Culturally appropriate hypertension care: from patients' perspectives towards practical tools
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Chapter 7

General discussion
General Discussion

The central objective of this thesis is to provide insight into the perceptions of hypertension and its management held by African Surinamese, Ghanaian and ethnically Dutch hypertensive patients in the Netherlands, and how this information can be used in the development of services for these patient groups in primary care settings. This final chapter summarises the main findings of the studies presented in this thesis. Next, it offers some reflections on our findings and on the methodology we applied in these studies. Further, there is a discussion of the implications for research and health care in this field.

Main findings

The patient’s perspective

According to clinical guidelines, hypertension is a chronic and asymptomatic condition, the causes of which are unclear, and one that may, in the longer term, gradually lead to degenerative cardiovascular damage and subsequently to cardiovascular disease. Cardiovascular damage can be prevented by blood pressure lowering medication and lifestyle modifications aimed at reducing the overall cardiovascular risk profile.

The first three chapters of this thesis report data from ‘Heebroedoe’, a study exploring how African Surinamese, Ghanaian and ethnically Dutch hypertensive patients perceive hypertension and hypertension management.

In Chapter 2 we analysed and compared the participants’ accounts regarding the nature, causes and consequences of hypertension. We found that patients in all three ethnic groups held explanatory models of hypertension that were at variance from the common medical perspective. The patients often understood hypertension to be a symptomatic disease, not a risk factor, with one or more identifiable causes. Stress was believed to be an important cause of hypertension, particularly by Ghanaian and Surinamese patients. We also found that almost all Ghanaian and Surinamese and half of the Dutch patients experienced symptoms of hypertension and believed that elevated blood pressure can cause immediate cardiovascular damage. Those symptoms were often seen as a cue to act at once (e.g. take rest immediately, seek medical advice). Although we found similarities in the explanatory models of hypertension among all three ethnic groups, there were also variations showing that customs from the country of origin played a role in how patients viewed their condition. For instance, patients in all groups viewed dietary habits as a cause of hypertension, but Ghanaians focused on the use of starch, which is common in the Ghanaian diet; Surinamese on the salty Surinamese diet; and Dutch patients on the consumption of liquorice. Besides cultural factors, migration-related factors also influenced the perspectives of ethnic minority patients on hypertension.
For example, ethnic minority patients often attributed the cause of their hypertension to the migration experience (changes in climate or stress due to adaptation to Dutch society). Many immigrants, particularly Ghanaians, felt that their hypertension was an episodic condition that would disappear when visiting or returning to their countries of origin. In contrast, Dutch patients regarded hypertension mostly as a chronic condition. We concluded that there is an important difference between the biomedical explanatory models of hypertension and those of patients. These differences are greater for patients from ethnic minority groups and cultural and migration-related factors play an important role in these explanatory models.

In Chapters 3 and 4 we analysed and compared explanations for patients’ decisions on the treatment of hypertension.

In the study reported in Chapter 3 we observed three patterns for the use of antihypertensive drug treatment among the interviewed participants: Use as prescribed, self-regulated use of prescribed medication, and shifting from self-regulated use to a prescribed pattern. In all groups, confidence in the doctor and beneficial effects of medication were reasons for taking prescribed antihypertensive dosage. Ethnic minority patients in particular reported lowering or discontinuing the prescribed medication dosage. Explanations for altering prescribed dosage comprised disliking chemical medications, fear of side effects and preference for natural treatments. Surinamese and Ghanain males also worried about the negative effects of antihypertensives on their sexual performance. Some Ghanaians mentioned fear of addiction or lack of money as explanations for altering prescribed dosage. Further analysis revealed that patients’ perceptions concerning the nature and cause of hypertension, as we reported in Chapter 2, were also reflected in their decisions about the use of antihypertensive medication. For example, patients who believe that hypertension is a symptomatic condition may decide to regulate their medication according to perceived symptoms. Another example is that a decision to stop taking medication during a visit to the country of origin (Ghana or Suriname) was often inspired by the belief that hypertension is caused by the stresses and changes in climate associated with migration to a new environment. We concluded that patients in all ethnic groups do not simply follow doctors’ orders but actively decide how to manage their prescribed medication regimens and that these decisions often diverge from the medical perspective. We further concluded that, although similarities exist in decisions on the use of medication between patients from the ethnic minority groups and the host culture, decisions by ethnic minority patients are also influenced by cultural (e.g. a preference for traditional remedies from the country of origin) and migration-related issues.

