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Chapter 1

Introduction

Since the final decades of the twentieth century, western mental healthcare has been confronted with growing numbers of patients from non-western ethnic minority groups. Prevalence of common mental disorders among these groups is high (De Wit et al., 2008; Liddle et al., 2006; Selten et al., 2012), which has given rise to serious concerns about the extent to which access to care, treatment adherence and treatment outcome of these groups in specialised mental healthcare are sufficiently guaranteed (Blom et al., 2010; Fassaert et al., 2010; Struijs & Wennink, 2000).

Currently, a substantial part of the population of the Dutch capital Amsterdam consists of citizens with a Turkish or Moroccan background. Many minority groups reside in the areas Amsterdam Nieuw-West and Amsterdam Oost (see Table 1.1).

The objective of this dissertation is to establish whether the concerns about migrants in Amsterdam who use specialised mental healthcare because they suffer from depression and/or anxiety problems are justified. To improve our understanding of ethnic disparities and similarities in specialised mental healthcare, we analysed several aspects, such as missed initial appointments, outpatient problem presentation and health beliefs, the influence of acculturation levels upon need of care, quality of life, and treatment effect.

We also aim to assess whether an intercultural module for therapists can positively contribute to the prevention of treatment dropout of Turkish and Moroccan migrant outpatients with depressive and anxiety disorders.

Migrants in the Netherlands

The non-western migrant population living in the Netherlands mainly consists of citizens with a Turkish, Moroccan, Surinamese, or Antillean background (see Table 1.2). In this

Table 1.1 Major migrant groups in Amsterdam in 2012

Ethnic group Amsterdam area	Moroccan		Turkish		Surinamese/ Antillean		Indigenous Dutch		Total Amsterdam population
	N	%	N	%	N	%	N	%	N
	Nieuw-West	28,383	20	17,597	13	11,413	8	53,096	38
Oost	12,777	10	6,078	5	11,287	9	63,276	52	122,275
Amsterdam total	71,460	9	41,519	5	80,429	10	390,813	49	790,044

O + S Amsterdam 2012

Table 1.2 Major migrant groups in the Netherlands within a total Dutch population of 16,730,348 in 2012

Migrant group and generation	Moroccan		Turkish		Surinamese/ Antillean		Total migrants in the Netherlands
	N	%	N	%	N	%	N
First generation	168,214	9	197,107	11	82,693	5	1,772,204
Second generation	194,740	11	195,816	11	61,299	4	1,721,989
Total	362,954	10	392,923	11	143,992	4	3,494,193

CBS: <http://statline.cbs.nl/StatWeb/publication>

dissertation, we focus on the two largest groups: the first and second generations of Turkish and Moroccan (guest) migrant workers.

Since the 1960s, the first generation of (male) workers migrated from predominantly Morocco and Turkey to western countries for economic reasons, with the intention to stay temporarily. The migrants who came to the Netherlands mostly settled in urban areas like Amsterdam, Rotterdam, The Hague or Utrecht. Instead of remigration, as originally intended, most migrants prolonged their stay, and eventually, their families joined them. As these migrants mostly performed manual and unskilled labour, on average their socio-economic status compared unfavourably to that of the indigenous Dutch population.

Nowadays, it is acknowledged that the successive generations of these migrants are here to stay. The fact that their socio-economic and educational levels lag behind in comparison to the indigenous Dutch population (Dagevos & Gijsbers, 2012; Huijink & Dagevos, 2012) causes concerns about the integration and development of these migrant groups. Currently, most of these migrants have Dutch citizenship, often in addition to a Turkish or Moroccan nationality. As a result, they are entitled to make use of, and have access to, all social arrangements (Brocker, 2000; Nelissen & Buijs, 2000).

In the Netherlands, a commonly used term to refer to these groups is the term 'migrant'. The exact definition of this term varies, depending on the generation to which it refers. The defining criterion for the first generation of migrants is based on their country of birth; for the second generation, the defining criterion is the country of birth of at least one of their parents (2012). The alternative terms 'cultural minorities' or 'ethnic minorities' are often used in international literature. Culture includes norms, beliefs and values which influence the way a person perceives, interprets and copes (Stronks et al., 2013). Ethnicity

refers to country of birth and to other aspects, such as religion, traditions, language, culture, history, and social background to which a person or a group feels attached (Suurmond et al., 2007; Kortman, 2006). All these terms are used in this dissertation, but in our Amsterdam studies, we have chosen to use the term 'migrant'. We have chosen to use the term 'indigenous Dutch' to refer to the Dutch native population, meaning those whose parents were both born in the Netherlands.

