The role of cultural background in diagnosing psychotic disorders: Misclassification of psychiatric symptoms in Moroccan immigrants in the Netherlands
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Chapter 6

General Discussion
The focus of this thesis is on the impact of cultural sensitive assessment of psychiatric symptoms to assess psychotic disorders and in particular schizophrenia in two generations of Moroccan immigrants in Utrecht, the Netherlands. The overall theme is culture based misdiagnosis as a potential bias in the frequently reported high rates of schizophrenia among Moroccan immigrants in The Netherlands.

6.1. Main findings

In chapter 2, we examined the procedural validity of a standardized instrument for the diagnosis of psychotic disorders in Morocco. For this purpose twenty nine patients from Casablanca, Morocco, with a psychotic or mood disorder were examined using the Comprehensive Assessment of Symptoms and History (CASH) and an adapted version using cultural formulations to make the instrument more culturally sensitive (CASH-CS). Chance corrected agreement was calculated between diagnoses based on these two versions of CASH and independent clinical diagnoses according to local psychiatrists. Interestingly, agreements for the standard CASH versus clinical diagnosis and for the standard CASH versus the CASH-CS were low but agreement between CASH-CS and clinical diagnosis was good. Particularly our study showed that the traditional CASH interview seems to be sensitive but not to be very specific for the assessment of positive symptoms of psychosis and may therefore give rise to false positive diagnoses of psychosis and to an overestimation of psychotic illnesses in epidemiological studies among Moroccan patients. We therefore concluded that standard instruments for the assessment of psychosis such as the CASH may be liable to cultural misinterpretations. These findings are relevant considering the various attempts to interpret the high incidence rates of schizophrenia among immigrants. The study shows that excluding cues about the cultural background of the patient, as applied as a method to exclude cultural bias by some authors (Selten et al., 2001; Fearon et al., 2006), may itself constitute a source of ethnic/cultural bias. More attention and informed interpretation of the emotional language of the patient is a crucial element in reaching a valid diagnosis in future epidemiological studies about the incidence of schizophrenia among various groups of immigrants.

In chapter 3, we presented the results of our incidence study of schizophrenia among Moroccan immigrants and native Dutch people in Utrecht, the Netherlands. We compared the risk of schizophrenia and other psychotic disorders among treatment seeking Moroccan and native Dutch patients using a standard semi-structured interview (CASH) and an adapted
version of the same instrument based on the principles of cultural formulation (CASH-CS). The overall observed risks of a first contact with the mental health services because of a suspected psychotic disorder of all psychotic disorders and of schizophrenia according to the CASH was significantly higher among Moroccans compared with the ethnic Dutch population (psychosis: RR=7.9; schizophrenia: RR=7.8) and these relative risks were even higher than the ones reported in a previous incidence study in the Netherlands by Selten and colleagues (Selten et al., 2001): psychotic disorders RR=4.8 (CI 95% 3.1-7.5); schizophrenia RR=5.0 (CI 95% 2.8-8.9). However, in our study, the RR for broadly defined psychosis was substantially attenuated when a culturally sensitive diagnostic procedure was applied (CASH-CS) but remained statistically significant (RR=7.9 → RR=4.2), whereas the RR for schizophrenia became non-significant (RR=7.8 → RR=1.5). Our conclusion was that first contact incidence of schizophrenia in Moroccans is similar to that among ethnic Dutch people when a cultural sensitive diagnostic procedure is applied and that the results of studies failing to take into account cultural issues in the diagnostic procedure should be seriously questioned.

It is important to note that broadly defined psychosis in our study included schizophrenia, schizophreniform disorder, schizoaffective disorder, delusional disorder, brief psychotic disorder, psychotic disorder not otherwise specified and also major depression or bipolar disorder with psychotic features.

Fifty-eight percent of Moroccan and 86% of Dutch native participants with a possible psychotic disorder (cases that where referred to the central reporting office with suspected signs of psychosis during the observation period) were diagnosed to have one of the psychotic disorders based on the CASH, and 15% of the Moroccan patients and 59% of the native Dutch participant with a possible psychotic disorder received a diagnosis of schizophrenia according to the CASH-CS. Non-psychotic Moroccan patients according to the CASH-CS were diagnosed with a mood disorder without psychotic features, a factitious disorder or a dissociative disorder. Non-psychotic native Dutch patients were all diagnosed with a non-psychotic bipolar disorder.

Surprisingly during the full inclusion period of 24 months no second generation Moroccan immigrants contacted the central reporting office in Utrecht for a suspected, possible or confirmed psychosis. This was independent of the type of interview used.

