Explaining health and healthcare utilisation of ethnic minorities in the Netherlands: A longitudinal perspective

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Chapter 6

Course of Post Traumatic Stress Disorder and healthcare utilisation among resettled refugees in the Netherlands

This chapter has been submitted as:
Abstract

Purpose
Post-traumatic stress disorder (PTSD) is a major health problem among refugees worldwide. After resettlement, the prevalence of PTSD remains high despite the fact that various PTSD treatments are known to be effective.

Methods
We examined the course of PTSD and the role of mental healthcare utilisation among a cohort of refugees from Iran, Afghanistan and Somalia at a 7-year interval in the Netherlands (2003-2010).

Results
The unchanged high prevalence of PTSD (16.3% in 2003 and 15.2% in 2010) was partly attributable to late onset of PTSD symptoms (half of the respondents with PTSD at T2 were new cases, for whom PTSD developed after 2003). The second reason concerned the low use of mental healthcare at T1. Only 21% of respondents with PTSD at T1 had had contact with a mental healthcare provider at that time, while the effectiveness of mental health care was shown in the multivariate analyses. Use of mental health care during the first wave increased the odds of improvement in PTSD symptoms between both measurements (OR 7.58, 95% CI 1.01; 56.85).

Conclusions
Healthcare professionals should be aware of a late onset of PTSD among refugees, being a first explanation for a remaining high prevalence of PTSD over time. A second explanation for this phenomenon is the general initial low use of mental healthcare among refugees. This is all the more important given that those who did use mental health care in the Netherlands, showed a better PTSD recovery.
Introduction

Post-traumatic stress disorder (PTSD) is a major health problem among refugees worldwide (1). A review by Fazel and colleagues (2) showed that the overall prevalence of PTSD among refugees resettled in western countries was about 9%, with substantial heterogeneity between studies. Although this overall percentage is not as high as suggested by others (3-5), Fazel and colleagues suggest that refugees resettled in western countries are about ten times more likely to have PTSD than age-matched general populations in those countries. For example, in the Netherlands, the lifetime prevalence of PTSD for the general population is 7.4% (6) whereas among refugees and asylum seekers from Afghanistan, Iran and Somalia it is around 20% (5).

After resettlement in the host countries the proportion of resettled refugees with PTSD drops but remains relatively high compared to the general population (5, 7). Although this might indicate the chronicity of a severe mental illness, it seems to be in contrast to the availability of effective forms of treatment for PTSD (8, 9). Since several PTSD treatments are known to be effective among diverse groups, including refugees, the question arises why there is little change in the proportion of resettled refugees with PTSD, even several years after resettlement (5).

A first possibility is that the prevalence of PTSD remains high, but that it represents this disease in different subjects. A quasi-unchanged proportion of refugees with PTSD over time does not necessarily mean that the positive cases are in fact the same persons. A late onset of PTSD, several years after the traumatic events took place, is highly probable (10) and changes must be examined taking this into account. A late onset of PTSD has been shown up to 14 years after the traumatic events (11).

A second possibility is that the available treatment services are inadequately used by refugees with PTSD, implying underutilisation. Timely use of appropriate mental healthcare is considered necessary for recovery from PTSD. A prompt intervention based on cognitive-behavioural treatment can relieve the complaints and prevent the development of PTSD (12-14). Dutch guidelines for general practitioners (GPs) recommend direct referral to mental healthcare (Dutch College of General practitioners
Explaining health and healthcare utilisation of ethnic minorities

Standard M62) (15). The regulations for access to Dutch healthcare provide refugees, asylum seekers and Dutch citizens with similar rights to primary healthcare and specialized mental healthcare through GP referrals. However, (mis)trust in mental healthcare, lack of knowledge about mental health treatment possibilities and language barriers might limit access to mental care among this group of newcomers, unfamiliar with a new country’s health system. Another study showed that, among refugees in the years following resettlement, many do not receive adequate care (16). Language barriers, acculturation issues and cultural beliefs regarding several forms of healthcare jointly contribute to an access problem for this group.

