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## **The role of ethnicity in access to care and treatment of outpatients with depression and/or anxiety disorders in specialised care in Amsterdam, the Netherlands**

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# Chapter 8

**Summary and general discussion**  
**Samenvatting (Dutch summary)**

## SUMMARY AND GENERAL DISCUSSION

### Objective of this dissertation

Currently, a substantial part of the Dutch urban population consists of non-western migrants. The prevalence of common mental disorders among migrants is high, and there are some serious concerns about ethnic differences in access to specialized mental healthcare, treatment adherence and treatment outcome. In this dissertation, we hypothesized that ethnic differences in access to specialized mental healthcare do indeed exist. We also hypothesized that ethnic differences in symptom profiles and health beliefs exist, and that acculturation influences the effectiveness of depression and/or anxiety care. Taking these ethnic differences into account, we finally hypothesized that culturally adapted guideline-driven treatment might reduce the differences in treatment adherence and outcome for migrant outpatients. As comparable work has mainly been carried out in the USA, little is known about these issues in Europe and the Netherlands. Therefore we formulated the following research questions, focusing on Turkish and Moroccan migrants who visit outpatient clinics for specialized depression or anxiety care in Amsterdam:

- A. Do ethnic differences exist in access to care, symptom profiles and trust in care between migrant and indigenous Dutch patients? Do acculturation levels influence need of care, symptom profiles, quality of life and treatment effect?
- B. Does culturally adapted guideline-driven depression and anxiety treatment improve treatment effectiveness and adherence?

In this final chapter, we will summarize the main results of the studies (**chapter 2-6**) and discuss these findings. Additionally, methodological limitations and strengths will be considered. Finally, our findings will be integrated and implications of the results and future directions for research and treatment policies will be discussed.

### Principal findings

#### ***Ethnic differences in specialized mental healthcare for depressive and anxiety disorders***

Part A of the dissertation focuses on ethnic differences in receiving specialized mental healthcare for affective disorders. Firstly, we explored ethnic differences in access to an

Amsterdam outpatient clinic for anxiety and depression treatment (**chapter 2**). Secondly, we studied ethnic differences in *symptom profiles and health beliefs* of outpatients with common mental disorders (CMD) (**chapter 3**). Thirdly, we analysed differences in *acculturation status* (skills, social integration, traditions, norms/values and feelings of loss) of Moroccan, Turkish and Surinamese migrants, and their effects on treatment outcomes (**chapter 4**).

In **chapter 2**, ethnic differences in access to an Amsterdam outpatient clinic for anxiety and depression treatment were explored by analysing attendance at the initial appointment. Based on the literature, our assumption was that at the patient level, apart from ethnicity, also age, gender, marital status, having children, waiting time after referral, and language problems are possible determinants of missed initial appointments. Medical files of 110 outpatients with a Moroccan or Turkish background and of 110 matched indigenous Dutch patients were selected from the referral list. In total, 44 referred patients (20%) missed the first initial appointment. This number consisted of thirty-four migrant patients (31%) versus 10 (9%) indigenous Dutch patients. Ethnicity was found to be the only significant determinant. After repeated invitations, these percentages were reduced to 13% for the migrant outpatients and 3% for the indigenous Dutch patients. The missed initial appointment rates we found were moderate compared to rates found in other international studies. In the Netherlands, Korrelboom et al. (2007) found comparable missed appointment rates, with ethnicity being a determinant. In our study, repeating invitations was an effective strategy, although an ethnic gap remained. Our study confirmed that concerns about ethnic differences in access to specialized mental healthcare are valid and should be a focus of attention in mental healthcare for migrants.

In **chapter 3** we explored ethnic differences in symptom profiles and health beliefs. Outpatients with a Turkish or Moroccan background (N=54) were matched on age and gender with outpatients with an indigenous Dutch background (N=108). Outpatients with a Turkish or Moroccan background had a lower score on depression severity, but anxiety severity scores were higher than in Dutch outpatients. Pain intensity and disability were significantly higher in the migrant group. Furthermore, functional disability in the domains of communication, mobility, self-care, and participation was significantly more pronounced, while trust in therapists and friends care was significantly lower in the ethnic minority groups. Possibly, these outcomes indicate that regular treatment of common mental disorders (CMD) should be targeted more explicitly at the anxiety,

pain and disability symptoms in these migrant groups. Also, extra attention should be paid, before and after referral, to patients' opinions of specialized care and to their trust in offered care.

In **chapter 4**, aspects of acculturation status (skills, social integration, traditions, norms/values and feelings of loss) were explored in a longitudinal cohort study, using data from Routine Outcome Monitoring (ROM) in Moroccan, Turkish and Surinamese migrants being treated in outpatient specialised mental health clinics. Also, the relation between acculturation status and symptom levels, quality of life, care needs and treatment effect were analysed. The acculturation status differed between the three ethnic groups. Turkish migrants showed the most cultural maintenance (traditions, norms/values), Surinamese migrants showed the highest level of participation (skills, social integration), while Moroccan migrants were situated in between. The higher cultural adaptation level was related to less need for care, lower symptom levels and a higher quality of life. Participation significantly predicted a lower symptom score and higher quality of life, six months after the treatment started. This study confirmed that acculturation status affects symptom levels, quality of life, and perceived need for care of migrants. Moreover, participation appeared to be a favourable influence for treatment effect.

Summarized, in section A, the main findings were:

- Turkish and Moroccan patients significantly more often missed the initial appointment at outpatient specialized mental healthcare compared to indigenous Dutch patients;
- migrant patients showed more anxiety severity, less depression severity, more functional disabilities, higher pain severity and disability, and less trust in therapist care, compared to indigenous Dutch patients;
- acculturation status affects symptom levels, quality of life, and perceived need for care of migrants. Participation in Dutch society appears to be a favourable factor for treatment outcome.

