

Standardisation in a Multi-Ethnic World: a Paradox?



The validity of guidelines in the treatment of
patients with different ethnic backgrounds

Dyno Radjesh Manna

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Standardisation in a Multi-Ethnic World: a Paradox?

The validity of guidelines in the treatment of patients
with different ethnic backgrounds

Standaardisatie in een multi-etnische wereld: een paradox?

De validiteit van richtlijnen in de behandeling van patiënten
met verschillende etnische achtergronden

Proefschrift

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Introduction | **1**

INTRODUCTION

Since the 1970s clinical practice guidelines have obtained a prominent position in western medicine and health care. Guidelines are meant as an instrument to reduce variation in processes and are originating from the industry. The reason guidelines entered the health care setting was the explicit belief that many, if not most, professionals were (are) working suboptimally through not practising with the best evidence available to their particular discipline or specialisation. By standardising care according to the best available scientific evidence inappropriate practice variation is reduced and health care professionals are supported in offering the most optimal treatment. In the beginning guidelines were based on consensus between experts and during the '90s guidelines became evidence based. Nowadays clinical practice guidelines are considered to be one of the most important tools for quality improvement and quality assurance in health care. As defined by the prominent Institute of Medicine (IOM) from the USA, clinical practice guidelines are "systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances."¹ Besides the obviously large number of advocates, clinical practice guidelines also have many critics in and outside the health care professions. They argue that guidelines lead to "cookbook medicine" and to "de-skilling", resulting in a diminishing quality of care and autonomy of the health care professional.² Advocates counter these arguments by stating that guidelines permit room for individual fine-tuning, that deviations from guidelines are allowed (if motivated), and that formalising a professional group's knowledge base will strengthen the profession's autonomy rather than threatening it. An area that has received less attention in such discussions is the "specific clinical circumstances" mentioned in the IOM's definition. Besides the disease-specific characteristics, the "specific clinical circumstances" usually refer to the age and gender of the patient. However, because of globalisation and the worldwide migration during the last 50 years, the western world became increasingly multicultural giving a new dimension to the discussion on (the validity of) guidelines. The concept of standardisation seems to be in contrast with the increasing diversity in the population. Although the concept of standardisation and guidelines explicitly state that professionals can autonomously deviate from the guidelines, guidelines base their recommendations on the average patient. An important issue in this is the characterisation of this average patient. Guidelines being evidence based it is obvious that the average patient is the average patient studied in the scientific evidence. In guidelines RCTs are considered to be the most powerful evidence (besides meta-analyses) and study participants in RCTs are not seldom formed by white, middle-aged men. So, the average patient in the guidelines could also be best described as being the white middle-aged man. The question arises whether recommendations based on the average patient can be applied to all subgroups of patients. Physicians can of course deviate from guidelines for individual patients, but

is there not reason for structural deviation from guidelines in specific subgroups, i.e. specific ethnic minority groups. Examples of reasons to assume that health care should address the patient's ethnicity as an important determinant are considerable in number. For instance, it seems that some specific diseases are especially found in specific ethnic groups, like sickle cell anaemia in people of African descent.³ Another important issue could be the religious background of the patient. Giving a blood sample for analysis or taking pills during the Ramadan could be very problematic.⁴ Furthermore, insulin derived from pigs or cows is not a treatment option in Muslims or Hindus. The relevance for medical treatment of these examples of ethnic differences is obvious. However, it is not clear whether these or other existing differences should be discussed in guidelines. The consequences of ethnic variation in patients are most evident in general practice in deprived neighbourhoods. In the Netherlands the population of some deprived neighbourhoods exists for more than 80% of ethnic minorities. Some GPs in deprived neighbourhoods have patient populations with patients from more than 60 different ethnic origins. Furthermore, because in the Netherlands the GPs are the gatekeepers of the health care system and they are therefore the first physician somebody who seeks care sees, the consequences in care for ethnic minorities are most manifest in general practice.

Central aim and outline of this thesis

The central question of this thesis is whether guidelines should pay more attention to ethnic differences. Because this study was performed in the Netherlands it focussed on the guidelines of diabetes mellitus type 2, hypertension and asthma in adults of the Dutch College of General Practitioners. The choice for these three conditions was made because of their prevalent and chronic character, these conditions have guidelines of the Dutch College of General Practitioners for many years, and there were indications that ethnic differences probably could be important in some of these conditions. The guidelines of the Dutch College of General Practitioners have an important position in Dutch general practices. The development process is shaped according to the principles of evidence based medicine and is well structured and executed. The development process is often considered as an (international) example of the way evidence based guidelines should be developed.⁵ That is also why the guidelines are highly valued by the general practitioners.⁶ In order to assess the need for ethnic diversity in guidelines it is especially interesting to focus on the best practice regarding guidelines.

The main question was divided into five sub questions:

1. Is there any reason or evidence for paying attention to ethnic differences in these chronic conditions (chapter 2, 3, and 4)? Chapter 2 presents the results of an systematic review of the scientific literature on differences in the prevalence of diabetes mellitus type 2, other cardiovascular risk factors, and cardiovascular

disease between Turkish and Moroccan immigrants compared with the indigenous population in North Western European countries. Chapter 3 presents the results of a comparison of the attention given to ethnic differences in primary care guidelines from the USA, the UK, Canada, and the Netherlands. Chapter 4 focuses further on the guidelines of the Dutch College of General Practitioners and shows results of the comparison of statements about relevant ethnic differences between the guidelines and their supporting evidence.

2. Does the GP's treatment differ between patients of different ethnic origin? This question is answered in chapter 5 in which results are presented of a retrospective analysis of patient files.
3. Is the GP's adherence to guidelines associated with the ethnic background of their patient? Chapter 6 provides an answer by presenting the results of a prospective study in which the adherence to guidelines was determined in specific contacts with patients.
4. Are there any ethnic differences in the association between treatment and clinical outcome of treatment? Chapter 7 shows the result of an analysis of the association between adherence to guidelines and the clinical outcome of treatment.
5. What is the opinion of GPs with many ethnic minorities in practice, regarding the usefulness of the current guidelines in the treatment of ethnic minorities? This question is addressed to in chapter 8 by presenting the results of qualitative interviews with the participating GPs.

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Prevalence of type 2 diabetes mellitus,
other cardiovascular risk factors, and
cardiovascular disease in Turkish and
Moroccan immigrants in North West
Europe: a systematic review.

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ABSTRACT

Background: The prevalence of diabetes, other cardiovascular risk factors, and cardiovascular morbidity and mortality varies between immigrant groups in Western societies, but epidemiological data on these topics are scarce for Turks and Moroccan immigrant living in North West Europe.

Methods: Medline and Embase were systematically searched for studies containing data on the prevalence of diabetes, cardiovascular risk factors, and cardiovascular morbidity and mortality in Turkish or Moroccan immigrants living in Northwestern European countries.

Results: Eighteen studies were identified. Corresponding findings were a high prevalence of type 2 diabetes in Turkish and Moroccan immigrants, a high prevalence of smoking among Turkish men, and a very low prevalence of smoking in Moroccan women compared to the indigenous population. Because of lack of valid studies, no definite conclusions could be drawn for in particular blood pressure and lipids. One German study showed exceptionally lower cardiovascular mortality rates in Turkish immigrants.

Conclusion: The reviewed studies yielded insufficient evidence for a good quality comparison of the cardiovascular risk profile between Turkish and Moroccan immigrants and indigenous populations. Diabetes mellitus was more prevalent in Turkish and Moroccan immigrants, smoking more prevalent in Turkish males, and very rare in Moroccan females.

INTRODUCTION

The prevalence of diabetes and other cardiovascular risk factors, and the incidence cardiovascular disease, varies between ethnic groups¹⁻⁴ and is influenced by genetic, environmental, social, and cultural factors⁵⁻¹⁰. This has been well described for ethnic minority groups of Black African or South Asian descent living in Western countries¹¹⁻¹⁷, but for other large ethnic minority groups living in West European countries, knowledge on these topics is limited. The largest foreign nationality in the European Community by far is Turkey, with over 3 million Turkish immigrants. Most Turkish immigrants live in Germany (about 2 million), but also in the Netherlands they form the largest ethnic minority group with 330,000 persons. Moroccan immigrants form one of the largest ethnic minority groups in France (500,000 persons), Belgium (125,000 persons), and the Netherlands (280,000 persons).

Studies have shown that populations in European Mediterranean countries (Italy, Portugal, France, Yugoslavia, Greece, and Spain) have a lower mortality rate from ischemic heart disease compared to northern European countries^{18,19}. Although Turkey and Morocco are also Mediterranean, a Turkish study reported that coronary death rates in Turkey can be ranked among the highest in Europe²⁰. It is, however, unknown whether cardiovascular risk factors and the cardiovascular death rates are influenced by migration of Turks and Moroccans to western European countries.

Given the increasing number of elderly among the Turkish and Moroccan immigrant populations, it is important to have some prognosis concerning cardiovascular morbidity and mortality in these groups soon.

To gain insight on this topic, we performed a systematic review to establish the prevalence of diabetes and other cardiovascular risk factors in Turkish and Moroccan immigrants in western European countries, and to determine what is known about cardiovascular mortality in these groups.

METHODS

Study selection

Analogue searches were made in Medline (1985–2002) and Embase (1985–2002) using the terms shown in Box 1. Articles were selected if the title or abstract made clear that the paper reported original prevalence data on diabetes and other cardiovascular risk factors (including hypertension, lipids, smoking, obesity), and cardiovascular morbidity and mortality on samples of Turkish or Moroccan adults living in a North West European country. Studies based on children and published studies before 1985 were excluded. In addition, we checked the reference lists from selected publications to collect missed publications. We also used the references of a recent report by the Dutch National

Institute for Public Health and the Environment ²¹, which investigated Dutch reports on cardiovascular risk factors in ethnic minorities in the Netherlands.

The selection was independently performed by two persons (PU and DM). In all cases of disagreement, consensus was reached.

BOX 1

Ethnic groups

1. Turks OR Turkish OR "Moroccan*" OR Arabs OR Arab OR "North African**"

North West European

2. Netherlands OR Dutch OR Belgium OR Belgian OR "German*" OR Denmark OR Danish OR UK OR English OR France OR "French*" OR Sweden OR Swedish OR Norway OR Norwegian OR Finland OR "Finn*" OR "North Europ**"
3. #1 AND #2

Diabetes mellitus type 2

4. "Diabetes mellitus", "Non-insulin-dependent" [MESH] OR NIDDM OR "Noninsulin dependent" OR "Non insulin dependent" OR "Non insuldependent" OR "Non-insulin-dependent" OR "Non-insulin dependent" OR "Type II diabetes" OR "Type 2 diabetes" OR "Diabetes type 2" OR "Diabetes type II"

Epidemiology

5. "Vital Statistics" [Mesh] OR Mortality OR Prevalence OR Incidence OR Morbidity Risk factors
6. Smoking OR Smoking [MESH] OR Cholesterol OR Lipids [MESH] OR "Lipid*" OR "Cardiovascular risk factor*" OR "Risk factors"[MESH] OR Hypertension [MESH] OR Hypertension OR "Blood pressure"

Cardiovascular disease

7. "Cardiovascular Diseases"[MESH] OR "Vascular disease" OR "Coronary artery disease" OR "Coronary disease" OR "Coronary heart disease" OR "Myocardial infarction" OR Cardiovascular OR "Cerebrovascular accident" [Mesh] OR Stroke OR "CVA" OR "Transient ischemic attack" OR "TIA" OR "Cerebral hemorrhage" OR "Carotid stenosis"
8. #4 OR #5 OR #6 OR #7
9. #3 AND #8
10. (Limits: Adult: 19+ years; text word)

Study selection and data extraction

The following methodological characteristics of the cross-sectional studies with prevalence data on diabetes and cardiovascular risk factors were evaluated: study population, sampling method (random versus nonrandom), sample size by ethnic group, age of the studied groups, response rate, and the methods used to identify patients and measuring cardiovascular risk factors and mortality.

TABLE 1

Characteristics of 14 studies from the Netherlands (NL) and Germany (D) with data on the prevalence of diabetes, cardiovascular risk factors, and cardiovascular disease in Turkish (T) and Moroccan (M) immigrants and the indigenous (I) population

First author & publication year	Study population	Sampling method	Age range (years)	Sample size by ethnic group	Response rate (%)	Available data	Method of data collection
Bleeker ²²	Amsterdam, Rotterdam, Utrecht, Gouda (NL)	random	12–69	T 1269 M 1266 I 1221	58	diabetes, hypertension, smoking	patient interview
Brussaard ²³	Amsterdam, Utrecht, Twente (NL)	random	24–58	T 50 M 25 I 79	15	cholesterol	actively measured
CBS ²⁴	general population (NL)	random	all ages	T 5306 I 15,860	83	hypertension, obesity	patient interview
Dijkshoorn ²⁵	population Amsterdam (NL)	random	35–74	T 774 M 686 I 903	71	diabetes, obesity, smoking	patient interview
Dijkstra ²⁶	diabetes patients admitted to hospital (NL)	no sampling ^a	not given	T 59 I 185	NR	ischemic heart disease	actively measured
Health survey the Hague ²⁷	population the Hague (NL)	random	16–75	T 287 M 147 I 867	43	diabetes, hypertension, smoking	patient interview
Köycü ²⁸	population Amsterdam (NL)	random	18–64	T 149 I 881	66	hypertension, obesity, smoking	actively measured
Middelkoop ²⁹	14 general practices (NL)	no sampling ^a (women not studied)	40–55	T 44 M 40 I 1961	NR	hypertension, obesity, smoking	derived from medical records
Porsch ³⁰	25 general practices (D)	no sampling ^b	>35	T 480 I NS	NR	hypertension, obesity, smoking	actively measured
Reijneveld ³¹	population Amsterdam (NL)	random	16–64	T 118 M 176 I 2448	61	smoking	patient interview
Swinkels ³²	general population (NL) ^c	random	>16	T 3371 I 9634	83	smoking	patient interview
Uniken-Venema ³³	population Rotterdam (NL)	random	16–69	T 248 I 241	67	diabetes, hypertension	patient interview
Weide ³⁴	103 general practices (NL)	no sampling ^a	18–65	T 1165 M 853 I 1471	NR	cardiovascular disease	derived from medical records
Weijers ³⁵	population of one borough in Amsterdam (NL)	no sampling ^a	28–84	T 1728 M 2021 I 8249	NR	diabetes	actively measured
Weijers ³⁶	diabetes patients admitted to hospital (NL)	no sampling ^a	20–90	M ^d 113 I 603	NR	cardiovascular disease	actively measured

NR = not reported, NS = not studied

^a All identified patients were included, no estimation was made of the proportion of non-identified patients.

^b Nonrandom: patients voluntarily underwent a health check-up and were not compared with the indigenous population.

^c Data derived from the CBS study.

^d Including other North African groups.

RESULTS

The searches on Medline and Embase yielded 354 papers. From these papers, 20 were selected based on title or abstract; there was a disagreement on 1 of the 20 papers (95% agreement). Ten of these studies had original prevalence data and were included in this review. Checking the references lists yielded an additional eight studies. Thus, finally, 18 publications were reviewed. Of these 18 reports, 16 had data on Turkish and 10 on Moroccan individuals.

Of the 18 selected studies, 12 were cross-sectional studies with prevalence data on diabetes and cardiovascular risk factors, 4 studies had data on incidence of cardiovascular disease, and 2 on cardiovascular mortality. Eleven studies were based in community settings and five in general practice or hospital. Most studies were specifically designed to focus on the prevalence of diabetes or other cardiovascular risk factors compared with the general or indigenous population. One study was designed to describe the use of a sentinel practice network, and two studies to describe differences in diabetes-related complications between various groups. One study did not compare prevalence data³⁰, and one study used data on the indigenous population from other studies as a comparison¹⁴.

Table 1^{22–36} shows that all studies, except one³⁰, were conducted in the Netherlands. Methods to establish the Turkish and Moroccan descent included name analysis^{24,28,32}, country of birth³⁰, registered as having the Moroccan nationality²², data from the municipal register (country of birth and parents' country of birth)^{25,27,31–36}, and as reported by the GP²⁹. The method was not mentioned in one study²⁶. The age range varied widely between studies. Response rates ranged from 43%²⁷ to 83%²⁴. In six studies, the response rates were not mentioned, probably because data were extracted from an existing database.

Smoking behavior was assessed with self-reports. Prevalence of hyperglycemia was determined by self-reports in three studies^{22,25,27} or blood samples^{30,35}. The presence of hypertension was assessed by self-reports in three studies^{22,24,27}, blood pressure measurement^{22,24}, or medical record²⁴. The lipid profile measurement was performed by taking blood samples^{28–30}. The presence of coronary heart disease was assessed by self-reports^{25,27}, from medical records³⁴, or based on ECG registrations³⁰.

Prevalence of diabetes

Five studies had data on the prevalence of diabetes (Table 2). In four studies with an indigenous comparison group, the prevalence of diabetes was 1.3–2.8 times higher in Turks and 1.9–3.2 times higher in Moroccans. The available data did not show a clear gender difference. In the only German study³⁰, the age-standardized diabetes prevalence rate in Turks was 7.8% in men and 9.9% in women, which was comparable with the prevalence of diabetes in Turks in Dutch studies, but 30% lower than the prevalence in German women (compared to Turkish women).

TABLE 2

Findings from 14 studies with data on the age- and gender-adjusted prevalence of diabetes, hypertension, smoking, and overweight or obesity in Turkish (T) and Moroccan (M) immigrants and indigenous (I) inhabitants in the Netherlands and Germany

First author	Method of data collection	Turks			Moroccans			Indigenous			P value for difference Turks/Moroccan versus indigenous population
		Men	Women	All	Men	Women	All	Men	Women	All	
<i>Prevalence of diabetes</i>											
Bleeker ²²	self-reported	–	–	5 ^a	5	5	5	–	–	0.5 ^a	NR
Dijkshoorn ²⁵	self-reported	–	–	3.8	–	–	3.8	–	–	2.0	NR
The Hague ²⁷	self-reported	–	–	4	–	–	7	–	–	3	NR
Porsch ³⁰	actively screened: fasting plasma (criteria not given)	7.8	9.9	–	–	–	–	NCIP			
Weijers ³⁵	actively screened whole blood glucose (WHO criteria '85)	12.3	9.9	10.9	11.9	14.2	121.4	4.0	3.6	3.8	<i>P</i> < 0.001
<i>Prevalence of hypertension</i>											
Bleeker ²²	self-reported	–	–	4 ^a	7	9	8	–	–	5 ^a	NR
CBS ²⁴	self-reported	3	3	3	NS	–	–	3	3	3	NR
The Hague ²⁷	self-reported	–	–	10	–	–	8	–	–	11	NR
Köycü ²⁸	actively screened	15	22	17	NS	–	–	NR			NR
Middelkoop ²⁹	data derived from, medical records (hypertension defined as DBP >95)	17	–	–	–	–	–	9	–	–	not statistically significant
Porch ³⁰	actively screened, hypertension defined as SBP >160 or DBP >95 mmHg	12.2	10.3	–	NS			NS			
<i>Prevalence of smoking</i>											
Bleeker ²²	self-reported	56	21	40	34	2	17	49	38	43 ^a	NR
Dijkshoorn ²⁵	self-reported	–	–	45	–	–	19	–	–	42	NR
The Hague ²⁷	self-reported	49	30	–	27	3	–	39	31	31	NR
Köycü ²⁸	self-reported	60	34	52	NS	50	48	49	NR		
Middelkoop ²⁹	data derived from medical records	73	–	–	54	–	–	42	–	–	T–I: <i>P</i> < 0.05
Porsch ³⁰	self-reported	42	13	–	NS			NS			
Reijneveld ³¹	self-reported	69	28	49	23	1	14	44	47	45	NR
Swinkels ³²	self-reported	58	22	42	NS			44	37	41	NR
CBS ²⁴	self-reported, criterion obesity: BMI >30	10	20	–	NS			4	5	–	NR
Dijkshoorn ²⁵	self-reported, criterion obesity: BMI >25	–	–	54	–	–	36	–	–	30	NR
Köycü ²⁸	actively screened, criterion not defined (increased BMI)	60	60	–	NS			NS			
Middelkoop ²⁹	derived from the medical record, criterion obesity: BMI >30	30	–	–	17	–	–	13	–	–	T–I: <i>P</i> < 0.05
Porsch ³⁰	actively screened, criterion obesity: BMI >30	21	48	–	NS			NS			

NCIP = not compared to the indigenous population, NS = not studied, NR = not reported, BMI = body mass index, DBP = diastolic blood pressure, SBP = systolic blood pressure, T–I = Turks versus Indigenous population.

^a Data on the Turkish and Dutch comparison groups originate from the CBS study²⁴.

Prevalence of cardiovascular risk factors

Hypertension

Five studies had data on the prevalence of hypertension in Turks and two in Moroccans (Table 2). The prevalence of hypertension in these studies varied widely. Three studies, using self-reported data, revealed no clear differences in the prevalence of hypertension between the Turkish, Moroccan, and the indigenous sample^{22,24,27}. One study with a small sample of Turkish males (using data from the medical record) showed a higher prevalence of hypertension in Turks, although the difference was not statistically significant²⁹. Two studies, with blood pressure measurements, did not directly compare the prevalence of hypertension with the indigenous population, but one of these studies compared blood pressure levels between Turks and Dutch, and showed a higher mean blood pressure level in both Turkish men and women aged over 30 years²⁸.

Plasma lipids

One Dutch study showed lower total cholesterol levels in Turkish persons than in the native Dutch population (mean total cholesterol in Turks, 4.8 mmol/L vs. 5.4 in Dutch)²⁸, whereas a German study showed comparable total cholesterol levels in Turks and Germans (mean level 6.1 mmol/L)³⁰. HDL-cholesterol levels in Turkish males were lower in both the Dutch and German studies compared to the indigenous population (mean HDL-cholesterol in Turkish Dutch males, 0.96 mmol/L vs. 1.20 mmol/L in Dutch males²⁸, and 0.93 mmol/L in Turkish Germans³⁰). One study compared total cholesterol levels in a small female Turkish (n = 50) and Moroccan (n = 25) group with Dutch indigenous females. The mean cholesterol level was 5.0 mmol/L in Turkish, 5.3 mmol/L in Moroccan versus 5.5 mmol/L in Dutch females (P < 0.05 between the Turkish and Dutch females). In Turkish and Moroccan females, 8% had a cholesterol level >6.5 mmol/L versus 13% in Dutch females (NS)²³.

Smoking

The prevalence of smoking was reported in seven studies (Table 2). The differences in the prevalence of smoking between men and women varied considerably between the ethnic groups. All studies show a higher prevalence of smoking in Turkish men (range, 42–73%) compared to Dutch men (range, 39 – 50%)^{22,27 – 29,31,32}. The lowest prevalence was found in Moroccan women (range, 1–3%)^{22,27,31}. The prevalence in other women ranged from 13% to 34% in Turkish^{22,27,28,30–32} and from 31% to 48% in Dutch women^{22,27,28,31,32}.

