or stopped taking your diabetes pills without telling your doctor because you felt worse when you took them?	4.64 (0.80)	4.75 (0.66)	4.50 (0.94)	<u>0.060</u>
When you travel or leave home, do you sometimes forget to bring along your diabetes pills?	4.63 (0.83)	4.69 (0.65)	4.55 (1.04)	0.313
When you feel like your diabetes is under control, do you sometimes stop taking your diabetes pills?	4.78 (0.61)	4.89 (0.35)	4.65 (0.81)	<b>0.017</b>
Taking diabetes pills everyday is difficult for some people. Do you find it difficult to take them everyday?	4.00 (1.25)	4.16 (1.09)	3.79 (1.40)	<u>0.078</u>
How often do you have difficulty remembering to take all your diabetes pills?	4.24 (1.21)	4.42 (0.92)	4.00 (1.47)	<b>0.038</b>
MMAS mean total score <sup>a</sup>	26.5 (3.73)	27.4 (3.01)	25.4 (4.27)	<b>0.001</b>
<i>B-IPQ: Beliefs about diabetes.<sup>c</sup></i>				
How concerned are you about your diabetes?	5.60 (3.45)	5.06 (3.47)	6.31 (3.32)	<b>0.032</b>
% (n) of patients reporting the following factor as a cause of diabetes:				
o stress	76.2% (109)	77.8% (63)	74.2% (46)	0.618
o lifestyle	54.5% (78)	59.3% (48)	33.8% (30)	0.196
<i>BMQ: Beliefs about OHA.<sup>d</sup></i>				
I sometimes worry about the long-term effects of my diabetes pills.	3.44 (1.30)	3.22 (1.27)	3.73 (1.30)	<b>0.021</b>
Mean score subscale 'Concerns'	14.03 (4.29)	13.59 (4.51)	14.60 (3.96)	0.166
Mean score subscale 'Necessities'	20.01 (4.10)	19.95 (4.18)	20.08 (4.02)	0.852
Mean total score 'Necessities – Concerns'	5.98 (5.18)	6.36 (5.12)	5.48 (5.26)	0.319
<i>Brief-COPE &amp; EAC: Coping with diabetes-related stress.<sup>e</sup></i>				
When I experience stress caused by my diabetes:				
o I've been learning to live with it.	2.66 (1.19)	2.48 (1.13)	2.89 (1.23)	<b>0.043</b>
o I've been making jokes about it.	1.52 (1.28)	1.40 (1.24)	1.69 (1.31)	0.167
o I've been getting help and advice from other people.	1.81 (1.40)	1.65 (1.37)	2.02 (1.42)	0.126

Table 4 (continued): Behavior and beliefs of adherers and nonadherers.

<i>Diabetes knowledge test</i>				
% (n) of patients providing a correct answer to the following statements:				
○ Taking diabetes medicines (insulin or diabetes pills) in the morning without having breakfast can lower your blood sugar level.	62.2% (89)	55.6% (45)	71.0% (44)	<u>0.060</u>
○ People with diabetes need to exercise at least 30 minutes a day	94.4% (135)	92.6% (75)	96.8% (60)	0.281
○ In people with diabetes the body makes too little insulin or the body is not sensitive enough to the effect of insulin.	58.0% (83)	51.9% (42)	66.1% (41)	<u>0.086</u>
○ People with diabetes have a higher risk of heart diseases	81.1% (117)	76.5% (62)	88.7% (55)	<u>0.062</u>
Mean total score (standard deviation) <sup>f</sup> :	6.05 (1.94)	5.75 (2.02)	6.44 (1.78)	<b>0.037</b>
<i>SIMS: satisfaction with information received about OHA. <sup>g</sup></i>				
% (n) of patients answering 'I received enough information' of 'I didn't need information' to the question 'How satisfied are you with the information you received about':				
○ the name(s) of your diabetes pills?	58.7% (84)	54.3% (44)	64.5% (40)	0.220
○ what you should do when you experience side effects of diabetes pills?	23.1% (33)	19.8% (16)	27.4% (17)	0.281
○ how diabetes pills work in your body?	33.6% (48)	38.3% (31)	27.4% (17)	0.173
Mean score (standard deviation):				
SIMS Subscale 'Action & usage'	2.71 (1.66)	2.72 (1.77)	2.69 (1.53)	0.973
SIMS Subscale 'Potential problems of medications'	1.01 (1.34)	0.95 (1.32)	1.10 (1.36)	0.519
SIMS total score	3.72 (2.69)	3.67 (2.76)	3.79 (2.63)	0.787
<i>PHQ-4: Patient Health Questionnaire for Depression and Anxiety. <sup>h</sup></i>				
PHQ-2 Anxiety	1.71 (1.56)	1.54 (1.61)	1.94 (1.48)	0.138
PHQ-2 Depression	1.80 (1.63)	1.72 (1.61)	1.92 (1.66)	0.461
PHQ-4 Total	3.51 (2.81)	3.26 (2.83)	3.85 (2.76)	0.210
<i>Social support: Multidimensional Diabetes Questionnaire (MDQ) / Diabetes Distress Scale (DDS) <sup>i</sup></i>				
MDQ Instrumental support (3 items)	9.93 (5.44)	9.75 (5.52)	10.16 (5.38)	0.658
DDS Emotional support (2 items)	6.94 (3.63)	6.40 (3.61)	7.66 (3.58)	<b>0.038</b>
<i>Expectations about treatment outcomes: Multidimensional Diabetes Questionnaire (MDQ) <sup>j</sup></i>				
MDQ outcome expectancies (5 items)	21.92 (2.92)	22.01 (2.72)	21.79 (3.18)	0.654
<i>Trust in GP: Wake Forest Trust in Physician Scale</i>				
% (n) of patients who respond 'completely disagree' or 'disagree' to the item 'Your general practitioner will do whatever it takes to get you all the care you need for your diabetes.'	7.0% (10)	3.7% (3)	11.3% (7)	<u>0.078</u>
Mean score (standard deviation) (10 items) <sup>k</sup> :	40.47 (6.15)	40.60 (5.81)	40.29 (6.61)	0.763
Data are presented as percentage (number) or mean (standard deviation). P-value: <b>bold</b> = p < 0.05, <u>underlined</u> = p < 0.10. <sup>a</sup> Summary of Diabetes Self-Care Activities (SDSCA): SDSCA General Diet subscale score (0-7 days), SDSCA Specific Diet subscale score (0-7 days), SDSCA Exercise subscale score (0-7 days). <sup>b</sup> MMAS item scores (0-5), MMAS total score (0-30) with higher scores indicating fewer barriers. <sup>c</sup> B-IPQ item scores (0-10) with higher scores indicating higher agreement. <sup>d</sup> BMQ item scores (1-5) with higher scores indicating higher agreement, BMQ subscale scores 'Concerns' / 'Necessities' (5-25) with higher scores indicating higher concerns / necessities, BMQ total score 'Necessities - Concerns' (-20 - +20). <sup>e</sup> Brief Cope and EAC item scores (0-4) with higher scores indicating a more frequent use of the coping strategy. <sup>f</sup> Diabetes knowledge scale total score (0-10) with higher scores indicating higher knowledge. <sup>g</sup> The SIMS Action and Usage subscale (0-5), SIMS Potential Problems of medication subscale (0-4) and SIMS total score (0-9) with higher scores indicating a higher level of satisfaction with the information received about OHA. An alternative coding in which the answer 'I received too much information' was coded as 1 (satisfied) did not lead to substantially different results. <sup>h</sup> PHQ-2 Anxiety (0-3), PHQ-2 Depression subscales (0-3) and PHQ-4 scale (0-6) with higher scores indicating higher levels of anxiety and/or depression. <sup>i</sup> MDQ Instrumental support(0-18) DDS Emotional support (0-12) with higher scores indicating perceptions of stronger social support. <sup>j</sup> MDQ outcome expectancies subscale total score (0-25) with higher scores indicating higher expectations. <sup>k</sup> Wake Forest Trust in Physician Scale total score (10-50) with higher scores indicating a higher level of trust in the GP.				

***Factors associated with nonadherence to OHA: logistic regression analysis.***

The final logistic regression model is shown in Table 5. Medication nonadherence to OHA in this sample was explained by the patients' employment status, living situation, the type of OHA regimen, forgetfulness and the trust put in the GP as diabetes care provider. Patients who are employed were at higher risk of being nonadherent. Approximately half of the employed patients work in shifts and 90% of shift workers reported forgetting to take their OHA. A low but statistically significant asymmetric association between employment status and forgetfulness was found ( $\Lambda = 0.21$ ,  $p:0.005$ ; Goodman & Kruksal Tau = 0.09,  $p:0.000$ ). Living alone reduced the risk of being nonadherent. Being treated with metformin as only OHA increased the risk of nonadherence compared to all other OHA regimens. There was no statistically significant difference for self-reported side-effects between patients on metformin or patients on other OHA regimens ( $p=0.421$ ), but a larger proportion of patients treated with metformin as only OHA used insulin (52% versus 21%,  $p=0.000$ ). Patients with lower scores (indicating a higher barrier) on the MMAS-item about forgetfulness were more likely to be nonadherent. Patients who responded 'completely disagree' or 'disagree' to the WF Trust in Physician item 'Your general practitioner will do whatever it takes to get you all the care you need for your diabetes' were more likely to be nonadherent. All other potential predictors did not contribute to the final model.

Logistic regression analysis was repeated with multiple imputation for missing values (5 imputed datasets,  $n=196$ ). The proportion of nonadherers was slightly higher than in the original dataset (44-50% in the imputed datasets versus 43% in the original dataset). The models and parameter estimates from the logistic regression with the imputed data sets did not differ substantially from the model and parameter estimates of the original dataset (data not shown). The only notable difference was the fact that the MMAS-item on forgetfulness did reach a  $p$ -value  $<.05$  in most but, unlike the other 4 parameters, not in all 15 regression models. Another MMAS-item measuring intentional nonadherence (When you feel like your diabetes is under control, do you sometimes stop taking your diabetes pills?) contributed to most of the logistic regression models for the imputed datasets but not for the model obtained from the original data set. In conclusion, analysis with multiple imputation for missing values confirmed the model obtained with the original dataset to a large extent.

The clinical importance of medication adherence in this sample was confirmed by the results of the logistic regression analysis with patients having a  $HbA1c \leq 7.0\%$  (53 mmol/mol) as outcome. The only two predictors in the final model were the MPR and the 'SDSCA General

Diet'-subscale (data not shown). In multiple linear regression a decrease of 10% in adherence to OHA was associated with a 0.1% (1 mmol/mol) increase in HbA1c.

Table 5: Logistic regression analysis of 135 patients' medication nonadherence to OHA (MPR < 80%).

Predictor	$\beta$	S.E. $\beta$	Wald $\chi^2$	p	OR (95%CI)	RR (95%CI)
Constant	4,343	1,344	10,442	,001	N.A.	N.A.
Not employed					1.00	1.00
Employed	1,715	,588	8,521	.004	5.56 (1.76-17.58)	1.44 (1.19-1.55)
Living together					1.00	1.00
Living alone	-2,328	1,010	5,311	.021	0.10 (0.01-0.71)	0.16 (0.02-0.76)
Monotherapy metformin					1.00	1.00
Other OHA regimen	-1,305	,429	9,251	.002	0.27 (0.12-0.63)	0.43 (0.21-0.78)
Do you sometimes forget to take your diabetes pills?	-,530	,220	5,835	.016	0.59 (0.38-0.91)	0.88 (0.65-0.98)
Insufficient trust in diabetes care provided by GP					1.00	1.00
Sufficient trust in diabetes care provided by GP	-2,048	,893	5,262	.022	0.13 (0.02-0.74)	0.19 (0.04-0.73)
<i>Test</i>			$\chi^2$	df	p	
Overall model evaluation						
Likelihood ratio test			33,405	5	.000	
Goodness-of-fit test						
Hosmer & Lemeshow			4,358	5	.499	
Cox & Snell R <sup>2</sup> = .219, Nagelkerke R <sup>2</sup> = .294, Gamma = .605, Somer's d <sub>yx</sub> = .305, c-statistic = 77.10%						
Because the outcome is common, odds ratios were translated into risk ratios according to the formula by Zhang <sup>35</sup> . Collinearity diagnostics showed no multicollinearity. None of the theoretical plausible interaction effects reached statistical significance. The Hosmer and Lemeshow goodness-of-fit test shows the logistic response function is appropriate. Plotting residuals against estimated probabilities showed no significant model inadequacy. Regression residuals diagnostics showed one poorly fit case, repetition of the analysis after omitting this case did not substantially change the obtained model or regression parameters. Measures of association (Gamma, Somer's d <sub>yx</sub> ) and the c-statistic (the 'area under the curve' from the ROC-analysis) show the validity of the model predicted probabilities. N.A.: not applicable.						

**Discussion**

This explorative study is the first on medication adherence to OHA among one of the largest ethnic minorities in Western-Europe. It is build on insights obtained from an extensive in-depth interview study, includes a large pool of potential predictors and confounders and provides the first, clinically important insights into adherence rates and influencing factors in this hitherto neglected population.

Approximately 40 % of T2DM patients of Turkish descent in this sample were nonadherent (MPR<80%) to OHA, which is similar to numbers in other ethnic groups<sup>36</sup>. The mean MPR was 82%, a result in line with mean adherence rates to OHA (60%-95%) found in other populations<sup>14,37</sup>. Compared to Whites several studies found lower adherence rates among

other ethnic groups<sup>38-42</sup>. No European studies, using reliable adherence measures, are available that compare adherence rates of T2DM patients of Turkish descent with those of the indigenous population.

Noteworthy is the number of nonadherers during (often long) stays in Turkey. A possible explanation, found in our interview study, is that patients experience less stress in Turkey while, in their view, stress has an important impact on their blood glucose levels<sup>13</sup>. Health care providers are often unaware of this practice.

Logistic regression results showed adherence to OHA in this sample was influenced by factors related to the patient's life circumstances, the OHA regimen and the GP-patient relationship. Nonadherence was higher among patients who are employed. A possible explanation is that most people in this low educated population work in shifts which can lead to forgetfulness. Employment status might have a larger impact on nonadherence among men of Turkish descent compared to women because, especially among first-generation migrants, traditional gender roles are widely accepted<sup>2</sup>.

Patients who live alone were less likely to be nonadherent. This seems surprising considering that house hold members can be an important source of social support<sup>42</sup>. However, again gender roles could be a possible explanation. Households extending nuclear families are not uncommon and even older women often are involved in house hold tasks and child care<sup>2</sup>, possibly leading to a more careless OHA intake. Another possibility, suggested by GPs and PHs, is the larger, negative impact of (often erroneous) ideas in the Turkish community about diabetes and OHA on adherence to OHA among patients who live together<sup>43</sup>.

Patients treated with metformin as only OHA were more likely to be nonadherent than patients on any other OHA regimen (most are treated with two different classes of OHA in loose pill combinations). The number of diabetes pills prescribed or self-reported side-effects of OHA had no impact on adherence. This result is in contrast to other studies showing the beneficial impact of a lower number of intakes on adherence to OHA<sup>14;44</sup>. A possible explanation is that more patients treated with metformin as only OHA also used insulin, which may imply they perceive OHA as less necessary than patients on other OHA regimens. However, the mean BMQ-necessities score and the mean BMQ 'Necessities – Concerns' score was higher for patients treated with insulin compared to patients not treated with insulin (21.42 versus 19.18,  $p=0.001$ ; 7.19 versus 5.27,  $p=0.032$ ). Another possible explanation might be found in beliefs about the seriousness of diabetes. Patients might believe taking more than

one class of OHA means their health has deteriorated, which, in turn, can lead to improved adherence.

Trust in the GP as diabetes care provider had an important influence on adherence to OHA in this sample, which confirms the finding from our interview study<sup>13</sup>. Although this subject is rarely studied, similar findings were reported in other studies. Bonds et al. found patients' trust in their physician was associated with better self-care activities (including medication taking) in a multiethnic, low-income group of T2DM patients<sup>45</sup>. A positive association between patient trust and medication adherence has also been found in a general primary care population<sup>46</sup>. Patient trust was also negatively associated with HbA1c-levels in T2DM-patients with different socio-economic and ethnic backgrounds, an association that might be attributable to the mediating effect of improved self-care<sup>47</sup>. Potential explanations for patients' trust in their GP are: empathy shown by the GP, the GP's communication style, technical competency, reducing status and power differences and patients' ethnic identity<sup>47;48</sup>. Several aspects of GPs' behaviour thus contribute to patients' trust. Although the mean level of trust in our sample was high, improving this level among patients who do not put sufficient trust in their GP as diabetes care provider could have an important beneficial effect.

Finally, forgetfulness appeared to be an important barrier to medication adherence. Positive effects of reminder systems on unintentional nonadherence have been shown<sup>49;50</sup>. Promoting the use of reminder systems in this population can contribute to improved adherence rates. However, results from logistic regression with the imputed datasets suggest that intentional nonadherence can also play a role. Intentional nonadherence may only be countered by exploring and adjusting patients' perspectives on diabetes and OHA.

Demographic factors, duration of (diabetes) treatment by the GP, medication beliefs, illness beliefs, coping strategies, diabetes knowledge, emotional support, mental health, polypharmacy and the use of complementary and alternative medicine (CAM) did not contribute to the explanatory model. In bivariate analyses some, mostly small, differences were detected that were not confirmed after controlling for a multitude of confounders in this small study sample. The fact that some results of the qualitative study were not confirmed can be due to differences in sampling procedures. A theoretical sampling procedure, meaning that the selection of patients to be interviewed depended on analysis results of previously interviewed patients, was used in our qualitative research while in this quantitative study at random sampling was used. This means that influencing factors detected in the qualitative study may be very important for some patients but, when looked at at a larger scale, only for a

minority of patients. A reason for the lack of a detectable influence of depression can be its high prevalence among Turkish migrants in general and diabetes patients of Turkish descent in particular<sup>51;52</sup>.

A final remark must be made on the use of self-report scales for medication adherence. Although these are easily applicable in study settings and clinical practice their validity can be questionable, as shown in this sample.

### ***Limitations.***

The translation of questionnaires is a first potential source of bias. However, the back translation process involved three professional translators and several bilingual volunteers of Turkish descent. Moreover, the pilot version was thoroughly tested in a small sample with characteristics comparable to the study sample and the necessary adjustments were made. Because of the populations' low educational level Turkish-speaking students, extensively trained by the research team, questioned the respondents. This method assured that respondents understood questions and measurement scales.

Other limitations of this study pertain to the sample. Firstly, the limited sample size prevents us from detecting minor influences of potential predictors while controlling for several confounders. More important is the uncertainty about the samples' representativeness. Using administrative databases to draw a random sample was not possible because of Belgian privacy legislation, because most people of Turkish descent obtained the Belgian nationality (by naturalization or birth) which can lead to potentially serious sampling errors when using administrative databases<sup>53</sup> and because Kurds can not be excluded from our study population based on nationality data. Instead we used a variety of recruitment channels involving tens of recruiters. Although this is a valid strategy and despite the similarity between sample and known population characteristics, we can not be completely sure if the sample accurately represents the population<sup>3;54</sup>. Analysis of the potential sampling bias was not possible because too few recruiters recorded information on patients' background characteristics and reasons for refusal. Possible consequences of these sample limitations are the detection of a limited number of influencing factors and an overestimation of the adherence rate. Overestimation of adherence seems likely since more patients without MPR are treated solely with metformin,

which had a negative impact on adherence, and these patients also reported slightly more barriers to medication adherence.

Medication adherence was based on pharmacy claims, the most objective measure available for this study. Self-report measures proved to be unreliable in this sample. Although pharmacy claims are more reliable they may overestimate the actual medication intake because patients may stock up medication.

In the discussion of the model we referred to possible gender differences. Because traditional gender roles are widely accepted, influencing factors may be different for men and women. Again the small sample size hindered the building of separate explanatory models according to sex.

### ***Conclusion***

This exploratory study found a low adherence rate to OHA among T2DM patients of Turkish descent. Adherence can even be lower during stays in Turkey. Life circumstances, the type of OHA regimen, forgetfulness and trust in the GP as diabetes care provider influenced adherence to OHA. These risk factors should be taken into account by health care providers in order to stimulate adherence and improve glycaemic control in this low-educated ethnic minority.

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***Chapter 7:***  
***General conclusions***  
***and recommendations***

### ***General conclusions***

We first summarize and integrate the main conclusions from our studies; then formulate the strengths and limitations; and conclude with recommendations for practice, policy and future research.

Results from our qualitative interview study (chapter 3) and our cross-sectional study (chapter 6) showed adherence to OHA was influenced by a multitude of barriers and facilitators. In the qualitative study (chapter 3) we showed the impact of factors that are distinctive for T2DM patients of Turkish descent: causal beliefs about stress and the Belgian climate, the adjustment of medication use to food intake or during Ramadan fasting, the widespread use of herbal medicine and the religious framework used to interpret diabetes. Our results also showed a potential gender effect: women seemed to adopt a more passive role towards the drug therapy of T2DM probably because of their low educational level, limited language proficiency and the adoption of culturally shaped traditional gender roles. However, many of the factors identified in the qualitative study are common across different ethnic groups (chapter 1). In our cross-sectional study (chapter 6); in which we used an objective measure of adherence to OHA (the medication possession ratio based on pharmacy databases); employment status, living situation, the type of OHA regimen, forgetfulness and the trust put in the GP as diabetes care provider influenced adherence to OHA. Results of the qualitative study were only partly confirmed, due to the small sample size and, to the fact that the influence of some of the factors identified in the qualitative study may only have an impact on adherence to OHA in a minority of patients. Furthermore, our cross-sectional study showed approximately 40 % of T2DM patients of Turkish descent were nonadherent (MPR<80%) to OHA. Although we used an objective measure for adherence to OHA these figures may still underestimate the true nonadherence rate in this population. The finding from our qualitative

study about nonadherence to OHA during stays in Turkey was confirmed. Approximately one out of four patients who had stayed in Turkey reported nonadherence to OHA. This might be explained by patients' perspectives of the influence of stress on diabetes.