In Chapter 4 we analysed what patients understood physical activity to mean and what they perceived as inhibitors or enablers of engaging in or maintaining regular physical activity. We found that patients in all ethnic groups designated many different activities as physical activity, and these included not only leisure activities (organised activities and non-organised activities) but also regular daily functional activities (at home or at work). Further analysis of the participants’ accounts of their physical activity led to a taxonomy.
of categories, subcategories and concepts. Patients’ perceived inhibitors and enablers of physical activity could be classified into seven main categories: hypertension and other health conditions; healthcare; social context; culture; finance; living environment and individual factors. All three patient groups mentioned the presence of health conditions, lack of priority, lack of social support, limited financial resources or access to sport facilities as inhibitors of physical activity. A particular inhibitor related to hypertension was the belief that exercise may be dangerous for people with hypertension. Common enablers included health-related incentives, support from physicians or family and having physically demanding work. Specific inhibitors of physical activity that were mentioned only by Ghanaians and Surinamese included inexperience with recommended ‘Western’ activities (bicycling, swimming), little access to their accustomed forms of physical activity (dancing), cultural preferences for large body sizes and characteristics of the host country (e.g. climate, transportation, housing, demands of participating in both Dutch society and their own communities). Specific enablers of physical activity for Ghanaians and Surinamese included access to community or church-based support groups. We concluded that, if interventions aimed to improve physical activity participation among patients in multi-ethnic clinical practices are to be effective, culturally specific factors and the specific living conditions which migrants experience in their new environment cannot be ignored.

Towards practical tools

Based on findings from ‘Heebroedoe’, in a follow-up project known as ‘Under Pressure’, we developed an intervention for health care providers to facilitate the delivery of culturally appropriate hypertension education. The intervention consisted of three components: six tools to support culturally appropriate hypertension education, an educational course, and feedback meetings to support Nurse practitioners and GP-assistants in using the tools. The intervention was piloted in three primary care health centres.

Chapter 5 evaluates how the intervention affected the attitudes and perceived competence of hypertension care providers with regard to culturally appropriate hypertension care. For this evaluation, we used a quasi-experimental design, contrasting intervention and control groups. We found that professionals who participated in the intervention considered it more important to address the patient’s culture when delivering care than they had before the intervention. The intervention did not influence experienced barriers and self-reported behaviour with regard to culturally appropriate care delivery. We concluded that the intervention and implementation strategy, in light of theories of professional behaviour change, specifically contributed to the acceptance of behaviour change with regard to culturally appropriate care delivery. This is an important condition for the next stages of change: actual change and maintenance.

In Chapter 6 we analysed factors that hampered or facilitated the implementation of the new tools by hypertension educators, using qualitative data that were collected at different stages in the implementation process. We found that barriers to implementation were associated with three main categories: the political context (health care system financing:
Reflections on the findings

The patient’s perspective

The role of stress

Variations between the patients’ and professional perspectives on hypertension have also been observed in studies among other populations. For example, our observation that patients view stress as an important causal factor for the onset of hypertension has also been reported elsewhere. However, Surinamese and Ghanaian patients in this study particularly associated stress with migration-related experiences. This is not surprising given the fact that many other studies have shown that migration can be a major source of stress. The experience of migration represents a major psychosocial transition: immigrants not only leave friends, families and places that are familiar to them, but also many of their customs. At the same time, migration requires many adjustments from the individual: learning a new language, building a new social network, integrating new norms and customs. Moreover, immigrants are often faced with (feelings of) discrimination, isolation and/or insecurity.

Our observations as well as evidence from other studies indicate that patients perceive stress as a fundamental cause of hypertension. This is not acknowledged in Dutch clinical guidelines, however, because convincing clinical evidence for the role of stress in the aetiology of hypertension is lacking. Nevertheless, if health care providers do not pay attention to patients’ views on the relation between stress and hypertension, mutual understanding between health care providers and patients about hypertension and its management may be thwarted. In turn, mutual understanding between health care providers and patients has been shown to be an important factor in promoting patient adherence. At the same time, by paying attention to patients’ stress-related experiences, health care providers may acquire a better understanding of why it is difficult for patients to reduce stress-related behaviours such as smoking and alcohol use or to
maintain health-promoting habits, such as engaging in physical activity and eating a healthy diet.

