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Involving migrants in shaping their primary care
Involving migrants in shaping their primary care

Erik Teunissen
Colophon
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Involving migrants in shaping their primary care

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Promotor

Prof. dr. C. van Weel

Copromotoren

Dr. M.E.T.C. van den Muijsenbergh
Dr. E.M. van Weel-Baumgarten

Manuscriptcommissie

Prof. dr. A.H. Schene
Prof. dr. P.L.H. Scheepers
Prof. dr. J. De Maeseneer, Universiteit Gent, België

Paranimfen

Ir. S.W. Nijenhuis
Ir. R. Lubbers
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General introduction
Introduction

This thesis focuses on migrants in primary care and consists of three parts.

The first part is focused on the mental health problems of undocumented migrants (UMs) and the role of General Practitioners (GPs) in the management of these problems. Most of these studies were performed in the Netherlands.

The second part is focused on improving communication with migrants in primary care. It describes the evaluation of stakeholders who were involved in the implementation of guidelines and training initiatives to support communication with migrants in cross-cultural general practice consultations. These stakeholders were migrants, GPs, policy makers and other primary care professionals. This evaluation is part of a project called RESTORE (REsearch into implementation STRategies to support patients of different ORigins and language background in a variety of European primary care settings), and took place in a European context.

The third part is a critical reflection of our experiences in involving undocumented migrants in research projects.

General Introduction

Background and motivation of this study

Europe is becoming increasingly multicultural: in 2014, there were 33.5 million migrants living in the European Union, 6.7% of its population. Because of the current large influx of refugees, with the prospect of large numbers permanently migrating, it is expected that in the coming years this number will rise. From January to November 2015, more than 870,000 migrants including refugees are reported to have arrived to Europe. In October 2015, the number of migrants and refugees entering Europe was roughly as high as that for the whole of 2014.

Of all migrants in the European Union, between 2.8 and 6 million do not possess a legal residence permit, the so-called undocumented migrants (UMs). This presents challenges to health systems. Access to healthcare is less favourable for migrants and health care outcomes are less favourable for migrants. In particular infectious diseases and mental health problems, but also non-communicable diseases are common in migrants. Amongst UM, health and access to healthcare is even more precarious, given their high-risk working and living conditions while being excluded from regular social services and health insurance.
This lends urgency to improve health systems’ responsiveness to ethnic diverse populations, and in particular to UMs, a group that is highly invisible and not much known about. Improving responsiveness to cultural diverse populations is important in primary care, as it is the entry point to health care for all patients and deals with a wide range of health problems. Primary care contributes to population health, is cost-effective care and equitable, providing continuous, coordinated and integrated healthcare. Improving responsiveness is particularly important for the frequently hidden group of UMs, whose access to care is often limited and who often remain outside the scope of health professionals. In the Netherlands’ contribution to the RESTORE project, it was decided to pay extra attention to this vulnerable group.

It is known that the perceived health status of UMs is low and that UMs report poor health three times more often than the general population. Especially, their psychological well-being is low: many feel lonely, lack emotional support and suffer from anxiety, depression and stress. Mental health is the most frequently reported health need amongst UMs. And in mental health care all aspects of doctor - patient communication play a crucial role. Particularly in mental health, differences in languages, culture, patterns of seeking help and ways of coping act as main barriers in cross-cultural general practice consultations. In line with the research topic of RESTORE, this made mental health, an interesting subject to explore more in depth. For that reason we decided to focus to mental health needs of UMs.

There are some data available of the UMs’ actual use of primary care: mental health problems are frequently presented, but the prevalence of mental health problems as recorded by GPs and prescription rates of sedatives were low. This may indicate a gap between the high mental health needs and low recording of these mental health problems in general practice. Possible explanations for this gap are varied and may concern the health care system itself (access and finance), the UMs (language and socioeconomic or cultural factors) and the healthcare providers (time and their ability to cope with different cultural backgrounds). However, this requires further empirical investigation.

In the first part of this thesis, this gap in knowledge will be further addressed. Through the RESTORE project it was possible to add to our studies on mental health care for UMs in the Dutch context, an exploration of some of these aspects in Crete, Greece. The health care context in Greece is very different from the Netherlands, but many of the problems experienced in the care for UMs are similar.
Part 2: Evaluation of guidelines and training initiatives to support communication in cross-cultural consultations: the RESTORE project

The second part of the thesis describes the evaluation by stakeholders of the implementation of guidelines and training initiatives to support communication with migrants in cross-cultural general practice consultations. This is part of the RESTORE project.

Background of the RESTORE project

To respond to cultural diversity in primary care, training in cultural competencies and use of professional interpreters have been advocated, and guidelines and professional training initiatives (G/TIs) have been designed for these purposes. Some of these G/TIs, like educational interventions on intercultural communication, have been proven to be effective in research settings. However, in general their implementation in day-to-day practice is poor, pointing to a significant translational gap between evidence and practice with little insight into why this is the case. On these grounds, the RESTORE project was started, a project that was focused on improving communication with migrants in primary care. It aimed to track and support the implementation of guidelines and training initiatives to improve cross-cultural communication in five primary care settings across Europe (Austria, England, Greece, Ireland and the Netherlands). RESTORE was the first study that combined a theoretical framework called Normalisation Process Theory (NPT) with the use of Participatory Learning and Action Research (PLA).

Normalisation Process Theory

NPT was developed as a response to multiple failures to implement innovations in complex health care contexts. Unlike other theories, it is concerned with the work what people do to operationalise complex interventions and new technologies into daily routine. It has been derived from empirical generalizations developed within studies of implementation processes in mainstream health. Only a few studies in the field of cross-cultural communication have taken an implementation focus, addressing i.e. implementation of interpreted consultations in general practice. So far, no theoretical frameworks were prospectively applied as recommended for implementation studies. NPT has been successfully used to retrospectively analyze emergent practices by those directly involved in implementation projects. When applied prospectively, the theory should raise awareness about levers and barriers to successful implementation. This specific prospective use of NPT has not yet been investigated, and RESTORE was the first study that explored the prospective use of the theory.
Participatory Learning and Action Research

A research method that had been applied successfully in previous research in the field of cross-cultural communication was Participatory Learning and Action Research, a participatory research methodology, enabling multiple stakeholders, including migrant service-users to work together in a democratic and empowering manner. PLA is highly relevant for the field of implementation science because it is a pragmatic multi-perspectival research methodology and known to be a helpful method to improve the quality of intervention design and guideline development.

The second part of this thesis was the contribution to Restore in which the Dutch team was the lead party. This part consisted of the evaluation work, which according to the applied theoretical framework is referred to as Reflexive Monitoring. In this thesis we report how stakeholders, including migrants, formally or informally evaluated and valued the G/TI in their daily practice, and what reconfigurations they proposed.

In three settings, it concerned the evaluation of adapted cultural competency trainings, and in two settings it concerned the evaluation of adapted guidelines to implement interpreting services in primary care. Evaluation is essential, to move the introduction and dissemination of new practices from short term success to the more challenging goal of their sustained and routine use i.e. normalization.

Part 3: A critical reflection of our experiences in involving undocumented migrants in research projects.

The third part of this thesis is a critical reflection of our experiences in involving UMs in research projects, the barriers and facilitators experienced and lessons learned. So far, only a few studies were conducted with UMs, despite the growing acknowledgment of the importance of involving service users in medical decision making and research. Involving UMs raises specific practical, ethical and methodological issues and the need to address these in a robust way. Our experiences will be presented to support future research in finding practical solutions in studies of UMs.

Stakeholders

The Netherlands

The Dutch stakeholders in RESTORE were GPs, practice nurses, practice assistants and migrant-service users from practice ‘Ondiep’. This is a practice located in a deprived area in Utrecht, and its patient list includes a large percentage of migrant patients from different origins. One of the migrant service-users who participated was an UM. The intensive involvement of UMs in an implementation project in a health care setting was, as far as we know, unique and had never occurred before.
For the research on mental health care for UM in primary care we approached a diverse group of UM, and GPs with experience in the care for UM.

**Greece**

For the research on mental health care for UM in primary care in Greece we approached GPs from Crete, with experience in the care for UM.

**RESTORE**

In RESTORE, a variety of stakeholders participated amongst whom various groups of migrant service users, GPs, practice nurses, service planners and policy makers.

### Study aim and research questions

Against the background as described above the following study objectives were formulated:

- To gain insight how often UM’s mental health problems are addressed and diagnosed in primary care and what is done with this diagnosis.
- To gain insight into how and to what extent UM seek help for mental health problems.
- To gain insight into the experiences of UM as well as GPs with consultations for mental health problems.
- To gain insight in the evaluation process of the implemented G/TIs, and the migrants and healthcare providers perceived value of these G/TIs.
- To gain insight how to succesfully involve UM in research.

To achieve these objectives we formulated the following research questions:

1. How do Dutch GPs diagnose and treat mental health problems of UM, compared with migrants with a documentary status? The results of this survey study are presented in Chapter 2: *Mental health problems in undocumented and documented migrants: a survey study*.

2. Do UM seek help for mental health problems, if so, where do they seek help and what are their experiences when consulting primary health care in the Netherlands for mental health problems? The results of this qualitative study are presented in Chapter 3: *Mental health problems of undocumented migrants (UMs) in the Netherlands: a qualitative exploration of help-seeking behaviour and experiences with primary care*.

3. How do Dutch GPs approach mental health problems in UM, and what barriers do they encounter in the consultations that impacted on recognition, recording and treatment? The results of this qualitative study are presented in Chapter 4: *Mental health problems of undocumented migrants in the Netherlands: a qualitative exploration of recognition, recording and treatment by General Practitioners*.
4. How do Greek GPs cope with UMs with mental health problems, what barriers and levers do they encounter and what solutions do they apply? The results of this qualitative study are presented in Chapter 5: *Reporting mental health problems of undocumented migrants in Greece: a qualitative exploration*.

5. What values did migrants and healthcare providers perceive of the implemented G/TI, which issues affected their sustainability and what modifications did stakeholders propose to improve sustainability over time? The results of this implementation study are presented in Chapter 6: *Improving the evaluation of cross-cultural communication interventions in General Practice: A qualitative study*.

6. What are the important issues and pitfalls in the involvement of UMs in research, what works and what does not? The results of this reflection are presented in Chapter 7: *Giving voice to the voiceless: how to involve vulnerable migrants in healthcare research*.

Chapter 8 provides a general discussion of the most important findings of the studies mentioned above and how they relate to the core-values of primary care. Chapter 9 presents a summary of each chapter in English and Dutch.
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Mental health problems in undocumented and documented migrants

a survey study

Erik Teunissen, Laura van den Bosch, Eric van Bavel, Francine van den Driessen Mareeuw, Maria van den Muijsenbergh, Evelyn van Weel-Baumgarten, Chris van Weel

Family Practice 2014; 31:571-7
Abstract

Background
Undocumented migrants (UMs) frequently report mental health problems. It is unknown to what extent these migrants seek help for these problems in general practice and how these issues are explored, discussed, registered and treated by general practitioners (GPs).

Objective
To gain insight in the registration and treatment of mental health problems in general practice of UMs compared to documented migrants (DMs).

Methods
A survey study of general practice patient records of UMs and DMs in nine general practices in the Netherlands. Consultation rates, registration of mental health problems, prescription of psychotropic medication and referrals to mental health care institutions of UM and DM patients were compared.

Results
A total of 541 migrants were included (325 UMs and 216 DMs). UMs consulted a GP significantly less than DMs (3.1 versus 4.9 times per year). Only 20.6% of the UMs had at least one mental health problem diagnosis registered compared to 44.0% of the DMs. In both groups, ~10% mentioned at least one main mental health complaint during the consultation that was not coded in the record. No significant differences were found in the prescription of psychotropic medication between the two groups. UMs were referred less to mental health care institutions but more often to psychiatrists than to psychologists.

Conclusion
UMs had less consultations with their GP, and in these consultations less mental health problems were registered. UMs were referred less to psychologists but more often to psychiatrists. GPs are advised to explore and register mental health problems more actively in UMs.
Introduction

In the European Union, between 2.8 and 6 million people do not possess a legal residence permit for their country of residence. These so called undocumented migrants (UMs) include visa ‘overstayers’, rejected asylum seekers and individuals who have entered a country illegally. In the Netherlands, the number of UMs from non-European countries is estimated to be between 60.000 and 120.000 and from European countries between 12.000 and 70.000. The largest group of UMs in the Netherlands consists of men under 40 years of age originating from Africa, Asia and Eastern-Europe; between 11% and 33% of these UMs are rejected asylum seekers.

Many of them live in difficult circumstances, characterized by difficult working and living conditions. Detailed information about their socio-economic situation is difficult to get, due to the large variety in UM characteristics and their illegal status. But in general, their socio-economic status is low.

In the Netherlands, UMs have no free access to social advisors, except to advisors from non-governmental organizations. UMs have to pay for all health services, and when they are not able to pay, physicians are obliged to provide all necessary medical care. The costs of this care can be reimbursed by a special fund installed by the government.

GPs are the main health care providers, and they can reimburse 80% of the consultation fee of UMs. UMs receive usual care by GPs, and this includes mental health care. All this care is based on available evidence-based guidelines. After referral, UMs have access to all secondary care services, including mental health care services. Psychiatrists in mental health care institutions receive 100% reimbursement, but psychologists are not reimbursed at all. UMs also have access to pharmaceutical care, including psycho-farmaca but have to pay a fee of 5 euro for every prescription. Pharmacists receive 100% reimbursement as well.

UMs bring problems from their country of origin with them- including their (medical) life history, and legal, political, financial and cultural issues. It is likely that these problems contribute to the uncertainty of their future and will lead to high prevalences of mental health problems.
Several studies have confirmed that mental distress is prevalent among UMs.\textsuperscript{9,10} From this, it can be inferred that access to professional care for mental health is a priority for UMs. However, it is unclear to what extent it is possible to respond to these needs: their illegal status in society is in itself an important barrier to access care. And culture and language are likely additional barriers to present mental health problems, when access to health care has been realized. GPs in the Netherlands play a coordinating role in the provision of health care, including the recognition and treatment of mental health problems.\textsuperscript{11,12} Provisions have been made for UMs to contact general practice, in case they need health care\textsuperscript{5} and there are some data available of their actual use of primary care: mental health problems are frequently presented,\textsuperscript{13} but the prevalence of psychiatric diagnoses and prescribing rates of sedatives were low.\textsuperscript{14} For that reason, we explored the mental health problems of UMs recorded in general practice.

Insight in the care of mental health problems of UMs is of growing importance, given the impact of immigration, and its related health problems, for the countries of Europe. This issue has grown in importance in the light of ongoing changes in immigrants’ and health care policies in different countries in Europe.

In summary, there seems to be a gap between the high occurrence of mental health problems amongst UMs and their actual registration rate in patient files in the Netherlands. This study aims to give a more detailed insight in the diagnosis and treatment of mental health problems of UMs by GPs, using migrants with a documentary status as a reference.

**Method**

**Cohort selection**

People without a legal status in society are difficult to identify under the prevailing social-political circumstances. To identify general practices with UMs on their practice list we used a snowball method. We contacted non-governmental organizations as well as general practices directly: these practices were involved in the care of UMs and/or located in areas where many UMs were residing (Amsterdam, Utrecht, the Hague, Rotterdam, Leiden, Breda, Nijmegen and Deventer).

Using the procedure described above, we approached general practices for participation in the study, with a letter with information of the research project.
Selection of undocumented migrants

UMs were identified in two ways: either through the electronic medical records in practices that had listed UM as such in their system or through their health insurance status. In the Netherlands, health insurance is compulsory for all citizens and the insurance company is registered in the patients’ files.\textsuperscript{15} UM however are not entitled to health insurance. In practices, patient files of uninsured patients were identified.

Identified patients’ files were included, when (i) the patient was a migrant from outside the European Union, (ii) there had been at least one contact with the GP during 2010 and (iii) the patient was \geq 18 years of age. Migrants whose status changed from undocumented to documented or vice versa during 2010 and 2011 were excluded from analysis. We searched their medical records for mental health problems during a time frame of the 2 years preceding the study (1 January 2010 to 31 December 2011). Of each patient, gender, age and geographical region of origin was established. If geographical region was not registered in the practice file, GPs and general practice assistants were asked to identify the region of origin of the patient. If they did not know, the region of origin was marked as unknown. No migrants from the European Union were included, because the group of UM was, after the expansion of the EU in 2004 and 2007, rather small and they couldn’t be identified as undocumented as most had a legal health insurance.\textsuperscript{16}

Control group

On basis of the provided list of UM, a list of documented migrants (DMs) was composed matched for age and gender, consisting of patients who visited the practice at least once. The patient files were checked for the region of origin. If the background was Western or unknown, the patient was excluded and the next patient file was selected till a patient was found of migrant origin whose region matched with the region of origin of the UM. If no match was found, the first non-western immigrant with known region of origin was selected.

Data collection

We extracted and anonymized data from patients’ records in the general practices on: date of birth, gender, country of origin (if available), date of first consultation, date of registration in the practice, number of contacts in 2010 and 2011 (consultations, telephone consultations, home visits, e-mail consultations), referrals for mental health care (to psychiatrists, psychologists or other mental counselors), prescriptions and recorded diagnoses. Most diagnoses were coded by the GPs, following the International Classification of Primary Care (ICPC) and we specifically looked for P (psychological)-ICPC codes.\textsuperscript{17} If the GP had not added an ICPC code, the researcher coded the described diagnosis into an ICPC code. All diagnoses in the problem list were included in the analysis. Main mental health complaints noted in the record but not recorded as a psychological problem were registered as ‘tags’ and analyzed separately.
Medication was registered by the researcher following the Anatomical Therapeutic Chemical Classification System (ATC) and all prescribed psychotropics were registered.\textsuperscript{18}

**Data Analysis**

Data were analyzed using SPSS 16.0. Chi-square tests were used to compare the patient characteristics between the two groups. Time at risk, average number of consultations and average amount of medications were compared between the two groups using independent samples \( T \)-test. For migrants who had been in contact with their GP for the very first time in 2010, the date of registration in the practice was listed, so the number of consultations per month could be corrected for the period patients were registered (time at risk).

The following ICPC-P codes were clustered for further analysis: Sleeping disorders (ICPC code P06), addiction problems (ICPC code P15, P17-P19), psychotic disorders including bipolar disorders (P72 -P73, P98), depression (P03, P76), anxiety problems (P01, P74) and Posttraumatic Stress Disorder (PTSD) (P02.01).

We used a logistic regression model to analyze whether having a P-code (one or more P-codes registered) was influenced by co-variates resident status, gender, age group, region of origin and time at risk.

**Results**

Of the general practices approached, nine responded that they provided care for UM\(\text{s} \) and were able and willing to participate.

These practices were located in Amsterdam, The Hague, Rotterdam, Utrecht, Nijmegen and Leiden. One practice (GP7) was a solo-practice, whereas the others were group practices consisting of two (GP3, GP4, GP6, GP9), four (GP1, GP5, GP8), and eight GPs (GP2). One practice was a leading academic practice with a regional role in the care of UM\(\text{s} \) (GP1).

A total of 325 UM\(\text{s} \) were included, and it was possible to identify 216 documented migrants, matched for gender, age and region of origin (Table 1).
Mental health problems in undocumented and documented migrants: a survey study

Table 1: Number identified patient files UMs and DMs from eight Dutch general practices (year 2010)

<table>
<thead>
<tr>
<th>City</th>
<th>Number of UMs included n (% of total study population undocumented)</th>
<th>Number of DMs included n (% of total study population documented)</th>
<th>Total n (% of total)</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP1 Nijmegen</td>
<td>63 (19.4)</td>
<td>58 (26.9)</td>
<td>121 (22.4)</td>
</tr>
<tr>
<td>GP2 Utrecht</td>
<td>29 (9.9)</td>
<td>27 (12.5)</td>
<td>56 (10.4)</td>
</tr>
<tr>
<td>GP3 Amsterdam</td>
<td>63 (19.4)</td>
<td>47 (21.8)</td>
<td>110 (20.3)</td>
</tr>
<tr>
<td>GP4 Rotterdam</td>
<td>31 (9.5)</td>
<td>33 (15.3)</td>
<td>64 (11.8)</td>
</tr>
<tr>
<td>GP5 Utrecht</td>
<td>3 (0.9)</td>
<td>5 (2.3)</td>
<td>8 (1.5)</td>
</tr>
<tr>
<td>GP6 Leiden</td>
<td>35 (10.8)</td>
<td>17 (7.9)</td>
<td>52 (9.6)</td>
</tr>
<tr>
<td>GP7 Amsterdam</td>
<td>26 (8.0)</td>
<td>0 (0)</td>
<td>26 (4.8)</td>
</tr>
<tr>
<td>GP8 Den Haag</td>
<td>60 (18.5)</td>
<td>15 (6.9)</td>
<td>75 (13.9)</td>
</tr>
<tr>
<td>GP9 Amsterdam</td>
<td>15 (4.6)</td>
<td>14 (6.5)</td>
<td>29 (5.4)</td>
</tr>
<tr>
<td>Total</td>
<td>325 (100.0)</td>
<td>216 (100.0)</td>
<td>541 (100.0)</td>
</tr>
</tbody>
</table>

Most UMs were men aged 31-50 years and main regions of origin were Sub-Saharan Africa and Turkey/Middle East/Northern Africa. The group of UMs included more men and more patients from Sub-Saharan Africa, Middle and South America and of unknown origin. Corrected for the shorter period of time registered, UMs contacted their GP significantly less often than DMs (monthly 0.26 versus 0.41, yearly 3.1 versus 4.9 times a year) (Table 2).

Table 2: Demographics and consultation frequency UMs and DMs (2010-2011)

<table>
<thead>
<tr>
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<th>Undocumented n (%)</th>
<th>Documented n (%)</th>
<th>Significance (test)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>325 (100)</td>
<td>216 (100)</td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td>0.050* (x²)</td>
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<tr>
<td>Male</td>
<td>205 (63.1)</td>
<td>118 (54.6)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>120 (36.9)</td>
<td>98 (45.4)</td>
<td></td>
</tr>
<tr>
<td>Age in years</td>
<td></td>
<td></td>
<td>0.069 (x²)</td>
</tr>
<tr>
<td>18-30</td>
<td>96 (29.5)</td>
<td>49 (22.7)</td>
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<td>31-50</td>
<td>168 (51.7)</td>
<td>111 (51.4)</td>
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</tr>
<tr>
<td>&gt;50</td>
<td>61 (18.8)</td>
<td>56 (25.9)</td>
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Chapter 2

<table>
<thead>
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<th>Region of origin</th>
<th>Undocumented n (%)</th>
<th>Documented n (%)</th>
<th>Significance (test)</th>
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<tr>
<td>Sub-Saharan Africa</td>
<td>79 (24.3)</td>
<td>40 (18.5)</td>
<td>0.002* (x²)</td>
</tr>
<tr>
<td>Turkey / Middle East / Northern Africa</td>
<td>98 (30.2)</td>
<td>95 (44.0)</td>
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</tr>
<tr>
<td>Afghanistan / Iran / Iraq / Pakistan</td>
<td>21 (6.5)</td>
<td>17 (7.9)</td>
<td></td>
</tr>
<tr>
<td>Eastern Europe (non-EU) / former USSR / former Yugoslavia</td>
<td>12 (3.7)</td>
<td>20 (9.3)</td>
<td></td>
</tr>
<tr>
<td>Middle and South America</td>
<td>47 (14.5)</td>
<td>24 (11.1)</td>
<td></td>
</tr>
<tr>
<td>Surinam</td>
<td>2 (0.6)</td>
<td>8 (3.7)</td>
<td></td>
</tr>
<tr>
<td>Asia</td>
<td>13 (4.0)</td>
<td>12 (5.6)</td>
<td></td>
</tr>
<tr>
<td>Unknown</td>
<td>53 (16.3)</td>
<td>0 (0.0)</td>
<td></td>
</tr>
<tr>
<td>Consultations Time at risk in months (SD)</td>
<td>21.78 (±3.61)</td>
<td>22.65 (±3.17)</td>
<td>0.003* (T-test)</td>
</tr>
<tr>
<td>Live consultations per month (SD)</td>
<td>0.23 (±0.26)</td>
<td>0.36 (±0.31)</td>
<td>0.000* (T-test)</td>
</tr>
<tr>
<td>Total consultations per month (SD)</td>
<td>0.26 (±0.29)</td>
<td>0.41 (±0.36)</td>
<td>0.000* (T-test)</td>
</tr>
</tbody>
</table>

*Significant (P < 0.05).

**Mental health problems diagnosed**

Of all mental health diagnoses registered in the patient records, 12% had not been ICPC-coded by the GPs and were coded by the researcher for further analysis. Twenty-one per cent of the UMs had at least one mental health problem registered in comparison to 44% of the documented control group.

The most common mental health problems encountered were: sleeping disorders, addiction and psychotic disorders, anxiety, depression, and PTSD (1.5%, 3.1%, 1.8%, 3.1%, 8.0% and 3.4% of UMs respectively). These diagnoses had been less often encountered than in DMs (Table 3).