To further investigate whether Ramadan fasting had an impact on adherence to antidiabetics we conducted a cross-sectional study on participation at Ramadan fasting, the use of OHA and/or insulin during Ramadan fasting and advice received from health care providers on Ramadan and diabetes (chapter 4). Because T1DM patients in Muslim countries also participate at Ramadan fasting we included this group in our sample<sup>1</sup>. Results showed the impact of Ramadan fasting on adherence to OHA and/or insulin seems to be of minor importance. Furthermore, the provision of information on Ramadan fasting and diabetes by health care workers was limited and should be improved. These results, however, are based on a small convenience sample and thus need to be validated in future studies using larger, at random samples.

Looking at perspectives of GPs and PHs, we found both professional groups have a rather accurate picture of factors influencing adherence to OHA among T2DM patients of Turkish descent (chapter 5). However, some of the influences described in our interview study were not recognized by most GPs and PHs. Moreover, GPs and PHs mentioned a multitude of barriers in promoting adherence to OHA. At the level of the patient socio-economic and cultural characteristics of this patient population were deemed to be important. At the level of diabetes care provision the lack of time, the fear to damage the patient-provider relationship and the lack of a close cooperation between GPs and PHs were mentioned as important barriers. GPs and PHs suggested several practical solutions to overcome these barriers and expressed the wish for a closer mutual cooperation.

In conclusion, nonadherence rates to OHA among T2DM patients of Turkish descent were high but most of the influencing factors were also found in other ethnic groups. Factors that are distinctive can have a clinically important impact on adherence to OHA in specific contexts. When further investigated, the impact of Ramadan fasting on medication adherence remains unclear due to sample size limitations in our study. GPs and PHs recognized most influencing factors but experienced a multitude of barriers in promoting adherence to OHA.

### **Strengths and limitations**

In this dissertation we presented the first studies investigating adherence to antidiabetics in DM patients of Turkish descent and perspectives of GPs and PHs on promoting medication adherence in this hitherto neglected population.

Our flexible research design and the use of both qualitative and quantitative methods proved to be a strength. Results from our systematic literature review (chapter 1) laid the foundation for our qualitative study with T2DM patients of Turkish descent (chapter 3). Insights from this in-depth interview study led to the quantitative study on diabetes and Ramadan fasting (chapter 4), informed our qualitative study on health care providers' perspectives (chapter 5) and formed the basis for our quantitative study on adherence to OHA (chapter 6).

Using qualitative methods allowed us to explore in detail patients' and health care providers' perspectives. The use of a theoretical sampling procedure in the in-depth interview study with T2DM patients of Turkish descent led to a well-informed inclusion of respondents covering a wide range of perspectives on diabetes, medicines and diabetes care. The use of

focus groups proved useful to stimulate an open discussion between health care providers. The purposive sampling procedure, maximizing diversity with respect to relevant background characteristics, assured the selection of health care providers experienced in treating this population while at the same time eliciting a broad range of perspectives.

The process of qualitative research was steered by three important quality criteria <sup>2</sup>. *Reflexivity* (meaning researchers are aware of their own preconceptions and the ways in which these can steer the different phases of qualitative research) was guaranteed by involving researchers and health care workers with different professional and ethnic backgrounds in designing the study, collecting and analyzing the data and interpreting the results. Open discussions and the writing of memos were important tools to reflect on this potential bias. *Validity* refers to the fact that the findings accurately describe the reality under study, in this case the perspectives of patients and health care providers. Again, in the phases of analyzing the data and interpreting the results, involving people with different backgrounds, using the method of constant comparisons, assessing intra-rater and inter-rater consistency, team discussions and memo writing were important tools to assure the validity of our results. Generalizability is not an aim in qualitative research. However, the reader should be able to judge to what extent results may be applicable in another context, often referred to with the term *transferability*. In order to guarantee this, we have tried to provide readers with a sufficiently detailed description of the methods used, the populations under study and the relevant characteristics of the health care system.

The use of quantitative methods allowed us to test the findings from our qualitative study with patients in, what probably was a representative sample. Testing these hypotheses about factors associated with adherence to OHA sheds a light on their relative importance in the total population, controlling for many other factors. However, from a clinical point of

view, it is important to note that factors which may be of little importance in most patients can have a major impact on adherence among a minority of patients. Results from the quantitative and qualitative studies both provide important insights and, when taken together, give a comprehensive and detailed picture of the factors influencing adherence to OHA.

The most important limitations of the two quantitative studies and the focus group study pertain to the samples that were obtained. In both quantitative studies the sample size was small. Moreover, we can not be sure about the representativeness of both samples because we are not able to judge whether we obtained a random sample of the population. Because it's difficult and time consuming to obtain a representative sample of T2DM patients of Turkish descent by linking administrative data bases while at the same time guaranteeing patients' privacy, we have tried to ensure the representativeness of our samples by using different recruitment methods. We asked recruiters to register background characteristics of patients who refused to participate and the patients' reasons for refusal. However, because few recruiters registered this information we are not able to judge if we are confronted with a sampling bias in these studies. In our focus group study we selected health care providers working in Ghent and most of the included GPs worked in community health centres. We have tried to provide sufficient detail on the sample and the setting in order to enable the reader to judge whether these results may be applicable in other settings. Within the scope of this dissertation it was also not possible to test the results from our focus group study on a larger scale.

The results from our studies can lay the foundation for the development of interventions to tackle barriers to medication adherence in this population. However, for

interventions to be effective the perspectives of this patient population and of GPs and PHs on the content and the methods of these interventions of can be explored in more detail.

## **General discussion and recommendations**

Nonadherence to antidiabetics can lead to poor glycaemic control, decreased cost-effectiveness, inappropriate intensification of pharmaceutical therapy, increased risks of diabetes related complications and mortality, increased health care utilization and health care costs<sup>3-7</sup>. During the last decades medication nonadherence has been recognized as an important problem, as is shown, for instance, by the publication of a WHO report in 2003<sup>8</sup> or the recent ABC report, financed by the European Union<sup>9</sup>. Scientific and, to a lesser extent, policy attention has risen, as has the number of interventions aimed at improving medication adherence<sup>9</sup>. Another important stakeholder, the pharmaceutical industry, has taken, up till now, few initiatives to tackle the problem of medication nonadherence<sup>9</sup>. Studies on interventions to improve adherence to OHA have shown beneficial impact on adherence rates, glycaemic control and health outcomes<sup>10-23</sup>. However, research on adherence to OHA in ethnic minority groups is limited (chapter 1) as are studies on interventions to improve adherence rates to OHA among patients from ethnic minorities<sup>19:24-28</sup>.

Insights from our studies on adherence to OHA among one of the largest non-EU ethnic minority groups living in Europe can lay the foundation for future interventions. In this discussion section we reflect on the design and implementation of interventions and give recommendations for practice, policy and research. We also broaden our scope from adherence to OHA among T2DM patients of Turkish descent to more general thoughts on guaranteeing health among ethnic minorities living in Belgium. We conclude with short notes on cultural competency in health care and the issue of patients' responsibility.

*Interventions to improve adherence to OHA*

In discussing interventions to improve adherence to OHA among T2DM patients of Turkish descent we will focus on the role of GPs and PHs while considering how policy measures can stimulate, and how research can underpin these interventions. Some of the reflections made are not limited to adherence to OHA in this population.

A first important condition for interventions tackling nonadherence to OHA is the availability of reliable adherence rates. From the focus groups we learned that GPs and PHs are not able to accurately assess their patients' medication adherence. Important information is not or rarely exchanged between both professions: GPs do not have access to pharmacy databases with patients' medication histories and PHs often mentioned the lack of accurate information on dosing regimens. Moreover, some patients obtain their OHA from several pharmacies or visit more than one GP.

Forgetfulness, or unintentional nonadherence, was an important factor in our study population. Although forgetfulness may be common, potential risk factors in this population were being professionally active (especially working in shifts) and living together. Intervention studies using different kinds of reminder systems (electronic monitoring, reminder charts, pill boxes, text messages, reminders by telephone) have shown their beneficial impact on adherence to OHA <sup>20;28;29</sup>. However, in the focus groups with GPs and PHs we identified some important barriers to using reminder systems in this population. The low educational level, high rates of illiteracy and limited knowledge of Dutch in this population ask for reminder systems that preferably use visual aids and are easy to understand. Changes in the medication regimen should be avoided whenever possible because

reminder systems need to be adapted, and patients can become confused which may lead to medication errors and nonadherence. A few PHs considered the use of reminder systems like text message reminders as too commercial.

Several factors may lead to intentional nonadherence to OHA: e.g. beliefs about diabetes and OHA, depression or ramadan fasting. Tackling intentional nonadherence asks for interventions that influence patients' knowledge, beliefs, skills and emotions. Behavioural interventions focussing on patients' skills and self-efficacy, social-psychological interventions focusing on patients' feelings and social support or educational interventions may have a beneficial impact on adherence to OHA <sup>10-19;21-23</sup>. However, these types of interventions require time from health care providers, and lack of time was often mentioned as an important barrier in the focus groups with GPs and PHs. Moreover, language barriers and differences in cultural backgrounds between patients and providers may hinder patient-provider interaction. Health care workers may also hesitate to tackle the influence of religion on adherence to OHA out of fear to damage their relationship with the patient.

### *Implications for practice*

GPs and PHs should be made more aware of the magnitude, the consequences and the known risk factors of nonadherence to OHA. In the (continuing) education of health care providers sufficient attention could be paid to the problem of medication nonadherence. Knowledge of risk factors will enable health care providers to identify patients at risk of being nonadherent in an efficient way. Short, validated screening tools (e.g. the PHQ-4 questionnaire for anxiety and depression <sup>30</sup>) can be used in clinical practice to enable this identification of risk factors. When necessary, e.g. in the case of mental health problems, patients should be referred to other health care providers.

The exchange of information between GPs and PHs, necessary to obtain accurate assessments of a patient's medication adherence, should be promoted. Legislation in Belgium already assures that pharmacies register important data on patients' medication use. The available pharmacy software can be used to calculate objective measurements of medication adherence. This information can be exchanged in an efficient way, e.g. by internet applications in which electronic patient files are stored and updated. Pilot projects for the electronic exchange of information are being implemented at the time of writing (for Flanders see [www.vitalink.be](http://www.vitalink.be)). More generally, GPs and PHs could cooperate more closely in promoting adherence to OHA. Sunaert et al. show that interventions to promote multidisciplinary diabetes care, based on the chronic care model, can succeed in achieving beneficial clinical outcomes<sup>31</sup>. However, their evaluation of Belgian pilot projects also shows that, while cooperation within primary care was strengthened, the quality of care at the patient level could be further improved<sup>31</sup>. PHs played a minor role in these Belgian pilot projects although involving PHs in multidisciplinary care can further strengthen this beneficial impact on clinical outcomes by promoting adherence to OHA<sup>10-19;21-23</sup>. The further involvement of PHs in multidisciplinary diabetes care asks for agreements on each health care provider's role in assuring an effective and safe drug therapy and educating the patient about diabetes and antidiabetics on the one hand, and measures that promote the PH's uptake of this role on the other hand.

Our studies showed that many T2DM patients of Turkish descent have limited knowledge of diabetes and antidiabetics. This lack of knowledge may lead to patients' perspectives on diabetes and antidiabetics that have a negative impact on medication adherence. Health care providers should regularly assess patients' perspectives and educational needs. Starting from an understanding of these perspectives and educational needs health care providers can provide education and try to motivate patients to adhere to their drug therapy. Refraining from providing information, e.g. on potential side-effects of OHA out of fear to arouse concerns,

should be avoided. Adopting a more patient-centred approach can help to support the patient in his self-care activities <sup>32</sup> and may lead to improvements in medication adherence and clinical outcomes <sup>33-38</sup>. However, adopting a concordance based model in which decision power is shared may not always be the most appropriate way of promoting medication adherence <sup>39</sup>. Our qualitative study showed that several patients, especially women, do not question the health care provider's medical expertise and adopt a passive attitude towards their treatment with OHA, a result also found in populations with similar characteristics <sup>32;40</sup>. Household members, apart from being an important source of instrumental and emotional social support, can also hinder a patient's medication adherence, e.g. by spreading incorrect ideas about diabetes and antidiabetics. Therefore, they should also be informed about diabetes and the importance of adherence to the diabetic regimen in general and drug therapy in specific. There is some evidence that involving household members can have a beneficial impact on the patient's health <sup>41</sup>. The fact that many patients rely on household members to bridge the language gap during consultations provides opportunities for this.

Language barriers were mentioned by GPs and PHs as one of the most important barriers to promoting medication adherence. Health care providers often have to rely on informal interpreters, often household members, during consultations. This can be an advantage because informal interpreters are often familiar with the patient's perspectives and life circumstances and take on the role of care provider in daily life <sup>42;43</sup>. However, compared to sufficiently trained professional interpreters, the use of informal interpreters leads to more translation errors that may have clinical importance <sup>44-46</sup>, while ensuring language concordance during physician-patient consultations is associated with better clinical outcomes among diabetes patients <sup>47;48</sup>. When necessary and possible, professional interpreters (e.g. by telephone) should be used during consultations but their availability in Belgian primary care

is limited<sup>49</sup>. Furthermore, educational materials in Turkish should be made readily available in general practices and pharmacies with large proportions of patients of Turkish descent.

Cultural and religious differences can also be a barrier to promoting medication adherence. Although the influence of cultural and religious factors on adherence to OHA might be limited or circumstantial, the impact on other aspects of the diabetic regimen or on patient-provider communication may be important. Involving members of the Turkish community, preferably people with some medical background, in consultations or educational activities may help to bridge cultural barriers. Cooperation between health care workers and mosques may help to tackle the influence of Ramadan fasting on adherence to OHA and other aspects of the diabetic regimen.

#### *Implications for health care policy*

Up till now there has been limited policy attention in Belgium for the association between health and ethnicity<sup>50;51</sup>, despite the fact that the multi-ethnic society with aging ethnic minorities has become a reality. In 2011 the 'ETHEALTH' expert group, consisting of scientists and health care workers, presented its recommendations on how to reduce ethnic inequalities in health in a report commissioned by the Belgian Ministry of Public Health<sup>50</sup>. This report can be considered as the first policy blueprint to tackle ethnic inequalities in health in Belgium. Whether these recommendations, that can be considered as specific and realistic within the Belgian health care context, will be translated into practice depends, at least partly, on the commitment of policymakers. The political background of responsibility for health care policy shared across different policy levels (federal and regional) and the sensitivity of migration issues will influence future policy developments.

One of the most important recommendations in order to reduce ethnic inequalities is the implementation of policy measures that enable health care workers to bridge language and cultural barriers. Existing educational materials in foreign languages should be made readily available. Organisations of health care professionals and patients (e.g. Domus Medica, APB or Vlaamse Diabetes Vereniging) could be stimulated to take up this responsibility. When necessary, primary care workers should be able to rely on the aid of professional interpreters. Policy measures could stimulate the availability and the use of professional interpreters in primary care <sup>44;49;52</sup>. In addition, professional interpreters can play a role in bridging cultural differences between care providers and patients. However, extending the role of interpreters to ‘cultural mediators’ requires a thorough knowledge of both the patient’s cultural background and the health care provider’s medical background that steers the patient-provider interaction. Cultural mediators should be properly trained to take up this role. Training health care workers’ cultural competency may also have a beneficial impact on the care provided to patients from ethnic minorities <sup>52-54</sup>. Furthermore, promoting the choice for health care professions among people from ethnic minorities can help to tackle important health problems in these populations <sup>48</sup>.

In Belgium’s aging society approximately 40% of patients suffer from one or more chronic diseases <sup>55;56</sup>. The lack of mutual cooperation was mentioned by GPs and PHs as an important barrier to providing diabetes care. Policy measures should stimulate the evolution towards a more efficient, chronic care based model of health care characterized by a strong primary care and multidisciplinary cooperation within and across the different levels of health care. A global vision on the care for chronic diseases in Belgium could be further developed in cooperation with representatives of health care workers and patients. First initiatives, e.g. the care pathways for diabetes and chronic kidney failure, will be evaluated and can be extended

to other chronic diseases. Policy measures could also stimulate the implementation of the conditions necessary for closer, mutual cooperation within primary care and across levels of health care: the electronic registration and exchange of patients' data while respecting patients' privacy and the evolution towards a more efficient division of labour by providing support (e.g. for administrative tasks in general practices) and by mutual agreements on each health care provider's role <sup>31</sup>.

Initiatives for the electronic exchange of information between health care providers are being developed, both at the federal level and at the level of the regions <sup>57;58</sup>. These pilot projects will be evaluated and conditions necessary for implementation at a larger scale should be created.

Innovations in health care need to be supported by health care workers <sup>59</sup>. Discussion between representatives of primary care workers about their role and their mutual cooperation should be stimulated. Changes in the patient population (ageing, rising number of chronically ill) and in health care personnel (e.g. ageing population of GPs, potential 'shortage' of GPs) can be seen as opportunities for a more efficient division of the work load. With respect to the cooperation between GPs and PHs the implementation and future development of pharmaceutical care will be of importance. Pharmaceutical care is defined as: "the responsible provision of drug therapy for the purpose of achieving definite outcomes intended to improve a patient's quality of life" <sup>60</sup> and has been implemented in Belgium in 2009 (Royal Decree of January 21th 2009). Providing patient education on medicines and promoting medication adherence are essential aspects of this redefined role of pharmacists. Changes in the remuneration of community pharmacists aim to stimulate the provision of pharmaceutical care. Although pharmaceutical care can have a beneficial impact on medication adherence and clinical outcomes, e.g. in diabetes care <sup>11-17</sup>, the perception that pharmaceutical care represents an expansion into the traditional roles of physicians should be avoided. The future

development of pharmaceutical care within the primary care system should be based on mutual discussions between GPs and PHs on their cooperation. Policy measures should stimulate these discussions with sufficient attention for the creation of a solid support base for the implementation of pharmaceutical care initiatives in a multidisciplinary care context.

An important condition to effectively promote adherence to OHA (or medication adherence in general) and to stimulate cooperation between GPs and PHs is that patients visit the same GP and PH. The chronically ill are already stimulated to visit the same GP (e.g. with the implementation of the global medical file). Measures that motivate patients to visit the same community pharmacy could strengthen the pharmacist-patient relationship and patients' perceptions of pharmacists as care providers (and not mere dispensers of medication). However, the patient's freedom of choice between providers should also be guaranteed as trust in the health care provider has a beneficial impact on health-related behaviour (e.g. adherence to OHA in our study population was influenced by trust in the GP).

Policy measures may also stimulate changes in the (continuing) education of health care workers. GPs and PHs may benefit from additional training in cultural competency, communication skills and motivational techniques. Also, continuing education could pay more attention to the problem of nonadherence.

### *Implications for research*

In order to reduce ethnic inequalities more research is needed on the health of ethnic minorities living in Belgium<sup>50;51;61;62</sup>. Health care costs could be reduced if more knowledge is gathered on the important health problems ethnic minorities are confronted with, and on how effective health related behaviour could be promoted in these populations. In times of

austerity research on ethnicity and health could be focussed on the cost-effective reduction on ethnic inequalities which could help to raise the necessary support among health care workers, the general public and policy makers. However, in order to do so, data on ethnic background of patients, stored in administrative databases, should be made available for linkage with data on health. Clinical and pharmaceutical data collected in general practices and community pharmacies provide an objective and detailed picture of a population's health status. If these data were made readily available and could be linked to data on ethnicity and socio-economic status, well-informed health care interventions and policy measures could be developed to tackle important health problems.

More specific, for research on medication adherence among chronically ill patients from ethnic minorities, recommendations to improve the methodological quality were given in Chapter 1. In our own studies on adherence to OHA among T2DM patients of Turkish descent we have tried to follow these recommendations by providing a clear argumentation for studying this topic in this specific ethnic group, by describing in detail the important background characteristics of this ethnic minority, by using the most objective measure available for assessing medication adherence, by combining qualitative and quantitative research methods and by including potential confounders, e.g. socio-economic characteristics, in the study designs. Although we were not able to conduct comparative studies, including T2DM patients of Belgian descent, we have shown that the effect of ethnicity, defined as 'differences in norms, values, language and religious background', on adherence to OHA probably is limited. Conducting carefully designed studies is important to identify factors that are otherwise masked by ethnicity. Furthermore, studies on health among socio-economically vulnerable patients from ethnic minorities will profit from the involvement of members of the ethnic group under study to facilitate access to the field, to make well-informed decisions on

research designs, to interpret results correctly, to disseminate findings and to develop interventions.

*A note on culturalization*

Our studies pointed out that factors influencing adherence to OHA among T2DM patients of Turkish descent might, in general, not be attributable to patients' culture. This can of course be different in other ethnic minorities<sup>63;64</sup>. In the focus group discussions some health care workers attributed the fatalism observed among some of these patients to their religious background. The beneficial impact religion can have on adherence to OHA, as shown in our qualitative study with patients, was not always recognized by health care workers. This is one example showing health care workers, researchers and policy makers should be aware of the risk of, what could be called, culturalization or 'attributing health related behaviour to factors deemed to be specific for an ethnic group'. This way of interpreting is understandable but can hinder a thorough understanding of health behaviour and a successful implementation of interventions.

Cultural barriers, like traditional gender roles, were reported by GPs and PHs to hinder communication between patient and health care provider. Training health care workers' cultural competency will probably have more beneficial effects when the focus is on skills necessary to communicate with patients from other cultural backgrounds than when 'cultural differences' are stressed, especially when these would be portrayed as static characteristics<sup>65</sup>. Norms, values, ways of thinking and behaving change, among others through contacts with other cultures (the process of acculturation). The effect of Ramadan fasting on adherence to OHA, for instance, might be more important in rural areas in Turkey than among patients

living in Turkish cities or in foreign countries. Stressing cultural differences may raise the risk of culturalizing health behaviour<sup>65;66</sup>.

*And a final note on patient's responsibility*

Uncovering factors influencing health related behaviour can lead to interventions and policy measures that improve health. However, especially in times of austerity, this also raises the risk of blaming the individual patient. Motivating patients to healthy behaviour is of course important, and patients should be made aware of the impact of their behaviour; not only on their own health but, through its effect on health care expenditures, on society as a whole. However, as our studies in this dissertation show, health related behaviour like nonadherence can be influenced by a multitude of factors which, in turn, may be linked to a patient's position in society (as member of an ethnic minority or socio-economically vulnerable group) and the resources (financial, knowledge, language skills, social support, ...) available to a patient. Stressing individual responsibility might thus turn into 'blaming the victim'. Instead, health is a collective good and the provision of health care a collective responsibility. Times of austerity can also be viewed as opportunities to create a more effective and efficient health care for all patients, regardless of their socio-economic position or ethnic background.