In chapter 4, we studied the predictive validity of the culture sensitive diagnostic procedure (CASH-CS) compared to the standard diagnostic procedure (CASH). In the absence of a gold standard to ascertain which of the two diagnostic procedures renders the most “truthful”
results, we had to rely on the results of a follow-up study investigating the possible differences between the two diagnostic procedures in terms of the stability of the diagnoses and in terms of the course and outcome of the disorders over 30 months. All Moroccan participants and an equal number of native Dutch patients were asked to be interviewed approximately two and a half years after the baseline assessment using the follow-up version of the standard diagnostic interview, the CASH-UP, to assess not only the subjects’ level of symptoms but also psychosocial functions, medication use and hospitalization. To prevent considering patients in sustained remission as having “no diagnosis”, the follow-up diagnosis was based on the combination of a structured interview (CASH-UP) and the recorded clinical information during the total follow-up period. Thus, a change in diagnosis from baseline to follow-up could not be attributed only to the (very recent) absence of psychotic symptoms during the follow-up assessment, but took into account the entire illness episode. To the best of our knowledge this is the first follow-up study assessing the impact of a systematic application of the principles of a cultural sensitive diagnosis compared to a standard diagnostic procedure in patients with a possible first episode psychosis.

Diagnostic stability according to the CASH was high for native Dutch (92%) but low for Moroccan patients (27%), whereas diagnostic stability according to the CASH-CS was high for both groups (85% and 81%, respectively). Moroccan patients who were diagnosed with schizophrenia using the standard CASH at baseline had a significantly better 30-month prognosis than native Dutch patients with the same CASH diagnosis. Prognosis of schizophrenia according to the CASH-CS was similar for Moroccan and native Dutch patients. This findings were corroborated by the comparison of the 30-months prognosis of Moroccan and native Dutch patients with a non-schizophrenic disorder at baseline: Moroccan patients showed a somewhat better prognosis than native Dutch patients according to both CASH and CASH-CS. This is remarkable because the Moroccan CASH-CS group with a non-schizophrenic disorder included many patients classified as having schizophrenia according to the standard CASH at baseline.

These findings show that in Moroccan immigrants a cultural specific diagnosis has superior stability and predictive validity compared to a standard, not culturally informed diagnosis. These data raise questions regarding the validity of the standard CASH in Moroccan migrants in the Netherlands and support the validity of the CASH-CS. These findings also confirm our doubts regarding the validity of previous studies showing an increased incidence of schizophrenia in immigrants using standard diagnostic procedures.
In **chapter 5**, we studied whether and how the application of a culture sensitive diagnostic interview (CASH-CS) compared to a standard semi-structured interview (CASH) affects symptom profiles in Moroccan immigrant patients compared to native Dutch patients referred for the first time to a mental health service for a possible psychotic disorder. In this exploratory study, all 26 Moroccan patients and the same number of native Dutch subjects were included and were interviewed twice in random order: once with the standard Dutch version of the (CASH) and once with the CASH-CS. The CASH raters were blind for the ratings of the CASH-CS and vice versa. The data showed that in native Dutch patients, symptoms profiles were very similar for CASH and CASH-CS. In contrast, among Moroccan immigrant patients, symptom profiles for CASH and CASH-CS were very different with more depression symptoms (+23%), more mania symptoms (+30%), less delusions (-31%), and less hallucinations (-23%) using the CASH-CS compared to the CASH. These results suggest that the previously reported overdiagnosis of schizophrenia in Moroccan immigrants with a first psychosis referral (Selten et al., 2001; Veling et al., 2006) are at least partly caused by a failure to recognize mood symptoms and a misinterpretation of stress-related expressions as psychotic symptoms.

### 6.2. Implications

Cultural factors relate to mental illness in several ways. For example, culture determines what is seen as normal and abnormal within a given society. In this study we put special emphasis on the cultural background of patients and the use of the principles of a cultural formulation for a valid evaluation of psychiatric symptoms in ethnic and culturally different populations. This culture-sensitive approach resulted in a substantial attenuation of the difference in the incidence of psychotic disorders and schizophrenia between Moroccan immigrant and native Dutch people and the observed higher rate of schizophrenia in Moroccan immigrants became statistically non-significant. Similar attenuations might have occurred in other studies that failed to (adequately) adjust for possible cultural bias in the diagnostic process. As a consequence, the generally accepted presence of a higher incidence and prevalence of schizophrenia in black immigrants (Saha et al., 2005; Bourque et al., 2011) should be reconsidered and popular explanations should be critically reviewed against this background. However, many studies still continue to use non-validated diagnostic procedures and serious misdiagnosis will remain the rule rather than the exception. In this regard we would like to
quote Ineichen (1991): “until the aetiology of the condition (or conditions) is clarified, and its validity well tested, epidemiological studies remain hazardous”.

The findings of our study may have a serious impact on our thinking about the causes of psychosis and schizophrenia and on the way we treat Moroccan patients with a suspected or possible psychosis.

In the last decade, most studies look at schizophrenia as a multifactorial developmental disorder (Khoury, 1993) with important gene-environment interactions as a crucial mechanism in the development and the onset of the disease (van Os et al., 2003, 2008). How these factors interrelate to cause the clinical symptoms of schizophrenia is mainly unsolved. The authors in this field are often referring to the increased rates of schizophrenia among immigrants. A better understanding of the possible mechanism of the confounding factors and the source of possible misclassification influencing the diagnosis of psychotic disorders may contribute to the answer to the question whether there is a truly increased rate of schizophrenia among immigrants and what this means for future theories on schizophrenia.

