Culturally appropriate hypertension care: from patients’ perspectives towards practical tools
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Chapter 1

General introduction
General introduction

Due to expanding migration, health care systems worldwide are increasingly confronted with a multiethnic patient population. Following a longer tradition in North America, also in Western Europe research on ethnicity and health is beginning to develop. Studies carried out in several European countries have identified significant differences in the health status of migrant populations and native European populations. One significant finding of these studies is that migrant populations of African descent have an increased risk of hypertension (high blood pressure). Another significant finding is that ethnic differences in blood pressure control seem to persist despite adequate access to care. Insufficient blood pressure control may be one explanation for the higher rates of hypertension-related morbidity and mortality that has been found in populations of African descent. Hypertension is modifiable through pharmacologic treatment and lifestyle changes. Consequently, there is an urgent need for interventions that facilitate adherence to these treatments by patients from ethnic minority populations in order to reduce the observed health disparities.

This thesis presents a series of studies that aimed to provide baseline information for the development of such interventions. These studies focussed on two ethnic minority (immigrant) populations of African descent living in the Netherlands. This introduction provides some information about the African-Surinamese and Ghanaian populations, research data on the prevalence, awareness, treatment and treatment outcomes of hypertension among these populations, the role of the patient’s perspective in health and illness and information about hypertension care. At the end of the introduction the objectives and research questions and outline of the thesis are presented. First, an overview of some terms used in the thesis will be given.

In this thesis, the term diversity refers to general differences among population groups, such as gender, ethnic origin, age and socio-economic circumstances. The term ethnicity refers to a multidimensional concept that comprises one or more of the following characteristics: shared origins or social background; a shared culture or tradition that is distinctive, maintained between generations, and leads to a sense of identity and group; and a common language or religious tradition. Culture is defined as the shared values, beliefs and perceptions of the world that lie behind people’s behaviour and are expressed in the ways people live. The characteristics that define ethnicity and culture are, however, not fixed and may change over time.

Populations of African descent in the Netherlands

The Netherlands is one of the European countries with an increasing number of immigrants. In 2009, 11% of the total population was of non-Western origin (1,810,000 people), with the four largest groups coming from Turkey (378,000), Morocco (342,000), Suriname (339,000) and the Antilles (134,000). Ethnic minority populations are concentrated in urban areas. In 2007 for example, 35% (260,000 people) of all the registered inhabitants
of Amsterdam were of non-Western origin. Of the registered inhabitants in the district of southeast Amsterdam (79,000 people), 63% (50,000 people) were of non-Western origin, with the two largest population groups coming from the former Dutch colony of Suriname (26,300 people) and from Ghana (7,300 people). More background information on the Surinamese and Ghanaian populations is given in Box 1.

Box 1 Surinamese and Ghanaian populations in the Netherlands

Migration history
Although the African-Surinamese and Ghanaian populations in the Netherlands have certain shared ancestral features, these groups differ in several respects, such as migration history, language, socio-economic position and culture. The Surinamese group migrated from the former Dutch colony of Suriname and consists largely of people of African (45%) and South Asian origin (45%). While the majority of the South Asians live in The Hague, the majority of the African-Surinamese live in Amsterdam. The initial Surinamese migrants to the Netherlands were from the higher socio-economic groups and migrated for educational reasons. The majority of the current immigrant population migrated when Suriname gained its independence in 1975 and when a visa requirement was introduced in 1980. The Ghanaian group, coming from sub-Saharan West Africa, migrated in two phases. The first phase, from 1974-1983, was a result of the worldwide oil crisis. Because of tightened restrictions on immigration to the UK, Ghanaians went to other countries, including the Netherlands. In a second phase, at the beginning of the 1990s, many Ghanaians emigrated because of an extreme drought, political instability and the expulsion of Ghanaians from Nigeria. The majority of the Ghanaian immigrants in the Netherlands live in Amsterdam, in particular in the southeast district. The majority are ethnic Ashanti, a group known in Ghana and in neighbouring parts of Africa as merchants. In addition to the registered Ghanaian immigrants in the Netherlands there is also a large number (estimates vary from four- to twelve-thousand) who are living in the country illegally.