**Tags**

Eleven per cent of UMs had main psychological complaints mentioned in the records (of consultations) that were not recorded as mental health problem diagnoses by the GPs. For DMs, this percentage was 8.3% (Table 3).
Table 3: Number of mental health diagnoses and tags (mental health problems noted in the record but not recorded as a psychological problem) of UMs and DMs in general practice patient records (2010-2011)

<table>
<thead>
<tr>
<th>Mental health diagnoses</th>
<th>Undocumented n (%)</th>
<th>Documented n (%)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>At least 1 P-code (ICPC)</td>
<td>67 (20.6)</td>
<td>95 (44.0)</td>
<td>0.000*</td>
</tr>
<tr>
<td>Sleeping disorder</td>
<td>5 (1.5)</td>
<td>12 (5.6)</td>
<td>0.012*</td>
</tr>
<tr>
<td>Addiction</td>
<td>10 (3.1)</td>
<td>20 (9.3)</td>
<td>0.002*</td>
</tr>
<tr>
<td>Psychosis</td>
<td>6 (1.8)</td>
<td>11 (5.1)</td>
<td>0.047*</td>
</tr>
<tr>
<td>Anxiety</td>
<td>10 (3.1)</td>
<td>17 (7.9)</td>
<td>0.088</td>
</tr>
<tr>
<td>Depression</td>
<td>26 (8.0)</td>
<td>28 (13.0)</td>
<td>0.193</td>
</tr>
<tr>
<td>PTSD</td>
<td>11 (3.4)</td>
<td>9 (4.2)</td>
<td>0.428</td>
</tr>
<tr>
<td>Tags</td>
<td>36 (11.1)</td>
<td>18 (8.3)</td>
<td>0.456 ($\chi^2$)</td>
</tr>
</tbody>
</table>

*S*Significant (*P* < 0.05).

**Sub-analysis: mental health diagnoses**

By using a logistic regression model, we found that when a patient was registered in the practice for a longer period of time (time at risk), the patient was more likely to have a mental health problem registered. Gender and age did not make a statistically significant difference in the chance to have been coded with at least one P-diagnosis. Migrants from Middle and South America were significantly less often diagnosed with a mental health diagnosis (Table 4).

Table 4: Risk of having at least one mental health diagnosis recorded (2010-2011)

<table>
<thead>
<tr>
<th>Resident status:</th>
<th>Odds-ratio (95% confidence intervals)</th>
</tr>
</thead>
<tbody>
<tr>
<td>DMs (UMs reference)</td>
<td>2.65 [1.69 - 4.15]</td>
</tr>
<tr>
<td>Gender:</td>
<td></td>
</tr>
<tr>
<td>Male (Female reference)</td>
<td>0.92 [0.58 -1.47]</td>
</tr>
<tr>
<td>Age group:</td>
<td></td>
</tr>
<tr>
<td>18-30 years</td>
<td>Reference 1.01 [0.59 - 1.72]</td>
</tr>
<tr>
<td>31-50 years</td>
<td>0.90 [0.46 - 1.74]</td>
</tr>
<tr>
<td>&gt; 50 years</td>
<td>1.17 [1.09 - 1.27]</td>
</tr>
<tr>
<td>Time at risk</td>
<td>1.17 [1.09 - 1.27]</td>
</tr>
</tbody>
</table>
### Chapter 2

#### 2nd ratio confidence intervals

<table>
<thead>
<tr>
<th>General Practice</th>
<th>Odds-ratio (95% confidence intervals)</th>
</tr>
</thead>
<tbody>
<tr>
<td>GP(1)</td>
<td>Reference</td>
</tr>
<tr>
<td>GP(2)</td>
<td>1.04 [0.48 - 2.22]</td>
</tr>
<tr>
<td>GP(3)</td>
<td>0.37 [0.17 - 0.81]</td>
</tr>
<tr>
<td>GP(4)</td>
<td>2.12 [1.03 - 4.34]</td>
</tr>
<tr>
<td>GP(5)</td>
<td>0.41 [0.07 - 2.31]</td>
</tr>
<tr>
<td>GP(6)</td>
<td>0.59 [0.26 - 1.37]</td>
</tr>
<tr>
<td>GP(7)</td>
<td>4.29 [0.35 - 52.93]</td>
</tr>
<tr>
<td>GP(8)</td>
<td>1.26 [0.57 - 2.76]</td>
</tr>
<tr>
<td>GP(9)</td>
<td>0.49 [0.17 - 1.45]</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Region of origin</th>
<th>Odds-ratio (95% confidence intervals)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sub Saharan Africa</td>
<td>Reference</td>
</tr>
<tr>
<td>Turkey / Middle East / Northern Africa</td>
<td>0.88 [0.47 - 1.65]</td>
</tr>
<tr>
<td>Afghanistan / Iran / Iraq / Pakistan</td>
<td>1.90 [0.79 - 4.58]</td>
</tr>
<tr>
<td>Eastern Europe (non EU) / former USSR / former Yugoslavia</td>
<td>0.92 [0.37 - 2.33]</td>
</tr>
<tr>
<td>Asia</td>
<td>0.62 [0.21 - 1.86]</td>
</tr>
<tr>
<td>Middle and South America</td>
<td>0.32 [0.12 - 0.86]</td>
</tr>
<tr>
<td>Surinam</td>
<td>2.42 [0.50 - 11.58]</td>
</tr>
</tbody>
</table>

#### Referrals

Of the UMs, 8% was referred to mental health care services - for DMs, this was 11.2%. Of the undocumented group, 0.3% was referred to a psychologist, 2.5% to a psychiatrist and 5.2% to a mental health care institution, in comparison with 5.1%, 0.5% and 5.6% of the DMs.

#### Prescriptions

The average number of prescriptions per patient in 2010 and 2011 was 3.8 for UMs and 5.3 for DMs. No significant difference was found in the prescription of benzodiazepines, anti-depressants or anti-psychotics between UMs and DMs (Table 5).

#### Table 5: Number of total prescriptions and number of prescriptions of psychotropics UMs and DMs (2010-2011)

<table>
<thead>
<tr>
<th>Average number of prescriptions per patient (SD)</th>
<th>Undocumented</th>
<th>Documented</th>
<th>P (&lt;0.05)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>3.78 ±3.99</td>
<td>5.31 ±4.80</td>
<td>0.00* (T-test)</td>
</tr>
<tr>
<td>Average number of prescriptions per patient per month (time at risk) (SD)</td>
<td>Total</td>
<td>0.17 ±0.18</td>
<td>0.23 ±0.21</td>
</tr>
<tr>
<td>At least 1 benzodiazepine n (%)</td>
<td>29 (8.9%)</td>
<td>15 (6.9%)</td>
<td>0.23</td>
</tr>
<tr>
<td>At least 1 anti-depressant n (%)</td>
<td>36 (11.1%)</td>
<td>19 (8.8%)</td>
<td>0.34</td>
</tr>
<tr>
<td>At least 1 anti-psychotic n (%)</td>
<td>13 (4.0%)</td>
<td>13 (6.0%)</td>
<td>0.28</td>
</tr>
</tbody>
</table>

*Significant (P < 0.05).
Discussion

Summary of main findings
This study analyzed GPs’ diagnoses and treatment of mental health problems in UMs and compared these with migrants of the same age, gender and region of origin, but who had a legal status in Dutch society. UMs can be characterized as a group that is largely invisible in their social engagement\textsuperscript{19} but with substantial (mental) health needs.\textsuperscript{4,9,10} The findings of this study should be seen against this background.

We have opted for an explorative retrospective study design because we were facing a number of uncertainties at the start of the study: we didn’t know if GPs recorded the problems of UMs, if UMs accepted recording of their problems in a patient record and if GPs were willing to give permission to access the data of their undocumented patients. That was also the reason to focus on mental health problems alone. We recruited practices from areas in the country where it was known that many UMs reside.

A first finding was that it was possible to access data of primary care for UMs, through a carefully planned study design and through collaboration with practitioners and organizations who were focused on UMs. This resulted in data of > 300 UMs - to the best of our knowledge, the largest survey of mental health care of this group. In addition, it was possible to relate the findings of this group to mental health care of otherwise highly comparable individuals with a legal status in society.

Comparison with existing literature
It is known that UMs perceive their own health as (very) poor and mention many mental health problems. A survey among 1.100 UMs in Europe showed that almost a third of undocumented men and a quarter of undocumented women perceived their health as bad or very bad; 16% spontaneously reported psychological problems like anxiety, stress or depression.\textsuperscript{4} A descriptive study of 100 female UMs in the Netherlands showed that almost two-third reported their health as poor, and psychological problems like anxiety, sleeplessness and agitation were mentioned by >70\% of the women, but often not spontaneously.\textsuperscript{9} Three-quarter of a group of 20 male UMs in the Netherlands reported their health as bad: mental health problems like sleeping problems and anxiety were mentioned by >80\% of the respondents.\textsuperscript{10}
GPs are highly aware of these problems, and this comes forward in this study: GPs and their practices are actively involved in the care of (mental) health problems of UMs: in diagnosis, counselling, prescription of psycho-pharmaca and referral to specialized services. These interventions should be seen against the major restrictions individuals without a legal status encounter in their daily functioning. Yet, the frequency of mental health problems is lower, when comparing their care with that of migrants with a legal status. And in comparison to the overall Dutch population this difference is even bigger when correcting for the sex and age composition (28%).

Intuitively one would assume that the mental health needs of UMs are high, as they live in difficult circumstances. Some studies have found this while others confirmed our lower levels. There seems to be a gap between the assumed high mental health needs of UMs and the low actual recording of these mental health problems in general practice. Possible explanations for this gap are varied and may concern the health care system itself (access and finance), the UMs (language and cultural factors) and the providers (time and their ability to cope with different cultural backgrounds).

All these factors have a negative effect on the provision of health care in general, but especially on mental health. The taboo and stigma around mental health problems will play a role for this group, while UMs may have other priorities when accessing care (burden of physical and social problems related to their undocumented refugee status). And UMs may be unaware that the GP can be approached for mental illnesses as well. The establishment of a relation of trust is an important precondition for effective health care and this plays in particular around precarious issues as mental health problems. And the status of UMs will hamper in particular the establishment of a relation of trust with a GP and other primary care professionals. In UMs who had consulted their GP more often, more mental health problems had been identified and treated. This finding may point to the importance of continuity of care for UMs, and the fact that it is possible for GPs to establish a professional relation with UMs.

Our study showed that UMs were referred less to mental health care, but more often to psychiatrists. As referral patterns to mental health care might be influenced by other confounding factors (financial, organisational), we have to be careful to draw conclusions on this. One explanation might be that their mental health problems, when registered by the GP, were more severe, another might be the fact that consultations of UMs with psychiatrists can be reimbursed whereas consultations of psychologists often cannot.
Another finding was that prescribing of benzodiazepines and antidepressants was the most common intervention, and higher than in another Dutch primary study of UMs. A possible explanation for this could be that the UMs in our study received more prescriptions in general (3.8 versus 2.7). An explanation for the high prescription rate of psychotropics in our study could be that because of the status of UMs, prescribing of psychotropics seems the best possible treatment option.

**Strengths and limitations of the study**

A strength of the study was that we were able to gain access to detailed patient data of UMs in a variety of different practices in different parts of the Netherlands. Therefore, we were able to cover data of mental health care of a representative group of UMs in the Netherlands with all main sub-groups involved. By our research methodology, we were able to investigate a variety of record keeping procedures and systems used in primary care, including files on paper. This was a valuable way of limiting the loss of data.

Due to the chosen research methodology, this explorative study has some limitations as well. As the study was performed in a selected group of GP practices with relatively large groups of UMs on their practice list, it is as yet unclear how representative these data are for UMs in Dutch general practice.

As UMs are a very dynamic group of patients, as their region of origin may rapidly fluctuate, it is as yet unclear how representative these data are for other settings and for the near future. On the other hand, we are confident that we accessed information that reflected the generic UM status.

We also realize that there are UMs who do not have any contacts with a GP at all. It would be important to gain insight in the (mental) health status and their access to care, of this group.

**Implications for future research and clinical practice**

This analysis of care for mental health problems of UMs leads to a number of conclusions. As we were able to gain access to detailed data of UMs, we can conclude that a prospective study is well applicable. Therefore, now we recommend this for future research.
UMs and GPs and their practices are engaged in active interactions around mental health problems. However, the large needs of this group are difficult to respond to, given the restrictions that the UM status imposes. Further qualitative research on reasons for under-disclosure and under-recording is highly recommended, in order to develop best practices and to create facilities for optimal response to the needs of this group. As this will require an intimate understanding of the needs, expectations and cognitions of UMs towards (mental) health problems and the role of primary care, UMs should be involved as stakeholders in this research.

As long as the gap between the assumed high mental health needs and the low recording is not clarified, we suggest GPs to explore and register mental health problems more actively in UMs.

Acknowledgements
We wish to thank all GPs who participated in our research. Also we thank Ir. H. Bor, Department of Primary Care, Radboudumc for his help with the statistical analysis.
References


Mental health problems of undocumented migrants (UMs) in the Netherlands: a qualitative exploration of help-seeking behaviour and experiences with primary care

Erik Teunissen, Jamilah Sherally, Maria van den Muijsenbergh, Chris Dowrick, Evelyn van Weel-Baumgarten, Chris van Weel

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Abstract

Objective
To explore health-seeking behaviour and experiences of undocumented migrants (UMs) in general practice in relation to mental health problems.

Design
Qualitative study using semi-structured interviews and thematic analysis.

Participants
15 UMs in the Netherlands, varying in age, gender, country of origin, and education, inclusion until theoretical saturation was reached.

Setting
Four cities in the Netherlands.

Results
UMs consider mental health problems to be directly related to their precarious living conditions. For support, they refer to friends and religion first, the general practitioner (GP) is their last resort. Barriers for seeking help include taboo on mental health problems, lack of knowledge of and trust in GPs competencies regarding mental health and general barriers in accessing healthcare as an UM (lack of knowledge of the right to access health care, fear of prosecution, financial constraints and practical difficulties). Once access has been gained, satisfaction with care is high. This is primarily due to the attitude of the GPs and the effectiveness of the treatment. Reasons for dissatisfaction with GP care are an experienced lack of time, lack of personal attention and absence of physical examination. Expectations of the GP vary, medication for mental health problems is not necessarily seen as good practice.

Conclusion
UMs often see their precarious living conditions as an important determinant of their mental health; they do not easily seek help for mental health problems and various barriers hamper access to health care for them. Rather than for medication, UMs are looking for encouragement and support from their GP. We recommend that barriers experienced in seeking professional care are tackled at an institutional level as well as at the level of GP.
Introduction

An estimated 60,000 - 134,000 undocumented migrants (UMs) live in the Netherlands.¹ The health of this particular group of migrants is often precarious, characterised by high-risk working and living conditions while being excluded from regular social and health services.² These migrants often suffer from mental health problems. In a study of 100 female UMs in the Netherlands, psychological problems such as anxiety, sleeplessness and agitation were mentioned by more than 70% of the women.³ In a European survey among UMs, more than one-third of 177 UMs in the Netherlands perceived their mental health as bad or very bad.⁴

Their limited access to health care services may impede adequate treatment of these problems by health care providers, usually general practitioners (GPs) who are in the Netherlands their first contact with health care.³ ⁵

Accessibility problems

In 1998 a Dutch law named Linking Act was passed making it impossible for UMs to obtain health care insurance.⁶ At the same time however - in accordance with various universal covenants- they are entitled to free ‘medically necessary’ care.⁷ From 1998 to 2009 the care was regulated by the Linking Act and financed by a special fund called ‘Koppelingsfonds’. In this period ‘medically necessary care’ and care to protect public health could be reimbursed, but it became apparent that service providers used different interpretations of these concepts. Therefore efforts were made to formulate a uniform system for reimbursement, and in 2009 a new law came into force with the following legislation:⁸

- The definition of ‘medically necessary care’ is equated with ‘basic health coverage’ as defined by the 2006 Health Insurance Act.
- UMs should be treated according the same standards and guidelines as of other patients, unless they are expected to leave the country soon.
- Costs can be reimbursed by a special fund from the National Health Care Institute to healthcare providers if they have failed in their efforts to let the UMs pay his own bill.
- With the exception of care for pregnant women and childbirth (for which 100% reimbursement is possible), only 80% of the costs of directly accessible care (general practice and emergency department) can be reimbursed.
- ‘For non directly accessible’ plannable care (e.g., other hospital departments, pharmacies, nursing homes, dispensaries) 100% reimbursement is possible, but only for a selected group of healthcare providers appointed in each region by the National Health Care Institute. For this care, UMs need a referral or prescription.
UMs are therefore entitled to receive primary care delivered by GPs which they have to pay for themselves. However, if UMs are unable to pay for these services, GPs can get a reimbursement from the aforementioned fund. After referral by the GP, UMs have access to all secondary care services but will be referred mostly to those hospitals, mental health care institutions and pharmacies that are appointed by the National Health Care Institute. After referral by the GP, UMs have access to all secondary care services but will be referred mostly to those hospitals, mental health care institutions and pharmacies licensed by the government to fully reimburse the costs of the care of UMs who are unable to pay the bill.

The Netherlands are known to have legislation to guarantee generous health care provision for UMs who cannot afford to pay the bills. In practice, however, the provision of this care is limited as legislation is complex and ineffectively implemented. Service providers are often not aware of their obligations to provide care for UMs; they are uncertain about the definition of ‘necessary care’ or unaware of the provision of reimbursement, resulting in denials of UMs particularly in hospitals. Because ‘proof of inability to pay’ is nowhere defined, there are great variations in billing UMs for services. The limited - and often variable - group of service providers in secondary care who are entitled reimbursement of costs of care of UMs also creates problems of accessibility. Although in principle every general practice is available, UMs tend to cluster in a limited number of practices known for rendering this type of services, leading to a high (administrational) workload for a small group of GPs. Several of these practices do not keep patient records of UMs which hampers continuity of care and adequate registration of medical histories.

Besides these barriers on the side of the care providers, UMs themselves have difficulty seeking help due to obstacles such as shame, fear of deportation and worries over bills. Various studies have shown that a large percentage of migrants are unaware of their medical rights and lack knowledge of the Dutch health care system. These problems are not exclusive to the Netherlands and have been reported in other countries as well.

Additionally, factors such as a lack of knowledge of informal networks of local citizens and healthcare professionals, administrative obstacles, social exclusion and indirect or direct discrimination are also mentioned. Language barriers and cultural differences add to the risk of inequity in healthcare access and quality. Studies on the accessibility of health care with a focus on UMs with mental health problems are scarce. Literature does exist on the perceptions of mental health, health care utilisation and accessibility of mental health care services at both national as well as international level but these concentrate on migrants in general and often exclude UMs.
Mental health problems

Studies conducted in the Netherlands reveal that refugees and asylum seekers experience more physical and psychological problems compared to native Dutch and other Western migrants.\textsuperscript{19,20} In turn, concordant with international literature asylum seekers report more health problems than refugees that have been granted asylum.\textsuperscript{21}

Among studies reporting health status of UMs in the European Union, psychological issues appear most widespread.\textsuperscript{2} Most of these mental health studies indicate that mental health problems are highly prevalent among UMs but detailed conclusions are hard to provide: studies used different criteria for mental health problems, research populations were highly heterogeneous and some studies lacked a rigorous design.\textsuperscript{2}

Just as in other EU countries, the UM population in the Netherlands is highly heterogeneous and there is a large variety in mental health profiles between and within groups. It is likely that UMs who suffer severely from social exclusion and forced migration will have a different mental health profile from UMs who have come voluntarily to the Netherlands and who mostly are relatively young and healthy (‘healthy migrant effect’).

Schoevers et al\textsuperscript{5} studied the health situation and specific health problems of undocumented female migrants in the Netherlands, concluding that psychological problems were highly prevalent but seldom mentioned spontaneously. Although the prevalence of mental health problems, such as post-traumatic stress disorder, depression and anxiety is high among UMs in the Netherlands,\textsuperscript{22} it is unclear from primary healthcare data to what extent professional care is responding to these needs.\textsuperscript{23}

The aim of this study was to gain insight into the experiences of UMs: do UMs seek help for mental health problems, if so, where do they seek help and what are their experiences when consulting primary health care in the Netherlands for mental health problems? By focusing on their health-seeking behaviours, barriers and facilitators experienced when accessing care, and specific needs and expectations, this study intends to shed light on the perspectives of the UMs.
Method

Setting
A qualitative study using semistructured interviews was conducted with UMs residing in four cities in the Netherlands.

Recruitment and sampling
UMs were recruited through trusted representatives of UMs from voluntary support agencies, migrant organisations, churches, general practices and the researcher’s own informal network. These persons were asked to give the UMs a letter, written in plain English or Dutch. This letter contained information about the purpose of the research project and an introduction of the interviewer and the research team. The letter also explained that anonymity was assured and that participation was voluntary. We asked the UMs to inform the trusted representative if they agreed to participate. If so, the representative asked the UMs permission to give the interviewer a phone number to make an appointment.

Sampling was purposive, striving for maximum diversity in terms of age, country of origin and educational background.

Migrants were approached if undocumented, first generation, of non-Western descent and able to communicate sufficiently in the three languages the interviewer was competent in (English, Dutch or Swahili). Western UMs were not recruited for the study because this group was, after the expansion of the European Union in 2004 and 2007, small and consisted mainly of ‘cyclical workers’ returning home at the end of each working season.1 The reason to include UMs who were able to speak the same languages as the interviewer was the expectation that the presence of informal interpreters would hinder UMs to speak freely about precarious issues such as mental health problems. Use of phone interpreting services was often not possible, as most meetings were held in public places. Mental health problems were defined in the broadest sense of the word, from minor mental health complaints to severe psychopathology. This definition was written down in plain language in the letter to the UMs and explained in the interview.

Once the migrant agreed to participate, the researcher (JS) generated contact by telephone to explain the study in more detail and to make an appointment. The interview, lasting approximately 1 h, was conducted at a venue of the migrant’s choice. A small financial compensation was offered for their efforts.
Mental health problems of undocumented migrants (UMs) in the Netherlands: a qualitative exploration of help-seeking behaviour and experiences with primary care

Data collection
An interview guide was developed following a review of the available literature. Topics included help-seeking behaviour for psychological problems, experiences with the GP in the treatment of these problems, barriers and facilitators to this care, and expectations and needs. The interview guide did not contain explicit questions about the participants’ personal mental health problems, but did contain questions about UMs’ experiences with peers having mental health problems, vignettes with mental health issues, and some implicit questions about personal mental health problems in general. They were asked if they have ever visited a GP for mental health problems and how they experienced the care of the healthcare providers.

Additionally, sociodemographic questions were included, such as country of origin, housing conditions, social support systems, occupation, education and duration of and reason for stay in the Netherlands. The guide was adjusted and fine-tuned throughout the research process according to insights gained during the interviews. This semistructured interview schedule is included as supplementary appendix 1. The research was carried out between April and June 2013.

This project was part of the EU-Restore project. For this specific study we contacted the committee again and their decision remained as it was, on condition that the questions for the migrants were not confrontational or stressful.

Before the interview, participants received a detailed verbal explanation of the study and were informed of its anonymous nature, the safe storage of information and the right to refuse answering a question and to terminate the interview. They were explicitly informed that the interview was for research purposes only and that their information would not be shared with their GP or with anyone else.

All participants were interviewed by the same female researcher with a migrant background, in English, Dutch or Swahili (JS); and no third parties were present. The interviewer was instructed not to ask explicit questions about the UMs personal health status. Only if UMs disclosed these problems spontaneously, and after careful consideration that the questions or conversation were not confrontational or stressful, was the interviewer allowed to ask more personal questions. The interview was semistructured in nature, allowing the interviewer to tailor the questions to the context of the participant and enabling a flexible exploration of sometimes sensitive issues. New participants were included until theoretical saturation was reached.
Data analysis
The interviewer kept all the information of UMs in a secure database and interviews were recorded and transcribed anonymously ad verbatim in the same language as the interview. Analysis was based on grounded theory and by a constant comparative method the data was interpreted. The first interviews were read and re-read to gain an overall impression of the material and were analysed line-by-line and open coded by two individual researchers (JS and ET). A long list of concepts was generated and conflicting thoughts and interpretations about these concepts were discussed with other team members (MvdM and EvW-B). Once consensus was reached on the concepts, they were categorized into a more sophisticated scheme by gathering the themes that appear to relate to similar phenomena.

Once a provisional coding scheme was developed with overarching themes, researchers (JS and ET) coded the other interviews and started to move to axial coding, in which they looked for relationships between categories. Finally, a more selective coding was applied from which the core categories emerged, looking for plausible explanations to enable the drawing of conclusions.

We attempted to develop theoretical insights and during all stages of the analysis close attention was paid to deviant cases. Analysis was performed with Atlas Ti and relevant citations were selected and translated into English for the purpose of this article.