Finally, a third possibility is that mental healthcare may not have the expected positive effect on the course of mental health for refugees who used mental healthcare services. For refugees, ineffectiveness of mental healthcare treatments for PTSD might account for long-lasting symptoms. Although current guidelines recommend trauma-focused psychotherapy for patients with PTSD (17, 18) and effective forms of treatment for PTSD are available (8, 9), very limited or no effectiveness of PTSD treatment is reported for the specific case of asylum seekers and refugees (19, 20). Albeit two pilot studies demonstrated the feasibility and effectiveness of some trauma-focused approaches for treating PTSD in refugees (21, 22), more evidence for treatment effectiveness in this group is needed.

The two latter hypotheses concern the use and effectiveness of mental healthcare. The role of mental healthcare utilisation on the course of mental health is embedded in the resettlement situation of refugees and is also related to events in the past. Traumatic events preceding the flight, whether experienced or witnessed, are direct risk factors for the onset of mental sickness (23), as well as for its persistence (7, 24). Post-migration factors can jeopardize mental health (25). Among post-migration factors, experienced living difficulties related to employment, social and family networks, dealing with a new culture and social position show a direct relationship with mental illness among resettled refugees (Lamkaddem et al. submitted). Therefore, the role of mental health care utilisation on the course of PTSD must be examined taking these pre- and post-migration factors into account.
To answer our research question on the persistent high prevalence of PTSD among resettled refugees, a longitudinal study design was required. Therefore, we examined the course of PTSD and the related role of mental healthcare utilisation among a cohort of refugees from Iran, Afghanistan and Somalia shortly after resettlement in the Netherlands.

**Methods**

**Study population**

In 2003-2004, a sample of 410 refugees from Iran, Afghanistan and Somalia with and without a residence permit (178 asylum seekers and 232 permit holders) was interviewed for the baseline measurement (T1). A more detailed description of the initial study population and measurements can be found elsewhere (26).

In 2010-2011 respondents were invited by mail to participate in the second wave (T2). Of the 410 T1 participants, 128 had no known address in the Netherlands because they were not granted asylum (n=65), or we had no valid address (n=59), or they had died (n=4). This left a sample of 282 refugees, most of whom has been granted a residence permit since the first wave (Figure 6.1). Of those 282 refugees, 172 were interviewed for follow-up (response rate 61%, retention rate 42%). Most of those who did not respond (n=110) could not be reached (43% of non-response) or refused to participate (30% of non-response).

At both T1 and T2, questionnaire-based face-to-face interviews were conducted in the language of choice of the participants (Dutch, Dari, Pashto, Farsi or Somali). Interviewers and respondents were matched on gender and ethnic background. Written informed consent (translated if required) was obtained from all respondents.

**Socio-demographic variables**

Information on age and gender was available from the survey and registers used for sample selection at T1 (for more details on the registers, see Gerritsen et al. (26)).
Pre-migration traumatic events

Traumatic experiences preceding the flight were assessed with part I of the HTQ, which includes 17 events (e.g. lack of food and water; being close to death) (27). Events experienced and/or witnessed were coded as 1 (vs. 0='no/heard about'). The total number of events experienced and/or witnessed (i.e. the sum of all items for which the response differs from ‘no’) was used.

Figure 6.1 Overview of data collection

<table>
<thead>
<tr>
<th>Respondents</th>
<th>Update contact</th>
<th>Outcome interview</th>
</tr>
</thead>
<tbody>
<tr>
<td>T1 (2003-2004)</td>
<td>178 PH 142 valid address 36 no valid address</td>
<td>104 interview 36 no interview</td>
</tr>
<tr>
<td>T2 (2010-2011)</td>
<td>104 long standing PH</td>
<td>68 new PH</td>
</tr>
<tr>
<td>232 asylum seekers</td>
<td>140 valid address 92 no valid address</td>
<td>68 interview 72 no interview</td>
</tr>
</tbody>
</table>