*And the future?*

Our studies on adherence to OHA among T2DM patients of Turkish descent living in Belgium are rather exceptional in the sense that the association between ethnicity and health is often neglected in research and health care policy in Belgium. Many of the barriers mentioned by GPs and PHs also pertain to the care for chronically ill and patients from ethnic minorities in general. If equity is an aim of Belgian health care, a research and health care policy should be developed that tackles, in a cost-effective way, the health problems of ethnic minorities.

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***Chapter 8:***  
***Summary***

## Summary

Scientific attention for medication adherence among people with chronic diseases has grown exponentially during the last decades. Despite the fact that the prevalence of DM is higher in non-White ethnic minorities only few studies on adherence to OHA in these populations were published. In chapter 1 (section 2), we presented the results of our systematic literature review on adherence to OHA in non-White ethnic minorities. Demographic, disease-related, treatment-related, socioeconomic and cultural factors were associated with adherence to OHA in the non-White ethnic minorities under study. However, because the included studies suffered from several methodological difficulties we also proposed methodological improvements for future research

The systematic literature review drew our attention to the multitude of factors, some of which may be culturally shaped, influencing adherence to OHA. As such it lay the foundation for our qualitative research study in which we explored perspectives of T2DM-patients of Turkish descent. Furthermore, the, often limited, insights and methodological shortcomings of the included studies strengthened the argumentation for our research design in which a detailed exploration, using qualitative methods, would precede a quantitative assessment of factors influencing OHA.

To explore factors influencing adherence to OHA among T2DM-patients of Turkish descent we first conducted a qualitative study, using in-depth interviews (chapter 3). A theoretical sampling procedure was used, meaning analysis results of earlier conducted interviews led to adjusted or new inclusion criteria for patients to be interviewed in the course of the study. This process stopped when theoretical saturation was reached. This cycle of data collection, data analysis and selection of new cases provided us with a broad overview of

factors potentially influencing adherence to OHA and a detailed exploration of how influencing factors are interconnected. Furthermore, this theoretical sampling procedure guaranteed the validity of our results because preliminary insights were confirmed, nuanced or sometimes contradicted by newly collected cases.

Results from our qualitative study showed adherence to OHA was influenced by a multitude of barriers and facilitators. Next to beliefs about OHA, polypharmacy, beliefs about the course of diabetes, forgetfulness, the perception of the doctor's medical expertise, feelings of depression and social support; factors which are also found in other ethnic groups; some factors distinctive for T2DM patients of Turkish descent emerged. Respondents' causal beliefs about stress and the Belgian climate often led to nonadherence during less stressful periods, like summer holidays in Turkey. Some respondents adjusted their medication use to food intake or during Ramadan fasting. Concerns about OHA led to the use of herbal medicine, which in turn can lead to nonadherence to OHA. The religious framework used to interpret diabetes led, in combination with feelings of depression, to nonadherence but facilitated medication adherence in other patients.

The use of qualitative methods also provided detailed insights into the ways these different factors are interconnected, and thus on how one or more factors can strengthen or counter the effect of another factor on adherence to OHA. The perception of the GP's medical expertise as diabetes care provider appeared to be important: firstly because it was able to counter the negative influence of factors like medication beliefs or illness beliefs on adherence to OHA and, secondly, because it may to be a factor distinguishing adherers from nonadherers. These patterns of interdependent factors may also be different from men and women, especially among first-generation migrants. Women seemed to adopt a more passive role towards the pharmacological treatment of T2DM probably because of their low

educational level, limited language proficiency and the adoption of culturally shaped traditional gender roles.

To further investigate whether Ramadan fasting had an impact on adherence to OHA and/or insulin we conducted a cross-sectional study on participation at Ramadan fasting, the use of OHA and/or insulin during Ramadan fasting and advice received from health care providers on Ramadan and diabetes (chapter 4). About half of the sample had received recommendations from their healthcare provider(s) about Ramadan fasting and diabetes. A low prevalence of Ramadan fasting among Turkish migrants with diabetes living in Belgium was observed. Six out of ten patients who actually fasted received recommendations about the intake of diabetes medication. Self-reported medication adherence during Ramadan, defined as following the (modified) regimen prescribed by the doctor, was very high. This study also showed health care workers could improve the provision of information on Ramadan fasting and diabetes. Furthermore, Ramadan fasting was less common among DM patients of Turkish descent living in Belgium compared to patients in Muslim countries. The impact of Ramadan fasting on adherence to OHA and/or insulin may be of minor importance. However, our results are based on a small convenience sample, and thus need to be validated in future studies using larger, at random samples.

Because GPs and PHs play an important role in promoting adherence to OHA we conducted a qualitative study, using focus groups, to explore their perspectives on factors influencing adherence to OHA among T2DM-patients of Turkish descent, and on barriers to promoting adherence to OHA in this population (chapter 5). Both professional groups identified most obstacles to adherence to OHA found in our qualitative study with T2DM patients of Turkish descent. GPs and PHs mentioned the lack of knowledge about diabetes

and hypoglycaemic medication, medication beliefs, culturally shaped illness beliefs, depression, social support, fatalism (often contributed to religiosity), religious and cultural habits, the health care provider's authority, financial barriers and policies encouraging generic prescribing as obstacles of medication adherence in this population. However, some of the influences described in our interview study were not recognized by most GPs and PHs: the influence of causal beliefs about stress and the Belgian climate, the use of herbal medicine and the positive impact of religiosity on medication adherence.

A multitude of barriers to promoting adherence to OHA, both at the level of the patient and at the level of diabetes care provision, were mentioned. At the level of the patient identified barriers were the low educational level, high rates of illiteracy, language discordance, a lack of continuity of care, cultural habits and religious demands, culturally shaped gender roles, the influence of ideas about diabetes treatment present in the Turkish community and expectations about consultations. At the level of diabetes care provision the barriers were: the lack of time in consultations (which hinders the exploration of patients' perspectives), a reluctance to discuss medication adherence (out of fear to damage the patient-provider relationship or to arouse concerns about OHAs) and the lack of a close cooperation between GPs and PHs.

GPs and PHs suggested several practical solutions to overcome barriers at the patient level: initiatives to overcome language barriers and the use of reminder systems to tackle unintentional nonadherence. Health care providers might also profit from training in cultural competencies and skills to promote behavioural change. At the level of diabetes care provision initiatives to stimulate cooperation between GPs and PHs could be taken, and patients could be stimulated to visit the same GP and PH.

To validate the results from our qualitative study and to provide an estimate of the nonadherence rate to OHA we conducted an exploratory, cross-sectional survey study in a, probably, representative sample of T2DM patients of Turkish descent (chapter 6). We have tried to obtain this representative sample of T2DM patients of Turkish descent living in Belgium using a wide variety of recruitment channels and tens of recruiters. Nonadherence to OHA was measured with the medication possession ratio, based on pharmacy databases. Approximately 40 % of T2DM patients of Turkish descent in this sample were nonadherent (MPR<80%) to OHA, with a mean medication possession ratio of 82%. These figures are comparable to nonadherence rates and mean medication possession ratios found in other ethnic groups. However, nonadherence may be underestimated because we can not be completely sure about the sample's representativeness and because adherence rates based on pharmacy databases do not measure the actual intake of medicines. The finding from our qualitative study that patients reduced or temporarily stopped their intake of OHA during their stays in Turkey was confirmed. Approximately one out of four patients who had stayed in Turkey reported these behaviours. According to the results of our qualitative study, this might be explained by patients' perspectives of the influence of stress on diabetes.

In order to identify factors influencing adherence to OHA we included a large pool of potential covariates based on the results from our qualitative study with patients, our systematic literature review and other literature reviews. Employment status, living situation, the type of OHA regimen, forgetfulness and the trust put in the GP as diabetes care provider influenced adherence to OHA in this sample. Medication beliefs, illness beliefs, social support, mental health, polypharmacy and the use of CAM did not influence adherence to OHA when controlling for a multitude of other covariates. Results of the qualitative study were only partly confirmed due to the small sample size in the cross-sectional survey study

and, to the fact that the influence of some of the factors identified in the qualitative study may only have an important impact on adherence to OHA in a minority of patients.

## **Samenvatting**

De wetenschappelijke aandacht voor medicatietrouw bij mensen met chronische ziektes is exponentieel gegroeid tijdens de laatste decennia. Ondanks het feit dat de prevalentie van DM hoger is bij niet-blanke etnische minderheden zijn er maar weinig studies gepubliceerd over medicatietrouw aan orale antidiabetica (OAD) bij deze populaties. In hoofdstuk 1 (deel 2), presenteerden we de resultaten van onze systematische literatuurstudie over medicatietrouw aan OAD bij niet-blanke etnische minderheden. Demografische, ziektegerelateerde, behandelingsgerelateerde, socio-economische en culturele factoren waren geassocieerd met medicatietrouw aan OAD bij de niet-blanke etnische minderheden die bestudeerd werden. Aangezien de geïncludeerde studies echter leden onder verschillende methodologische problemen stelden we ook methodologische verbeteringen voor toekomstig onderzoek voor.

De systematische literatuurstudie vestigde onze aandacht op een veelheid aan factoren, waarvan sommige cultureel bepaald kunnen zijn, die medicatietrouw aan OAD beïnvloeden. De systematische literatuurstudie legde dus de basis voor onze kwalitatieve studie waarin we de perspectieven van T2DM patiënten van Turkse afkomst onderzochten. Bovendien versterkten de (vaak beperkte) inzichten en methodologische tekortkomingen van de geïncludeerde studies de argumentatie voor onze eigen onderzoeksdesign, waarin een gedetailleerde verkenning, met behulp van kwalitatieve methoden, vooraf zou gaan aan een kwantitatieve bepaling van de factoren die medicatietrouw aan OAD beïnvloeden.

Om in kaart te brengen welke factoren medicatietrouw aan OAD beïnvloeden bij T2DM patiënten van Turkse afkomst voerden we eerst een kwalitatieve studie uit, gebruik makend van diepte-interviews (hoofdstuk 3). We maakten gebruik van een theoretische

steekproeftrekking, wat betekent dat analyseresultaten van eerder uitgevoerde interviews leidden tot aangepaste of nieuwe inclusiecriteria voor de patiënten die geïnterviewd zouden worden in het verdere verloop van de studie. Dit proces werd beëindigd wanneer theoretische saturatie bereikt werd. Door middel van deze cyclus van dataverzameling, data-analyse en selectie van nieuwe cases verkregen we een breed overzicht van de factoren die medicatietrouw aan OAD mogelijk beïnvloeden, en een gedetailleerd beeld van hoe deze factoren onderling verbonden zijn. Bovendien garandeerde deze theoretische steekproeftrekking de validiteit van onze resultaten omdat voorlopige inzichten bevestigd, genuanceerd of soms weerlegd werden door inzichten uit de nieuw geïnccludeerde cases.

De resultaten van onze kwalitatieve studie toonden aan dat medicatietrouw aan OAD beïnvloed werd door een veelheid aan barrières en stimulerende factoren. Naast denkbeelden over OAD, polyfarmacie, denkbeelden over het verloop van diabetes, vergeetachtigheid, de perceptie van de dokter's medische expertise, gevoelens van depressie en sociale steun; factoren die ook teruggevonden werden bij andere etnische groepen; kwamen enkele factoren naar voren die kenmerkend zijn voor T2DM patiënten van Turkse afkomst. Respondenten hun denkbeelden over stress en het Belgisch klimaat als oorzaken van diabetes leidden vaak tot medicatieontrouw tijdens minder stressvolle periodes, zoals zomervakanties in Turkije. Sommige respondenten pasten hun medicatiegebruik aan aan hun voedselinname of tijdens het vasten. Bezorgdheden over OAD leidden tot het gebruik van kruidengeneeskunde, wat op zijn beurt kan leiden tot medicatieontrouw aan OAD. Het religieus kader dat gebruikt werd om diabetes te interpreteren leidde, in combinatie met gevoelens van depressie, tot medicatieontrouw maar stimuleerde de medicatietrouw bij andere patiënten.

Het gebruik van kwalitatieve methoden verschaftte ons ook een gedetailleerd inzicht in de wijze waarop de verschillende factoren onderling verbonden zijn, en dus in hoe één of meer factoren het effect van een andere factor op medicatietrouw aan OAD kunnen versterken

of tegengaan. De perceptie van de dokter's medische expertise bleek belangrijk te zijn: ten eerste, omdat deze de negatieve invloed op medicatietrouw aan OAD tegenging van factoren zoals denkbeelden over de medicatie en denkbeelden over de ziekte en, ten tweede, omdat het een factor zou kunnen zijn die medicatietrouwe patiënten onderscheidt van medicatieontrouwe patiënten. De patronen van onderling verbonden factoren zouden ook verschillend kunnen zijn voor mannen en vrouwen, vooral onder migranten van de eerste generatie. Vrouwen lijken een meer passieve rol ten aanzien van de medicamenteuze behandeling van T2DM aan te nemen, waarschijnlijk omwille van hun laag opleidingsniveau, hun beperkte kennis van het Nederlands en de, cultureel bepaalde, traditionele gender rollen.

Om verder te onderzoeken of het vasten tijdens de ramadan een impact had op medicatietrouw aan OAD en/of insuline voerden we een cross-sectionele studie uit over de deelname aan het vasten tijdens de ramadan, het gebruik van OAD en/of insuline tijdens het vasten en het advies dat verkregen werd van gezondheidszorgwerkers over ramadan en diabetes (hoofdstuk 4). Ongeveer de helft van de respondenten had aanbevelingen gekregen van gezondheidszorgwerkers over diabetes en vasten tijdens de ramadan. Er werd een lage prevalentie van deelname aan het vasten geobserveerd onder Turkse migranten die in België leven. Zes van de tien patiënten die vastten hadden advies gekregen over de inname van hun antidiabetica. De zelfgerapporteerde medicatietrouw, gedefinieerd als het volgen van de door de arts voorgeschreven (aangepaste) behandeling, was zeer hoog. Deze studie toonde ook aan dat het door gezondheidszorgwerkers verstrekken van informatie over diabetes en vasten tijdens de ramadan verbeterd kan worden. Verder was het vasten tijdens de ramadan minder algemeen verspreid onder DM patiënten van Turkse afkomst die in België leven dan onder patiënten in moslimlanden. De impact van het vasten tijdens de ramadan op medicatietrouw aan OAD en/of insuline zou dus van minder groot belang kunnen zijn. Echter, onze resultaten

zijn gebaseerd op een kleine, niet representatieve steekproef en moeten dus getoetst worden in toekomstig onderzoek dat gebruikt maakt van grotere toevalssteekproeven.

Aangezien huisartsen (HA) en apothekers (AP) een belangrijk rol spelen in het stimuleren van medicatietrouw aan OAD voerden we een kwalitatief onderzoek uit, gebruik makend van focusgroepen, om hun visies in kaart te brengen op de factoren die de medicatietrouw aan OAD bij T2DM patiënten van Turkse afkomst beïnvloeden, en op de barrières voor het stimuleren van medicatietrouw aan OAD in deze populatie (hoofdstuk 5). Beide professionele groepen identificeerden de meeste van de obstakels voor medicatietrouw aan OAD die we vonden in onze kwalitatieve studie bij T2DM patiënten van Turkse afkomst. HA en AP vermeldden het gebrek aan kennis over diabetes en hypoglykemiërende medicatie, denkbeelden over medicatie, cultureel bepaalde denkbeelden over ziekte, depressie, sociale steun, fatalisme (wat vaak werd toegeschreven aan religiositeit), religieuze en culturele gewoonten, de autoriteit van de gezondheidszorgverstreker, financiële barrières en beleidsmaatregelen die het voorschrijven van generieken stimuleren als obstakels voor medicatietrouw in deze populatie. Sommige beïnvloedende factoren, beschreven in onze interview studie, werden echter niet onderkend door de meeste HA en AP: de invloed van denkbeelden over stress en het Belgisch klimaat als oorzaken van diabetes, het gebruik van kruidengeneeskunde en de positieve invloed van religiositeit op medicatietrouw.

Er werd een veelheid aan barrières vermeld voor het stimuleren van medicatietrouw aan OAD, zowel op het niveau van de patiënt als op het niveau van het verstrekken van diabeteszorg. De geïdentificeerde barrières op het niveau van de patiënt waren het lage opleidingsniveau, de hoge graad van analfabetisme, een gebrek aan continuïteit in de zorg, culturele gebruiken en religieuze eisen, cultureel bepaalde gender rollen, de invloed van denkbeelden over diabetesbehandeling aanwezig in de Turkse gemeenschap en patiënten hun

verwachtingen over consultaties. De barrières op het niveau van het verstrekken van diabeteszorg waren: het gebrek aan tijd tijdens consultaties (wat het exploreren van de denkbeelden van patiënten belemmert), een terughoudendheid om medicatietrouw te bespreken (uit vrees om de relatie met de patiënt in gevaar te brengen of uit vrees om bezorgdheid over OAD te veroorzaken) en het gebrek aan nauwe samenwerking tussen huisartsen en apothekers.

Huisartsen en apothekers suggereerden verschillende praktische oplossingen om de barrières op het niveau van de patiënt te overwinnen: initiatieven om de taalkloof te overbruggen en het gebruik van systemen om de patiënt te herinneren aan de medicatie-inname in het geval van niet-intentionele medicatieontrouw. Gezondheidszorgverstrekkers zouden ook gebaat kunnen zijn met trainingen in het verwerven van culturele competenties en in vaardigheden voor het aanzetten tot gedragsverandering. Op het niveau van het verstrekken van diabeteszorg zouden initiatieven kunnen genomen worden om de samenwerking tussen HA en AP te stimuleren en zouden patiënten ertoe aangezet kunnen worden om een vaste HA en AP te consulteren.

Om de resultaten van ons kwalitatief onderzoek te valideren en een schatting te kunnen geven van de mate van medicatieontrouw aan OAD voerden we een verkennend, cross-sectioneel onderzoek uit bij een, naar alle waarschijnlijkheid, representatieve steekproef van T2DM patiënten van Turkse afkomst (hoofdstuk 6). We hebben gepoogd om een representatieve steekproef te trekken uit de populatie van T2DM patiënten die leven in België door gebruik te maken van een grote verscheidenheid aan rekruteringskanalen en tientallen rekruteerders. Medicatieontrouw aan OAD werd gemeten aan de hand van de ‘medicatie bezit verhouding’ (MBV), gebaseerd op databases van apotheken. Ongeveer 40% van de T2DM patiënten in deze steekproef waren medicatieontrouw (MBV<80%) aan OAD, met een

gemiddelde MBV van 82%. Deze cijfers zijn vergelijkbaar met degene gevonden in andere etnische groepen. De medicatieontrouw kan echter wel onderschat zijn omdat we niet zeker kunnen zijn van de representativiteit van de steekproef en omdat deze cijfers, gebaseerd op databases van apotheken, niet de eigenlijke medicatie-inname meten. De bevinding uit ons kwalitatief onderzoek dat patiënten hun inname van OAD stopten of tijdelijk verminderden tijdens hun verblijf in Turkije werd bevestigd. Ongeveer één op de vier patiënten die in Turkije verbleven hadden rapporteerden dit gedrag. Volgens de resultaten van ons kwalitatief onderzoek kan dit mogelijk verklaard worden door de denkbeelden van patiënten over de invloed van stress op diabetes.

Om de factoren te identificeren die de medicatietrouw aan OAD beïnvloeden includeerden we een groot aantal mogelijke covarianten, gebaseerd op de resultaten van onze kwalitatieve studie, onze systematische literatuurstudie en andere literatuurstudies. De tewerkstellingsstatus, de leefsituatie, het type van behandeling met OAD, vergeetachtigheid en het vertrouwen dat gesteld werd in de huisarts als verstrekker van diabeteszorg beïnvloedden de medicatietrouw aan OAD in deze steekproef. Denkbeelden over medicatie en ziekte, sociale steun, geestelijke gezondheid, polyfarmacie en het gebruik van complementaire en alternatieve geneeskunde hadden geen invloed op medicatietrouw aan OAD, na controle voor een veelheid aan andere covarianten. De resultaten van het kwalitatief onderzoek werden enkel deels bevestigd, wat te wijten is aan de kleine steekproefgrootte en aan het feit dat de invloed van sommige van de factoren die geïdentificeerd werden in de kwalitatieve studie wellicht enkel een belangrijke impact hebben bij een minderheid van de patiënten.



***Addendum 1:***  
***Tabel orale antidiabetica***

Oral hypoglycaemic agents used in Belgium in 2013.

<b>Class</b>	<b>Compounds</b>	<b>Action(s)</b>	<b>Main advantages</b>	<b>Main disadvantages</b>
<b>Biguanides</b>	metformin	↓ insulin resistance ↓ hepatic glucose production	No weight gain No hypoglycaemia ↓ cardiovascular events and mortality	Gastrointestinal side-effects Vitamin B <sub>12</sub> deficiency Lactic acidosis (rare)
<b>Sulfonylureas</b>	glibenclamide gliclazide glimiperide glipizide gliquidon	↑ insulin secretion	↓ microvascular complications	Hypoglycaemia Weight gain Gastrointestinal side-effects
<b>Meglitinides</b>	repaglinide	↑ insulin secretion	↓ postprandial hyperglycemia	Hypoglycaemia Weight gain Gastrointestinal side-effects Dosing frequency
<b>Glitazones</b>	pioglitazone	↓ insulin resistance	No hypoglycaemia ↑ HDL cholesterol ↓ Triglycerides	Gastrointestinal side-effects Weight gain Heart failure ↑ risk bone fractures Oedema
<b>DPP-4-inhibitors</b>	linagliptin saxagliptin sitagliptin vildagliptin	Inhibits DPP-4 activity, prolongs survival of endogenously released incretin hormones	No weight gain No hypoglycaemia	Gastrointestinal side-effects Infections upper respiratory system Allergic reactions Musculoskeletal pain
<b>α-Glycosidase inhibitors</b>	acarbose	Inhibits intestinal α-Glycosidase	↓ postprandial hyperglycemia	Gastrointestinal side-effects Dosing frequency
<b>Combination products:</b> metformin + glibenclamide; metformine + vildagliptin; metformin + sitagliptin; metformin + linagliptin; metformine + saxagliptin				

This table is based on information from the Vlaamse Diabetes Vereniging, BCFT and ADA.