To summarize: Turkish and Moroccan migrants are the largest migrant groups in the Netherlands. The level of integration and the socio-economic status of the Turkish and Moroccan migrant groups tend to be low. Commonly used terms for these groups, also used in this dissertation, beside 'migrants' are 'ethnic or cultural minorities groups'.

Depression and anxiety in the general Western context

Depression and anxiety have a high prevalence in the general world population (Patel & Prince, 2010; Prince et al., 2007; Vos et al., 2012). The lifetime prevalence in the overall Dutch population amounts to 20.1% for depressive disorders and 19.6% for anxiety disorders (De Graaf et al., 2012). In the Netherlands, depressive and anxiety disorders are not only in the top five of disease burdens, but also in the top ten of most expensive disorders. In Amsterdam, 7.4% of the population suffer from severe depression and/or anxiety problems, and 39% suffer from moderate or mild problems (according to the GGD Amsterdam health monitor 2012). In the literature, anxiety and depressive disorders are also referred to as 'common mental disorders' (CMDs).

According to DSM-IV (American Psychiatric Association, 2001), depression is defined as: 'feeling down and gloomy or experiencing a severe loss of interest and pleasure in normally enjoyable activities most of the day for at least two weeks. When these criteria are met and there are at least three or four additional symptoms (such as eating problems, major change in weight, insomnia, loss of energy, feelings of restlessness or inhibition, melancholy, feeling useless/ worthless, feelings of guilt, and recurrent suicidal thoughts) a major depressive disorder (MDD) or unipolar disorder may be present' (American Psychiatric Association, 2001).

Anxiety Disorders can be subdivided into a number of disorders, whose primary overlapping feature is abnormal or inappropriate anxiety. The anxiety symptoms become a problem when they occur without any recognizable stimulus or when the stimulus does

not warrant such an extreme reaction. In DSM-IV, anxiety disorders can be subdivided into panic disorder, generalized anxiety disorder, specific phobia (including social phobia), obsessive-compulsive disorder, posttraumatic stress disorder and acute stress disorder. The classification of anxiety disorders has changed considerably in DSM-5. As the studies reported in this dissertation were conducted using DSM-IV, we have chosen to use the DSM-IV classification throughout this dissertation.

The most prevailing anxiety disorders in the general population are:

- *Panic disorder*, characterized by sudden anxiety attacks, accompanied by bodily symptoms like gasping for breath, cardiac palpitation, chest pain, nausea, dizziness, shivering, trembling, sweating, cold tremors, or tinglings. Patients with a panic disorder often have feelings of derealisation (the outer world appears unreal) and depersonalization (living outside the body/mind like in a dream), and they sometimes avoid situations or places in which they have experienced attacks before or that seem arousing/provoking (also known as agoraphobia). Agoraphobia also exists without panic disorders; persons only exhibit a fear of getting panic-like symptoms, and they avoid crowds or situations from which one cannot escape (crowded situations in shops, public transport, driving through tunnels), without actually experiencing a panic attack.
- *Generalized anxiety disorder* is characterized by continuously pondering about daily worries such as work, finance, health and shelter, without any concrete immediate cause. The bodily symptoms include fatigue, concentration problems, irritability, dry mouth, cardiac palpitations, aching muscles, sweating, swallow complaints, diarrhoea, and faint view.
- *Specific Phobia (including Social Phobia)* symptoms include extreme anxiety and fear, either associated with the object or with the situation that is avoided. Fear of eating, writing and speaking in public or being in the middle of attention in general is called social phobia and is often accompanied by panic-like bodily symptoms. To be diagnosed, the symptoms must disrupt everyday functioning (American Psychiatric Association, 2001).

Comorbidity levels of depressive and anxiety disorders are high: of all those who have a depressive disorder, about 60% also suffer from an anxiety disorder, and comparable prevalence rates are found for those with anxiety disorders as well as depressive disorders

(Kendler et al., 1993; Kessler et al., 2005). Persons with these mental disorders run a high risk of developing an anxiety disorder with a chronic course, and the disorder is likely to have a serious impact on their physical, social and occupational functioning (Ormel et al., 2008; Hoffman et al., 2008; Judd et al., 2005) Chronic depressive and anxiety disorders constitute a large burden to society (Hoffman et al., 2008; Lopez et al., 2006).