PH = residence permit holders

Post-traumatic Stress Disorder

PTSD was measured using the Harvard Trauma Questionnaire (HTQ) part IV (27). For the present study, of the total 30 items on the HTQ only the first 16 items were taken into account; the remaining 14 items were considered to be less specific for PTSD (26). Individuals with a mean score ≥ 2.5 (range 1-4) on the first 16 items were considered to be having PTSD. Change scores were determined by subtracting scores at T1 from scores at T2. For the multivariate analyses, this information was dichotomized as
1=improvement in PTSD score between T1 and T2, and 0=deterioration in PTSD score between T1 and T2.

**Mental healthcare use in the Netherlands**

At T1, respondents were asked whether they had had any contact with a mental health worker in the past 12 months. The options included social workers, psychologists, psychiatrists, psychotherapists and other (unspecified) kinds of psychosocial care providers. For use in the multivariate models, the answers were dichotomized into 0 (‘no contact with any of those mental healthcare providers’) and 1 (‘contact with at least one of those mental healthcare providers’).

**Post-migration living difficulties**

The respondents were asked about possible stressful experiences they had experienced in the Netherlands. The checklist included 18 problems often reported by refugees in research on post-migratory stressors (e.g. delays in the application for a residence permit; loneliness) (28-30). Respondents were asked to indicate the extent to which any of these problems had bothered them in the previous month (1=not at all, to 4=extremely). A mean score was calculated (range 1-4) for both T1 and T2. Change scores were calculated by subtracting scores at T1 from scores at T2.

**Analyses**

We first examined the course of symptoms of PTSD at a 7-year interval (first hypothesis on the late onset of PTSD). Second, we examined the extent to which refugees with PTSD during the first and the second wave reported mental healthcare utilisation at that time (second hypothesis on mental health services utilisation). Finally, we examined the course of the symptoms in relation to prior mental healthcare utilisation (third hypothesis on effectiveness of mental healthcare).
Course of PTSD between T1 and T2
To examine the possible late-onset or persistence of PTSD, respondents with PTSD at T2, but not at T1, are shown as a percentage of the total study population. Similarly, the proportion of respondents persistently having PTSD is calculated as a percentage of the total number of respondents having PTSD at T1. The change in PTSD symptoms severity is further examined looking at the average scores at T1 and T2, using paired-samples testing techniques.

Mental healthcare utilisation at T1
To examine the use of healthcare in relation to PTSD, cross-tables and chi-square tests are used to present and test the association between use of mental healthcare (yes/no) and having PTSD at T1 (yes/no).

Improvement in PTSD symptoms between T1 and T2, and pre- and post-migration factors and mental healthcare utilisation
To examine the effectiveness of mental healthcare use on PTSD symptoms severity, taking into account pre- and post-migration factors, a logistic regression model was used to assess the multivariate association of improvement in PTSD score between T1 and T2 (dependent variable) with the number of traumatic events witnessed/experienced before the flight (measured at T1), the change in number of experienced post-migration living difficulties between T1 and T2, and the mental healthcare utilisation in the past 12 months prior to T2 (at T1). The analyses are adjusted for age, gender, mental healthcare utilisation at T2 and PTSD score at T1. All analyses were performed using SPSS 16.00 for Windows.

Results

Study population
Table 6.1 presents the main socio-demographic characteristics of participants in both waves compared to the initial study population. Proportionally, participants in both T1 and T2 did not differ from the initial study population regarding the main socio-demographic characteristics, except for residence permit and country of origin. The two-wave cohort
included proportionally more permit holders than asylum seekers (status at T1). This results from a selection of the initial population: not all asylum seekers at T1 had obtained a permit at T2 (see Methods), which explains the overrepresentation of longstanding permit holders in the two-wave cohort.