***Addendum 2:***  
***Topics lijst voor de interviews met diabetes***  
***type-2 patiënten van Turkse afkomst.***

## Topiclijst Turkse diabetici.

### Thema 1: Beleving en historiek van de aandoening.

Ziektegeschiedenis, verwerkingsproces, visie op oorzaken, steun, plaats in dagelijks leven

Ziekte

Hoofdvraag: Toen je te horen kreeg dat je diabetes had, wat was toen je eerste reactie?

Topics:

Ziekte:

- Wanneer werd diabetes type-2 vastgesteld?
- Naar aanleiding waarvan: symptomen? Bij controle van bloed?
- Wanneer en waarom werd stap naar artsbezoek gezet? Zette u zelf die stap? Werd u gestimuleerd door anderen om die stap te zetten? Door wie werd u gestimuleerd?
- Wat was de eerste reactie van de respondent op de diagnose? Wat was de reactie van familie en directe omgeving?
- Kende u ten tijde van de diagnose mensen in uw omgeving die ook diabetes hebben? Ging u bij hen te rade?
- Welke informatie kreeg respondent in aanvangsfase over de oorzaken van de ziekte? Van wie? Hoe werd deze informatie gegeven? Was deze begrijpelijk? Zocht de respondent op eigen initiatief verdere informatie? Welke impact had de ingewonnen informatie op de gedachten en gevoelens van de respondent?
- Wat was ten tijde van de diagnose in de perceptie van de respondent de oorzaak van de aandoening? Wat is momenteel in de perceptie van de respondent de oorzaak van de aandoening? Religieus, genetisch, levensstijl, stress?
- Hoe belangrijk is de aandoening vandaag in het leven van de respondent? Beïnvloedt de aandoening uw leven? Ervaart u de aandoening als een probleem? Waarom / waarom niet? Zijn er andere problemen die voor u zwaarder wegen dan uw aandoening?

Hoofdvraag: Hoe denk je dat je diabetes er over een aantal jaren uit zal zien (ervoor zal staan / evolueert)?

Topics:

Complicaties:

- Is de respondent zich bewust van het risico op complicaties ten gevolge van diabetes? Indien de vraag te abstract is concreter verwoorden: denkt u dat diabetes een risico is (gevaarlijk is) voor uw ogen / voeten / hart / nieren?
- Ziet de respondent diabetes als een chronische of als een acute ziekte?
- Zijn er op dit moment complicaties ten gevolge van diabetes?
- Wanneer werden deze complicaties voor het eerst vastgesteld? Hoe werden ze behandeld? Hoe worden ze momenteel behandeld? (Hier kunnen dus kort al contacten met gezondheidswerkers zoals diëtist, oogarts, ... aan bod komen. Voor ons is vooral van belang of ze bij aanwezigheid van complicaties naar deze gespecialiseerde gezondheidswerkers gaan en of dat in voldoende mate gebeurt. De vragen over de kwaliteit van de relatie, zie thema 3, met de zorgverstrekker dienen enkel gesteld te worden voor de huisarts, de apotheker en indien van toepassing voor de specialist).
- Welke informatie kreeg de respondent over deze complicaties? Van wie? Op welke manier werd hierover gecommuniceerd? Zocht de respondent zelf bijkomende informatie over deze complicaties?
- Hoe worden deze complicaties ervaren door de respondent? Wat zijn de gevoelens van de respondent in verband met aanwezige complicaties? Wat zijn de gevoelens van de respondent in verband met mogelijke complicaties in de toekomst?
- Wat zijn in de perceptie van de respondent de oorzaken van deze complicaties? Zijn ze in de perceptie van de respondent te wijten aan diabetes?
- Huidige comorbiditeit?
- Beleving van andere aandoeningen en invloed op beleving van diabetes?
- Behandeling voor comorbiditeit?
- Heeft deze invloed op behandeling voor diabetes?

**Thema 2: Ervaringen met orale antidiabetica en medicamenteuze behandeling van comorbiditeit**

Hoofdvraag: Kan je je medicatiegebruik tijdens een normale weekdag eens beschrijven? Je staat op en ...

Topics:

- Beschrijving dagritme: insteek voor gesprek over omgaan met medicatie in dagelijks leven; bij de beschrijving door middel van doorvragen ingaan op factoren als stress, taakverdeling in huishouden, ... en invloed op omgaan met medicatie en levensstijlanbevelingen.
- Kan u ons zeggen welke geneesmiddelen u momenteel inneemt (zowel OAD als geneesmiddelen voor andere chronische aandoeningen)? Noteer op het overzicht welke geneesmiddelen de respondent nog neemt.

**Overzicht geneesmiddelen**

Merksnaam geneesmiddel	Indicatie (letterlijke neerslag)	Posologie (aantal innames per dag x aantal eenheden)

- Wordt er soms een dosis van medicatie vergeten? Hoe vaak gebeurt dit? Hoe komt het dat het innemen van medicatie soms vergeten wordt?
- Wordt de medicatie op het voorgeschreven tijdstip ingenomen?
- Verandert de respondent zelf de dosis (verminderen van dosis / vermeerderen van dosis)? Motivatie daarvoor?
- Zijn er periodes waarin gestopt wordt met medicatie? Motivatie?
- Worden voorgeschreven dosis soms overgeslaan? Waarom?
- Herkenning van geneesmiddelen (naam, kleur, grootte)
- Orale antidiabetica altijd voorgeschreven door arts (of nemen op aanraden van familie/vrienden)?
- Vind je dat je meer moet besteden aan je gezondheid sinds je diabetes hebt? (Wordt medicatiegebruik uitgesteld omwille van de kostprijs? Wordt opvolgen van leefstijladvies uitgesteld omwille van de kostprijs? Wordt controle bloedsuikerspiegel uitgesteld omwille van de kostprijs?)

Hoofdvraag: Je neemt nu medicatie voor je diabetes. Hoe voel je je daarbij?

Topics:

- Welk effect heeft het innemen van medicatie op de manier waarop de patiënt zichzelf ziet (bvb. sommige diabetici beschouwen zichzelf pas als 'ziek' vanaf het moment dat ze medicatie nemen)?
- Geloof respondent in de werking van geneesmiddelen bij zichzelf?
- Geloof respondent in de werking van oad bij zichzelf?
- Geloof de respondent dat de door de arts voorgeschreven manier van inname (bvb. 2 per dag voor eten) invloed heeft op het verloop van de ziekte bij hem?
- Geloof de respondent dat door medicatie te nemen complicaties op lange termijn vermeden worden? Vindt de respondent dat medicatie vooral een onmiddellijk effect moet hebben? Of gelooft hij/zij dat zonder dat er een onmiddellijk effect merkbaar is medicatie toch nuttig is op lange termijn?
- Vervangen pillen dieet of lichaamsbeweging?
- Kennis van nadelen van medicatie? Ervaart of ervoer de respondent nadelen van de medicatie? Is dat een reden om te stoppen of om medicatie op een andere manier in te nemen?

- Wordt er over neveneffecten gepraat in de omgeving ?
- Wordt er over neveneffecten gepraat met de huisarts / de apotheker / andere zorgverstrekkers?
- Aan wat schrijft de respondent de neveneffecten van de geneesmiddelen toe?
- Kent de respondent de werking van het geneesmiddel (Wat doet het geneesmiddel juist in het lichaam?)
- Hoe gebruikt respondent oad en andere medicatie tijdens reizen?
- Welke religieuze adviezen/voorschriften gelden er in de ogen van de respondent voor het omgaan met medicatie en leefstijladviezen? Volgt de respondent deze adviezen/voorschriften? Waarom / waarom niet?
- Hoe gebruikt respondent oad en andere medicatie tijdens de Ramadan?

Hoofdvraag: We keren even terug in de tijd. Kan je eens zeggen welke behandeling voor je diabetes werd voorgeschreven na de diagnose? Hoe ervaarde je dit?

Topics:

- Welke behandeling werd na eerste diagnose voorgeschreven? Medicamenteus? Levensstijl? Glucosemonitoring? Door wie?
- Welke informatie kreeg de respondent over de behandeling? Van wie? Op welke manier werd deze informatie gegeven? Zocht de respondent zelf naar informatie over de behandeling?
- Begreep de respondent deze informatie over de behandeling? Werd door de arts of door andere betrokken gezondheidswerkers nagegaan of de verstrekte informatie begrepen werd door de respondent?
- Welke impact had de informatie op gevoelens en gedachten van patiënt over diabetes? Over de behandeling?
- Welke informatie werd gegeven over de opstart van OAD en/of insuline? Op welke manier werd deze gegeven?
- Welk effect had deze informatie en de wijze waarop ze gegeven werd op het beeld dat de respondent ontwikkelde van OAD en/of insuline?
- In hoeverre had de respondent inspraak in de wijze van behandeling?
- Veranderde de behandeling doorheen de tijd? Wat waren de redenen die artsen hiervoor gaven? Hoe ziet de respondent deze redenen? Op welke wijze werd

informatie over het veranderen van de behandeling gecommuniceerd naar de patiënt toe? Had de respondent inspraak in de verandering van de behandeling?

- Wat vond en vind de respondent makkelijk / moeilijk aan de opvolging van de behandeling? Waarom? Voelt de respondent zich in staat om de verschillende adviezen ivm medicatie en zelfzorg op te volgen?
- Gelooft de respondent in het nut van alle behandelingsvoorschriften: medicatie, voeding, beweging, controle bloedsuikerspiegel?
- Hoe belangrijk is de behandeling vandaag in het leven van de respondent? Beïnvloedt de behandeling uw leven? Ervaart u de behandeling als een probleem? Waarom / waarom niet?

Hoofdvraag: Krijg je in het omgaan met je diabetes steun van mensen uit je omgeving?

Topics:

- Wordt medicatiegebruik afgeremd/gestimuleerd door gezin/ directe omgeving/ gemeenschap?
- Gelooft gezin/ directe omgeving/ gemeenschap in nut van medicatie?
- Ziet de respondent geneesmiddelen in België als even/minder/meer efficiënt als medicatie in Turkije?
- Gebruikt respondent natuurlijke geneesmiddelen (kruiden, voedingssupplementen, ...)? Waarom (niet)? Welke worden gebruikt? Wanneer worden ze gebruikt (in welke gevallen)? Worden ze regelmatig of sporadisch gebruikt? Worden die gebruikt als vervanging van medicatie of als aanvulling erop?
- Wat is de invloed van gezin/ directe omgeving/ gemeenschap op de betekenis van medicatie voor de respondent?
- Wordt opvolgen van leefstijladvies op het vlak van voeding en beweging afgeremd/gestimuleerd door gezin/ directe omgeving/ gemeenschap?
- Wat is tijdens de Ramadan de invloed van gezin/ directe omgeving/ gemeenschap op hoe je omgaat met leefstijladvies en medicatiegebruik?
- Als de respondent voor een langere tijd naar Turkije gaat, neemt hij dan een voorraad geneesmiddelen vanuit België mee? Waarom wel/waarom niet?

## Addendum 2

- Gebruikt respondent alternatieve geneeswijzen (homeopathie, fitotherapie, gebedstherapie, andere)? Welke worden gebruikt? Wanneer worden ze gebruikt (in welke gevallen)? Worden die gebruikt als vervanging van medicatie of als aanvulling erop?

### **Thema 3: Relatie met belangrijkste gezondheidswerkers en drempels in de toegankelijkheid van de gezondheidszorg.**

**Onderstaande vragen telkens herhalen voor de huisarts / apotheker / diabetesspecialist / verpleegkundige.**

*Hoofdvraag: wat vind je van je contact met je apotheker (huisarts / specialist/ verpleegkundige)?*

#### Topics communicatie met apotheker:

- Ga je altijd naar dezelfde apotheker?
- Wat betekent de apotheker voor jou?
- Heb je een goed contact met de apotheker ?
- Heb je gehoord van mensen die problemen hebben met apotheker?
- Hoe verloopt communicatie met je apotheker (degene waar het meest een beroep op wordt gedaan)?
- Verloopt de communicatie altijd op een voor jouw begrijpelijke manier? Gaat de apotheker na of de informatie die gegeven wordt begrepen wordt door jou?
- Is er een taalprobleem?
- Verwacht je meer uitleg vanwege de apotheker?
- Ga je zelf naar de apotheek ? Kind ? Familielid?
- Als iemand anders voor jou naar de apotheek gaat, gaat er misschien een beetje informatie verloren. Vormt dit een probleem?

#### Topics: Perceptie van de kennis en vaardigheden van de apotheker

- Krijg je van apotheker nuttige informatie in verband met je ziekte(n) en de geneesmiddelen ervoor?
- Heb je vertrouwen in je apotheker ?
- Heb je na de informatie die je in de apotheek kreeg nog nood aan extra informatie? Waar haal je die dan?

Hoofdvraag: Als je kan kiezen tussen een huisarts (apotheker / specialist/ verpleegkundige) uit de Turkse gemeenschap of een Belgische huisarts (apotheker / specialist/ verpleegkundige) voor wie kies je dan? Waarom?

Topics: Perceptie van het gedrag van apotheker ten overstaan van Turkse patiënten

- Houdt de apotheker rekening met je? Past hij zijn gedrag aan?
- Is de informatie die hij geeft aangepast aan je wensen en noden?
- Houdt de apotheker rekening met je leefsituatie indien hij informatie of advies geeft?
- Houdt de apotheker rekening met je culturele achtergrond indien hij informatie of advies geeft?

Hoofdvraag: Is het al eens gebeurd dat je bepaalde zorgen (bvb. een bezoek aan de huisarts of specialist, het aankopen van medicatie of testmateriaal) moest uitstellen tot later? Hoe kwam dit dan? Hoe probeer je dit dan op te lossen?

Topics: Toegang tot de gezondheidszorg

- Zijn er soms financiële oorzaken die verhinderen dat de respondent optimaal voor zichzelf zorgt?
- Zijn er soms administratieve oorzaken die verhinderen dat de respondent optimaal voor zichzelf zorgt? (bvb. een document niet kunnen invullen omdat het niet begrepen wordt)
- Zijn er soms logistieke oorzaken die verhinderen dat de respondent optimaal voor zichzelf zorgt? (bvb. geen goede vervoersmogelijkheid naar het ziekenhuis voor consult bij specialist)

**Dankwoord.**

***Addendum 3:  
Topics lijst voor de focusgroepen met  
huisartsen en apothekers.***

<b>Thema 1: Percepties van apothekers en huisartsen van de factoren die medicatietrouw beïnvloeden bij Turkse diabetici</b>	
Moderator	Observator
Zorg ervoor dat doorheen de hele focusgroep de focus blijft liggen op antidiabetica. Laat de groep geen ruimte om andere aspecten van de behandeling aan te halen want de tijd is te beperkt hiervoor.	
<p>1. geef een voorbeeld uit uw eigen praktijk van een patiënt waarvan u meent dat deze zijn antidiabetica goed gebruikt. Waarom denkt u dat dit in dit geval goed loopt?</p> <p>2. geef een voorbeeld uit uw eigen praktijk van een patiënt waarvan u meent dat deze zijn antidiabetica slecht gebruikt. Waarom denkt u dat dit in dit geval slecht loopt?</p> <p>Doe een rondvraag in de groep, geef de deelnemers vooraf enkele minuten om na te denken over deze 2 vragen</p> <p>Noteer zelf ook per deelnemer de factoren die deze deelnemer opsomt in je eigen notities. Noteer waarom de deelnemer denkt dat deze factoren een rol spelen</p>	Noteer de factoren die aangehaald worden op p1 van de flip chart
<p>3. bekijk de lijst, zijn er andere factoren die naar jullie mening een rol spelen?</p> <p>Zorg dat iedere deelnemer aan bod komt, por de deelnemers aan om bijkomende factoren te vermelden (indien nodig).</p> <p>Noteer per deelnemer deze bijkomende factoren in je eigen notities. Noteer waarom de deelnemer denkt dat deze factoren een rol spelen</p>	Vul de lijst op p1 van de flip chart aan

<p>4. Ga na waarom de deelnemers denken dat bepaalde factoren een rol spelen. Vraag verduidelijking en aanvulling bij de eerder opgesomde factoren.</p> <p>Gebruik je notities, ga na bij welke factoren verduidelijking nodig is. Vraag dit aan de deelnemer die deze factoren vermeldde, ga na bij de rest van de groep of ze al dan niet akkoord gaan, vraag om verduidelijking waar nodig.</p>	<p>Gebruik 2 verschillende kleuren om de opgesomde factoren te onderlijnen: 1 kleur voor factoren waarover consensus is, 1 voor factoren waarover afwijkende meningen bestaan.</p>
<p>5. Doe een rondvraag: laat iedere deelnemer de 3 belangrijkste factoren uitkiezen,</p> <p>Ga na over welke factoren de deelnemers van mening verschillen, vraag om verduidelijking</p>	<p>Noteer achter elke factor cijfers per deelnemer: 1 = belangrijkste factor, 2 = 2<sup>e</sup> belangrijkste, 3 = 3<sup>e</sup></p>
<p>6. zien jullie een samenhang tussen de factoren in deze lijst? Wat beïnvloedt wat? Zelf vb achter de hand houden.</p> <p>Voor zover dit in de voorgaande discussie al niet aan bod kwam nagaan tussen welke factoren de deelnemers een samenhang zien.</p>	<p>Maak een visuele voorstelling / samenvatting van de voorgaande discussie.</p> <p>‘medicatierouw’ centraal in voorstelling, teken lijnen tussen medicatierouw en de vermelde factoren en tussen de vermelde factoren onderling. Gebruik verschillende kleuren om afwijkende meningen weer te geven.</p>

<p>7. Bekijk het schema, vraag nog een laatste maal om reacties aan de deelnemers.</p>	
<p>8. verwijst naar de interviews, enkele voorlopige resultaten aan hen voorleggen, hun reactie peilen, bedoeling is na te gaan of de deelnemers zich bewust zijn van de denkwijze van Turkse diabetici:</p> <ul style="list-style-type: none"> <li>a. citaat oorzaken diabetes: stress</li> <li>b. citaat wantrouwen OAD</li> <li>c. vraag of ze dit herkennen? Vervolgens peilen naar of ze hierover praten met hun patiënten, waarom (niet)? Kan u advies geven, wanneer wel / wanneer niet? Is het mogelijk om u in te leven in de denkwijze van deze patiënten? Is het mogelijk om een vertrouwensrelatie uit te bouwen met patiënten uit deze groep?</li> </ul>	
<p>9. Vat een laatste maal de discussie samen, vraag om de laatste reacties op de tot hiertoe behandelde vragen. Doe hiervoor een rondvraag.</p>	
<p>PAUZE 10 minuten</p> <p>Moderator en observator geven elkaar kort feedback.</p>	

<b>Thema 2: Visie van huisartsen en apothekers op hun rol in het begeleiden van Turkse diabetici op het vlak van medicatietrouw.</b>	
<p>10. Welke rol zie je voor jezelf in het begeleiden van deze mensen in het gebruik van hun antidiabetica?</p> <p>Zorg dat lijst factoren zichtbaar is voor de hele groep maar ga hier niet opnieuw gedetailleerd op in. Gebruik de lijst als een geheugensteun voor de deelnemers.</p> <p>Doe een rondvraag in de groep, zorg dat iedere deelnemer aan bod komt, beklemtoon dat meningen mogen afwijken.</p> <p>Indien deelnemers geen of een beperkte rol zien voor zichzelf vraag dan naar de redenen van deze stellingname.</p> <p>Vraag om verduidelijking waar nodig.</p>	<p>Laat de lijst met opgesomde factoren opnieuw aan de groep zien</p>
<p>11. Wat maakt het mogelijk om deze rol op te nemen? Wat maakt het moeilijk om deze rol op te nemen? Doen jullie op dit moment al concrete inspanningen specifiek voor deze groep?</p> <p>Stel 3 bovenstaande vragen niet in 1 keer. Zorg dat iedereen aan bod komt.</p>	<p>Lijst de stimulerende en belemmerende factoren op, p3 flip chart. Gebruik 2 verschillende kleuren;</p>
<p>12. Wie heeft er nog een rol? Wie heeft welke rol?</p> <p>Vraag om verduidelijking.</p> <p>Ga na waarom deelnemers eventueel afwijkende meningen hebben op de rol van andere actoren.</p>	<p>Lijst de andere actoren en hun rol. Gebruik verschillende kleuren om afwijkende meningen te visualiseren;</p>
<p>13. Kan een samenwerking met andere gezondheidswerkers een oplossing zijn voor een betere begeleiding van deze groep?</p>	

<p>14. bekijk de lijst met factoren: op welke kan jij als apotheker / huisarts ingrijpen?</p> <p>Vraag verduidelijking: waarom kan op een bepaalde factor wel ingegrepen worden? Waarom op een andere niet?</p>	<p>Zorg ervoor dat de lijst met factoren (p1 flip chart) zichtbaar is</p>
<p>15. vat de voorgaande discussie samen; vraag een laatste maal om reacties van de deelnemers.</p>	

<b>Thema 3: Ramadan en medicatiegebruik</b>	
16. Uit weliswaar schaars onderzoek blijkt dat vele Turkse diabetici willen deelnemen aan de Ramadan. Is dit een indruk die u kan bevestigen vanuit uw praktijkervaring?	
17. Denk aan voorbeelden uit uw eigen praktijkervaring: Wat zijn volgens u de redenen waarom Turkse diabetici al dan niet deelnemen aan de Ramadan?	Lijst de redenen die vermeld worden op.
18. Heeft u zelf voldoende informatie over de Ramadan (periode/religieuze regels over vrijstelling van deelname/bestaande richtlijnen over begeleiding van diabetici die wensen deel te nemen aan de Ramadan)?	
19. Bespreekt u de deelname aan de Ramadan met uw patiënten? Waarom wel? Waarom niet?	Lijst de redenen om deelname aan de ramadan al dan niet te bespreken op; gebruik 2 verschillende kleuren.
20. Neemt u zelf het initiatief om dit te bespreken of laat u het initiatief aan de patiënt? Waarom?	Lijst de redenen op waarom men dit zelf bespreekt / waarom men het initiatief aan de patiënt laat. Gebruik 2 verschillende kleuren.
21. Geeft u concreet advies over het gebruik van antidiabetica tijdens de Ramadan? Waarom (niet)? Waarop baseert u zich om advies te geven?	
22. Denk aan uw eigen praktijkervaring: wat is er volgens u nodig om patiënten die deelnemen aan de Ramadan op een goede manier te kunnen begeleiden?	