### **Effectiveness of culturally adapted care for common mental disorders**

The second part (B) of the dissertation explored the effectiveness of cultural adaptations added to treatment guidelines for depression and/or anxiety in specialized mental healthcare. Firstly, we explored the literature on effectiveness of culturally adapted

depression or anxiety treatments in **chapter 5**. Secondly, we designed a randomized controlled trial study in which we wanted to test the effectiveness on treatment dropout of a cultural competence module, added to the treatment guideline for depressive and anxiety disorders in two Amsterdam clinics in **chapter 6**. Thirdly, we analysed the result of this RCT study in **chapter 7**.

In **chapter 5** the empirical literature on the effectiveness of culturally adapted guideline-driven depression and anxiety interventions was reviewed systematically. Nine eligible randomized controlled trials (RCT) were identified. These studies were all conducted in the USA. All studies identified a focus on cultural values and beliefs as an important aspect of cultural adaptation. The pooled effect size on clinical outcome for all studies was significant 1.06 (CI 95% 0.51-1.62,  $p < .00$ ). Two of these studies demonstrated a significant pooled effectiveness (95% CI 0.22-1.14,  $p < .00$ ) of cultural adaptation per se because they compared culturally adapted guideline-driven treatment to unadapted guideline-driven treatment. The other seven studies compared culturally adapted guideline-driven depression, and/or anxiety outpatient treatment as a whole, to control conditions such as waiting lists or other treatments, like muscle relaxation. Whether the effectiveness found in these seven studies was indeed due to the cultural adaptation per se remained undetermined. This means that there is some evidence in favour of the effectiveness on clinical outcome of the cultural adaptation as such. Although the cultural adaptations applied in the reviewed studies are not all relevant for the Dutch study population, and although the ethnic backgrounds of the study populations were different from Dutch migrant research groups, many issues are more generally applicable. The outcome is motivating and underscores the need for comparable trials outside the USA.

In **chapter 6** we described the design of the RCT in which we wanted to test whether a cultural competence module, added to the treatment guideline for depressive and anxiety disorders, was effective in reducing dropout and no-show of migrants. In **chapter 7** we described the results of the RCT. 220 Moroccan and Turkish adult outpatients who were referred to these outpatient clinics for depressive and/or anxiety disorders participated in this study. They were randomly assigned to mental health therapists who were trained in a cultural module and to therapists who were not. Several possible determinants of outcome were explored during a 6-month period after the intake session. No significant differences were found in dropout rates between the intervention group and the control group (21% versus 12%, chi-square 3.27,  $p = .07$ ) nor for no-show (mean of one missed appointment for both groups). The dropout rate of the intervention group was

unexpectedly higher compared to the control group. This means we could not prove that training the therapists in cultural competence reduced the dropout and no-show rates. Overall, the dropout rates in both groups seemed moderate compared to rates found in other studies, including studies with a broader perspective, and not focusing specifically on migrants (Arnow et al., 2007; Tarricone et al., 2010). Nevertheless, a substantial part of the study population dropped out. Surprisingly, language problems predicted a significantly lower dropout rate in both condition groups. Other unexpected findings were that the treatments (psychotherapy and/or pharmacotherapy) started relatively long after the intake phase (mean of 10-14 weeks), that the frequency of treatment contacts was low (a mean of 4 to 5 sessions psychotherapy or pharmacotherapy over a six months period), and that patients often only received one step of the medication protocol. The question remains to what extent these findings are due to either organisational problems in the clinics, or to patient factors.

Summarized, in section B, the main findings were:

- culturally adapted guideline-driven depression and/or anxiety treatments had a positive effect on clinical outcome for US migrants (chapter 5).
- a positive additive effect of cultural adaptation of treatment guidelines for depression and/or anxiety could not be demonstrated. There was no significant difference in dropout rates between the intervention and control group (chapter 7).

## **Reflection on the findings**

### ***Missed initial appointment***

In those cases where general practitioners (GP) did recognize a CMD and decided to refer to specialized mental healthcare, a lower rate of migrant patients, as compared to indigenous Dutch patients, started specialized treatment. As described by the consumption of care filtering model of Goldberg and Huxley (Goldberg & Huxley, 1980), the first filter was thus (most often) carried out by the GP, but not all referred and invited patients arrived at the specialised mental healthcare clinic. A further selection mechanism seemed to interfere. We do not know the patients' reasons for the missed initial appointments. A possible explanation is that the patient did not recognise the same health problem (defined by the GP as a depressive or anxiety disorder), or that they did not understand the reason for referral. In addition, some of them probably did

not understand the invitation letter, which had been written in Dutch. Furthermore, the non-attendance might have to do with less trust in care, which is an important issue, as was demonstrated in **chapter 3**. Therefore, more attention should be paid to the referral process, for example by culturally adapting the invitation letter (e.g. translation into different languages), and by paying more attention to the patients' opinion and expectations about the referral.

### ***Dropout problem for migrants?***

In our Amsterdam RCT (**chapter 7**) we found no evidence that dropout during treatment can be reduced by culturally adapted guideline-driven depression and anxiety treatment. As we did not make a comparison to indigenous Dutch patients, we do not know whether the overall dropout problem was higher in the migrant population than in the mental health patient population as a whole. A 16% dropout rate for the total study population is not higher than what was found in other international studies with a broader patient perspective. Yet, we did find some specific aspects that might be targeted at the prevention of dropout. We found that ethnic differences do exist in attendance at intake sessions, in symptom profiles and in trust in care. As we saw in **chapter 3**, migrant outpatients in depression or anxiety care showed more somatic (pain) and functional disability compared to indigenous Dutch outpatients. The findings that migrants missed first appointments more often and had less trust in care suggests that in this patient group, more attention should be paid to psycho-education on depression and anxiety, and to motivation for treatment. Besides, in the standard depression and anxiety treatment protocols, attention to disability and pain symptoms to prevent dropout has not been implemented. Extra attention should be paid to these problems, for example through collaborate care.