Results

Characteristics of the UMs
After 15 interviews no new themes emerged. Nine men and six women participated, with an age range of 21-73 years and representing the main non-Western migrant nationalities (box 1). Four patients were recruited via GPs, and 11 were recruited via trusted representatives of churches, migrant organisations and voluntary organisations. Additionally, the duration of and reason for stay in the Netherlands varied, respondents lived in different regions of the country and had different educational backgrounds. Further characteristics are illustrated in table 1.
Mental health problems of undocumented migrants (UMs) in the Netherlands: a qualitative exploration of help-seeking behaviour and experiences with primary care

Box 1: Countries of origin of the undocumented migrants

Country of origin
- Burundi
- Dominican Republic
- Egypt
- Eritrea
- Ghana
- Morocco
- Nepal
- Nigeria
- Philippines (2)
- Sierra Leone
- Somalia
- Surinam
- Uganda
- Zambia

Table 1: General characteristics undocumented migrants (UMs)

<table>
<thead>
<tr>
<th>General characteristics</th>
<th>UMNs (n=15)</th>
</tr>
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<tbody>
<tr>
<td>Age (years)*</td>
<td>40.3 (mean)</td>
</tr>
<tr>
<td></td>
<td>21 - 73 (range)</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>9</td>
</tr>
<tr>
<td>Female</td>
<td>6</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>2</td>
</tr>
<tr>
<td>Primary</td>
<td>5</td>
</tr>
<tr>
<td>Secondary</td>
<td>5</td>
</tr>
<tr>
<td>Tertiary</td>
<td>3</td>
</tr>
<tr>
<td>Reason to come to the Netherlands</td>
<td></td>
</tr>
<tr>
<td>Political</td>
<td>8</td>
</tr>
<tr>
<td>Economic</td>
<td>7</td>
</tr>
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### General characteristics UMs (n=15)

<table>
<thead>
<tr>
<th>Presence of family in the Netherlands</th>
<th>UMs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>3</td>
</tr>
<tr>
<td>No</td>
<td>12</td>
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</table>

<table>
<thead>
<tr>
<th>Housing</th>
<th>UMs</th>
</tr>
</thead>
<tbody>
<tr>
<td>With friends</td>
<td>8</td>
</tr>
<tr>
<td>With family&lt;sup&gt;b&lt;/sup&gt;</td>
<td>2</td>
</tr>
<tr>
<td>In organisation&lt;sup&gt;c&lt;/sup&gt;</td>
<td>3</td>
</tr>
<tr>
<td>Homeless</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Duration of residence in the Netherlands (years)</th>
<th>UMs</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.9 (mean)</td>
<td></td>
</tr>
<tr>
<td>&lt;1 - 23 (range)</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Duration of undocumented residence (years)</th>
<th>UMs</th>
</tr>
</thead>
<tbody>
<tr>
<td>6.6 (mean)&lt;sup&gt;d&lt;/sup&gt;</td>
<td></td>
</tr>
<tr>
<td>&lt;1 - 23 (range)</td>
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</tbody>
</table>

<sup>a</sup> One respondent did not know her age.

<sup>b</sup> With husband and/or children.

<sup>c</sup> Shared housing provided by migrant organisation.

<sup>d</sup> For one respondent the length of the undocumented residence was unclear.

Noteworthy was that most of the interviewed UMs did not have any family in the Netherlands. Friends formed a substantial and crucial basis for support. Voluntary support agencies and migrant organisations were also an important source of information which they often turned to in times of need (paperwork, bills, juridical advice, etc).

> ‘The hospital give me the bill for pay, I say ‘what?!’ I go home, I say ‘Maria (contact person at voluntary support agency), Maria, look!’ Maria say ‘come’, she see for the letter.’ (R9, female, Dominican Republic)

### Self-reported general and mental health

Of the 15 UMs, three reported their general health as good (‘good’ or ‘very good’), six as moderate and six as poor (‘bad’ or ‘very bad’). After the interviewer explained what was meant by mental health problems, the question whether they knew peers with mental health problems, and the presentation of vignettes with mental health problems, all but one respondent spontaneously reported some form of mental health problems.
During the interviews some respondents used remarks as ‘hearing voices’, ‘sleeping problems [caused] by stress’, ‘I always cry’, ‘to have nightmares’ and ‘stress and problems with husband,’ but did not mention them as mental health problems specifically. All these remarks were labelled by the researchers as mental health problems as well.

The majority of the UMs attributed their mental health problems to their status as UMs. Unemployment, precarious and insecure housing conditions, financial instability, fear of being arrested and deported, and constant worries about documents were mentioned repeatedly. A second perceived cause was traumatizing experiences in the country of origin (war, torture, prostitution) and worries about family members they left behind. One respondent believed that mental health problems were related to personal character traits; that despite difficult circumstances one could still stay positive. However, on the whole, respondents attributed their problems to a combination of factors: past experiences exacerbated by their current environment.

‘... mental problems because of the past experience from their country because go through wars, go through difficulties, I mean, loss of family members, those things are already make them mentally break down. And they when they came here also I mean, the paper issue are up again and then it break them finally.’ (R7, male, Sierra Leone)

**Contact with General Practice**

Thirteen of the UMs interviewed were registered with a GP practice. Two were not; one because she did not know she had the right to medical care and the other due to fear of deportation.

‘For undocumented we would say it’s illegal to be sick. So we don’t want to get sick you know because it is one thing that we like to avoid getting sick because of fear you know going to the doctor undocumented you’re personal data will be, I mean even to. Although I know we are, there is an existing right as far as I know, access to medical health care but sometimes you want it to make it sure.’ (R1, male, the Philippines)

Most reported having consulted the same GP since initial access to primary care had been achieved. If there was a change of practice this was due to the respondent moving residence, the GP retiring or receiving an appointment with a different GP in the same practice. However, it often took a considerable period (up to 6 years) to gain access to a GP in the first place. Reasons to this delay are discussed in more detail in the next sections.
The primary reason UMs visited the GP was because of physical symptoms. Most commonly mentioned were general and unspecified symptoms (eg, fatigue, chickenpox), skin problems (eg, wounds, acne), and respiratory problems (eg cough and lung problems). Only two out of the 15 interviewees mentioned mental health problems immediately when asked for the reasons they visited the GP. One of them mentioned psychological problems as reason for encounter, and another mentioned the need for psychotropic prescriptions. Overall, the GP still seemed to be perceived as a doctor who cures only physical ailments.

‘Headache, my hand, that hand, look, tuberculosis here, the hand is always not good for me, medicine for the blood pressure, my daughter girl of 6 years.’ (R4, female, Morocco)

Two UMs reported going straight to the emergency department of the hospital when confronted with serious illness. These were the two respondents who were not registered in a GP practice.

‘Well of course I would immediately call my friends and then of course we would decide to accompany me to emergency.’ (R1, male, the Philippines)

Experiences of primary care

Experiences of migrants with GP visits

The UMs answered questions about various aspects of the general practice visits: generally, they were satisfied with the services. Appointments were made by phone or passing by in person. Several interviews highlighted the preference of receiving an appointment immediately upon request; often UMs were willing to wait at the practice for as long as it took to see a doctor the same day.

In general, the general practice assistants (GPAs) were experienced as welcoming and friendly by the UMs. GPAs have an important role in Dutch general practice: they perform an administrative and clinical support function and are the first point of contact for patients, both at the reception desk and by phone. They briefly explore the reasons for encounter and schedule the appointments for GPs and practice nurses. GPAs also offer medical counselling to patients and assist GPs with small (surgical) procedures. Some small medical-technical proceedings are done independently by GPAs, for example giving injections and measuring blood pressure.
The waiting room was considered as comfortable and professional by all UMs. All but one migrant were satisfied with the timeslot they received with their GP. The privacy was considered to be adequate and most respondents experienced little to no communication problems. None of the UMs had experience with an interpreter in primary care and various respondents even expressed dislike towards this idea, mainly for privacy reasons. Information documented in the computer was not seen as a threat to privacy; on the contrary, this, and the ease with which prescriptions were digitally sent to the pharmacy, were valued. With a few exceptions, the respondents encountered no problems when collecting medication at the pharmacy.

‘Because when I go to the pharmacy they already know my history. It’s like when I have my medicine - yesterday - it has to be taken before mealtime but under record you have problems stomach so you take it after mealtime. So ok! Very good!’ (R8, female, the Philippines)

Although a few respondents had bad experiences.

‘The first time at the pharmacy I experienced no problems, but the second time there was a lady at the desk saying: sir, where is your legitimation? You have to pay for the medicines. But I can’t pay these medicines, I am not insured, I have nothing ...’ (R15, male, Egypt)

Positive experiences GP
The majority of the UMs were extremely satisfied with their GPs. Three main overarching reasons could be identified for this satisfaction: effective treatment, positive personal qualities of the GP and a good doctor-patient interaction. UMs appreciated effective treatment and timely referral when this was considered necessary. It increased the trust they had in their GP.

‘The doctor, good, very good. He the arm pain pain, I bring for me for the medicine, ouch no sleep, he say ok, he give the medicine for relax, yeah, is good!’ (R9, female, Dominican Republic)

Various positive qualities were identified and mentioned: being polite and respectful, friendly and compassionate, a good listener and understanding, intelligent and hardworking all contributed to the GP as being perceived as a ‘good doctor’. Encouragement especially was a recurrent theme that was apparently valued very highly.

‘Always smiling, organises everything, so everything neat, can’t say but a fat 9 (grade, out of 10) yes yes!’ (R15, male, Egypt)
The most important determinant of quality of care mentioned, however, was the nature of the interaction between the respondent and the GP. Important for a good doctor-patient relationship was the GP showing that he genuinely cared for the respondent. This could be through showing interest in their personal situation, performing physical examinations, giving explanations on the diagnosis and going just that step further to help. The following citation demonstrated this.

‘He always, he always explains everything to me. Whenever he wants to give me a drug he always asked me how it’s working, he sends me to lab (…) So he’s doing his best for me. Because if not him I don’t know what I would do! (laughter)’ (R13, male, Nigeria)

Negative experiences GP
A lack of personal interest, a lack of providing information and health education were mentioned as negative features of some GP encounters, as was emphasized by one UM who expressed missing these aspects in the contact with her GP:

‘Because I really want more information, something like I didn’t say ok, this is your sickness, ok, then this is the medicine, ok, then go. I want to know more, what cause of it, what is the prevention, how to avoid it, something like that. I don’t see it here.’ (R8, female, the Philippines)

Analysis of the data indicated that the extent to which the participant was satisfied with their GP was strongly determined by experiences with doctors in the country of origin. Aspects that were especially missed in the Netherlands were a longer and more in-depth consultation (more extensive), physical examination and additional tests.

‘Because in the Philippines when you go to the GP, they check everything, your heartbeat, they do some status like something like that, but here they just talk to you and they in the Philippines they have this medical doctor they check everything.’ (R8, female, the Philippines)

Furthermore, a theme that emerged in many of the interviews was the experienced emphasis of watchful waiting approaches by the GP and reliance on simple and safe self-medication (‘take rest and take paracetamol’). Many UMs expressed aversion towards this approach, but also mentioned that better explanation of the underlying motivation for this approach would nurture understanding and improve overall satisfaction for patients.
R: ‘Because when a person comes to you that you think the person does not require medication, you have to talk to the person the way what they need that they would take home. Like for example if let’s say the person does not take the medication talk to the person: ‘ok, you don’t need the medication this is your problem understand’.

I: ‘So you have to explain to the patient why you are not prescribing medication?’

R: ‘Exactly! Properly explain, let them understand your reason why they don’t need medication.’ (R7, male, Sierra Leone)

One participant spoke of how he had felt very embarrassed when, during his first visit, his GP had begun to ask ‘inappropriate’ questions related to the risk of tuberculosis and HIV/AIDS and not related to the reason for encounter. He expressed feeling discriminated against and explained how this experience had tainted the relationship with his GP.

‘The reason why he asked me those questions, maybe it is like he thought like for example I am an immigrant or maybe I don’t have a paper. That is it. I am educated, I know those questions.’

(R7, male, Sierra Leone)

Help-seeking behaviour for mental problems

In our study population, eight UMs were receiving some sort of professional help for mental health problems; either from psychiatrists or psychologists (6) or from their GP (2). Five UMs received no help and one reported not having any mental health problems to seek help for.

While these numbers suggest that a substantial proportion of the study population visited their GP with mental health problems, UMs indicated that professional medical care was only sought after other means had failed. The concept of the GP being a ‘last resort’ emerged consistently throughout the data, with UMs exploring alternatives first. These included undertaking activities to divert oneself (walking, reading, watching TV, spending time with friends, working, joining community activities), asking advice from others (friends, pastor) and turning to God. The pivotal role of God in dealing with mental health problems was mentioned by all UMs.

‘The most important is something is if I’m so stressed I pray. Because those things they bring me relief because praying is like I put all, everything into the feet of God.’ (R7, male, Sierra Leone)
One migrant reported using a friend’s psychotropic medication when he had no access to care. Friends formed an important source of support for the majority of the respondents. Confiding in them and speaking openly about mental health problems was perceived as a healthy means of coping with the problems. Yet this was mentioned with reservation. Some UM explained they preferred to keep mental health problems to themselves because of fear of gossip in their community (Dominican Republic, Morocco, Ghana, Somalia), fear of being shunned (Sierra Leone, Somalia) or because that was how you deal with mental health problems in the country of origin (the Philippines). The respondent from Sierra Leone described how the stigma associated with mental health problems in African communities often caused patients to lose all their friends.

‘Yes friends, yes I talk to some friends but some friends if you tell them they will started saying you’re crazy. So I don’t tell many people.’ (R2, male, Ghana)

The reliance on these help-seeking alternatives seemed unaffected by their status, as all but two UMs told they would do the same if they had a residence permit. Only the two UMs who did not have a GP stated they would act differently if they had not been undocumented.

‘If I had a residence permit I would go to a doctor for professional advice. And I would also see my friends too! But yes, absolutely, it’s different advice from the expert and from friends.’ (R1, male, the Philippines)

**Barriers in accessing professional health care**

Reasons for the GP being considered a last resort for treatment of mental health problems can be classified under two main categories: general barriers and barriers specific to mental health care.

**General barriers**

Lack of knowledge about the right to medical health care and where and how to attain it was a major theme highlighted across the interviews. The majority of the UMs - including the ones who were being treated for their mental health problems - described how this (had) impeded their access to general practice. It was through voluntary support agencies, migrant organisations and lawyers that they were informed of the options and steps to find a GP followed.

‘There were times I was sick, I was not getting medication, because I was outside the procedure, I didn’t know where to go to get medication.’ (R5, male, Burundi)

Fear of prosecution was also an important factor deterring respondents from visiting the GP.
'So when the pills got finished I didn’t know what to do! And I was a little bit freaked out because I didn’t know what to do, I didn’t want to go back to prison, I was locked up for ten months without committing any crime. So I was a little bit freaked out about who, I didn’t know where to go, who to talk to. So I was a little bit reluctant and I waited for three months, but I realised I’m not doing ok. I realised I’m not doing ok, I need help.’ (R6, male, Uganda)

A third important factor was fear of financial costs:

‘Because I’ve heard about the doctor, yeah because I don’t have insurance, I don’t have the insurance so I was thinking, I’m not sure, before I go to the doctor too much, then one day I have to pay.’ (R8, female, the Philippines)

Two UMs expressed concerns of being discriminated on basis of their undocumented status.

‘Yeah and then the person information they don’t have insurance, they then they won’t look at you in the same, different look yeah. That’s also one thing, when no insurance then they will look at you something like ‘hmph’.‘ (R8, female, the Philippines)

Having said this however, most UMs did state that in their experiences GPs did not treated them differently because of their undocumented status.

‘As far as the doctor is concerned I believe they don’t see whether you are documented or undocumented.’ (R1, male Philippines)

Mistrust in Dutch doctors was also mentioned as a disincentive by the Somali participant. She explained how a combination of superstition, negative experiences and conspiracy theories about Dutch healthcare spread in the community and made her more hesitant to visit a GP.

‘The women who have experience, they tell me: ‘(name respondent) don’t.’ They are so scared. ‘(name respondent) never go to a hospital, no, never, you say I have headache, they take your kidneys!’ You know they believe that? (…)People tend to get more scared of the care, coz when you say you have psychological problems, and one day just break down, they just insert you the valium thing or whatever, I don’t know, and they take you, they have specific building for those people with the break down, you know.’ (R14, female, Somalia)

There were also practical barriers that impeded access to medical care, such as the distance to the medical centre and inability to pay for transport and having to cancel work for the appointment.
‘Also, because I have to cancel my job also, I go there I have to I mean when I ask sometimes yeah even when I ask with the doctor that ‘can I have on this time on this day’, they say ‘no no’, or something like I have to follow their schedule, but I have work!’ (R6, female, the Philippines)

Barriers specific to mental health care
Prominent in the majority of the interviews was the notion that a GP was responsible for treating physical ailments and possessed no expertise when it came to managing mental health problems. The following citation demonstrated unawareness in the GP as a doctor of mental health.

‘Yeah but we didn’t knew that you can go to a GP with depression, we didn’t know that.’ (R8, female, the Philippines)

Certain UMs based their distrust in the GP on past experiences in which both medication as well as ‘talking and talking’ had not solved anything.

‘I don’t want to remember. Finish! For what? I talk two, three years, nobody help me, for what I will talk?(...)This people they say if you talk it’s good they think, but it’s not good (...) my eyes every time I cry if I talk to you like this, every day, every week, I’m tired.’ (R10, female, Eritrea)

Sometimes the attitude of the GP kept respondents from talking about their mental problems. One UMs explained how she would have liked to speak to her GP about her mental health problems but his perceived uninterested and unconcerned attitude prevented her from doing so.

‘Because I don’t know, it never came up with the topic, he only said that what is your complaint and that, because they don’t ask me many things because especially if I have a problem, they don’t ask about it, it’s just what’s your problem, I say ok, you say what you complain about, ok are these your complaints, ok this is your medicine.’

Some UMs also thought that mental health problems did not belong with a doctor, were a natural part of every day life and could only be solved by oneself.

‘No, but I say the doctor this is normal problem for my, for my problem. (...) This not for the doctor no. For me!’ (R9, female, Dominican Republic)
For certain UMs, the stigma and taboo associated with mental health problems was also a barrier in consulting the GP.

‘Because I’ve never thought of going, in my culture going to a psychologist, something you are already mad, insane, in our culture, even yeah I just now when you’re angry or you’re just a little depressed then you can go to psychology, but in the Philippines it’s a once you go to a psychiatrist or a psychology then there is a notion that something already in your mind, so you’re insane already, so.’ (R8, female, the Philippines)

Facilitators in accessing professional health care

In contrast with the experiences of the UMs discussed above, various UMs did report confidence in the ability of their GP to help them with mental health problems. Some trusted their GPs because they had established a previous positive relationship with them, whereas others saw their doctor as a professional with expertise in this subject.

‘Of course a doctor is the expert in addressing that kind of problems, psychological problems.’ (R1, male, the Philippines)

Another important facilitator was knowledge and information. Confidence in their right to medical care and the assurance of confidentiality and financial warranty were the reasons for most UMs to finally take the step of visiting a GP. Voluntary support agencies, migrant organisations and lawyers played an important role here.

‘Because the GAST organisation (voluntary support agency), they, when you have a contract with them, or when you, they get all decide to help you, they give you this form to explain to you the right you have when you’re there. If you seek you have the access to medical treatment, so that give me the right or the confidence.’ (R7, male, Sierra Leone)

When the GP had been visited once, familiarity with the system and positive experiences with primary care facilitated the UMs in visiting again.

‘Let’s say because I have already been many times. And when I am with her (the GP) many times, other times I am free I take a phone and call her to make an appointment since I’m used to it.’ (R5, male, Burundi)
Solutions for mental health problems
When possible solutions to existing mental health problems were discussed, all UMs unanimously agreed that receiving a residence permit was the most important factor. It would cater to many of the problems associated with their current undocumented status causing the mental problems: work, income, accommodation and freedom of travel for instance.

R: ‘Because I know my problem is when I have documentation I will get a relief.’
I: ‘Yes?’
R: ‘Yeah, I hope.’
I: ‘What would you get a relief from?’
R: ‘Yeah from thinking, because now I can’t do anything. I can’t do nothing without documents you know. So it’s a difficult situation, though I live, I have somewhere to sleep, I eat, but you know, life must go on, you know. I cannot stay like this.’ (R13, male, Nigeria)

Asked about their expectations of professional care for mental problems the UMs had little idea about the various forms of treatment the GP could offer or about their own preferences. The decision was often left to the GP, placing blind trust in him as a professional.

‘Doctor knows these things for patients. He knows how to help.’ (R3, male, Nepal)

Medication was suggested by a few UMs as a possible means of treatment. However, nearly all 15 UMs emphasized that medication alone could not solve anything. Many were reluctant to take psychotropics. The GP as a means of support and as someone who listened, encouraged and provided professional advice was given preference.

‘If I am so sick, and so tired, and so scared, and I think about what I can do, what I have, what this, what that. And then I go to the doctor and she speaks to me, so nicely, that is also medicine! You know? If she start to speak to me, that is medicine (...) Speak and let me speak with you. Or what is inside my head, that is what I mean. But medicine is not going to solve.’ (R15, male, Egypt)

When it came to other forms of help a GP could offer, opinions were divided. A number of UMs expressed strong beliefs that it was the GP’s responsibility to help them acquire a residence permit, for instance through writing medical reports to the authorities. One respondent mentioned explicitly how important it was for GPs to go beyond their strict role as health workers and also accommodate to the other needs of UMs, such as providing information on where to get shelter and food.
Some of them (...) think the doctors can get them out of the situation. Like for example, like writing back to the authority (...) Because the doctors have to reach out, they have to do their reach out more, they have to go beyond their medical practice, beyond!' (R7, male, Sierra Leone)

Yet others remarked that they did not see their GP as the most appropriate person to do this.

‘She’s (the GP) like ‘well that is not good, but we cannot do anything about that, the only help we can give you here is medical assistance’. And I understood it, and I respect it coz I mean, it’s like going to a bookshop to buy shoes. It’s not there!’ (R6, male, Uganda)

Discussion

Summary of main findings and comparison with existing literature
Concordant with previous Dutch studies among UMs, mental health problems were frequently reported by the UMs. These problems were spontaneously reported throughout the interviews without explicitly being asked about, and that counted for their own as well as those of other undocumented relatives. The majority of the respondents were under the impression that their mental health problems and those of their peers were directly related to their status as UMs. This is a finding that has not emerged so clearly in earlier research and indicates that UMs regard their mental health problems as ‘a normal response to an abnormal situation.’ Knowledge about the effects of the lack of status on the different areas of life seems to be essential for health care providers helping UMs with mental health problems. This knowledge might help the GP to find the underlying reasons for their mental health problems and might prevent unnecessarily ‘medicalising’ and ‘pathologising’ of UMs psychological responses to their difficult life circumstances.

Even though most migrants reported having mental health problems, they rated their general wellbeing as better than expected based on an earlier study with 100 undocumented women in the Netherlands in which 65% rated their health as ‘poor’. Possible explanations for this disparity include the different rating scales used (Schoevers et al distinguish only two categories (moderate/poor and good/very good excellent)), the inclusion of men in our study, and the facts that in our study population all could speak English or Dutch and already had access to a GP and received some form of psychological treatment. The challenge for further studies lies in recruiting the ‘hidden’ group of UMs with mental health problems lacking local language skills and access to health care.
The GP as a ‘last resort’ for help in case of mental problems is a theme that emerged consistently throughout the data, with UMs exploring alternatives first. This does not seem very different from what native patients do; primary care research in Australia showed that patients with depression explored many alternatives to cope with mental distress, but contrary to the UMs interviewed by us, a lot of these patients considered the GP a first resource of help for their depression.28 Nevertheless, a large number of native patients diagnosed with mental disorders did not present their mental health problems to a GP either.29

All UMs interviewed used religion and religious rituals as important positive coping mechanisms to deal with mental distress. A Dutch study comparing indigenous patients with migrant patients showed that this positive coping mechanism was found in many documented migrants as well, but much less frequent in Dutch citizens, of whom the majority had no affinity with religion.30

In contrast with Dutch citizens and documented migrants with depression and depressive symptoms, none of the UMs reported negative coping mechanisms such as abandonment-by-God or expression of anger to God.30 Perhaps this can be explained by the fact that nearly half of the UMs interviewed was of Muslim origin, a group known to have generally lower scores for negative religious coping.30 Additionally, the fact that the interviewer was of Muslim origin as well might have contributed to a more positive expression of religion, as critical expressions towards Allah possibly evoked the worry that the interviewer regarded the respondent as a non-true Muslim.30

The crucial role of friends as a source of support in times of mental distress was a striking finding of this study. For indigenous patients, friends were an informal source of help as well, but their role was less outspoken.

Although friends were an important source of help for some UMs, they were also often cautious about speaking to friends about their mental health out of fear of rejection and gossip, a phenomenon well known among documented migrants as well.31,32 Fear for stigmatization by friends was reported in Caucasian patients as well, as shown in a US primary care study and was not clearly associated with ethnicity.33
None of the UMIs mentioned family as an important informal source of support in times of distress, even though most came from collectivistic family-oriented cultures. An explanation for the fact that none of the interviewed UMIs mentioned family as a source of support, could be caused by the fact that the large majority had no family nearby, and that they received support from friends instead of from the family members. This needs to be further explored.

Factors that inhibited UMIs from visiting a GP when confronted with mental distress could be categorized into general barriers and barriers specific to mental health. The general barriers included a lack of knowledge concerning the right and means of access to primary health care; fear of prosecution; fear of financial contribution; and practical difficulties. This was in accordance to findings of previous research and also the perceived barriers of GPs. However, contrary to expectations, language was not cited as a barrier in this study even though no interpreting service was used in consultations with the participants. Our findings contradict other studies with UMIs that showed that language was a main obstacle to access primary health care, and often a main barrier to discuss mental health problems with a GP. Once again, this could be partly explained by selection bias introduced by including only respondents who were able to understand the three languages the interviewer was competent in.