Addendum 3

23. Vat de discussie samen, vraag een laatste maal om reacties van de deelnemers.	
Geef kort uitleg over de studie die uitgevoerd wordt over Ramadan en medicatiegebruik. Vraag aan de deelnemers of ze bereid zijn om in hun praktijk Turkse diabetici te rekruteren.	
Dankwoord. Geef de deelnemers geschenkbonnen als dank voor hun deelname.	

***Addendum 4:***  
***Vragenlijst Ramadan en diabetes.***

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**DEEL 1 :**

**RAMADAN & DIABETES**

---

Datum: ...../...../.....

Patiëntcode: .....

**A. ALGEMEEN**

1. Geslacht :  
 man  vrouw
  
2. Leeftijd : ..... jaar
  
3. Geboorteland : .....
  
4. Hoelang woont u al in België? ..... jaar
  
5. Gewicht: ..... kg
  
6. Lengte: ..... cm
  
7. Wat is uw hoogst afgemaakte opleiding? Kruis aan wat voor u van toepassing is.  
 Geen opleiding afgemaakt  
 Lagere school  
 Middelbaar tot en met het 3<sup>e</sup> jaar  
 Middelbaar tot en met het 6<sup>e</sup> jaar  
 Hogeschool  
 Universiteit  
 Andere: .....
  
8. Wat is uw huidige beroepssituatie? Kruis aan wat voor u van toepassing is.  
 Student(e)  
 Werkzoekende (stempelen)  
 Huisman/huisvrouw  
 Arbeider/arbeidster  
 Bediende  
 Zelfstandige  
 Vrij beroep (arts, advocaat, ...)  
 Gepensioneerd  
 Invalide

9. Welke personen wonen bij u in? **(meerdere antwoorden mogelijk)**

- Niemand
- Partner
- Kind(eren)
- (Schoon)ouder(s)
- Schoondochter
- (Schoon)broer(s)/(schoon)zus(sen)
- Kleinkinderen
- Grootouder(s)
- Andere: .....

10. Wat is uw burgerlijke staat?

- Ongehuwd
- Samenwonend
- Gehuwd
- Gescheiden
- Weduwnaar/weduwe

11. Wat is uw kennis van het Nederlands? Duid aan met een kruisje wat voor u van toepassing is:

	Geen kennis	Zeer slecht	Slecht	Goed	Zeer goed
Begrijpen wat mijn arts, diabetesspecialist of apotheker in het Nederlands tegen mij zegt	<input type="checkbox"/>				
Spreken met mijn arts, diabetesspecialist of apotheker in het Nederlands	<input type="checkbox"/>				
Informatie over mijn gezondheid of mijn ziekte lezen in het Nederlands	<input type="checkbox"/>				

12. Welke personen uit uw omgeving hebben ook diabetes?

- Geen
- Partner
- Vader en/of moeder
- Broer(s) en/of zus(sen)
- Kinderen
- Vrienden
- Buren
- Kennissen uit de moskee
- Anderen: .....

13. Heeft u, naast diabetes, nog andere ziekten?

Neen

Ja, dewelke? **(meerdere antwoorden mogelijk)**

- Hoge bloeddruk
- Te hoge cholesterol
- Ernstige hart- en vaatziekten (hartinfarct, aderverkalking, ...)
- Longziekte
- Dof gevoel en/of tintelingen in de ledematen
- Nierproblemen
- Oogproblemen (slecht zien, blindheid, ...)
- Slecht genezende wonden aan de voeten
- Depressie
- Andere: .....

14. Voor **elk geneesmiddel** dat u **dagelijks** inneemt: vul de naam, de dosis in milligram (mg) en het aantal dat u dagelijks inneemt in. Kruis het tijdstip aan waarop u dat geneesmiddel meestal inneemt en noteer voor welke aandoening u dat geneesmiddel gebruikt.

Merknaam geneesmiddel	Ik gebruik dit geneesmiddel voor mijn:	Dosis in mg	Aantal per dag	Ochtend	Middag	Avond	Voor maaltijd	Tijdens maaltijd	Na maaltijd
<b>Voorbeeld: Omeprazole</b>	<b>Maagzuur</b>	<b>10</b>	<b>1</b>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
.....	.....	.....	.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
.....	.....	.....	.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
.....	.....	.....	.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
.....	.....	.....	.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
.....	.....	.....	.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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.....	.....	.....	.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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.....	.....	.....	.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
.....	.....	.....	.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**B. ZIEKTEPERCEPTIE**

Hieronder staan een aantal vragen over de ziekte diabetes. Omcirkel bij elke vraag het getal dat **uw mening** het beste weergeeft. Er zijn geen goede of foute antwoorden, het gaat om **uw eigen mening**.

Voorbeeld:  
U vindt dat u over het algemeen vrij bezorgd bent over uw diabetes → U duidt daarom, hieronder het nummer 7 aan  
Hoe bezorgd bent u over uw diabetes?

0    1    2    3    4    5    6    7    8    9    10

Helemaal niet bezorgd Ze  
er bezorgd

15. In welke mate beïnvloedt uw diabetes uw leven?
0    1    2    3    4    5    6    7    8    9    10
Helemaal niet <span style="float: right;">Ze er veel</span>
16. Hoelang denkt u dat uw diabetes zal duren?
0    1    2    3    4    5    6    7    8    9    10
Een zeer korte tijd <span style="float: right;">Mijn hele leven</span>
17. Hoeveel controle vindt u dat u heeft over uw diabetes? (Er wordt bedoeld: In welke mate voelt u zich baas over uw diabetes?)
0    1    2    3    4    5    6    7    8    9    10
Helemaal geen controle <span style="float: right;">Ze er veel controle</span>
18. In welke mate denkt u dat uw behandeling kan helpen bij uw diabetes?
0    1    2    3    4    5    6    7    8    9    10
Helemaal niet <span style="float: right;">Ze er veel</span>
19. In welke mate ervaart u klachten door uw diabetes?
0    1    2    3    4    5    6    7    8    9    10
Helemaal geen klachten <span style="float: right;">Veel ernstige klachten</span>

20. Hoe bezorgd bent u over uw diabetes?										
0	1	2	3	4	5	6	7	8	9	10
Helemaal niet bezorgd									Zeer bezorgd	
21. In welke mate vindt u dat u uw diabetes begrijpt?										
0	1	2	3	4	5	6	7	8	9	10
Helemaal geen begrip									Zeer veel begrip	
22. In welke mate beïnvloedt uw diabetes uw stemming? (Bijvoorbeeld: maakt uw diabetes u boos, bang, van streek of somber?)										
0	1	2	3	4	5	6	7	8	9	10
Helemaal niet									Zeer veel	
23. Noem de 3 belangrijkste factoren die naar uw opvatting uw diabetes hebben veroorzaakt, in volgorde van belangrijkheid.					De belangrijkste oorzaken voor mij zijn:					
					1. ....					
					2. ....					
					3. ....					

**C. DIABETES & DIABETESMEDICATIE**

24. Welk type diabetes heeft u?

- Type I
- Type II
- Ik weet het niet

25. Hoeveel jaar weet u al dat u diabetes heeft? ..... jaar

26. Welke diabetesbehandeling volgt u? Duid aan met een kruisje wat voor u van toepassing is:

	Ja	Neen
<b>Dieet</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Diabetespillen</b>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Insuline</b>	<input type="checkbox"/>	<input type="checkbox"/>

27. Hoelang neemt u al diabetespillen in?

..... jaar ..... maanden

Ik neem geen diabetespillen in

28. Hoelang gebruikt u al insuline?

..... jaar ..... maanden

Ik gebruik geen insuline

29. Gebruikt u, op dit moment, naast diabetespillen en/of insuline nog andere methoden om uw diabetes te behandelen? (Bvb. kruiden, honing, ...)

Ja → dewelke? .....

Neen

30. Meet u uw bloedsuikerwaarde zelf?

Ja

Neen

31. Past u dan zelf, op basis van het resultaat van uw bloedsuikermeting, uw diabetesmedicatie aan?

Ja

Neen

Ik meet mijn bloedsuikerwaarde niet zelf

**Indien u geen diabetespillen gebruikt:  
ga naar vraag 35 op blz. 9**

## DIABETESPILLEN

32. Soms doen er zich situaties voor waardoor u uw voorgeschreven **diabetespillen** niet kan innemen. Duid aan met een kruisje op welke dag(en), van de afgelopen 7 dagen, zich zo'n situatie voordeed.

Maandag	Dinsdag	Woensdag	Donderdag	Vrijdag	Zaterdag	Zondag

33. Waarom kon u, de afgelopen 7 dagen, niet altijd uw voorgeschreven **diabetespillen** innemen? (**meerdere antwoorden mogelijk**)

- Ik nam mijn diabetespillen altijd in
- Ik vergat mijn diabetespillen in te nemen
- Ik ondervond teveel bijwerkingen van mijn diabetespillen
- Ik denk dat mijn diabetespillen verslavend werken
- Ik denk dat mijn diabetespillen hun effect verliezen als ik ze lange tijd gebruik
- Ik voelde mij goed zonder mijn diabetespillen in te nemen
- Ik verkoos een andere behandelingsmethode (bvb. kruiden, honing, ...) in plaats van mijn diabetespillen
- Ik had geen diabetespillen in huis
- Andere reden: .....

34. Met wie praat u over de reden(en) waarom u uw voorgeschreven **diabetespillen** niet altijd inneemt? (**meerdere antwoorden mogelijk**)

- Ik neem mijn diabetespillen altijd in
- Ik praat er niet over
- Gezinsleden
- Familie
- Vrienden
- Huisarts
- Diabetesspecialist
- Apotheker
- Verpleger/verpleegster
- Andere personen: .....

**Indien u geen insuline gebruikt:  
ga naar vraag 39 op blz. 10**

**INSULINE**

35. Voor elke soort **insuline** dat u gebruikt: vul de naam en het aantal keren dat u deze per dag gebruikt in en kruis ook het tijdstip aan waarop u deze meestal gebruikt:

Merksnaam insuline	Aantal injecties per dag	Ochtend	Middag	Avond	Voor het slapen gaan
.....	.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
.....	.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
.....	.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

36. Soms doen er zich situaties voor waardoor u uw voorgeschreven **insuline** niet kan gebruiken. Duid aan met een kruisje op welke dag(en), van de afgelopen 7 dagen, zich zo'n situatie voordeed.

Maandag	Dinsdag	Woensdag	Donderdag	Vrijdag	Zaterdag	Zondag
<input type="checkbox"/>						

37. Waarom kon u, de afgelopen 7 dagen, niet altijd uw voorgeschreven **insuline** gebruiken? **(meerdere antwoorden mogelijk)**

- Ik gebruikte mijn insuline altijd
- Ik vergat mijn insuline te gebruiken
- Ik ondervond teveel bijwerkingen van mijn insuline
- Ik denk dat mijn insuline verslavend werkt
- Ik denk dat mijn insuline haar effect verliest als ik ze lange tijd gebruik
- Ik voelde mij goed zonder mijn insuline te gebruiken
- Ik verkoos een andere behandelingsmethode (bvb. kruiden, honing, ...) in plaats van mijn insuline
- Ik had geen insuline in huis
- Andere reden: .....

38. Met wie praat u over de reden(en) waarom u uw voorgeschreven insuline niet altijd gebruikt? **(meerdere antwoorden mogelijk)**

- |   |   |
|---|---|
| <ul style="list-style-type: none"> <li><input type="checkbox"/> Ik gebruik mijn insuline altijd</li> <li><input type="checkbox"/> Ik praat er niet over</li> <li><input type="checkbox"/> Niemand</li> <li><input type="checkbox"/> Gezinsleden</li> <li><input type="checkbox"/> Familie</li> <li><input type="checkbox"/> Vrienden</li> </ul> | <ul style="list-style-type: none"> <li><input type="checkbox"/> Huisarts</li> <li><input type="checkbox"/> Diabetesspecialist</li> <li><input type="checkbox"/> Apotheker</li> <li><input type="checkbox"/> Verpleger/verpleegster</li> <li><input type="checkbox"/> Andere personen: .....</li> <li>.....</li> </ul> |
|---|---|

39. Hieronder staan een aantal uitspraken, die ooit door andere mensen gedaan zijn over hun **diabetesmedicatie**. Wilt u aangeven in hoeverre u het eens of oneens bent met deze uitspraken. Zet een kruisje in het vakje dat het beste **uw mening** weergeeft. Er zijn geen goede of foute antwoorden, het gaat om **uw eigen mening** over de invloed en de rol van uw diabetesmedicatie in uw leven.

		Helemaal akkoord	Akkoord	Neutraal	Niet akkoord	Helemaal niet akkoord
1	Op dit moment hangt mijn gezondheid af van mijn diabetesmedicatie	<input type="checkbox"/>				
2	Ik maak me zorgen over het feit dat ik diabetesmedicatie moet innemen	<input type="checkbox"/>				
3	Mijn leven zou onmogelijk zijn zonder mijn diabetesmedicatie	<input type="checkbox"/>				
4	Zonder mijn diabetesmedicatie zou ik heel ziek zijn	<input type="checkbox"/>				
5	Soms maak ik me zorgen over de effecten van mijn diabetesmedicatie op lange termijn	<input type="checkbox"/>				
6	Ik begrijp niets van mijn diabetesmedicatie	<input type="checkbox"/>				
7	Mijn toekomstige gezondheid hangt af van mijn diabetesmedicatie	<input type="checkbox"/>				
8	Mijn diabetesmedicatie ontwricht mijn leven	<input type="checkbox"/>				
9	Soms ben ik bang dat ik té afhankelijk zal worden van mijn diabetesmedicatie	<input type="checkbox"/>				
10	Mijn diabetesmedicatie voorkomt dat mijn gezondheid slechter wordt	<input type="checkbox"/>				

40. Heeft u deze vragenlijst alleen ingevuld?

Ja

Neen → ik kreeg hulp van: .....

**BEDANKT VOOR UW MEDEWERKING**

**NA DE RAMADAN ONTVANGT U DEEL 2 VAN DE VRAGENLIJST**

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## VRAGENLIJST

### DEEL 2 :

## RAMADAN & DIABETES

---

Datum: ...../...../.....

Patiëntcode: .....

**Veel mensen met diabetes willen graag deelnemen aan de Ramadan. Uw antwoorden zullen helpen om, in de toekomst, mensen beter te begeleiden voor, tijdens en na de Ramadan.**

### A. DIABETES TIJDENS DE RAMADAN

1. Hoe belangrijk is het voor u om te kunnen deelnemen aan de Ramadan? Kruis aan wat voor u van toepassing is.
  - Helemaal niet belangrijk
  - Niet belangrijk
  - Neutraal
  - Belangrijk
  - Erg belangrijk
  
2. Weet u dat bepaalde personen, zoals diabetespatiënten, volgens de Koran niet hoeven deel te nemen aan de Ramadan? Kruis aan wat voor u van toepassing is.
  - Ja
  - Neen
  
3. Bent u bereid een **extra persoonlijke inspanning** (bvb. uw dieet goed volgen, meer bewegen, vermageren, uw medicatie correct innemen, ...) te doen, zodat u de volgende keer **gemakkelijk kunt deelnemen** aan de Ramadan?
  - Ja
  - Neen
  
4. Nam u deel aan de voorbije Ramadan?
  - Ja, elke dag (→ **ga naar vraag 7**)
  - Ja, gedeeltelijk: ..... dagen (→ **ga naar vraag 5**)
  - Neen, geen enkele dag (→ **ga naar vraag 5**)

5. Waarom kon u (soms) niet deelnemen aan de voorbije Ramadan? (**meerdere antwoorden mogelijk**)

- (1) Omdat ik diabetes heb
- (2) Omdat ik mij lichamelijk te slecht voelde als ik deelnam
- (3) Omdat ik meerdere chronische ziekten heb
- (4) Omdat de Koran mij vrijstelde van deelname
- (5) Omdat het mij werd afgeraden door: (**meerdere antwoorden mogelijk**)
- |                                   |  |
|-----------------------------------|--|
| <input type="radio"/> Gezinsleden | <input type="radio"/> Diabetesspecialist |
| <input type="radio"/> Familie     | <input type="radio"/> Verple(e)g(st)er   |
| <input type="radio"/> Vrienden    | <input type="radio"/> Apotheker          |
| <input type="radio"/> Imam        | <input type="radio"/> Andere: .....      |
| <input type="radio"/> Huisarts    |  |
- (6) Andere reden: .....

6. Wat is voor u, van bovenstaande redenen, **dé belangrijkste reden** waarom u (soms) niet kon deelnemen aan de Ramadan? Vul het passende nummer uit vraag 5, dat bij deze reden hoort, in: (.....)

**Indien u geen enkele dag kon vasten:**

**ga naar deel C op blz. 7**

7. Waarom nam u wel deel aan de voorbije Ramadan? (**meerdere antwoorden mogelijk**)

- (1) Omdat ik het sociaal contact belangrijk vind
- (2) Omdat ik de familiebanden wil aanhalen
- (3) Omdat ik de versterking van het geloof belangrijk vind
- (4) Omdat ik verplicht ben deel te nemen van mijn geloof
- (5) Omdat ik mij lichamelijk en emotioneel in staat voel om deel te nemen
- (6) Andere reden: .....

8. Wat is voor u, van bovenstaande redenen, **dé belangrijkste reden** om wel deel te nemen aan de Ramadan? Vul het passende nummer uit vraag 7, dat bij deze reden hoort, in: (.....)

9. Waarom kon u slechts **gedeeltelijk** aan de voorbije Ramadan **deelnemen**?

- Omdat ik moest werken
- Omdat de Koran mij tijdelijk vrijstelde van deelname
- Omdat ik mij lichamelijk te slecht voelde om deel te nemen
- Omdat één of meerdere van mijn gezinsleden stopten met vasten
- Ik nam elke dag deel aan de Ramadan
- Andere reden: .....

10. Denkt u dat vasten een **invloed** heeft gehad op uw **diabetes**?

- Ja, een positieve invloed
- Ja, een negatieve invloed
- Neen
- Ik weet het niet

**B. HET GEBRUIK VAN DIABETESMEDICATIE TIJDENS DE RAMADAN**

**DIABETESPILEN**

11. Wat deed u meestal met de inname van uw **diabetespillen** tijdens de voorbije Ramadan (op de dagen dat u deelnam aan de Ramadan)?

- Ik paste de inname van mijn diabetespillen aan (→ **ga naar vraag 12**)
- Ik stopte met het innemen van mijn diabetespillen (→ **ga naar vraag 15**)

12. Hoe nam u meestal uw **diabetespillen** in tijdens de voorbije Ramadanperiode?

Ik nam alle diabetespillen meestal na iftar en voor sahur in:

- Ja
- Neen

Het **aantal** diabetespillen dat ik **per dag** innam was meestal:

- Minder dan buiten de Ramadanperiode
- Evenveel als buiten de Ramadanperiode
- Meer dan buiten de Ramadanperiode

Het **aantal keer per dag** dat ik mijn diabetespillen innam was meestal:

- Minder dan buiten de Ramadanperiode
- Evenveel als buiten de Ramadanperiode
- Meer dan buiten de Ramadanperiode

13. Van wie kreeg u advies over de aanpassing(en) van uw **diabetespillen**? (**meerdere antwoorden mogelijk**)

- |                                      |   |
|--------------------------------------|---|
| <input type="checkbox"/> Niemand     | <input type="checkbox"/> Diabetesspecialist                   |
| <input type="checkbox"/> Gezinsleden | <input type="checkbox"/> Apotheker                            |
| <input type="checkbox"/> Familie     | <input type="checkbox"/> Verple(e)g(st)er                     |
| <input type="checkbox"/> Vrienden    | <input type="checkbox"/> Media: tv, radio, krant, tijdschrift |
| <input type="checkbox"/> Huisarts    | <input type="checkbox"/> Andere: .....                        |

14. Wanneer nam u de **middagdosis** van uw **diabetespillen** in, tijdens de voorbije Ramadan?

- Ik neem geen middagdosis in (buiten de Ramadanperiode)
- Ik nam ze niet in
- Ik nam ze in bij iftar
- Ik nam ze 's nachts in, bij de maaltijd
- Ik nam ze in bij sahur

15. Hoeveel dagen tijdens de voorbije Ramadan nam u **geen enkele diabetespil** in? ..... dagen

16. Waarom nam u uw **diabetespillen** niet altijd in, tijdens de voorbije Ramadan?

**(meerdere antwoorden mogelijk)**

- Ik nam mijn diabetespillen altijd in
- Ik vergat mijn diabetespillen in te nemen
- Ik had geen diabetespillen bij mij, op het moment dat ik ze moest innemen
- Ik ondervond teveel bijwerkingen van mijn diabetespillen tijdens de Ramadan
- Ik voelde mij goed zonder mijn diabetespillen in te nemen
- Ik verkoos een andere behandelingsmethode (bvb. kruiden, honing, ...) in plaats van mijn diabetespillen
- Ik had geen diabetespillen in huis
- Andere reden: .....

17. Hoe moeilijk was het voor u om de **vasten** te combineren met het gebruik van uw **diabetespillen**?

- Heel gemakkelijk
- Gemakkelijk
- Noch gemakkelijk, noch moeilijk
- Moeilijk
- Heel moeilijk

**Indien u geen insuline gebruikt:  
ga naar deel C op blz. 7**

**INSULINE**

18. Wat deed u meestal met het gebruik van uw **insuline** tijdens de voorbije Ramadan (op de dagen dat u deelnam aan de Ramadan)?