Table 6.1  Socio-demographic characteristics of participants in one (T1) and both waves (T1 and T2)

<table>
<thead>
<tr>
<th>Country of origin</th>
<th>T1 (n=410)</th>
<th>T1 and T2 (n=172)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Afghanistan</td>
<td>206 (50.2)</td>
<td>82 (47.7)</td>
</tr>
<tr>
<td>Iran</td>
<td>117 (28.5)</td>
<td>63 (36.6)</td>
</tr>
<tr>
<td>Somalia</td>
<td>87 (21.2)</td>
<td>27 (15.7)</td>
</tr>
<tr>
<td>Age in years: mean at T1 (SD)</td>
<td>37.0 (12.4)</td>
<td>39.1 (13.1)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Residence status</th>
<th>T1 (n=410)</th>
<th>T1 and T2 (n=172)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Permit holder at T1 (=longstanding permit holder at T2)</td>
<td>178 (43.4)</td>
<td>104 (60.5)</td>
</tr>
<tr>
<td>Asylum seeker at T1 (=new permit holder at T2)</td>
<td>232 (56.6)</td>
<td>68 (39.5)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>T1 (n=410)</th>
<th>T1 and T2 (n=172)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>241 (58.8)</td>
<td>84 (48.8)</td>
</tr>
<tr>
<td>Female</td>
<td>169 (41.2)</td>
<td>88 (51.2)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education at T1 (T1 n=408)</th>
<th>T1 (n=410)</th>
<th>T1 and T2 (n=172)</th>
</tr>
</thead>
<tbody>
<tr>
<td>None/primary</td>
<td>109 (26.6)</td>
<td>35 (20.7)</td>
</tr>
<tr>
<td>Secondary</td>
<td>142 (34.6)</td>
<td>62 (36.0)</td>
</tr>
<tr>
<td>Vocational/university</td>
<td>159 (38.8)</td>
<td>75 (43.3)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Marital status at T1 (T1 n=408)</th>
<th>T1 (n=410)</th>
<th>T1 and T2 (n=172)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Divorced</td>
<td>17 (4.2)</td>
<td>7 (4.1)</td>
</tr>
<tr>
<td>Never married</td>
<td>40 (9.8)</td>
<td>20 (11.6)</td>
</tr>
<tr>
<td>Married/living together</td>
<td>252 (61.6)</td>
<td>111 (64.5)</td>
</tr>
<tr>
<td>Widowed</td>
<td>100 (24.4)</td>
<td>34 (19.8)</td>
</tr>
</tbody>
</table>
Course of PTSD

Figure 6.2 shows the number of respondents having PTSD during the first and second wave, using the standard cut-off point of ≥ 2.5 (see Methods). During the first wave 16.3% (n=28) of the respondents have scores above the cut-off, compared with 15% (n=26) at the second wave. When examining changes in average HTQ part IV scores of PTSD using paired-measurement methods, the average at T1 (1.81; SD 0.68) and at T2 (1.74; SD 0.69) showed no significant difference. Thus, based on the severity of experienced symptoms, respondents showed (on average) no improvement at T2 compared to their mean score at T1. However, when examining the time of onset of PTSD, 50% of the PTSD cases at T2 were already having PTSD at T1 (n=13), while the remaining 50% were new cases, i.e. without PTSD at T1 (n=13). Also, 53.6% of the respondents with PTSD at T1 recovered (46.4% remained symptomatic).

<table>
<thead>
<tr>
<th>PTSD at T1</th>
<th>PTSD at T2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes 28 (16.3%)</td>
<td>Yes 13 (7.6%)</td>
</tr>
<tr>
<td>No 144 (83.7%)</td>
<td>Yes 13 (7.6%)</td>
</tr>
</tbody>
</table>

Mental healthcare utilisation and PTSD at T1

At T1, examination of the association between PTSD symptom severity and use of mental healthcare shows that those reporting having used mental healthcare also reported significantly higher scores of PTSD at T1 (2.42 vs. 1.75). Moreover, table 6.2 shows that, at T1, most respondents who were having PTSD (≥ the cut-off point of 2.5) did not use mental healthcare at T1. Only 21% of respondents with PTSD had contact with a mental healthcare provider at that time, while 79% did not (p<0.05). At T2, the proportion of respondents with PTSD who used mental health care at T2 increased to 54% (table 6.3). Also for the group under the PTSD cut-off point at T2, the
proportion of respondents who used mental healthcare doubled compared to the situation at T1 (13% vs. 6%).