An explanation for the relatively moderate overall dropout rates among migrants in this study might be the fact that the intake dropout filtered the risk group for treatment dropout in advance. In our RCT study in **chapters 6 and 7**, the outpatients were included after the intake. The groups of migrants who started treatment were possibly the more motivated patient groups with more need of care. An additional explanation might be that the effort of the therapists to overcome the cultural gap and the complex problems during the first half year after the intake resulted in treatment adherence. During the training and peer group meetings, we observed a highly motivated and dedicated attitude towards overcoming the cultural gaps; we did not quantify the motivation and



dedication of the therapists, but according to the literature, the therapists' motivation or cultural desire (Campinha-Bacote, 2003a; Campinha-Bacote, 2003b; Campinha-Bacote, 2008) is an important aspect of adequate cultural competence besides cultural awareness, skills and knowledge.

### **Adding cultural adaptations to guideline-based treatment**

In studies from the USA that were discussed in our review (**chapter 5**), evidence was found that culturally adapted treatment is effective for ethnic minority outpatients with CMD, and probably more effective than comparable treatment without adaptation. There is still little evidence for the effectiveness of the cultural adaptation as such. We aimed to add to this evidence, but our study (**chapter 7**) showed that it is very difficult to research the effectiveness of a cultural adaptation of treatment in a clinical setting. Firstly, it was very difficult to include migrant outpatients for interviews, which is why we decided to collect data by analysing the files of the randomised patients to find answers to our research questions. Secondly, the evaluation time of six months proved too short, as it sometimes took 3 months after the intake to start treatment, and therefore only a few treatment sessions were given. Probably, differences would have become more visible after a longer treatment time. The low contact frequency might be due to organisational problems, but also to factors of the outpatients themselves. Further research, including qualitative research, into this subject matter is needed to address this issue. Thirdly, the motivation and experiences for both intervention group and control group therapists to work with patients with a different cultural background was possibly comparable and for both groups at a high level. This made it difficult to demonstrate superiority of the intervention group. Fourthly, we offered a package of cultural adaptations. By using this pragmatic strategy, we could not identify the effectiveness of individual elements of cultural adaptation in **chapter 7**. In the literature, cultural adaptations are defined in several ways (**chapter 5**). For example, cultural adaptation may be operationalized by the employment of bilingual therapists or by assessing the cultural background or peer group support. In none of the studies the effectiveness of each aspect was disentangled. Given the fact that ethnic differences do exist, it seems worthwhile to test the effectiveness of more isolated aspects of cultural adaptation (e.g. the cultural formulation instead of a module with several skills and instruments) to improve treatment adherence and outcome in the most vulnerable migrant outpatients.

## **Methodological considerations**

Research on migrants in specialised mental healthcare has to deal with practical and methodological barriers such as language problems, accessibility and motivation of the study population. An additional problem is the lack of validated questionnaires for the specific cultural minority groups. This, in combination with more common difficulties in performing clinical trials in non-academic centres, makes intercultural research truly challenging. In this paragraph, we discuss the methodological considerations which were relevant for the dissertation in general.

## **Strengths**

Firstly, in this dissertation we have collected clinical data of migrant outpatients (most often first generation) with depressive or anxiety disorders who were referred to specialised mental healthcare. Relatively little is known about this group of patients, as they are mostly excluded from clinical research, due to a lack of fluency in the dominant language. Furthermore, non-western migrants are often less familiar with research compared to indigenous patients, and consequently, they have more reservations (or they refuse) to participate in clinical trials. For clinical studies, few successful recruitment strategies are known. In this study, our recruitment strategies were based on successful field work experience in recent (population based) studies among Amsterdam migrants (De Wit et al., 2008; Stevens et al., 2005). For example, we trained bilingual students in inviting patients to participate and in interviewing. We asked interviewers to repeat invitations for an interview by telephone, if necessary up to eight times, and to act very flexible in offering appointments regarding time and interview location. Patients received compensation (€ 15) for their participation in an interview. By using these strategies, we managed to include 40 migrant outpatients for the complete interviews that we originally described in the design paper. 17 of these participants (31.5%) preferred to be interviewed in Turkish or Moroccan Arabic.

Secondly, much effort was put in finding questionnaires and methods for adequate data collection, that would allow us to answer our research questions. We used several instruments that had been translated into Turkish and partly into Moroccan Arabic by the Municipality of Amsterdam (De Wit et al., 2008) for the population based research project of the Amsterdam Health Monitor (AHM). We added some more questionnaires used in the NESDA study, which had been translated into Turkish and partly into

Moroccan-Arabic by bilingual mental health professionals and bilingual psychology and medical students, via the Dutch Translation Agency (Tolk Vertaal Centrum, TVcN). These translated questionnaires were all translated back and compared to the original versions. Using the same instruments as the NESDA and AHM studies, comparisons to our study outcomes was made possible. Dropout and no-show data (**chapter 7**) were retrieved from the medical files (2). In **chapter 4**, we used a longitudinal dataset of Routine Outcome Monitoring (ROM) data of two outpatient clinics for depression and anxiety disorders in Amsterdam (Arkin) in which a relatively large group of migrant outpatients had participated. This gave us the opportunity to get more insight into the association between acculturation, mental health and treatment effect. An overview of the measures, can be find in the Appendix of this dissertation.

Thirdly, as far as we know, our research has been the first European RCT on the effectiveness of culturally adapted guideline-driven depression and anxiety treatment.