Obesity

The prevalence of overweight and obesity was reported in five studies (Table 2). In three of these reports, the prevalence was compared with the indigenous population. Overweight or obesity was more prevalent in Turks^{24,25,29}, equally or more prevalent

TABLE 3

Data from the nine studies with data on the prevalence of cardiovascular disease and cardiovascular mortality in Turkish and Moroccan immigrants and indigenous inhabitants in the Netherlands, Germany, and France

	Turks	Moroccans	Indigenous population	P value	Study
Cardiovascular disease (general population)					
Self-reported (%)	28	17	21	NR	Dijkshoorn ²⁵
Self-reported heart disease (%)	2	1	3	NR	The Hague ²⁷
Self-reported stroke (%)	1	0	1	NR	The Hague ²⁷
Diagnosed by GP [OR (95% CI)]	0.85 (0.25–0.82)	0.46 (0.55–1.32)	reference	–	Weide ³⁴
Diagnosed (ECG) (men, women) (%)	10.4, 6.5		10.5, 7.2	NR	Porsch ³⁰
Cardiovascular disease (in diabetes patients)					
Diagnosed (ECG) (%)	–	1.1	9.0	$P < 0.001$	Weijers ³⁶
(age-adjusted odds ratio)	0.19 (0.06–0.65)	–	reference	$P < 0.02$	Dijkstra ²⁶ Dijkstra ²⁶
<i>Mortality from cardiovascular disease in the Netherlands, Germany and France</i>					
Cardiovascular mortality (percentage of all-cause mortality)					
Netherlands	25–44 years (m, f)	28, 19	22, 16	NR	Mackenbach ³⁷
	45–64 years (m, f)	48, 40	44, 28	NR	
Germany	25–64 years (m, f)	34, 27			
France	25 years and above				Khlat ³⁸
	disease of the circulation system (m, f) of which:	18, 26			
	ischemic heart disease (m, f)	7, 5			
	cerebrovascular disease (m, f)	4, 8			
	other vascular disease (m, f)	8, 14			
Cardiovascular Mortality (death rates per 100,000)					
Germany	25–44 years (m, f)	76, 41	107, 44		Razum ³⁹
	45–64 years (m, f)	789, 498	1338, 747		
Mortality risk (relative risk) ^a					
France	Disease of the circulatory system (m, f) of which:	0.71, 1.13	reference	$P < 0.01$, $P < 0.01$	Khlat ³⁸
	ischemic heart disease (m, f)	0.65, 0.93	reference	$P < 0.01$, NS	
	cerebrovascular disease (m, f)	0.60, 0.98	reference	$P < 0.01$, NS	
	other vascular disease (m, f)	0.83, 1.35	reference	$P < 0.01$, $P < 0.01$	

m, f = male, female, NR = not reported, NS = not statistically significant.

^a Data on the German comparison group originate from a different study. 1072 P.J.M. Uitewaal et al. / Preventive Medicine 39 (2004) 1068–1076

in Turkish women than in men. Differences between Moroccans and the indigenous population (two reports) were less clear^{25,29}.

Cardiovascular disease and mortality

Table 3 shows the results of six studies with data on the prevalence of cardiovascular disease: four studies in the general population^{25,27,30,34} and of two studies in type 2 diabetes patients admitted to hospital^{26,36}. The prevalence of cardiovascular disease was comparable in Turkish immigrants and the Dutch or German indigenous population^{25,27,30,34}. In Turkish diabetes patients, ischemic heart disease was found less often than in

Dutch diabetes patients (9% vs. 23%; $P < 0.02$)²⁶. Compared to the indigenous population, all available data show lower prevalence of cardiovascular disease in Moroccans^{25,27,34}. Three studies compared cardiovascular mortality in Turks^{37,39} or Moroccans³⁸ with the indigenous population in the Netherlands, Germany, and France. Cardiovascular mortality as a percentage of the overall mortality was higher in Turkish immigrants in the Netherlands, particular in Turkish females³⁷. Such a higher percentage in cardiovascular mortality in females was also found in the German population³⁹. However, age-adjusted cardiovascular disease mortality rates in Germany were 43% lower in Turkish men than in German men (period between 1981 and 1994), and in Turkish women, the cardiovascular mortality rates were 21% lower than in German women (period between 1993 and 1994)³⁹. The French study showed that Moroccan men had a lower mortality risk than men in the general population, but Moroccan women had a higher mortality risk compared to the French general population³⁸. Two reports had data on stroke in Turks or Moroccans and the indigenous population^{27,38}, and no clear differences between the groups were observed.

DISCUSSION

The reviewed studies proved only a limited number of valid estimates of cardiovascular risk in Turks or Moroccans immigrants versus the indigenous population. Available evidence shows that diabetes mellitus is more prevalent in both Turkish and Moroccan immigrants; smoking more is prevalent in Turkish males and less prevalent in Moroccan females. In addition, HDL-cholesterol seems lower in Turkish men, and the prevalence of obesity is higher in Turkish men and women. Data on cardiovascular death rates are rare: in one study, the rate was strikingly lower in Turkish German immigrants compared to the German population.

Study quality

To assess study quality, important indicators of quality are the methods to measure cardiovascular risk, the response rate and sample size. In most studies, measurements were based on self-reports and are therefore inadequate for assessing the “true” prevalence of hyperglycemia or diabetes, hypertension, and hypercholesterolemia, and the presence of cardiovascular disease. The response rate was often low (less than 70%) in five studies, and not even mentioned in five other studies. Therefore, response could have biased the results. In addition, the study sample size in about 50% of the studies was less than 250 persons, and due to the population structure of immigrant groups, the proportion of elderly immigrants in all study samples was very small. Because risk factors are related to aging^{40,41}, larger numbers of elderly immigrants are needed in a study to allow valid conclusions to be drawn.

Prevalence of diabetes and other cardiovascular risk factors

Type 2 diabetes is more frequent among Turkish and Moroccan immigrants than among Europeans. A higher frequency of type 2 diabetes among immigrants was also reported in many other studies^{8,10,42,43}. This phenomenon can be explained by genetic susceptibility, which is unmasked by environmental factors such as nutritional factors, obesity, physical inactivity, and stress^{10,43}. Obesity is strongly associated with type 2 diabetes^{44,45}, and the high prevalence of diabetes may be caused by a high prevalence of obesity in Turks and Moroccans^{46,47}.

The prevalence of smoking in Turkish male immigrants is comparable to the reported prevalence among Turks in Turkey (58% versus 51%) and higher than in the indigenous population (44%). The prevalence of smoking in Turkish female immigrants is, however, higher than reported among Turkish females in Turkey (24% vs. 11%)⁴⁰. This might be explained by an unfavorable influence of Westernization on smoking behavior among Turkish women, but in particular, not in Moroccan female immigrants, since smoking is rare in the latter group. However, this difference might also be due to selection of the migrant population.

For total cholesterol and hypertension, the picture remains unclear. Studies including measurements in large samples in Turkish or Moroccan immigrants are rare and produce contrasting results.

Cardiovascular disease and mortality

In one of the few available studies, the cardiovascular mortality rate in Turkish immigrants in Germany (both men and women) was lower than the rate in the German indigenous population, particular in men, while the proportion of all-cause mortality attributable to cardiovascular disease was somewhat higher in Turkish men and evidently higher in Turkish women. The combination of a higher contribution of cardiovascular disease to mortality in Turkish immigrants and lower cardiovascular death rates can only be explained by an even lower overall mortality in Turks, particular in Turkish women, compared to the indigenous population. Low overall mortality rates in immigrants are found in Germany⁴⁸ and were also reported among Turkish and Moroccan immigrants in the Netherlands^{49,50}, in Sweden⁵¹, and North African immigrants in France⁵². Lower mortality rates among immigrants are often explained by “the healthy migrant effect”, implying that migrants represent a relatively healthy selection from a population. The fact that in a French study, North African women had a higher risk of dying from a cardiovascular disease and a similar overall mortality risk is probably partly attributable by a lack of such a positive selection, since the reason for migration was not related to work⁵². Other explanations for low overall mortality rates in migrants are also possible.

Firstly, the studied populations are not fixed but are largely extended by newcomers⁵³.

Data on the Turkish population in Germany show a 27% increase of the Turkish population between 1981 and 1994, but the same data show that a large number (over 40%) of Turkish immigrants aged 35 years and older left Germany in this same period³⁹. Thus, low mortality rates in immigrants could be the result of loss to follow-up. Secondly, data on remigration are not given to the national registration authorities, resulting in overestimations of the immigration population (i.e., the denominator of the mortality rate), resulting in lower mortality rates. Indeed, by trying to adjust for such an overestimation of the immigrant population, the mortality rates in immigrant Turks in Sweden increased⁵¹. A very recent report (September 2003) from Sweden showed higher relative risk of cardiovascular disease in Turks compared to Swede [in men, 1.44 (95% CI 1.24–1.66); in women, 1.52 (1.23–1.88)]⁵⁴. This finding gives further proof that the CVD rates in Turkish immigrants are possibly underestimated.

Search limitations

The first step was a search in MEDLINE, and EMBASE yielded 354 papers of which 20 were selected. Most of the not-selected articles contained no original prevalence data on diabetes or cardiovascular risk factors or involved other groups than the Turks or Moroccans. With the second step, we searched the selected reports to collect missed publications. This, however, concerns earlier reports; therefore, recent publications (from 2002) may have been missed. Furthermore, by using a Dutch report investigating other Dutch reports on cardiovascular risk as source for identifying relevant publications, the chance for a Dutch study to be selected for this review is larger than studies from other countries. This could have led to over-presentation of Dutch studies in this review. However, this potential overpresentation of Dutch studies probably did not effect our main conclusions on diabetes and smoking because the different studies reviewed all had similar conclusions.

We conclude that in other minority groups in Western societies, type 2 diabetes in Turkish and Moroccan immigrants is more prevalent than among the indigenous population, and smoking is more prevalent in Turkish men and rare in Moroccan women. The available data on the prevalence of the other cardiovascular risk factors (hypertension and lipid profile) and cardiovascular disease in these groups are, however, insufficient to allow definite conclusions. More studies using objective screening methods (such as ECG and blood samples) and well-standardized criteria for the diagnosis of cardiovascular disease are needed. The finding of lower cardiovascular mortality rates in a single study in Turkish men requires confirmation from future studies.

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Ethnic specific recommendations in
clinical practice guidelines: a first
exploratory comparison between
guidelines from the USA, Canada, the
UK, and the Netherlands.

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ABSTRACT

Objectives: To investigate whether clinical practice guidelines in different countries take ethnic differences between patients into consideration and to assess the scientific foundation of such ethnic specific recommendations.

Design: Analysis of the primary care sections of clinical practice guidelines.

Setting: Primary care practice guidelines for type 2 diabetes mellitus, hypertension, and asthma developed in the USA, Canada, the UK, and the Netherlands.

Main outcome measures: Enumeration of the ethnic specific information and recommendations in the guidelines, and the scientific basis and strength of this evidence.

Results: Different guidelines do address ethnic differences between patients, but to a varying extent. The USA guidelines contained the most ethnic specific statements and the Dutch guidelines the least. Most ethnic specific statements were backed by scientific evidence, usually arising from descriptive studies or narrative reviews.

Conclusion: The attention given to ethnic differences between patients in clinical guidelines varies between countries. Guideline developers should be aware of the potential problems of ignoring differences in ethnicity.

INTRODUCTION

Over the past 20 years clinical practice guidelines have become an increasingly popular tool for implementation of scientifically based clinical information to improve the quality of health care. Many countries have produced such guidelines, mainly via specialist and/or general practice organisations. As defined by the Institute of Medicine (USA), clinical practice guidelines are “systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances”.¹ These statements should be based on the best available scientific evidence and practical knowledge; however, the increasing number of clinical guidelines has stimulated discussion about their value.²⁻⁶

An area that has received less attention in such discussions is the “specific clinical circumstances”. Besides the disease specific characteristics, the “specific clinical circumstances” usually refer to the age and sex of the patient. However, with the increase in migration to western countries during the last 50 years, these western countries have increasingly become more multicultural and physicians are increasingly confronted with patients from diverse ethnic groups. In some of these groups particular diseases can be more prevalent or more severe, and this may also determine the patient’s clinical circumstance.⁷⁻¹⁰ Ignorance of ethnic differences between patients could lead to inferior quality of care for ethnic minorities. Many potentially avoidable procedures such as amputations, avoidable hospital admissions and readmissions, avoidable pain from cancer, untreated disease, and deaths are associated with a lower quality of care for ethnic minorities.^{11 12} The question as to whether ethnicity should be a specific clinical circumstance systematically taken into consideration in clinical practice guidelines has not yet been fully addressed. The aim of the present study was to investigate whether clinical practice guidelines in different countries take ethnic differences between patients into consideration, and the scientific basis and strength of such ethnic specific recommendations.

METHODS

The clinical guidelines for three prevalent and chronic health problems—type 2 diabetes mellitus, hypertension, and asthma—used in four western countries were examined between 2000 and July 2001. These particular health problems were selected because of the relatively high impact of these diseases in western countries and because of the expected differences between members of different ethnic groups. For these three health problems primary care guidelines from national organisations in the USA, Canada, the UK, and the Netherlands were analysed (n=13; one guideline per disease from each country except the Dutch asthma guidelines which consisted of two separate guidelines, one for diagnostics and one

BOX 1**Categories of strength of evidence of statements in clinical guidelines (developed by the North of England evidence-based guideline development project)**

- Ia: Evidence from meta-analysis of randomised controlled trials
- Ib: Evidence from at least one randomised controlled trial
- IIa: Evidence from at least one controlled study without randomisation
- IIb: Evidence from at least one other type of quasiexperimental study
- III: Evidence from descriptive studies, such as comparative studies, correlation studies and case controlled studies
- IV: Evidence from expert committee reports or opinions or clinical experience of respected authorities, or both.
- IV*: Narrative reviews

Narrative reviews could not be properly categorised into the categories of the North of England evidence-based guideline development project. For this reason we added IV to the existing categories.

for treatment). The USA guidelines were developed by the National Heart, Lung and Blood Institute (asthma 1997; hypertension 1997) and the American Diabetes Association (2001),¹³⁻¹⁵ the Canadian guidelines by the Canadian Medical Association (asthma 1999; hypertension 1999; diabetes 1998),¹⁶⁻¹⁸ the British guidelines by the British Thoracic Society (1997), the British Hypertension Society (1999), and Diabetes UK (2000),¹⁹⁻²¹ and the guidelines used by Dutch general practitioners (GPs) were developed by the Dutch College of General Practitioners (asthma 2001; hypertension 1997; diabetes 1999).²²⁻²⁵ Because some guidelines covered the whole spectrum of care and others focused on primary care only, we studied only the primary care sections of the different guidelines. Each guideline was carefully examined (by DRM) and any ethnic specific statement and/or recommendation made was marked and noted. This procedure was repeated (by MAB) and an inter-rater agreement was calculated. Consensus was reached in all cases of disagreement. The identified statements were then organised into the following coherent themes:

- epidemiology (including aetiology);
- diagnostics (including screening);
- treatment (including therapy);
- patient education;
- (content of) medical record;
- (overall) cultural sensitivity.

The statements were designated either as merely empirical information/facts or as specific recommendations in the guidelines. The underlying scientific evidence for each

ethnic specific statement was collected by checking all the references mentioned in the guideline for the specific statements; by reading the evidence, the strength of the evidence was then graded according to an adjusted version of the schemes of the North of England guideline development project (box 1).²⁶

RESULTS

The overall inter-rater agreement was good. Forty seven segments of text regarding ethnic differences were identified in the guidelines, of which 42 were identified by both authors (inter-rater agreement: 89%). All 47 were included in the analysis.

TABLE 1

Guidelines on diabetes mellitus type 2: comparison between countries on ethnic specific statements ²⁷⁻⁴⁰						
Category	Type of statement	Statement about ethnic differences	Country	Evidence	Strength	
Epidemiology	Empirical	Higher prevalence	USA	Fujimoto (1987) ²⁷	III	
				Zimmet (1992) ²⁸	IV*	
			CAN	Harris (1995) ²⁹	IV*	
				Dean (1992) ³⁰	III	
				Delisle (1993) ³¹	III	
				Fox (1994) ³²	III	
				Harris (1997) ³³	III	
				Harris (1997) ³⁴	III	
				Dean (1998) ³⁵	IV	
				Tuomilehto (1992) ³⁶	IV	
				UK	No reference	-
				NL	Berghout (1995) ³⁷	III
			Bongers (1995) ³⁸		III	
			Diagnostics	Recommendation	Testing for diabetes at younger age or more frequently	USA
CAN	No reference	-				
Recommendation	Screening if patient is 45 years (or older) and member of ethnic group	NL		Berghout (1995) ³⁷ †	III	
				Bongers (1995) ³⁸ †	III	
Recommendation	Aggressive screening for complications	CAN		Querido (1995) ³⁹	III	
				Reitsma (1995) ⁴⁰	IV*	
Recommendation	Community based screenings programs should be established	CAN		Harris (1997) ³³ †	III	
				Harris (1997) ³³ †	III	
Recommendation	Primary prevention programs initiated by Aboriginal communities should be encouraged	CAN		Delisle (1993) ³¹ †	III	
				Harris (1997) ³³ †	III	
Recommendation	In identifying patients the higher prevalence should be remembered	UK		No reference	-	
Patient education	Recommendation	Nutrition recommendations should consider cultural and ethnic background		USA	No reference	-
					CAN	No reference
Medical record	Recommendation	Medical history and management plan should consider important cultural factors	USA	No reference	-	
Cultural sensitivity	Recommendation	Respect for unique cultural issues	CAN	No reference	-	

*Narrative reviews.
†There was no reference mentioned for this particular statement in the guideline, but because this statement is based on information about risk factors (high prevalences), it is probably based on the evidence about a higher prevalence in certain ethnic groups.

Ethnic specific information in diabetes guidelines

Table 1 gives the analysis of the diabetes guidelines. All four guidelines made an empirical statement about a higher prevalence of diabetes among certain ethnic groups. The US, Canadian and, to a lesser extent, the UK and Dutch guidelines had some additional statements (related mainly to diagnostics/screening) about the consequences of this higher prevalence. The statements in the Canadian guideline were presented in a separate section dedicated to diabetes among their aboriginal population, except the recommendation to obtain insight into the ethnic and cultural influences on the nutrition of the patient.

TABLE 2

Guidelines on hypertension: comparison between countries on ethnic specific statements^{8 41-58}

Category	Type of statement	Statement about ethnic differences	Country	Evidence	Strength		
Epidemiology	Empirical	Higher prevalence, more severe and higher risk for complications	USA	Klag (1997) ⁴¹	IIb		
				Burt (1995) ⁴²	III		
				Fang (1996) ⁴³	III		
				Singh (1996) ⁴⁴	III		
				Havas (1996) ⁴⁵	IV*		
				Hall (1997) ⁴⁶	IV*		
			UK	Balarajan (1991) ⁵⁶	III		
				McKeigue (1991) ⁵⁷	III		
				Cappuccio (1997) ⁸	III		
				Williams (1995) ⁵⁸	IV		
Treatment	Empirical	Difference in response to pharmacological treatment	USA	Townsend (1990) ⁴⁷	Ib		
				SOLVD (1991) ⁴⁸	Ib		
				Materson (1993) ⁴⁹	Ib		
				Chen (1993) ⁵⁰	IIa		
				Chen (1995) ⁵¹	IIa		
				Materson (1993) ⁴⁹	Ib		
			UK	Materson (1993) ⁴⁹	Ib		
				Weinberger (1996) ⁵²	IV*		
			USA	No reference	-		
				No reference	-		
	Recommendation	Black subjects require multi-drug therapy because of more severe hypertension	USA	Burt (1995) ⁴² †	III		
				Hall (1997) ⁴⁶ †	IV*		
				Burt (1995) ⁴² †	III		
				Hall (1997) ⁴⁶ †	IV*		
				UK	McKeigue (1991) ⁵⁷	III	
					Williams (1995) ⁵⁸	IV	
				UK	Good blood pressure control important in South Asians with diabetes	No reference	-
					Aspirin and/or statin treatment may be indicated for South Asians at high risk of CHD	No reference	-
				CAN	The start of drug therapy should be influenced by black race	No reference	-
				Patient education	Empirical	Requirement of more focused education	USA
Howard (1996) ⁵⁴	III						
Winkleby (1996) ⁵⁵	III						
Havas (1996) ⁴⁵	IV*						
UK	Advice to reduce fat and refined sugar intake and to increase exercise	No reference	-				

*Narrative reviews.

†There was no reference mentioned for this particular statement in the guideline, but because this statement is based on information about risk factors (high prevalences), it is probably based on the evidence about a higher prevalence in certain ethnic groups.

Scientific basis of ethnic specific information in diabetes guidelines

For diabetes the different guidelines used different sources of evidence (research papers) for their ethnic specific statements. The evidence was mainly type III (descriptive) prevalence studies and all addressed their own national situation.

Ethnic specific information in hypertension guidelines

Table 2 presents the analysis of the hypertension guidelines. The Dutch guideline contained no ethnic specific statements, the Canadians had only one such statement (albeit an important one), and the US and UK reported more extensively (in separate paragraphs) about ethnic differences. The guidelines made empirical statements about (1) a higher prevalence, more severe hypertension, and a higher risk of complications in certain ethnic groups; (2) the difference in response to pharmacological treatment; and (3) the higher sensitivity to dietary salt restriction among black subjects. These empirical statements led to different treatment recommendations in the respective guidelines.

Scientific basis of ethnic specific information in hypertension guidelines

For epidemiology the evidence was primarily from type III (descriptive) studies or narrative reviews, while the evidence for the differential response to pharmacological treatment was mainly from randomised controlled trials. One study (type Ib) was used as evidence in both the US and UK guidelines.

Ethnic specific information in asthma guidelines

In the asthma guidelines (table 3) one empirical statement about the ethnic variability of lung function was found in both the US guideline (in a separate paragraph) and in the Dutch guideline. The US guideline also stressed the importance of a culture sensitive approach to the patient. The Canadian guideline made no ethnic specific statements, and the UK guideline had only one minor remark about the failure of attending education programmes.

Scientific basis of ethnic specific information in asthma guidelines

Almost all evidence in the guidelines for asthma were based on type III (descriptive) studies.

DISCUSSION

The results of this study show that clinical guidelines from the four western countries do contain ethnic specific information and recommendations, but to a varying extent. The Dutch guidelines contained only a few empirical facts and only once made an additional specific recommendation based on these facts. The other three guidelines

TABLE 3Guidelines on asthma: comparison between countries on ethnic specific statements⁵⁹⁻⁷⁵

Category	Type of statement	Statement about ethnic differences	Country	Evidence	Strength
Epidemiology	Empirical	Hospitalisation and death rates highest among black subjects	USA	CDC (1996) ⁵⁹	III
Diagnostics	Empirical	Lung function varies across ethnic groups	USA	Woolcock (1972) ⁶⁰	III
				Hsu (1979) ⁶¹	III
				Wall (1982) ⁶²	III
				Coultas (1988) ⁶³	III
				Crapo (1988) ⁶⁴	III
				Marcus (1988) ⁶⁵	III
				Coultas (1994) ⁶⁶	IV*
Patient education	Empirical	Failure of attending education programs is associated with minority ethnic group	UK	Quanjer (1983) ⁷⁴	IV*
				Quanjer (1993) ⁷⁵	IV*
	Recommendation		USA	Fitzgerald (1994) ⁷³	IV
				Manson (1988) ⁶⁷	III
				Pachter (1993) ⁶⁸	III
Medical record	Recommendation	Sociocultural beliefs should be an item in medical history	USA	Pachter (1995) ⁶⁹	III
				Risser (1995) ⁷⁰	III
				Kleinman (1978) ⁷¹	IV
				Woloshin (1995) ⁷²	IV
				No reference	–

*Narrative reviews.

added more recommendations to the empirical facts, only for hypertension in the case of the UK, only for diabetes in the case of Canada, but for all three health problems in US guidelines. The US guidelines therefore gave the most attention to ethnic differences by presenting empirical facts as well as formulating specific recommendations.

Because most of the statements about ethnic differences in the different guidelines were based on differences in epidemiology (prevalences), the scientific evidence used consisted mainly of descriptive studies or narrative reviews and addressed their national situation. The US guidelines tended to use more evidence.

This is a first exploratory study of the attention given in clinical practice guidelines to ethnic differences. We focused on guidelines from only four western countries and thereby narrowed our scope considerably. Although our comparison is useful, it would be interesting to broaden it in further research by including guidelines from other countries with a relatively large group of subjects from ethnic minorities.