Socio-economic status, language and religion
The average socio-economic status of the Surinamese and Ghanaian immigrant groups is lower than that of the ethnic Dutch population. However, compared to other immigrant groups in the Netherlands the Surinamese enjoy a somewhat higher socio-economic status. A relatively high proportion of immigrant groups in the Netherlands are unemployed and have household incomes that are lower than ethnic Dutch residents. Although the official language of Suriname is Dutch, ethnic groups within Suriname have their own languages (e.g. Sranantongo, spoken by African-Surinamese and Sarnami, spoken by South Asians). Because the Surinamese had some familiarity with the Dutch language and culture prior to immigration, they have had few difficulties with the Dutch language. The Ghanaians, in contrast, come from a country whose official language is English and where many different languages are used within the various ethnic groups. The majority of both the African-Surinamese and Ghanaian immigrants in the Netherlands are Christian. Among the Christians, a great variety of religious movements are represented.

Hypertension in populations of African descent
Hypertension is considered to be present when a person’s blood pressure is consistently at least 140 mmHg systolic or 90 mmHg diastolic. Hypertension is a major risk factor for cardiovascular morbidity and mortality, contributing to cerebrovascular disease, ischaemic
heart disease, and kidney disease. The cause of hypertension is generally unknown. However, conventional risk factors (e.g. dietary intake, physical inactivity, obesity) can negatively affect blood pressure.9

More than one-quarter of the world’s adult population had hypertension in 2000 and this is expected to increase by about 60% (1.56 billion) by 2025.10 In the Western hemisphere, ethnic minority populations of African descent in particular are disproportionally affected by hypertension and hypertension-related complications.11,12,13,14 For example, a study conducted in the UK found that, in the study population, 51% of men and 54% of women of African descent had hypertension as compared to 33% and 24% in white men and women.15 Data from the USA also reported higher prevalence rates among people of African descent: 43% and 45% among African American men and women compared with 30% and 24% in white men and women.16 These ethnic disparities were also found in the Netherlands. In line with the UK data recent research from the Netherlands reported a prevalence of hypertension of 47% in people of African descent (47% men; 46% women) compared with 33% in white people (41% men; 26% women).11,17 The higher prevalence of hypertension is also reflected in a higher degree of incidence of cardiovascular disease morbidity and mortality (e.g. stroke, kidney disease) among populations of African origin.1,2,3

Although there are several hypothetical explanations pointing to the role of genetic factors (salt sensitivity,18 creatine kinase,19 low birth weight,20) and conventional risk factors (low socio-economic status,21 obesity,22 unhealthy diet,23 physical inactivity,24) the reasons for the higher prevalence of hypertension among populations of African descent living in Western countries remain uncertain.20,25

**Awareness, treatment, and control of hypertension**

Despite the observed higher prevalence rates of hypertension among people of African descent in the Netherlands, there are no differences in awareness and pharmacological treatment rates of hypertension compared with ethnic Dutch people.11 However, people of African origin who receive antihypertensive treatment are less likely to have their blood pressure adequately controlled compared to their white counterparts, and this is especially true for men: only 14% of African-Surinamese men and 48% of African-Surinamese women were found to have adequately controlled blood pressure, versus 42% of ethnic Dutch men and 50% of ethnic Dutch women.11 These control rates are low, especially among men, when compared with their African American counterparts in the USA (48% of men and 44% of women),26 and their African Caribbean counterparts in the UK (57% of men and 67% of women).27 Strict blood pressure control can reduce the occurrence of cardiovascular events. For example, by achieving the target of 140 mm Hg systolic, there would be an estimated reduction of 28–44% in cases of stroke and 20–35% in cases of ischaemic heart disease depending on age.28 Moreover, some hypertension guidelines in the USA recommend aggressive management of hypertension in people of
African descent, with a targeted goal of below 130 mm Hg systolic and below 85 mm Hg diastolic.\textsuperscript{20} The reasons for lower blood pressure control rates among African populations in the Netherlands are unclear. However, many studies suggest that patient adherence to antihypertensive therapy (medication-weight control-physical activity) is poor, particularly among ethnic minority populations in Western Europe and the USA.\textsuperscript{11,29,30,31} This could be one possible explanation for inequalities in blood pressure control rates among populations of African descent.

The patient perspective and illness behaviours
In the management of chronic diseases like hypertension patients themselves are the principal caregivers. Health care providers have the important task of teaching their patients how to do this and supporting them in doing so.\textsuperscript{32} This requires an understanding of how patients’ beliefs about their disease and its treatment may affect health behaviours,\textsuperscript{33,34,35,36,37,38,39} as patients have their own ideas about their health or illness. Several so-called ‘common sense models’ have emphasized the importance of the patient perspective as a factor influencing illness behaviours.