Unawareness and a lack of trust were the main barriers specific to mental health; not recognising and not trusting the GP as a doctor who could treat mental illness. The lack of trust was often provoked by past negative experiences. Furthermore, factors such as an unfavourable relation with the GP, stigma and taboo associated with mental distress and the belief that problems needed to be solved individually also induced alternative help seeking means. These findings were supported by Dutch and European literature on the mental health of migrants in general and many of these barriers accounted for other hard-to-reach groups as well.

These factors might explain why UMIs often did not mention mental health problems as a reason for encounter to visit a GP. The taboo on discussing mental health problems was a striking finding of this study. Most of the respondents who mentioned this came from African communities, known to have strong collectivistic oriented cultures. At the same time, some African UMIs said that they did not experience mental health problems as a taboo at all, indicating that there is a large variety of opinion about this within the same communities.
Initial access to health care was often found to be problematic, but once access has been gained, overall satisfaction with primary care was exceptionally high. Contrary to another Dutch report, no huge impediments existed in the continuity of care.\textsuperscript{10} Perhaps satisfaction bias was introduced through the inclusion of UMs who were referred to or registered at practices in which GPs had affinity with this group. Another explanation may be the dependent position UMs find themselves in, as one respondent mentioned: ‘Beggars can’t be choosers’ (R6, male, Uganda) and thus respondents opted to be optimistic and grateful.

As for expectations of primary health care concerning mental health problems: when it came to the treatment specifically, most had a paternalistic mentality with the notion that the doctor knew best. This is in concordance with the way in which many healthcare systems outside Western Europe function and the role of doctors there.\textsuperscript{36} Aside from this however, respondents expressed opposing views. Whereas some thought that a GP had the responsibility of solving practical difficulties associated with a lack of documents, others did not consider the GP to be the right person to arrange this. All UMs had a similar view on prescription of psychotropic medication by GPs: similar to findings in another study, respondents were more inclined to approve of a GP who listened and gave advice than one who only prescribed medication for mental health problems.\textsuperscript{37}

\textit{New findings}

To the best of our knowledge, this is the first study that explores the help-seeking behaviour of UMs for mental health problems and their experiences when consulting primary health care for these problems.

We find that:

- Most UMs cited the lack of documents as the main problem that contributed to their distress.
- UMs explore a wide range of different strategies to cope with mental distress; religious support and support from friends are the most outspoken sources of support; family is never mentioned.
- There is a large time-delay before UMs consult a GP and when they do, they often believe that it is not the role of a GP to help with mental distress.
- A substantial part of the UMs think that practical support associated with the lack of documents (eg, writing letters to a lawyer) is a domain of the doctor.
- None of the UMs seem to mind recording of their information in the electronic medical record (EMR).
Strengths and limitations of the study

This study is the first to focus specifically on ways UMs seek help for mental health problems and offers interesting new insights into a group that is usually hidden from society’s view. The current parliamentary debate on the criminalisation of illegal residence in the Netherlands is receiving much public attention. Because of the sensitivity of this discourse it was challenging to recruit participants, yet it made the study more rewarding as it offers a timely contribution. Although concentrating on the Dutch situation, access to healthcare is restricted in other countries too. We therefore think that the findings of this study are generalisable to many other countries despite varying national policies and health care systems.4,38,39

The recruitment method, using stakeholders from many different organisations to recruit participants resulted in a good representation of the different sub-groups of UMs in the Netherlands who have access to and experience with general practice. A strength of this study was that we were able to have UMs interviewed by the same medical student - researcher who spoke Dutch, English and Swahili. The fact that all interviews were conducted without the presence of any third parties at a location where respondents felt safe, by an interviewer with migrant roots herself, created an atmosphere of honesty and openness, resulting in valuable information and insights. Participants felt safe to express themselves, as was illustrated by the fact that none of the respondents had problems with taping the interview and all spontaneously reported mental health problems without being asked to do so.

Methodological limitations included the fact that all UMs, with a few exceptions, were registered in a general practice so this study did not represent the group of UMs without access to general practice. Nevertheless, many spoke of their experiences in retrospect or about peers without access to a GP, providing the researchers with valuable insight into the means and routes undertaken to gain this access. Furthermore, only UMs who were able to communicate with the interviewer without the help of interpreting services or informal interpreters were included in the study. This could have biased the results, especially since linguistically stronger individuals are often more informed of their rights. It could also explain the surprisingly low incidence of language barriers experienced. Another limitation was that the coding and thematic review was not shared with the UMs participants. This is generally recommended but was not possible in the timeframe of a 3-month student research project.40
Implications for policy makers and clinical practice

From the interviews evolves a picture that UMs are very satisfied with the help of their GP, but at the same time, they do not consult a GP for mental health problems. Although most UMs visit the same GP for their health problems, and mention to have a good relationship with this GP, UMs do not perceive this GP to be the person to help them with mental health problems as well. This perception, in combination with the stigma and taboo around mental health problems and the UM’s assumption that their mental health problems are caused by external factors, namely their illegal status, seem to be the main barriers why UMs do not ask for help for their mental health problems when they are in contact with a GP. This is a problem of main concern, as professional help can be effective.

On policy level, several recommendations can be made. A first recommendation is to engage UMs as stakeholders to help other UMs to gain access to primary care; for example by informing their peers about the key role of the GP in the recognition and treatment of mental health problems. The recruitment of UM stakeholders needs to be done in close co-operation with primary care organisations, mental health care organisations and advocacy groups.

Second, we suggest that primary care organisations make the problems around (mental) health care for UMs more transparent; not only for primary care professionals and policymakers but also for the native Dutch population. In the current political climate in the Netherlands, in which UMs are being criminalised, they are becoming more isolated in society. Further criminalisation and isolation have negative consequences for their mental health, and will contribute to further inequity of care. By getting this message on the political and public agenda, primary care organisations can help to protect the fundamental rights of this vulnerable group of patients.

Acknowledgements

We wish to thank all migrants who participated in our research.
Appendix 1: Semi-structured interview schedule

My name is Jamilah Sherally and I am studying to be a doctor in Nijmegen. I am doing research through which we would like to discover what migrants think about the care given by their family doctors (huisarts). Once we know this, we can let family doctors know what migrants find important and how they can take care of their patients in the best possible manner. Family doctors often find this difficult, especially for patients with psychological problems. This could be anything, from stress to thinking too much, being sad, having nightmares, finding life tough and being afraid, but also for example hearing voices that do not exist or reliving unpleasant experiences. That is why I would like to speak to you about your experiences with family doctors and with psychological problems.

This interview will take approximately one hour. If you would rather not answer a question this is no problem, you just have to tell me so. You can also stop with the interview at any time. Everything you say stays between you and me. No one else will hear what you said, not even your own family doctor.

I would like to record this conversation on a voice recorder. Later on I will listen to the interview again and use your answers for the research. Then I will delete the conversation from the voice recorder. Are you ok with that?

Is everything clear? Do you have any questions? Can we start?

I will start with some general information about you:

A. Personal details
   Gender
   Country of birth (Where were you born?)
   Age (How old are you?)
   Social context (How do you live? With who do you live? Where is your family?)
   Reason of coming to the Netherlands (Why did you come to the Netherlands?)
   Time in the Netherlands (How long have you lived in the Netherlands?)
   Length of undocumented stay in the Netherlands. Length of undocumented stay in other countries (How long have you not had a residence permit in the Netherlands? Time spent in an AZC does not count. How long have you not had a residence permit in general, so also in other countries?)
   Education (What kind of education have you had? Primary school/Secondary school/University? How many years of primary school in case it is primary school?)
   Literacy: Can you read?
Can you write?
If yes: Can you read and write in Dutch? Can you read and write in English?
Profession (what kind of job did you have in your country (of origin)? What kind of job do you have here?)

**B. Help-seeking behaviour**
How would you describe your general health? As ‘excellent’, ‘good’, ‘moderate’, ‘bad/poor’ or ‘very bad/poor’?
Do you have a family doctor/huisarts?
If no: why not?
If yes: how did you find this family doctor? How long have you had this family doctor? Do you know if you are registered in the clinic of this family doctor?
Have you had more than one family doctor here in the Netherlands?
If yes: how many? In the same clinic or different ones? Why did you change from family doctor?
With what kind of complaints/problems do you go to your family doctor?
Do you know people with psychological problems?
If yes: what kind of problems are these?
What causes these problems?
What helps for these problems?
Do you ever talk to your family doctor about psychological problems?
If not: with whom do you talk about these problems? (Family? Friends? Religious leader? Community leader? Doctor in country of origin?)
Now I am going to name some examples of psychological problems and I would like to know what you would do if you were suffering from them:
Let’s say you have headaches because you are not sleeping well due to worries, what would you do?
Let’s day you are staying inside the whole day because you are too scared to go outside, what would you do?
Let’s day you are very sad and don’t see purpose/meaning in life anymore, what would you do?
Do you think a family doctor could help solve problems such as not being able to sleep, fear or sadness? Why? Why not?

**C. Experiences with the family doctor in the treatment of psychological problems**
Have you ever joined someone else who went to the family doctor with psychological problems?
How did this go?
Did you experience any problems?
What did you think of the communication/interaction with the family doctor?
What did you think of the advice and treatment that the family doctor gave?
Did this meet your expectations? Was the person you went with satisfied?
What was the treatment suggested? Did the one you went with have to:
  - Get medication?
  - Go to the RIAGG/GGZ?
  - Go to a social worker?
  - Go to a psychologist?
  - Go to a psychiatrist?
How did this go?

Have you ever visited a family doctor with psychological problems yourself?

If you think back of the last time you visited a family doctor with psychological problems, what went well and what went less well:

a) Before the visit:
  - making an appointment (Who arranges this for you? Do you make a phonecall? Do you pass by? How is the interaction with the assistant? How did payment go? Did you feel comfortable?)

b) During the visit:
  - entry into the clinic (Did you know where to go? Did you feel comfortable? How was the interaction with the assistant?)
  - waiting room (Did you feel comfortable?)
  - communication with the family doctor (Did you manage to explain your problems to the family doctor? Was there someone else with you? Did you have the feeling that your family doctor understood you? Was there enough privacy? Was there enough time? Did you trust your family doctor? Was there an interpreter/translator? Did you like this?)

c) After the visit:
  - Treatment (What did you think of the treatment suggested? Did you agree with it? Did you know what you had to do? Were there any problems in doing so? For example in getting medication or visiting other health workers such as a social worker, psychologist, psychiatrist?)
  - Was the problem solved after your visit to the family doctor?

_E. Barriers and facilitators help-seeking behaviour_

What makes it easy to go to the family doctor?
What makes it difficult to go to the family doctor?
Would you go to the family doctor more easily if you had a residence permit?
Chapter 3

F. Expectations
If you would visit the family doctor with psychological problems, what would you want him/her to do?

G. Needs and wishes
Let’s say a good friend of yours with the same cultural background decides to go to the family doctor with psychological problems. What would the family doctor have to take into consideration? How would your friend be helped best?

Are you satisfied about the primary health care in the Netherlands? If yes, about what in particular?

What could be better in primary health care in the Netherlands?

What would make you visit the family doctor more often with psychological problems?

H. Additional information
Is there anything else you would like to say?
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Mental health problems of undocumented migrants in the Netherlands
a qualitative exploration of recognition, recording and treatment by General Practitioners

Erik Teunissen, Eric van Bavel, Francine van den Driessen Mareeuw, Anne MacFarlane, Evelyn van Weel-Baumgarten, Maria van den Muijsenbergh, Chris van Weel

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Abstract

Objective
To explore the views and experiences of general practitioners (GPs) in relation to recognition, recording, and treatment of mental health problems of undocumented migrants (UMs), and to gain insight in the reasons for under-registration of mental health problems in the electronic medical records.

Design
Qualitative study design with semi-structured interviews using a topic guide.

Subjects and Setting
Sixteen GPs in the Netherlands with clinical expertise in the care of UMs.

Results
GPs recognized many mental health problems in UMs. Barriers that prevented them from recording these problems and from delivering appropriate care were their low consultation rates, physical presentation of mental health problems, high number of other problems, the UM’s lack of trust towards health care professionals, and cultural differences in health beliefs and language barriers. Referrals to mental health care organisations were often seen as problematic by GPs. To overcome these barriers, GPs provided personalized care as much as possible, referred to other primary care professionals as social workers or mental health care nurses in their practice, and were a little less restrictive in prescribing psychotropics than guidelines recommended.

Conclusions
GPs experienced a variety of barriers in engaging with UMs when identifying or suspecting mental health problems. This explains why there is a gap between the high recognition of mental health problems and the low recording of these problems in general practice files. It is recommended that GPs address mental health problems more actively, strive for continuity of care in order to gain trust of the UMs, and look for opportunities to provide mental care that is accessible and acceptable for UMs.
Introduction

In the European Union, between 2.8 to 6 million migrants reside without a legal staying permit. Most of these so called undocumented migrants (UMs) live in difficult circumstances, characterized by poor living and working conditions and problems in accessing health care services. These difficult living conditions coupled with uncertain future perspectives lead to mental distress: mental health problems are highly prevalent amongst UMs.2-4

Between 60,000 and 133,000 UMs reside in the Netherlands, mainly men under 40 years of age originating from Africa, Asia and Eastern-Europe. Between 11-33% are rejected asylum seekers.5 The Netherlands is one of the few EU member states where UMs are entitled to health services access beyond emergency care.16 They have the right to receive ‘medically necessary care’, which means that UMs have the right to receive the same usual care by the same professional standards and guidelines as other patients.7 However, UMs do not have the right to get health care insurance. If UMs are not able to pay for health care provisions themselves, health care professionals and institutions can gain reimbursement for their costs.8 As general practitioners (GPs) and primary care have a gatekeeping or navigation function in the Dutch health care system,9 primary care is the main health care provision for UMs. In this, GPs provide comprehensive care that includes prevention and all physical and mental health problems.8,10 In the Netherlands, GPs have a fixed practice list and every insured patient is enlisted with one general practice. UMs are not officially part of this practice list, and have the right to visit every GP. GPs have the opportunity to make an electronical medical record of the UMs and to register them as uninsured patients.

Given their uncertain socio-economic situation and difficult personal experiences,4 it is a reasonable assumption to expect poor health status among UMs, and in particular poor mental health.2-4 This may underline the need for access to health care for this group. However, despite the above-mentioned rights of UMs to obtain health care and the possible reimbursement for health care professionals,8 there are contradictory reports of the levels of mental health problems presented, recorded and treated in primary care.11-13 While one study showed that mental health problems were frequently presented in primary care,11 other studies showed low recording rates of mental health problems and low prescription rates of psychotropics.12-13 These studies indicate a gap between the high prevalence of mental health problems presented by UMs and the low recording of these problems by GPs. A number of reasons could play a role here: structural aspects of the health care system itself (access and finance issues), the complexity of interactions between UMs and GPs who have different language or cultural backgrounds, and also the GPs as providers (a minority of GPs considered emergency care only as part of their responsibilities for UMs).
These GPs didn’t consider non-emergency care, for example care for mental health problems, as one of their tasks. However, this requires further empirical investigation and this qualitative study was designed to address this gap in knowledge. This study is part of a larger research project, including research where UMs were interviewed about their mental health problems, mental health needs and their experiences with primary care. The aim of this study was to gain insight into the way GPs approached mental health in UMs and barriers they encountered in the consultations that impacted on recognition, recording and treatment.

**Methods**

**Recruitment and sampling**
To recruit GPs with UMs on their practice list we contacted general practices in seven cities involved in the care of UMs and/or located in areas where many UMs were residing. These areas were identified based on estimations from migrant organisations and from a previous study on UMs in the Netherlands. Sampling of GPs was purposive, striving for maximum diversity in terms of age, practice location and practice organization. Using the procedure described above, we approached general practices for participation in the study, using a letter giving information about the research project.

**Data collection**
An interview topic guide was developed based on a review of the available literature and on the basis of expert opinions (MvdM, EvW-B). Topics included barriers and facilitators in the GPs’ work in these consultations with specific attention to recognition, recording, and treatment of mental health problems of UMs. In order to gain more insight into the specific impacts of consulting with UMs, the topic guide also included barriers and facilitators regarding consultations with documented migrants (DMs). Additionally, socio-demographic questions were included such as GP and practice characteristics. As per the iterative process in qualitative research, this topic guide was adjusted and fine-tuned throughout the research process according to insights gained during the interviews.

All GPs were interviewed in their own practices by two medical students (EvB, LvdB), who were trained by two senior researchers, an experienced GP with expertise in UMs (MvdM) and a GP specialized in communication skills (EvW-B). All interviews were audio taped with permission of the participating GPs. The interview was semi-structured in nature, allowing the interviewers to tailor the questions to the context of the participant. Interviews were conducted until no new information was imparted, and theoretical saturation had thus been reached.
This project was submitted for ethical approval and was waived by the Ethical committee of the Radboud University Medical Centre (Nijmegen, the Netherlands) on the grounds that analysis of health care professionals into the quality of their care - in this case of UMs - was an integral part of their professionalism.22

Data analysis
Interviewees were assigned codes and all interviews were processed anonymously and transcribed verbatim. Analysis was based on a constant comparative method.23 The first four interviews were read and re-read to gain an overall impression of the material and were analysed line-by-line and open coded by two individual researchers (EvB and ET). A list of themes was generated and conflicting thoughts and interpretations about these concepts were discussed with other team members (LvdB, MvdM, FvDM, and EvW-B). When consensus was reached on the themes, they were categorized into a more sophisticated scheme by combining themes that were conceptually related.

Once a provisional coding scheme with overarching themes was developed, researchers EvB and ET coded the other 12 interviews and started to move to axial coding, in which they looked for relationships between categories. Finally, a more selective coding was applied from which the core categories emerged, looking for plausible explanations to enable the drawing of conclusions.

We attempted to develop theoretical insights and during all stages of the analysis close attention was paid to deviant cases. Coding and analysis were performed with Atlas Ti (atlasti.com) and relevant citations were selected and translated into English for the purpose of this article.

Results

Characteristics of the study population
Sixteen GPs participated in our study; they were aged between 30 and 64 years and nine were male. Their practices were located in Nijmegen, Amsterdam, Utrecht, Rotterdam, The Hague and Deventer. The GPs estimated the percentage of migrants on the practice list, documented as well as undocumented, to comprise between 6% and 95% of the total practice list. The total number of UMs ranged from five to 600 per practice list, with an average of 141. Three GPs were unable to estimate the number of UMs on their practice list, and made an estimation of the number of UMs who consulted them in one month. Two of them estimated seeing 1-2 UMs per month, and one estimated seeing 15 UMs per month. These characteristics, and further characteristics of the practice (practice organisation, practice list and number of documented migrants), are presented in Table 1.
Table 1. Characteristics of the GPs, location of the practice, practice organization, practice list, number of documented migrants in practice, and number of undocumented migrants in practice.

<table>
<thead>
<tr>
<th>General practitioner</th>
<th>Gender (M=male, F=female)</th>
<th>Age</th>
<th>Location of practice</th>
<th>Practice organization</th>
<th>Practice list</th>
<th>Number of documented migrants in practice</th>
<th>Number of undocumented migrants in practice</th>
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<tbody>
<tr>
<td>GP1</td>
<td>F</td>
<td>55</td>
<td>Nijmegen</td>
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<td>180</td>
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<td>Duo practice</td>
<td>Own</td>
<td>2363</td>
<td>400</td>
</tr>
<tr>
<td>GP3</td>
<td>M</td>
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<td>Amsterdam</td>
<td>Duo practice</td>
<td>Own</td>
<td>1733</td>
<td>200</td>
</tr>
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<td>M</td>
<td>46</td>
<td>Utrecht</td>
<td>Group practice</td>
<td>Own</td>
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<td>20</td>
</tr>
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<td>Own</td>
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</tr>
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<td>55</td>
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<td>Own</td>
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<td>55</td>
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</table>

Note: *Special general practice for homeless patients.
Results from the interviews

Disclosure of mental health problems by UMs

Although the GPs believed that almost every UM must have mental health problems, they had the impression that UMs waited longer, compared with DMs, before consulting them and presenting mental health problems. GPs assumed that lack of knowledge concerning the right to medical care, feelings of shame about illegal residency, fear of reporting to authorities, and other priorities of UMs were contributing factors. The presumed medical role of the GP, and the lack of friends or relatives who could encourage the UMs to visit a GP for mental health problems were also mentioned as possible reasons.

A few GPs explained that rejected asylum seekers were an exception to the rule: this group of UMs presented mental health problems at an earlier stage than other UMs. GPs assumed that rejected asylum seekers were, more than other UMs, familiar with the coordinating role of GPs in the recognition and treatment of mental health problems, because they got acquainted with Dutch GP care in the asylum seeker centre.

In general, UMs presented their mental health problems more often through physical symptoms than DMs. GPs thought that a physical presentation of distress happened more in UMs than in DMs because UMs more often lack the necessary trust in the GP to present mental health problems. The following quote illustrates that lack of trust plays an important role:

‘It is complicated to discuss mental health issues with UMs. Sometimes you have to deal with people who are extremely distrustful and fearful, so they don’t tell you many things.’ (GP1)

According the GPs this has to do with a general lack of trust in professionals among UMs and with the lack of continuity of care for them in general practice: many UMs are not enlisted with one GP, but visit different GPs on different occasions. They also thought that the attendance of volunteers from local non-governmental organisations who supported the UMs in visiting a GP contributed to more physical presentation of distress as UMs felt embarrassed to present mental health issues in front of the volunteer.

Recognition of mental health problems by GPs

Most GPs reported that they recognize mental health problems in the large majority of UMs in the consultation room. They didn’t report evident barriers in the recognition of these problems, even though these problems were often not presented by the UMs as such. In general, these problems were recognized by the way in which the UM presents himself in the consultation room (often depressed or anxious), and through the presentation of symptoms (often physical problems caused by symptoms of distress). The following quote illustrates this:
‘They often come with a complaint like stomach pain or pain somewhere else, that’s what they come with, but you immediately recognize it’s psychological, you see it in their faces ....’ (GP6)

GPs thought that UMs, even more than DMs, are prone to develop mental health problems because of their difficult social situation. Also, GPs considered the fact that the UMs have no hope for a better future could contribute to persisting of mental health problems. While reflecting on the reasons for the high prevalence of mental health problems in UMs one GP said:

‘The uncertainty of UMs about what is going to happen in the future is the main problem. They are not allowed to work, actually their life stands still, that makes them very passive.’ (GP10)

A minority of GPs thought that a few UMs exaggerated their mental health problems but they believed this was done out of desperation, in order to receive a legal status for medical reasons.

**Discussing mental health problems by GPs with UMs**

According to most GPs, an important problem affecting any discussion of a mental health problem was lack of time to discuss mental health issues. UMs attended less frequently and often presented other more urgent problems as well. Sometimes, because of time pressures in the practice, GPs ignored mental health problems and focused on these other problems they could more easily help the patient with. Reflecting on the reasons why these problems were not discussed one GP said:

‘Discussing mental health problems with the UMs takes so much time, and I don’t have 45 minutes for a consultation. Sometimes it is more important to arrange some practicalities for the UMs first.’ (GP10)

Another problem mentioned by GPs as a reason why mental health problems were not discussed was the lack of options in treatment. For many of the UMs’ mental health problems, GPs had the feeling that they could not help these patients. Therefore they often decided not to bring up these mental health issues at all. They also mentioned cultural and language barriers that hampered discussing (and recording) of mental health problems in consultations with UMs as well as DMs. Cultural health beliefs, and especially a taboo on mental illness were often mentioned:

‘Yeh, it is difficult to discuss these problems, especially when it is about psychosis or depressions. They react differently. Sometimes they have the idea that they are demonised, that this is the cause of their problems. They often have magical thoughts.’ (GP8)
Language barriers played an important role as well. In this respect some GPs considered it necessary to use phone interpreting services to discuss mental health problems with migrants, but since 2012 GPs no longer receive compensation for this service in the Netherlands, and many GPs have stopped using this service. One of the GPs said:

‘I haven’t used the interpreter phone anymore since 2012, but I think it is necessary, especially for mental health problems.’ (GP3)

Instead of professional interpreters, GPs needed to rely on family and friends who can help to translate. For UMs this is often a friend or relative, often from church or mosque; for DMs this is often a family member.

Recording of mental health problems by GPs
According to the GPs, the main reasons for under-recording of mental health problems were the previously mentioned problems in disclosure of mental health problems by UMs and the barriers in the discussion of these mental health issues with UMs. Some GPs also stated not recording these mental health problems as they could be considered as ‘a normal reaction to an abnormal situation’. Labelling and recording these problems as psychological could easily lead to a situation in which UMs feel stigmatized.

The following quote shows an example of why GPs do not always discuss and record mental health problems:

‘When an UM presents many physical symptoms, there is a significant chance that he is depressed. But if you say you are gloomy and you have a depression, that is way outside their system.’ (GP5)

The lack of treatment options in mental healthcare was also mentioned as a reason why mental health problems were not labelled and coded as such. According to GPs, labelling of mental health problems without adequate treatment options was not very useful, and didn’t contribute to the mental well-being of the patient and that is why they did not record them as such.