It is difficult to give an explanation for the difference in focus on ethnic differences in the guidelines found in this study because the guidelines are produced and used in the complex environment of a healthcare system. Ethical, economic, legal, political, and cultural aspects are involved which vary in the different countries. Because of historical developments, countries may have their own specific way of approaching ethnic differences. The USA and Canada, for example, have a long history of being multicultural societies with relatively large groups of native inhabitants and other subgroups. In the UK and the Netherlands, however, ethnic minorities are a more

recent phenomenon resulting from labour and colonial migrants. These differences in historical background have led to political and cultural differences in facing questions concerning minority groups. Whereas the USA places both cultural and political emphasis on differences in ethnic identities, other countries do this to a lesser extent, resulting in other normative values. All these aspects could impact on the process of guideline development—for example, on the composition of the panel developing the guidelines which, in turn, could influence the process of decision making in the selection of relevant evidence and in the content of the guidelines.^{6 76–80} Although guidelines are considered to be products of evidence-based medicine and therefore primarily based on available scientific evidence, they always contain (either explicit or implicit) normative values of (individual) panel members.

Another factor to consider is the possibility that, because mainly local/national evidence was used to develop the ethnic specific recommendations, panel members in one country may consider that data are only applicable to ethnic groups in the country where the research was conducted. But do Afro-Americans in the USA differ from black subjects in the Netherlands and the UK; and do South Asians living in the USA differ from those in the UK, Canada or the Netherlands? As far as the medical differences discussed in this paper are concerned, the answer is probably not, because it is often reported that the higher prevalence and severity of diabetes and hypertension in certain ethnic groups and the differences in response to drugs result, at least in part, from genetic differences and the migration process.^{82 83}

The above considerations raise interesting questions as to whether cultural differences between countries can explain different normative values between groups of guideline developers resulting in more or less ethnic specific recommendations in the guidelines, and whether health information about certain minority ethnic groups is applicable to similar groups in other countries. Since disease or health specific data on white subjects are accepted worldwide, it is legitimate to question why this does not apply to scientific data on differences between other ethnic groups. Future research should try to find the answers to these questions.

The development of guidelines is a complicated process in which many heterogeneous considerations are weighed against each other. Guidelines must be feasible and as clear, understandable and unambiguous as possible, given current healthcare practices. There will always be some reluctance about changes in current practice, and in describing exceptions and, for example, ethnic differences. Nevertheless, ethnic differences are present in all western societies and this issue can expect a higher priority in future research and health care. However, at present, the proportion of ethnic minorities in deprived neighbourhoods in the UK and the Netherlands is very large and, for the care in those underprivileged areas, ethnic specific recommendations in guidelines can already help practitioners in their daily practice and therefore should be implemented as soon as possible. If clinical recommendations do not accept the existence of

clinically relevant ethnic differences in, for example, prevalence/complications and response to pharmacological treatment, suboptimal or even harmful practices may occur.⁶⁴ This also applies to the need for ethnic specific education and counselling and sensitivity towards differences in cultural values and norms, particularly when a positive clinical effect has been proved. By disregarding scientific evidence, the guideline may provide inaccurate information and thereby compromise the quality of care⁸⁴; and by disregarding scientific evidence, the higher morbidity and mortality and the higher risk of complications with hypertension and diabetes will continue or even get worse because, in the Netherlands, for example, members of the ethnic minority groups are relatively young and will therefore be faced with more morbidity in the future.

CONCLUSIONS

Differences in the attention given to ethnic differences between patients in clinical practice guidelines exist between countries. Whatever the explanations may be for these differences, guideline developers should be aware of the potential problems for patients from ethnic minority groups. Ethnic differences should play an important part in both screening the available evidence and in the development of the guideline—for example, the composition of the expert panel. With the increasing movement of people between countries, this aspect will become even more important in the future.

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The Dutch College of General Practitioners' clinical practice guidelines on diabetes mellitus type 2, hypertension and asthma in adults, does not sufficiently reflect the information on ethnic minorities available in the scientific justification.

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ABSTRACT

Objective: To assess whether ethnic differences were present in the scientific foundation of GP-guidelines and whether these ethnic-specific remarks resulted in ethnic specific information in the guidelines.

Design: Content analysis

Method: The used scientific foundation for the guidelines about type 2 diabetes mellitus (DM2), asthma in adults and hypertension was collected and carefully screened. Relevant ethnic-specific information was written down and compared to the content of the guidelines.

Results: Different relevant ethnic differences were mentioned in the scientific foundation. Differences in prevalence, onset and complications were stated. The foundation for asthma mentioned differences in lung-volume and for hypertension mentioned differences in prevalence, onset, complications, and response to pharmacological treatment and dietary salt restriction. The DM2-guideline mentioned a higher prevalence of diabetes in Hindustanic people and recommended earlier screening. The asthma guidelines mentioned that the lung volume is dependent of ethnicity. The hypertension guideline did not mention any ethnic-specific information

Conclusion: A limited number of ethnic differences in the scientific foundation were taken over in the guidelines. Possible explanations could be normative values from guideline developers about the adaptation of evidence in guidelines and the possible political or social reluctance against distinctions based on ethnicity. However, a possible consequence is an ineffective or sub-optimal care for ethnic minorities. Especially GPs in multicultural neighbourhoods, with a relatively large ethnic population, benefit from guidelines which pay attention to ethnic differences between patients.

INTRODUCTION

Since the 1960s the Netherlands has increasingly changed into a multicultural society. More than 9 percent of the Dutch population currently belongs to an ethnic minority group and the forecast is that this will increase to 15 percent by 2015. ¹ Many multicultural, deprived neighbourhoods in large cities contain numbers of ethnic minority inhabitants that often exceed the corresponding number of native inhabitants. This increase in ethnic minorities has led to situations in which general practitioners in multicultural neighbourhoods are increasingly faced with ethnically diverse patient populations. Compared to the native populations, such populations show differences in, among other things, the incidence and prevalence of certain diseases as well as complications, responses to medical therapy, experience of sickness, sickness behaviour, ideas about the origin of diseases, and often also differences in a linguistic sense ^{2,3}. Such differences may, as a result of communication problems and cultural differences between ethnic minority patients and (native) general practitioners, lead to a reduction in the quality of health care, manifesting itself in incorrect diagnoses, increased workload for GPs, lower patient compliance and the incorrect or unnecessary use of health care provisions. ^{4,5}

Official guidelines of medical treatment are important and universally accepted instruments that GPs have at their disposal in support of their daily practices. Such guidelines, as developed for Dutch GPs by the Dutch College of General Practitioners (NHG), have proved effective instruments in quality improvement. ⁶ By issuing these guidelines, the NHG aims to provide greater support for GPs as well as to reduce unacceptable differences in GP treatment. We hypothesise that, in order to achieve the same effective support for daily GP practice in multicultural districts, guidelines will have to take into account the ethnically diverse patient populations of GPs. Earlier research showed that the NHG refers relatively infrequently to ethnic differences in its standards, compared with, in particular American, but also British and Canadian guidelines. ⁷ Such infrequency may have various causes. We examined, first, whether ethnic differences between patients are, in fact, referred to in the scientific evidence gathered by the NHG in substantiation of its guidelines and, second, whether such references are traceable in the guidelines.

RESEARCH METHOD

Of the four NHG standards concerning the chronic diseases diabetes mellitus type 2 (1999), hypertension (1997) and asthma in adults (2001), we examined the professional literature which was referred to as the guidelines' scientific justification. ⁸⁻¹¹ The asthma standard consists of two parts: one diagnostic part and one treatment part. (Text) books were

TABLE 1

Terms indicating ethnicity in relation to which the scientific justification in the four NHG guidelines was screened*

'race', 'racial'

'ethnic', 'ethnicity'

'blacks', 'whites'

'African-Americans', 'Indian patients', 'Asians', et cetera

'minority'

'migrant'

'native', 'non-native'

'immigrant'

'culture', 'cultural'

* The Dutch equivalents of these terms were also used in the screening process.

excluded from the analysis (n=58), leaving original research documents, review articles, (consensus) guidelines, doctoral theses and editorials. (n=528). Each manuscript examined was carefully screened for terms referring to ethnicity (as indicated in table 1). Each time a term was used, the text was marked. Since most references to ethnic differences were limited to largely irrelevant comments -- varying from a research population containing a certain ethnic subgroup about which the analysis subsequently had nothing further to say, or references to ethnicity-based adjustments in analyses, to marginal comments on ethnic differences in introductions or discussions – and since such references were consequently not usable as a form of scientific justification for standards, a distinction was made between relevant and irrelevant comments. A comment was marked as relevant if it was, first, based on empirical research (in which expert consensus was also being assumed to be empirical substantiated) and, second, if it compared an ethnic minority group with a native/dominant group. Subsequently, the text of the standard was read and the comments in the literature were compared with those in the standard.

RESULTS

Table 2 shows the number of manuscripts used as scientific justification for the four standards plus the number that was eventually screened. Five manuscripts referred to could not be found. 523 manuscripts, accounting for nearly 90 percent of the scientific justification, were screened. In just over 7 percent of works screened, relevant information on ethnic differences was found. That information is summarised in table 3.

TABLE 2

The number of manuscripts (%) used as a scientific justification for four NHG guidelines

	Diabetes	Asthma	Hypertension
Total number of manuscripts	187 (100%)	207 (100%)	191 (100%)
Excluded manuscripts*	14 (9%)	33 (16%)	11 (6%)
Undiscovered manuscripts	1	2	2
Screened manuscripts	172 (92%)	173 (84%)	178 (93%)
Manuscripts containing some ethnic information	62 (36%)	25 (14%)	43 (24%)
Total number of manuscripts containing relevant ethnic information**	15 (9%)	7 (4%)	16 (9%)

* (text) books excluded

** A comment was deemed 'relevant' if it was based on empirical evidence (judgements of experts being assumed to be similarly based on empirical evidence) and if it compared an ethnic minority group with a native/dominant group.

TABLE 3

The most important ethnic differences referred to in the scientific justification of four NHG guidelines and in the standards themselves

	Justification	Guideline
Diabetes mellitus type 2		
Higher prevalence	+	+
Earlier onset	+	-
Higher risk of serious complications	+	-
Three-yearly screening	-	+
Hypertension		
Higher prevalence	+	-
Higher chance of serious complications	+	-
Higher sensitivity to reduced salt intake	+	-
Differential effects of medicines	+	-
Earlier onset	+	-
More 'aggressive' treatment required	+	-
Asthma		
Difference in lung function	+	+
Higher incidence and degree of seriousness	+	-
Higher hospitalisation rate and mortality in black persons (in the US)	+	-

Diabetes mellitus type 2

The relevant comments on ethnic differences in the literature relating to the diabetes standard concerned higher prevalence¹²⁻²¹, earlier onset¹²⁻¹⁴ and a more serious course of the disease, combined with higher incidence of complications or risk factors such as micro-albuminuria²²⁻²⁴, diabetic nephropathy²², insulin resistance¹⁵ and (abdominal) obesity, in different ethnic groups.^{15,16}

The literature with relevant ethnic differences included three Dutch studies.¹²⁻¹⁴ A case-control study showed that the prevalence of type 2 diabetes was four times higher and that the onset of cardiovascular disease occurred eight years earlier in Asian patients.¹² The researchers in question concluded that, as a result of insulin resistance, type 2 diabetes is a key contributory factor in the early onset of cardiovascular disease in Hindustani patients (in the Netherlands). A patient file study at three GP practices showed a higher prevalence of diabetes than expected in Surinamese and Moroccan patients. The average age of the patients was also lower.¹³ The last Dutch manuscript examined concluded that in Hindustani patients the prevalence of diabetes is higher, onset is earlier and complications are more serious.¹⁴

Two non-Dutch guidelines used by the NHG standard as scientific justification also stressed ethnic differences. One American consensus guideline referred to Afro-American patients as being less inclined than white patients to monitor their glucose levels one or more times per day.²⁵ One expert panel reported that healthy persons in ethnic risk groups should be screened earlier and more often.¹⁷ Finally, two review articles concluded that black type 1 diabetes patients showed an increased risk of mortality and amputation.^{18,26}

The NHG standard refers to the higher incidence of diabetes in Hindustani patients and advises three-yearly screening for Asian patients older than 45 years of age.

Hypertension

All ethnicity-related comments in the hypertension guideline evidence concerned black patients and can be summarised under the following three main headings. The first is higher prevalence, earlier onset, and a greater risk of and more serious complications.²⁷⁻³¹ The second main heading concerns the reduced effectiveness of beta blockers compared to diuretics and calcium antagonists, which, among other things, was demonstrated in double-blind, randomised clinical trials.³⁰⁻³⁸ Finally, there is the higher positive effect on the blood pressure of reduction in the intake of table salt (sodium chloride) in the diet.^{30,39}

In regard to these three subjects, guidelines and expert reports used as scientific justification of the NHG guideline contained a number of comments and recommendations on the treatment of hypertension in black patients. A Canadian guideline regards membership of “the black race” as a risk factor in the development of hypertension.⁴⁰ Diuretics are a preferred form of medication, whereas monotherapy with beta blockers or ACE reducers has proved less effective.^{30,31} As a result of the higher prevalence of serious hypertension it is advised that black patients should be treated with multiple medications, while GPs should not hesitate to use the strongest medicines.³⁰ One last comment is included in a review of *The Women’s Caucus* on hypertension among US women: “Ethnicity has a significant effect on the onset of hypertension, as well as on the selection of antihypertensive medication

and responses to treatment. That is the reason why a universal algorithm for the treatment of hypertension, which ignores patients' ethnicity, is no longer appropriate".²⁷ In addition, the authors state that, because black female patients clearly benefit from an aggressive treatment of hypertension, such treatments, accompanied by screening and tracing (case finding), may constitute a key public health care measure for this group.²⁷

The researchers of the *San Antonio Heart Study* state that treatment strategies which simultaneously reduce hypertension and increase insulin sensitivity are to be strongly preferred, especially in persons with a significant risk of developing type 2 diabetes (including certain ethnic groups).⁴¹ Finally, the researchers calculated different specific predictive values for routine blood pressure measurement for white and black patients (men and women), which could be used in screening for hypertension.⁴²

The NHG hypertension guideline does not mention ethnic differences between patients.

Asthma

The relevant references in the literature concerning the asthma guideline relate to two subjects. First, the fact that ethnicity codetermines the lung capacity and, consequently, the reference values for peak expiratory flow.⁴³⁻⁴⁸ Second, the prevalence and seriousness of asthma is higher for some ethnic groups, and increased asthma-related mortality rates in the United States occur predominantly in the black patient group.⁴⁴⁻⁴⁹ It is, however, supposed that environmental factors and lower social-economic status rather than ethnicity are the main determinants in these cases.⁴⁴

The NHG 'asthma in adults' guideline mentions that lung function reference values depend, among other things, on the country of origin.

DISCUSSION

Our inventory shows that the scientific justification of the NHG guidelines refers to several relevant ethnic differences between patients. However, the NHG guidelines adopt the scientific evidence to different degrees. For example, the guideline for diabetes mellitus type 2 and asthma in adults include important differences, in one case leading to a specific recommendation in the diabetes guideline, whereas the NHG hypertension guideline makes no reference to ethnic differences, despite the considerable attention paid to such differences in the scientific justification.

The discussion emerging from these results raises two questions: first, given the information that is currently available, do NHG guidelines make sufficient reference to ethnic differences;

and, second, when should scientific evidence be mentioned in guidelines? NHG guidelines consist of carefully considered, well-founded judgements, which, as a matter of logic, can only be formulated after the provision of several sources of evidence by various studies. Thus, evidence needs to be solid before being included in the guidelines. The impression emerged that what the NHG was waiting for was solid *Dutch* evidence. This was shown, for example, by the higher incidence reported for Hindustani patients in the diabetes guideline, which was based on Dutch studies. The fact that, in the comment that lung function depends on ethnic origin in the NHG standard '*COPD en astma bij Volwassenen: diagnostiek*' [diagnostics for COPD and asthma in adults] no further reference is made to Dutch specific ethnic subgroups, seems to confirm our impression, given that the information contained in the comment is based on a non-Dutch source.

Whereas the ethnicity-specific evidence available in the Netherlands for the most important ethnic groups is rather limited, the contrary is certainly the case internationally; for example, in the United States and United Kingdom, as is also shown by the guidelines issued in those countries.⁷ The guidelines in question show that the considerable problems of hypertension among black patients and diabetes among South-Asian (e.g. Hindustani) patients have often been demonstrated in research, which is reflected in the guidelines. Research in the countries referred to also demonstrates the reduced effectiveness of certain antihypertensive medicines (in controlled as well as randomised studies), as well as highlights the positive effect of reduced intake of table salt on blood pressure. In our view, such clinical information is relevant and deserves to be included in medical guidelines. The same consideration applies to the earlier onset and more unfavourable prognoses for diabetes in Hindustani patients, besides the higher prevalence referred to in the guideline.

Why should evidence from other countries not be used in Dutch guidelines? After all, the evidence found in white populations abroad is universally applied to the white (or even the entire) population in the Netherlands. What, in fact, is the difference between an Afro-American patient in the United States and a Creole Surinamese or Ghanaian patient in the Netherlands in relation to the differences noted? Or between a South-Asian patient in Britain or Canada and an Hindustani or Pakistani patient in the Netherlands? In our view, such differences are marginal in relation to properties that are attributable to specific population groups and that may be important for effective medical treatment. Ignoring such sources of evidence is a waste of the wealth of information that has been gathered worldwide, while it may well result in Dutch general practice having to run after the facts.

A different type of explanation is provided by Wiersma, who offers us a behind-the-scenes glimpse of guideline development.⁵⁰ He describes how specific recommendations for women in relation to cholesterol screening were considered socially unfeasible and unpromotable in the doctor-patient contact, and therefore were not included in the NHG cholesterol guideline (despite demonstrable clinical differences, based on solid evidence). Given the social debate

surrounding ethnic differences in health care, the situation might be analogous: perhaps the differentiated approach to different population groups was similarly considered unfeasible or undesirable. If so, the entire course of guideline development would seem to consist of stages in which various normative decisions are or need to be taken.⁵¹ In view of the evidence and the need for attention to ethnic differences, these differences should receive a place in the guideline development process besides criteria such as age and sex. This might, for example, be achieved through selection of the expert panel, which usually consists of general practitioners with more than average knowledge of, or interest in, the relevant disease. The inclusion of an additional general practitioner who is reasonably well-informed about, and takes a higher than average interest in, ethnic differences or who works in a multicultural neighbourhoods, might in itself act as a considerable awareness-raising factor in this area.⁵² Health care workers in multicultural neighbourhoods, in particular, are constantly faced with all the differences that exist between various ethnic groups (including the native Dutch population).³ Consequently, the tendency towards a greater focus on ethnic differences that is noticeable in Dutch health care research seems only logical. In fact, the diabetes and asthma guidelines have already taken the first steps towards a narrower focus on the differences in question, and it is expected that the revised version of the NHG Hypertension guidelines, which is to be published this year, will follow the same route. Given the importance of this approach in view of the continuing multiculturalisation of the Netherlands, we would advocate a more proactive attitude by the NHG in these matters. Greater justice could be done to the required quality of care in an increasingly diverse population through a combination of various factors: by being more sensitive to potential ethnic differences in the development of guidelines for medical procedures; by including in working groups general practitioners who work with ethnic minorities on a daily basis; by looking over the borders to see what information is already available; and by including ethnic differences in the structural development of guidelines (assigning them equal status with age and sex).

CONCLUSION

NHG guidelines are generally regarded as precious instruments in the Dutch medical world. They have been a mainstay for general practitioners in their daily practices for years. However, the attention paid to clinically relevant ethnic differences has as yet been limited, despite the international evidence for the existence of such differences. Given the fact that general practitioners in multicultural districts, in particular, might benefit considerably from guidelines that incorporate the multicultural character of patient populations -- with the associated diagnostic consequences, information, treatment and attitudes in relation to patients from ethnic minorities -- it would be wise to include such international evidence in the development of NHG standards.

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Do ethnic specific differences in
treatment of asthma, diabetes, and
hypertension in general practice exist?

5

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INTRODUCTION

Evidence shows worse outcomes of care in chronic conditions like asthma, diabetes mellitus type 2, and hypertension in ethnic minorities.¹⁻³ Reasons for these ethnic differences are unclear and several theories have been proposed, like a greater burden of disease among ethnic minorities, disease severity, genetic predisposition and patient compliance. Other important possible explanations for ethnic disparities in health outcomes are inadequate access to health care facilities, and ethnic differences in treatment and quality of care⁴. Nowadays many studies confirming ethnic differences in treatment of chronic diseases are published.⁵⁻⁸ Many of these studies are limited to US and UK populations. Over the last years these ethnic differences in treatment in the US and UK have sometimes been explained by the existence of institutional racism.⁹⁻¹⁰ Institutional racism is described as “the collective failure of an organization to provide an appropriate and professional service to people because of the color, culture or ethnic origin”.¹¹ Many expressions of institutional racism have been provided in the USA and UK.¹¹

On the European continent ethnic differences in outcome of care are also found, although research on possible explanations is still limited.^{2,12} Furthermore, the discussion on institutional racism in health care has not yet reached the European continent, probably partly because scientific information regarding ethnic differences in treatment of chronic conditions is scarce. The demographic and ethnic composition, and the specific historical background and political context of the ethnic minority population on the European continent differs from that in the USA and to a lesser extent the UK. Furthermore there are large differences in the structure and financing of health care between the US, UK, and the European continent. Given these differences evidence found in the USA or even the UK does not automatically apply to populations of the European continent. Therefore, the question arises whether institutional racism in health care in fact also occurs on the European continent.

In the Netherlands, chronic diseases are treated for a large part in general practice. GPs have a central and important role in the Dutch health care system as gatekeepers for specialist care. Research has shown that the management of chronic conditions in Dutch general practices seems more difficult in ethnic minorities with worse health outcomes as a consequence.¹² It is often stated that because of cultural and language differences many GPs experience difficulties in delivering optimal care to patients from ethnic minority groups, especially in the treatment of chronic conditions.¹⁶ If so, institutional racism could also be present as a potential problem in Dutch health care. Our aim was to assess whether ethnic differences in the treatment of chronic conditions exist and thereby contribute to the discussion of the explanations of worse health outcomes in ethnic minorities and the existence of institutional racism.

METHODS

General Practices

Treatment data was electronically extracted from patient records in general practices. Because the software used to extract the patient records was only compatible with one type of GP information system i.e. Elias[®], we approached general practices that used Elias[®]. At the moment Elias[®] was one of the most widely used GP information systems. These general practices were also located in or near a deprived neighborhood because of their relatively high share of ethnic minorities. We asked the general practices to participate in this project, which consisted of a retrospective analysis of patient records and prospective data collection.

Patients

Patients were included in several steps. First, a computerized search in the GP information system identified patients with asthma, diabetes mellitus type 2 and hypertension, using codes of the International Classification of Primary Care (ICPC), the Anatomical Therapeutic Chemical (ATC) classification of drugs, or free text (table 1). The search was restricted to patients under treatment over the last two years (from March 2000 to March-June 2002). During the second step ethnic background of identified patients was assigned, based on their surnames, by research assistants from corresponding ethnic groups. This method is proven valid for most ethnic groups in the Netherlands.¹⁷ In case of doubt, GPs were asked to check our assignment. Subsequently, we selected patients from the three largest ethnic minority groups in the Netherlands, i.e. Moroccan, Turkish, and Surinamese and from a Dutch comparison group. In the Surinamese group a distinction was made between African-Surinamese and Hindustani-Surinamese, because of large and important ethnic differences within the Surinamese group.