Table 6.2  Percentage of respondents above cut-off for PTSD and use of mental healthcare at T1

<table>
<thead>
<tr>
<th>Contact with mental healthcare provider at T1</th>
<th>No (%)</th>
<th>Yes (%)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>PTSD at T1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>135 (93.8%)</td>
<td>9 (6.2%)</td>
<td>144 (83.7%)</td>
</tr>
<tr>
<td>Yes</td>
<td>22 (78.6%)</td>
<td>6 (21.4%)</td>
<td>28 (16.3%)</td>
</tr>
<tr>
<td>Total</td>
<td>157 (91.3%)</td>
<td>15 (8.7%)</td>
<td>172 (100%)</td>
</tr>
</tbody>
</table>

Table 6.3  Percentage of respondents above cut-off for PTSD and use of mental healthcare at T2

<table>
<thead>
<tr>
<th>Contact with mental healthcare provider at T2</th>
<th>No (%)</th>
<th>Yes (%)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>PTSD at T2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>127 (87.0%)</td>
<td>19 (13.0%)</td>
<td>146 (84.8%)</td>
</tr>
<tr>
<td>Yes</td>
<td>12 (46.2%)</td>
<td>14 (53.8%)</td>
<td>26 (15.2%)</td>
</tr>
<tr>
<td>Total</td>
<td>139 (80.8%)</td>
<td>33 (19.2%)</td>
<td>172 (100%)</td>
</tr>
</tbody>
</table>

Improvement in PTSD symptoms, pre- and post-migration factors and mental healthcare utilisation

Taking migration and socio-demographic factors into account, prior mental healthcare use (during the first wave) was significantly associated with an improvement in PTSD score between both waves (table 6.4). In other words, those who made use of mental healthcare during the first wave were up to 7 times more likely to see an improvement in their PTSD symptoms than those who did not, regardless of differences in the above-mentioned covariates. However, these data do not give an accurate estimate due to the small numbers.
Further, the number of pre-migration traumatic events was not significantly associated with an improvement in PTSD score (OR=0.905, p>0.05). An increase in experienced post-migration living difficulties between T1 and T2 as negatively related to an improvement in PTSD score between both waves (OR=0.813, p<0.05).

### Table 6.4 Logistic regression coefficients of improvement in PTSD score between T1 and T2

<table>
<thead>
<tr>
<th></th>
<th>Odds ratio (95% CI)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Contact with of mental healthcare at T1 (ref. no contact)</td>
<td>7.583 (1.011;56.858)</td>
<td>0.049</td>
</tr>
<tr>
<td>Change in living difficulties between T1-T2</td>
<td>0.813 (0.706;0.937)</td>
<td>0.004</td>
</tr>
<tr>
<td>Number of traumatic events</td>
<td>0.905 (0.795;1.030)</td>
<td>0.130</td>
</tr>
</tbody>
</table>

1 Adjusted for age, gender, contact with mental healthcare at T2, and PTSD score at T1

### Discussion

In this paper we examined the course of PTSD among refugees after resettlement. The results show that the seemingly unchanged high rate of refugees with PTSD over a 7-year interval has two main explanations.

The first concerns the onset and persistence of PTSD symptoms. Only half of the respondents with PTSD during the second measurement were also having PTSD during the first measurement. The other half concerned new cases, for which PTSD developed later, i.e. between both measurements.

The second explanation concerns the use of mental healthcare at T1. We saw that at T1, relatively few respondents with PTSD had had contact with a mental health provider (21%). Those who made use of mental healthcare during the first wave were more likely to see an improvement in PTSD symptoms during the second wave, which provides indications to suggest that the low use of health care also contributes to the remaining high prevalence of PTSD.