## **Limitations**

In this study we had to face several limitations. The first limitation concerned the patient recruitment and data gathering for the RCT (**chapter 7**). As was mentioned before, It proved to be hard to find patients who were willing to participate in the interviews. Furthermore, therapists were supposed to have an active role in recruiting patients. Therapists who saw the patients at the initial appointment were asked to hand over a letter with information about the study and to give a sign to the researchers when a patient was eligible and interested. After that, a bilingual research assistant would approach the patient within two weeks by phone for informed consent and an invitation for an interview. However, in practice, the therapists were not used to participating in research or they felt uncomfortable to bother the patients with this research question. Also, high work and production pressure made it difficult for them to follow the research instructions. Thus, these therapist factors limited the process of including patients in the study. Another difficulty was that few patients could be reached after information had been handed over or sent to the patients afterwards. Only a small percentage (20%) of the reached patients were willing to participate in the interviews, most often because of planning difficulties. Even a € 15 fee did not increase the response substantially. Because of this low response (after the recruitment period had been prolonged for one year, 40 patients (18%) participated in the first assessment and 20 patients (9%) in the second),

we decided to retrieve data from the medical files (**chapter 2 and 7**) and from Routine Outcome Monitoring (ROM) data (**chapter 4**). ROM is a relatively new method in Dutch mental healthcare, devised to systematically and repeatedly collect data of each patient, aiming to assess treatment effectiveness. During the research period for this dissertation, the implementation of ROM was not completed in any of the clinics. A team of trained bilingual research assistants has put much effort in trying to reach patients for the ROM measures, but with limited results. Fortunately, a ROM data set from several clinics of Arkin that covered a former and longer period (2005-2009) could be used to gain more insight into the outcome of treatment of migrant outpatients.

The second limitation concerned the implementation of the study design (**chapter 6**). Eligible respondents were identified after referral, based on the information of ethnic background and psychiatric problem profile from the referral letter. After assigning the outpatients randomly to the intervention or control therapists, it was difficult for the researchers and administration professionals to mark the medical patient files and to trace, follow and check whether the assigned condition of the intake and treatment therapists were correct. Several outpatients were assigned to the wrong intake or treatment condition, and this was a main cause for contamination of the control condition and the dilution of the intervention effect. During the trial, we reached more control, for example by deploying a research assistant at every site, who strictly monitored the assignment process. Nevertheless, the original time schedule (**chapter 6**) could not be maintained and the study was prolonged for a year. Also, the implementation of the intervention by the therapists was more complicated than expected. Although therapists were willing to collaborate, the design described in **chapter 6** could not be carried out in everyday clinical practice. For example, therapists did not adhere to the instruction to systematically incorporate the main aspects of the cultural interview in the initial treatment session. Although it proved from the medical files that topics from the Cultural Interview were significantly more often discussed in the intervention group, this did not take place systematically. The main explanation the therapists gave was that they lacked time to prolong the initial interview, which was at that time restricted to 45 minutes, as a general rule in the clinic. This example indicates how difficult it is to implement additional knowledge and skills with a minimum of extra time and financial resources, while for more complex groups, such as patients with a low income and low-skilled patients with a different cultural background, this extra time seems necessary for building a therapeutic relationship and gathering and providing adequate information.

The third limitation was the difficulty of measuring the effectiveness of a cultural competence training as such (**chapter 7**). We did not find differences between the intervention and control condition; this might be explained by the fact that general cultural competencies were at a relatively high level in therapists from both conditions, as was discussed earlier. Bearing this in mind, we can assume that it will always be difficult to study the effects of training in cultural competencies as such.

The fourth limitation concerns the questionnaires used. Not all instruments were cross-culturally validated, and the risk for some construct bias or measurement non-equivalence exists (Fassaert et al., 2009; Van der Vijver & Tanzer, 2004). Nevertheless, most instruments had already been used in previous population based studies, and also among Amsterdam citizens with a Turkish and Moroccan background, or other international and cross-cultural studies. It is difficult to find better alternatives, since validation is a difficult and costly process.

Finally, the results of our study are influenced by local mental health circumstances and specific migrant groups. Therefore, generalizability of our findings may be limited. However, some general aspects can be distinguished that also hold true for migrants in other countries. For example, the healthcare systems in other western countries (such as the US) operate very similarly concerning healthcare delivery. They tend to give primary care as a first point of entry, and operate under regional and speciality subsystems. Also, the guideline-based mental health treatments that were offered are comparable. This makes it worthwhile to compare the research findings in the field of culturally adapted treatments from different countries, to learn from the evidence of that research and to use it for future research and practice.

## **Implications for treatment policy**

### ***Adapted specialized mental healthcare for the most vulnerable migrants***

During the research for this dissertation, the professionals shared the opinion that the dropout of migrant patients was high compared to indigenous Dutch outpatients, and they considered the usual interventions to be less effective for migrant outpatients. In this study, we did indeed find higher intake dropout, but the treatment dropout rates did not seem very high compared to other studies. Beside the high intake dropout for migrants, we also found ethnic differences in symptom profiles, trust in care (**chapter 3**), and we found that acculturation levels do matter in treatment (**chapter 4**). We could

not prove that the cultural module for therapists reduced dropout (**chapter 7**). Taking these findings together, we still plead for the investments in culturally sensitive care, supported by the results of our systematic review (**chapter 5**). As it is to be expected that more migrant patients with more diverse cultural backgrounds will enter (mental) health institutions in the near future, it would be advisable for every therapist/doctor to develop a culturally sensitive way of thinking and treating and, above all, a desire to bridge the gap. The ability to connect to a broad spectrum of patients from different cultural backgrounds should be part of the basic education of therapists and doctors. Most of the participating therapists in this study had a cultural training module in their basic education to become a mental health professional. The therapists told us after the cultural training module that the module offered in this study (**chapter 6**) was partly experienced as a repetition of the cultural knowledge they had already had, although the exercises or skills (e.g. working with an interpreter, using the cultural formulation) were found to be difficult. The theoretical insight of the participating therapists already seemed adequate, whereas their practical skills were relatively untrained. Possibly, the cultural module we offered should have focused more on training and implementing the cultural skills in order to improve the effect of this intervention.

Another suggestion is the use of professional interpreters in the case of insufficient command of the Dutch language. Until 2012, the government stimulated the use of professional interpreters to improve treatment adherence and quality of patients with insufficient command of the Dutch language. Since 2012, the Dutch policy has changed, and interpreters are not reimbursed by the government any longer, resulting in a reduced use of interpreters. Nevertheless, interpreters can help to bridge the cultural gap and prevent dropout (Flores, 2005; Flores, 2006). Using family members as interpreters seems less appropriate for mental health treatment, as trust in family care is low (24%) among migrant outpatients (**chapter 3**). Additionally, in collectivistic cultures, such as the Turkish and Moroccan cultures, family involvement has a high impact on an individual's functioning. Involving family members in specialized mental health treatment, not as interpreters, but as partners, is of great importance in treatment migrants, and this also needs attention.