To enhance validity of our identification process we reviewed the records of patients identified on the basis of free text. In case of a false positive identification patients were excluded. False positive identification could occur when the selection text term: 1. was part of a negation (e.g. *“patient does not have diabetes”*); or 2. referred to a family member of the patient (e.g. *“patient’s father has diabetes”*); or 3. referred to another disease (e.g. *“patient has cardiac asthma”*). Finally, all identified patients from the selected ethnic minority groups were included in the sample, added with a random sample of Dutch patients per diagnosis per general practice.

Data collection and measurements

The complete electronic patient records of study patients were extracted from the GP information systems. Data in two practices were only extractable from 2002. We obtained data on patient characteristics (i.e. sex, year of birth, and insurance state); dates and the journal text of all GP visits; dates and contents of all prescriptions; dates

TABLE 1

Terms used to identify asthma-, type 2 diabetes- and hypertension patients from the GP information system			
	ICPC	ATC	Free Text
Asthma	R96*	R03AB* R03AC02 R03AC03 R03AC04 R03AC05 R03AC12 R03AC13 R03AK02 R03B* R03CB03 R03CC02 R03CC03 R03CC04 R03DA04	ASTMA ASTHMA
Type 2 diabetes	T90.0 T90.2	A10B*	DIAB*
Hypertension	K86.0	†	HYPERTE*

* Truncated from here
† In hypertension the ATC-classification was not used because of the large numbers of false-positives.

and specification of all referrals to medical specialists, and patient specific prevalence of relevant co-morbidity.

For our analysis, we selected GP visits, prescriptions, or relevant referrals if they contained one of the indicators regarding free text, ICPC coding, ATC-coding or the WCIA 12 specialist codes (which is a Dutch classification system of medical specialists) shown in table 2. According to the clinical practice guidelines of the Dutch College of General Practitioners the following referrals were defined as relevant: for asthma a referral to the lung specialist; for diabetes a referral to the internist, podiatrist, ophthalmologist, and dietician; and for hypertension a referral to the internist and cardiologist.¹⁸⁻²⁰ Co-morbidity was defined as relevant when its presence had consequences for the treatment of the GP according to guidelines of the Dutch College of General Practitioners.¹⁸⁻²⁰ The following conditions were defined as relevant: in diabetes: hypercholesterolemia, hypertension, kidney problems, and obesity; in hypertension: angina pectoris, arrhythmia, ankle oedema, asthma/COPD, diabetes, gout, heart failure, hypercholesterolemia, stroke, myocardial infarction, kidney problems, obesity, and peripheral arterial disease. In asthma the presence of other conditions does not interfere with treatment and therefore co-morbidity had no relevance for asthma in this study.

To enhance validity, all selected contacts, prescriptions and referrals were manually checked by screening the patient records. False positive selections (of treatment data) were excluded. An example of a false positive selection concerned GP visits that were identified as an asthma visit because the journal text contained the term “pf” (a frequently used abbreviation of “peak flow”), while in some cases “pf” represented the first characters of the word “Pfeiffer”.

TABLE 2

Terms used to identify GP visits, prescribed medications and referrals

	ATC*	Free Text†	Specialist codes‡
Asthma	R03-	astma- asthma- R96- piek- Pf- fev- peak- pkf- fvc- pef-	015: lung specialist
Type 2 diabetes	A10-	diab- dm- d.m.- gluc- hba1c- glyhb- gly hb- T90-	012 : internist 045 : internist 017 : ophthalmologist 049 : dietician POD : podiatrist##
Hypertension	C02- C03- C07- C08- C09-	hyperte- K86- rr-	003: cardiologist 012: internist 045: internist

* used to identify study contacts and prescribed medication

† used to identify study contacts

‡ WCIA 12: used to identify referrals

There is no numeric code in the WCIA12 for a podiatrist. This was coded with the abbreviation POD.

Data analysis

We retrospectively followed patients from March 1st 2000 to March 1st 2004. In two practices patients were followed from March 1st 2002 to March 1st 2004. For patients referred, died or deleted from the register, the date of referral, death or deletion from the register meant the end of follow-up. Patients were excluded from the analysis if they had been referred to a relevant specialist one year prior to the study period, because we assumed the patient could still be under treatment of the specialist.

To compare the number of GP visits and prescriptions between the different ethnic groups we computed contact- and medication frequencies per person-year by dividing the number of contacts during follow up by the length of the follow up period. Patients with a follow up of less than six months led to outliers of contact and medication frequencies, and were therefore excluded from the analysis. We also compared the number of prescriptions of specific medications. Regarding referrals we calculated the percentage of patients per ethnic group referred to relevant specialists.

We first performed t-tests to detect differences in the number of visits and prescriptions between ethnic minority groups and the indigenous Dutch group. Subsequently we

TABLE 3

Characteristics of patients in analysis*

	Hindustani-Surinamese (N = 151)	African-Surinamese (N = 20)	Moroccan (N = 109)	Turks (N = 163)	Indigenous Dutch (N = 262)	Total (N = 705)
Asthma (N=230)	52	0	45	62	61	220
Males (%)	21 (40)	0 (0)	19 (42)	25 (40)	26 (43)	91 (41)
Mean age (SD)	48 (15)	xx	45 (16)	42 (13)	53 (19)	47 (16)
Insurance by sick benefit fund (%)	45 (87%)	xx	37 (82)	51 (82)	42 (69)	175 (80)
Mean follow-up period	2.60 (1.20)	xx	2.71 (1.28)	3.13 (1.05)	2.78 (1.25)	2.82 (1.20)
Diabetes (286)	58	11	44	60	95	268
Males (%)	26 (45)	5 (45)	25 (57)	35 (58)	38 (40)	139 (52)
Mean age (SD)	59 (10)	63 (11)	55 (10)	58 (10)	68 (12)	61 (12)
Insurance by sick benefit fund (%)	47 (81)	11 (100)	41 (93)	57 (95)	68 (72)	224 (84)
Comorbidity N (%)						
- kidney	2 (3)	1 (9)	3 (7)	1 (2)	2 (2)	9 (3)
- hypertension	9 (16)	4 (36)	7 (16)	8 (13)	40 (42)	68 (25)
- hypercholesterolemia	5 (9)	3 (27)	7 (16)	9 (15)	21 (22)	45 (17)
- obesity	3 (5)	1 (9)	3 (7)	10 (17)	18 (19)	35 (13)
Mean follow-up period	2.77 (1.31)	2.33 (1.13)	2.88 (1.14)	3.04 (1.01)	2.70 (1.20)	2.81 (1.18)
Hypertension (217)	41	9	20	41	106	217
Males (%)	17 (41)	6 (67)	16 (80)	15 (37)	47 (44)	101 (47)
Mean age (SD)	61 (11)	56 (13)	59 (13)	59 (10)	66 (13)	63 (12)
Insurance by sick benefit fund (%)	36 (88)	9 (100)	14 (70)	35 (85)	66 (62)	160 (74)
Comorbidity N (%)						
- angina pectoris	1 (2)	1 (11)	2 (10)	4 (10)	7 (7)	15 (7)
- arrhythmia	1 (2)	0 (0)	0 (0)	0 (0)	0 (0)	1 (1)
- ankle oedema	1 (2)	0 (0)	0 (0)	0 (0)	4 (4)	5 (2)
- asthma/copd†	1 (2)	0 (0)	2 (10)	4 (10)	12 (11)	19 (9)
- diabetes	7 (17)	3 (33)	6 (30)	6 (15)	30 (28)	52 (24)
- gout	0 (0)	1 (11)	0 (0)	0 (0)	2 (2)	3 (1)
- heart failure	0 (0)	0 (0)	0 (0)	0 (0)	2 (2)	2 (1)
- hypercholesterolaemia	2 (5)	2 (22)	3 (15)	3 (7)	13 (12)	23 (11)
- stroke	1 (2)	0 (0)	0 (0)	0 (0)	6 (6)	7 (3)
- myocardial infarction	0 (0)	0 (0)	0 (0)	1 (2)	2 (2)	3 (1)
- kidney problems	2 (5)	0 (0)	2 (10)	1 (2)	3 (3)	8 (4)
- obesity	2 (5)	1 (11)	3 (15)	3 (7)	16 (15)	25 (12)
- peripheral artery disease	2 (5)	0 (0)	0 (0)	2 (5)	5 (5)	9 (4)
Mean follow-up period (SD)	2.45 (1.26)	3.09 (1.31)	2.67 (1.31)	2.80 (1.23)	2.62 (1.23)	2.65 (1.24)

* Statistical significant differences between Dutch and other groups are mentioned in bold ($\alpha = 0.05$)

† COPD = Chronic Obstructive Pulmonary Disease

performed multivariate regression analyses to control for differences in age, sex, and insurance status (because in the Netherlands GPs receive an annual capitation fee for their public insured patients, while they receive a fee for service from their private insured patients), and relevant co-morbidity. In the analysis of the number of prescriptions, the number of visits, was also added as a confounder. Since our patient sample differed between general practices we used a random effects model in which we controlled for differences between GPs.

Analyses were performed in SPSS 12.0 and SAS 8.1.

RESULTS

We approached 145 general practices of which 16 (11%) practices with 30 GPs agreed to participate in this study. Main reasons for refusal were the lack of a sufficient number of ethnic minorities in the practice, the high workload, and the perceived time-consuming character of the prospective data collection.

Table 3 shows some characteristics of the study population. A total of 705 patients were included in the analysis. The mean number of included patients per practice was 62 (sd. = 23). Sex distribution differed between ethnic groups and between diseases. Mean age was lower in ethnic minorities compared to indigenous Dutch in all three conditions. The relative share of patients with private insurance was higher in Dutch than in ethnic minorities, although most of the Dutch were also insured through a public sick-benefit fund. Mean follow up period did not differ between the different ethnic groups and fluctuated between 2.45 and 3.13 years. In the diabetes and hypertension groups, Dutch patients had more frequent registered co-morbidity than Hindustani-Surinamese, Moroccan and Turkish patients.

GP visits

Table 4 shows that all ethnic groups visited their GP less often compared to the Dutch. Differences were statistically significant in Turks with asthma (2.3 visits compared to 3.4 in Dutch), and Hindustani-Surinamese diabetes patients (7.0 visits versus 8.6 in Dutch). After controlling for confounders and differences between GPs ethnic differences in mean number of GP visits no longer were significantly different, although the number of visits remained lower in all ethnic minority groups. The relative covariance estimate of the GP factor shows that the distribution of mean number of GP visits per ethnic group did not differ much between GPs.

Prescriptions

The yearly number of prescriptions was significantly lower in Turks with asthma compared to Dutch with asthma (2.5 compared to 3.9). The same applied to Moroccans with hypertension (2.1 compared to 4.3 in Dutch hypertension patients). We did not find any other statistically significant differences regarding the mean number of prescriptions. The analysis of specific medication shows that Hindustani-Surinamese asthma patients received more prescriptions of a beta2sympathicomimetica (74% versus 54% in Dutch), and received fewer prescriptions of corticosteroids (20% versus 35%). Turkish asthma patients received fewer prescriptions of anticholinergica as compared to Dutch (2% versus 10%). The relative share of metformin of the total medication was higher in African-Surinamese diabetes patients compared to Dutch (71% versus 35%). African-Surinamese received a beta-blocker less often than Dutch (5% versus 31%), but more often a calcium antagonist (52% versus 15%). These differences were all statistical significant.

TABLE 4

GP visits per ethnic group						
	Hindustani-Surinamese	African-Surinamese	Moroccan	Turks	Indigenous Dutch	Total
Mean number GP visits per person-year (SD)						
- asthma	3.4 (4.0)	xxxxx	2.5 (2.0)	2.3 (1.8)*	3.4 (3.1)	2.9 (2.9)
- diabetes mellitus type 2	7.0 (3.7)*	7.1 (3.4)	7.7 (4.6)	8.1 (4.3)	8.6 (4.5)	8.0 (4.2)
- hypertension	4.1 (2.4)	5.4 (3.4)	4.0 (3.2)	4.4 (3.2)	5.0 (3.4)	4.6 (3.2)
Multivariate regression model GP visits β (95%-CI)*						Relative covariance estimate GPs
- asthma	-0.290 (-1.446, 0.865)	xxxxxx	-0.654 (-1.843, 0.536)	-0.433 (-1.631, 0.766)	Reference group	5%
- diabetes mellitus type 2	-1.034 (-2.567, 0.499)	-1.773 (-4.325, 0.779)	-0.993 (-2.653, 0.668)	-0.264 (-1.807, 1.278)	Reference group	8%
- hypertension	-0.879 (-2.127, 0.369)	0.235 (-1.979, 2.448)	-0.777 (-2.359, 0.804)	0.050 (-1.224, 1.323)	Reference group	11%

* In this analysis was controlled for differences in age, sex, insurance status, and the presence of relevant comorbidity (added with the number of visits in the analysis of the number of prescriptions).

TABLE 5

Prescriptions per ethnic group						
	Hindustani-Surinamese	African-Surinamese	Moroccan	Turks	Indigenous Dutch	Total
Mean number of prescriptions per personyear (SD)						
- asthma	4.3 (5.4)	xxxxxx	3.1 (3.0)	2.5 (2.3)*	3.9 (4.4)	3.4 (4.0)
- diabetes mellitus type 2	4.3 (3.1)	4.8 (4.0)	4.8 (3.6)	3.9 (3.1)	4.5 (3.6)	4.4 (3.4)
- hypertension	3.5 (3.5)	6.1 (7.9)	2.1 (2.1)*	3.6 (3.9)	4.3 (3.8)	3.9 (3.9)
Multivariate regression model prescriptions β (95%-CI)*						Relative covariance estimate GPs
- asthma	0.004 (-1.563, 1.572)	xxxxxx	-0.533 (-2.174, 1.080)	-0.344 (-1.970, 1.282)	Reference group	4%
- diabetes mellitus type 2	0.541 (-0.811, 1.893)	0.296 (-1.952, 2.544)	0.815 (-0.646, 2.276)	0.087 (-1.270, 1.445)	Reference group	0%
- hypertension	-0.395 (-1.926, 1.135)	2.168 (-0.547, 4.883)	-1.540 (-3.480, 0.400)	0.235 (-1.328, 1.797)	Reference group	15%

* In this analysis was controlled for differences in age, sex, insurance status, and the presence of relevant comorbidity.

After controlling for confounders and differences between GPs, ethnic differences in general became smaller and were not statistically significant. The most pronounced remaining difference in prescription rate concerned Moroccan and Dutch hypertension patients, in which the prescription rate remained 1.5 times lower in the former. The relative covariance estimate of the GP factor shows that the distribution of mean number of prescriptions per ethnic group did not differ much between GPs.

Referrals

Although none of the differences were statistically significant, table 6 shows that Dutch asthma patients were more frequently referred to the lung specialist than ethnic minority asthma patients, and ethnic minorities with diabetes were more frequently referred to the internist compared to Dutch patients. Referrals in Dutch hypertension patients were almost equally divided between the internist and cardiologist, while ethnic minorities were more often referred to the internist.

After controlling for confounding and differences between GPs, ethnic differences in referrals were still not statistically significant. However, the odds of a referral to the lung specialist are lower in ethnic minorities with asthma compared to Dutch patients. Furthermore the odds of a referral to the internist was 2.5 times higher in Moroccan hypertension patients compared to Dutch, while the odds of getting referred to the cardiologist was 0.37 in Moroccan hypertension patients.

The relative covariance estimate of the GP factor shows that the distribution of referrals regarding diabetes, and to a lesser extent hypertension, differed somewhat between GPs.

DISCUSSION

Our aim was to assess whether ethnic differences exist in the treatment of chronic diseases in Dutch general practices. In general we conclude that when differences in age, sex, insurance status and the prevalence of co-morbidity between the different ethnic groups are taken into account, ethnic differences in the number of GP visits and prescriptions do not exist in the treatment of patients with asthma, diabetes mellitus type 2, and hypertension. Furthermore, the chance of referral to a specialist does not differ between Dutch and ethnic minorities. Particularly demographic differences between ethnic minorities and indigenous Dutch in our sample explained ethnic differences found in the univariate analyses.

Although evidence of ethnic differences in treatment in primary care is well established in the US and UK, our study did not show these differences in Dutch general practices. This is in line with Agyemang et al. who found that treatment received by Dutch hypertension patients by the GP was similar in different ethnic groups, and with Uitewaal et al. who did not find any ethnic disparities in treatment of diabetes in Dutch general practices.^{2 12} Because health care treatment is the same, this implies that institutional racism is not apparent in primary care in the Netherlands. However equal treatment is only one part of equal access. In research the access of health care is normally defined by objective and quantitative indicators of use and treatment. Both Agyemang et al. and Uitewaal et al. found that although treatment was similar in different ethnic groups, the clinical outcome of treatment was worse in ethnic minorities. This could be explained by other

TABLE 6

Referrals per ethnic group						
	Hindustani-Surinamese	African-Surinamese	Moroccan	Turks	Indigenous Dutch	Total
Percentage referrals						
Asthma						
- to lung specialist	15	xxxxxx	18	15	25	18
Diabetes						
- to internist	28	27	23	27	15	22
- to chiropodist	2	0	5	7	5	4
- to ophthalmologist	60	73	75	72	66	68
- to dietician	28	18	30	30	28	28
Hypertension						
- to internist	32	22	45	39	26	31
- to cardiologist	24	11	15	24	23	22
- to internist or cardiologist	44	22	45	54	44	45
Multivariate regression model referrals odds ratios (95%-CI)						
Asthma						
- to lung specialist	0.617 (0.226, 1.686)	xxxxx	0.771 (0.278, 2.136)	0.620 (0.231, 1.665)	Reference group	0%
Diabetes						
- to internist	1.094 (0.406, 2.944)	1.978 (0.395, 9.894)	0.945 (0.314, 2.843)	1.236 (0.463, 3.302)	Reference group	50%
- to chiropodist	0.408 (0.059, 2.807)	xxxxx	0.806 (0.161, 4.029)	1.136 (0.289, 4.462)	Reference group	58%
- to ophthalmologist	1.087 (0.451, 2.625)	1.366 (0.302, 6.173)	1.716 (0.635, 4.639)	1.841 (0.745, 4.550)	Reference group	56%
- to dietician	1.164 (0.466, 2.907)	0.896 (0.157, 5.107)	1.007 (0.373, 2.714)	1.000 (0.401, 2.492)	Reference group	55%
Hypertension						
- to internist	0.800 (0.308, 2.074)	0.788 (0.308, 2.074)	2.412 (0.804, 7.237)	1.508 (0.606, 3.751)	Reference group	38%
- to cardiologist	1.383 (0.502, 3.812)	0.146 (0.001, 2.285)	0.371 (0.067, 2.051)	1.129 (0.401, 3.177)	Reference group	47%
- to internist or cardiologist	0.826 (0.326, 2.092)	0.195 (0.024, 1.577)	0.928 (0.286, 3.015)	1.262 (0.505, 3.159)	Reference group	32%

less objective indicators of access such as poorer mutual understanding between the GP and the ethnic minority patient, resulting in a lower patient compliance in ethnic groups.²¹ This suggests that the same treatment by the GP does not mean the same level of access and quality of care and the conclusion that institutional racism does not occur in Dutch primary care is still too premature. Furthermore, in the introduction of this paper institutional racism is described as *“the collective failure of an organization to provide an appropriate and professional service to people because of the color, culture or ethnic origin”*. It is proven in several studies that asthma, diabetes and hypertension are more prevalent and more aggressive in ethnic minorities^{2 6 22 23}. It seems therefore that the specific need for care differs between ethnic groups, while treatment is the same, resulting in worse health outcomes. So one could argue that Dutch health care has failed to deliver appropriate services to ethnic minorities and institutional racism

could be in fact present. Research on the reasons for the worse health outcomes in ethnic minorities should give more insights in the presence of institutional racism in Dutch health care.

The fact that ethnic differences in health do not lead to differences in treatment while health outcomes are worse in ethnic minorities has implications for the concept of standardization and clinical practice guidelines in a multicultural setting. Guidelines assume a standard or preferred treatment for the whole (patient) population, unless exceptions in specific subgroups are scientifically justified. Research has shown that the Dutch GP guidelines mention less ethnic specific information compared to their British, American, and Canadian counterparts.²⁴ Dutch guidelines could therefore propagate a lack of awareness in Dutch GPs about important ethnic differences, resulting in the same treatment but worse outcomes. Studies on the adherence to guidelines in different ethnic patient groups and the effect of adherence on the outcome of treatment should provide valuable insight into the (external) validity of clinical practice guidelines in a multicultural setting.

There are some limitations to this study. First, because only 12% of the GPs we approached participated in this study, our study population could be an unrepresentative sample of all GPs. Although a high workload was the main reason for refusal to participate in this study, there are in fact no indications of a lower workload in the practices of participating GPs. To our knowledge, the participating practices do not differ in practice characteristics or in patient population from the non-participating practices. Our participating GPs are probably more research minded and/or have a special interest in the topic of ethnic disparities in treatment. Therefore they may put more effort into the treatment of their ethnic minority patients. However, because our results are in line with results from other studies we assume that our sample of GPs did not affect our results. Second, the data used are not registered for research purposes, so incompleteness and consequently the quality of the data could lead to validity problems. However, since we expect that this will apply equally to all ethnic groups under study, we assume that these problems did not influence our comparison.

CONCLUSIONS

In this study we did not find any ethnic differences in treatment in Dutch general practices. However, research has shown that despite the same treatment the clinical outcome in ethnic minorities is worse. Therefore, further research on the relationship between treatment and health outcomes should provide more more insights into the reasons for these worse health outcomes in ethnic minorities and on whether institutional racism is an issue in Dutch health care.

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Do GPs in the Netherlands differ in
adherence to clinical practice guidelines
in the treatment of patients with
different ethnic backgrounds?
A first exploration.

6

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Submitted.

ABSTRACT

Background: In western countries, much of the evidence on ethnic disparities in the quality of care indicates a lower quality of care amongst ethnic minorities. Clinical practice guidelines (CPGs) can be an important tool in the effort to rectify these disparities.

Aim: To assess whether ethnic disparities exist in adherence to guideline recommendations from GPs in the Netherlands.

Design: Cross-sectional study with prospective data collection.

Setting: General practices in and around deprived neighbourhoods in large cities in The Netherlands

Methods: Adult patients with asthma, diabetes mellitus type 2 or hypertension were selected from the GP information systems of 17 general practices (31 GPs). All ethnic minority patients were included in this study plus a random sample of Dutch patients for each diagnosis. A contact registration form was created to assess adherence to the recommendations of the guidelines. This form was implemented into the GP information systems and linked to the records of the study patients. After every visit by a patient for the disease of inclusion, the GP was asked to complete the form.

Results: 1149 patients were included and 402 forms were completed (regarding contacts with 238 patients). This study found no statistically significant ethnic differences in adherence. With an adherence rate of about 75%, our study showed that GPs generally treat their patients according to guidelines. Furthermore adherence differed a great deal between GPs, while the differences in adherence were smaller between patients and ethnic groups.

Conclusion: This study did not reveal any ethnic disparities in adherence to CPG by GPs. Moreover, because CPGs are assumed to be quality instruments, it seems that there are no ethnic disparities in the quality of care.

INTRODUCTION

Ethnic disparities in health status have been documented extensively. Much of the evidence suggests a health gap to the disadvantage of ethnic minorities in western countries. Established ethnic differences in health extend over a large spectrum and includes differences in morbidity and mortality of type 2 diabetes, hypertension, asthma, end-stage renal disease and many others.¹⁻⁶ Reasons for these ethnic disparities in health are complex. Socio-economic-, cultural-, behavioural-, genetic- and other factors are often used to explain this. Recently the US Institute of Medicine (IOM) reported, based on an analysis of several studies, that ethnic disparities in quality of care also play an important role in the existence of the health gap.⁷ These ethnic disparities in quality of care exist in many aspects of the health care process, such as diagnostic and therapeutic procedures, the intensity of medical care received, and pain control, and still remain after adjustment for socio-economic differences and other health care access-related factors.⁷ Thus, one could argue that physicians differ in their treatment depending on the ethnicity of the patient in front of them.