To summarize: depression and anxiety disorder or CMD prevalence are high in general populations. The most prevailing anxiety disorders in the general population are *Panic disorder*, *Generalized anxiety disorder*, and *Specific Phobia (including Social Phobia)*. Comorbidity levels of depressive and anxiety disorders are high as well.

Ethnic diversity in depression and anxiety prevalence: theoretical frameworks

As mentioned before in this dissertation, it was found that non-western minority groups living in western countries run a higher risk of developing common mental disorders (CMD) than indigenous groups (Carta et al., 2005; Bhugra, 2003; Kessler et al., 2009; Breslau et al., 2011). Table 1.3 shows depression and anxiety rates of Amsterdam citizens (self-registration with K10) (Donker et al., 2010) from several countries of origin. Various models exist that can help to explain this higher risk of CMD. According to the vulnerability-stress model (Brown & Harris, 1978 Routledge NY) (Kendler et al., 1993), at least 40% of the vulnerability for CMD has a genetic origin. However, the actual onset of depression and anxiety is triggered by genetics in combination with a stressful social environment. Migration is one such stressful event that can cause feelings of loss. A connecting theory with the vulnerability-stress model is the learned helplessness theory (Seligman, 2014),

Table 1.3 Rates of severe depression and/or anxiety problems among adult citizens (19+), based on country of origin, 2012

Amsterdam citizens (country of origin)	Severe depression and/or anxiety problems (K10) %
Dutch	3.7
Turkish	24.9
Moroccan	16.6
Surinamese	8.5
Other non-western country	10.3

Amsterdam municipal health monitor 2012

which explains that successive negative and less successful experiences can trigger CMD in migrants. Bhugra and Jones (Bhugra & Jones, 2001) describe three stages of migration to illustrate the substantive influence of migration on mood disorders. The following stages can be distinguished. The first one is the pre-migration stage, in which someone plans to leave their country of origin for economic reasons (the most occurring reason within the scope of this dissertation), or for marriage and family reunion. The second stage is the migration itself from a non-western country or area to a western country, and most often to an urban environment. The third migration stage is when the migrant has to deal with the social and cultural framework of the host society. For migrants with low-skilled jobs, all stages can be stressful or experienced negatively. Various aspects have been found that influence the coping ability of migrants during these stages and that can moderate mental health. In epidemiological studies it was found that depression or anxiety in ethnic minority groups are associated with characteristics such as genetics, culture, gender (Sieberer et al., 2012), language proficiency (Takeuchi et al., 2007), host-country policies (Stafford et al., 2011), educational levels, socio-economic status, and acculturation levels (Yoon et al., 2011; Bhugra, 2003; Bhugra & Mastrogianni, 2004; Bhugra & Arya, 2005; Fassaert et al., 2011). Acculturation can be defined as one's adaptation to life in a new cultural environment. It can be conceptualized in several ways. For example, the domains of acculturation can be subdivided into participation in the new society through skills and/or social integration, through cultural maintenance or loss of traditions, and through adapting to norms and/or values. All these domains are associated with psychological distress (Mooren et al., 2001; Fassaert et al., 2011). These characteristics, combined with risk factors such as physical, behavioural, psychosocial, or biological factors, influence health (Stronks et al., 2013). It seems fair to assume that accumulation of risk factors and stressful events can lead to CMD. These risk factors, combined with migration and loss, also known as 'condición migrante', would thus increase the CMD risk for migrants, compared to indigenous Dutch citizens. In this dissertation, the theories mentioned above can help to explain the outcome of the research.

To summarize: the higher risk for non-western migrants to develop CMD may be explained by theories that take migration and acculturation into account.