GPs did not mention authorities (like the police) as a barrier to record UMs’ (mental) health problems, and also the recording procedure itself was not the main cause for under-recording: almost all GPs recorded the consultations with UMs in their electronic medical records (EMR); only one recorded the consultations of UMs on paper. In general, GPs thought they recorded the consultations for UMs as accurately as for DMs, and attach a code following the International Classification of Primary Care (ICPC) to almost every diagnosis.
Only one GP said that she was less precise in giving ICPC codes to UMs in the EMR; she considered this less necessary because UMs visited her practice less often than DMs. One GP did not use ICPC codes at all for any consultations in the EMR.

_Treatment of mental health problems by GPs_

Most GPs reported no difference in their practice of prescribing psychotropic drugs for UMs and DMs. Other GPs, however, prescribed fewer psychotropic drugs because they believed that good continuity of care was needed to prescribe these drugs safely. As many UMs do not reside in one place and change doctors frequently, GPs felt unable to provide good continuity of care for this group. Reflecting on the treatment with psychotropic drugs one GP said:

> ‘To treat UMs with mental health problems appropriately, you have to see the patient more frequently. As a GP, I do the best I can which is mostly talking with them.’ (GP12)

Other GPs stated to prescribe psychotropics more easily because they had the feeling they had nothing else to offer:

> ‘Yeh, I prescribe medicines regularly. Psychotropics to make them sleep better for example .... In documented migrants I often talk about their traumas as well .... But it is not very useful to talk about your traumas when you are homeless.’ (GP4)

GPs stated that they referred UMs less often to mental health care institutions than DMs. Reasons given were: their own unfamiliarity with the possibilities for UMs to access this care, and the required financial contributions by patients, which they thought UMs could not afford. Besides, GPs reported that referrals to mental health care organizations often failed; these organizations often did not consider the care for the mental health problems of the UMs as medically necessary and for that reason access was refused. GPs who encountered this problem repeatedly stopped making such referrals.

_Solutions to overcome barriers in treatment_

GPs described a number of solutions to cope with treatment barriers in order to provide optimal mental health to UMs. From the perspective of the GPs, the most important solution was to establish trust in the relationship with the UMs. This trust was essential to facilitate disclosure of mental health problems, and could only be gained in a long-term relationship with the patient. GPs explained that they tried to establish more continuity of care by being very accessible for UMs and by concentrating the consultations with UMs with one of the GPS in the practice. One of the GPs, who worked part-time in a group practice with four other colleagues, said:
'We try as much as possible that UMs come to me or to R.(colleague), also because for reasons of expertise ... I think that 90% of the consultations of the UMs, who I consider to be my patients, are done by me.' (GP1)

They also explicitly asked the UMs to visit this one GP for all their health complaints, and to come back to them. One GP said:

‘There is a group of illegal patients who come to me with complaints I can’t solve, backpain for example, and they tell me that they visit another GP as well. I explain to them: it is not good to shop around. You need to stay with one doctor, because this doctor has a good overview of your situation.’ (GP9)

Problems in referrals were solved by using the resources available in the practice, for example by referring the UMs to other primary care colleagues such as social workers and practice nurses who were specialized in mental health. Sometimes GPs referred UMs to psychiatrists who, they knew, would not charge the UMs.

As mentioned earlier, some GPs deliberately decided to be less restrictive in the prescription of psychotropics, although they acknowledged that psychotropics often were not the best solution, nor were advised in guidelines.

**Discussion**

**Summary of principal findings**

This paper reports a qualitative study of GPs’ experiences with mental health problems of UMs. They recognized, recorded and treated mental health problems of UMs as far as possible and in the same way as they did for other patients. GPs recognized many mental health problems in UMs, but at the same time experienced barriers that prevented them from comprehensively recording these problems and from delivering appropriate care: UMs consulted a GP less frequently, waited longer to present these mental health problems to the GP, and when they did it was mainly through physical symptoms. GPs mentioned the high number of other problems (physical and social) competing for the available time as well. They were aware of the fact that UMs often distrusted them and other professionals, partly due to a lack of continuity of care, and felt they had limited treatment options. Cultural differences in health beliefs and language barriers were experienced by the GPs with DMs as well.
GPs explained that these barriers - low consultation rate, somatic presentation, lack of continuity, lack of treatment options, cultural differences and language problems, and above all lack of trust, - were the reasons why mental health problems were often not labelled as such. They explained that these barriers hampered the ability to find with the UMs the common ground needed to treat mental health problems appropriately. They appeared to be well aware of the danger that labelling psychological problem under these circumstances, without mutual agreement and without adequate treatment options, could easily lead to further stigmatization.

GPs described a number of solutions to cope with these barriers and to provide optimal mental health care for their UMs, under the prevailing circumstances. They strive to provide continuity of care as much as possible in order to enhance a relationship of trust, which might facilitate disclosure of mental health problems. It seemed that only when this is possible will GPs be confident to label and record more mental health problems.

GPs also described different strategies to overcome problems in referrals. Although GPs acknowledged that psychotropics were not always the best solution, some of them would prescribe these more easily to UMs as they felt they had nothing else to offer.

**Strengths and limitations of the study**

As far as we know, this is one of the first studies in Europe focusing on GPs’ experiences with UMs’ mental health problems. A strength of this study was that we were able to get access to a group of GPs who had significant experience in the care for UMs and who were able to provide a lot of detailed information about the levers and barriers in the recognition, recording and treatment of UMs’ mental health problems. As they all practised in the main areas where many UMs were residing, we think the findings of this study are representative of the Dutch context. The majority of these GPs participated in an earlier survey study, and in this study we showed that their undocumented patients represented the general UM population in the Netherlands.

However, we should stress was that this was a qualitative study with a small sample exploring the field for the first time. There might be a bias in information by the inclusion of GPs who are most engaged and experienced in UMs’ problems. On the other hand, the richness of their information and the fact that theoretical saturation was obtained suggests a robust analysis of the issues.
Another strength of the study was that GPs were very open and willing to share their experiences of the provision of mental health care for their undocumented patients. This is positive as the study took place at a time when in the Netherlands legal action was considered against those who supported UMs. GPs described how they felt a large responsibility for the mental well-being of UMs. Because of their openness and responsibility, we were able to capture a number of solutions in coping with the difficulties in providing care for UMs. As GPs operate in a political context that changes rapidly, and UMs are a very dynamic group of patients, it is as yet unclear how representative the findings of the GPs are for the near future. On the other hand, we are confident that most of the GPs’ experiences reflected generic problems in the mental health care of UMs.

**Findings in relation to other studies**

The GPs in our study were very engaged in efforts to provide good care for UMs. This is in line with prevailing medical ethics to provide care for all, and take responsibility for vulnerable and excluded groups despite their difficult legal, financial and social circumstances. The GPs in our study mentioned that they recognized many mental health problems amongst UMs. This is in line with survey studies that UMs reported many mental health problems in general practice settings. The patient-delay in consulting GPs reported in this study was also mentioned in a previous Dutch survey amongst a representative group of almost 250 GPs, where a quarter of the GPs observed that the health complaints of UMs were more serious than the health complaints of documented migrants.17

Barriers mentioned by GPs, such as unawareness among UMs of their right to medical care, their lack of knowledge of the health care system, shame of being undocumented, and fear of visiting officials, as well as other conflicting priorities, are well known barriers for UMs, and have a large impact on the accessibility and availability of healthcare for undocumented patients. For instance, 70% of a group of 100 undocumented female migrants reported problems in accessing care and half of them were not registered with a GP at all.14 The impression of the GPs in this study, that a lack of knowledge of and trust in GPs’ competencies regarding mental health played an important role as well, was confirmed in a recent study amongst UMs in the Netherlands.18

The impression of our GPs that UMs more often than DMs present physical complaints, probably as a symptom of distress, is in line with the finding in the previously mentioned survey amongst GPs, in which half of them stated that UMs presented more somatization of distress than DMs.17 A study of patient records in general practice confirms the impression of the GPs of a high number of competing demands in their consultations with UMs: in almost a third of the consultations with UMs more than one reason for encounter was recorded.11 The presented problems were, on average, more urgent than those of regular patients, and GPs recorded longer consultation times in the group of UMs.11
Cultural differences in health beliefs and language barriers are well known obstacles in providing adequate mental health care to migrants in general. However, one can imagine that these barriers are more profound in migrants who are less integrated in Dutch society. The lack of continuity of care for UMs as mentioned by the GPs in our study is a well known problem that impedes good quality of care, especially in the case of mental health problems. The experienced problems in referrals to mental health care organizations are in line with findings from the previous mentioned survey amongst GPs that reported that more than one-fifth of the referrals of UMs to secondary care failed.

All these barriers explain why there is a gap between the high mental health needs and the relatively low recording of these needs in general practice files. The solutions GPs provide to overcome the barriers in treatment and referral - by striving for more continuity of care and thus building a relationship of trust, referring to social workers and practice nurses specialized in mental health in their own practice, and sometimes applying guidelines for prescribing medication a little less strictly - illustrate the way GP care is patient-centered, tailored to the context of the patient. This patient-centered approach by cultural competent GPs is essential to create more equal access and quality of care for this ‘hard to-reach’ group.

**Meaning of the study and implication for clinicians and policy makers**

This study provides insight into the reasons why there is a gap between the high prevalence of mental health problems in UMs and the low recording of these problems in general practice. To narrow this gap, we recommend GPs to strive for continuity of care as far as possible. This can be achieved by improving the accessibility to the practice for UMs, by concentrating the UMs’ care on one GP, and by explaining the importance of continuity of care to UMs.

We also recommend that GPs address UMs’ mental health problems more actively and look for creative solutions in order to provide patient-centred, cultural sensitive mental health care for UMs of equal quality to that offered to other patients.
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Mental health problems of undocumented migrants in the Netherlands: a qualitative exploration of recognition, recording and treatment by General Practitioners
Reporting mental health problems of undocumented migrants in Greece

a qualitative exploration

Erik Teunissen, Alexandra Tsapras, Aristoula Saradaki, Maria Trigoni, Evelyn van Weel-Baumgarten, Chris van Weel, Maria van den Muijsenbergh, Christos Lionis

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Abstract

Background
Mental health problems are highly prevalent amongst undocumented migrants (UMs), and often part of their consultations with general practitioners (GPs). Little empirical data are available of how GPs and UM engage around mental health in Greece, a country with a lack of balance between primary and secondary care and limited health care provisions for UM.

Objective
To acquire insight in the barriers and levers in the provision of mental healthcare for UM by GPs in Greece.

Methods
This was a qualitative study using semi-structured interviews with 12 GPs in Crete, Greece with clinical expertise in the care of UM. All interviews were audio-taped and transcribed verbatim and were analysed using thematic content analysis.

Results
Greek GPs recognized many mental health problems in UM and identified the barriers that prevented them from discussing these problems and delivering of appropriate care: growing societal resistance towards UM, budget cuts in healthcare, administrative obstacles and lack of support from the healthcare system. To overcome these barriers, Greek GPs provided UM with free access of care and psychotropic drugs free of charge, and referred to other primary care professionals rather than to mental health care institutions.

Conclusion
Greek GPs experienced substantial barriers in the provision of mental healthcare to UM and political, economic and organisational factors played a major role.
Introduction

In the European Union, between 1.9 to 3.8 million migrants reside without a permit.1 These so-called undocumented migrants (UMs) include rejected asylum seekers, individuals who have entered a country illegally and visa ‘over-stayers’.2 They often live in harsh circumstances and with insufficient income for their basic needs.3 Their perceived health status is low, UMs report poor health three times more often than the general European population.3 In particular, their psychological well-being is low: many feel lonely, lack emotional support, and suffer from anxiety, depression and stress.3-5 Mental health is the most frequently reported health need but their access to professional care for mental health problems varies widely between the EU-member States, owing to differences in healthcare system and in legislation.6-8 In Greece, UM are entitled to receive only emergency care in case of life-threatening conditions; they are not entitled to have health insurance.7 Greek GPs act, just as the other GPs in the European Union, as a point of first contact for many health problems, and provide comprehensive care, including mental health services.9,10 Their ambition to play a gatekeeping and coordinating role for patients is difficult to fulfil because of a shortage of GPs in the unbalanced medical workforce in Greece.10 The drastic health reforms have created a huge burden on primary care, with rising health care needs and higher utilization of primary care by the Greek population.11

Greece is a popular destination country for migrant populations; although the exact numbers of UM is unclear, they comprise almost 9% of the total population.12 If UM can find work this is usually ‘informal’ employment, in the agriculture and construction sectors.13,14 In case of medical needs, they visit primary care centres or NGO services, but many undocumented patients give up on seeking healthcare, according to a study by Medicins du Monde.3

Mental health problems in UM are reported in the international (primary health care) literature, but little is known about the problems Greek GPs encounter in UM.3,5,15-17 The aim of the study was to gain insight in how Greek GPs cope with UM with mental health problems, the barriers and levers encountered and solutions applied. We anticipate the results of this study will be useful for the policy makers when the primary health care reform is under development.
Methods

Recruitment and sampling
This study focussed on Crete with a population of 600,000 citizens and approximately 241 GPs. Semi-structured in-depth interviews were performed with GPs who had experience in caring for UMs. GPs were recruited from the Cretan practice-based primary healthcare network of the clinic of social and family medicine of the University of Crete. Sampling was purposive, striving for maximum variation in terms of age, location, work experience, and practice organization. By a snowball method, GPs outside the network were recruited as well. Inclusion continued until no new information was imparted, and theoretical saturation had been reached. The study took place between November 2012 and April 2013.

Data collection
For the interviews, the Dutch topic guide was used, translated and culturally adapted to the Greek context. It included topics about GPs’ experiences with UMs, in particular with mental health problems, and the barriers and facilitators UMs and GPs face regarding accessing to and delivery of healthcare to UMs with mental health problems. The same medical student (AT), trained by two senior researchers (MvdM, EvW-B), interviewed all GPs. The interviews lasted between 35 and 60 minutes, were audio-taped, processed anonymously and transcribed verbatim.

Data analysis
Analysis was based on the constant comparative method. Interviews were open-coded by two researchers (AT and MT). A list of themes was generated, and conflicting interpretations were discussed with other team members (AS, CL). Once consensus was reached on the themes, a more selective coding was applied from which the core categories emerged, looking for plausible explanations to enable the drawing of conclusions and to develop further theoretical insights about the impact of economy, society and health system on the access and the provision of (mental) health care for UMs. During all stages, close attention was paid to deviant cases. Permission to perform this study was obtained from the Bioethical Committee of the University Hospital of Crete (bio-ethics approval number 7729/14-11-2012).
Results

Fourteen GPs were recruited, and twelve GPs participated in the study; the characteristics of the participants are presented in Table 1. The GPs estimated that 1-30 UMs visited their practice every month with an average of 7 per month. Most UMs were male, came from Albania, Pakistan, Afghanistan, India, Bulgaria, African countries and the former Soviet Union, and spoke their native language. The following main themes emerged:

Table 1: Characteristics of the GPs, working area, work experience, practice organisation

<table>
<thead>
<tr>
<th>GP</th>
<th>Gender</th>
<th>Location</th>
<th>Work experience (years)</th>
<th>Practice organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>M</td>
<td>Rural</td>
<td>11</td>
<td>Group practice</td>
</tr>
<tr>
<td>2</td>
<td>F</td>
<td>Rural</td>
<td>10</td>
<td>Duo practice</td>
</tr>
<tr>
<td>3</td>
<td>F</td>
<td>Rural</td>
<td>7</td>
<td>Duo practice</td>
</tr>
<tr>
<td>4</td>
<td>M</td>
<td>Urban</td>
<td>12</td>
<td>Duo practice</td>
</tr>
<tr>
<td>5</td>
<td>M</td>
<td>Rural</td>
<td>22</td>
<td>Group practice</td>
</tr>
<tr>
<td>6</td>
<td>M</td>
<td>Rural</td>
<td>2</td>
<td>Solo practice</td>
</tr>
<tr>
<td>7</td>
<td>F</td>
<td>Rural</td>
<td>10</td>
<td>Group practice</td>
</tr>
<tr>
<td>8</td>
<td>M</td>
<td>Rural</td>
<td>2</td>
<td>Group practice</td>
</tr>
<tr>
<td>9</td>
<td>M</td>
<td>Rural</td>
<td>1</td>
<td>Group practice</td>
</tr>
<tr>
<td>10</td>
<td>M</td>
<td>Urban</td>
<td>15</td>
<td>Duo practice</td>
</tr>
<tr>
<td>11</td>
<td>F</td>
<td>Rural</td>
<td>9</td>
<td>Solo practice</td>
</tr>
<tr>
<td>12</td>
<td>M</td>
<td>Urban and Rural</td>
<td>8</td>
<td>Solo practice</td>
</tr>
</tbody>
</table>

M = male, F = Female

UMs often avoid contact with general practice

Most GPs observed that, because of the current economic crisis, UMs visited their healthcare centres even less frequently than before. Austerity measures in primary care, in particular a recent consultation fee of five euros, stricter governmental measures towards UMs, like measures to restrict UMs’ freedom of movement in society, and a hardened attitude of the population towards UMs were mentioned as reasons. At the same time, the participating GPs emphasized that racism was less prevalent in Crete than in the urban areas of Athens and that the Greek health system is one of the most accessible systems within the European Union. GPs had the impression that UMs were very reluctant to visit for mental health problems. Cultural and language barriers, the UMs’ dependency on the employer to bring UMs to a healthcare centre, and their fear that the employer would find out that they suffer from mental health problems were mentioned as important reasons.
Some of the GPs mentioned that they had been instructed by the government to report UMs to the authorities, but considered it highly unethical and refused to adhere to these instructions. Others were not aware about this letter, and never received instructions to report UMs (Box 1).

Box 1: Quotations of GPs about barriers in access of UMs’ care and problems in disclosure and engagement with UMs

**Opinions about the access of care for UMs:**

‘Illegal migrants wait longer to present psychological issues compared to other migrants. I believe this is because they are worried of being arrested and handed over to the authorities.’ (GP7)

‘I believe however that the Greek health system is the most accessible system in the world. Migrants can approach the health care system very easily. They can go to any primary health care center or hospital, or go to a private doctor; nobody will tell them that they are not allowed to come there.’ (GP8)

**Opinions about presentation mental health problems:**

‘Illegal migrants wait longer to present psychological issues compared to other migrants. I believe this is because they are worried of being arrested and handed over to the authorities.’ (GP7)

‘All these migrants are people who have difficulties in opening up. They are very cautious, very closed, especially under current circumstances of crisis in Greece. The current situation can create a melancholic and a depressed mood, which can lead them into actions we have to suspect before they actually do them. This is not always easy, having opposite you a patient who displays signs of psychological burden.’ (GP4)

‘From my experience, illegal immigrants mention their problems more easily than legal immigrants. Legal migrants already are living some years in the country and the region, they have worked or still work, resulting in relative economic comfort, they also have a social life with fellow Greeks, families have adapted to the manners and customs of the area, and they face no problems in daily situations.’ (GP2)
Opinions about the role of the government:

‘What the government did, to send a paper to hospitals and health centers that they must record immigrants and report them to the police, in my opinion this is illegal! How can you make a doctor do this? Hardly any doctor reports these UMs to the police, thumbs up to all my colleagues that keep doing this!’ (GP3)

‘I do not know anything about this letter, so I cannot answer your question about this. Honestly, in my experience I have never heard of this.’ (GP8)

GPs experienced problems in engagement:

High workload: ‘Sometimes you see that something is wrong ... But we have a very high work load, there is not much time for me to look very deeply into other problems.’ (GP10)

Language problems: ‘The biggest problem in the care for migrants is the fact that I cannot speak to the patient to figure out exactly what problem it is. Sometimes you just need to guess. In addition even when there is somebody available who acts as a translator, I am still not sure whether the translation is right. It has happened to me that the translator says something, which has nothing to do with the case and what I see.’ (GP3)

Opinions about the mental health problems of UMs in relation to the Greek population:

‘I believe I see more psychological problems in the Greek patient population than in the migrant population. Immigrants generally have passed the most difficult times before coming here, instead of passing them now. They do not have psychological problems in particular. Those who have psychological problems, are the Greeks, who saw their lives torn apart due to the crisis. I see a lot of Greek patients with depressions, anxiety and too much stress. We all experience too much stress the last years.’ (GP10)

‘Compared with the Greek patients, the illegal patients certainly have more psychological problems. And not just simple psychological problems, but also heavier mental illnesses, like psychoses.’ (GP5)
Barriers in disclosure and engagement

Most GPs recognized mental health problems in most UMs in the consultation through an anxious or depressed symptom presentation, or through the presentation of symptoms linked to distress like headache or stomach pain. The mental health problems they encountered most were depression and anxiety disorders, acute stress reactions, post-traumatic stress disorders, chronic alcohol and other substance abuse, and domestic violence. According to GPs, uncertainties about their job and dependency on the goodwill of the employer were the main sources of stress for UMs. GPs reported that these problems were seldom directly mentioned by UMs, presumably due to feelings of shame, lack of trust in healthcare professionals, other priorities (often urgent physical problems) and fear. Some GPs reported that UMs mentioned their mental health problems more readily than documented migrants, presumably because of their precarious situation and lack of confidantes to discuss their mental health problems (Box 1).

The lack of UMs’ knowledge about the GPs’ role in mental health, the presence of the employer in the consultation room, and language and cultural barriers were listed as additional reasons why mental health problems were not mentioned more often. Translation services are not available in the Greek primary health care setting. In some cases, somebody was available for translation, usually a fellow patient, and a few GPs asked their own staff members to translate, often with limited success. GPs explained that these barriers in disclosure hampered a meaningful engagement with UMs. However, the high turnover of UMs, the lack of time to discuss mental health problems and the presentation of other more urgent problems made this engagement even more problematic. Sometimes, GPs ignored mental health problems and focused on other problems they could help the patients with. Some GPs thought that UMs’ mental health problems were less urgent problems, and mentioned the psychological burden of the Greek population, caused by the economic crisis, as a problem of main concern (Box 1).

Recording by GPs

GPs explained that, since the introduction of the Electronic Medical Record (EMR) in 2012, they stopped recording the UMs’ health problems as it was impossible to register UMs in the EMR. The absence of administrative personnel out of hours, the time when UMs usually came to the practice, and the low follow-up rates of UMs were additional reasons why GPs often avoided making a medical file of the UMs. In some practices, the data and insurance number of the employer was used for the UMs, and, therefore, no personal file was made for the UM (Box 2).
Box 2: Quotations of GPs about problems in the recording and treatment of UMs’ mental health problems

Recording UMs’ mental health problems:

‘We treat all patients equal. Besides, we do not have an official registration in particular for migrants in our health center. Even though we try, sometimes they are not recorded at all, and we do not keep their data, since the employer that accompanies them or a fellow migrant sometimes gives us false data, especially if the undocumented patient does not have an official identification document.’ (GP1)

‘Visits of undocumented migrants are only recorded in the big registration book of our GP office. In any other way we do not record them; they do not have a medical file, in that way it is like they do not exist. The main reason for not keeping medical records is because many of them I see only once or twice.’ (GP4)

Treatment and referral:

‘We treat every patient the same, write the same drugs and dosages to all patients. Sometimes however it is difficult for them to pay the medications due to lack of money. Then we have contact with the public pharmacies, to see if they have in stock the medication that is required. If so, the patient will get this for free.’ (GP12)

‘When an UM needs therapy, we try to do as much as possible by ourselves. Sometimes we ask our social worker, but illegal immigrants usually do not want to go to the social worker, they do not want to get in trouble with social services.’ (GP10)

‘Recently we had an extreme case of an UM with an acute psychosis … We sent him by ambulance and police escort for admittance at the closed psychiatric ward. However until now we did not hear back what happened to this case, we almost never do.’ (GP3)

‘After leaving free primary health care, the secondary hospital care needs money: there illegal immigrants and many not insured Greek patients face the same problems. There are some social structures by the Medical Association like social pharmacies or social practices, but in the case of hospitalization or specialized examinations, this is purely a question of money. All physicians who work in the hospitals could consider seeing these illegal immigrants, because we are doctors and we do not care whether the patient is illegal or not. But when we come to the subject of more thorough examination and intervention, the problem of the money ends it all.’ (GP4)
Problems in treatment

Although they were convinced that the UMs’ mental health needs were high and that GPs should play a role in the treatment of these needs, GPs frequently mentioned not doing so. Besides the previously mentioned barriers in disclosure and engagement, they encountered problems in the prescription of psychotropic drugs and referrals to mental healthcare institutions. Some GPs seldom prescribed psychotropics to UMs because they could not prescribe electronically, and costs were not reimbursed, while others mentioned this did not prevent them from prescribing the same psychotropics.

Referrals to mental health institutions often failed because of the required co-payment by patients and the inability for UMs to travel to these institutions. A few GPs also mentioned that UMs were not welcome in these institutions. In general, after referral, mental health institutions did not report back, so GPs were not sure if the UMs had received adequate mental health after referral (Box 2).