Our results on the course (onset and persistence) of PTSD are confirmed by other longitudinal studies among other ethnic groups (whether or not...
refugees). PTSD symptoms can remain several years after exposure to trauma (31, 32), and can also show a late onset whereby symptoms only become apparent several years after the traumatic events took place (33, 10). These results stress the importance of a longitudinal cohort design when examining the course of PTSD. Our study shows that the late onset of PTSD is an important reason of the ongoing high prevalence of PTSD after resettlement.

Our results on the effectiveness of mental healthcare provide evidence for the effect of mental healthcare utilisation for this group. Refugees that had used mental healthcare generally show an improvement of PTSD symptoms. The few studies which specifically addressed this topic among refugees confirm these findings. One Dutch clinical study reported that 73% of patients diagnosed with PTSD no longer met the criteria for the diagnosis 6 months after treatment, whereas 90% of those who had refused treatment were later diagnosed with PTSD (34). Therefore, accessing and using mental health care for refugees is an important condition for improving PTSD status.

Whereas mental health care seems to be beneficial for PTSD recovery, our results show that the percentage of refugees that actually use this type of mental healthcare services is relatively low, i.e. one fifth of those reporting PTSD symptoms. These results are similar to studies in other countries of resettlement, but few studies have specifically examined the Dutch mental healthcare services. The last study on this topic was conducted among Iraqi asylum seekers (35) and indicated the large unmet need for mental health care. Over 90% of asylum seekers with a psychiatric disorder did not visit a Dutch mental healthcare service; in the present study among refugees with PTSD, this percentage was almost 80%. The reasons for the low use of mental healthcare services among refugees need to be further investigated. Barriers in accessing mental healthcare can be due to low language fluency (36), lack of knowledge of existing treatments (37) and culturally unsuitable forms of information about the mental healthcare supply. These factors might in turn affect the perceived mental healthcare needs of refugees, similar to other types of migrants (38), and impede access.

The present study has several limitations. First, only 172 respondents took part in both waves of the study. This might affect analyses on the extent to which pre-migration factors (i.e. traumatic events before the flight) impact the course of PTSD after resettlement. The same analyses among a larger sample might show a significant (negative) association between the
number/severity of traumatic events and PTSD recovery. Also, the extent to which those who made use of mental healthcare during the first wave were more likely to see an improvement in their PTSD symptoms cannot be accurately assessed (the large 95% CI reflects the uncertainty of the estimation).

Second, our study includes three different ethnic groups, representing only a part of the refugee population in the Netherlands. The extent to which these results can be generalized to all refugee groups in the Netherlands and elsewhere remains to be confirmed in broader research samples.

Third, the measurement of PTSD is not a clinical one, and the questionnaire used for this purpose must be seen as only an approximation of PTSD. However, studies have successfully used the HTQ (or parts of it), yielding results comparable to clinical diagnoses (39, 40).

Finally, the information on the use of mental healthcare services was not directly linked to the diagnosis. We have no evidence that the reported contacts of refugees with symptoms of PTSD with mental healthcare providers were in fact specifically for PTSD treatment. Therefore, we can not conclude on the specific PTSD treatment effectiveness, but merely on the association between use of mental health care in general and course of PTSD symptoms.

Despite these limitations, the explanations presented here for the seemingly unchanged high rates of PTSD offer interesting insights for further research on refugees’ mental health. The findings emphasise the need for primary care providers to follow existing guidelines on quick referral to mental healthcare for patients presenting with PTSD symptoms, and underline the possibility of late onset of PTSD. Finally, the results show the importance of improvements in contextual factors (e.g. in employment, social/family networks, getting familiar with the new culture and social position) in addition to the use of mental healthcare in the course of PTSD.

**Conflict of interest**

On behalf of all authors, the corresponding author states that there is no conflict of interest.
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