Ethnic diversity in diagnostics and problem presentation

Although there is evidence in favour of high prevalence of CMD among migrants, there is discussion about the adequacy of the way psychiatric disorders are currently diagnosed in non-western patients. In epidemiological studies, research results are most often based on studies among western patients. These research results are also used to define criteria for mental health disorders such as CMD. The diagnostic criteria have been described in the psychiatric diagnostic and statistical manual (DSM-IV) and, since 2013, in the DSM-5. Although the DSM-5 has integrated several cultural aspects and idioms of distress, these manuals are nonetheless criticized for their universalistic medical assumptions (Mezzich et al., 1999; De Jong, 2012). It remains contentious whether the DSM approach is appropriate for diagnosing non-western patients. The use of these criteria can result in not recognizing CMD in migrants by care professionals because of differences in problem presentation, illness narratives or explanatory model and behaviour (Kleinman, 1988). An example is the assumption that non-western migrants are more prone to somatising their distress. Somatic symptoms serve as cultural idioms of distress in many ethno-cultural groups (Ulusahin et al., 1994). Turkish and Moroccan migrants are also known to focus on somatic symptoms in cases of mental health problems (Ebert & Martus, 1994; Levecque et al., 2007; Spijker et al., 2004). Cultural differences in problem presentation, in combination with often complicated doctor-patient communication due to language problems or educational disadvantages, decreases the probability that mental health problems are reported or identified as specifically mental during a General Practitioner consultation (Stronks et al., 2001; Meeuwesen et al., 2006; Claassen et al., 2005).

To summarize, there are discussions and concerns about the adequacy of the most often used DSM criteria for diagnosing non-western patients with mental health problems, through which symptoms can be misinterpreted, or be overlooked altogether.

Ethnic differences in access to specialised mental health care

Dutch healthcare is organised as a referral system. General Practitioners (GP's) act as gatekeepers: they have to recognize a potential CMD, and may subsequently refer to specialised mental healthcare (Verhaak et al., 2004). If the GP recognizes the mental health problem and refers to specialised mental healthcare, the task of specialised mental health services is to diagnose and treat more complex (common) mental disorders. Goldberg and Huxley designed a filter model in which aspects of pathways through healthcare

are roughly illustrated (Figure 1.1). Most western patients are familiar with this system, but non-western ethnic patients often lack knowledge of the way the mental healthcare system is organised. In 2001, the Dutch Council for Public Health and Healthcare (Raad voor Volksgezondheid en Zorg, RVZ) implemented a special taskforce in order to improve accessibility and quality of healthcare services for migrants (Olthuis & van Heteren, 2003). For access to mental healthcare, this migrant policy already seemed effective for migrants with chronic mental problems in Amsterdam (Schrier et al., 2005). Furthermore, there is evidence that Turkish and Moroccan migrants seem to be well represented in Dutch general practice (Uiters et al., 2006; Stronks et al., 2001). However, so far, little is known about the differences in access to specialised mental healthcare for migrant outpatients with CMD and possible differences of adherence during their treatment period in the Netherlands. One study that was conducted among the population of Amsterdam found evidence for minor ethnic differences in uptake in specialised mental health care (Fassaert et al., 2009b). However, another Dutch study showed a significant high missed intake outcome rate among migrant patients, compared to indigenous Dutch patients. Therefore, concerns still exist (Korrelboom et al., 2007). An explanation for frequent intake no-show is the possible resistance of non-western patients towards western-oriented mental health treatment because of the fear of stigmatization within their own ethnic group or family (Gary, 2005; Bhui et al., 2012; Bhui et al., 2006; Knifton et al., 2010). Another explanation might be that many migrants possibly have limited,

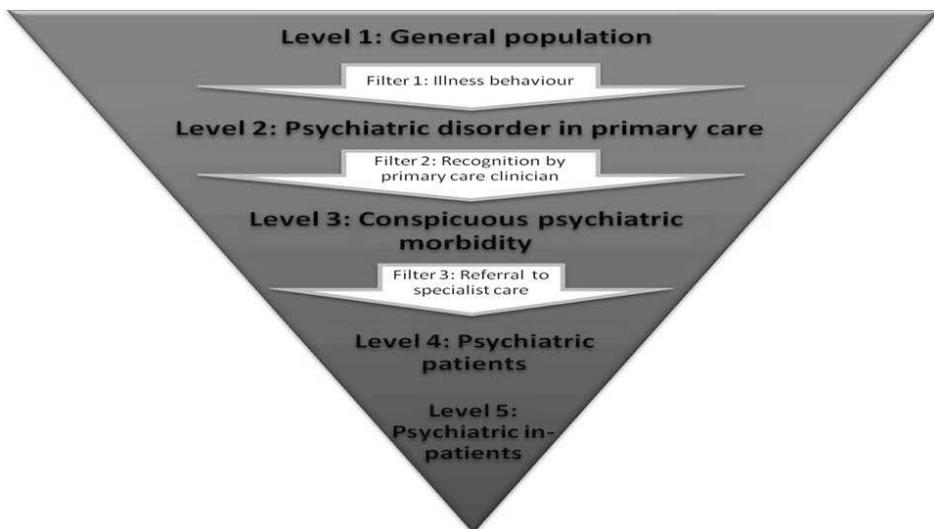


Figure 1.1 The filter model for psychiatric problems and care (Goldberg & Huxley, 1992).

vague, or negative expectations of the potential benefits of mental health treatment, and they may doubt the prudence of investing in it.