**Culture and migration**

Chapters 2, 3 and 4 showed that explanatory frameworks for hypertension that are held by patients from the two ethnic minority groups that were included in our study are complex. On the one hand, these explanatory frameworks show similarities with those of the Dutch. On the other hand, they contain elements specific to the cultural background and/or the migration experiences of each group. Studies among immigrant populations with hypertension and/or diabetes in other countries support our findings that, in addition to culture, migration appears to have a major impact on perceptions of illness and behaviour.\(^{16,17}\) Table 1 summarises the cultural and migration-related elements we found in the explanatory model of hypertension in Ghanaian and Surinamese patients. Health

<table>
<thead>
<tr>
<th>Element of Explanatory Model</th>
<th>Migration-related</th>
<th>Culture-related</th>
</tr>
</thead>
<tbody>
<tr>
<td>Causes</td>
<td>Changes in diet or environment (e.g., weather)</td>
<td>Culturally specific nutritional habits</td>
</tr>
<tr>
<td></td>
<td>Stress major cause of hypertension; migration is major trigger for stress</td>
<td>Traditional explanations of health and illness (very few)</td>
</tr>
<tr>
<td></td>
<td>(Dutch society; family in homeland)</td>
<td></td>
</tr>
<tr>
<td>Duration</td>
<td>Episodic condition: Return to country of origin may cure hypertension</td>
<td></td>
</tr>
<tr>
<td>Medication-management</td>
<td>Discontinuing medication when visiting country of origin (perceive hypertension not to be present in homeland)</td>
<td>Preference for remedies from countries of origin (indigenous herbs)</td>
</tr>
<tr>
<td></td>
<td>Reducing dosage: concerns about addiction should one return to homeland</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Self-alteration: problematic access for unregistered migrants (health insurance)</td>
<td></td>
</tr>
<tr>
<td>Lifestyle management</td>
<td>Weather conditions (cold, rainy) in host country impede physical activity</td>
<td>Not able to carry out recommended ‘Western’ forms of exercise (swimming, bicycling)</td>
</tr>
<tr>
<td></td>
<td>Unfamiliarity with host country, spending time indoors, fewer social relationships impede physical activity</td>
<td>Little access to habitual forms of exercise (dancing)</td>
</tr>
<tr>
<td></td>
<td>Pressures associated with ‘immigrant condition’ impede physical activity</td>
<td>Cultural preferences for large body sizes (beauty, prosperity) represent barriers to engaging in weight controlling activities</td>
</tr>
<tr>
<td></td>
<td>(busy work schedules, demands of participating both in Dutch society and own communities)</td>
<td>Support from church and community enables physical activity</td>
</tr>
<tr>
<td></td>
<td>Fewer ‘natural’ opportunities for walking due to greater access to motorised transportation in host country</td>
<td></td>
</tr>
</tbody>
</table>
care providers must not only pay attention to a patient’s cultural background but also to migration-related experiences in order to be able to understand and address barriers to hypertension management.

Towards practical tools

Patient-centred care - culturally appropriate care

Our study provided us with detailed information about the specific beliefs of Ghanaian and Surinamese patients about hypertension and hypertension management. Hypertension guidelines recommend the use of generic patient-centred educational approaches to encourage providers to explore the beliefs and needs of individual patients and to find a common ground regarding treatment. However, several researchers have argued that in addition to patient-centred care, patients from ethnic minority groups may also require culturally competent or culturally adapted care. Indeed, there is increasing evidence that culturally appropriate educational methods can positively influence medication use and lifestyle changes in ethnic minority patients. For this reason, in our thesis we opted for the idea that, in addition to a patient-centred approach, a culturally appropriate approach could be beneficial to hypertensive patients from ethnic minority populations. Such an approach explicitly acknowledges the importance of culture and the migration experience to patients’ perspectives on health and incorporates this acknowledgment into the process of health care delivery. This approach recognises that an understanding of the specific meaning that ethnic minority patients may attach to hypertension is needed, as well as the adaptation of lifestyle recommendations and educational materials to the language and customs of these groups. Thus, ‘patient-centred culturally appropriate care’ includes a generic patient-centred part and a culturally specific part, in which the specific needs of ethnic minority groups are acknowledged. It should be noted however, that a focus on a patient’s culture may not always evoke favourable reactions. For example, it may be interpreted by patients as intrusive or as contributing to stigmatization and discrimination. This should be taken carefully into account.