The misinterpretation of symptoms may also have serious consequences at the individual patient level, including over-prescription of antipsychotics and under-prescription of antidepressants and mood stabilizers with negative effects on the prognosis in this group. Considering the increasing dissatisfaction of patients from ethnic minorities with the quality of health care, misdiagnosis only adds to this negative attitude and further hampers the therapy process (Saha et al., 1999). This may be partly due to a mismatch between patients and treatment providers based on a range of culturally embedded factors as religion, ethnic background, personal history, the experience of illness and perceptions of health (Steffenson & Colker, 1982). We therefore like to encourage the use of a cultural formulation as a central element in the assessment of the symptoms of psychotic and affective disorders in immigrant patients. Cultural sensitive training and supervision are needed to address the cultural relativity of psychopathological symptoms and syndromes (Whaley, 1997).

Finally, there is evidence of substantial variation between ethnic groups in voluntary and compulsory admissions and more complex pathways to specialist care. However. If there is no increased incidence of psychotic disorders or schizophrenia in (dark) immigrant then there is no objective reason for increases rates of compulsory admissions and there must be seriously worrying practices that are leading to disproportionate levels of compulsory admission” (Patel and Heginbotham, 2007), resulting in underserved restrictions of freedom for migrant patients with a mental disorder.
6.3. Strengths and Limitations

A very important strength of this study is that in this study we assessed for the first time the impact of a systematic application of the principles of cultural formulation in the context of a standardized diagnostic interview. We were able to compare the results of two diagnostic interviews. Despite the absence of a gold standard to ascertain which of the two diagnostic procedures renders the most “truthful” results, we were able to test the validity of each procedure using the results of a follow-up study comparing the stability of the diagnoses and the course and outcome of the disorders over an extended period of time (predictive validity). We therefore consider the absence of a significant difference between Moroccans and native Dutch patients in the treated incidence of schizophrenia according to a cultural sensitive diagnostic procedure as a valid observation. Another strength is that our cohort from Utrecht was highly representative as was shown by another research group that obtained information from the Psychiatric Case Register (Selten et al., 2011; Zandi et al., 2011b).

The limited sample size can be considered as the main limitation of this study and we are aware that no final conclusions can be drawn about the reported incidence rates of schizophrenia among Moroccans and about the significance of the difference in incidence rates between the two ethnic groups. In a larger sample the difference, although seriously attenuated, would probably have been significant. Another limitation is that our analyses were not controlled for possible differences between the ethnic groups in terms of socio-economic characteristics. Although, a previous study in the Netherlands reported only minor effects of socio economic status based on neighborhood (Selten et al., 2001), we regard socio-economic adversity as an important potential confounder of the relation between ethnicity on the presence of psychotic disorders. Therefore future studies should take both cultural sensitive diagnostic procedures and differences in socio-economic differences into account simultaneously in order to arrive at the best comparison of incidence rates of psychotic disorders and schizophrenia between different ethnic groups.

6.7. Future studies

In the last decades there are increasing claims about the importance of acknowledging ethnic identity. However, differences in cultural interpretation of symptoms is still not considered to be a crucial strategy to prevent information bias in immigrant studies in Europe. The
clinician’s cultural competency in multicultural settings is an important determinant and is essential in dealing with patients with different cultural backgrounds (Alarcón et al., 2002; Smedley et al., 2003; Hyaman 2004; Alegria et al., 2008; Cummings & Druss, 2011). Anthropological should help us to clarify the distinction between traditional symbols and culturally sanctioned idioms of distress and pathological phenomena. This also means that the methodology of new studies should be more subtle in addressing the issue of cultural background of the immigrant patients.

If, as most of the incidence studies argue, migration as a newly identified risk factor that can change the risk of an illness or produce new forms of the illness among a particular group, the research tools must not only be cross culturally valid but also be able to detect and differentiate these atypical cases from already existing types of psychosis (McKenzie et al., 2008).

We hope that our results will inspire future methodological studies on the standardisation of diagnostic interviews and the development of new versions of these diagnostic tools for other ethnic groups. Subsequently, the equivalence of diagnostic and research tools used in different incidence studies should be tested in different populations. In addition, new incidence studies with properly adapted instruments, using long-term follow-ups, and with proper adjustments for socio-economic differences between ethnic groups may result in a better estimate of the difference in incidence rates of psychotic disorders between ethnic groups. There is no doubt that cultural differences may contribute to health disparities, but unjustified differences in diagnostic evaluation and unequal access to the mental health care system should be reduced as much as possible in order to achieve equity in terms of treatment. In order to reach this goal, the issue of cultural diversity has to be seriously addressed both in health science and in health care practice (Alegria et al., 2010).
References


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