Clinical practice guidelines (CPGs) play an important role in improving quality of care. As defined by the IOM, CPGs are “systematically developed statements to assist practitioners and patient decisions about appropriate health care for specific clinical circumstances”.⁸ According to this definition CPGs are developed for, among other things, defining appropriate care and therefore quality assurance in care. Furthermore, by standardising care according to the principles of evidence-based medicine, (ethnic) variation in treatment is discouraged, and therefore guidelines could be an important tool in the struggle with ethnic disparities in the quality of health care.⁹ To determine the potential of guidelines in reducing ethnic variation in treatment and quality of care, it is important to determine whether GPs differ in their adherence to guideline recommendations in the treatment of patients from different ethnic groups. It is often hypothesised that cultural differences between GPs and ethnic minority patients negatively affect the quality of care.^{10, 11} In the Netherlands guidelines for general practice are issued by the Dutch College of General Practitioners. Studies focussing on ethnic differences in adherence to guidelines are rare, and have mostly been based on analyses of patient records and therefore suffer from several validity problems.¹² The aim of this study was to assess whether ethnic disparities exist in adherence to guideline recommendations from GPs in the Netherlands, using a methodology and a validated data collection and –analysis instrument specifically developed to measure adherence to guideline recommendations in general practice.

METHODS

In this study we focussed on three chronic health problems with known ethnic differences in morbidity, which are highly prevalent in general practice and the corresponding guidelines of those health problems, i.e. asthma in adults, type 2 diabetes mellitus and hypertension.¹³⁻¹⁵

General Practices

Practices were selected on the basis of their GP information system, because the data collection was computerised and the data collection instrument was only compatible with one type of GP information system (i.e. Elias®). We approached (by mail and telephone) 145 general practices using Elias® (one of the most used GP-information systems) and located in or near a deprived neighbourhood (because of the relatively high share of ethnic minorities).

Patients

Patients were included in several steps. First, a computerised search in the GP-information system identified patients with asthma, diabetes mellitus type 2 and hypertension, using codes of the International Classification of Primary Care (ICPC), Anatomical Therapeutic Chemical (ATC) classification of drugs, or free text (table 1). The search was restricted to patients under treatment in the last two years (from March 2000 to March-June 2002). In the second step ethnic background of identified patients was assigned, based on their surnames, by research assistants from corresponding ethnic groups, which is a valid method for most ethnic groups¹⁶. In case of doubt, GPs checked our assignment. The selection of patients was limited to the largest ethnic groups in the Netherlands, i.e. Dutch, Moroccan, Turkish, African-Surinamese, and Hindustani-Surinamese. Subsequently, the patient records of patients identified on basis of text terms were analysed and in case of a false positive identification patients were excluded. False positive identification could occur when the selection text term: 1. was part of a negation (e.g. *“patient does not have asthma”*), or 2. referred to a family member of the patient (e.g. *“patient’s father has diabetes”*), or 3. referred to another disease (e.g. *“patient has cardiac asthma”*). Finally, all identified patients from the selected ethnic minority groups were included in the sample, added with a random sample of Dutch patients per diagnosis per general practice.

Data-collection and measurements

We used a validated instrument developed by the Dutch College of General Practitioners and the Centre for Quality of Care to measure adherence.¹⁷ Adherence means that the care was given according to the recommendation of the guideline. The instrument consists of two parts:

TABLE 1

Terms used to identify asthma-, type 2 diabetes- and hypertension patients from the GP information system

	ICPC	ATC	Free Text
Asthma	R96*	R03AB* R03AC02 R03AC03 R03AC04 R03AC05 R03AC12 R03AC13 R03AK02 R03B* R03CB03 R03CC02 R03CC03 R03CC04 R03DA04	ASTMA ASTHMA
Type 2 diabetes	T90.0 T90.2	A10B*	DIAB*
Hypertension	K86.0	†	HYPERTE*

* Truncated from here

† In hypertension the ATC-classification was not used because of the large numbers of false-positives.

- 1 For the data collection, a contact registration form, which comprised questions about the patient's clinical situation (including relevant co-morbidity) and the treatment (in the present as well as the past) by the GP of the patient, was used. A computerised design was used to facilitate data collection in which the form was linked to the patient number of the included patients. Every time the GP closed the electronic patient file of an included patient the form popped up on the computer screen asking him to answer the questions of the data collection instrument. However, the GP always had the opportunity to cancel a form. Information on the gender and year of birth from the included patients was also collected from the GP information systems. Data was collected over 6 to 9 months per practice between 14-4-2003 and 15-9-2004.
- 2 For the data analysis, key recommendations of the specific guidelines were determined by an expert panel and indicators for adherence were formulated. The adherence indicators consist of a clinical action and none, one, or more relevant clinical details or circumstances. For the three guidelines a total of 39 adherence indicators were constructed (11 for asthma; 16 for type 2 diabetes; 12 for hypertension). Since recommendations are intended to guide clinical decisions by defining how to act under specific case conditions or existent clinical details, each adherence indicator was constructed by relating clinical actions to relevant and specific clinical details using "if then" algorithms. In this way different cases meet different, yet more specified, criteria and thus certain aspects of case-mix are accounted for. Specific software calculated the adherence score by comparing

TABLE 2

Comparison of patient-GP contacts for non-response analysis

	Contacts with completed forms	Contacts without completed forms	Total
Disease of inclusion (%)			
- Asthma	47 (17)	258 (20)	305 (19)
- Diabetes mellitus type 2	128 (45)	558 (43)	686 (43)
- Hypertension	108 (38)	481 (37)	589 (37)
Ethnic group (%)			*
- Hindustani-Surinamese	49 (17)	304 (23)	353 (22)
- African-Surinamese	19 (7)	48 (4)	67 (4)
- Moroccan	61 (22)	210 (16)	271 (17)
- Turkish	61 (22)	299 (23)	360 (23)
- Dutch	93 (33)	436 (34)	529 (33)
Gender (%)			*
- Male	145 (51)	518 (40)	663 (42)
- Female	138 (49)	779 (60)	917 (58)
Mean age (SD)	59,1 (13,1)	61,2 (13,2)	60,8 (13,2)
Total	283	1297	1580

* Chi² p<0.05

clinical action of the GP with the adherence indicators (1 = adherence, 0 = non adherence). So in every patient-GP contact 11, 16 or 12 (respectively for asthma, type 2 diabetes, and hypertension) adherence scores could be calculated.

Furthermore, a distinction is made between positive and negative recommendations, in which positive means the GP has to do something and negative means the GP has to refrain from a specific action, because GPs are more likely to adhere to negative- than to positive recommendations¹⁸.

Non-response analysis

The workload in general practices in deprived neighbourhoods is relatively high and to get GPs to participate in this study we left them the opportunity to withhold from filling in a form.

Every time a patient record of an included patient was opened, the software used for computerising the data collection registered, the date, GP-code, patient number, and the answer of the GP regarding the request to fill in the data collection form for this included patient now (yes or no). So all contacts between included patients and the GPs during the study period were registered. We performed a non-response analysis to get insight in the number of times and reasons a GP did not complete a form. This is necessary for determining the external validity of this study. We compared all contacts registered by the software with the content of the patient records of the included patients. For the non-response analysis we focussed on the study contacts. These were the contacts for the diseases for which the patient was included (e.g. a patient included for asthma who comes to the GP for his asthma). In this we compared

TABLE 3

Characteristics of completed data collection forms by GPs

	Asthma (n=83)	Type 2 diabetes (n=198)	Hypertension (n=121)	Total (n=402)
Number of forms per ethnic group				
- Hindustani-Surinamese	13	36	15	64
- African-Surinamese	2	6	11	19
- Moroccan	23	51	18	92
- Turkish	24	45	25	94
- Dutch	21	60	52	133
- Total	83	198	121	402
Number of forms of males (%)				
- Hindustani-Surinamese (n=64)	5 (39)	7 (19)	5 (33)	17 (27)
- African-Surinamese (n=19)	0 (0)	3 (50)	10 (91)	13 (68)
- Moroccan (n=92)	11 (48)	32 (63)	16 (89)	59 (64)
- Turkish (n=94)	7 (29)	31 (69)	3 (12)	41 (44)
- Dutch (n=133)	7 (33)	32 (53)	21 (40)	60 (45)
- Total (n=402)	30 (36)	105 (53)	55 (46)	190 (47)
Mean age per form (SD)				
- Hindustani-Surinamese (n=64)	51 (16)	63 (11)	57 (9)	59 (13)
- African-Surinamese (n=19)	77 (0,7)	71 (2)	59 (6)	65 (8)
- Moroccan (n=92)	52 (13)	54 (9)	52 (14)	53 (11)
- Turkish (n=94)	48 (24)	57 (10)	54 (9)	54 (11)
- Dutch (n=133)	59 (21)	68 (11)	67 (13)	66 (13)
- Total (n=402)	53 (15)	61 (12)	60 (13)	59 (13)
Mean number of forms per GP (range)				
- Hindustani-Surinamese (n=64)	0,4 (0-2)	1,2 (0-11)	0,5 (0-4)	2,1 (0-12)
- African-Surinamese (n=19)	0,07 (0-2)	0,2 (0-5)	0,4 (0-6)	0,6 (0-11)
- Moroccan (n=92)	0,8 (0-6)	1,7 (0-18)	0,6 (0-14)	3,1 (0-35)
- Turkish (n=94)	0,8 (0-7)	1,5 (0-15)	0,8 (0-10)	3,1 (0-29)
- Dutch (n=133)	0,7 (0-4)	2,0 (0-13)	1,7 (0-11)	4,4 (0-22)
- Total (n=402)	2,8 (1-17)	6,6 (1-52)	4,0 (1-38)	13,4 (1-102)
Number of clinical decisions in analyses (missings)				
- Hindustani-Surinamese	135 (0)	402 (26)	129 (25)	666 (51)
- African-Surinamese	24 (0)	68 (4)	91 (21)	183 (25)
- Moroccan	219 (3)	583 (25)	162 (28)	964 (56)
- Turkish	238 (11)	525 (15)	217 (36)	980 (62)
- Dutch	222 (2)	671 (34)	444 (68)	1337 (104)
- Total (number missing)	838 (16)	2249 (104)	1043 (178)	4130 (298)

the contacts in which a form was completed with the contacts in which was not, regarding patient characteristics, i.e. ethnic group, age, and gender and the disease of inclusion.

Data analysis

In the data analysis we performed analyses of variances to detect differences in mean adherence between ethnic groups and in case of a statistical significant outcome, we performed t-tests to detect differences in mean adherence between specific ethnic minority groups and the Dutch group. A multivariate multilevel logistic regression analysis was performed to adjust for differences in disease-, age-, and sex distribution between the different ethnic groups (Dutch group was reference) and in which patient- and GP random effects were taken into account.

To pinpoint the potential ethnic differences in adherence we further explored our findings by testing the models per diagnosis and per field of decision making of the GP. The latter is categorised into seven areas: physical examination, instrumental examination, evaluation, prescribing medicine, giving information, giving advice, and referrals. Because of too little observations, we focussed in this explorative analysis only on total adherence.

Analyses were performed in SPSS 12.0 and SAS 8.1.

RESULTS

Seventeen general practices (12%) with 31 GPs, were willing to participate in this project. The main reasons for refusal were the high workload in the practices and the alleged time-consuming character of the project.

Because of technical problems data from one practice (with one GP) could not be extracted. Therefore data was obtained from 16 general practices (30 GPs) in which a total of 1149 patients were included and 402 forms were completed. These 402 forms were completed for 238 patients (mean form per patient = 1,68; SD = 1,2). The 238 patients consisted of 40 (17%) Hindustani-Surinamese, 8 (3%) African-Surinamese, 50 (21%) Moroccans, 57 (24%) Turks, and 83 (35%) Dutch. During the study period a total of 8435 patient-GP contacts were registered. 1580 (19%) of the patients-GP contacts were study contacts. During those 1580 study contacts, 283 data-collections forms were completed. Table 2 gives information on the 1580 study contacts and shows that response was relatively poor and that there were differences between the contacts with filled in forms and without filled in forms in the relative distribution of ethnic group, and gender.

Table 3 shows characteristics of the completed forms and patients. The most forms concerned type 2 diabetes, and the least asthma. 64 Forms concerned the treatment of Hindustani-Surinamese patients, 19 of African-Surinamese patients, 92 of Moroccan, 94 of Turkish, and 133 of Dutch patients. Dutch patients were older than patients from other ethnic groups, except the African Surinamese. The African-Surinamese- and Moroccan group contained more men than women contrary to the other ethnic groups. The mean number of questionnaires completed by the 30 GPs is 13,4, with a range of 1 to 102. A total of 4130 clinical decisions (838 for asthma, 2249 for type 2 diabetes, and 1043 for hypertension) were used in the analyses of adherence.

Table 4 shows the influence of the patient's ethnic group on GP's adherence to the guidelines. The univariate analysis shows that the mean percentage of the number of clinical decisions in which the GPs were adherent to the guideline is equal in the

TABLE 4

Association of patient's ethnic group with GP's adherence to the guidelines

	Number of clinical decisions	GP's adherence by ethnic group (SD)	Multivariate model ‡ OR (95%-CI)
Total adherence			
- Dutch	1337	74% (.44)	Reference group
- Hindustani-Surinamese	666	75% (.43)	0,85 (0,64-1,11)
- African-Surinamese	183	81% (.39) †	1,50 (0,90-2,49)
- Moroccan	964	75% (.43)	0,86 (0,65-1,12)
- Turkish	980	76% (.43)	0,83 (0,63-1,09)
- Total	4130	75% (.43)	xxxx
Relative covariance estimate (%)			
- GP	xxxx	xxxx	30%
- Patient	xxxx	xxxx	17%
Adherence positive recommendations			
- Dutch	928	71% (.45)	Reference group
- Hindustani-Surinamese	422	70% (.46)	0,86 (0,60-1,25)
- African-Surinamese	135	80% (.40)†	1,26 (0,64-2,49)
- Moroccan	649	67% (.47)	0,74 (0,52-1,06)
- Turkish	659	71% (.45)	0,74 (0,52-1,06)
- Total	2793	71% (.46)*	xxxx
Relative covariance estimate			
- GP	xxxx	xxxx	20%
- Patient	xxxx	xxxx	8%
Adherence negative recommendations			
- Dutch	409	81% (.39)	Reference group
- Hindustani-Surinamese	244	84% (.37)	1,05 (0,57-1,96)
- African-Surinamese	48	83% (.38)	2,37 (0,70-8,08)
- Moroccan	315	91% (.29) †	1,73 (0,90-3,33)
- Turkish	321	85% (.35)	1,14 (0,61-2,14)
- Total	1337	85% (.36)*	xxxx
Relative covariance estimate			
- GP	xxxx	xxxx	12%
- Patient	xxxx	xxxx	42%

* Significant result analysis of variances between groups ($\alpha = .05$).
† Significant difference with Dutch; Independent sample T-test ($\alpha = .05$)
‡ $Y(\text{adherence}) = X1(\text{ethnic group}) + X2(\text{disease}) + X3(\text{patient's age}) + X4(\text{patient's gender}) + \epsilon$, with random effects for GPs and patient

different ethnic groups (around the 75%), except for the African-Surinamese (81%). GPs were adherent to the guideline in 71% of the clinical decisions when it concerned positive recommendations in Hindustani-Surinamese, Turkish, and Dutch. This is lower in Moroccan patients (67%), although not statistically significant, while this is higher in African-Surinamese (80%). Mean adherence to negative recommendations is comparable in Hindustani-Surinamese (84%), African-Surinamese (83%), Turkish (85%), and Dutch (81%), while it is higher in the Moroccan group (91%). Adherence to positive recommendations is lower than adherence to negative recommendations in all ethnic groups.

In the multivariate multilevel model we adjusted for confounders and the effect of differences between GPs and between patients and the relative covariance estimate

shows what part of the variances in the outcome is explained by these differences. Differences between GPs are larger than differences between patients except concerning adherence to negative recommendations. Although total adherence and adherence to positive recommendations is worse (except in the African-Surinamese) and adherence to negative recommendations is better in the different ethnic minority groups than in Dutch, none of the findings are statistically significant.

Disease-specific exploration of these results shows no statistically significant differences in adherence or adherence to positive recommendations.

Analysis of the different phases of the patient's consultations indicates no ethnic differences in adherence, except regarding the instrumental examination in Turkish patient (OR (95%-CI) = 0,28 (0,09-0,91)) and giving information in Moroccan patients (OR (95%-CI) = 0,22 (0,05-0,99)), which are statistically significant lower than in Dutch patients.

DISCUSSION

Summary of main findings

Overall, GPs treat their patient to a large extent according to existing guidelines. Our prior hypothesis that GPs would have more difficulties adhering to guideline recommendations in the treatment of ethnic minorities is not supported by our findings. However, some differences were found in the instrumental examination in Turkish patients and giving information in Moroccan patients. However, because these findings concerned very small subgroups, further exploration is needed. This study also showed that, although patients are often treated according to guidelines, ethnic differences in adherence between GPs are relatively large.

Strengths and the limitations of this study

To our knowledge, this is the first study that has ever assessed ethnic disparities in guideline adherence using a specifically developed and validated instrument instead of retrospectively analysing patient records. To increase the willingness of GPs to participate in this study and to facilitate data collection, we implemented a data collection instrument in the GP information systems and we allowed GPs to elect not to complete a form. Therefore, in the situation of - for instance - a crowded waiting room, a GP could choose not to complete a form, so patients would not have to wait any longer than necessary. However, this strategy resulted in a relatively small number of completed forms and probably some selection bias. Our non-response analysis showed some ethnic differences in the number of times a contact led to a completed form. Differences were found in the Hindustani-Surinamese and Moroccan patients, although these differences were relatively small and therefore probably did not affect our results

very much. Differences in gender were also found when comparing contacts, resulting in a completed form with contacts that did not. However, gender was adjusted for in our analyses. Another important reason for the GP not to fill in a form could have been the clinical condition of the patient. However, because our measurement of adherence took into account the specific clinical condition of the patient, we did not include this in the non-response analysis.

Because only 12% of the GPs we approached participated in this study, our study population could also be an unrepresentative sample of all GPs. Although a high workload could be the main reason for refusal to participate in this study, there are in fact no indications of a lower workload in the practices of the participating GPs. To our knowledge, the participating practices do not differ in practice characteristics or in patient population from the non-participating practices. Our participating GPs are probably more research minded and/or have a special interest in the topic of ethnic disparities in the quality of care. They probably also put more effort into the treatment of their ethnic minority patients by trying to treat them as much as possible according to the guidelines, in spite of the many challenges surrounding care for ethnic minorities. This could have resulted in a higher adherence to guidelines in ethnic minorities in our participating GPs compared to other GPs.

This study shows the many difficulties with a prospective data collection in general practices in deprived neighbourhoods. The number of completed forms was relatively small and GPs mentioned a crowded waiting room, and therefore a lack of time, as the main reason for not completing forms. However, this study provides valuable insight in the quality of GP care in ethnic minorities.

Comparison with existing literature

Because clinical practice guidelines are often used as quality improvement instruments by defining appropriate health care, our results suggest that the quality of GP care is comparable in ethnic minority and indigenous patients. This conclusion is not in line with many other studies showing that ethnic minorities are substantially less likely to receive either key diagnostic procedures or effective therapies after adjustment for important clinical conditions^{19, 20} However, most of the scientific information on ethnic disparities in health care quality comes from the USA, and to a lesser extent the UK, and mostly does not concern GP-care. Studies from the Netherlands are scarce. Stronks and her colleagues found that access to the general practice in the Netherlands is equal for different ethnic groups²¹ Once in the general practice it seems that patients with different ethnic backgrounds are treated alike. Agyemang et al. found that the treatment received by Dutch hypertension patients by the GP was alike in different ethnic groups.²² The study by Uitewaal and colleagues was the first and only other study focussing on ethnic disparities in GP's adherence to guidelines and it also found no ethnic disparities in treatment and adherence.¹² However both Agyemang et al. and Uitewaal et al. found that although

treatment was alike in different ethnic groups, the clinical outcome of the treatment was worse in the ethnic minority groups.^{12, 22} This could be explained by a lower compliance with treatment in ethnic minorities caused by a lower mutual understanding between the GP and the patient from the ethnic minority group.²³ So, it seems that adherence to the guidelines is not enough in the treatment of ethnic minorities. However, another explanation for the worse clinical outcome (of a similar treatment) in ethnic minorities is given by the recent debate on the external validity (generalisability) of CPGs.^{24, 25} One of the issues in this debate is whether guidelines take into account the specific circumstances of health care for ethnic minorities.^{25, 26} Research has shown that Dutch GP-guidelines mention less ethnic specific information than their British, American, and Canadian counterparts²⁵ Dutch guidelines could therefore preserve a lack of awareness in Dutch GPs about important ethnic differences, resulting in a worse outcome of their treatment.

Implications for future research or clinical practice

Because of the relatively small numbers it would be worthwhile to repeat this study. Especially because we tend to see some ethnic differences in our results in the multivariate model. Although the odds ratios of the ethnic minority groups differ from the indigenous Dutch, the confidence intervals are too large to make the differences statistically significant. Furthermore, when focussing on special phases in a contact, ethnic differences in adherence become more likely to appear. When repeating this study, it would be important to get a larger GP-sample and a larger share of contacts in which forms are completed. To achieve this, methods should be found to shorten the form or to make a more optimal use of the GP-information system, so the time needed to complete the forms could be reduced. This would also avoid problems with non participation. Furthermore, it would be interesting to assess whether the same treatment approach has the same effect on health outcomes in different ethnic groups. This will help to determine whether or not there are no ethnic disparities in the quality of Dutch general practices. Such a study should preferably be done with a data collection instrument like ours, because it gives a more valid estimate of adherence compared to retrospective analysis of patient records.

CONCLUSION

This study did not reveal any ethnic disparities in adherence to CPGs by general practitioners. Because CPGs are assumed to be quality instruments, it seems that there are no ethnic disparities in the quality of care. However, before making that conclusion, it is worthwhile to assess whether the same level of GP's adherence in ethnic minorities, compared with the indigenous majority, leads to the same positive health outcomes. Only then will it be possible to conclude that a similar degree of adherence to guidelines seen amongst different ethnic groups is synonymous to a similar quality of care.

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Are clinical practice guidelines good for your health? Ethnic disparities explored. | 7

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INTRODUCTION

Clinical practice guidelines (CPGs) could be an important tool to achieve better health outcomes and represent a potentially powerful tool to reduce ethnic differences in health outcomes. While adherence to CPGs by Dutch GPs is relatively high and comparable between patients of different ethnic groups, the clinical outcome of care is often worse in ethnic minorities compared to indigenous Dutch patients.^{1,2} In this study we assessed whether adherence to CPGs has a positive effect on the clinical outcome of asthma, diabetes, and hypertension treatment, and we explored whether this relationship between adherence and clinical outcome differs between different ethnic groups.

PARTICIPANTS, METHODS, AND RESULTS

The study design and methods are described in detail elsewhere.¹

We prospectively collected data in 17 general practices (with 31 GPs) for 6 to 9 months per practice between April 2003 and September 2004. We included all ethnic minority adult patients receiving treatment in the previous two years for asthma, diabetes mellitus type 2 or hypertension. A random sample of Dutch patients per diagnosis and per general practice was added.