Strategies to provide mental health

GPs described some solutions to the barriers encountered. They improved the accessibility of primary care by not charging a consultation fee, by asking the employer or others to pay this fee, by allowing UMs to visit anonymously, and/or to use the insurance card of their employer. Problems with the reimbursement of costs for psychotropics were solved by asking employers to pay for the treatment, by prescribing cheaper (generic) medication or by providing the psychotropics for free. Problems in referrals were overcome by using the resources available in the local community, for example, non-governmental organisations or social workers. When referral was not possible, GPs mentioned that they provided care and support without revealing further details of the interventions they applied (Box 3).
Reporting mental health problems of undocumented migrants in Greece: a qualitative exploration

Required changes to improve care

According to the GPs, fundamental changes are needed, in the community setting and the health care system, to improve the access and quality of mental health care of UMs. Reflecting on these changes one GP said:

‘First of all, I would like to have GPs offices equipped with more doctors, more nurses and the support of a secretary ... I believe the problem is political, it is very large and not improving ... The situation is getting worse every day!’ (GP10)

GPs frequently mentioned as solutions a more positive societal attitude towards UMs; better information about their rights and means to access care; abolishment of the consultation fee; strengthening of Greek primary health care; better collaboration between primary care and mental health institutions; and free access to psychotropics.

Box 3: Quotations of GPs about strategies to provide mental health care

‘The costs for every consultation, medications and referrals, are usually covered using the health insurance of the Greek employers of the undocumented migrants or the health insurance of a fellow patriot who is legally here.’ (GP1)

‘We GPs should cooperate with local social organizations, to give UMs that solidarity needed to enable them to cope with this difficult part of life. The slightest improvement in any of these mentioned problems will give them the strength to continue. It is very important to help these people in their many problems, and NOT to treat them like any other Greek patient who has a life, a family, a job, in general another background from the immigrant. The Greek patient you need to help more with medication and some other interventions, the undocumented migrants you need to help in every aspect of their lives to improve their health.’ (GP4)

‘We collaborate with social workers in the community, we refer to them; the collaboration is very good. We are a close community and we are far away from other institutes.’ (GP5)
Discussion

Main findings
GPs recognized mental health problems in most UMs, but mentioned serious barriers in providing appropriate care: UMs’ problems in access to care and problems in disclosing mental health problems; while GPs faced major difficulties to create patient files for UMs to document their health needs and care provided, and more in general, experienced barriers to providing treatment. To overcome barriers in accessibility and quality of mental healthcare GPs agreed that fundamental changes are needed in the community setting, policy level and the health system. At the same time, the GPs presented creative solutions to overcome these barriers and serve the needs of UMs as well as they could.

Comparison with existing literature
Cretan GPs were, just as GPs from other European countries, very engaged in providing good mental health care for UMs, as they considered this part of their responsibility. Most barriers in the access to care had also been reported by GPs from countries where access to primary mental health care is legally possible: UMs’ lack of knowledge of their rights, means to access primary care, fear of being reported, and lack of trust in healthcare professionals. It indicates that many barriers were unrelated to the healthcare system. The role of the employer, the obligatory consultation fee and the profound impact of austerity measures on the accessibility and quality of primary care are more specific for the Greek context. As has also been reported in the Netherlands, Cretan GPs mentioned societal resistance to work with UMs and governmental measures to criminalize UMs. There is general apprehension about immigration and integration in the European Union, with variation between countries. It is particularly strong in Greece since the economic crisis. The harsh approach of the Greek authorities towards UMs, including operations to restrict their freedom of movement, have been criticised. Besides political and economic factors, the healthcare system also plays an important role as Greek GPs mentioned a lack of support from their healthcare system to provide mental healthcare to UMs and reported barriers in providing high-quality primary care services during the economic crisis.
Our findings signal that Greek GPs share their professional values with other European GPs. But throughout Europe GPs have to put these values into effect under health systems that vary in what is allowed for UMs, from ‘no access at all’ through ‘only to access emergency care’ to the right to access more extensive care.\textsuperscript{7,9} It may explain why the creative solutions of Cretan GPs differ from the ones of Dutch GPs, for example.\textsuperscript{16,31} All these attempts can be categorized as patient and community centred approaches by committed GPs, and are essential creating more equal access and quality of mental care for this ‘hard- to-reach’ group, regardless of the primary healthcare setting these GPs are working in.\textsuperscript{32-35}

**Strengths and weaknesses of the study**

As far as we know, there is very limited research focussing on GPs’ experiences with UMs’ mental health problems in Greece. Even though the qualitative methodology and relatively small number of GPs could be seen as limitations of this study, they are also a strength. We were able to get access to a group of Cretan GPs who were prepared to stick-out their neck to discuss openly how they acted in a controversial area, where they had often to act against regulations.\textsuperscript{7} This study was based on GPs from Crete, and although it is likely that GPs elsewhere in Greece experience comparable problems in the mental health care of UMs; this requires further study.

As this was the first exploration of experiences of GPs with the UMs’ mental health care in Crete, for which a short period of a three-month student research internship was available, the best approach possible was to build on a thorough study in the Netherlands on UM mental health care. That study had identified relevant topics, which served to structure the interviews. Alternatives like an open interview format would have exceeded the time constraints for this study. This time constraint was also the reason to refrain from member checking and triangulation. A student researcher in an internship with limited time could be seen as a limitation as well. However, this Dutch student had intimate knowledge of the social and primary care context in which GPs in Crete are working. This made it possible to build on research experience in the Netherlands, to conduct international research collaboration and to engage Cretan GPs in a study of a sensitive nature. This, we are inclined to see as a strength of the study.
Implications for clinical practice

First, we recommend that UMs will have full privacy in the consultation room to discuss their mental health problems with the GP, without the presence of their employer. Second, GPs did strive to provide the best mental healthcare that was possible, and they considered it a key component of their professionalism. Although the circumstances for providing mental healthcare were less than ideal, this should be seen as a constructive contribution. Third, there is a lack of specific services for vulnerable groups in Greece, and guidelines for common mental health problems was introduced and disseminated only recently. With this study, a clear message is sent to regional and healthcare policy makers to fill this gap in clinical practice as mental health services are not well integrated in primary health care services in Greece. Despite this setback, GPs can become aware of locally available mental health services and community services for UMs and start an active horizontal collaboration to refer their patients. This is also an issue for the vocational scheme for general practice, which can also benefit from the experiences in cross-cultural healthcare. Fourth, mental health problems should be recorded more actively by GPs during regular consultations. This might be achieved by informing UMs about the GP’s role in mental health.

Conclusions

Greek GPs were committed to help UMs with mental health problem problems, they looked for creative solutions but experienced substantial barriers preventing them from delivering appropriate care.
Case vignette 1

*GP 7 about problems in referral/lack of staff in handling a case of acute psychosis after substance abuse.*

A 16 year old homeless undocumented Algerian boy came to the healthcare centre with symptoms of an acute psychosis. Because this boy was underage, he had the right to direct access to the healthcare system. The GP accompanied him to a psychiatric clinic in the ambulance and the boy was admitted to this clinic for a period of 3 weeks. His psychosis was most likely caused by substance abuse and his urine test was positive for cannabis. After discharge from the clinic, he was placed in a shelter for underage migrants, because he had nowhere else to go. A few days later, he was brought to the healthcare centre again, and it turned out he was psychotic again after substance abuse. This time he had cut himself in the leg and became so aggressive that the GPs and nurses decided to lock him up in the healthcare centre while waiting for assistance from the police. Due to his violent behaviour and the lack of manpower in the centre, the GP was not able to give him an injection with a sedative. Unfortunately, he broke through the doors and damaged the healthcare centre. Six hours later the police arrived with extra reinforcements and took the patient with them after the patient had been given a sedative. The GP had no idea how this case had ended, since there was no further communication between the GP and the clinic.

Case vignette 2

*GP 3 about problems with referral: lack of transport to the mental healthcare hospital*

There was this case that the ambulance drivers did not want to bring an undocumented patient from the primary healthcare centre to the nearest mental healthcare center. The man was suffering from a psychotic depression, and really needed to be admitted. As there was no alternative, the GP took this patient in her car and brought him to the mental healthcare hospital herself. She accompanied him to the clinic, and the patient was admitted. However, the undocumented migrant had difficulties in accepting the fact he needed to be admitted and that he had to receive therapy. It was very difficult for the GP to get the patient into the car and into the clinic; and the drive to the mental healthcare centre was a very stressful event for both the GP and the patient. Reflecting on this situation, the GP stated that she probably would not do this again and that the risks that something would happen on their way to the clinic were too high.
References


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Improving the evaluation of cross-cultural communication interventions in General Practice

a qualitative study

Erik Teunissen, Maria van den Muijsenbergh, Evelyn van Weel-Baumgarten, Francine van den Driessen Mareeuw, Tomas de Brún, Nicola Burns, Chris Dowrick, Katja Gravenhorst, Christos Lionis, Catherine O’Donnell, Mary O’Reilly-de Brún, Frances Mair, Maria Papadakaki, Aristoula Saridaki, Wolfgang Spiegel, Chris van Weel, Anne MacFarlane

Submitted for publication
Abstract

Background
GPs in Europe have to deal with increasing ethnic and cultural diversity, and therefore need specific knowledge and skills. Guidelines and training initiatives (G/TIs) in cultural competencies exist but are poorly implemented in day-to-day practice. Little is known about how GPs value these G/TIs and evaluate their implementation.

Aim
To report the evaluation of these G/TIs and proposed modifications to improve sustainability in daily practice.

Design and Setting
Qualitative case study in primary care in five countries across Europe as part of RESTORE, a European FP7 project.

Method
This study combined Normalisation Process Theory (NPT) as analytical framework, with Participatory Learning and Action (PLA) as research method to engage migrants, healthcare providers and other stakeholders to improve interventions. Stakeholders were recruited by purposeful sampling at each site. Data were audio recorded, coded and thematically analysed in each team.

Results
Sixty-five stakeholders, including migrants, planned and conducted formal evaluation activities. All stakeholders reported benefits of the implemented G/TIs in daily practice. Training resulted in a more tolerant attitude and more effective communication, with better focus on migrants’ needs. Implementation of interpreter services was more difficult mainly due to lack of finances and resources. But when used, more trust of migrants in GP’s diagnoses was achieved and GPs reported a clearer picture of migrants’ symptoms.

Conclusion
Migrants, GPs and other stakeholders like practice assistants are able to collaboratively evaluate G/TIs, revealing valuable information which enhances sustainability of implementation of guidelines and training to improve cross-cultural communication in daily practice.
Introduction

Over the last years Europe faces a large influx of refugees and other migrants. Access to healthcare and health outcomes are less favourable for migrants, which lends urgency to improve health systems’ responsiveness to culturally diverse populations. This is particularly important in primary care, as the entry point to healthcare for all patients in European countries. Primary healthcare contributes to population health, is cost-effective care and equitable, providing continuous, coordinated and integrated health and well-being. Empowerment of people is as relevant as biomedical interventions. To harness health systems to address cultural diversity, it is essential to preserve the person-centered approach and overcome the difficulties in applying this with patients with different ethnic, cultural and language backgrounds, in particular for vulnerable groups (undocumented migrants, refugees and asylum seekers).

Migration relates negatively to health outcomes in a variety of ways: problems in access, finance and insurance, migrants’ health perceptions and expectations of care, and professionals’ lack of cultural competencies, and time. Training in cultural competencies and use of professional interpreters have been advocated to overcome these problems, and guidelines and professional training initiatives (G/TIs) have been designed for these purposes. The effectiveness of some of these G/TIs have been proven. However, in general their implementation in day-to-day practice is poor, pointing to a significant translational gap between evidence and practice with little insight into why this is the case. Only a few studies in the field of cross-cultural communication have taken an implementation focus, addressing i.e. implementation of interpreted consultations in general practice. No theoretical frameworks were prospectively applied as recommended for implementation studies, nor were the stakeholders’ appraisal (evaluation) of the value of G/TIs comprehensively examined for adaptations to sustain their employment in daily practice. Appraisal provides insights into the sustainability of newly adopted interventions and the adaptations (reconfigurations) required to sustain their use in practice. This is essential, to move the introduction and diffusion of new practices from short term success to the more challenging goal of their sustained and routine use i.e. normalization.

This paper reports on the appraisal of G/TIs designed to improve communication in cross-cultural consultations in primary care practice.
This research was conducted as part of the RESTORE project, an EU participatory implementation research project funded under the FP7 programme. Its novelty is that implementation theory was combined with participatory research to prioritise the involvement of migrants and healthcare providers in primary care, to collaboratively progress the implementation of relevant G/TIs.23,26 (Box 1 and 2).

Box 1: Summary of RESTORE project activity33

In RESTORE we combined Normalisation Process Theory (NPT) and Participatory Learning and Action (PTA) research to prospectively investigate and support the implementation of G/TIs to improve communication for migrants in primary care settings. NPT provided a heuristic device to keep us alert to four important forms of implementation work28 and PLA provided a methodology to create a participatory space where migrants and other key stakeholders could work together in a democratic and empowering manner.35

We conducted a comprehensive mapping process in six European countries (Ireland, England, Austria, the Netherlands, Greece, and Scotland) and identified twenty guidelines and training initiatives that were designed to support communication in cross-cultural consultations.

Research teams in five countries (Ireland, England, Austria, the Netherlands, and Greece) used NPT to appraise a smaller set of four or five which had the strongest chance of being successfully implemented in primary care in their countries.42

Migrants and other key stakeholders in each setting were invited to examine the set of four or five G/TIs relevant to their setting and were given the opportunity to select one as an implementation project for a primary care site in their region.

As an example, migrants and other stakeholders in Greece selected a guideline from Ireland that promoted the use of training interpreters in general practice consultations as their implementation project. In the English setting, a Dutch training initiative to improve health professionals skills to deliver culturally sensitive care was selected (see Box 2 for a list of the five selected and adapted G/TIs).

Migrants and other stakeholders drove the implementation of their selected G/TI forward, meeting regularly over a two year period to engage in a PLA brokered dialogue.29 This was designed to encourage sharing of knowledge and expertise from all stakeholders to adapt, introduce, integrate and sustain its use in daily clinical practice.
Box 2: Adapted Guideline/Training initiatives in the local settings

<table>
<thead>
<tr>
<th>Country</th>
<th>Guideline and Training Initiative</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ireland</td>
<td>Working with an Interpreter is Easy: Self-Directed Training Package for Health Professionals, SPIRASI, Ireland</td>
<td>Adapted: Aimed at inter-stakeholder multi-cultural multi-disciplinary group, Agreement on need to use formal interpreters, Additional training session on the dynamics of culture, Complemented by PLA style ‘Walk-Through’ to allow stakeholders to practise the application of knowledge from training into practice.</td>
</tr>
<tr>
<td>England</td>
<td>Ears of Babel: Culturally Sensitive Primary Healthcare, Pharos, the Netherlands</td>
<td>Two training sessions (1½ hour, 2½ hours), Aimed at multidisciplinary practice team, Delivered by professional drama based training company, Focus on mental health, Actor performed scenarios &amp; adapted role play, group discussion.</td>
</tr>
<tr>
<td>Austria</td>
<td>New European Migrants and the NHS: Learning from each other, Manual for Trainers, First Edition February 2009’, NHS Lothian, Dermot Gorman, Scotland</td>
<td>Aimed at GPs, Content adapted to Turkish, African and Arabic migrants in Austria, Material focused on healthcare issues relevant to GPs, Lectures, quality circles and e-learning module.</td>
</tr>
<tr>
<td>The Netherlands</td>
<td>‘Did I explain it clearly?’ How to communicate with migrants with lower education and less command of the Dutch language, Pharos, the Netherlands</td>
<td>Two training sessions (4 hours, 3 hours), Aimed at entire practice team (including GPs and practice nurses), Use of formal and informal interpreters, Focus on migrants and natives with limited education and command of the Dutch language, Developing ‘improvement plans’ with GP practice, Regular evaluations of the impact of the training.</td>
</tr>
</tbody>
</table>
The aim of this paper is to provide insight in the evaluation process, the migrants and healthcare providers perceived value of the implemented G/TIs, issues affecting their sustainability and proposed modifications to improve sustainability over time. This will inform General Practitioners considering improvement of their cross-cultural communication, what works and under what conditions.

**Methods**

*Study design*

RESTORE was a qualitative case study (2011 - 2015), using a combination of Normalisation Process Theory (NPT) and Participatory Learning and Action Research (PLA).

We used NPT as our analytical framework as it engages directly with the work of those involved in implementation processes. According to NPT the chances of successful implementation and subsequent ‘normalisation’ of a new way of working are dependent on work in four constructs (Box 3). We built our methodological structure on the basis of these four constructs, in order to investigate and support key elements of the implementation process. In this paper we focus on the fourth construct of NPT, Reflexive Monitoring: how stakeholders formally or informally appraised/evaluated and valued the G/TI in their daily practice, and what reconfigurations they proposed.

PLA, a participatory research methodology enabling multiple stakeholders to work together in a democratic and empowering manner, can improve the quality of intervention design and guideline development. PLA has been used successfully in previous research with migrants and other stakeholders in this field.

---

**GREECE**

Guideline: *Guidance for communication in cross-cultural general practice consultations: Developed using a participatory research approach, Discipline of General Practice, Centre for Participatory Strategies, Health Services Executive & the Health Research Board, Ireland*

- Introduced in setting without face-to-face interpretation services
- Setting up telephone interpretation service
Box 3: NPT constructs

<table>
<thead>
<tr>
<th>Construct</th>
<th>What it addresses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coherence</td>
<td>Can those involved in the implementation make sense of it?</td>
</tr>
<tr>
<td>Cognitive Participation</td>
<td>Can those involved in the implementation maintain their involvement and get others involved and engaged?</td>
</tr>
<tr>
<td>Collective Action</td>
<td>What has to be done to make the intervention being implemented work in routine practice?</td>
</tr>
<tr>
<td>Reflexive Monitoring</td>
<td>How can the intervention be monitored and evaluated? Can it be re-designed?</td>
</tr>
</tbody>
</table>

**Settings**

The research took place in all five sites that had implemented the G/TIs, in primary care practices in England, Greece, the Netherlands, Ireland and Austria.

**Sampling and recruitment**

As per our study protocol, our aim was to have a mixed stakeholder group in each setting working together over time as an ‘implementation group’ to drive the project forward. Stakeholders were recruited by purposeful sampling through established networks and snowball sampling to obtain a balance of representation across key stakeholder groups: migrants (representatives and service users), GPs, practice nurses, receptionists, practice assistants, practice managers, academics, interpreters, health service planners and policy makers. The sample changed slightly over time depending on stakeholders’ interest and availability to select the G/TIs, introduce them in practice and appraise its worth.

**Data generation and analysis**

In each setting data were generated by RESTORE researchers who had been trained in NPT and PLA. We used PLA style focus groups to foster and support a dialogue between stakeholders in the implementation group in each setting so that they could explore shared and differential perspectives to the implementation work in an equitable and respectful environment. During the 15-19 months implementation process 62 2-3 hour PLA style focus groups were held (average of 12 per setting), audio-recorded and transcribed verbatim.
In addition each team produced a series of five reports using a standardised template to facilitate comparative analysis across settings. These reports provided a rich narrative description of fieldwork, reflecting on what went well in the implementation and on challenges and problems encountered. The content of the reports was derived from PLA data displays from focus groups, research team meeting minutes and researchers’ fieldwork debriefings. Fieldwork updates and reports were discussed in the consortium by Skype and at face to face consortium meetings encouraging a process of iterative reflection and cross-country comparison and exchange.

Following the principles of PLA, stakeholders co-analysed data generated about appraisal during their PLA style focus groups. The research teams in each setting followed the principles of a deductive framework analysis, informed by NPT to analyse the transcripts of the PLA style focus groups using the same coding framework in all sites (Figure 1 for sensitising questions that relate to the construct about appraisal double coding by two researchers in each team and discussion about discrepancies).

Figure 1: Sensitising questions to appraise the implementation of G/TIs and their effects

<table>
<thead>
<tr>
<th>Reflexive monitoring</th>
<th>How do stakeholders appraise implementation practices and what are the effects of those practices?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Systematisation</td>
<td>Can stakeholders determine how effective and useful the guideline/training initiative is in their local setting, using formal or informal evaluation methods?</td>
</tr>
<tr>
<td>Communal appraisal</td>
<td>As a result of formal monitoring, do stakeholders collectively agree, or not, about the worth of the guideline/training initiative in their local setting?</td>
</tr>
<tr>
<td>Individual appraisal</td>
<td>Do stakeholders involved with, or affected by, the guideline/training initiative think it is worthwhile?</td>
</tr>
<tr>
<td>Reconfiguration</td>
<td>Can stakeholders, individually or collectively, modify their work in response to the appraisal of the guideline/training initiative?</td>
</tr>
</tbody>
</table>

**Results**

Sixty-five stakeholders participated in this phase of RESTORE. The sample covered seven distinct stakeholder groups, and represented a range of socio-cultural backgrounds, thus providing the rich multi-perspectival sample that was desired in each implementation group (Figure 2).
Figure 2: Description of stakeholders who drove the implementation forward and who were involved in the evaluation (appraisal) process

<table>
<thead>
<tr>
<th>Country</th>
<th>Ireland</th>
<th>Netherlands</th>
<th>Greece</th>
<th>England</th>
<th>Austria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of stakeholders</td>
<td>13</td>
<td>12</td>
<td>18</td>
<td>12</td>
<td>10</td>
</tr>
</tbody>
</table>

**Socio-demographics of stakeholders**

A) Gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>Ireland</th>
<th>Netherlands</th>
<th>Greece</th>
<th>England</th>
<th>Austria</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a1) Male</td>
<td>3</td>
<td>1</td>
<td>6</td>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td>(a2) Female</td>
<td>10</td>
<td>11</td>
<td>12</td>
<td>-</td>
<td>-</td>
</tr>
</tbody>
</table>

B) Age group

<table>
<thead>
<tr>
<th>Age group</th>
<th>Ireland</th>
<th>Netherlands</th>
<th>Greece</th>
<th>England</th>
<th>Austria</th>
</tr>
</thead>
<tbody>
<tr>
<td>(b1) 18-30</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>1</td>
<td>-</td>
</tr>
<tr>
<td>(b2) 31-55</td>
<td>13</td>
<td>10</td>
<td>13</td>
<td>8</td>
<td>-</td>
</tr>
<tr>
<td>(b3) 56 plus</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>-</td>
</tr>
</tbody>
</table>

C) Background Stakeholder to self-select which to answer)

<table>
<thead>
<tr>
<th>Country of origin</th>
<th>Chile: 1 Democratic Republic of Congo: 1 Nigeria: 1 Poland: 1 Russia: 1 Portuguese: 1 Dutch: 1 Irish: 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Netherlands: 8 Turkey: 1 Morocco: 2 Ethiopia: 1</td>
<td>Greece: 15 Netherlands: 1 Syria: 1 Albania: 1</td>
</tr>
<tr>
<td>UK: 4 England: 2 Scotland: 1 Pakistan: 1 Iran: 1 Other: 1</td>
<td>Missing: 2</td>
</tr>
</tbody>
</table>

C) Stakeholder Group

<table>
<thead>
<tr>
<th>Nationality</th>
<th>Chilean: 1 Congolese:1 Nigerian:1 Polish: 1 Russian: 1 Portuguese: 2 Dutch: 1 Irish: 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>No stakeholder chose to respond to the nationality category</td>
<td>Greece: 15 Netherlands: 1 Syria: 1 Albania: 1</td>
</tr>
<tr>
<td>British: 9 Scottish: 1</td>
<td>-</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Ethnicity</th>
<th>No stakeholder chose to respond to the ethnicity category</th>
</tr>
</thead>
<tbody>
<tr>
<td>No response: 5</td>
<td>Greek: 15 Dutch: 1 Syrian: 1 Albanian: 1</td>
</tr>
<tr>
<td>White: 4 Black British: 1 British Asian: 1 Arab: 1</td>
<td>-</td>
</tr>
</tbody>
</table>

| Migrant community | 5 | 3 | 2 | 6 | 3 |
| Primary care doctors | 2 | 2 | 4 | 1 | 4 |
| Primary care nurses | 0 | 3 | 5 | 0 | 0 |
| Primary care admin/management staff | 2 | 2 | 1 | 1 | 0 |
### Country

<table>
<thead>
<tr>
<th>Country</th>
<th>Ireland</th>
<th>Netherlands</th>
<th>Greece</th>
<th>England</th>
<th>Austria</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total number of stakeholders</td>
<td>13</td>
<td>12</td>
<td>18</td>
<td>12</td>
<td>10</td>
</tr>
</tbody>
</table>

### Socio-demographics of stakeholders

<table>
<thead>
<tr>
<th>Role</th>
<th>Ireland</th>
<th>Netherlands</th>
<th>Greece</th>
<th>England</th>
<th>Austria</th>
</tr>
</thead>
<tbody>
<tr>
<td>(d5) Interpreting community</td>
<td>3</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>(d6) Health service planning and/or policy personnel</td>
<td>1</td>
<td>1</td>
<td>7</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>(d7) Trainers or academics</td>
<td>-</td>
<td>-</td>
<td></td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>

**Development of Appraisal Plans: Systematisation**

At each site, stakeholders started planning ways to appraise the impact of their selected G/TI on practice, early in the implementation journey. Stakeholders spontaneously considered this focus in most settings (England, Ireland, the Netherlands) and the researchers brought it to the attention of stakeholders in others (Greece, Austria).