- Ik paste het gebruik van mijn insuline aan (→ ga naar vraag 19)
- Ik stopte met het gebruiken van mijn insuline (→ ga naar vraag 20)

19. Hoe gebruikte u meestal uw **insuline** tijdens de voorbije Ramadanperiode?

Ik gebruikte mijn insuline meestal na iftar en voor sahur:

- Ja
- Neen

De **hoeveelheid** insuline die ik **per dag** gebruikte was meestal:

- Minder dan buiten de Ramadanperiode
- Evenveel als buiten de Ramadanperiode
- Meer dan buiten de Ramadanperiode

Het **aantal keer per dag** dat ik mijn insuline gebruikte was meestal:

- Minder dan buiten de Ramadanperiode
- Evenveel als buiten de Ramadanperiode
- Meer dan buiten de Ramadanperiode

20. Van wie kreeg u advies over de aanpassing(en) van uw **insuline**? (**meerdere antwoorden mogelijk**)

- |                                      |   |
|--------------------------------------|---|
| <input type="checkbox"/> Niemand     | <input type="checkbox"/> Diabetesspecialist                   |
| <input type="checkbox"/> Gezinsleden | <input type="checkbox"/> Apotheker                            |
| <input type="checkbox"/> Familie     | <input type="checkbox"/> Verple(e)g(st)er                     |
| <input type="checkbox"/> Vrienden    | <input type="checkbox"/> Media: tv, radio, krant, tijdschrift |
| <input type="checkbox"/> Huisarts    | <input type="checkbox"/> Andere: .....                        |

21. Hoeveel dagen tijdens de voorbije Ramadan gebruikte u **geen insuline**? ..... dagen

22. Waarom gebruikte u uw **insuline niet** altijd, tijdens de voorbije Ramadan? (**meerdere antwoorden mogelijk**)

- Ik gebruikte mijn insuline altijd
- Ik vergat mijn insuline te gebruiken
- Ik had geen insuline bij mij, op het moment dat ik ze moest gebruiken
- Ik ondervond teveel bijwerkingen van mijn insuline tijdens de Ramadan
- Ik voelde mij goed zonder mijn insuline te gebruiken
- Ik verkoos een andere behandelingsmethode (bvb. kruiden, honing, ...) in plaats van mijn insuline
- Ik had geen insuline in huis
- Andere reden: .....

23. Hoe moeilijk was het voor u om de **vasten** met het gebruik van uw **insuline** te combineren?

- Heel gemakkelijk
- Gemakkelijk
- Noch gemakkelijk, noch moeilijk
- Moeilijk
- Heel moeilijk

**C. ADVIES OVER HET GEBRUIK VAN DIABETESMEDICATIE TIJDENS DE RAMADAN**

De volgende vragen gaan over het advies over het gebruik van uw diabetesmedicatie tijdens de voorbije Ramadan. Er wordt u 3 maal hetzelfde gevraagd: 1 maal voor de huisarts, 1 maal voor de diabetesspecialist en 1 maal voor de apotheker.

**DE HUISARTS**

24. Heeft u een vaste huisarts?	<input type="checkbox"/> Ja	<input type="checkbox"/> Neen
25. Spreekt uw huisarts Turks?	<input type="checkbox"/> Ja	<input type="checkbox"/> Neen
26. Hoeveel keer heeft u zelf, het afgelopen jaar, uw huisarts bezocht?	..... keer	
27. Heeft uw huisarts u <b>spontaan advies gegeven</b> over het gebruik van uw diabetesmedicatie tijdens de Ramadan ?	<input type="checkbox"/> Ja	<input type="checkbox"/> Neen
28. Heeft u <b>zelf</b> aan uw huisarts advies <b>gevraagd</b> over het gebruik van uw diabetesmedicatie tijdens de Ramadan?	<input type="checkbox"/> Ja	<input type="checkbox"/> Neen
29. <u>Welk advies</u> heeft u gekregen?	<input type="checkbox"/> Ik heb geen advies gekregen of gevraagd <input type="checkbox"/> Het advies om niet te vasten <input type="checkbox"/> Het advies om mijn diabetesmedicatie te veranderen	
Kon u het <u>advies</u> van de huisarts <u>volgen</u> ?	<input type="checkbox"/> Ja	<input type="checkbox"/> Neen
	<input type="checkbox"/> Ik heb geen advies gekregen of gevraagd	

**DE DIABETESSPECIALIST**

30. Heeft u een vaste diabetesspecialist?	<input type="checkbox"/> Ja	<input type="checkbox"/> Neen
31. Spreekt uw diabetesspecialist Turks?	<input type="checkbox"/> Ja	<input type="checkbox"/> Neen
32. Hoeveel keer heeft u zelf, het afgelopen jaar, uw diabetesspecialist bezocht?	..... keer	
33. Heeft uw diabetesspecialist u <b>spontaan advies gegeven</b> over het gebruik van uw diabetesmedicatie tijdens de Ramadan ?	<input type="checkbox"/> Ja	<input type="checkbox"/> Neen
34. Heeft u <b>zelf</b> aan uw diabetesspecialist advies <b>gevraagd</b> over het gebruik van uw diabetesmedicatie tijdens de Ramadan?	<input type="checkbox"/> Ja	<input type="checkbox"/> Neen
35. <u>Welk advies</u> heeft u gekregen?	<input type="checkbox"/> Ik heb geen advies gekregen of gevraagd <input type="checkbox"/> Het advies om niet te vasten <input type="checkbox"/> Het advies om mijn diabetesmedicatie te veranderen	
36. Kon u het <u>advies</u> van uw diabetesspecialist <u>volgen</u> ?	<input type="checkbox"/> Ja	<input type="checkbox"/> Neen
	<input type="checkbox"/> Ik heb geen advies gekregen of gevraagd	

**DE APOTHEKER**

37. Heeft u een vaste apotheker?	<input type="checkbox"/> Ja	<input type="checkbox"/> Neen
38. Spreekt uw apotheker Turks?	<input type="checkbox"/> Ja	<input type="checkbox"/> Neen
39. Hoeveel keer heeft u zelf, het afgelopen jaar, uw apotheker bezocht?	..... keer	
40. Heeft uw apotheker u <b>spontaan advies gegeven</b> over het gebruik van uw diabetesmedicatie tijdens de Ramadan ?	<input type="checkbox"/> Ja	<input type="checkbox"/> Neen
41. Heeft u <u>zelf</u> aan uw apotheker advies <u>gevraagd</u> over het gebruik van uw diabetesmedicatie tijdens de Ramadan?	<input type="checkbox"/> Ja	<input type="checkbox"/> Neen
42. <u>Welk advies</u> heeft u gekregen?	<input type="checkbox"/> Ik heb geen advies gekregen of gevraagd <input type="checkbox"/> Het advies om niet te vasten <input type="checkbox"/> Het advies om dit te bespreken met mijn huisarts en/of diabetesspecialist	
43. Kon u het <u>advies</u> van uw apotheker <u>volgen</u> ?	<input type="checkbox"/> Ja	<input type="checkbox"/> Neen
	<input type="checkbox"/> Ik heb geen advies gekregen of gevraagd	

**D. UW MENING: ADVIES OVER HET GEBRUIK VAN DIABETESMEDICATIE TIJDENS DE RAMADAN**

Om in de toekomst het advies over het gebruik van diabetesmedicatie tijdens de Ramadan te verbeteren, is **uw mening belangrijk**. In de volgende vragen wordt u 3 maal hetzelfde gevraagd: 1 maal voor de huisarts, 1 maal voor de diabetesspecialist en 1 maal voor de apotheker.

**DE HUISARTS**

<p>44. Stel dat u advies zou krijgen, over het gebruik van uw diabetesmedicatie tijdens de Ramadan. Wat zouden voor u redenen zijn om het advies van uw huisarts <u>wel</u> te volgen?</p> <p><b>Duidt de 3 belangrijkste redenen aan. Vul voor de belangrijkste reden nummer ( 1 ) in, voor de tweede belangrijkste reden nummer ( 2 ) en voor de minst belangrijke reden nummer ( 3 ).</b></p> <p>(.....) Wanneer mijn huisarts moslim zou zijn</p> <p>(.....) Omdat ik vertrouwen heb in mijn huisarts</p> <p>(.....) Omdat het advies overeenkomt met dat in de Koran</p> <p>(.....) Omdat het advies overeenkomt met dat van de imam</p> <p>(.....) Omdat het advies overeenkomt met dat van de diabetesspecialist</p> <p>(.....) Omdat het advies overeenkomt met dat uit mijn omgeving</p>
---

45. Stel dat u advies zou krijgen, over het gebruik van uw diabetesmedicatie tijdens de Ramadan. Wat zouden voor u redenen zijn om het advies van uw huisarts niet te volgen?

**Duidt de 3 belangrijkste redenen aan. Vul voor de belangrijkste reden nummer ( 1 ) in, voor de tweede belangrijkste reden nummer ( 2 ) en voor de minst belangrijke reden nummer ( 3 ).**

- (.....) Omdat mijn huisarts geen moslim is
- (.....) Omdat ik onvoldoende vertrouwen heb in mijn huisarts
- (.....) Omdat het advies niet overeenkomt met dat in de Koran
- (.....) Omdat het advies niet overeenkomt met dat van de imam
- (.....) Omdat het advies niet overeenkomt met dat van de diabetesspecialist
- (.....) Omdat het advies niet overeenkomt met dat uit mijn omgeving

46. Zou u het waarderen moest uw huisarts met u praten over het gebruik van uw diabetesmedicatie tijdens de Ramadan?  Ja  Neen

### DE DIABETESSPECIALIST

47. Stel dat u advies zou krijgen, over het gebruik van uw diabetesmedicatie tijdens de Ramadan. Wat zouden voor u redenen zijn om het advies van uw diabetesspecialist wel te volgen?

**Duidt de 3 belangrijkste redenen aan. Vul voor de belangrijkste reden nummer ( 1 ) in, voor de tweede belangrijkste reden nummer ( 2 ) en voor de minst belangrijke reden nummer ( 3 ).**

- (.....) Wanneer mijn diabetesspecialist moslim zou zijn
- (.....) Omdat ik vertrouwen heb in mijn diabetesspecialist
- (.....) Omdat het advies overeenkomt met dat in de Koran
- (.....) Omdat het advies overeenkomt met dat van de imam
- (.....) Omdat het advies overeenkomt met dat van de huisarts
- (.....) Omdat het advies overeenkomt met dat uit mijn omgeving

48. Stel dat u advies zou krijgen, over het gebruik van uw diabetesmedicatie tijdens de Ramadan. Wat zouden voor u redenen zijn om het advies van uw diabetesspecialist niet te volgen?

**Duidt de 3 belangrijkste redenen aan. Vul voor de belangrijkste reden nummer ( 1 ) in, voor de tweede belangrijkste reden nummer ( 2 ) en voor de minst belangrijke reden nummer ( 3 ).**

- (.....) Omdat mijn diabetesspecialist geen moslim is
- (.....) Omdat ik onvoldoende vertrouwen heb in mijn diabetesspecialist
- (.....) Omdat het advies niet overeenkomt met dat in de Koran
- (.....) Omdat het advies niet overeenkomt met dat van de imam
- (.....) Omdat het advies niet overeenkomt met dat van de huisarts
- (.....) Omdat het advies niet overeenkomt met dat uit mijn omgeving

49. Zou u het waarderen moest uw diabetesspecialist met u praten over het gebruik van uw diabetesmedicatie tijdens de Ramadan?  Ja  Neen

**DE APOTHEKER**

50. Stel dat u advies zou krijgen, over het gebruik van uw diabetesmedicatie tijdens de Ramadan. Wat zouden voor u redenen zijn om het advies van uw apotheker wel te volgen?

**Duidt de 3 belangrijkste redenen aan. Vul voor de belangrijkste reden nummer ( 1 ) in, voor de tweede belangrijkste reden nummer ( 2 ) en voor de minst belangrijke reden nummer ( 3 ).**

- (.....) Wanneer mijn apotheker moslim zou zijn
- (.....) Omdat ik vertrouwen heb in mijn apotheker
- (.....) Omdat het advies overeenkomt met dat in de Koran
- (.....) Omdat het advies overeenkomt met dat van de imam
- (.....) Omdat het advies overeenkomt met dat van de huisarts
- (.....) Omdat het advies overeenkomt met dat van de diabetesspecialist
- (.....) Omdat het advies overeenkomt met dat uit mijn omgeving

51. Stel dat u advies zou krijgen, over het gebruik van uw diabetesmedicatie tijdens de Ramadan. Wat zouden voor u redenen zijn om het advies van uw apotheker niet te volgen?

**Duidt de 3 belangrijkste redenen aan. Vul voor de belangrijkste reden nummer ( 1 ) in, voor de tweede belangrijkste reden nummer ( 2 ) en voor de minst belangrijke reden nummer ( 3 ).**

- (.....) Omdat mijn apotheker geen moslim is
- (.....) Omdat ik onvoldoende vertrouwen heb in mijn apotheker
- (.....) Omdat het advies niet overeenkomt met dat in de Koran
- (.....) Omdat het advies niet overeenkomt met dat van de imam
- (.....) Omdat het advies niet overeenkomt met dat van de huisarts
- (.....) Omdat het advies niet overeenkomt met dat van de diabetesspecialist
- (.....) Omdat het advies niet overeenkomt met dat uit mijn omgeving

52. Zou u het waarderen moest uw apotheker met u praten over het gebruik van uw diabetesmedicatie tijdens de Ramadan?  Ja  Neen

**BEDANKT VOOR UW MEDEWERKING!**

**UW ANTWOORDEN ZULLEN HELPEN OM, IN DE TOEKOMST, MENSEN BETER TE BEGELEIDEN VOOR, TIJDENS EN NA DE RAMADAN**



*Addendum 5:  
Vragenlijst medicatietrouw  
orale antidiabetica.*

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## VRAGENLIJST

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### Uw diabetes en uw diabetesbehandeling

---

Datum: ...../...../.....

Patiëntcode: .....

#### DEEL 1. ALGEMEEN

1. Geslacht:  
 man  vrouw
2. Geboortejaar: 19.....
3. Geboorteland: .....
4. Hoelang woont u al in België? ..... jaar
5. Gewicht: ..... kg
6. Lengte: ..... cm
7. Wat is de hoogste opleiding die u afmaakte? *Kruis aan wat van toepassing is.*
  - Geen opleiding afgemaakt of lagere school
  - Middelbaar tot en met het 3<sup>e</sup> jaar
  - Middelbaar tot en met het 6<sup>e</sup> jaar
  - Hogeschool of universiteit
8. Werkt u momenteel? *Kruis aan wat van toepassing is.*
  - Ja:
    - Arbeider/arbeidster of bediende in ploegen
    - Arbeider/arbeidster of bediende met een vast uurrooster
    - Zelfstandige
    - Vrij beroep (arts, advocaat, ...)
  - Nee:
    - Gepensioneerd
    - Invalide
    - Werkloos (stempelen)
    - Huisman/huisvrouw
    - Student(e)
9. Wie woont er bij u in?
  - Niemand
  - Leden van mijn gezin, familie of schoonfamilie
  - Andere: .....

10. Wat is uw burgerlijke staat?

- Gehuwd of samenwonend
- Gescheiden of weduwnaar/weduwe
- Alleenstaande

11. Wat is uw kennis van het Nederlands? *Duid aan met een kruisje:*

	Geen kennis	Zeer slecht	Slecht	Matig	Goed	Zeer goed
Mijn kennis van het Nederlands	<input type="checkbox"/>					

## DEEL 2. UW GEZONDHEID

12. Rookt u?

- Ja
- Nee

13. Heeft u, naast diabetes ook .....

Te hoge bloeddruk?	<input type="checkbox"/> Ja	<input type="checkbox"/> Nee
Te hoge cholesterol?	<input type="checkbox"/> Ja	<input type="checkbox"/> Nee
Ernstige hart- en vaatziekten (hartinfarct, aderverkalking, ...)?	<input type="checkbox"/> Ja	<input type="checkbox"/> Nee
Dof gevoel of tintelingen in de ledematen (handen, voeten)?	<input type="checkbox"/> Ja	<input type="checkbox"/> Nee
Nierproblemen?	<input type="checkbox"/> Ja	<input type="checkbox"/> Nee
Oogproblemen (slecht zien, blindheid, ...)?	<input type="checkbox"/> Ja	<input type="checkbox"/> Nee
Slecht genezende wonden aan de voeten?	<input type="checkbox"/> Ja	<input type="checkbox"/> Nee
Depressie?	<input type="checkbox"/> Ja	<input type="checkbox"/> Nee
Andere gezondheidsproblemen? Zo ja welke?:.....	<input type="checkbox"/> Ja	<input type="checkbox"/> Nee



**DEEL 3. UW DIABETES & DIABETESBEHANDELING**

15. Hoeveel jaar weet u al dat u diabetes heeft? ..... jaar
16. Welk type diabetes heeft u?
- Diabetes Type .....
- Ik weet het niet
17. Wordt u behandeld door een diabetesspecialist in het ziekenhuis?
- Ja  Nee
18. Wordt u momenteel begeleid door een diëtist?
- Ja  Nee
19. Wordt u momenteel begeleid door een diabeteseducator?
- Ja  Nee  Ik weet het niet
20. Wordt u momenteel begeleid binnen het zorgtraject diabetes?
- Ja  Nee  Ik weet het niet
21. Zijn er leden van uw gezin, familie of schoonfamilie die ook diabetes hebben?
- Ja  Nee
22. Zijn er burens, vrienden, kennissen of collega's die ook diabetes hebben?
- Ja  Nee
23. Schreef uw dokter u een dieet voor voor de behandeling van uw diabetes?
- Ja  Nee
24. Hoelang neemt u al diabetespillen in? ..... jaar ..... maanden
25. Hoelang gebruikt u al insuline? ..... jaar ..... maanden
- Ik gebruik geen insuline

26. Gebruikt u, op dit moment, naast diabetespillen en/of insuline nog andere methoden om uw diabetes te behandelen? (Bvb. kruiden, thee, ...)

- Ja → welke? .....
- Neen

27. Meet u uw bloedsuikerspiegel zelf (door bloed te prikken)?

- Ja  Nee

28. Heeft u momenteel bijwerkingen van uw diabetespillen?

- Ja  Nee

De volgende vragen gaan over **hoe u uw diabetespillen gebruikt**. Als u 2 soorten diabetespillen gebruikt denk dan aan beide soorten diabetespillen.

Het is heel normaal dat mensen soms minder diabetespillen innemen dan voorgeschreven door de dokter. Mensen kunnen een goede reden hebben om minder diabetespillen in te nemen of om er een tijdje mee te stoppen. Om u en anderen mensen goed te kunnen helpen is het **heel belangrijk dat u eerlijk antwoordt**. Uw antwoorden worden **niet doorgegeven aan uw dokter, een familielid of aan iemand anders**.

Eerst willen we u vragen of u de voorbije week één van de volgende activiteiten deed Tijdens de voorbije week:

- bent u bij iemand op bezoek gegaan of heeft u bezoek ontvangen?
- heeft u overnacht op een andere plaats dan in uw eigen huis?
- bent u naar een feest geweest of heeft u zelf een feest gegeven?
- bent u thuis of in bed gebleven omdat u ziek was?
- is er iets gebeurd dat uw normale dagelijkse gewoonten verstoortde?

**Veel mensen vergeten wel eens om hun diabetespillen in te nemen** wanneer ze deze activiteiten doen of wanneer er iets onverwacht gebeurt. Soms zijn er ook andere **goede redenen**: sommige mensen maken zich bijvoorbeeld zorgen over hun diabetespillen of ze voelen zich goed zonder dat ze al hun diabetespillen innemen.

29. Als u denkt aan wat er de afgelopen week gebeurd is, op welke dagen nam u minder diabetespillen in dan voorgeschreven? *Noteer het gemiste aantal. Indien er geen pillen gemist werden vul dan 0 in*

Gisteren nam ik ..... pillen minder in dan de dokter voorschreef
Eergisteren nam ik ..... pillen minder in dan de dokter voorschreef
3 dagen geleden nam ik ..... pillen minder in dan de dokter voorschreef
4 dagen geleden nam ik ..... pillen minder in dan de dokter voorschreef
5 dagen geleden nam ik ..... pillen minder in dan de dokter voorschreef
6 dagen geleden nam ik ..... pillen minder in dan de dokter voorschreef
1 week geleden nam ik ..... pillen minder in dan de dokter voorschreef

30. Waarom kon u, de **afgelopen week**, niet al uw voorgeschreven diabetespillen innemen? (*meerdere antwoorden mogelijk. Indien er geen pillen vergeten werden kruis antwoord 1 aan en ga naar vraag 33*)

- 1. Ik nam mijn diabetespillen altijd in (**Ga naar vraag 33**)
- 2. Ik vergat mijn diabetespillen in te nemen
- 3. Ik ondervond teveel bijwerkingen van mijn diabetespillen
- 4. Ik denk dat mijn diabetespillen gevaarlijk zijn als ik ze lange tijd gebruik
- 5. Ik denk dat mijn diabetespillen mij te weinig of niet helpen
- 6. Ik voel mij goed zonder mijn diabetespillen in te nemen
- 7. Ik verkies een andere behandeling (bvb. kruiden, thee, ...) in plaats van mijn diabetespillen
- 8. Ik had geen diabetespillen in huis of bij mij.
- 9. Andere reden: .....

31. Wat was de **belangrijkste reden** waarom u de afgelopen week niet al uw voorgeschreven diabetespillen kon innemen?

Vul het cijfer dat hierboven bij de reden staat in: .....

32. Als u diabetespillen niet inneemt praat u daar dan over met iemand?

- Ja  Nee

Zo ja, met wie? .....

33. U beantwoordde net de vragen over de hoeveelheid diabetespillen die u de afgelopen week gebruikte. Probeer even terug te denken aan de **laatste 3 maanden**. Is de hoeveelheid pillen die u de afgelopen week innam hetzelfde als de hoeveelheid die u per week innam de afgelopen 3 maanden?

- Ja, het is hetzelfde
- Nee, ik nam de afgelopen 3 maanden meestal minder diabetespillen per week in.
- Nee, ik nam de afgelopen 3 maanden meestal meer diabetespillen per week in.

34. Bent u tijdens de laatste 2 jaar naar Turkije geweest?

Nee

Ja (vul de periodes in):

.....

.....

.....

.....

.....

.....

35. Tijdens een **vakantie in Turkije of een ander land** nemen mensen soms **minder diabetespillen** in. Wat doet u meestal wanneer u langer dan 1 week in Turkije bent?