Yet, in the recently changed care system in the Netherlands, the barrier to referral to specialized mental healthcare has become higher. The new system is aimed to reduce referrals to specialised mental healthcare and to keep patients in primary care (most often GP), in basic mental healthcare, community or family care. Nevertheless, in our opinion,

referral to specialized mental healthcare for those migrants who suffer from persistent and severe CMD in combination with low acculturation levels and/or other (physical) problems seems relevant. Based on the higher intake dropout rates we found for migrants compared to indigenous Dutch patients, the transition from GP to specialised mental healthcare should be improved. One suggestion to improve the transition is by giving more psycho-education at the GP practice, aimed to increase realistic expectations and trust in specialised mental healthcare. Furthermore, clinics should use a more (culturally) adapted referral and invitation strategy (e.g. translated information leaflets). In addition, more intensive collaborative care, case management or maybe community care can facilitate this referral.

### ***Guideline-treatment for migrant outpatients***

In our RCT (**chapter 7**) it became clear that the clinics did not succeed in carrying out treatment guidelines efficiently. For example, there was a relatively long time between intake and the start of the treatment, and the frequency of the treatment contacts was low, for pharmacotherapy as well as for psychotherapy. Additionally, in pharmacotherapy, often only one step of the antidepressant guideline was followed, regardless of the symptom levels of the patients. Although the duration of the waiting time did not seem to influence the dropout rates, there is evidence that more intensive treatment, i.e. a higher frequency of treatment sessions, improves effectiveness (Cuijpers et al., 2013).

### ***Migrant outpatient participation in specialised mental healthcare***

As mentioned before, the major transition in the Dutch healthcare system is to decrease governmental social and care arrangements and to replace them by participation in community (family, neighbour and peer group) care, or other types of care. Participation is the keyword for contemporary (municipal) policies, which aim to change the attitudes of citizens. Participation should improve feelings of responsibility for one's own and one's peers' wellbeing, health and lifestyle. As participation of especially Turkish but also Moroccan citizens in Dutch society lags behind (Van der Vliet et al., 2012) it is a challenge for policymakers to find ways to increase the numbers of non-western participating citizens. Beside the intention of the government to encourage citizen participation, it has been suggested that healthcare institutions should adapt to these policy changes too (Dorgelo et al., 2013). Patient participation is already a known phenomenon in mental healthcare, and implemented in patient counsels or patient interest groups. The

number of non-western patients participating in these counsels or groups is small or unknown. Assumptions are that increased participation will have a beneficial effect on migrant quality of care, patient empowerment and effectiveness (Dorgelo et al., 2013). In our study (**chapter 4**), the relation between participation and treatment outcome is confirmed. Possibly, patient participation can also increase trust in mental healthcare among migrant outpatients.

## **Implications for research**

### ***Opportunities in migrant mental health research***

As many questions about the role of ethnicity in mental health (care) for migrant patients with depression and anxiety remain unanswered, further research is still necessary. From this dissertation we learned that a clinical trial is not the most successful research method for research on migrant outpatients in specialised mental healthcare. With regard to the problems in data collection, it is worthwhile to explore other possibilities to gain useful clinical data of migrant patients. As Stevens et al. (2005) described, extra effort has to be made to improve the response of these groups. This dissertation (**chapter 7**) confirmed the difficulties in recruiting migrant mental health patients for participation in a randomised trial and committing interviews in a clinical setting. Possibly, anonymized ROM (if solidly implemented), as well as file and registration data (for example the Psychiatric Case Register (PCR) or Health Insurance data) can overcome this lack of response for quantitative research. For both quantitative and qualitative research it is of importance to continue investment in increasing the structural participation of migrants in clinical research (Dorgelo et al., 2013). Much effort of specialised mental health organisations is needed to accomplish this goal, because Turkish and Moroccan patients not only display low research participation, but their participation in client counsels of Dutch mental healthcare organisations is low as well. So far, little is known about methods to improve this participation. Cooperation with existing migrant organisations with a focus on care seems one step to improve this participation.

### ***Cultural validation of instruments***

Finally, as we are still motivated to gather information concerning Turkish and Moroccan migrants, we plead that more (translated) instruments are validated (conceptual, semantic, criterion, technical and content validity) for the major Dutch migrant (outpatient)



populations. A difficult and costly aim, since a valid translation requires different steps (Van Ommeren et al., 1999). To test the psychometric properties for each migrant group is only possible with a relatively high response. As we learned, much effort is needed to accomplish research response from these groups.

As the latest population based studies of the Amsterdam Municipal Health Monitor (2012) show that especially the Turkish population seems to be vulnerable for depression and anxiety problems in the Netherlands, investments targeted at this patient group are of utmost importance.

### **Final comments**

The findings in this dissertation may help to provide some more insight in treatment processes and symptom profiles of Moroccan and Turkish outpatients who are referred to specialized depression and/or anxiety care. For the first time, the effectiveness of culturally adapted depression and/or anxiety treatment was measured in a European clinical setting. This dissertation also shows how difficult it is to elaborate high-quality research in a non-academic clinical setting among these groups. Taking together all results from this dissertation and the knowledge that the group of Moroccan and Turkish patients with depression and anxiety is increasing, we plead for more research concerning the treatment of the most vulnerable and less acculturated migrant patients, aiming to improve treatment adherence and outcome and to prevent chronicity and prolonged disability.