Adherence to guidelines was assessed by comparing clinical actions of the GPs with key recommendations of the CPGs, as measured by an electronic validated contact registration form that took into account the patient's specific clinical condition.³ Clinical outcome of care was measured for hypertension using systolic blood pressure (SBP) and diastolic blood pressure (DBP), for diabetes using blood glucose level and for asthma the GP was asked whether optimal lung capacity was reached or maintained. In addition, we constructed dichotomous outcome variables indicating whether the treatment target was reached. We did this overall and for all the three conditions separately. For hypertension, the treatment target was reached when the DBP was ≤ 95 mmHg and the SBP was ≤ 160 mmHg for hypertension, and for diabetes mellitus type 2, the treatment target was reached when the fasting blood glucose level was < 8 mmol/l or the non-fasting blood glucose level was < 10 mmol/l. The target in asthma treatment was reaching or maintaining an optimal lung capacity. To determine the relationship between mean adherence and the outcome of care we used a multivariate multilevel regression model in which we controlled for the covariates of patient gender and age and for variation at the patient and GP level. To explore ethnic disparities in the relationship between adherence and outcome, we performed the analyses for Dutch patients and ethnic minorities separately (Dutch versus non-Dutch, and Dutch versus the specific ethnic groups).

TABLE 1

Association between mean adherence and reaching treatment targets

	Mean adherence (%)	Treatment target reached (%)	Odds ratio (95%CI)*	Relative covariance (%GP / %patient)
Total (n = 401)	75	63	28.2 (3.8, 211.6) †	6/78
Hypertension (n = 120)	75	57	109.2 (2.7, 4421.2)	12/74
Diabetes (n = 198)	79	70	110.0 (3.59, 3369.3)	13/65
Asthma (n = 83)	66	52	0.5 (0.0, 88.2)	36/5
Dutch (n = 132)	75	67	149.7 (2.6, 8487.0)	0/86
Non-Dutch (n = 269)	75	61	21.8 (1.8, 268.7)	0/85
Difference between Dutch patients and other patients (per ethnic minority)				
- Hindustani-Surinamese (n = 64)	0	-7	10.2 (0.0, 3230.2)	0/69
- African-Surinamese (n = 19)	+6	+1	Not computable	Not computable
- Moroccan (n = 92)	0	-14	55.7 (0.5, 6690.7)	32/61
- Turkish (n = 94)	0	+1	26.8 (0.1, 5113.8)	14/82

* Multivariate multilevel model: $Y(\text{treatment target reached}) = X(\text{mean adherence}) + X(\text{patient's age}) + X(\text{patient's gender}) + \epsilon$, with random effects for GPs and patients. ($\alpha = .05$)

† In this regression model, the diagnosis was included to adjust for differences between hypertension, diabetes and asthma.

The GPs completed a total of 401 forms, regarding 238 patients, consisting of 40 (17%) Hindustani-Surinamese, 8 (3%) African-Surinamese, 50 (21%) Moroccans, 57 (24%) Turks, and 83 (35%) Dutch patients.

We observed a strong relationship between adherence to the guidelines and reaching the treatment target overall, in hypertension, and diabetes mellitus type 2, but not in asthma (see table 1). We found a statistically significant relationship between adherence and blood glucose level with a β -coefficient of -5.01 (95%CI = $-9.23, -0.80$). The relationship between adherence and blood pressure was not statistically significant with β -coefficients of -11.52 (95%CI = $-38.39, 15.34$) for systolic BP and -4.17 (95%-CI = $-17.78, 9.44$) for diastolic BP.

The table shows that while adherence rates did not differ between Dutch patients and patients in other ethnic groups, the treatment target was more often attained in Dutch patients. The relationship between adherence and attainment of treatment target was stronger in Dutch patients compared to non-Dutch patients, illustrated by the larger odds ratios seen for the Dutch patients than for the non-Dutch patients (see table 1, OR=149.7 vs. 21.8). However, the confidence intervals for these odds ratios overlap. Analyses using the specific ethnic minority groups showed considerably lower likelihoods of achieving treatment targets compared to the Dutch, although no statistically significant odds ratios were observed.

COMMENT

This study shows that treatment targets are more often reached when GPs adhere to guidelines. This effect was particularly evident in the effect of adherence on blood glucose levels. Adherence to guidelines leads to better clinical outcomes in Dutch patients as well as in ethnic minorities. Given the explorative nature of this study and the lack of statistical significant differences, one could argue that there is a lack of any true ethnic variation in the effect of adherence to guidelines on treatment outcomes. Therefore, further research is necessary to test our conclusions. However, the results of this study suggest that the positive effect of adherence to guidelines on clinical outcomes is stronger in Dutch patients compared to ethnic minorities. If this is the case, the next step would be to determine why this is so. The differences might be explained by a mismatch between the content of the guidelines and the treatment acquired by ethnic minorities.⁴ Another explanation might be a difficulty in communication between GP and patient, leading to a poorer mutual understanding and ultimately reduced patient compliance.⁵ If our findings are true, further research would be invaluable in explaining why these ethnic disparities exist.

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Guidelines of the Dutch College of
General Practitioners and the care for
ethnic minorities. General practitioners'
views on the value of NHG-guidelines
in a multicultural setting.

8

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INTRODUCTION

Guidelines of the Dutch College of General Practitioners (NHG) are an integral part of general practice nowadays. The clear and scientific procedures laid down in the guidelines of the NHG have earned them not only acceptance by GPs, but also respect both at home and abroad. Nonetheless, from the moment they were introduced, the guidelines also met opposition. It was thought they would not do justice to the complexities of medical treatment and would lead to “cookbook medicine”.¹

Several years ago we posed the question: to what extent are guidelines valid in a multicultural society such as the Netherlands? In many deprived areas of large cities for example, the immigrant population is far greater than that of the native Dutch. The increasing immigrant population has resulted in GPs being confronted more frequently with an ethnically diverse patient population in which relatively large contrasts exist regarding the prevalence and incidence of certain illnesses and complications, the reactions to medical treatment, how people experience and react to an illness and its cause, and often language.^{2,3} Analyses of American, English, Canadian and Dutch primary care guidelines and their scientific justifications have shown that guidelines of the NHG include relatively little information on relevant ethnic differences.⁴ Moreover, although the scientific justifications for the guidelines of the NHG did describe a number of ethnic differences, these were not incorporated into the final guidelines.⁵ The publication of this information provoked a discussion with the NHG regarding the extent to which the guidelines fulfil the requirements for ethnic minority patient care.^{6,7} However, GPs with a multicultural patient population, specialists dealing with ethnic minorities, and others who use these guidelines have not yet been given their say in this discussion. We interviewed a number of GPs in order to gain insight into the extent to which those working in deprived areas consider the guidelines relevant when treating patients from ethnic minority groups. Their insights can help the discussion on the relevance of guidelines of the NHG in a multicultural setting.

METHOD

We asked nine GPs for an interview for this study. The nine GPs were selected from 30 GPs who had participated in a study entitled “NHG guidelines and the care of ethnic minorities”. This study examined whether a patient’s ethnic origin influences the extent to which GPs follow the recommendations in the guidelines of the NHG, and whether the relationship between acting according to the guideline and the clinical results of the treatment given is affected by a patient’s ethnic origin. The selection of these nine GPs was based on the amount of data they had delivered for the study, and their relatively large immigrant patient population. These GPs could therefore be described as experts in

this field. Seven of the nine chosen GPs were prepared to be interviewed. One GP had already retired and the other was too busy due to the fact that a large number of GPs were on strike at the time of the interviews. The interviews took place in May and June 2005.

In this study we opted for a qualitative exploratory design, and an open interview technique. The interviews began by asking whether the current guidelines of the NHG were useful in the multicultural general practice. GPs were then asked if they deviated from certain specific recommendations for certain specific ethnic minority groups.

All interviews were recorded first on tape and then in writing. Due to the exploratory nature of this study, a method of analysis was chosen in which the written texts were categorised according to a number of central themes. Relevant results were presented in the GPs own words as far as possible.

RESULTS

Almost all interviewed GPs said they treated immigrant patients no differently than native Dutch patients, nor did they always deviate from the recommendations in the guidelines for particular ethnic groups. On further questioning about ethnic differences that potentially affect treatment, one important point was mentioned by all interviewees: the significant difference in the effect of treatment. GPs often find immigrant patients more difficult to regulate than native Dutch patients. In their opinion, there are three essential differences: 1. Compliance and attitude to illness 2. Diet and exercise 3. Unfamiliarity with the concept of general practice. Although these three aspects are interlinked, they are discussed separately below. Opinions regarding the value of the guidelines of the NHG in the treatment of ethnic minorities will also be discussed.

Compliance and attitude to illness

Diabetes and hypertension are disorders that do not cause immediate distress, but do carry risk factors for life-threatening complications and illnesses such as cardiovascular disease. According to the GPs interviewed, poor understanding of the concepts “chronic illness” and “risk factor” is partially due to the fact that immigrant patients have often had a poorer education than their native Dutch counterparts. The patients do not feel ill and therefore do not realise the seriousness of the situation. This also applies to native Dutch patients, but to a lesser extent, even if only due to the fact that information is more easily communicated. This attitude to illness causes significant problems regarding compliance. Compliance presents a greater a problem with immigrant patients because they do not understand that, even though they do not feel ill at present, they could become seriously ill in the future. Why should they take medication if they do not feel ill?

“They do not understand the relation between risk factors in the present and potential illness in the future. Nor, therefore, do they understand that they need treatment now in order to prevent problems in the future. This results in very poor compliance and a vague disposition. The concept of “I feel good so why should I take medication” is therefore prevalent in such groups, particularly with Turkish and Moroccan patients.”

“My biggest problem with my immigrant diabetic patients is that they do not really consider diabetes an illness which requires treatment. It is an illness with few perceptible symptoms, yet one for which patients constantly have to take medication.”

The GPs also reported having difficulty in responding to such situations, for instance when patients say they have taken their medication but the GP doubts this to be the case, perhaps because the patient has not requested a new prescription for some time. The patient’s understanding of the illness remains poor, but the GP does not dare to respond by increasing the dose of medication.

“The patient collects the prescribed medication, but I have my doubts as to whether it is taken. I have several patients who return 3 months later with the entire prescribed dose and yet say they have been taking it. Their compliance is definitely worse.”

“Immigrant patients often present with increased blood pressure or blood sugar levels, but I dare not increase their medication as I do not know whether it is being taken properly at home. Then there is a real danger that the patient will experience a hypo. I would rather that my patient has increased glucose levels than become hypoglycaemic. It is very difficult to judge how a patient deals with the illness when he is at home. That leaves me feeling helpless.”

The GPs also reported that these patients sometimes deal well with their illness and take their medication as prescribed whilst in the Netherlands, but forget this as soon as they are on holiday in their native country. Patients then feel fine and no longer stick to their diet and medication. When they return, the patients tell their GP that they felt fine on holiday, suffered no stress (which they often consider to be the cause of high blood sugar levels or high blood pressure), and that their blood sugar levels were normal. What the patients often do not realise is that their blood sugar levels and/or blood pressure have been rising significantly during their holiday, and that the GP then has to do all he possibly can to get them back under control.

In addition to compliance with medication, compliance with appointments is also worse among immigrant patients. This is often due to some groups’ unfamiliarity

with the concept of general practice. General practitioners enjoy an important position within health care in the Netherlands. In many other countries, and particularly those countries from which immigrants in the Netherlands originate, the concept of a “general practitioner” and his role as ‘gatekeeper’ to secondary health services, are unknown. In the Netherlands, patients suffering from diabetes or high blood pressure have to visit their GP every three months, even though they experience no symptoms. And the lack of symptoms is the reason they so often fail to keep follow-up appointments.

“The health care system is very different in the countries these immigrants come from. If a patient is ill, he goes to the hospital. If not, he stays at home and there is no need to contact a doctor. If diabetes is diagnosed in those countries, the patient is not called back. The initiative lies much less with the physician, and more with the patient. For this reason, patients receive medical care much later. And you see that here too. People from other cultures think it is strange when asked to return every three months to have their blood sugar levels checked. They have no symptoms, so why see a doctor? They would rather do something else, and that has become a habit. They are not familiar with general practice. That is a big problem. And if a patient does come with, for example, a headache, they immediately ask to be referred to a specialist or for a CT scan.”

“Immigrant patients also avoid check-ups, do not have their blood tested regularly or simply do not take their medication as prescribed, or in the prescribed dose. They sometimes decrease the prescribed dose without consultation because they are feeling better.”

“Immigrants do not understand that they have an appointment so they often do not turn up. I think that is a problem that receives little attention in health care. They do not understand that they have to come back to the doctor in three months because they do not feel ill. They think it is only necessary to see a doctor if they are feeling unwell.”

Another important cultural difference concerns what we refer to as the “Health Locus of Control”. People from western countries generally have an internal health locus of control, whilst many ethnic minority groups in the Netherlands have an external health locus of control. Patients with an internal locus of control take responsibility for their illnesses and the effect of the treatment. Patients with an external locus of control place the cause of, and responsibility for, their illness beyond themselves. They often seek explanations in supernatural phenomena such as the ‘evil eye’, or God in the event of diabetes or hypertension, which results in noncompliance.⁸

“I once spent half an hour explaining to a patient that he had to take his own responsibility. He nodded pleasantly with a glazed look in his eyes. When I had finished he said: “Yes, but doctor, yesterday I had a dream that two men tried to kill me, then Allah came between us and said it was not yet my time. So what you are saying is not true. As a human being, you can do nothing.”

Poor compliance can also result in GPs deviating from the guidelines more often with their immigrant patients.

“You accept more from immigrant patients. If, for example, they return from a holiday with highly abnormal blood sugar levels, you don’t immediately increase their medication because you know the patient has probably not been following your instructions.

Diet and exercise

“Just try to get an overweight, traditional, burqua-clad immigrant mother of five to adapt her lifestyle to include, for example, aquarobics. They all see swimming lessons as an amusing idea, but none take them. Sport is not an option, so you have to try to get them to take walks. But it is difficult to get Dutch patients to change from a sedentary lifestyle, let alone immigrant patients.”

This quote reflects the problems of overweight, diet and exercise. The GPs reported that diabetes and hypertension often go hand in hand with obesity in immigrant patients, particularly women.

“My immigrant patients are significantly heavier. The specific problem is that they do not want to exercise. They experience aching legs because they are overweight, and do not take exercise because of the pain in their legs.”

The GPs described a cultural difference in the degree to which patients exercise. Sport is part of the Dutch culture, in which everyone cycles and many people regularly visit a sport club. The same does not apply to immigrants. It is therefore more difficult to motivate them to exercise. The effect is, of course, strengthened by their lack of compliance and their beliefs surrounding illness, which have already been described.

“Many immigrant patients are heavily overweight and have been for many years. This applies less often to native Dutch patients.”

“Men in particular are terrified that their heart will stop if they start to exercise. This again is due to lack of understanding. I also get the impression that in the subcultures

I deal with, the car is a kind of holy cow to be worshipped together. To travel by bike is a sign of poverty. You can't get immigrants to leave the car at home."

To some extent, not wanting to exercise explains their worse regulation. The quotes below show that GPs for this reason often deviate from guidelines.

"Yes, sport is of course a Dutch pastime. I don't think I would even consider suggesting it to immigrant patients. They wouldn't do it anyway, so there is no point."

"I treat my immigrant diabetic patients, particularly the youngsters, with medication straight away because if I didn't, I think they would be back in six months and then need it anyway. You cannot get a 40-year old Turkish woman with abnormally high blood sugar levels to exercise her way back to health. I've seen that fail all too often. Sooner or later, those patients all die of an infarct, so for heaven's sake let them have medication straight away."

NHG guidelines and the care of ethnic minorities

Almost all participating GPs thought that information on ethnic and/or cultural differences should only be included in guidelines once it has been scientifically proven. The moment we no longer strictly adhere to that requirement, NHG guidelines can no longer be taken seriously. According to the interviewees, the fact that little regarding ethnic differences has yet been proven in the Netherlands, unlike in the United States and Great Britain, explains why information on ethnic differences in the guidelines is limited. Moreover, these GPs expect the guidelines to include more on ethnic differences in the future due to the slow but sure increase in the scientific results available. It did strike them that in the last update of the guideline on hypertension no mention was made of the reduced effectiveness of medication on patients of African origin. According to the GPs, the proven differences that should be included in the guideline are those regarding the higher prevalence of diabetes, also regarding Turkish and Moroccan people, and the increased prevalence of hypertension in Creole Surinamese and Ghanese patients. Some physicians consider that differing perceptions of illness described in the study entitled "Hee Broedoe" should be included in the guideline on hypertension.⁹

"An article was published recently in Huisarts & Wetenschap on hypertension in Surinamese patients and their perceptions of the condition. It was all very familiar to me. For example, Creole Surinamese patients who say: it is stress; no more stress, no more hypertension. These patients will not take medication if you prescribe it. The ideas that circulate among the Surinamese should be included in the guideline."

However, GPs expect to face difficulties if cultural differences are included in guidelines. The question remains: Where do you start? There are often fewer cultural differences between ethnic groups than within them, and is it possible to take all the differences into account?

“It would be a very complex task to outline the perceptions of specific illnesses per ethnic group and include these in the guideline. There are many different ways in which Dutch people perceive specific illnesses. That also applies to persons of all ethnicities.”

“A guideline must be succinct and specific, and it makes no difference whether the patient was born in Casablanca or Amsterdam. They all need equal conscientious medical care. What we know about the various cultural backgrounds is not a topic for the guideline. That would make the guideline far too complex.”

One GP had trouble accepting the NHG’s passive attitude regarding the study of ethnic and cultural differences.

“I am irritated by the passive attitude taken by the guidelines. It is already a well-known fact that diabetes is often diagnosed at a late stage, and statistics show that half of all diabetics do not even know they have it. Postponing the diagnosis instead of anticipating these statistics is highly dangerous. This applies in particular to immigrant patients. Patients should therefore be screened much sooner.

I am also concerned about the way the guidelines generalise, just because evidence is found within one particular group. Further research must be carried out in which a differentiation is made between ethnic groups. I also think that evidence from abroad could be put to good use in the Dutch situation. If you see that everything is the same, why repeat everything? It’s not that different in the Netherlands. The main problem is that the NHG is waiting for information that is solely applicable to the Netherlands. It will be many years before we have that, while we already know the difference.

The guideline is no use to me whatsoever. Screening at the age of 50 is far too late. I prefer ‘anticipatory’ medicine whilst the NHG prefers prevention for the majority. No-one needs to know that some groups think differently, and what you don’t know can’t hurt you.”

DISCUSSION

In this study, we asked GPs for their opinions regarding the value of guidelines of the NHG in a multicultural setting. Apart from a few exceptions, the GPs interviewed considered that NHG guidelines do pay sufficient attention to the ethnic differences between patients. The GPs also reported that they do not treat immigrant patients differently to native Dutch patients, nor do they deviate more often from the guidelines when treating people from

ethnic minority groups. This information was based on the results of their own studies into ethnic differences regarding adherence to guidelines and treatment given by general practitioners.¹⁰ Nevertheless, certain situations were described that appear to be more prevalent among immigrant patients and in which the GPs did deviate from the guideline. The GPs were less apt to increase medication if immigrant patients remained unwilling to cooperate, or were unwilling to cooperate following a holiday. Some also reported making less effort to change the patient's behaviour in favour of starting medication earlier. These examples, however, show that the information in the guideline is, although correct, more difficult to implement for immigrant patients.

The GPs mentioned that immigrant patients often fail to adjust to their illness. This was generally assumed to be due to the patient's poor understanding and the cultural differences affecting lifestyle and compliance.

However, our method does appear to have certain shortcomings. The GPs we interviewed were all from a select group that had participated in a study of NHG guidelines and the care of ethnic minorities. This group may well be particularly interested in improving the quality of care for ethnic minorities and therefore have a different opinion to GPs who had not taken part in the study. This study, however, did not aim to make generalisations based on the views of a typical GP working in the Netherlands. The GPs interviewed in this study were all experts, in other words they all had many years of experience in treating patients from various ethnic backgrounds. No, on the contrary, the aim of this study was to gain the views of these experts, as they could probably best determine whether the guidelines of the NHG suffice in multicultural general practice.

The interviews had an open character and no topic list was used. This was done deliberately so that the GPs were influenced as little as possible, and to give the interviewees the opportunity for own input. Almost all the GPs interviewed reported no differences in the care given to different ethnic minority groups. Nevertheless, further questioning did reveal issues that are discussed in this article. It is possible that the GPs, through further questioning, revealed problems that were rather exceptions than rules. To present the information in this way could give an incorrect and unfavourable impression of the care received by ethnic minority groups in general practice. However, since all the GPs interviewed reported the same ethnic differences mentioned in this article, it would seem that the problem has by no means been overestimated. In fact, we think that GPs have become so used to dealing with the "problems" described here that they did not even mention them at first. We do recommend, however, that future studies examine the extent of the problems outlined in this article.

The comments made by the GPs in this study are comments that have been made in health care since the 1980s.^{11 12} One could even regard these comments as immigrant

patient “stereotyping”. These GPs do, however, have practices in deprived areas and/or have many immigrant patients and therefore wide experience in this subject. In addition to a variety of stereotype problems still faced on a regular basis, the GPs stated that immigrant patients are more difficult to treat, which leads to poorer clinical results. It is remarkable that all these years later the same problems surrounding the care of immigrant patients in general practice still exist, and it poses doubts about the health care policies over the last decades. These policies appear to have had little effect on patient care in multicultural general practice. The problem GPs still encounter is a continuing lack of communication with immigrant patients, which causes much distress and high expenditure as a result of secondary complications. As primary care provider and gatekeeper, the GP faces these problems on a daily basis yet has few resources with which to solve them adequately. Political attention is therefore still essential.

Despite the problems outlined above, the GPs did consider the NHG guidelines to be more than adequate, also for the treatment of ethnic minorities. But how tenable is this viewpoint if they admit deviating from the guidelines due to problems of treating immigrant patients, and while research shows that the care given yields poorer results?^{13 14} The GPs felt that more specific attention for ethnic differences would only be indicated if more Dutch evidence becomes available, and even then should be limited so as not to undermine the value of the guidelines. This is a very valid consideration that is also being argued by the NHG. We do feel, however, that ethnic differences must be recognised in view of the fact they have been an issue in general practice for so many years now. Dutch policy has largely ignored the problem so far, and therefore new or other ways must be found to assist GPs in providing care for ethnic minorities. The guidelines can be highly instrumental in this regard. The NHG guidelines are accepted and respected everywhere. A more pro-active attitude towards specifying the relevant ethnic differences could therefore improve the care given to ethnic minority groups. The government should also continue to stimulate research and intervention with a view to improving the medical treatment of these patients in the Netherlands. This will result not only in a better quality of care for ethnic minorities, but will also save on expenditure by preventing many unnecessary illnesses and complications. Fortunately, the NHG has devoted regular attention to ethnic differences, which is evident for example in the recent publication of the NHG guideline on diabetes mellitus type 2.¹⁵ However, the fact that no mention has been made of ethnic differences in the recently published NHG Guideline on Cardiovascular Risk Management shows that the problem is still not being acknowledged, even though many ethnic differences have already been established.¹⁶ There is, therefore, still much to be gained.

CONCLUSION

NHG guidelines are an important, respected and accepted instrument in improving the quality of care provided by general practitioners in the Netherlands. Little has changed over the last decades regarding the problems surrounding immigrant patient care in general practice. For this reason, the NHG would be justified in taking a more proactive attitude towards acknowledging ethnic differences in their guidelines. The NHG is now giving more structured attention to ethnic differences in the development of its guidelines.

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Discussion | 9

OVERALL CONCLUSION

This thesis was focussed on the question whether guidelines of the Dutch College of General practitioners should pay more attention to ethnic differences between adult patients with diabetes mellitus type 2, hypertension and asthma. This question was divided into five sub questions:

1. Is there any reason or evidence for paying attention to ethnic differences in these chronic conditions?
2. Do GPs' treatment differ between patients of different ethnic origin
3. Is GPs' adherence to the guidelines associated with the ethnic background of their patient?
4. Are there any ethnic differences in the association between treatment and clinical outcome of treatment?
5. What is the opinion of GPs with many ethnic minorities in practice, regarding the usefulness of the current guidelines in the treatment of ethnic minorities?