Beside the GP and the patients, a third important partner in the referral and access procedure is the mental healthcare institute itself. The question is whether the invitation and intake procedure fits the migrant patients in general as well as it fits indigenous Dutch patients. Until now, little is known about this area of research.

To summarize: The prevalence of depression and anxiety problems among more vulnerable non-western migrant patients is high, and there are ethnic differences in access to care. However, so far, little is known about the access differences in specialised mental health care for migrant outpatients with CMD. More research at the level of specialised mental healthcare is therefore needed.

Ethnic differences in specialised mental health treatment, adherence, and clinical outcome

Over the past three decades, there has been an increased focus on empirical information regarding treatment development, efficacy, or effectiveness of the effort to achieve uniformity in improving care to a broad base of clients in western mental healthcare. Several forms of psychotherapy and pharmacotherapy have been proven effective, and they provide the basis for guideline-based treatments for depression and anxiety disorders (Multidisciplinary Guideline Depression 2013 and Multidisciplinary Guideline Anxiety Disorders 2010). The most studied guideline-based psychotherapy treatment options for depression in western mental health research are: problem solving treatment (PST), cognitive behavioural treatment (CBT), and interpersonal psychotherapy (IPT). One major point of criticism, in line with the point of criticism on the DSM, is that these treatments are mostly based on outcomes of research that was conducted among western patients. Notwithstanding these restrictions, several USA studies have shown that guideline-driven IPT, PST and CBT for depressed patients were also applicable to ethnic minority patients, such as Asian, as well as to Latin and African Americans (Areal et al., 2005; Joo et al., 2010; Schmalings & Hernandez, 2008; Munoz & Mendelson, 2005). A Dutch study showed an effectiveness after IPT treatment completion for ethnic minority patients (n=35) (Blom, 2007) that was comparable to the results for indigenous Dutch patients. There are several small CBT studies for PTSD patients in which effectiveness for ethnic minority patients is shown (Kubany et al., 2004; Paunovic & Ost, 2001; Zoellner

et al., 1999). Nevertheless, worries remain whether ethnic minority patients are offered these guideline-based mental health treatments as often as indigenous Dutch. In a USA study it was found that African and Latin American patients were 50% less likely to receive psychotherapeutic treatments than White Americans (Simpson et al., 2007). In two other studies it was found that in cases where psychotherapy treatments were offered, dropout rates for ethnic minority patients with depressive disorders were higher (Blom et al., 2010; Organista et al., 1994) compared to indigenous Dutch patients (Brown et al., 1999; Fassaert et al., 2009a). Several studies showed improved adherence among ethnic minority patients when more intensive treatments were offered. In the case of additional clinical case management, Miranda et al showed a dropout reduction for CBT treatment for ethnic minority patients (Miranda et al., 2003; Miranda et al., 2006). It also turned out that collaborative depression care, consisting of both antidepressant medication and psychotherapy, resulted in significant lower depression severity and health-related functional impairment for patients from ethnic minorities (African and Latin Americans), compared to usual depression care (Areal et al., 2005). Some special provisions were made for these groups, including child support, cost reduction, transport support, bilingual treatment, and information material that had been adjusted to the patients' cultural backgrounds.

When focusing on pharmacotherapy, Bjornsson et al. (Bjornsson et al., 2003) concluded in a review that the available literature on ethnic differences in drug responsiveness was found to be heterogeneous. For example, Roy-Byrne et al. (2005) found little ethnic difference in antidepressant effectiveness in their study, but others did find pharmacokinetic differences among ethnic groups (Tamminga et al., 2001; Lin et al., 2001; Bjornsson et al., 2003). When focusing on medication compliance, ethnic minority patients showed lower compliance rates than majority group patients (Han & Liu, 2005; Blom et al., 2010). Not only is there little knowledge on ethnic differences in drug responsiveness and only some knowledge on adherence, until now, there is also little evidence of the extent to which migrants are offered guideline-driven pharmacotherapy for depression as often as indigenous patients.