**Box 2** Key concepts of ‘common sense models’

**Leventhal: representations of illness**
- Patients form their own representations of their illness
- Illness representations are implicit ideas about the nature of a disorder and are generated under the influence of cognition and emotions
- Illness representations are linked to five components
- Illness representations play a key role in decision making about treatment recommendations: patients are ‘Active Problem Solvers’

**Kleinman: Explanatory Models**
- Health care professionals as well as patients use their own explanatory models
- Explanatory models contain basic assumptions about health care guidelines and about health-related behaviours
- Explanatory models outline five components of an illness
- Explanatory models are expressions of ‘clinical reality’, which evolves in the context of shared opinions, shared habits and behaviours with significant others
- Difference between ‘disease’ and ‘illness’
- Discrepancies between the explanatory models used by health care providers and those seeking care can lead to conflict and affect treatment outcomes

In health psychology a well-known theoretical model that addresses this issue is Leventhal’s ‘self-regulation model’,\textsuperscript{40} which has been extensively studied and validated across a wide range of illness conditions.\textsuperscript{41} According to this model, patients typically gather information about their condition from different sources and subsequently form their own representations of their illness on the basis of this information. These representations may be linked to one or more of five components: (a) the identity of the illness, based on
the diagnosis and the symptoms thought to be associated with it; (b) the timeline of the illness (acute, cyclic, or chronic); (c) the short- and long-term consequences of the illness; (d) the factors contributing to the illness; and (e) the perceived control over the illness, which includes perceived self-efficacy, treatment efficacy and actual abilities. Based on these representations, patients will develop action plans or coping strategies which will then influence their behaviours and emotional responses.

According to the theory developed by medical anthropologist Arthur Kleinman, health care professionals as well as patients use their own explanatory models of disease. The components of Kleinman’s explanatory models are very similar to the five components of illness representation proposed by Leventhal. They also include the definition of the problem, the perceived causes, symptoms, duration, severity, the expected consequences, the appropriate treatment and the anticipated outcomes. According to Kleinman, explanatory models used by health care providers are shaped by the biomedical model which they learned during medical training. They rely mostly on scientific logic, objectivity and evidence and place an emphasis on the individual. While the explanatory models of professionals focus on the disease, those used by patients focus on the experience of the disease, which Kleinman refers to as illness. The explanatory models of patients are not fixed but shift over time, are often context-dependent and vary according to personality and socio-cultural factors. In contrast to Leventhal, Kleinman has put more emphasis on the influence of cultural factors such as the personal experiences, family attitudes and group beliefs that shape patients’ health beliefs (‘clinical reality’). One of the prerequisites for effective intercultural communication is that patient and physician agree on the health problem of the patient and understand, acknowledge and respect each other’s explanatory model for the health problem. The fact that health care providers and patients often hold discrepant models of health and illness and the fact that this may influence the manner in which health problems are presented can affect the outcome of a clinical visit; for example, patient non-compliance with advised therapy. The way to get more acquainted with each other’s ‘clinical reality’ is by exchanging explanatory models. Of the various ‘common sense models’, the models in health psychology put forward basic elements for ‘patient-centred care’. The models in medical anthropology, which put more emphasis on the role of the broader socio-cultural context, form the basic elements for the ‘cultural competence movement’ in health care. Both movements have garnered a great deal of attention in the last decade. Although both movements have many principles in common and both aim to improve the quality of health care, the emphasis of each is on different aspects of quality. The primary aim of patient-centredness has been to individualize quality, to complement the health care quality movement’s focus on process measures and performance benchmarks with a return to an emphasis on personal relationships and ‘customer service’. As such, patient-centredness aims to elevate quality for all patients. The primary aim of the cultural competence movement has been to balance quality, to improve equity and reduce disparities by specifically improving care for ethnic minority populations and other disadvantaged populations.
Studies among ethnic minority populations in the USA and the UK suggest that cultural factors have an impact on the manner in which patients from these groups explain hypertension. Because Kleinman’s explanatory model framework emphasizes the importance of the broader socio-cultural context for effective intercultural communication, this model forms the guiding theoretical framework for this thesis.