They considered a wide range of potential strategies to formally evaluate the effectiveness of the intervention in practice and realised plans to gather data in Ireland, England, the Netherlands and Austria using interviews, evaluation forms and email communication with service users, healthcare providers and practice staff (Table 1).
Table 1: Overview of Formal Evaluation of G/TIs on Practice

<table>
<thead>
<tr>
<th>COUNTRY</th>
<th>Stakeholder group(s) involved</th>
<th>Appraisal activity Number of:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Ireland</td>
<td>Ireland</td>
</tr>
<tr>
<td></td>
<td>England</td>
<td>England</td>
</tr>
<tr>
<td></td>
<td>Austria</td>
<td>Austria</td>
</tr>
<tr>
<td></td>
<td>The Netherlands</td>
<td>The Netherlands</td>
</tr>
<tr>
<td></td>
<td>Greece</td>
<td>Greece</td>
</tr>
<tr>
<td>Appraisal activity Number of:</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Interviews to appraise impact on practice of the implemented G/TI</td>
<td>Ireland</td>
<td>England</td>
</tr>
<tr>
<td>4 SU</td>
<td>1 GP</td>
<td>1 PS</td>
</tr>
<tr>
<td>Evaluation Forms to appraise training and impact on practice</td>
<td>Ireland</td>
<td>England</td>
</tr>
<tr>
<td>1 (M, GP, PS, I, H, T)</td>
<td>7 (GP)</td>
<td>15 (GP, PN, PS)</td>
</tr>
<tr>
<td>E-mails to appraise impact on practice</td>
<td>Greece</td>
<td></td>
</tr>
<tr>
<td>6 (GP, PN, PS)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

SU = migrant service users
GP = General Practitioner
PN = primary care nurses, receptionists and practice assistants
PS = primary care administration/management staff
I = member of interpreting community
H = Health service planning and/or policy personnel

In Greece no formal evaluation data could be generated about the implementation of their guideline on the use of the interpreter services, due to problems recruiting migrants who actually used these services. Instead, Greek stakeholders discussed at length reasons of why migrants did not use these facilities, and conditions to be fulfilled in order to make uptake possible.

During their PLA style focus groups the stakeholders in the implementation groups were able to examine the data from these formal evaluations and, also, to discuss and evaluate informally their own personal perspectives on the worth of the G/TIs.

These multidisciplinary participatory groups sessions were highly valued by stakeholders. The positive input of migrants in the evaluation helped to consolidate the implementation particularly in the Netherlands and Ireland, as it confirmed for practice members that the selected G/TI was of value in that setting.

Perceived worth of the implemented G/TIs on clinical practice: Individual and communal appraisal

Drawing on both formal and informal evaluation data it was clear that overall individually and collectively most stakeholders reported benefits of the implemented G/TI in daily practice (Box 4 for selected quotes).
Box 4: Benefits of implemented G/TIs in practice

1. ‘Yes it [the training] stimulates a change in mindset; also team building is a positive aspect.’ (the Netherlands PN SH4)

2. ‘I am reacting much calmer now than I did before, with more patience’. (the Netherlands PN SH5)

3. ‘The receptionists were all talking about it (…), which was good, because you know from that the other girls were saying positive things.’ (England PN SH15)

4. ‘RESTORE helped me open my eyes to my migrant patients and their needs, where in the past I just scanned over them.’ (Greece GP SH4)

5. ‘We could also go to a training low literacy together, and then go home, and then you have heard the information and that’s it. But we really have worked with each other, and therefore it is more relevant … ‘ (the Netherlands PN SH5)

6. ‘In my case, it’s easy to trust when the interpreter is present, because I knew that she would be able to convey everything that I meant and that I would be understood. I did not feel any discomfort about it [the presence of the interpreter].’ (Ireland Migrant #2)

7. ‘Actually I think I got all answers, what I wanted to get.’ (Ireland Migrant #4)

8. ‘I think you understood most of the stuff yourself, it was just more confirmation, if I get it right. Like listening to interpreter, you could confirm that you get it properly.’ (Ireland Migrant #3)

9. ‘So the advantages - definitely you got a lot more information out of her, so I got a much truer picture of the type of symptoms she was having, and therefore [knew] which treatment to give her, because the last day she told me what she thought her diagnosis possibly was and I gave her a treatment; she was keen for me to give her treatment, even without the interpreted consultation. And I gave her the script that probably fit with that but that wasn’t at all appropriate. So today we revised that, I told her to get rid of that prescription and I gave her the treatment based on what her new symptoms were. So clearly we got a lot further today and got a much more appropriate diagnosis and treatment.’ (Ireland GP #1)
10. ‘I think after the first few sentences she [the patient] actually realised that the communication is flowing and the fact that she’s speaking only Polish means she can focus on what she wanted to say. Not on how to translate it herself. And I think I could see that the difficulty she had was with medical terminology. There was a name of a medical condition that she had and that was interpreted - I think this is where I gained the trust.’ (Ireland interpreter #7)

SH = Stakeholder
PN = primary care nurses, receptionists and practice assistants
GP = General Practitioner

Focusing on the data from the formal evaluations, the training in cultural competencies and communication skills led to the following positive effects in consultations: a more tolerant and positive attitude towards migrants (migrant service users and practice members in England and the Netherlands (quotes one, two, three), more effective communication between healthcare professionals and migrants with low literacy (GPs and practice nurses the Netherlands), better understanding of migrants social and health issues (the Netherlands and England quote 4), better knowledge among GPs of the mental health problems of migrants (GPs in Austria).

The training initiatives had positive effects at practice level, in particular to reception staff interactions with migrants: increased flexibility in accommodating migrants’ appointments amongst all staff (England), adaptation of the practice to the needs of low literate migrants (the Netherlands). Interestingly, stakeholders in England and the Netherlands considered that these practice level changes were due to the fact that all practice members had been involved collectively in the training and thus shared the responsibility to implement the G/TI in the practice (quote 5).

The available data about training to use interpreters in Ireland indicates advantages in consultations for migrants such as better confidence in the GP’s diagnosis and treatment and a reported ease about having a ‘stranger’ i.e. the interpreter in the consultation (quotes 6, 7). Even migrants who believed they had adequate English reported an improvement in their understanding and hoped to use interpreters in the future (quote 8). No disadvantages were reported.
The GP described advantages in terms of having a clearer picture of symptoms and more confidence devising treatment plans (quote 9). The trained interpreter involved remarked on this positive feature of the consultation as well (quote 10). Interestingly, she also commented on the benefits of working with a GP and the fact that they had trained together.

Exploration of the reasons for no uptake of the newly establish interpreter service which the Greek stakeholders’ selected guideline recommended, provided valuable insights. General practice staff was keen to try this innovative new service and had overcome resource challenges to actually provide the service, but migrants identified barriers in implementation not previously foreseen: fear among migrants that it would cost them money or that they would have to use their own cellular phone for the telephone interpreter. Furthermore migrants’ employers often attended their consultations to act as their interpreter, while migrants preferred a formal interpreter but felt obstructed to express this.

Disadvantages of interpreted consultations mentioned in Ireland and Greece relate to practice level challenges - the lack of structural resources to provide interpreters, and logistic challenges organising triadic consultations and difficulties accessing trained interpreters (Box 5 for challenges and suggested adaptations/solutions).

Box 5: Challenges for sustaining the use of implemented G/TIs in practice - and the ideas for reconfiguration

1. Difficult to ‘retain’, mainly because of time restraints.
   ‘If we are not reminded of it regularly, it doesn’t stick.’ (the Netherlands GP3
   Reconfiguration: it was proposed to put the topics of the training on the agenda of regular meetings of the practice staff members.

2. Disadvantages of interpreted consultations mentioned in Ireland and Greece were their lack of structured provision and logistic challenges organising and accessing interpreters.
   ‘Yeah to reasons why it won’t work, one is the funding but the other one is its so much time and so difficult and so many steps involved to try, even when we had access.’ (Ireland GP#1)
   ‘In the current situation patient phones reception and says I want an appointment today or this afternoon, no problem is 3 o’clock okay? Yes, thank you what’s your name, okay goodbye, ten seconds? New process first of all how do you even know that the patient needs an interpreted consultation? How do they know? Its usually too late when you find out they’ve already had the consultation, okay so they’ve come in and you realise five minutes into the consultation hang on they don’t understand me and I don’t understand them. Its too late for this one, so now you think okay well its too late, their problem will be too serious by next week when you can arrange
somebody but if you could arrange it then you’ve got to find out the nationality, you’ve got to find can you get an interpreter? Somebody in reception has to make contact with an interpreter then you have to try and find a slot that suits them, the patient is probably gone home by now so then you have to try and provisionally arrange that. Then maybe contact the patient and see does that suit and if it does then okay, if it doesn’t suit them then you have to go back, the whole process could take days and this is just one person. So it’s a huge logistical difficulty. So I don’t know how to address that but they are the two things to come from that.’ (Ireland GP#1)

Reconfiguration: none identified.

3. The need for structural support specifically finances for interpreter.

‘We [the practice] clearly can’t pay for it [interpreted consultation service], it would be whether the State can pay for it, or whether the patient to pay for it. You know, a general practice isn’t resourced that way … So will the HSE [Health Service Executive] pay for it, as they do in the hospital, which I think they should - and I think that would make a huge difference. Then we would also need a smooth access [structure] where, from the time that [service-users] try to make an appointment, we know that they need an interpreter, and who is going to arrange that.’ (Ireland GP#1)

Reconfiguration: none identified but solution put forward that state funding for trained interpreters in primary care is required.

4. The need to find ways to reach migrants.

‘I don’t have my mind when I walk in the health centre to look and read posters because usually they are all in Greek plus, I want to see a doctor fast.’ (Greece MSU SH3)

Reconfiguration: non identified but solution put forward that primary care professionals should play an important role in advertising the new service to migrants.

5. The need for ‘health advocacy’ for migrants.

‘If the services available were clear to us migrants, on what rights we have and this was posted at the health centres, in many cases I wouldn’t bring someone with me. I am lost when I enter the health centre.’ (Greece MSU SH3)

Reconfiguration: Suggestion: The migrants stressed that they need a health advocate in every area with many migrants, someone telling them what their rights are and what they can have access too. They felt GPs could play an important role in informing them as well as their employers about the health services and their rights.

SH = Stakeholder
GP = General Practitioner
MSU = Migrant service user
Further adaptation (Reconfiguration) process

The dominant challenges in each setting to sustaining the new ways of working recommended by the G/TIs in daily practice were time constraints that would undermine good intentions to continue new ways of working, or simply forgetting to keep a new practice going. While stakeholders could consider possible strategies for reconfiguration for these challenges, it was more difficult when the challenges related to lack of resources for on-going funding beyond the lifetime of RESTORE (Box 5 for quotes). As above, the lack of structural support, specifically finances for interpreter services, was a major barrier in Ireland and Greece. Another challenge identified during the evaluation in Greece was that migrants were unaware of their rights when it comes to their health and they themselves stated that a ‘health care advocate’ is essential in their community. Stakeholders were well aware that these issues were related to local or national policy and anticipated that data from RESTORE could bring about changes to improve the organisational and contextual conditions to facilitate the sustained use of the G/TIs in practice.

Discussion

Summary of main findings

Our study showed that it was possible for healthcare professionals and migrants in General Practice to collaboratively develop and conduct formal and informal evaluation activities to appraise the effect of guidelines and training to improve cross-cultural communication. In fact, the need for evaluation was brought up spontaneously by most stakeholders involved in the implementation process. PLA provided a valuable method to engage all stakeholders in evaluation and heightened the value of the G/TIs for practice staff members. The involvement of migrants did lead to the identification of barriers that otherwise had remained unknown - in particular around interpreting services - and this in turn motivated healthcare providers to continue improving implementation.

Comparison with existing literature

Our study resonates the findings of earlier research that cultural competency training improves knowledge, attitudes and skills of GPs and practice nurses and results in more patient satisfaction. The involvement of all practice members, including practice assistants, made it possible to clarify long-term agreements about improvements in their local settings for daily practice. These are novel findings in relation to implementation of G/TIs in this field and resonate with previous research that inter-professional collaborative agreements are needed to effectively change the practice long-term.
The involvement of migrants and other key stakeholders is rare and our study shows that it had a positive impact on implementation processes, as has been reported in other fields but not yet in relation to the evaluation of interventions in the field of migrant care. Our study showed that with PLA it is possible, to involve migrants, practitioners and other stakeholders in a meaningful way.

**Strengths and limitations**

A major strength of this study was that it was a theoretically informed qualitative case study across European settings involving migrants which is in line with Public and Patient Involvement imperatives. The combination of PLA and NPT were not used before to prospectively explore appraisal as a form of implementation work in this field.

The generalizability of findings from this qualitative study are limited although the comparative analysis across settings has identified transferrable points. Although we have a lot to say about the process of evaluation the outcomes of the formal evaluations are limited because they were not the primary analytic focus.

**Implications for research and practice**

Involving migrants and other key stakeholders in developing and conducting formal evaluations in General Practice is highly recommended.

It is advised to involve all clinical and administrative practice members in training on cultural competence and considerations about the evaluation of training, this seems likely to ensure greater buy in to future practice chances.

More research is needed about the implementation of professional interpreter services in Primary Care. Here we have looked at implementation and evaluation of G/TIs to enhance cross-cultural communication in general practice but it would be important to undertake further research to explore the effects, if any, of these interventions on practitioner knowledge and behaviour as well as migrants’ health outcomes.

**Conclusions**

Migrants, GPs and other stakeholders like practice assistants are able to collaboratively evaluate G/TIs aiming to improve cross-cultural communication in General Practice. This collaborative evaluation revealed valuable information otherwise unknown and seems to enhance sustainability of the implementation of guidelines and training to improve cross-cultural communication in daily practice.
Improving the evaluation of cross-cultural communication interventions in General Practice: a qualitative study

References


Giving voice to the voiceless

How to involve vulnerable migrants in healthcare research

Maria van den Muijsenbergh, Erik Teunissen, Evelyn van Weel-Baumgarten, Chris van Weel

Abstract

The increasing influx of migrants in Europe, with the prospect of large numbers permanently staying, poses a challenge to health care. Primary care plays a key role in the provision of affordable care of high quality for these groups. There is a lack of guidance for migrant care, due to insufficient knowledge of refugees’ morbidity patterns and health care needs. Generating knowledge of migrants’ health through research and guideline development is a priority for policies and practices tailored to their needs. Service users are experts by experience, and especially the experiences of migrants living in unusual, unhealthy circumstances don’t resonate with the life-world of researchers and practitioners. Although complex, there is a growing experience of successful engagement of migrants in research, even those ‘undocumented’. In this paper we present practical guidance for research on and with migrants.
Introduction

Migration, with the prospect of large numbers of people permanently staying in a country, poses a challenge to society including the healthcare sector. This has been magnified by the large numbers of migrants and refugees that are currently entering Europe. Most of the refugees will stay over the years, some of them without ever getting permission to stay and thus becoming undocumented. In this article we use the term ‘migrants’ as an overarching term for refugees, undocumented, and other migrants. Primary care plays a key role in the provision of high-quality, affordable care for these groups, who face large health inequities and barriers to accessing health care. European general practice has acknowledged its responsibility to this group. However, stating good intentions in its professional approach alone will be insufficient. Even under stable conditions there is a lack of guidance for migrant care, due to insufficient knowledge of morbidity patterns and healthcare needs. This is not unique for migrants, and is also relevant for other marginalised groups. In that respect, primary health care may benefit, in coping with the current challenge of migrants and refugees, from its experience with care for other marginalised groups. At the same time primary health care can use this crisis to strengthen its generic approach towards marginalised groups. It is essential to understand the values and expectations attached to health before it is possible to respond to patient needs. As with other vulnerable groups, research with and for migrants and refugees, ‘giving them a voice’, is vital to generate the knowledge that informs policy and practice. Under the current politicised conditions, it is a moral obligation to avoid a ‘tokenist’ involvement, and to contribute to the quality of migrant health care. Service users, including migrants, are experts by experience. Although complex, there is a growing understanding of successful engagement of migrants in research, even those who are ‘undocumented’. Although the strategies identified are not significantly different from those advocated for the involvement of other service users in research (for example, INVOLVE [http://www.ivo.org.uk/]), the language and cultural differences, and migrants’ precarious legal position - in particular those without appropriate documents - pose specific challenges. In this editorial we present practical guidance on how to overcome these challenges, based on our experiences.

Reasons for under-representation

Researchers face practical problems in engaging migrants. There are few representative networks of patient organisations; research methods rely heavily on the language and reading skills of participants; and migrants have concerns about confidentiality and have other priorities in life. Legal barriers involving (undocumented) migrants can play a role, as can ethical issues: concerns whether participation is truly voluntary or that migrants may have unrealistic expectations about the benefits for their conditions.
Practical guidance on how to involve migrants in research

In general, recruitment and involvement of migrants takes time. However, this investment of time can lead to rich results.

Study design

Participatory action methods can ensure that the voices of hard-to-reach groups are heard and that research is performed with them instead of on them. Particularly exciting is the possibility of engaging migrants as co-researchers, who share language and cultural background with the study group. This helps to adjust instruments to the needs of the participants, provides deeper understanding of the data, and helps to disseminate the results within the community. Recruiting interviewers from the community increases response rates. A mixed-methods approach combining participatory qualitative and quantitative methods is likely to produce the evidence needed by policymakers and practitioners. Representative sampling is often not possible as the target population is seldom precisely known, given the changeable status of migrants. However, case-control studies are feasible and can provide valuable information on health and use of healthcare facilities, comparing groups of migrants or with native people. Surveys and questionnaires have to be translated and back-translated. ‘Translated’ is broader than linguistic: it includes checking the cultural meaning, appropriateness, and relevance towards the research population. It is preferably done jointly with representatives from the research population.

Recruitment

Using multiple recruitment strategies optimises numbers involved and at the same time minimises the risk of selection bias. Snowball tactics, or chain sampling using networks of researchers, practitioners, and volunteers, are often used successfully. Recruitment through GPs usually leads to a high response rate because migrants trust GPs, but it misses those who do not have access to GP care. Migrants may feel obliged to participate, whereas GPs might be overprotective and not invite migrants in difficult personal circumstances. Refugees and undocumented migrants can often be reached through churches and mosques, NGOs supporting these groups, shelters for refugees or for the homeless, and budget stores.
Informed consent

Obtaining informed consent is particularly delicate when involving vulnerable groups. Personal verbal explanation, emphasising confidentiality, can reassure migrants to sign the consent form, which has to be designed in a user-friendly format: written in simple, short sentences and without references to legal issues. Sometimes ethical committees have to be convinced of the necessity to use these instead of the regular ones. User-friendly procedures are best adjusted to the occasion when an opportunity for contact arises and it is possible ‘to make hay while the sun shines’. Participants should be informed about the study in a single process and, when willing to join, should fill in the consent form (Box 1). This ‘opt in’ method depends heavily on the ethical conduct of the researcher, who will have to be convinced that participation is voluntary and deliberate.

Box 1 example of recruitment procedure undocumented migrant women

1. The researcher and research assistant visit a shelter for undocumented women and provide group education on reproductive health issues. Various informal interpreters are present to translate where necessary into different languages.
2. At the end of the meeting, the researcher explains the aim and design of the study on health and health needs of undocumented women and what participants can expect, and answers to questions.
3. All women receive an information leaflet written in plain, simple Dutch and an informed consent form. The researcher and research assistant leave the room for about 15 minutes.
4. In those 15 minutes all women read the information, where necessary receive translation into their language by the interpreters, and decide to participate or not.
5. Those who want to participate, sign the form and leave it on a pile in the room. The meeting is over.
6. When the women have left the room, the researcher and assistant re-enter, gather the informed consent forms and approach the women who have indicated their willingness to participate.
7. With those women they schedule time-slots and interpreters for the interview (3 hours per woman, including medical assessment and information on health care).
8. Before the start of the interview the research assistant explains the procedure and content of the participation again, and assesses if this is well understood by the woman, and if she is still willing to participate. If so, the woman is included and the interview can start.
**Contacting participants**

Many migrants, in particular undocumented ones and refugees, do not have a permanent living place and do not answer their phone to an unknown caller’s number. Instead, researchers may need to use their own mobile phone and make their numbers known in advance.

**Data collection**

**Location**

Ensure the location for research meetings is safe and discreet, and used by many people throughout the day, like a health centre or community building. The location should be easily accessible by public transport and not in the vicinity of a police station. If women are participating, make sure there is a room for children, as many are single without babysitting facilities.

**Money**

Travel costs will have to be reimbursed and a fair fee for participation given, taking into account that most migrants are short of money. Food and drinks or small gifts are also good rewards. When migrants can only be paid in cash, creative solutions have to be found to justify these costs to the financial department of the research institution.

**Translation**

Migrants often do not speak the native language, nor commonly-used languages like English. Translation will be needed. Professional interpreters are costly and cannot always be trusted; sometimes friends or family can be used, but not when discussing sensitive topics like mental health issues. Here the value of migrants as co-researchers is highlighted because they speak the migrants’ language and are trusted.

‘Giving back’

Research has the potential to foster a bond with migrants, with positive effects in ensuring health care too. In this way, migrant-participants can be given something back in return for their contribution to the research. For example, migrants were provided with information on the (Dutch) healthcare system and received support to be ‘registered’ in a general practice.
Conclusion

Using elements of this guidance will help to involve vulnerable migrants in healthcare research and give them a voice. This can provide an empirical basis from which to engage with policymakers and professionals for essential improvements in health care for migrants and refugees. At the same time the urgency of the situation around migrants and refugees may provide an opportunity for primary health care to further strengthen research methodology to engage marginalised individuals and communities in the design of their care.
Giving voice to the voiceless: how to involve migrants in healthcare research

References


General Discussion
Europe is becoming increasingly multicultural: in 2014, 33.5 million migrants were living in the European Union, 6.7% of its population. This presents challenges to health systems. For example, access to healthcare and healthcare outcomes are less favourable for migrants, and migrants share a wide range in health problems, like an increased vulnerability to particular infectious diseases, non-communicable diseases and mental health problems. This lends urgency to improve health systems’ capacity to respond to ethnic and cultural diversity of patients and their health problems.

This is particularly important in primary care, as the entry point to health care for all patients and deals with a wide range of health problems. Primary health care contributes to population health, is cost-effective care and equitable, providing continuous, co-ordinated and integrated health and well-being. To respond to cultural diversity, training in cultural competencies and use of professional interpreters have been advocated, and guidelines and professional training initiatives (G/TIs) have been designed for these purposes. Some of these G/TIs have been proven to be effective in research settings. However, in general their implementation in day-to-day practice is poor, pointing to a significant translational gap between evidence and practice with little insight into why this is the case. On these grounds, the RESTORE project was started, a project that was focused on improving cross-cultural communication in primary care. It aimed to track and support the implementation of guidelines and training initiatives to improve cross-cultural communication in five primary care settings across Europe (Austria, England, Greece, Ireland and the Netherlands), using a combination of Participatory Learning and Action Research (PLA) and Normalisation Process Theory (NPT). In RESTORE, stakeholders were different groups of migrant service users along with other stakeholders, like GPs, practice nurses, service planners and policy makers.
This thesis arose from RESTORE, a study that took place in a European context and was focused on migrants in the European Union who experience language and cultural barriers in their host countries. In the Dutch setting, special attention was paid to one of the most vulnerable groups of migrants, those without a legal status - so called undocumented migrants (UMs). This focus was chosen because health and access to healthcare for this group is even more precarious, given their high-risk working and living conditions, while being excluded from regular social services and health insurance. Their limited access to health care services may impede adequate treatment by general practitioners (GPs) who are in the Netherlands their first contact with health care. We paid special attention to the mental health problems of UMs, because of the high prevalence of mental health problems amongst UMs, and because mental health is the care par excellence where all aspects of communication play a crucial role. This made mental health, in line with the research topic of RESTORE, an important subject to explore. The overall goal of our research was to provide insights into how to optimize the delivery of primary healthcare to migrants in general, and UMs with mental health problems in particular.

To summarise, this thesis included three foci:

1. Four studies on UMs with mental health problems in primary care in which we searched for answers to the following questions: How often are these problems addressed and diagnosed in primary care and what is done with this diagnosis, how and to what extent do UMs seek help for mental health problems and what are the experiences of UMs as well as GPs with consultations for mental health problems?
2. The Dutch contribution to Restore in which the Dutch team was the lead party in -the evaluation work-, which according to the applied theoretical framework is referred to as Reflexive Monitoring. In this thesis we report the process and outcome of the evaluation, to understand how stakeholders, including migrants, in different European contexts, valued the G/TIs that were implemented to improve communication in cross-cultural consultations.
3. A critical reflection of our experiences in involving UMs in research projects and a practical guidance for researchers considering research on or with UMs.
One quantitative survey study was undertaken of general practice patient records of UMs and documented migrants, in order to get a more detailed insight in diagnosis and treatment of mental health problems of UMs by Dutch GPs. (Chapter 2) In four studies, qualitative research methods were used. In the Dutch setting, in depth-interviews were held, with UMs (Chapter 3) and GPs (Chapter 4). Most research about UMs was done in the Dutch context, but we also had the opportunity to explore some of these aspects in the Greek context, as Greece was one of the partners in our Restore project. This is a country with a different health care context, but with many similar problems in the care for UMs. (Chapter 5) In the European project a combination of PLA/NPT was applied (Chapter 6). On top of this, we reflected on our experiences in involving UMs in research projects (Chapter 7).