To summarize, there is some evidence that guideline-driven depression and anxiety treatment is applicable for ethnic minority patients. Nevertheless, there are concerns about higher treatment dropout rates. Possibly, more collaborative, intensive and/or adapted treatments can improve treatment adherence. Research is needed to shed more light on this relationship.

Cultural adaptation of mental healthcare

There is considerable evidence that culture and context influence almost every aspect of diagnostics, treatment outcome and patient evaluations of care (Sue et al., 2009; Hernandez et al., 2009; Anderson et al., 2003; Beach et al., 2005; Bhui et al., 2007; Bernal et al., 2009; Betancourt et al., 2003). Although there is some evidence that guideline-driven anxiety and depression treatment is also effective for migrant patients (Ünlü Ince et al., 2014) , there is a call for culturally tailored treatment. One concern about guideline-based treatment is that it can increase the risk of adopting a one-size-fits-all-approach for interventions, and that this is contrary to the aim of personalizing treatment to the need and context of the individual (Bernal et al., 2009; Kirmayer, 2012) An answer to these concerns is cultural competence care, which is meant to enable clinicians to respond appropriately to the cultural backgrounds and social contexts of their clients (Benish et al., 2011). Cultural competence can be established at different levels in health care profession:

- provider and treatment level,
- agency or institution level, and
- system level (for example, systems of care in the community).

In this dissertation, we will focus on the provider and treatment level. At provider and treatment level, several cultural competence trainings for therapists are being developed. Some trainings were developed for a specific ethnic minority patient (sub)group, and some were designed to bridge the cultural gap between therapist and ethnic minority or migrant patients in general. Most of these trainings aim to improve the therapists' cultural knowledge, skills and awareness. Nevertheless, it is doubtful whether simply introducing a method will suffice. Another doubt is whether cultural competency can be distinguished from general treatment competences (Bernal et al., 2009). So far, several randomized controlled trials (RCT) have been conducted, mainly in the USA, resulting in evidence that culturally tailored treatment is more effective. This underscores the need for an RCT, conducted in a European and Dutch clinical setting, to compare culturally adapted CMD treatments.

To summarize: although there is some evidence that guideline-driven anxiety and depression treatment is also effective for ethnic minority patients, there is a call for culturally tailored treatment. Until now, there has been a lack of information about the effectiveness of these tailored treatments in Europe and in the Netherlands.

Outline and aims of the dissertation

In this dissertation we seek to answer two main questions regarding migrants in specialised depression and anxiety outpatient care:

- A. Do ethnic and acculturation differences influence care?
- B. Can culturally adapted treatment improve treatment adherence?

The outline of this dissertation is as follows.

Section A investigates the ethnic differences in specialised mental healthcare access, symptoms, beliefs and treatment results for migrant outpatients. **Chapter 2** examines the ethnic disparities in missed initial appointment rates after referral to secondary care for affective disorders in a comparative study between ethnic Dutch and Turkish and Moroccan outpatients. In **chapter 3**, indigenous Dutch and Turkish and Moroccan outpatients with anxiety and depressive disorders were compared, based on questionnaire outcomes concerning symptom severity, pain, locus of control, disability, and trust in care. In **chapter 4**, migrant patients are compared at acculturation level and associations are analysed with quality of life, perceived need of care, and treatment effect.

Section B explores the effectiveness of culturally adapted treatments for ethnic minority patients with affective disorders. **Chapter 5** reviews the literature on this subject. **Chapters 6 and 7** describe the design and outcome of a randomized controlled trial which aimed to reduce dropout rates of Turkish and Moroccan outpatients with affective disorders in specialised mental healthcare. Finally, in **chapter 8**, the results of chapters 2 to 7 are summarized and discussed, and implications for practice, policy and research are described.

Data sources

Several data sources were used:

- Data from medical files from two clinics of GGZ inGeest and Arkin to investigate access to care and dropout rates, in **chapters 2 and 6**
- Data from the Netherlands Study of Depression and Anxiety (NESDA) to investigate symptom profiles and trust in care, in **chapter 3**

- Routine Outcome Monitoring (ROM) of Arkin to investigate the association between acculturation and treatment effectiveness, in **chapter 4**
- A literature review to investigate the effectiveness of culturally adapted specialised depression and anxiety treatment, in **chapter 5**

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