Our study has made clear that specialized mental health care is available for migrants but that extra effort is needed to increase access and to improve treatment procedures. Possibly, the first steps are to pay extra attention to increased trust in mental healthcare for this group, to improve the intake process, to collaborate with primary and community care if problems are complex, and to realize more intensive treatment (with a higher frequency) in specialized care. For research, other methods than RCT or interviewing have to be explored in order to gain more useful clinical data concerning migrant patients. In line with contemporary policy, mental health institutions have to find ways to increase the participation of the migrant groups within the institutions, aiming to improve treatment policy for migrants.

## SAMENVATTING (DUTCH SUMMARY)

*De rol van etniciteit in toegang tot zorg en behandeling van poliklinische patiënten met depressie en/of angststoornissen in de gespecialiseerde zorg in Amsterdam, Nederland*

### Doel van de dissertatie

De prevalentie van veelvoorkomende psychiatrische stoornissen bij migranten is hoog, en er zijn ernstige zorgen over verschillen in de toegang tot gespecialiseerde geestelijke gezondheidszorg, behandelingstrouw en behandelingsuitkomst, die zijn terug te voeren tot etniciteit.

In deze dissertatie is de hypothese opgenomen dat er inderdaad verschillen bestaan in de toegang tot geestelijke gezondheidszorg en dat die verschillen zijn terug te voeren tot etniciteit. Een volgende hypothese in deze dissertatie is dat etnische verschillen in symptoomprofielen en gezondheidsovertuiging bestaan en dat acculturatie de effectiviteit van de behandeling van depressie en/of angststoornissen beïnvloedt. Door deze etnische verschillen in ogenschouw te nemen, is de uiteindelijke hypothese dat een cultureel aangepaste behandeling, die is gebaseerd op een behandelrichtlijn, de verschillen in behandelingstrouw en behandelingsuitkomst van poliklinische migrantenpatiënten mogelijk kan verminderen.

Vergelijkbaar onderzoek over deze onderwerpen is tot nu toe voornamelijk in de Verenigde Staten uitgevoerd, weinig is tot nu over deze onderwerpen bekend in Europa en Nederland. Om deze reden hebben wij de volgende onderzoeksvragen geformuleerd, gericht op Turkse en Marokkaanse migranten die in behandeling zijn van in depressie en angststoornissen gespecialiseerde poliklinieken in Amsterdam.

- A. Bestaan er etnische verschillen tussen migranten en van oorsprong Nederlandse patiënten voor wat betreft de toegang tot zorgbehandeling, symptoomprofielen en het vertrouwen in de zorgbehandeling ?
- B. Verbetert een cultureel aangepaste depressie- en angstbehandeling de effectiviteit van de behandeling en behandeltrouw?

In dit laatste hoofdstuk vatten wij de belangrijkste resultaten samen van de onderzoeken (**hoofdstukken 2-6**) en bespreken wij deze resultaten. In aanvulling daarop zullen

beperkingen en sterke punten van methodologie worden beschouwd. Tot slot zullen onze bevindingen worden geïntegreerd en implicaties van de resultaten en toekomstige aanwijzingen voor onderzoek en behandelingsbeleid worden besproken.

## **Belangrijkste bevindingen**

### ***Etnische verschillen in gespecialiseerde depressie- en angstbehandeling***

Deel A van de dissertatie richt zich op de etnische verschillen in het ondergaan van gespecialiseerde depressie- en/of angstbehandeling. Eerst hebben wij etnische verschillen in de toegang tot de angst- en/of depressiebehandeling van een Amsterdamse polikliniek onderzocht (**hoofdstuk 2**). Ten tweede hebben wij etnische verschillen in symptoomprofielen en gezondheidsovertuiging van poliklinische patiënten met depressie en/of angststoornissen onderzocht (**hoofdstuk 3**). Ten derde hebben wij verschillen in acculturele status (vaardigheden, sociale integratie, tradities, normen en waarden en gevoelens van verlies) van Marokkaanse, Turkse en Surinaamse migranten in gespecialiseerde poliklinische geestelijke gezondheidszorg alsook de effecten van die verschillen op de behandeluitkomst geanalyseerd (**hoofdstuk 4**).

In **hoofdstuk 2** zijn de etnische verschillen in toegang tot een polikliniek voor depressie- en angstbehandeling onderzocht door de aan- en afwezigheid van de patiënt bij de eerste afspraak te analyseren. Op grond van de literatuur was de veronderstelling dat op het patiëntniveau naast etniciteit ook leeftijd, geslacht, huwelijks staat, het hebben van kinderen, de wachttijd na doorverwijzing en taalproblemen, mogelijke risicofactoren voor het missen van een eerste afspraak zijn. Medische dossiers van 110 poliklinische patiënten van Marokkaanse of Turkse afkomst en van 110 gepaarde dossiers van autochtone patiënten werden geselecteerd uit een lijst van verwijzingen. In totaal misten 44 patiënten (20%) de eerste afspraak. Van dit aantal waren 34 (31%) migranten patiënten tegen 10 (9%) autochtone patiënten. Etniciteit bleek de enige significante factor. Na herhaalde uitnodigingen voor een eerste afspraak werden de percentages gereduceerd tot 13% voor de migrantenpatiënten en 3% voor de autochtone patiënten. De door ons gevonden aantallen en percentages van gemiste eerste afspraken bleken bescheiden vergeleken met de in andere, internationale, studies gevonden aantallen en percentages van afwezigheid. In Nederland hebben Korrelboom en collega's (Korrelboom et al., 2007) vergelijkbare aantallen gemiste afspraken gevonden als in ons onderzoek, met etniciteit als determinant. In ons onderzoek bleken herhaalde uitnodigingen een

effectieve remedie, al bleef een etnisch verschil bestaan. Ons onderzoek bevestigde dat er terecht zorgen bestaan over etnische verschillen met betrekking tot de toegang tot gespecialiseerde geestelijke gezondheidszorg en dat dit een aandachtspunt moet zijn binnen de geestelijke gezondheidszorg voor migranten.