Ik neem evenveel of meer diabetespillen in dan in België

Ik neem minder diabetespillen in dan in België

Ik neem tijdens de meeste dagen geen enkele diabetespil in

36. Nu volgen nog een paar **laatste vragen** over hoe u uw **diabetespillen** gebruikt. *Kruis het vakje aan dat van toepassing is.*

1. Vergeet u uw diabetespillen in te nemen?	Nooit <input type="checkbox"/>	Bijna nooit <input type="checkbox"/>	Soms <input type="checkbox"/>	Vrij vaak <input type="checkbox"/>	Bijna altijd <input type="checkbox"/>	Altijd <input type="checkbox"/>
2. Heeft u ooit, zonder dit aan uw dokter te zeggen, minder of geen diabetespillen ingenomen omdat u zich slechter voelde als u ze nam?	Nooit <input type="checkbox"/>	Bijna nooit <input type="checkbox"/>	Soms <input type="checkbox"/>	Vrij vaak <input type="checkbox"/>	Bijna altijd <input type="checkbox"/>	Altijd <input type="checkbox"/>
3. Wanneer u reist of het huis verlaat vergeet u dan om uw diabetespillen mee te nemen?	Nooit <input type="checkbox"/>	Bijna nooit <input type="checkbox"/>	Soms <input type="checkbox"/>	Vrij vaak <input type="checkbox"/>	Bijna altijd <input type="checkbox"/>	Altijd <input type="checkbox"/>
4. Wanneer u denkt dat uw diabetes onder controle is, stopt u dan met het innemen van uw diabetespillen?	Nooit <input type="checkbox"/>	Bijna nooit <input type="checkbox"/>	Soms <input type="checkbox"/>	Vrij vaak <input type="checkbox"/>	Bijna altijd <input type="checkbox"/>	Altijd <input type="checkbox"/>
5. Elke dag medicatie innemen is moeilijk voor sommige mensen. Vindt u het moeilijk om dit vol te houden?	Nooit <input type="checkbox"/>	Bijna nooit <input type="checkbox"/>	Soms <input type="checkbox"/>	Vrij vaak <input type="checkbox"/>	Bijna altijd <input type="checkbox"/>	Altijd <input type="checkbox"/>

6. Hoe vaak heeft u het moeilijk om eraan te denken alle diabetespillen in te nemen?	Nooit	Bijna nooit	Soms	Vrij vaak	Bijna altijd	Altijd
	<input type="checkbox"/>					

Werd u de afgelopen 2 jaar gehospitaliseerd?     Ja     Neen

Indien ja, hoelang (in het totaal)? Ongeveer .....dagen

Kreeg u bij uw ontslag een voorraad diabetespillen van het ziekenhuis mee naar huis?  
 Ja, een voorraad voor ongeveer .....weken (in het totaal)     Neen

Hoe vaak tijdens de afgelopen drie maanden heeft u uw vaste apotheker (de apotheker waar u het meest gaat) bezocht? .....keer

De volgende vragen gaan over uw dieet en de beweging die u neemt. Om u en anderen mensen goed te kunnen helpen is het heel belangrijk dat u eerlijk antwoordt. Uw antwoorden worden niet doorgegeven aan uw dokter, een familielid of aan iemand anders. Omcirkel het aantal dagen.

<b>37. Hoeveel van de laatste 7 dagen heeft u een gezond dieet gevolgd?</b>							
0	1	2	3	4	5	6	7
<b>38. Denk even terug aan de voorbije maand. Hoeveel dagen, gemiddeld gezien, per week heeft u, uw dieet gevolgd?</b>							
0	1	2	3	4	5	6	7
<b>39. Hoeveel van de laatste 7 dagen heeft u minstens 5 porties fruit of groenten gegeten?</b>							
0	1	2	3	4	5	6	7
<b>40. Hoeveel van de laatste 7 dagen at (of dronk) u voedsel met een hoog vetgehalte: bijvoorbeeld rood vlees, baklava, pizza, noten, zonnebloempitten, volle melk, volle yoghurt?</b>							
0	1	2	3	4	5	6	7
<b>41. Hoeveel van de laatste 7 dagen nam u minstens 30 minuten beweging (bvb. huishouden doen of lichamelijke arbeid)?</b>							
0	1	2	3	4	5	6	7
<b>42. Hoeveel van de laatste 7 dagen ging u wandelen, zwemmen, fietsen of had u andere vormen van beweging buiten uw beroep of huishoudelijke taken?</b>							
0	1	2	3	4	5	6	7

**DEEL 4. DENKBEELDEN DIABETES EN DIABETESMEDICATIE**

Hieronder staan een aantal vragen over de ziekte diabetes. Omcirkel bij elke vraag het getal dat **uw mening** het beste weergeeft. Er zijn geen goede of foute antwoorden, het gaat om **uw eigen mening**.

Voorbeeld:

*Hoe bezorgd bent u over uw diabetes? U vindt dat u over het algemeen vrij bezorgd bent over uw diabetes → U duidt daarom, hieronder het nummer 8 aan*

0    1    2    3    4    5    6    7    8    9    10

*Helemaal  
niet  
bezorgd*

*Ze  
er  
bezorgd*

43. In welke mate beïnvloedt uw diabetes uw leven?

0    1    2    3    4    5    6    7    8    9    10

Helemaal  
niet

Ze  
er  
veel

44. Hoelang denkt u dat uw diabetes zal duren?

0    1    2    3    4    5    6    7    8    9    10

Een zeer  
korte tijd

Mijn hele  
leven

45. Hoeveel controle vindt u dat u heeft over uw diabetes? (Er wordt bedoeld: In welke mate voelt u zich baas over uw diabetes?)

0    1    2    3    4    5    6    7    8    9    10

Helemaal  
geen controle

Ze  
er  
veel  
controle

46. In welke mate denkt u dat uw behandeling kan helpen bij uw diabetes?

0    1    2    3    4    5    6    7    8    9    10

Helemaal  
niet

Ze  
er  
veel

47. In welke mate ervaart u klachten door uw diabetes?

0    1    2    3    4    5    6    7    8    9    10

Helemaal  
geen klachten

Veel ernstige  
klachten

Addendum 5

<b>48. Hoe bezorgd bent u over uw diabetes?</b>										
0	1	2	3	4	5	6	7	8	9	10
Helemaal niet bezorgd									Zeer bezorgd	
<b>49. In welke mate vindt u dat u uw diabetes begrijpt?</b>										
0	1	2	3	4	5	6	7	8	9	10
helemaal niet									volledig	
<b>50. In welke mate beïnvloedt uw diabetes uw stemming? (Bijvoorbeeld: maakt uw diabetes u boos, bang, van streek of somber?)</b>										
0	1	2	3	4	5	6	7	8	9	10
Helemaal niet									Zeer veel	
<b>51. Noem de 3 belangrijkste factoren die volgens u uw diabetes hebben veroorzaakt, in volgorde van belangrijkheid.</b>					<b>Volgens mij zijn de belangrijkste oorzaken:</b> 1. .... 2. .... 3. ....					

52. Hieronder staan een aantal uitspraken, die ooit door andere mensen gedaan zijn over hun **diabetespillen**. Wilt u aangeven in hoeverre u het eens of oneens bent met deze uitspraken. Zet een kruisje in het vakje dat het beste **uw mening** weergeeft. Er zijn geen goede of foute antwoorden, het gaat om **uw eigen mening**.

		Helemaal akkoord	Akkoord	Neutraal	Niet akkoord	Helemaal niet akkoord
1	Op dit moment hangt mijn gezondheid af van mijn diabetespillen	<input type="checkbox"/>				
2	Ik maak me zorgen over het feit dat ik diabetespillen moet innemen	<input type="checkbox"/>				
3	Mijn leven zou onmogelijk zijn zonder mijn diabetespillen	<input type="checkbox"/>				
4	Zonder mijn diabetespillen zou ik heel ziek zijn	<input type="checkbox"/>				
5	Soms maak ik me zorgen over de effecten van mijn diabetespillen op lange termijn	<input type="checkbox"/>				
6	Ik begrijp niets van mijn diabetespillen	<input type="checkbox"/>				
7	Mijn toekomstige gezondheid hangt af van mijn diabetespillen	<input type="checkbox"/>				
8	Mijn diabetespillen ontwrichten mijn leven	<input type="checkbox"/>				
9	Soms ben ik bang dat ik té afhankelijk zal worden van mijn diabetespillen	<input type="checkbox"/>				
10	Mijn diabetespillen voorkomen dat mijn gezondheid slechter wordt	<input type="checkbox"/>				

## DEEL 5. DIABETES & STRESS

53. Leven met diabetes kan stress geven. Mensen kunnen ook op verschillende manieren **omgaan met stress**. Als u terugdenkt aan de **stress** die u kreeg door **diabetes** hoe heeft u dan **meestal gereageerd**? Als u **geen stress** heeft gehad door uw diabetes **hoe zou u reageren**? Hieronder staan verschillende manieren waarop mensen reageren. Kruis bij elke mogelijke reactie aan of u dit meestal nooit/zelden/soms/meestal/altijd deed.

Als ik stress heb (of zou hebben) door mijn diabetes dan:	Nooit	Zelden	Soms	Meestal	Altijd
neem ik acties om de situatie te verbeteren	<input type="checkbox"/>				
denk ik hard na over welke stappen genomen kunnen worden	<input type="checkbox"/>				
zoek ik naar het goede in wat gebeurd is	<input type="checkbox"/>				
leer ik ermee leven	<input type="checkbox"/>				
maak ik er grappen over	<input type="checkbox"/>				
probeer ik troost te vinden in mijn religie	<input type="checkbox"/>				
zoek ik emotionele steun bij anderen	<input type="checkbox"/>				
zoek ik advies en hulp bij anderen	<input type="checkbox"/>				
richt ik me op het werk of andere activiteiten om mijn gedachten te verzetten	<input type="checkbox"/>				
weiger ik om te aanvaarden dat het gebeurd is	<input type="checkbox"/>				
geef ik het op	<input type="checkbox"/>				
verwijt ik het mezelf dat het gebeurd is.	<input type="checkbox"/>				
neem ik de tijd om uit te zoeken wat ik echt voel	<input type="checkbox"/>				
laat ik mezelf toe mijn emoties te uiten	<input type="checkbox"/>				

**DEEL 6. DIABETES EN ANTIDIABETICA: KENNIS**

54. We spelen nu een **kleine quiz over uw kennis van diabetes en de behandeling**. Van de **10 uitspraken** zijn **sommige juist, andere zijn fout**. Kan u ons **bij elke uitspraak zeggen of deze volgens u juist of fout is**. **U mag niet gokken**. Als u niet weet of een uitspraak juist of fout is antwoordt u met 'ik weet het niet'.

Diabetespillen maken ons lichaam gevoeliger voor insuline en daardoor verlaagt de suiker in het bloed.	Juist <input type="checkbox"/>	Fout <input type="checkbox"/>	Ik weet het niet <input type="checkbox"/>
Insuline zorgt ervoor dat ons lichaam suiker kan opnemen om te gebruiken als energiebron.	Juist <input type="checkbox"/>	Fout <input type="checkbox"/>	Ik weet het niet <input type="checkbox"/>
Wanneer u 's morgens uw diabetesmedicatie (insuline, diabetespillen) genomen heeft zonder te ontbijten, dan kan dit uw bloedsuikergehalte doen dalen	Juist <input type="checkbox"/>	Fout <input type="checkbox"/>	Ik weet het niet <input type="checkbox"/>
4à5 kleine maaltijden per dag zijn beter voor mensen met diabetes dan 2 à 3 grote maaltijden	Juist <input type="checkbox"/>	Fout <input type="checkbox"/>	Ik weet het niet <input type="checkbox"/>
Mensen met diabetes mogen geen suiker eten	Juist <input type="checkbox"/>	Fout <input type="checkbox"/>	Ik weet het niet <input type="checkbox"/>
Een laag suikergehalte in het bloed kan het gevolg zijn van te weinig beweging	Juist <input type="checkbox"/>	Fout <input type="checkbox"/>	Ik weet het niet <input type="checkbox"/>
Mensen met diabetes moeten minimaal 30 minuten per dag bewegen	Juist <input type="checkbox"/>	Fout <input type="checkbox"/>	Ik weet het niet <input type="checkbox"/>
Te zwaar wegen is een oorzaak van diabetes	Juist <input type="checkbox"/>	Fout <input type="checkbox"/>	Ik weet het niet <input type="checkbox"/>
Bij mensen met diabetes maakt het lichaam te weinig insuline of is het lichaam ongevoelig voor het effect van insuline.	Juist <input type="checkbox"/>	Fout <input type="checkbox"/>	Ik weet het niet <input type="checkbox"/>
Mensen met diabetes hebben meer kans op hart- en vaatziekten	Juist <input type="checkbox"/>	Fout <input type="checkbox"/>	Ik weet het niet <input type="checkbox"/>

**DEEL 7. INFORMATIE OVER DIABETESMEDICATIE: UW TEVREDENHEID**

55. We vragen u nu **hoe tevreden u bent over de informatie die u kreeg over uw diabetespillen**. Hiermee bedoelen we **alle diabetespillen**. Als u dus verschillende soorten diabetespillen neemt geef dan een **algemene beoordeling** over uw tevredenheid. Let op, het gaat over de **tevredenheid over de informatie** die u kreeg, niet over uw tevredenheid over de diabetespillen zelf. Antwoord bij elk van de vragen met: ik kreeg te veel informatie/ ik kreeg voldoende informatie/ Ik kreeg te weinig informatie/ Ik kreeg geen informatie/ Ik had geen informatie nodig.

Hoe tevreden bent u met de informatie die u kreeg over	ik kreeg te veel informatie	ik kreeg voldoende informatie	Ik kreeg te weinig informatie	Ik kreeg geen informatie	Ik had geen informatie nodig
de naam van de diabetespillen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
waarvoor uw diabetespillen dienen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
hoe uw diabetespillen werken in uw lichaam?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
hoelang het duurt voor de diabetespillen werken?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
hoe u uw diabetespillen moet gebruiken?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
mogelijke bijwerkingen van uw diabetespillen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
wat u moet doen wanneer u bijwerkingen zou hebben van uw diabetespillen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
de combinatie van diabetespillen met andere medicijnen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
wat u moet doen wanneer u een diabetespil vergeten bent?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**DEEL 8. GEESTELIJK WELZIJN**

56. Diabetes of andere problemen kunnen het leven soms moeilijk maken. We willen u nu graag vragen **hoe u zich de afgelopen twee weken gevoeld heeft**. Kan u ons vertellen hoe vaak u last heeft gehad van de volgende gevoelens. U kan antwoorden met helemaal niet/ verschillende dagen/ meer dan de helft van de dagen (meer dan 1 week)/ bijna elke dag.

Hoe vaak had u de afgelopen 2 weken last van:	helemaal niet	verschillende dagen	meer dan de helft van de dagen (meer dan 1 week)	bijna elke dag
u nerveus, angstig, gespannen of prikkelbaar voelen?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
niet kunnen stoppen met u zorgen te maken?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
u teneergeslagen, depressief of hopeloos voelen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
weinig interesse of plezier vinden in het doen van dingen	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

57. Wordt u momenteel of werd u de afgelopen 2 jaar behandeld voor depressie?

Ja

Nee

**DEEL 9. SOCIALE STEUN**

58. De volgende vragen gaan over **de steun die u krijgt van uw omgeving: dus van uw gezin, familie, vrienden, buren of kennissen**. Let op, deze vragen gaan **niet** over de steun door uw **dokters, apotheker, diëtist of andere professionele gezondheidswerkers**. Zeg telkens hoe sterk u akkoord of niet akkoord gaat met de volgende uitspraken.

	Helemaal niet akkoord	Niet akkoord	Eerder niet akkoord	Neutraal	Eerder akkoord	Akkoord	Helemaal akkoord
Mijn omgeving moedigt me aan om mijn dieet te volgen	<input type="checkbox"/>						
Mijn omgeving moedigt me aan om mijn diabetespillen in te nemen zoals voorgeschreven	<input type="checkbox"/>						
Mijn omgeving moedigt me aan om dagelijks voldoende te bewegen	<input type="checkbox"/>						
Ik vind dat mijn omgeving beseft hoe moeilijk het leven met diabetes kan zijn	<input type="checkbox"/>						
Ik vind dat mijn omgeving mij de emotionele steun geeft die ik wil	<input type="checkbox"/>						

**DEEL 10. VERWACHTINGEN VAN DE BEHANDELING**

59. We vragen nu **hoe belangrijk u denkt** dat de **verschillende delen van uw diabetesbehandeling zijn** om uw diabetes goed onder controle te houden. Het gaat om **uw eigen mening** dus niet om wat uw dokter of andere mensen belangrijk vinden. Geef het antwoord dat het best past bij uw eigen mening. U kan telkens kiezen uit: helemaal niet belangrijk/ niet belangrijk/ eerder onbelangrijk/ eerder belangrijk/ belangrijk/ zeer belangrijk.

Om mijn diabetes te controleren is ...	helemaal niet belangrijk	niet belangrijk	eerder onbelangrijk	eerder belangrijk	belangrijk	zeer belangrijk.
het volgen van mijn dieet	<input type="checkbox"/>					
het nemen van diabetespillen zoals voorgeschreven	<input type="checkbox"/>					
beweging	<input type="checkbox"/>					
het volgen van mijn hele diabetesbehandeling (dieet, medicatie, beweging)	<input type="checkbox"/>					
<b>Om de complicaties van diabetes te voorkomen</b> is het volgen van mijn hele diabetesbehandeling (dieet, medicatie, beweging)	<input type="checkbox"/>					

**DEEL 11. VERTROUWEN IN DE HUISARTS**

Tot slot zullen we u nog een paar vragen stellen over uw relatie met uw huisarts. **Beantwoord deze vragen eerlijk** alstublieft, uw antwoorden worden niet aan uw huisarts doorgegeven. Indien u meer dan 1 huisarts ziet voor uw diabetes denk dan bij het antwoorden aan de huisarts die u het vaakst ziet voor uw diabetes. Let op, de vragen gaan niet over de dokter in het ziekenhuis maar over uw huisarts.

- 60. Uw huisarts, sinds hoeveel jaar is hij/zij uw vaste huisarts? ..... jaar
- 61. Denk even terug aan de afgelopen 3 maanden. Hoe vaak ongeveer bent u de afgelopen 3 maanden bij uw huisarts op consultatie geweest (voor alles, niet enkel voor uw diabetes)? ..... keer.

62. Op de volgende uitspraken over uw relatie met uw huisarts kan u antwoorden met helemaal akkoord/ akkoord/ neutraal/ niet akkoord/ helemaal niet akkoord. **Antwoord eerlijk** alstublieft, uw antwoorden worden niet doorgegeven aan uw huisarts.

	Helemaal akkoord	Akkoord	Neutraal	Niet akkoord	Helemaal niet akkoord
In het algemeen heeft u volledig vertrouwen in uw huisarts.	<input type="checkbox"/>				
Uw huisarts zal al het nodige doen om u de zorg te geven die u nodig heeft voor uw diabetes	<input type="checkbox"/>				
Soms vindt uw huisarts uw diabetes minder belangrijk dan dat wat voor hem/haar gemakkelijk is	<input type="checkbox"/>				
Uw huisarts zijn / haar medische vaardigheden voor het behandelen van uw diabetes zijn niet zo goed als ze zouden moeten zijn.	<input type="checkbox"/>				
Uw huisarts is extreem grondig en nauwgezet.	<input type="checkbox"/>				

	Helemaal akkoord	Akkoord	Neutraal	Niet akkoord	Helemaal niet akkoord
U vertrouwt de beslissingen van uw huisarts over welke medische behandelingen het best zijn voor uw diabetes volledig.	<input type="checkbox"/>				
Uw huisarts is volledig eerlijk wanneer hij/zij u vertelt over de beschikbare behandelingskeuzes voor uw diabetes	<input type="checkbox"/>				
Soms schenkt uw huisarts geen volledige aandacht aan wat u hem/haar probeert te vertellen over uw diabetes	<input type="checkbox"/>				
U heeft er geen problemen mee om uw leven in de handen van uw huisarts te leggen	<input type="checkbox"/>				
Uw huisarts zou u nooit het verkeerde medicijn voorschrijven voor uw diabetes.	<input type="checkbox"/>				

	Helemaal akkoord	Akkoord	Neutraal	Niet akkoord	Helemaal niet akkoord
Ik zou mijn huisarts aanraden aan familie en vrienden	<input type="checkbox"/>				
In het algemeen ben ik zeer tevreden over mijn huisarts.	<input type="checkbox"/>				

63. Heeft u tijdens de laatste 12 maanden op eigen initiatief (dus niet na doorverwijzing door uw huisarts) een andere arts geconsulteerd voor uw diabetes omdat u te weinig vertrouwen had in uw eigen huisarts?  Ja  Nee

64. Wat is uw huisarts zijn / haar kennis van het Turks?

	Geen kennis	Zeer slecht	Slecht	Matig	Goed	Zeer goed
Mijn huisarts zijn / haar kennis van het Turks	<input type="checkbox"/>					

Addendum 5

Kent u andere mensen met diabetes die zouden willen meewerken aan deze studie?

Ja

Nee

Zo ja, kan u ons hun contactgegevens geven?

Naam: .....

Adres: .....

Telefoonnummer: .....

**Wij willen u hartelijk danken voor al uw antwoorden en voor uw tijd. Uw medewerking is heel belangrijk en zal ons helpen om mensen met diabetes beter te helpen.**

**BEDANKT VOOR UW MEDEWERKING!**

***Addendum 6:***  
***Diabetes en ramadan:***  
***praktische aanbevelingen.***

Gepubliceerd als:

Peeters B., Mehuys E., Boussery K. Diabetes en ramadan : achtergrond en praktische aanbevelingen. *Farmaceutisch Tijdschrift voor België* (2013); 89(2):18-19.

## **Diabetes en ramadan: achtergrond en praktische aanbevelingen**

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Naar aanleiding van het observationeel onderzoek naar diabetes en vasten tijdens de ramadan onder Turkse migranten in België, maken we van de gelegenheid gebruik om praktische richtlijnen te formuleren. Deze vormen een handleiding voor de begeleiding van deze bijzondere patiëntengroep in de apotheek.

**Betekenis:** De ramadan is één van de vijf pijlers van de Islam. Voor moslims is het een heilige maand waarin ze verplicht zijn om zich te onthouden van eten, drinken en roken tussen zonsopgang en zonsondergang. Ook de inname van medicijnen wordt veelal geïnterpreteerd als het doorbreken van de vasten en is dus in principe verboden. Chronische ziekten zijn vrijgesteld van deelname maar velen verkiezen om toch deel te nemen.