Based on the studies described in this thesis I conclude that much relevant evidence on ethnic differences exist which mostly does not lead to ethnic specific remarks or recommendations in the Dutch guidelines. Furthermore, although GPs do not differ in the degree of adherence to guidelines or treatment between ethnic groups, the association between the GPs' adherence to guidelines and the patients' positive health outcomes is stronger in Dutch patients. Finally, almost all GPs indicated that the current guidelines were adequate for the treatment of ethnic minorities.

With answering all five sub-questions an overall conclusion regarding the question whether the guidelines of the Dutch College of General Practitioners should pay more attention to ethnic differences can be made. Given the relatively large ethnic disparities in health, the evidence based character of the guidelines and the relatively large number of relevant available evidence the guidelines should pay more attention to ethnic differences. Especially because it seems that the same treatment and the same degree of adherence to the recommendations of the guidelines have a smaller association with reaching treatment targets in ethnic minorities compared to in Dutch patients. Our findings that in the participating GPs' opinion the current guidelines are as useful in ethnic minority patients as in Dutch does not negatively affect this conclusion. First, because the GPs point out that if evidence is available it should be taken into consideration in the development of the guidelines and second, because they experience differences in outcome and explain it with patient factors, which of course also could be addressed in the guidelines.

LIMITATIONS OF THIS STUDY

Considering all analyses performed in this thesis the question arises whether selection bias is a relatively large problem in some of the studies. In this thesis selection bias could have occurred through the sample of GPs or the completed data collection forms.

GP sample and selection bias

In this study 145 practices using a specific type of information system (Elias) and located in or near deprived neighbourhoods were approached to participate in this study. Only 17 practices out of the 145 agreed to participate. Participation implied extracting patient records (which were made anonymous) from the GP information system, and more importantly prospectively filling in a data collection form after visits of selected patients. Especially the alleged time-consuming character of the prospective part of this study led to the low participation rate of GPs. 50 general practices should be included according to the project proposal, while only 17 did. This selection of GPs could have been a source of bias with consequences for the results in two ways. First because only GPs using Elias were approached, and second, because only 12% of the approached GPs agreed to participate.

The reason why “only” practices using Elias were approached is explained by the collaboration with the Department of Medical Informatics of the Erasmus MC. The Department of Medical Informatics has much experience in writing software tools for computerised data-collection. They developed and installed software in the GP information systems for the computerised data collection of this study. However, at that time their experience was limited to one type of GP information system, e.g. Elias. Although at that time Elias had one of the largest market shares in the Netherlands, only around 25% of all GPs used this information system. There are no indications that the GPs using Elias differ from other GPs in such a way that it could influence the findings presented in this thesis. Therefore we do not expect that the selection of GPs using Elias negatively affected the external validity of this study.

Only 12% of the approached practices finally participated in the study. As mentioned, the main reason for refusing participation was the alleged time consuming character of this study. The participating practices seemed not to differ from other practices. The participating practices were located in or near deprived neighbourhoods in different cities in the Netherlands, like The Hague, Rotterdam, Amsterdam, Utrecht, Delft and Arnhem. Furthermore the participating GPs consisted of males as well as females and were distributed proportionally over different age categories. The practices also ranged from solo-practices to practices with two or three GPs and large health centres. So it seemed that neither the practices nor their patient population differed from non-participating practices. The reason for participation could therefore be found in the participating GPs being more research-minded and/or being more interested in the

topic of the quality of care for ethnic minorities. However, I did not perform a proper non-response analysis, so I can not make any scientifically grounded conclusion in this regard. However, in my opinion it was a source of bias, because it is not unthinkable that research-minded GPs with special interest for ethnic minorities pay more attention to the care given to ethnic minorities. This type of bias could have led to for instance an underestimation of the ethnic differences in health outcomes found in this thesis, because they put special care in their treatment of ethnic minorities. It has to be noted, however, that the interviews with the GPs did not seem to confirm this. The GPs did not feel the guidelines should give more specific attention to ethnic differences. Nor was there any hint of a different approach in their work vis-à-vis ethnic minorities compared to other GPs.

Completed data collection forms and selection bias

To assess differences in adherence to guidelines and the association between adherence and health outcomes, we used a data collection form, which we implemented in the GP-information systems. After every visit of an included patient the GP was asked whether the visit concerned the disease for which the patient was included in this study. If so, the GP was asked whether he would like to fill in the data collection form. If the GP answered one of these two questions with NO the data collection form did not appear on his computer screen. After the data collection period it turned out that a disappointingly small number of forms was completed in the practices. When confronting the GPs with this low response they all mentioned the high workload as the only reason for not completing the forms more frequently.

The low number of completed forms led to problems with statistical power (see below) and could have caused selection bias, because the completed forms are a selection of the forms potentially completed. Bias could have arisen when a GP would have not completed forms when s/he doubted whether appropriate care was delivered. Consequently, the completed forms could concern those visits that the GPs were willing to have reviewed, because of perceived high adherence to the guidelines. This bias could obviously be a large problem when GPs excluded forms because of the perceived high or low adherence more often in one or more specific ethnic group or the Dutch reference group. Because GPs indicated that the high workload was the main reason for not completing a form and a high workload is often associated with care for ethnic minorities there is a strong probability that selection bias could have had an effect on our findings. To estimate this effect a non-response analysis was performed, which is partly described in chapter six. The Chi²-analyses in the non-response analysis showed differences in visits with and without completed forms between ethnic groups. However further t-test analyses showed that the differences between the ethnic groups did not concern differences between the Dutch reference group and the different ethnic minority groups. Also not when focussing on the specific diseases. What is also important

and is not mentioned in chapter 6 is that we also included the number of prescriptions in the non-response analysis to see whether characteristics of visits in which a form was completed differed from visits without a completed form. No differences were found. So, based on this analysis of non-response I conclude that the visits do not seem to differ from each other in a relevant way and therefore it seems that visits with completed forms are comparable with visits without completed forms.

The clinical condition of the patient could also be an important reason for GPs for not completing a form. This clinical condition (i.e. the existence of relevant co-morbidity) is not included in the non-response analysis, because it is an integral part of the data-collection form. The clinical situation of the patients determines the specific action (according to the guidelines) required by the GP. And this was taken into account in the data collection and –analysis instrument. Therefore we conclude that the clinical situation is not a factor of relevance for this non-response analysis.

So, although the low number of completed forms and therefore non-response was an important issue in the prospective part of this study, the non-response analysis did not reveal large difference. Therefore I conclude that our results are probably not biased.

Although the low numbers of completed forms in this study I think that data collection forms integrated in the GP's information system for research purposes can be a powerful way to gather data. It is however important that such an integrated data collection form does not intervene with the GP's work. So, the question the GP has to answer should be kept to a minimum. One way to do that is to copy data which the GP filled in his patient file automatically in the form.

Statistical power and effect on results

The relatively low numbers of participating GPs and completed forms led to problems with statistical power in the analyses presented in the chapters six and seven of this thesis. This lack of statistical power in all subgroups led to relatively wide confidence intervals. This partly explains why no ethnic differences in the results were found. When closely considering the different confidence intervals some appear to approach statistical significance. For instance the analysis of adherence to positive recommendations in guidelines presented in chapter six show ORs of 0.74 in Moroccan and Turkish patients. The confidence intervals were between 0.52 and 1.06. It is plausible that statistical significance is not reached because of the lack of statistical power. In all analyses in this thesis two-sided hypothesis testing was done in which a significance level of 0.05 (and 95% confidence intervals) was used, which is common in epidemiology and health services research. However, two-sided hypothesis testing is often automatically chosen because of this commonness. It is rather questionable whether two-sided hypothesis testing should always be the standard. Actually, two-sided hypothesis testing should only be performed when

prior hypotheses regarding the direction of the expected differences or associations do not exist. In one-sided hypotheses testing prior hypotheses of differences and associations exist. It can be argued that in many analyses presented in the scientific literature including in our own analyses one-sided hypothesis testing should be preferred. In this thesis for example prior hypotheses were that adherence to guideline recommendations, the association between adherence and outcome, and treatment would be better in Dutch patients. Therefore, one-sided testing is defensible in this thesis. Figure 1a. and 1 b. shows the effect of the choice between one-sided and two-sided hypothesis testing on the confidence intervals and therefore the results of the analysis.

Figure 1a two-sided hypothesis testing

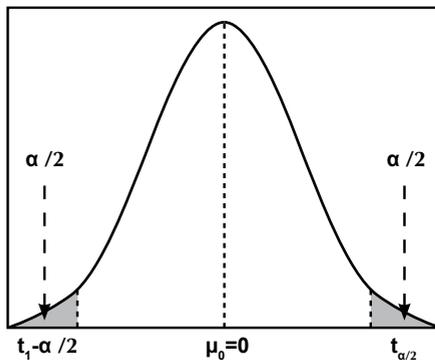
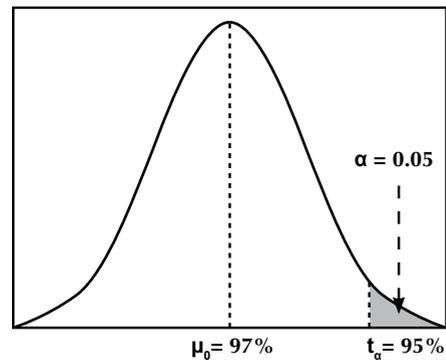


Figure 1b one-sided hypothesis testing



Both figures indicate that one-sided testing would more often yield statistically significant differences, also regarding the analyses presented in this thesis. Realising this is relevant because of the differences between statistical significance and clinical relevance. All of the (not statistically significant) ethnic differences found in this study indicate the same finding which is that adherence, treatment and association between adherence and outcome is worse in (some) ethnic minority groups. If the hypotheses were tested one-sided some differences would probably be statistically significant

However a 95% confidence interval was chosen in this study and therefore our conclusion still remains that there are little statistically significant ethnic differences in adherence and treatment. Although it would be worthwhile to repeat this study with an improved design in which more GPs should be included and more completed forms should be obtained.

GENERAL DISCUSSION

Ethnic disparities in health are nowadays extensively described in the scientific literature. Evidence of this ethnic health gap is particularly present in the diseases under focus in this thesis. In diabetes and hypertension a higher prevalence in ethnic minorities, earlier onset, and more (severe) complications are proven. It is not totally clear whether asthma is more prevalent in ethnic minorities, although the risk of hospitalisation and the number of department visits are higher.¹ Explanations for these ethnic disparities in health are complex. Health outcomes can be considered as the outcome of the interaction between the physician and the patient. One of the many forces influencing this doctor-patient interaction are the guidelines. In the following part of this chapter I will focus on the validity of guidelines as a possible explanation for ethnic inequalities in health outcomes.

Validity of guidelines

The international scientific literature is filled with evidence of ethnic disparities in the quality of health care. It is proven in the US and UK that ethnic disparities in the quality of care are an important potential explanation for ethnic inequalities in health outcomes.^{2,3} Standardisation and guidelines are considered important quality improving concepts and instruments. This thesis implicitly explored the validity of the concept of standardisation in a multicultural setting and how guidelines in a multicultural society are related with the ethnic health gap. Opinions on this matter can be classified along the continuum between two perspectives. First, the perspective that the concept of standardisation in Western medicine is in contrast with the Western world becoming more and more ethnically divers. And second, standardisation of care according to the principles of evidence-based medicine discourages ethnic variation in treatment, and therefore could be an important tool to diminish ethnic disparities in the quality of health care and consequently in ethnic disparities in health. The results of this thesis confirm earlier findings that treatment and adherence to guidelines of Dutch GPs do not differ between ethnic groups and that the same treatment does lead to relatively worse health outcomes in ethnic minorities.^{4,5} So, the question arises whether standardisation and clinical practice guidelines could overcome these worse health outcomes.

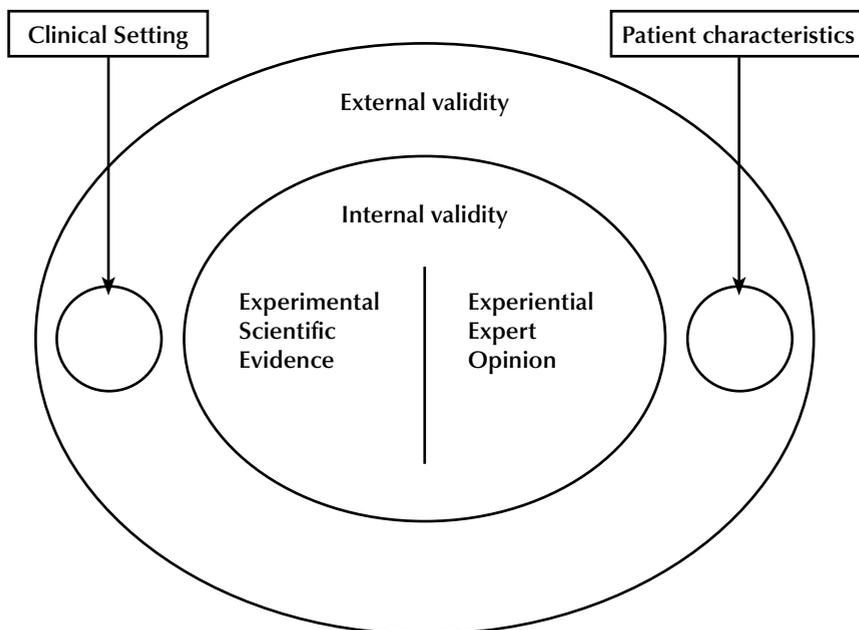
The history of guidelines goes back to the industry in the 1930's where it became apparent that variation in processes should be reduced as much as possible.⁶ In the last 20 years this management wisdom called "standardisation" has entered health care services. The reason for this was a need for better quality health services. The explicit belief was that many, if not most, professionals were working sub-optimally through not practising with the best evidence available to their particular discipline. Examples of wide variations in outcomes between hospitals

or treatment units were often quoted in support of the general condemnation, fuelled by comparisons with other sectors, service and manufacturing, where often such variation has been successfully brought under managerial control.⁷ The principle of standardisation and guidelines aims on defining the best treatment for the average population based on the best available evidence. Exceptions between patients should only be made when these exceptions seem necessary and are proven with scientific evidence. Obviously physicians still retain their autonomy and therefore can deviate from the recommendations of the guidelines when necessary in best interest for their patients.

The concept of standardisation and guidelines are by now a legitimate and structural part of health care and medicine. However, when developing a guideline stating the best treatment practice based on the best available evidence the users of the guidelines should be certain whether the guideline is indeed the best-practice for the patient in front of him. This is not always the case. Apart from human considerations such as inadvertent oversights by busy or weary members of the guideline group, guideline developers may err in determining what is best for patients for several reasons.⁸ For instance, scientific evidence about what to recommend is often lacking, misleading, or misinterpreted and recommendations are influenced by the opinions and clinical experience and composition of the guideline development group. Flawed clinical guidelines harm practitioners by providing inaccurate scientific information and clinical advice, thereby compromising the quality of care.⁸ The greatest danger of flawed clinical guidelines is to patients. Recommendations that do not take due account of the evidence can result in sub-optimal, ineffective, or harmful practices. What is best for patients overall, as recommended in guidelines, may be inappropriate for individuals or specific subgroups, like ethnic minorities.⁸ Thus the frequently touted benefit of clinical guidelines e.g. more consistent practice patterns and reduced variation, may come at the expense of reducing individualised care for patients with special needs.⁸

To determine whether guidelines could be a reason or a solution for ethnic differences in health outcomes the question on validity of the guidelines should be addressed. Graham et al. (2000) created a conceptual framework to explain variances in clinical outcomes.⁹ Figure 2 shows that the internal as well as the external validity of guidelines can have an effect on ethnic differences in clinical outcome.

In figure 2, the level of scientific evidence and experience of the expert panel determines the internal validity. The external validity is determined by patient characteristics and the clinical setting in which the guideline is used. Patient characteristics refer to the possibility that personal factors, e.g., social, physiological, and economic, of patients may affect relationships between guidelines and care outcomes, thus limiting their

Figure 2 Explaining variances in clinical outcome by the validity of guidelines⁹

generalisability to specific patients. Clinical setting refers to limitations in extrapolating from guideline-related circumstances in one clinical context to another.

Internal validity

As stated above, according to the conceptual framework of Graham et al. the internal validity of guidelines is based on the level of evidence or the level of experience of the guideline developers.⁹ The guidelines used in this study are developed according to the principles of evidence-based medicine. The guideline development process of the Dutch College of General Practitioners serves as a worldwide example of an evidence based medicine standard setting procedure.¹⁰ The expert panels responsible for the specific guidelines are in general experts in the specific health problems in general practice. The (most recent updates of the) guidelines on the health problems under study in this thesis are also developed by panels with members with much expertise on the specific subjects, also concerning these health problems in ethnic minorities. The guideline development process has a comment phase in which 50 randomly selected GPs can give feedback on a draft of the new guideline. Finally the standard development procedure ends with an authorisation procedure that consists of a session in which the

expert panel has to defend its' product before a critical committee of wise men and women. Their wisdom is derived from various academic chairs of general practice or a long experience in general practice.¹¹ So, in conclusion one should be confident in the expertise of the guideline developers. However, parts of this thesis emphasise the importance of the role of normative values in the development process. Guidelines are highly influenced by the human factor, i.e. feelings, behaviour, values, needs, rationality and subjectivity.¹¹ The whole guideline development process takes place in a normative and subjective context. The choice of the members of the expert panel, the topics in the guidelines, and the search and selection of evidence are all partly based on normative powers and values.

The guidelines under study in this thesis were very reserved with giving attention to ethnic differences. In chapter three and four I concluded that despite the existence of relevant evidence about ethnic differences most of these differences were not mentioned in the guidelines. This could refer to problems with the internal validity of the guidelines. In a reaction, the developers of the guidelines (the Dutch College of General Practitioners) mentioned different arguments for this reservation, which all seemed valid.¹² First, they mentioned that the evidence of ethnic differences in care or health found in the Netherlands does not make ethnic specific recommendations necessary. Furthermore, evidence found in other settings or countries could not be deemed to be necessarily applicable on the Dutch context.

Second, they mentioned that relevant ethnic differences are implicitly already incorporated in the guidelines. For instance, it is well known that people from African descent are more sensitive to sodium restrictions. The guideline states that the GP has to inform all of his patients to cut down on salt, so this will automatically benefit the patients of African descent as well.

Third, they mentioned that the treatment by the GP is based on clinical values rather than social constructs (like ethnicity). This means that for example the blood glucose level or the (lack of) success of the treatment should influence the actions of the GP. When a specific medication does not work in a specific ethnic subgroup, the blood pressure will not be controlled and the GP will automatically reconsider his treatment according to the guideline.

Their first argument, the alleged lack of Dutch scientific evidence on ethnic differences, is only partly true. Although in general evidence is still limited, ethnic differences in some health problems are by now fully established. Differences in prevalence, severity, ages of onset, and effectiveness of treatment are found in diabetes and hypertension. However, even in the most recent updates of the guidelines on diabetes and hypertension ethnic differences are scarcely or not mentioned. Furthermore, evidence found in other western countries with the same ethnic groups should not be disregarded. It's not defensible that while evidence found in white men in the USA or UK is automatically

applied to the entire population in western society and therefore the Netherlands, evidence on ethnic differences should only be considered when found in the own country. Ethnic differences found in other countries should surely be considered with caution. Evidence found in the USA for instance cannot automatically be applied on the Dutch situation, because of the relative large differences between the ethnic groups and to a lesser extent their position in the host country. However, some ethnic groups with the same background are scattered over different (European) countries, like the Turks, Ghanaians, South East Asians and Moroccans. So evidence found in Turks in Germany, for example, can surely be used in the Dutch setting.

Not everything stated in the guideline, as we argued before, is evidence based. On some specific issues evidence is lacking or not straightforward. In those situations often a minimum intervention philosophy is followed in the Netherlands or the expert panel will decide on the content of a specific recommendation based on their expertise. A minimum intervention philosophy is probably often a preferable strategy to resist for instance medicalisation or to control costs. But when scientific evidence is lacking or is not so strong while many experts or signs are pointing to a large health problem in ethnic minorities, a more pro-active attitude could be desirable. When recommendations are based on the expertise of the panel the composition of the panel becomes a very important determinant for the content of the guideline. Therefore it is important that the expert panel should always be a reflection of all users.

There are many problems surrounding the second argument of the Dutch guideline developers. First, research has shown that Dutch GPs adhere to approximate 70% of the recommendations in the guideline.¹³ So 30% of the recommendations are not followed because of several reasons. It is never assessed whether the salt restriction recommendation is followed or not but it is not unthinkable that this particular recommendation is not followed by every GP every time. It is known that salt restriction has a larger blood pressure lowering effect in black people, who have much larger problems regarding hypertension than the general population. So the specific mentioning in the guideline of the effect of salt restriction in blacks could enlarge the adherence to this specific recommendation in the treatment of blacks and could have a positive effect on their hypertension burden. Not mentioning this ethnic specific information could lead to an unnecessary lower quality of care. Second, one of the most important objectives of the guidelines is to provide GPs with a quick-reference-guide regarding the current scientific knowledge on a specific subject. It is only fair that proven ethnic differences should be stated in this reference book. It alerts GPs to pay attention to specific circumstances regarding care to ethnic minorities, like compliance or difficulties in the management of diabetes or hypertension. The mentioning of the higher burden of these diseases could lead to GPs treating more actively in stead of trying and waiting on the effect.

The third argument that the treatment of the GP is based on clinical outcome

measures like the blood glucose or blood pressure levels, and therefore ethnic specific recommendations would not be necessary because GPs automatically will react (according to guidelines) when a positive effect stays away, is odd. It would mean that inaccurate information is knowingly stated in the guideline. The guideline developers know that the treatment recommended would probably not have an effect in a specific ethnic group, but it remains the first preferred treatment. Only after some months, when the treatment does not have the intended effect, GPs will start an alternative treatment.

The above briefly described discussion is very interesting and it is not easily determined who is right in this matter. However, the purpose of illustrating this discussion is to show that the above-described arguments of the guideline developers can be categorised as mainly normative and subjective (as are mine) with large consequences for the content and the internal validity of the guidelines. This normative and subjective context cannot be eliminated, because guidelines are still developed by humans. Guidelines could even also benefit from the human factor. So is the possibility of reaching consensus on a multitude of questions which are important for the day to day functioning of GPs, one of the most prominent benefit of the human factor.¹¹ The potentially negative sides of the human factor such as subjectivity can be curtailed by a rigid development procedure.¹¹ Perhaps the greatest challenge to guideline developers is making explicit the values used in formulating recommendations. This would improve the internal validity of the guideline.

Because of the relevance of ethnic inequalities in health I suggest to make this an integral part of the guideline development process or of the guideline. The first means that ethnic differences should always be one of the important topics that need to be considered in the update of the guideline. The second means that standard a box is reserved in the guideline that addresses the topic of important differences between ethnic groups. Although the topic of ethnic inequalities in health can still vanish in the subsequent development process, the chance it will be properly discussed will probably be larger.

External validity

The external validity of guidelines is as stated above determined by the usefulness of the guideline in all patients and all clinical settings.