In **hoofdstuk 3** onderzochten wij etnische verschillen in symptoomprofielen en gezondheidsovertuiging. Poliklinische patiënten van Turkse of Marokkaanse achtergrond (N=54) werden naar leeftijd en geslacht gepaard aan van oorsprong Nederlandse poliklinische patiënten (N=108). Poliklinische patiënten met een Turkse of Marokkaanse achtergrond hadden een lagere score op de ernst van depressie, maar de scores naar de ernst van de angststoornis waren hoger dan die bij autochtone poliklinische patiënten. Scores op pijnintensiteit en onvermogen door pijn waren significant hoger in de migrantengroep. Verder bleek in de migrantengroep functioneel onvermogen voor wat betreft communicatie, mobiliteit, zelfzorg en participatie significant meer uitgesproken te zijn, terwijl het vertrouwen in therapeuten en de zorg door vrienden significant lager was. Deze uitkomsten wijzen er mogelijk op dat de gewone behandeling van veelvoorkomende psychiatrische stoornissen expliciet meer gericht moet zijn op angstklachten, ernst van en onvermogen door pijn en functioneel onvermogen in deze migrantengroepen. Ook dient voor en na doorverwijzing meer aandacht te worden gegeven aan de mening van de patiënt over de gespecialiseerde zorg en aan hun vertrouwen in de aangeboden zorg.

In **hoofdstuk 4** zijn aspecten van acculturele status (vaardigheden, sociale integratie, tradities, normen en waarden en gevoelens van verlies) onderzocht in een longitudinaal cohortonderzoek, waarin gegevens zijn benut afkomstig uit Routine Outcome Monitoring (ROM) gegevens van Marokkaanse, Turkse en Surinaamse migranten die werden behandeld in poliklinieken van gespecialiseerde geestelijke gezondheidszorg. Ook werd de relatie tussen acculturatiestatus en niveaus van symptomen, kwaliteit van leven, zorgbehoefte en behandel-effectiviteit geanalyseerd. De status van acculturatie verschilde tussen de drie etnische groepen. Turkse migranten lieten het meeste culturele behoud zien (tradities, normen en waarden). Surinaamse migranten toonden het hoogste niveau van integratie (vaardigheden, sociale integratie), terwijl Marokkaanse migranten zich tussen deze twee groepen bevonden. Het hogere niveau van culturele aanpassing was gerelateerd aan een minder grote zorgbehoefte, lagere symptoomniveaus en een hogere kwaliteit van leven. Participatie voorspelde op significante wijze een lagere score op symptomen en een hogere score voor kwaliteit van leven, zes maanden na de start

van de behandeling. Het onderzoek bevestigt dat acculturatiestatus invloed heeft op symptoomniveaus, kwaliteit van leven en waargenomen zorgbehoefte van migranten. Bovendien leek participatie een positieve invloed op het behandelingsresultaat te hebben.

Samengevat zijn de voornaamste bevindingen in sectie A:

- Turkse en Marokkaanse patiënten misten significant vaker de eerste afspraak in een polikliniek voor gespecialiseerde depressie- en angstbehandeling, vergeleken met autochtone patiënten.
- Migrantepatiënten vertoonden ernstiger angststoornissen, minder ernstige depressie, meer functionele beperkingen, hogere mate van pijnintensiteit en onvermogen door pijn en minder vertrouwen in therapeutische zorg vergeleken met autochtone patiënten.
- Acculturatieniveau beïnvloedt symptoomniveaus, kwaliteit van leven en waargenomen zorgbehoefte van migranten. Participatie in de Nederlandse samenleving lijkt een positieve factor voor het behandelingsresultaat.

### **Effectiviteit van cultureel aangepaste zorg van voorkomende geestelijke stoornissen**

In het tweede deel (B) van de dissertatie is de effectiviteit van culturele aanpassingen die zijn toegevoegd aan behandelingsrichtlijnen voor depressie en/of angststoornis in gespecialiseerde geestelijke gezondheidszorg onderzocht. Ten eerste is in **hoofdstuk 5** de literatuur over effectiviteit van cultureel aangepaste behandelingen van depressie en angststoornissen onderzocht. Ten tweede hebben wij in **hoofdstuk 6** de opzet van een gerandomiseerde gecontroleerde studie (RCT) met controlegroep beschreven waarin wij het effect wilden onderzoeken van een culturele competentie-module voor therapeuten op behandelingsuitval in twee Amsterdamse poliklinieken. Deze module voor therapeuten was toegevoegd aan de behandelingsrichtlijn voor depressie en angststoornissen. Ten derde hebben wij de resultaten van dit gerandomiseerde en gecontroleerde onderzoek in **hoofdstuk 7** geanalyseerd.

In **hoofdstuk 5** is de empirische literatuur over de effectiviteit van cultureel aangepaste en op richtlijnen gebaseerde behandelingen voor depressie en angststoornissen systematisch geëvalueerd. Er zijn negen gerandomiseerde en gecontroleerde onderzoeken

geïdentificeerd die in aanmerking kwamen. Deze onderzoeken zijn allen in de Verenigde Staten (VS) uitgevoerd. In alle onderzoeken was een focus op culturele waarden en overtuigingen te identificeren als een belangrijke factor van culturele aanpassing. Het gepoolde effect op de klinische uitkomsten was significant 1.06 (95% CI 0.51-1.62,  $p < .00$ ). Twee van deze onderzoeken lieten een significant gepoold effect zien van culturele aanpassing per se (95% CI 0.22-1.14,  $p < .00$ ) omdat deze onderzoeken een cultureel aangepaste en op richtlijnen gebaseerde behandeling vergeleken met niet aangepaste op richtlijnen gebaseerde behandeling. De andere zeven onderzoeken vergeleken cultureel aangepaste en op richtlijnen gebaseerde poliklinische depressie en/of angstbehandeling als geheel met controlecondities zoals wachtlijsten of andere behandelingen, zoals spierontspanningsoefeningen. Of het gevonden effect in deze zeven onderzoeken was te herleiden tot de culturele aanpassing per se bleef onbevestigd. Dat betekent dat er enig bewijs is dat in het voordeel spreekt van het effect op het klinische resultaat door de culturele aanpassing. Hoewel de culturele aanpassingen zoals toegepast in de geëvalueerde onderzoeken niet allemaal relevant zijn voor de Nederlandse onderzoekspopulatie en de etnische achtergronden van de onderzoekspopulaties uit de VS-studies verschillen van de Nederlandse migrantenonderzoeksgroepen, zijn veel onderwerpen meer algemeen toepasbaar. Het resultaat bemoedigt en benadrukt de noodzaak voor vergelijkbare trials buiten de VS.