**Wanneer:** De Islamitische tijdsrekening volgt de maancyclus wat betekent dat de ramadan elk jaar een tiental dagen vroeger start. De ramadan start in 2013 op 9 juli, in 2014 op 28 juni, in 2015 op 18 juni. Het vasten eindigt op de 29<sup>e</sup> of 30<sup>e</sup> dag na aanvang van de ramadan (<http://www.kalender-365.nl/feestdagen/ramadan.html>).

**Het breken van de vasten:** Het aantal uren dat men dagelijks vast varieert afhankelijk van het seizoen waarin de ramadan valt. Meestal gebruikt men twee maaltijden per dag: de Iftar, na zonsondergang, en de Suhur, voor zonsopgang.

**Risico's voor diabetici die deelnemen aan de vasten:** Naast dehydratie rapporteren studies een verhoogd risico op hypoglykemie en hyperglycemie bij mensen met type-1 of type-2 diabetes die vasten. Dit verhoogd risico geldt ook voor de ernstige vormen van hypo- en hyperglycemie die hospitalisatie vereisen. Daarnaast wordt ook een verhoogd risico op diabetische ketoacidose gerapporteerd (Al-Arouj et al. 2005; Salti et al. 2004).

**Doorverwijzing:** Vraag of uw diabetespatiënten willen deelnemen aan de ramadan en verwijs hen tijdig naar de huisarts of specialist. Houd er rekening mee dat vele diabetespatiënten, vooral migranten van de eerste generatie, al in mei of juni voor een langere

periode terugkeren naar hun thuisland. Een medisch consult over deelname aan de ramadan vindt best 1 tot 2 maanden voor de start van de ramadan plaats.

**Advies over deelname aan de ramadan:** Een bestaande richtlijn van de American Diabetes Association (ADA) beklemtoont dat het advies over deelname en over de aanpassing van de diabetesbehandeling bij patiënten die deelnemen afgestemd moet worden op de individuele situatie van de patiënt (Al-Arouj et al. 2005). De behandelende arts dient de patiënt te informeren over de risico's, over wat deze dient te doen wanneer complicaties optreden en stelt indien nodig een aangepast behandelingsplan voor. Daarnaast is het voor patiënten die deelnemen belangrijk dat ze regelmatig een zelfcontrole van de bloedglucose uitvoeren (Al-Arouj et al. 2005).

In deze richtlijn van de ADA worden patiënten ingedeeld in groepen afhankelijk van hun risico op complicaties ten gevolge van het vasten (Al-Arouj et al. 2005). Het BCFI hanteert een vereenvoudigde risico-indeling (Folia Pharmacotherapeutica sept 2006). Het vasten wordt daarin afgeraden aan:

- Patiënten met type-1 diabetes
- Patiënten met (een hoog risico op) diabetesgerelateerde complicaties
- Patiënten met ongecontroleerde of instabiele glycemie
- Zwangere vrouwen met diabetes

**Het gebruik van antidiabetica:** Er zijn slechts een beperkt aantal, veelal kleinschalige studies beschikbaar over de aanpassing van antidiabetica tijdens een vastenperiode. De beschikbare adviezen zijn dan ook ten dele gebaseerd op praktijkervaringen hoewel ze grotendeels in overeenstemming zijn met elkaar (Ahdi et al. 2008; Al-Arouj et al. 2005; Beshyah, Benbarka, and Sherif 2007; Hassanein 2010; Hui et al. 2010; Karamat, Syed, and Hanif 2010). Het is van groot belang dat patiënten de symptomen van hypoglykemie en hyperglycemie herkennen en het vasten breken wanneer zich een episode van hypoglykemie of hyperglycemie voordoet. De behandelende arts dient de individuele situatie van elke patiënt in te schatten en indien nodig de medicamenteuze behandeling aan te passen, rekening houdend met een veranderend voedings- en bewegingspatroon. Algemeen wordt aangenomen

dat bij medicatie met een hoger risico op hypoglykemie (hypoglykemiërende sulfamiden, gliniden, insuline) de dosis best gereduceerd wordt. Hier staat tegenover dat het veranderd eetpatroon, met name de vaak uitgebreide maaltijd die gebruikt wordt na zonsopgang, een hoger risico op postprandiale hyperglycemie met zich meebrengt (Hassanein 2010).

*Metformine* kan meestal in dezelfde dosis gebruikt worden als buiten de vastenperiode Omdat de Iftar-maaltijd doorgaans de grootste maaltijd van de dag is kan wel overwogen worden om de metforminedosis op te splitsen zodat 2/3 van de totale dagdosis bij Iftar ('s avonds) wordt ingenomen en 1/3 bij Suhur ('s ochtends). Voor 3x500 mg metformine per dag komt dit dan neer op 1000 mg bij Iftar en 500 mg bij Suhur (Hui et al. 2010).

*Hypoglykemiërende sulfamiden.* Hypoglykemiërende sulfamiden veroorzaken frequenter hypoglykemie, waardoor ofwel een dosisreductie ofwel een wijziging van het innametijdstip kan overwogen worden:

- Dosisreductie: verminderen van de Suhurdosis (= ochtend) bij een 2x daags doseerschema (bv. wijziging van 2x80 mg gliclazide per dag naar 80 mg bij Iftar en 40 mg bij Suhur)
- Wijziging innametijdstip: bij een 1x daags doseerschema (bv. glimepiride) wordt aanbevolen om het geneesmiddel bij Iftar (de avondmaaltijd) in te nemen, i.p.v. de gebruikelijke inname 's ochtends.

*Gliniden.* Repaglinide kan in een ongewijzigde dosering ingenomen worden bij Iftar (de avondmaaltijd) en Suhur (de ochtendmaaltijd) (Hui et al. 2010). Bij *glitazonen* dient de dosis die normaal één maal daags 's morgens wordt ingenomen bij Iftar ('s avonds) genomen te worden (Beshyah, Benbarka, and Sherif 2007).

Voor *DPP-4 inhibitoren* kan de dosis ongewijzigd blijven. In combinatie met hypoglykemiërende sulfamiden is het risico op hypoglykemie hoger en kan een dosisreductie aangewezen zijn (Karamat, Syed, and Hanif 2010).

*Incretinemimetica* kunnen ongewijzigd gebruikt worden. Een reductie van de dosis kan aangewezen zijn bij misselijkheid en in combinatie met hypoglykemiërende sulfamiden. (Hui et al. 2010; Karamat, Syed, and Hanif 2010).

*Acarbose* kan tijdens de ramadan in ongewijzigde dosis bij de maaltijden ingenomen worden, dit betekent dus bij Suhur en Iftar (de middagdosis valt weg) (Hui et al. 2010).

*Insuline.* Men zal het insulineschema aanpassen, bvb. door een kortwerkend insuline te geven voor de maaltijden en een insuline met intermediaire werkingsduur voor 's nachts (Kobeissy, Zantout, and Azar 2008).

**Controle tijdens en na de ramadan:** Een medische controle tijdens en na afloop van de ramadan is aangewezen wanneer er zich complicaties hebben voorgedaan.

**Rookstop:** Voor diabetici die roken is de ramadan een goede periode om hen aan te zetten tot rookstop.

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***Addendum 7:***  
***Methodological addendum***  
***Chapter 6.***

## Methodological addendum Chapter 6.

### *Calculation of the medication possession ratio (MPR).*

Pharmacists (PH) provided the patient's medication history from January 1st 2010 until the interview date. The MPR time period starts on the first date, after January 1st 2010, on which OHA were provided (e.g. January 17th 2010). It ends the day before the last dose of OHA was obtained (e.g. interview date May 14th 2012, last dose obtained on April 29th 2012, end of MPR time period April 28th 2012). This end date was chosen because most patients of Turkish descent spend several months a year in Turkey and, since OHA are provided for free in Belgium, take stocks with them. The MPR was calculated as the number of days for which OHA were obtained divided by the number of days in the time period<sup>18</sup>. We asked the patient's GP whether there were changes in the dosing regimen (e.g. twice daily to three times daily, the addition/replacement of an OHA). When this was the case we used different time periods for each prescribed dose or newly prescribed OHA and calculated the MPR as a weighted mean, using time periods and doses as weights. When patients used two or three OHA we calculated a MPR for each OHA and the final MPR as the weighted mean for all OHA (time periods and doses as weights). For patients obtaining OHA from several pharmacies a MPR was not calculated.

### *Logistic regression analysis.*

A series of multiple logistic regression analyses, using SPSS 21.0, was performed according to recommendations in the literature<sup>30-32</sup>. The aim was to build the 'best fitting model to our data' in order to explain medication nonadherence, defined as MPR<80%. A series of bivariate analyses was performed for each potential predictor with the MPR as outcome. When the p-value from the bivariate analysis (likelihood ratio  $\lambda^2$  test for contingency tables, Wald statistic for univariate logistic regression) was <0.30 covariates were added to our set of model-building covariates (40 covariates). The p-value of 0.30 was used because lower values can lead to the exclusion of relevant covariates<sup>30;33</sup>. Irrespective of their p-value covariates that were of theoretical importance, based on our previous qualitative research and insights from the literature<sup>12-14</sup>, were added to the model-building covariates set. Linear regression was used to test for multicollinearity. Secondly, because little is known about medication adherence in this population, we used a stepwise forward selection procedure with backwards

elimination to build a preliminary main effects model. To maximize the selection of authentic variables we followed Sun et al.'s recommendation to 'set the p-value to 0.15 to 0.25 for entering variables and from 0.10 to 0.15 for deleting variables'<sup>33</sup>. Alternative models were then assessed by deleting and adding covariates based on the Wald statistic and their theoretical relevance. The obtained preliminary model was also compared to a model built with the stepwise backward elimination method. The likelihood ratio test, Akaike's information criterion and Schwarz Bayesian criterion (the latter two were calculated manually) were used to compare the different models. In a next step, theoretically plausible interaction effects were added to the preliminary model. The Hosmer –Lemeshow Goodness of Fit Test was used to assess the goodness-of-fit, regression residuals diagnostic plots were used to assess the influence of poorly fit cases. Measures of association between predicted and observed probabilities and ROC-analysis were used to validate the predicted probabilities. Because of the small number of observations dividing the data set into a model-building and a validation data set was not possible.

Initially, analysis was performed on the subsample with MPR (listwise deletion of missing values). Because listwise deletion of missing values can lead to biased parameter estimates and loss of statistical power, we repeated the multiple logistic regression (stepwise forward selection with backward elimination using three different p-values from 0.15 to 0.25 for entering covariates and from 0.10 to 0.15 for deleting covariates) with multiple imputations for missing values in order to validate results<sup>34</sup>. Missing values analysis showed values were missing at random (Little's MCAR test  $p=0.082$ ) with a nonmonotonic missing values pattern. Fully conditional specific multiple imputation was used to obtain 5 imputed datasets. To estimate the missing values we used the covariates from the model-building data set as well as several auxiliary variables because the use of "auxiliary variables reduces bias due to MNAR missingness and can partially restore lost power due to missingness. Furthermore, subsequent analyses involving the imputed data benefit from the auxiliary variables, whether or not those variables appear in the analysis of substantive interest."<sup>34</sup>. For 10 out of 35 independent covariates in the model building data set 1 to 10 cases (mean 2.5 cases) received imputed values, for the dependent variable (MPR) 53 cases received imputed values (5 imputed data sets with  $n=196$ ). Logistic regression models and parameter estimates from the imputed data sets were compared with the model and parameter estimates from the original data set. Clinical relevance of medication adherence was assessed with multiple logistic regression with the patients reaching the goal of  $HbA1c \leq 7\%$  (53 mmol/mol) as dependent and

medication adherence, adherence to diet, adherence to exercise, diabetes duration and age as covariates.

***Psychometric properties of the measurement scales for the covariates.***

Internal consistency of the different scales was good to very good (Chronbach  $\alpha$ : 0.70-0.88). Criterion validity was shown by statistically significant associations in the theoretically expected direction (e.g. statistically significant associations between the WF Trust in Physician and items, measured on a 5-point Likert scale, on ‘general satisfaction with GP’, ‘recommend GP to family and friends’, ‘second opinion because of not being satisfied with the GP’s provision of diabetes care’). Detailed psychometric results of the different scales can not be reported within this scope.

***Addendum 8:***  
***Curriculum Vitae***

*Curriculum Vitae*

PERSOONLIJKE GEGEVENS	
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<b>e-mail:</b>	b.peeters@ugent.be
<b>Geboortedatum- en plaats:</b>	01/12/1971 te Leuven
<b>Nationaliteit:</b>	Belg
<b>Burgerlijke staat:</b>	alleenstaande
OPLEIDING	
<b>Middelbaar onderwijs</b>	
1983-1984 tot en met 1988-1989 Sint-Jozef College, Turnhout Algemeen Secundair Onderwijs: economie	
<b>Hoger onderwijs</b>	
1989-1990 tot en met 1990-1991 Universitaire Faculteiten Sint-Ignatius Antwerpen (Ufsia) Kandidaat in de Politieke en Sociale wetenschappen (onderscheiding).	
1991-1992 tot en met 1992-1993 Katholieke Universiteit Leuven (KU Leuven) Licentiaat in de Sociologie, godsdienst- en cultuursociologie / sociaal beleid.	
1993-1994 Katholieke Universiteit Leuven (K.U.Leuven) Bijzondere licentie in de Culturele Studies, optie podiumkunsten.	
1996-1997 Rijksuniversiteit Gent (R.U.G) Enige kandidatuur in de Wijsbegeerte: niet voltooid wegens tewerkstelling Ufsia.	
2000-2002 Toneelacademie Maastricht Deeltijdse opleiding regie/dramadocent: niet voltooid	
<b>Bijkomende opleidingen (selectie)</b>	
Statistiek: <ul style="list-style-type: none"> <li>- Structural equation modelling</li> <li>- Multivariate analyse</li> <li>- Variantieanalyse</li> <li>- Logistische regressie</li> <li>- Qualitative comparative analysis</li> <li>- R</li> </ul>	

**Expertisedomeinen**

- Diabeteszorg
- Etnische minderheden en gezondheid
- Armoede en sociale uitsluiting; armoedebestrijding; armoedebeleid
- Gezondheidszorgbeleid; toegankelijkheid van de gezondheidszorg
- Onderzoeksmethodologie: kwantitatief en kwalitatief onderzoek

**PROFESSIELE ERVARING**

1. September 1994 - September 1995  
 Werkgever: Cultureel Centrum Leuven  
 Functie: Dramaturg  
 Taken: Dramaturgische begeleiding theaterproductie, redactionele werkzaamheden
  
2. Oktober 1995 - Februari 1996  
 Werkgever: Vlaams Theater Instituut, Brussel  
 Functie: Wetenschappelijk medewerker  
 Taken: Onderzoek en redactie Kritisch Theaterlexicon
  
3. Februari 1996 - September 1996  
 Werkgever: Survey § Action, Watermaal – Bosvoorde (marktonderzoek)  
 Functie: Field Manager  
 Taken: Organisatie en begeleiding onderzoek, coördinatie team
  
4. April 1997 - Mei 2000  
 Werkgever: Universitaire Faculteiten Sint-Ignatius Antwerpen (Ufsia)  
 Vakgroep Sociologie en Sociaal Beleid  
 Onderzoeksgroep Oases (o.l.v. Prof. Dr. Jan Vranken)  
 Functie: Wetenschappelijk medewerker  
 Taken: Kwalitatief en kwantitatief onderzoek naar armoede, sociale uitsluiting, geestelijke gezondheidszorg
  
5. Juli 1999 – Juni 2002  
 Werkgever: Theatremakersgroep de Queeste v.z.w., Hasselt  
 Functie: Dramaturg  
 Taken: Dramaturgische begeleiding theatergezelschap en producties, redactionele werkzaamheden, subsidiedossiers, netwerking
  
6. September 2003 – December 2007  
 Werkgever: Arteveldehogeschool, Gent; opleiding Verpleegkunde (70%)  
 Functie: Lector Sociologie / Projectcoördinator Onderzoek  
 Taken: Coördinatie PWO-project 'Gezondheidsbevordering en Armoede', uitvoeren diverse onderzoeken, lector sociologie, lid van de Onderzoeksraad en het Bureau van de Onderzoeksraad Arteveldehogeschool (2003 – 2007)  
 Werkgever: Arteveldehogeschool, Gent; COMPahs (30%)  
 Functie: Onderzoeksbegeleider  
 Taken: methodologische begeleiding onderzoek, lesgever onderzoeksmethodologie, initiatiefnemer en kernlid Kwalitatief Sterk (Vlaams netwerk voor kwalitatief onderzoek).

7. Februari 2008 – Augustus 2008	
Werkgever:	Universiteit Gent, Vakgroep Huisartsgeneeskunde en Eerstelijnsgezondheidszorg
Functie:	Onderzoeksmedewerker
Taken:	Medewerking aan doctoraatsstudie over etnische minderheden en gezondheid (Dr. Stephanie De Maesschalck) methodologische ondersteuning van onderzoeksprojecten over sociale ongelijkheid en gezondheid (Prof. Dr. Sara Willems)
8. September 2008 – Januari 2014	
Werkgever:	Universiteit Gent, Faculteit Farmaceutische Wetenschappen, Eenheid Farmaceutische Zorg
Functie:	Doctoraatsstudent
Taken:	Titel: Adherence to oral hypoglycaemic agents among type-2 diabetes patients of Turkish descent. Systematische literatuurreview, kwalitatief onderzoek, kwantitatief onderzoek.
Promotor:	Prof. Dr. Koen Boussery
Copromotoren:	Prof. Dr. Jean Paul Remon, Prof. Dr. Sara Willems

#### PUBLICATIES

Artikels in internationale, peer-reviewed tijdschriften opgenomen in één van de ISI Web of Science databanken(A1).

Als eerste auteur:

**Peeters,B., Mehuys,E., Van Tongelen,I., Van Bever,E., Bultereys,L., Avonts,D., Yildiz,G., Remon,J.P., Boussery,K. (2012)**

Ramadan fasting and diabetes: an observational study among Turkish migrants in Belgium. *Primary Care Diabetes*, 6(4), 293-296.

**Peeters,B., Van Tongelen,I., Boussery,K., Mehuys,E., Remon,J.P., Willems,S. (2011).**

Factors associated with medication adherence to oral hypoglycaemic agents in different ethnic groups suffering from Type 2 diabetes: a systematic literature review and suggestions for further research. *Diabetic Medicine*, 28(3), 262-275.

**Peeters,B., Van Tongelen,I., Duran,Z., Yüksel,G., Mehuys,E., Willems,S., Remon,J.P., Boussery,K., (accepted for publication in *Ethnicity and Health*).**

Understanding medication adherence among patients of Turkish descent with type 2 diabetes: a qualitative study.

**Peeters,B., Van Tongelen,I., Mehuys,E., Remon,J.P., Willems,S., Boussery,K. (in review)**

Perspectives of general practitioners and community pharmacists on barriers to promoting medication adherence among Turkish migrants with type-2 diabetes.

**Peeters,B., Van Tongelen,I., Mehuys,E., Remon,J.P., Willems,S., Boussery,K. (in preparation)**

Medication adherence in European ethnic minorities: an explorative, cross-sectional study among type-2 diabetes patients of Turkish descent.

Als co-auteur:

**De Visschere,L., de Baat,C., De Meyer,L., van der Putten,G-J., Peeters,B., Söderfelt,B., Vanobbergen,J. (accepted for publication in *Gerodontology*)**  
The integration of oral healthcare into day-to-day care in nursing homes: a qualitative study.

Artikels in internationale, peer-reviewed tijdschriften (A2).

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**Peeters,B., Van Tongelen,I., Boussery,K., Mehuys,E., Willems,S., & Remon,J.P. (2011).**

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#### LEZINGEN EN POSTERPRESENTATIES

Als presenterende auteur (selectie).

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Als co-auteur (selectie).

**Beeckman D., Duprez V., Peeters, B., Vanrolleghem S., De Spiegelaere M., Nuyttens C., De Pover M. (2010).** Diabetes: psychometric evaluation of an instrument to evaluate the effectiveness of education. 15th Annual Conference of the Federation of Diabetes Nurses (FEND), 19-20 september 2010, Stockholm, Zweden.

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ANDERE WETENSCHAPPELIJKE ACTIVITEITEN	
<ul style="list-style-type: none"> <li>• <b>Docent:</b></li> </ul>	<ul style="list-style-type: none"> <li>- Sociologie</li> <li>- Inleiding in kwalitatief onderzoek</li> <li>- Kwalitatieve interviewtechnieken</li> <li>- Kwalitatieve data-analyse</li> <li>- Software voor kwalitatief onderzoek (NVivo, erkend trainer software ontwikkelaar QSR)</li> </ul>
<ul style="list-style-type: none"> <li>• <b>Reviewer:</b></li> </ul>	<ul style="list-style-type: none"> <li>- Tijdschrift voor Sociologie</li> <li>- Clinical Therapeutics</li> <li>- Forum Qualitative Sozialforschung / Forum Qualitative Social Research</li> </ul>
<ul style="list-style-type: none"> <li>• <b>Lid wetenschappelijk comité congres:</b></li> </ul>	<ul style="list-style-type: none"> <li>- Congressen van Kwalitatief Sterk 2006 – 2010</li> <li>- Kwalon 2010</li> </ul>

ANDERE VAARDIGHEDEN	
<ul style="list-style-type: none"> <li>• <b>Talenkennis:</b></li> </ul>	<ul style="list-style-type: none"> <li>- Moedertaal Nederlands</li> <li>- Zeer goede kennis Frans en Engels</li> <li>- Basiskennis Duits</li> <li>- Basiskennis Turks</li> </ul>
<ul style="list-style-type: none"> <li>• <b>Computerkennis:</b></li> </ul>	<ul style="list-style-type: none"> <li>- Windows, Office, Internet, E-mail</li> <li>- Software voor kwalitatief en kwantitatief onderzoek: SPSS, R, AMOS, LISREL, NVivo, fsQCA.</li> <li>-</li> </ul>
<ul style="list-style-type: none"> <li>• <b>Andere:</b></li> </ul>	<ul style="list-style-type: none"> <li>- Rijbewijs B</li> </ul>