Implementing culturally appropriate hypertension education

There are a number of challenges to implementing culturally appropriate hypertension education: First, it requires a patient-centred approach and even though current hypertension guidelines recommend this approach it cannot always be assumed that health care providers apply it (Chapter 6). Second, the delivery of culturally appropriate hypertension education requires specific training, experience and resources. Third, the implementation of culturally appropriate hypertension education may be hampered by general resistances to innovations on the part of care providers or by a specific resistance to registering ethnicity. These obstacles need attention early in the implementation trajectory of culturally appropriate hypertension education.
Reflection on research methods

Several methods were used to answer the main research questions outlined in the introduction. Some aspects of the research methods warrant further reflection.

General comments on the design of the studies

This thesis includes two projects designed to analyse ethnic differences in hypertension care. The designs of the studies reflect some of the stages of the model for planning and evaluation in health care described by Grol and others, which is commonly used in projects that aim to improve the behaviour of health care professionals.25,26

In keeping with the study’s objectives of gaining an in-depth understanding of explanatory models of hypertension, in chapters 2-4, we did not formulate prior hypotheses but instead adopted a qualitative inductive research approach based on detailed open interviews. The strength of this method is that it builds on the direct experiences of patients.27 The analysis of the interviews was inductive and based primarily on the coding procedures and constant comparative method developed by Strauss (grounded theory).28 To be best able to elicit the experiences of hypertensive patients we constructed a topic list for the interviews in several steps. As a consequence of our study objective to make comparisons between the three ethnic groups, all interview topics had to be addressed in all three groups. To be able to make comparisons between the groups our study included a relatively large number of respondents as compared to other qualitative studies.29 Qualitative studies often use an iterative approach in which the instrument of data collection is continuously adapted on the basis of the analysis of the data.30 In this study this approach was used only while we constructed the interview guide (topic list). Therefore, some of the themes that emerged from the data analysis may not have been explored and analysed entirely. Together, the interviews provided rich data on culturally specific and migration-related issues that are important for hypertensive patients in the three ethnic groups we studied. Moreover, very few new themes emerged in the later interviews. Hence, it appears that data saturation was reached which is a criterion for sufficient sample size in qualitative studies.

In the study reported in Chapter 5 we used a quantitative approach with a quasi-experimental design, contrasting intervention and control groups, to evaluate the effects of the intervention with regard to the attitudes and self-reported behaviour of care providers. Selection bias and contamination could not be ruled out, which may explain why the observed effects were modest. In Chapter 6, content analysis of the qualitative data that were collected during the implementation of the intervention provided an in-depth understanding of factors that may have hampered the use of a culturally appropriate approach in routine practice. This second project (Chapters 5-6) was limited to the collection of data on how providers experienced the newly developed approach, not on patient outcomes. Consequently, we cannot say whether the intervention contributed to improved satisfaction or to patients’ medical outcomes.
Subjectivity in data collection and analysis

All studies in this thesis were explorative in nature and, in line with the objectives, consisted mainly of qualitative research methods. Qualitative studies are usually not strictly planned in advance. For this reason the decisions that researchers make in the course of these studies may encompass some subjective elements. For instance, in qualitative research the researcher is also the research instrument. Before I started my work as a researcher, I had 15 years of working experiences as a physiotherapist in a primary care health centre in an economically disadvantaged, multi-ethnic neighbourhood. In addition to the existing evidence on ethnic disparities in hypertension, my working experiences were also an important motive for starting this project. As a physiotherapist, I found that communication with some of my patients from ethnic minority groups was particularly problematic; for example, in addition to language barriers, reasons for the encounter were sometimes unclear, compliance was sometimes poor and the difficulties and intercultural misunderstandings in discussing psychosocial matters were sometimes substantial. Consequently, as a researcher I did not enter this field without any opinions about this research topic, which may have generated bias during the research. For example, my education and work experiences in a biomedical context may have contributed to blind spots with regard to patients’ perspectives and to bias during data collection. It may also have led to an excessive focus on culture during the data collection, or, during the data analysis, to a focus on cultural explanations for issues that actually are common cross-cultural issues (culturalisation).