Professor Thompson wrote “In the same way that no one can be against quality, no right-minded person can be against evidence. What is at stake is the nature of that evidence, how it was created and how it will be used”.⁷ This summarises the main problems regarding external validity. Many authors question whether clinical guideline recommendations of demonstrated efficacy (internal validity) within epidemiological research can be generalised to general practice.⁹

Evidence based medicine weighs the strength of the evidence (see box 1). As shown

BOX 1

Evidence weighing in the North of England evidence based guideline development project¹⁵

Strength of recommendation

- A Directly based on category I evidence
- B Directly based on category II evidence or extrapolated recommendation from category I evidence
- C Directly based on category III evidence or extrapolated recommendation from category I or II evidence
- D Based on the group's clinical opinion

Categories of evidence

- I Based on well designed randomised controlled trials, meta-analyses, or systematic reviews
- II Based on well designed cohort or case control studies
- III Based on uncontrolled studies or external consensus

in box 1 randomised controlled trials (RCTs) are considered to be the best available evidence. The evidence found in RCTs is considered to be the best available evidence and is the most important input for guidelines. However, care in general practices has its specific needs for research. For instance, Mant et al. assessed differences in the characteristics between participants of a large RCT (which served as the main basis for a guideline for stroke in the UK) and patients in English general practices. They concluded that these populations were not sufficiently similar to warrant widespread use of the guidelines.¹⁴ Problems arise because of the specific rules of RCTs. The study population in RCTs, for example, are generally kept as uniform as possible to be able to determine the effect of the study.

In practice, this means that evidence found in a very small subgroup of mostly white, middle aged men is used to describe the best treatment for the average population. This focus on RCTs can lead to problems with the external validity of guidelines. These problems are especially large in general practices in deprived neighbourhoods, which is a setting contextually very complex. The patient population of GPs in deprived neighbourhoods is very different from the study populations of the RCTs and even from the average population targeted by the guidelines. General practices in deprived neighbourhoods are often confronted with patients with different ethnic backgrounds and lower social economic status with specific consequences for the health status of the population.

Because ethnic minorities are seldom included in RCTs, evidence in ethnic minorities of the highest quality is very scarce. So the question is whether to structurally generalise RCT evidence to the whole (average) population (including ethnic minorities) or to use evidence of ethnic inequalities in health of lower strength. The answer depends on the specific context, e.g. the health problem, the RCT, the potential existence of relevant differences in ethnic groups and so forth. Guideline developers should realise that while the current guidelines state the preferred treatment for the average patient population in the Netherlands, the patient population in deprived neighbourhoods is one of the extremes in that continuum and therefore deviates significantly of the average.

My suggestion is the same as described above to improve the internal validity: make the care for ethnic minorities an integral part of the guideline development process or the guideline. Furthermore I would suggest that guideline developers should not be too careful with mentioning relevant ethnic differences in guidelines. A more pro-active attitude is desirable. Evidence of a lower quality (than RCTs) and opinions of experts are also a very important source of input for the guideline, especially when combined with common sense.

The caution with or reluctance against ethnic diversity in the Dutch guidelines is in my opinion not a main reason of the existing ethnic differences in health and specifically in diabetes and hypertension, because the standard treatment is probably not very harmful for ethnic minorities and otherwise GPs probably would react upon that by deviating from the guidelines in the treatment of ethnic minorities. However the current guidelines are also not a solution to the ethnic health gap, whereas they potentially could be. A more pro-active attitude towards the mentioning of important ethnic differences could be an important and powerful tool in the struggle against ethnic inequalities in health.

Doctor-patient interaction and patient compliance

So far the focus on explanations of the worse health outcomes was sought in the guidelines. But explanations could also be found in the interaction between the GP and the patients and (its consequences for) the patients' compliance with treatment. Harmsen showed in his thesis the importance of the cultural background of patients for the mutual understanding between the GP and the patient.¹⁶ The main outcome of his work was that the patient's cultural background is a very important patient characteristic, because of its consequence for the mutual understanding, communication and perceived quality of care. Furthermore, mutual understanding proved to be the best predictor for medical compliance.¹⁶ GPs studied in my thesis point out that compliance is worse in ethnic minorities, which seems to be confirmed by other research.¹⁷ Problems with compliance in ethnic minorities are mostly explained by a lack of knowledge and therefore for a large part by the inability of the GP to explain his treatment. Although one can argue to what point physicians can be held responsible for the compliance of their patients,

they do play a vital role in improving compliance. It has been shown that compliance is associated with health outcomes.¹⁸⁻²⁰ In my opinion, reducing the knowledge gap and improving compliance in ethnic minorities will yield the most benefit in reducing ethnic health inequalities. This should therefore be an important focus in health care research and policy. Physicians and the health care system should take their responsibility and do their best to tackle this problem. Guidelines could play a role in this by stating information to support the GP in not only improving the treatment but also patient compliance. For instance the health locus of control of ethnic minority patients or the social normative values of ethnic groups are important for compliance and therefore the treatment. Informing GPs about these issues can help in improving health outcomes. However, stating such information would probably not be the most effective or feasible way. There are other ways to inform GPs than by guidelines, although guidelines are highly valued by the GPs and therefore one of the most powerful tools to reach GPs. It is more important to educate physicians in the cultural backgrounds of patients as one of the most important aspects of the patient's context.¹⁶ This education should already begin at the university where future doctors are being prepared.

In this respect, the patients' responsibility should also not be forgotten. The improvement of health literacy (especially knowledge about chronic diseases and its treatment) and knowledge about Dutch health care system and especially the role and communication style of the general practitioners are important. GPs could play an important role in this. However, studies showed that to provide culturally competent care and to meet the individual needs of immigrant patients a particular set of skills is required, including, adapting communication patterns, modifying diabetes education programmes, and eliciting information about the patient's logic on non-compliance.²¹ It is difficult for GPs to obtain all these skills. In my suggestion community intervention strategies with intercultural mediators or peer health educators can play an important role in this. Culturally tailored intervention programmes delivered by intercultural mediators or peer health educators are proven effective.²²

Another potentially effective way to improve the compliance and health status of chronically ill ethnic minorities, which should be further explored, are combination pills. In diabetes and hypertension treatment for instance co-morbidity is a large problem and for every chronic condition patients have to take several pills. This has negative consequences for an already low compliance. When the effect of different pills can be combined in one pill, this could result in a better effect on health, perhaps despite other negative consequences of combining different pills into one.

Standardisation in a multi-ethnic world: a paradox?

To give an answer to the title of this thesis one should first establish the role of clinical practice in health care. In Dutch health care there is a development towards a structure in which health care becomes more transparent and providers become more accountable

for the delivered (quality of) care. In many health care organisations quality of care is measured by scores on a broad range of clinical performance indicators based on adherence rates to clinical practice guidelines. Furthermore, higher adherence rates to guidelines performance measures is often considered to be evidence of improved quality of care.²³ However, many pitfalls exist when converting guidelines into quality measures.²⁴ The most important pitfall in this context is extracting indicators from guidelines that are based on RCTs, which at best allow generalised statements about population averages, not what to do in individual cases or specific ethnic subgroups. Treatment according to the guidelines leads to relatively worse health outcomes in ethnic minorities. Deviation from the guidelines should therefore not automatically indicate a lower quality of care in ethnic minorities, because deviation could be good for their health. This brings us again to the question of the role of clinical practice guidelines. When they are considered to be just one of the many instruments to support physicians in daily practice and therefore comprehend just a small part of health care, guidelines and the multi-ethnic population probably do not refer to a paradox. However when the role of guidelines is enlarged by deriving national indicators from them to evaluate the quality of health care providers or health care sectors, as described above, guidelines and the multi-ethnic society are becoming paradoxical.

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SAMENVATTING

De ontwikkeling van medische standaarden heeft de laatste decennia een vogelvlucht genomen. Standardisatie was het antwoord op de grote praktijkvariatie die er tussen artsen bleek te bestaan. Het idee was dat veel artsen suboptimale zorg leverden, omdat niet volgens het best beschikbare wetenschappelijk bewijs werd behandeld. Het in kaart brengen van de best mogelijke behandeling op basis van wetenschappelijk bewijs of de meningen van experts levert uiteindelijk de standaard op. Deze standaard is de aanbevolen behandeling voor een type klacht waarin rekening wordt gehouden met specifieke klinische karakteristieken van de patiënt. Tegelijk met deze tendens van standardisatie is de gehele westerse wereld vanwege allerlei migratiestromen (met verschillende redenen) steeds etnisch diverser geworden. In deze dissertatie staat deze ogenschijnlijk paradoxale situatie centraal. Valt standardisatie te rijmen met een steeds diverser wordende (patiënten)populatie? Hoe valide en bruikbaar zijn richtlijnen daardoor in de praktijk? De centrale vraag van deze dissertatie is: "Dienen standaarden meer rekening te houden met etnische verschillen tussen patiënten?" Deze centrale vraag is opgedeeld in vijf subvragen:

1. Is er 'wetenschappelijke bewijs' dat wijst op de noodzaak van verschillende aanbevelingen op het gebied van diagnostiek en/of behandeling voor diverse etnische groepen? Deze vraag komt aan de orde in de hoofdstukken 2, 3 en 4.
2. Verschilt de verleende huisartsenzorg aan patiënten van verschillende etnische afkomst? Deze vraag komt aan de orde in hoofdstuk 5.
3. Is de mate van adherentie aan standaarden van huisartsen verschillend naar gelang de etniciteit van de patiënt? Deze vraag wordt besproken in hoofdstuk 6.
4. Bestaat er een etnisch verschil in de associatie tussen het volgen van de standaard en de klinische uitkomst van de behandeling? Deze vraag komt aan de orde in hoofdstuk 7.
5. Wat is de mening van huisartsen over de bruikbaarheid van standaarden in de behandeling van patiënten met verschillende etnische achtergronden? Deze vraag komt aan de orde in hoofdstuk 8.

Omdat dit onderzoek is uitgevoerd bij huisartsen is in dit onderzoek gefocust op de standaarden van het Nederlands Huisartsen Genootschap (NHG). Vanwege hun veel voorkomende en chronische karakter focust deze dissertatie zich verder op de aandoeningen diabetes mellitus type 2, hypertensie en astma bij volwassenen. In dit onderzoek is gebruik gemaakt van verschillende kwantitatieve en kwalitatieve onderzoeksmethoden.

Na de beschrijving van de achtergrond van deze dissertatie en de introductie van de onderzoeksvragen in hoofdstuk 1 wordt in de hoofdstukken 2 tot en met 8 een antwoord gegeven op de bovenstaande vragen.

Hoofdstuk 2 beschrijft de resultaten van een systematische review van de wetenschappelijke literatuur naar de prevalentie van diabetes type 2, andere cardiovasculaire risicofactoren en cardiovasculaire morbiditeit en mortaliteit bij Turkse en Marokkaanse immigranten in Noordwest-Europa. De meeste bestudeerde studies baseren hun metingen op zelfrapportage en zijn daarom ontoereikend om de “werkelijke” prevalentie van diabetes, andere cardiovasculaire risicofactoren en de aanwezigheid van cardiovasculaire ziekte te schatten. De bestudeerde onderzoeken boden daarom onvoldoende materiaal voor een kwalitatief goede schatting van het cardiovasculaire risico bij Turkse en Marokkaanse immigranten en de autochtone bevolking. Niettemin toont het beschikbare bewijs voldoende aan dat: diabetes mellitus vaker voorkomt bij zowel Turkse als Marokkaanse immigranten, dat Turkse mannen vaker roken, en Marokkaanse vrouwen zelden roken. Gegevens over cardiovasculaire sterftecijfers zijn schaars: in een studie was het sterftecijfer opvallend lager bij Turks-Duitse immigranten in vergelijking met de Duitse bevolking.

In hoofdstuk 3 worden de resultaten gepresenteerd van een vergelijking van de aandacht aan etnische verschillen in Nederlandse, Britse, Amerikaanse en Canadese standaarden. De Amerikaanse standaarden schonken verreweg de meeste aandacht aan etnische verschillen, gevolgd door de Britse en Canadese standaarden. De Nederlandse standaarden schonken de minste aandacht aan etnische verschillen. Alleen de Nederlandse diabetes standaard schonk aandacht aan etnische verschillen in de prevalentie en voegde daar een aanbeveling aan toe om op jongere leeftijd te screenen naar diabetes bij bepaalde etnische groepen. Opvallend was dat de Nederlandse hypertensie standaard geen enkele aandacht schonk aan etnische verschillen, terwijl de andere standaarden hier uitvoerig op in gingen. In deze standaarden werden verschillende empirische verschillen in het voorkomen van hypertensie bij bepaalde groepen beschreven en werden verschillende aanbeveling gedaan om de behandeling meer toe te spitsen op deze groepen.

In hoofdstuk 4 wordt dieper ingegaan op de Nederlandse standaarden en wordt bekeken of er in de wetenschappelijke onderbouwing van de standaarden etnische verschillen besproken worden. Verschillende relevante etnische verschillen worden genoemd in de wetenschappelijke onderbouwing van de NHG-standaarden. Voor diabetes zijn dat prevalentieverschillen en verschillen in het klinische beloop. Voor astma zijn dat longinhoudverschillen en voor hypertensie verschillen in prevalentie, klinisch beloop, respons op medicatie en gevoeligheid voor zout beperking. De NHG-standaarden noemen een hogere prevalentie van diabetes bij Hindoestanen en adviseren eerdere screening bij deze groep. De astma standaard meldt dat de longinhoud etnisch bepaald is en de hypertensie standaard noemt geen etnische verschillen. Verreweg de meeste publicaties uit de wetenschappelijke onderbouwing

zijn verzameld met een ander doel dan het onderbouwen van etnische verschillen en het betekent dus niet dat de NHG de meldingen van etnische verschillen uit die publicatie bewust heeft gewogen en terzijde heeft gelegd. Desondanks toont deze studie dat er wel relatief veel bekend is over etnische verschillen en dat dit bewijs betrokken moet worden in het richtlijnontwikkelingsproces.

In hoofdstuk 5 worden de resultaten besproken van een analyse van patiëntendossiers. De historische dossiers van 705 patiënten met diabetes, hypertensie of astma van 30 huisartsen zijn onderzocht in de periode tussen 2000 en 2004 op het aantal huisartsenbezoeken, het aantal recepten en het aantal verwijzingen naar de specialist. Turkse astmapatiënten gingen gemiddeld minder vaak naar de huisarts en kregen gemiddeld minder vaak een prescriptie mee. Marokkaanse hypertensiepatiënten kregen ook gemiddeld minder medicijnen voorgeschreven. Deze verschillen verdwenen echter als er gecorrigeerd werd voor verschillen in leeftijd, geslacht, verzekeringsstatus en co-morbiditeit. Er bleken ook geen etnische verschillen in het aantal verwijzingen uit deze studie.

In hoofdstuk 6 is door middel van een dwarsdoorsnede onderzoek met een prospectieve dataverzameling onderzocht in hoeverre de mate waarin de huisarts de standaard volgt afhankelijk is van de etniciteit van de patiënt voor hem. Hiervoor is in 17 huisartspraktijken (met 31 huisartsen) in en rond achterstandswijken in verschillende grote Nederlandse steden een meetinstrument in het huisartsinformatiesysteem geïnstalleerd die bij een aselekt geselecteerde groep patiënten de huisarts confronteerde met een lijst met vragen over de behandeling van de patiënt. Met die lijst vragen is bepaald in welke mate de standaard is gevolgd. Uiteindelijk zijn er 402 volledige lijsten door de huisartsen ingevuld over in totaal 238 patiënten. Het bleek dat huisartsen over het algemeen redelijk goed de aanbevelingen uit de standaarden volgen (rond 75% van de aanbevelingen wordt opgevolgd). Dit verschilde echter veel tussen de verschillende huisartsen. Het bleek dat huisartsen geen verschil maakten in het volgen van de standaard bij patiënten van verschillende etnische groepen.

Omdat aanbevelingen in standaarden gebaseerd zijn op het beste wetenschappelijke bewijs is de verwachting dat het volgen van standaarden een gunstig effect heeft op de klinische uitkomst van de behandeling. In hoofdstuk 7 wordt een antwoord gegeven op de vraag of deze associatie tussen het volgen van de standaard en de klinische uitkomst van de behandeling verschilt bij patiënten uit verschillende etnische groepen. In het bovengenoemde meetinstrument dat geïnstalleerd is in de huisartsinformatiesystemen werden naast vragen over de behandeling door de huisarts ook klinische uitkomstmaten gevraagd. Voor diabetes betrof dat de bloedglucosewaarde, voor hypertensie de systolische- en diastolische bloeddruk en bij astma werd gevraagd of een optimale longcapaciteit bereikt of gehandhaafd was.

Er bleek een sterk verband te bestaan tussen de mate van adherentie aan de standaard door de huisarts en een positieve klinische uitkomst bij de patiënt. Dit gold voor diabetes en hypertensie en niet voor astma. Zowel in de behandeling van autochtone Nederlanders als etnische minderheden had het volgen van de standaard een sterke associatie met een positievere klinische uitkomst. Deze associatie was alleen aanzienlijk groter bij autochtone Nederlanders in vergelijking met de etnische minderheden (odds ratio van 150 bij autochtone Nederlanders versus een odds ratio van 22 bij etnische minderheden). Omdat de aantallen waarnemingen in deze studie laag waren, bleek het verschil tussen de twee odds ratio's niet statistisch significant te verschillen. Uit toekomstig onderzoek zal moeten blijken of dit etnische verschil in de associatie tussen het volgen van de standaard en de klinische uitkomst echt aanwezig is.

In hoofdstuk 8 worden de resultaten weergegeven van een kwalitatief onderzoek bij een aantal huisartsen waarbij data voor de eerdere hoofdstukken is verzameld. Deze huisartsen zijn gekozen op basis van het aantal ingevulde lijsten en het aandeel etnische minderheden in hun praktijk. Het grote aandeel etnische minderheden in hun praktijk maakt deze huisartsen met recht deskundig als het gaat om huisartsenzorg aan etnische minderheden. Negen huisartsen zijn benaderd en uiteindelijk 7 huisartsen zijn geïnterviewd. Deze huisartsen is gevraagd of de huidige standaarden bruikbaar zijn in de behandeling van etnische minderheden en of ze het gevoel hebben vaker af te wijken van de standaard bij patiënten met een specifieke etnische achtergrond. De huisartsen gaven bijna allen aan dat de huidige standaard bruikbaar was in de behandeling van etnische minderheden en dat ze niet het gevoel hadden vaker af te wijken bij bepaalde etnische minderheden. Unaniem waren ze wel in hun mening dat de behandeling van etnische minderheden moeizamer is en zij ook moeilijker goed in te stellen zijn. Hiervoor gaven zij ook haast unaniem 3 redenen: 1. ziektebeleving en therapietrouw; 2. dieet en beweging; 3. onwennigheid met huisartsenzorg. Bij doorvragen bleken huisartsen overigens wel degelijk vaker af te wijken van aanbevelingen uit standaarden bij etnische minderheden, maar dit werd niet veroorzaakt doordat de aanbevelingen onjuist zijn, maar doordat ze moeilijker implementeerbaar/ uitvoerbaar zijn bij etnische minderheden. Opvallend in dit onderzoek was dat de opmerkingen die de huisartsen maakten over de problematiek betreffende de zorg aan etnische minderheden (in achterstandswijken), opmerkingen zijn die 25 jaar geleden ook al gemaakt werden. Deze conclusie zet dan ook kanttekeningen bij het effect van het minderhedenbeleid van de laatste decennia.

Uit de resultaten van de onderzoeken gepresenteerd in deze dissertatie concludeer ik dat relatief veel relevant bewijs bestaat over etnische verschillen wat tot op heden over het algemeen nog niet leidt tot etnisch specifieke opmerkingen of aanbevelingen in de Nederlandse (NHG-)standaarden. Verder concludeer ik dat ondanks dat huisartsen niet verschillen in hun behandeling of het volgen van de standaard bij etnische minderheden

in vergelijking met autochtone Nederlanders, de associatie tussen het volgen van de standaard en positieve klinische uitkomsten kleiner lijkt in de behandeling van etnische minderheden. Tot slot concludeer ik dat volgens de huisartsen zelf de huidige standaard voldoet in de behandeling van etnische minderheden.

Met deze conclusies kan een antwoord geformuleerd worden op de hoofdvraag van deze dissertatie: Dienen standaarden meer rekening te houden met etnische verschillen tussen patiënten? Gezien de relatieve grote etnische verschillen in gezondheid en uitkomsten van zorg, het evidence-based karakter van standaarden en de relatief grote hoeveelheid bewijs over etnische verschillen, dienen standaarden meer rekening te houden met etnische verschillen. Vooral omdat het erop lijkt dat dezelfde behandeling en dezelfde mate van volgen van de standaard tot minder positieve uitkomsten van zorg leiden. De mening van de deelnemende huisartsen dat de huidige standaarden bruikbaar zijn in de behandeling van etnische minderheden hoeft niet tegenstrijdig te zijn met deze conclusie. Allereerst omdat de huisartsen zelf aangeven dat als er bewijs bestaat over etnische verschillen deze zeker meegenomen moeten worden in de standaard. En omdat de huisartsen duidelijk aangeven dat ze moeite hebben goede behandelingsuitkomsten te behalen bij etnische minderheden. Ook al denken zij dat het laatste vooral aan patiënt factoren ligt en niet aan de standaard, kunnen relevante patiënt factoren natuurlijk ook benoemd worden in de standaard.

Is standaardisatie in een multi-etnische wereld een paradox? Om hierop een antwoord te kunnen geven dient eerst bepaald te worden wat nu eigenlijk de rol is van standaarden. In de Nederlandse gezondheidszorg is er een ontwikkeling gaande naar meer transparantie. Aanbieders van zorg moeten meer verantwoording afleggen over hun presteren dan in het verleden. In verschillende gezondheidszorg organisaties wordt de kwaliteit van zorg gemeten door zogenaamde prestatie indicatoren die deels gebaseerd zijn op het volgen van standaarden. Het is zelfs zo dat het beter volgen van standaarden wordt beschouwd als bewijs voor een verbeterde zorgverlening. Maar deze dissertatie maakt duidelijk dat er verschillende valkuilen bestaan als standaarden worden omgezet naar kwaliteitsindicatoren. Een belangrijke valkuil in deze is dat in deze context indicatoren worden opgesteld vanuit standaarden die gebaseerd zijn op RCT's, welke op zijn best generaliserende statements voor de gemiddelde populatie opleveren. En zeker niet voor individuele patiënten of specifieke etnische groepen. Het behandelen volgens deze standaarden levert relatief slechtere uitkomsten op bij etnische minderheden. Afwijken van de standaard is in dit geval dus niet hetzelfde als het leveren van mindere kwaliteit van zorg, aangezien afwijken van de standaard een positiever effect op de gezondheid van de patiënt kan hebben. Dit brengt ons weer op de rol van standaarden. Worden zij 'slechts' beschouwd als een van de instrumenten die de arts tot zijn beschikking heeft ter ondersteuning van het dagelijks handelen, dan hoeft standaarden in een multi-etnische populatie niet op een paradox te wijzen. Maar als de rol van standaarden belangrijker wordt gemaakt door bijvoorbeeld als basis te dienen voor landelijke kwaliteitsindicatoren dan worden standaarden in een multi-etnische wereld wel degelijk paradoxaal.

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ABOUT THE AUTHOR

Radjesh Manna was born in 1974 in the city of Paramaribo in Surinam, South America. At the age of 7 months he migrated with his parents to The Netherlands. Since then he lives in the city of The Hague. In 1993 he graduated from the Gymnasium Haganum. He studied health care sciences at the Erasmus University Rotterdam. During his study he got interested in the quality of health care for ethnic minorities and after graduating he started his professional career in 1999 as a scientific researcher at the Institute of Health Policy and Management of the Erasmus University Rotterdam where he did research on the quality and access of care for ethnic minorities and was responsible for the development of teaching programs and taught different subjects to students. In 2006 Radjesh made a career move and now works as an business consultant at Plexus Medical Group. Radjesh is married to Amanda and they have a son, Ryan-Jay, together.