**Hypertension care**

In the Netherlands, general practitioners play an important role in the treatment of hypertensive patients. The modern treatment of hypertension consists of long-term pharmacotherapy and lifestyle changes (e.g., weight control; increased physical activity; avoidance of salt, alcohol and tobacco) in order to reach target blood pressure levels and reduce the overall cardiovascular risk profile. Clinical practice guidelines for hypertension recommend patient education as a means for improving patients’ ability to take control of and manage their condition. Even though European and Dutch clinical practice guidelines stress the need to take the patient’s beliefs about hypertension and its treatment into account, they do not provide any recommendations on how hypertension care providers might address cultural variations in patients’ perspectives on hypertension. Moreover, studies from the UK and USA found that explanatory models of hypertension and treatment may differ between ethnic groups.

Given the high prevalence rates of hypertension among African-Surinamese and Ghanaian immigrant populations in the Netherlands, there is an urgent need to improve prevention and control of hypertension among these groups. Although similarities do exist, the socio-cultural backgrounds of these immigrant groups differ from those of the ethnic minority populations that have been studied in the UK and the USA. There is no data available on the explanatory models of hypertension among these groups, on the impact of socio-cultural and migration-related factors on the use of antihypertensive medications and lifestyle changes, or how this information might be used to optimize care for hypertensive patients in multi-ethnic primary care settings.

**Objectives and research questions of the study presented in this thesis**

The findings in this thesis are based on the data derived from two research projects financed by ZonMw as part of their ‘healthy living’ and ‘ethnic minorities in health care’ programmes. The funding of both projects emphasized the desire that the projects would lead to results that were practically useful to patients and care providers. For these projects a stepwise approach was followed: The first project ‘Heebroedoe’ was designed to explore and compare the patient perspectives of African-Surinamese, Ghanaian and ethnically Dutch hypertensive patients who were treated in primary care and to explore the need and possibilities for a culturally appropriate approach in primary care for these patient groups. The follow-up study, ‘Under Pressure’, was designed to develop a provider intervention to enhance culturally appropriate hypertension care and to evaluate whether
the intervention would improve the cultural competence of hypertension care providers in a multi-ethnic primary care setting.

Both projects were generally explorative in nature and, in line with the objectives, consisted mainly of qualitative research methods. Such an approach offers the opportunity of studying phenomena in natural settings, giving due emphasis to the meanings, direct experiences, and views of the participants, and in particular, to uncovering themes that the researchers may not have anticipated. The main qualitative methods used were interviews and focus group discussions; the main quantitative methods used were questionnaires. Details about all these methods are described in the following chapters.

The main objective of the studies presented in this thesis was to explore and compare explanatory models of hypertension among African-Surinamese, Ghanaian and ethnically Dutch hypertensive patients in order to foster the development and evaluation of services that focus on the improvement of primary health care for hypertensive patients among these groups in the Netherlands.

To address this goal, we formulated the following research questions:

1. With regard to hypertension patients in a Dutch multi-ethnic primary-care setting:
   - What are the explanatory models of hypertension of African-Surinamese, Ghanaian and ethnic Dutch patients who are treated for hypertension? This question focuses particularly on socio-cultural and migration-related influences on:
     a. Perceptions of hypertension
     b. Management of prescribed antihypertensive medications
     c. Inhibitors or enablers of adopting or maintaining regular physical activity

2. With regard to hypertension care in a Dutch multi-ethnic primary-care setting:
   a. How can an intervention to stimulate culturally appropriate hypertension education for African-Surinamese and Ghanaian patients among health care providers be developed?
   b. What is the effect of a provider-based intervention to enhance culturally appropriate hypertension education with regard to the attitudes and perceived competence of hypertension care providers?
   c. Among health care providers, what are the barriers and enablers to adopting a culturally appropriate approach to hypertension education?

**Outline of the thesis**

The first research question will be answered in Chapters 2, 3 and 4. The data in these chapters were derived from a qualitative study using individual in-depth interviews. The second research question will be answered in Chapters 5 and 6. Chapter 5 focuses on (a) the culturally appropriate hypertension education programme that was developed and (b) on the health care providers' attitudes and perceived competence with regard to culturally appropriate care. For this, quantitative data from a questionnaire were used. Chapter 6 describes (c) the implementation of a culturally appropriate hypertension education programme.
education programme in a routine primary care setting. For this, qualitative data from different sources were used. Chapter 7, the general discussion, summarizes and reflects on the main findings, discusses some methodological considerations and discusses the implications for health care and research in this field.
Reference List

8 Onderzoek & Statistiek Amsterdam. Internet [2010 Available from: http://www.os.amsterdam.nl/].