Because I was aware of this issue, several measurements were taken during the study to ensure validity and reliability. In the first project, the research design, contrasting three ‘reference’ groups of diverse ethnic origin, contributed to the internal validity of the findings. This design made an inter-ethnic comparison of the issues derived from the interviews possible and increased possibilities for reflection on any ‘culturalisations’. Our study demonstrated, for example, that the migration experiences and circumstances of daily life of immigrant populations are an important part of the explanatory model of hypertension, perhaps even more important than the cultural traditions of the country of origin. Furthermore, I described the decisions in the analysis and reflections on the data in memos (methodological, theoretical, reflexive memos). Reading and re-reading these memos and discussing them with my supervisor and other researchers also contributed to the study’s internal validity. Furthermore, the use of Maxqda computer software in the data analysis contributed to internal reliability. To increase the reliability of the code list, a second researcher and I coded interviews independently to check for inter-coder consensus concerning the assignment of text segments to major themes. The supervisor of this study and I compared thematic matrices from each ethnic group independently, discussed the similarities and variations and reached a consensus about the conclusions. If no consensus could be reached we resolved the issue by going back to the original data. Finally, the main conclusions that were drawn were presented, discussed and verified in a
larger group of researchers, and in a group of primary care providers from practices that were involved in the study, to gather feedback about the plausibility of the conclusions. In the second study, a local quality improvement project, an action-oriented design was used,\(^2\) in order to uncover barriers to implementation as well as take actions that could be relevant. As a consequence of this choice the researcher had the role of both observer and interventionist. This may have influenced the validity of the research findings. To ensure internal validity, member checks of the collected data and data triangulation (e.g. discussion meetings, video registration, individual consultations) were used. Furthermore, the possible influence of the involvement of the researcher on the validity of the research was compensated for by reflection on findings and conclusions at different levels: by the supervisor of this study, by the project committee and, in the final stage, by a group of 25 experts from different disciplines in hypertension care, including guideline development, medical education, patient education and culturally appropriate care.\(^1\)

**Generalisability**

In the first project, we decided to match the three ethnic groups by several characteristics, other than ethnicity, in order to make comparison in the qualitative analysis feasible. Therefore, the group we interviewed had a relatively homogeneous character: participants were limited to hypertensive patients who were between 35-65 years old, had been prescribed medication, were without co-morbidities or cardiovascular disease, and, chiefly, had a lower to middle socio-economic status. A drawback of this choice is that our findings may not capture the perspectives of other patient groups, for example hypertensive patients with cardiovascular complications or second-generation groups. Caution should, therefore, be exercised when making generalisations from the results to patient groups with other characteristics. Secondly, while participants had hypertension for an average of 5 years, the Dutch patients generally had longer histories of hypertension. This might have contributed to the differences between the explanatory models of Dutch patients and those of ethnic minority patients. For example, particularly ethnic minority patients were highly concerned about their condition and believed that immediate damage can occur if the blood pressure rises too high. It might be possible that after living with hypertension for many years patients become less concerned and change their views on the course of this condition.

This study was conducted in the Netherlands, and because of the structure of the Dutch healthcare system, most participants (with the exception of two Ghanaians who did not have residence permits) had equal access to health care. It is possible that our findings would not be similar in countries where access to health care is different than in the Netherlands, as poor access to health care may give rise to barriers to hypertension management. However, looking at the international literature on decisions regarding hypertension management among ethnic minority groups, many of our findings are confirmed, such as that medication decisions are influenced by traditional cultural beliefs.
and by practices from the country of origin. The facilitating role of community networks and faith-based organisations on participation in physical activity is also confirmed. A limitation of the second project, with regard to the generalisability of the results to hypertension care in other settings, was its relatively small scale and its rather specific local context (Dutch primary care health centres).

**Implications and recommendations**

Some implications and recommendations for research, clinical practice and health policy follow from the findings of this study.