In **hoofdstuk 6** beschreven wij het ontwerp van de RCT waarin wij wilden testen of een culturele competentie-module voor therapeuten, toegevoegd aan de behandelingsrichtlijn voor depressie en angststoornissen, effectief bleek in het verminderen van de uitval van behandeling van migranten. In **hoofdstuk 7** beschreven wij de resultaten van de aangepaste RCT. De reden voor de aanpassingen was met name de lage respons voor deelname aan een interview. Om deze reden is ervoor gekozen om een behandeldossier-analyse uit te voeren. 220 volwassen Turkse en Marokkaanse poliklinische patiënten die waren verwezen naar deze poliklinieken voor angst- en/of depressiestoornissen namen deel aan dit onderzoek. Zij werden gerandomiseerd toegewezen aan therapeuten van de genoemde poliklinieken die in een culturele module waren getraind en aan therapeuten die niet waren getraind in deze culturele module.

Meerdere mogelijke determinanten voor het resultaat werden zes maanden na de eerste intakesessies onderzocht. Er werden geen significante verschillen in behandeluitval tussen de interventiegroep en de controlegroep aangetroffen (21% tegen 12%,  $\chi^2$ -kwadraat 3.27,  $p = .07$ ), ook niet voor het niet verschijnen of een gemiste afspraak. De

uitval was verrassend genoeg hoger in de interventiegroep dan in de controlegroep. Dat betekent dat wij niet hebben kunnen aantonen dat de culturele competentietraining voor de therapeuten de kans op behandeluitval en het niet verschijnen op de afspraak vermindert. In het algemeen leek de behandeluitval in beide groepen gematigd vergeleken met andere onderzoeken, waaronder ook onderzoeken met een breder perspectief, waarin niet specifiek naar migranten werd gekeken (Arnou et al., 2007; Tarricone et al., 2010). Desalniettemin viel een aanzienlijk deel van de onderzochte populatie uit. Verrassend genoeg voorspelden taalproblemen een lagere uitval in beide groepen. Andere bevindingen waren: een lange wachttijd na intake tot de start van de behandelingen (psychotherapie en/of medicatiebehandeling), gemiddeld genomen 10-14 weken wachttijd, een lage frequentie therapiecontacten (gemiddeld genomen 4 tot 5 sessies psychotherapie of medicatiebehandeling over een periode van zes maanden), en dat patiënten vaak slechts één stap van het medicatieprotocol werd aangeboden. De vraag blijft in welke mate deze bevindingen zijn toe te schrijven aan organisatorische problemen in de klinieken of aan patiëntgebonden factoren.

Samengevat zijn de bevindingen in onderdeel B dat:

- cultureel aangepaste en richtlijngebaseerde angst- en/of depressiebehandelingen een positieve invloed hadden op de klinische resultaten voor migranten in de VS (**hoofdstuk 6**).
- een positief bijkomend effect van de culturele aanpassing van behandelingsrichtlijnen voor depressie en/of angst niet kon worden aangetoond. Er werd geen significant verschil van behandeluitval gevonden tussen de interventiegroep en de controlegroep (**hoofdstuk 7**)

## **Beschouwing**

De bevindingen in deze dissertatie kunnen bijdragen aan het verkrijgen van enkele inzichten in het behandelproces en de symptoomprofielen van Marokkaanse en Turkse poliklinische patiënten die zijn verwezen naar gespecialiseerde depressie- en/of angstbehandeling. Voor zover wij weten werd voor de eerste keer de effectiviteit van cultureel aangepaste depressie- en angstbehandeling onderzocht in een Europese situatie. Deze dissertatie toont ook aan hoe moeilijk het is een onderzoek van hoge kwaliteit uit te voeren in een niet-academische behandelsetting met deze onderzoekspopulatie. Alle

resultaten van deze dissertatie bij elkaar genomen, en in ogenschouw nemend dat samen met de kennis dat de groep Marokkaanse en Turkse inwoners met depressie en angstklachten toeneemt, doet ons ervoor pleiten dat meer onderzoek nodig is op het gebied van depressie- en angstbehandeling. Dit onderzoek zal met name gericht moeten zijn op de meest kwetsbare patiënten met een laag acculturatieniveau met als doel de behandeltrouw en behandeluitkomst te verbeteren en zo chronische problematiek en beperkingen te voorkomen.

Onze studie heeft duidelijk gemaakt dat gespecialiseerde zorg voor migranten wel beschikbaar is, maar dat extra inspanningen nodig zijn om de toegang tot deze zorg en het behandelproces te verbeteren. Een mogelijke eerste stap is extra aandacht te besteden aan het vertrouwen in de geestelijke gezondheidszorg en de aanmeld- en intakeprocedure te verbeteren. Daarnaast is een goede samenwerking met de eerstelijnszorg, zoals de huisarts en de sociale wijkteams, van belang indien er sprake is van complexe problematiek. Ook lijkt het zinvol meer intensieve richtlijnbehandeling te bieden in de gespecialiseerde zorg. Met betrekking tot onderzoek is het aan te bevelen andere methoden dan een gerandomiseerde gecontroleerde studie en interviewmethodes te verkennen om waardevolle klinische informatie over deze migrantengroepen te kunnen verzamelen. In lijn met het hedendaagse beleid zouden instellingen voor geestelijke gezondheidszorg manieren moeten vinden om migrantengroepen meer te laten participeren en te betrekken binnen de organisatie met als doel beter aansluitende zorg voor deze groepen te ontwikkelen.



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