**Research**

The thesis has shown that the implementation of an intervention to enhance culturally appropriate hypertension care is feasible and that it may positively influence the acceptance of a culturally appropriate approach to hypertension care among care providers. Questions with regard to the effects of the intervention on patient outcomes remained and have yet to be answered. For this reason we are currently conducting a cluster randomised trial with the aim of evaluating the effect of culturally appropriate hypertension education on blood pressure control, adherence and satisfaction with care. The study protocol has been included as an appendix to this thesis.

To increase the external validity of our findings qualitative studies of the explanatory models of hypertension in other ethnic minority groups or generations than those studied in this thesis are needed. Our step-wise approach can also serve as an example for the study of other chronic conditions. For example, based on the studies in this thesis, a mirror project for diabetes care among ethnic minority patients (‘Soekroe’) has been developed. In addition to qualitative studies, quantitative studies may be needed to provide more insight into associations between specific elements of patients’ explanatory models of hypertension and psychological, behavioural or biomedical outcomes (e.g., the link between the perception that hypertension is a symptomatic condition and medication use). The topics and taxonomies identified in this thesis can be taken as a point of departure. Further research is needed to examine the relation between migration-related stress and the aetiology and management of hypertension.

The recommended future studies may not only provide more evidence, but also further theoretical insight into the ongoing debate on concepts of patient-centredness and cultural competence and how they relate to each other. Future studies may also provide further evidence to improve training in medical communication.

Any further studies in this field require the registration of a patient’s ethnicity by practitioners as well as other relevant data, such as those describing patients’ explanatory
models of hypertension. At the same time, it should be recognised that this may present major challenges for clinical care.\textsuperscript{38,39}

**Clinical practice**

Poor adherence to antihypertensive medication and therapeutic lifestyle changes is an important factor contributing to ethnic disparities in blood pressure control and cardiovascular complications.\textsuperscript{40,41} Hypertension guidelines and systematic reviews recommend patient-centred hypertension education as a tool for improving adherence.\textsuperscript{12,18,42,43,44} Our study emphasises that, in addition to a patient-centred approach, hypertensive patients from ethnic minority populations may benefit from culturally appropriate health education. This implies that care providers should not only focus on individual barriers to hypertension management, but also on how factors related to culture may influence such barriers. Moreover, in addition to the cultural context, the immigration experience needs to be recognised. A failure to address the role of migration experiences risks interpreting the social issues related to migration as cultural phenomena.

Our findings may help health care providers to understand why and how to address patients' perspectives and how to provide advice that is tailored to these perspectives. For example, helping hypertensive patients to understand that treatment must be continued even if psychosocial stress and/or symptoms are not present, and that it is safe to exercise when having hypertension. Our findings may also help health care providers promote suitable culturally appropriate lifestyle initiatives. The concrete tools, the teaching course and other support strategies we developed in our study (Chapter 5 and 6) are easily transferable and may be useful for this purpose. Although our study focussed on African Surinamese and Ghanaian patients in particular, the results may also contribute to the development of patient-centred approaches in clinical practice for ethnic Dutch or other ethnic minority hypertensive patients.

**Health policy**

Our findings illustrate that the implementation of a culturally appropriate approach in health care does not only require transformations in individual professionals but also in the organization in which they work. The organization needs to allocate sufficient resources, and time for conducting culturally appropriate care and make arrangements for an adequate division of labour between the health care professionals. It should also provide culturally tailored information materials, and allow the registration of ethnicity in the routine health care data registry. The latter, however, may be a sensitive issue in light of potential risks (e.g.; stigmatisation, discrimination), as was found in Chapter 6 in line with other research,\textsuperscript{45} and implies that this topic needs specific attention early in the implementation strategy.

Next, it should be recognised that ethnic disparities in health and optimizing culturally appropriate care is not only a responsibility of health care providers alone. As in the case of health promotion it may require concerted efforts by (primary) health care
institutions, ethnic minority community organisations, community services and public health organisations within a given catchment area. Finally, recent task substitution changes in the primary health care field have yielded an increasing role to general practice assistants and nurse practitioners in the education of patients with chronic conditions such as hypertension. The training and tools that have been developed in this study therefore may be useful for the allied medical professions as well as physicians.
Reference List