**The most striking findings and the relation to primary care**

*It was possible to involve hard to reach groups in the implementation*

Our European study, which is the second focus of our thesis, adds the striking finding to the literature that it is possible to involve even the most vulnerable migrant service users, like UMs, in a meaningful way, in all stages of the implementation and evaluation of G/TIs in primary care. This is striking, as true participation of patients in research, and in particular of hard to reach groups as migrants, has only been achieved on a limited scale.\(^\text{23,24}\) The reason for this successful involvement was the use of the participatory research method PLA. The attention in PLA to overcome language and cultural barriers, to reduce power imbalances in the group, and to give the most vulnerable stakeholders a strong voice, were the main reasons why migrants could be involved in an equal position, next to the other stakeholders, as full co-designers and co-evaluators. Their involvement and input was helpful, as they created awareness amongst the service providers about the relevance of the G/TIs, and because they identified barriers for the uptake of interpreter services otherwise unknown. This in turn motivated service providers to continue improving the implementation.
NPT/PLA is a key factor for successful implementation

It is known that the implementation of G/TIs to overcome barriers in cultural diversity is often poor, with little insight why this was the case.\textsuperscript{13-16} Only a few studies in the field of cross-cultural communication have taken an implementation focus, addressing implementation of services i.e. interpreted consultations in general practice only.\textsuperscript{15,16,25} So far, no theoretical frameworks were prospectively applied as recommended for implementation studies.\textsuperscript{26} Our European study was the first study in which implementation theory was combined prospectively with participatory research, to prioritise the involvement of migrants and healthcare providers in primary care, to collaboratively progress the implementation of relevant G/TIs. This study design turned out to be a key factor for successful implementation and evaluation of the G/TIs to improve cross-cultural communication. It led to successful involvement of migrant-service users and service providers in the implementation and evaluation, and this involvement did lead to significant adaptations of the original G/TIs and to real commitment, both evaluated by the stakeholders as pre-requisites for successful implementation. The attention in PLA for minimizing power imbalances, the consultation of migrant service-users on key hiring decisions as the choice which G/TI to apply, and the trustful environment in primary care probably explains why in our project the elsewhere described problem of establishing mutual trust between the patients and other stakeholders did not occur.\textsuperscript{27} As PLA/NPT was successful across multiple primary care settings in Europe, it seems likely at other sites this combination will lead to successful implementation as well. This made PLA/NPT a promising method for a broader application in primary care. The method, that is focused on exploration of the needs and expectations of local populations and patients, and to ensure that their voice and choice decisively influence the way in which health care services are designed and operate, fits perfectly with the patient oriented and population oriented core values of primary care.\textsuperscript{28,29} This study also showed that PLA/NPT is an outstanding method for optimising the quality of care for those patients with the highest needs, like UMs, and can contribute to more equity of care, which is an important value in primary care.\textsuperscript{30}
Drawing on the stakeholders’ evaluation data, it became clear that a cultural competency training adapted by practice members and migrant service users did lead to sustainable improvements in the local setting for daily practice. First of all, knowledge, attitudes and skills of GPs and practice nurses improved, and migrant service-users reported more patient satisfaction. Second, the involvement of all practice members (including practice assistants) in the adaptation and implementation of the training made it possible to clarify long-term agreements about improvements in their local settings. In the Netherlands for example, all practice members agreed to pay structural attention to the recognition and recording of the diagnosis ‘low literacy’, to use a ‘care notebook’ for migrants with chronic diseases, and to install pictograms for migrant service-users. Interestingly, the stakeholders considered that these practice level changes were due to the fact that all practice members had been involved collectively in the training and thus shared the responsibility to implement the G/TI in the practice. These are novel findings in relation to implementation of G/TIs in this field and resonate with previous research that inter-professional collaborative agreements are needed to effectively change the practice long-term.31,32

**GPs see continuity of care as most valuable to deal with the health needs of undocumented migrants**

It is known that mental health problems are highly prevalent amongst UMs, and that in the Dutch health care system primary care is the main health care provision for UMs, including mental health.18-21 The Netherlands is one of the few EU member states where UMs are entitled to receive health services access beyond emergency care.33 They have the right to receive ‘medically necessary care’, which means that UMs have the right to receive the same usual care by the same professional standards and guidelines as other patients, including mental health care.34 The Dutch study amongst GPs, that was part of the second focus of our thesis, adds the finding that GPs recognized many mental health problems in UMs, but at the same time experienced barriers to deliver usual care: UMs consulted a GP less frequently, waited longer to present these mental health problems to the GP and when they did, it was mainly through physical symptoms compared to documented migrants (DMs). GPs mentioned the high number of other problems (physical and social) competing for the available time as well. They were aware of the fact that UMs often distrusted them and other professionals, partly due to a lack of continuity of care, and felt to have limited treatment options.
GPs described a number of solutions to cope with treatment barriers in order to provide optimal mental health to UMs. From the perspective of the GPs, the most important solution was to establish trust in the relation with the UMs. This trust was essential to facilitate disclosure of mental health problems, and could only be gained in a long-term relationship with the patient. GPs explained they tried to establish more continuity of care by being very accessible for UMs and by concentrating the consultations with UMs at one of the GPs in the practice. They also explicitly asked the UMs to visit this one GP for all their health complaints, and return to the same GP for their problems. Problems in referrals were solved by using the resources available in the practice, for example by referring the UMs to other primary care colleagues such as social workers and practice nurses who were specialized in mental health. This response of GPs, to provide personal continuity to the greatest extent possible and to refer to colleagues within the primary care team, echoes what is seen as the core values of primary care: providing generalist, patient-oriented and continuous care. Also for UMs, patients who were not on their patients’ list, GPs strive to provide continuous care that is person-centered and adjusted to the UMs’ context as much as possible.

Research showed that there are contradictory reports of the frequency of UMs’ mental health problems presented, recorded and treated in Dutch primary care. These studies indicate a gap between the high prevalence of mental health problems presented by UMs and the low recording of these problems by GPs.

Our study adds an explanation why mental health problems of UMs are often not labeled as psychopathology by GPs. In the study amongst Dutch GPs, that was part of the second focus of our thesis, GPs explained that they did not feel these labels were helpful, as many barriers existed to deliver optimal care to this group, for example lack of treatment options, cultural differences and language problems, and lack of trust that hampered the ability to find a common ground needed to treat mental health problems appropriately.

A second, even more important reason was that GPs seemed to be aware that labeling these problems as mental health problems could easily lead to further stigmatization of patients whose problems often were seen as ‘a normal response to abnormal living circumstances’. This was in line with the findings in our study with UMs, where the majority of the UMs mentioned that their mental health problems were directly related to external factors, namely their precarious living conditions and lack of status.
GPs seemed to consider that this labeling did not contribute to empowerment of these UMs. Providing support to UMs for their mental health problems without labeling is in line with primary mental health care in general and with the Dutch primary care guidelines for mental health problems, as illustrated by the recent revision of the Dutch guideline ‘Depression’, that restricts the diagnosis depression for pathological situations only, and not for normal, transient reactions to loss or to difficult living circumstances.\textsuperscript{28,39}

**Conclusion and recommendations**

Our study showed that, despite important barriers, GPs strived to safeguard the core-values of primary care as much as possible for the hard-to-reach group of UMs, in order to create equal access and quality of care. These values were seen as highly important, not only by the GPs themselves, but by the UMs as well, indicating the high relevance of generalist, patient-oriented and continuous care for UMs. Our study pointed out that more continuity of care strengthened the quality of this care, and therefore we recommend further incentives for GPs to increase their possibilities to deliver continuity of care to undocumented migrants in their practice, as this is one of the best strategies to deliver appropriate care and to prevent unnecessary care for this vulnerable group. This faciliation of comprehensive care and continuity of care should not be restricted to the Netherlands only, but should be facilitated in other countries as well.

We found that NPT/PLA was a helpful and innovative method to empower primary care professionals to overcome barriers in cultural diversity and in line with the core-values of primary care. As we considered NPT/PLA a promising method for broader application in primary care, and ‘par excellence’ helpful to involve different groups of patients, we strongly recommend using NPT/PLA in other primary care projects with other groups of patients as well. In our study we used NPT/PLA extensively, with a large group of stakeholders, trained researchers and financial resources. As there is a gap between our approach and the possibilities in every-day practice of GPs, where time and resources are limited, we recommend further implementation research studying how to make NPT/PLA more applicable for every-day practice. When this gap of knowledge has been overcome, we really have a promising strategy to strengthen primary care together with patients.
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This thesis focuses on migrants in primary care through a series of studies: (1) first, mental health problems of undocumented migrants (UMs) are studied and in it the role of general practitioners (GPs) in the management of these problems. This part took place in the Netherlands and Greece and emphasized the importance of communication between migrants and GPs; (2) the second part is directed at strategies to improve communication, through guidelines and training initiatives, with migrants in primary care and the evaluation of their implementation. This part is based on a European EU project RESTORE (REsearch into implementation STRategies to support patients of different ORigins and language background in a variety of European primary care settings). A key factor in this is the active involvement of migrants as co-designers in this process; and (3) as a third step a critical reflection of our experiences in involving migrants, in particular the most vulnerable (UMs) in research projects to shape effective health care, with an eye on further research in this field.

In **Chapter 1** the rationale for this study and the study aims and research questions are described. It sketches the multiculturalization of Europe, the important role of primary care in the provision of care for migrants and the less favourable access to healthcare and health care outcomes for migrants and in particular for UMs. It describes that mental health problems are the most frequently reported health need amongst UMs, and that research shows a gap between the high mental health needs and low recording of these needs in general practice. This requires further empirical investigation which in this thesis is described. The crucial role of communication in the care of migrants is discussed, and in particular in the provision of mental health care, and the need for better uptake of guidelines and training initiatives (G/TIs) to support communication with migrants in general practice consultations. The RESTORE project is introduced, a qualitative case study amongst five primary care settings in Europe (Austria, England, Greece, Ireland and the Netherlands) were in each setting a diverse group of stakeholders, including migrants, implement and evaluate a G/TI to support cross-cultural communication in primary care. Normalisation Process Theory (NPT) is used as analytical framework, with Participatory Learning and Action (PLA) as research method to engage the stakeholders, including migrant service-users.

It states that there is a growing need for and experience of successful engagement of migrants in research. However, meaningful engagement of vulnerable migrant groups like UMs or refugees is not easy and our experiences have taught us several lessons on what works and what does not. Therefore a practical guidance is presented for research with vulnerable migrant groups.
Mental health problems of UMs and the role of GPs in the management of these problems

Chapter 2-6 are focused on mental health problems of UMs and the role of GPs in the management of these problems. The aim of chapter 2 is to get insight in the registration in patient records by GPs of diagnosis and treatment of mental health problems of UMs compared to documented migrants (DMs). By a snowball method, general practices involved in the care of UMs were approached. Of them, nine responded and were able and willing to participate. A total of 325 UMs were included whose files were compared with 216 DMs, who matched for gender, age and region of origin. Data were collected from the patient records starting two years prior to the start of this study. We found that UMs consulted a GP significantly less than DMs (3.1 versus 4.9 times per year) and that only 20.6% of the UMs had at least one mental health problem diagnosis registered, compared to 44.0% of the DMs. In both groups, about 10% mentioned at least one main mental health complaint during the consultation that was not coded in the record. Prescription of benzodiazepines and antidepressants was the most common intervention for the treatment of mental health problems, for DMs as well as UMs. UMs were referred less to mental health care institutions than DMs, but more often to psychiatrists than to psychologists. Based on these findings, we advise GPs to explore and register mental health problems more actively in UMs.

In Chapter 3 we describe the views of a heterogeneous group of 15 UMs regarding their health-seeking behaviour and experiences in Dutch general practice in relation to mental health problems. Almost all UMs involved mentioned having mental health problems, for which the large majority cited the lack of documents as the main reason for their mental distress. UMs mentioned friends and religion as the main sources of support while GPs were often seen as the last resort. In general, they mentioned a large time-delay before they consult a GP and even when they did, they often believed it is not the role of the GP to help them how to cope with mental distress. Many barriers for seeking help in general practice were mentioned but once access had been gained, the majority of UMs were very satisfied with the care of the GPs. The large majority do not see medication as an appropriate treatment for mental health problems. We suggest to engage UMs as stakeholders to help other UMs to gain access to primary care and to inform their peers about the key role of the GP in the recognition and treatment of mental health problems, and to put the problems around (mental) healthcare for UMs on the political and public agenda.
Chapter 4 describes the views and experiences of 16 Dutch GPs with clinical expertise in UMs’ care with mental health problems of UMs. GPs explained that they recognized, recorded and treated mental health problems of UMs as far as possible and in the same way as they do for other patients, but at the same time experienced barriers that prevented them from recording these problems and from delivering appropriate care. Main barriers were the low consultation rate of UMs and the resulting high number of other urgent problems, the presentation of mental health problems through physical symptoms, cultural differences in health beliefs, the lack of treatment options, the lack of continuity of care, and above all UM’s lack of trust towards healthcare professionals. GPs mentioned that referrals to mental health care organizations were often problematic. In their opinion, the mental health problems of UMs are often a normal reaction to an abnormal situation and labelling psychological problems under these circumstances can easily lead to further stigmatization. To overcome these aforementioned barriers, GPs tried to provide personalized care as much as possible, referred to other primary care professionals such as mental healthcare nurses, and were a little less restrictive in prescribing psychotropics. We recommend GPs to strive for continuity of care as much as possible and to look for creative solutions in order to provide patient-centred cultural-sensitive mental healthcare for UMs.

In Chapter 5 the findings are presented of semi-structured interviews with 12 GPs from Crete in Greece regarding the barriers and levers in the provision of mental health care for UMs. Greece is one of the partners in the RESTORE project and has a different healthcare context where UMs are entitled to receive only emergency care in case of life-threatening conditions. We find that Greek GPs as the Dutch GPs were very engaged in providing good mental health care for UMs, but that they faced even more serious barriers in providing appropriate care. Most barriers had also been reported by GPs from the Netherlands: UMs’ lack of knowledge of their rights, means to access primary care, fear to be reported, and lack of trust in health care professionals. Specific barriers for the Greek context were the obligatory consultation fee, the role of the employer who compagnies the UM during the consultation and the profound impact of austerity measures on the accessibility and quality of primary care in Greece in general. On top of this, GPs experienced that the economic crisis had increased the societal resistance to UMs and they mentioned various governmental measures to criminalize UMs.
At the same time, GPs presented creative solutions to overcome these barriers: they didn’t charge the consultation fee, asked the employers to pay for this fee, allowed UMs to visit anonymously, provided psychotropics for free, and problems in referral were overcome by using resources available in the local community, for example social workers. These findings lead to the following recommendations: more privacy for UMs in the consultation room, better integration of mental health services in primary care, the start of an active collaboration between GPs and locally available mental health services and community services, and more active recording of mental health problems of UMs.

**Strategies to improve communication, through guidelines and training initiatives, with migrants in primary care and the evaluation of their implementation (RESTORE)**

In Chapter 6 we report on the evaluation of the implementation in primary care of guidelines and training initiatives aimed at improving cross-cultural communication, as part of the RESTORE project. Sixty-five stakeholders (migrants, GPs, practice nurses, receptionists, practice assistants, practice managers, academics, interpreters, health service planners and policy makers) across five European primary care settings (England, Greece, the Netherlands, Ireland and Austria) are involved in this implementation and evaluation process. In three settings this concerned a training initiative to improve cultural competences, in two settings a guideline to implement interpreting services. Normalisation Process Theory (NPT) is used as analytical framework, with Participatory Learning and Action (PLA) as research method to engage the stakeholders. We find that the training initiatives had a positive impact at practice level and resulted in a more tolerant attitude and more effective communication with migrants, with a better focus on the migrants’ needs. Implementation of interpreting services were more difficult to achieve mainly due to lack of finances and resources. But when used, more trust of migrants in GP’s diagnoses was achieved and GPs reported a clearer picture of migrants’ symptoms. Migrants identified barriers that were not previously foreseen like fear that the interpreting service cost them money or that they had to use their own cellular phone. We conclude that migrants, GPs and other stakeholders are able to collaboratively evaluate G/TIs, and that this reveals valuable information which enhances sustainability of implementation of G/TIs in daily practice.
A critical reflection of our experiences in involving migrants, in particular the most vulnerable (UMs) in research projects

Chapter 7 presents a practical guidance how to successfully involve vulnerable groups of migrants, like UMs, in healthcare research. We discuss the following issues: which study designs work best to ensure participation, how to successfully recruit migrants, how to minimise selection bias and how to overcome dilemmas concerning informed consent. Other practical issues, for example the location of the research meetings, time and financial issues, the use of interpreters and member checking are discussed as well. We conclude that the use of elements from this guidance can help to involve vulnerable migrants in research and give them a voice, and that this will contribute to better healthcare.

The final Chapter 8 discusses the most striking findings of this thesis in relation to the core values of general practice. It ends with a conclusion and recommendations for intervention strategies and suggestions for future research. One of the major findings of this thesis is that it is possible to involve even the most vulnerable migrant service users, like UMs, in all stages of the implementation of a guideline or training initiative in primary care, and that PLA makes this possible. We conclude that the combination of PLA with NPT is a promising method to shape better healthcare for vulnerable patients, and in line with the core values of primary care (generalist, patient-oriented and continuous care). We recommend to use NPT/PLA in other primary care research projects as well and suggest further implementation research how to make NPT/PLA applicable for everyday practice of GPs.

Another major finding of this thesis is that the majority of GPs mention the establishment of trust as the most important solution to provide mental health to UMs, and that they strive to safeguard the core values of primary care as much as possible for this hard-to-reach group. We recommend further incentives for GPs to increase their possibilities to deliver continuity of care to UMs, not only in the Netherlands but in other countries as well, as this is one of the best strategies to deliver appropriate care and to avoid unnecessary care for this vulnerable group.
Samenvatting
Samenvatting

Dit proefschrift gaat over migranten in de eerstelijnszorg en bestaat uit drie onderdelen. Het eerste deel focust op de psychische problemen van ongedocumenteerde migranten (OM) en de rol van de huisarts in de behandeling van deze problemen. De studies uit dit deel van het proefschrift zijn verricht in Nederland en Griekenland en benadrukken het belang van communicatie tussen migrant en huisarts.

Het tweede deel richt zich op strategieën om de communicatie tussen migrant en huisarts te verbeteren. In dit deel worden de implementatie en evaluatie van richtlijnen en trainingsprogramma’s, gericht op het verbeteren van communicatie tussen migrant en huisarts, verder onderzocht. Dit is een onderdeel van een Europees onderzoeksproject RESTORE (REsearch into implementation STrategies to support patients of different ORigins and language background in a variety of European primary care settings), waarin de deelname van migranten in het ontwerp en implementatie van trainingen en richtlijnen centraal staat. Het derde deel van het proefschrift is een beschouwing van onze ervaringen met betrekking tot het actief betrekken van migranten in onderzoek gericht op het vormgeven van effectieve zorg. Hierin richten wij ons met name op het betrekken van de meest kwetsbare groepen, zoals OM.

In Hoofdstuk 1 worden de aanleiding van het proefschrift, de studiedoeleinden en onderzoeksvragen verder uitgewerkt. Het beschrijft de multiculturalisering van Europa, de belangrijke rol van de eerstelijnszorg voor migranten, de problemen die migranten ervaren in de toegang tot zorg, en de slechtere gezondheidsstatus van (ongedocumenteerde) migranten. Er wordt beschreven dat psychische problemen bij OM veel voorkomen, en dat onderzoek een verschil aangeeft tussen het veelvuldig voorkomen en de registratie daarvan in de huisartsenpraktijk. Om dit verschil te kunnen verklaren is verder empirisch onderzoek nodig, dat in dit proefschrift beschreven wordt.

Het beschrijft de belangrijke rol van communicatie in de zorg voor migranten, in het bijzonder bij psychische problematiek, en de behoefte aan een betere implementatie van richtlijnen en trainingen gericht op het verbeteren van communicatie met migranten in de huisartsenpraktijk.
Het RESTORE project wordt geïntroduceerd: dit is een kwalitatieve casus studie die plaatsvindt in huisartsgeneeskundige settings in Europa (Oostenrijk, Engeland, Griekenland, Ierland en Nederland), waarbij in ieder land een diverse groep deelnemers (inclusief migranten) samen een richtlijn implementeren en evalueren die gericht zijn op het verbeteren van de communicatie met migranten in de huisartsenpraktijk. Normalisatie Proces Theorie (NPT) wordt gebruikt als analytisch raamwerk, en een participatoire onderzoeksmethode PLA (Participatory Learning and Action) als methode om de deelnemers, inclusief migranten, actief te betrekken in de implementatie.

In dit hoofdstuk wordt benoemd dat er een stijgende behoefte is aan het succesvol betrekken van migranten in onderzoek maar dat het moeilijk is om kwetsbare groepen zoals OM of vluchtelingen op een betekenisvolle wijze te betrekken. Ons onderzoek heeft ons diverse lessen geleerd over wat wel en niet werkt en daarom presenteren wij een praktische richtlijn hoe onderzoek te doen met deze kwetsbare groepen.

**Psychische problemen van ongedocumenteerden en de rol van huisartsen in de behandeling van deze problemen**

**Hoofdstuk 2 tot en met 6** zijn gericht op de psychische problemen van OM en de rol van huisartsen in de behandeling van deze problemen. Het doel van hoofdstuk 2 is om inzicht te krijgen in de registratie en de behandeling van psychische problemen van OM door huisartsen, in vergelijking met gedocumenteerde migranten. Via een bepaalde methode (sneeuwbalmethode) zijn huisartsenpraktijken benaderd die betrokken zijn in de zorg voor OM. Negen praktijken reageerden en waren bereid om deel te nemen aan het onderzoek. In totaal zijn er 325 OM geïncludeerd en hun medische dossiers zijn vergeleken met 216 gedocumenteerde migranten, gematched voor geslacht, leeftijd en land van herkomst. Deze data werden verzameld uit de huisartsendossiers tot twee jaar voor aanvang van de studie. We ontdekten dat OM significant minder bekend zijn als zodanig gecodeerd in het dossier. Het voorschrijven van rustgevende medicatie en antidepressiva is de meest voorkomende interventie voor de behandeling van psychische problemen, zowel voor gedocumenteerden als voor OM. OM worden minder vaak naar GGZ instellingen verwezen dan gedocumenteerden, maar vaker naar psychiaters dan naar psychologen. Op basis van deze bevindingen adviseren wij huisartsen om psychische problemen bij OM actiever te exploreren en registreren.
In Hoofdstuk 3 beschrijven we het hulpzoekgedrag van een heterogene groep van 15 OM voor psychische problemen en hun ervaringen met de Nederlandse huisartsen wat betreft de behandeling van deze problematiek. Bijna alle OM vertellen psychische problemen te hebben, en de overgrote meerderheid benoemt het ontbreken van een verblijfsdocument als belangrijkste reden hiervoor. Vrienden en religie zijn de belangrijkste hulpbronnen bij psychische problemen, en de huisarts wordt meestal gezien als laatste redmiddel. In het algemeen duurt het lang voordat OM een huisarts bezoeken, en als ze dat al doen is er vaak de aanname dat het niet de rol van de huisarts is om te helpen met psychische problemen. Zij noemen veel barrières die hen weerhouden om hulp te zoeken bij de huisarts, maar wanneer zij eenmaal contact hebben gehad is de meerderheid erg tevreden met de geleverde zorg. De grote meerderheid beschouwt medicatie niet als een goede behandeling om psychische problemen te behandelen. Wij suggereren om OM actief te betrekken als stakeholders om andere OM te helpen toegang te krijgen tot huisartsenzorg en hen te informeren over de rol van de huisarts in de herkenning en behandeling van psychische problemen. Ook adviseren wij om de problemen rondom (psychische) zorg voor OM op de politieke en publieke agenda te krijgen.

Hoofdstuk 4 beschrijft de meningen en ervaringen van 16 Nederlandse huisartsen over de huisartsgeneeskundige zorg voor psychische problemen van OM. Deze huisartsen, allen ervaren in de zorg voor OM, vertellen dat zij (psychische) problemen van OM zoveel mogelijk op dezelfde manier proberen te registreren en behandelen als bij andere patiënten, maar dat zij veel barrières ervaren die hen weerhouden deze problemen te registreren en hen ook belemmeren in het leveren van adequate zorg.

Belangrijke barrières zijn de lage consultfrequentie en de veelvuldige aanwezigheid van andere meer urgente problemen, de uiting van psychische problemen via lichamelijke symptomen, culturele verschillen in opvattingen over gezondheid, het gebrek aan behandelmogelijkheden en vertrouwen van OM in gezondheidswerkers. Huisartsen geven aan dat verwijzingen naar GGZ instellingen vaak problematisch verlopen. Huisartsen zijn vaak van mening dat de psychische problemen een normale reactie zijn op abnormale leefomstandigheden en dat het labelen van deze problemen als ‘psychologisch’ gemakkelijk zou kunnen leiden tot verdere stigmatisatie. Om de barrières in de zorg te overbruggen verlenen huisartsen zoveel mogelijk persoonlijke zorg, verwijzen ze specifiek naar zorgverleners in de eerstelijn zoals praktijkondersteuners GGZ, en zijn ze iets minder terughoudend in het voorschrijven van medicatie. Wij adviseren huisartsen om zoveel mogelijk te streven naar continuïteit van zorg en op zoek te gaan naar creatieve oplossingen om patiëntgerichte cultureel-sensitieve psychologische zorg te bieden aan OM.
In Hoofdstuk 5 presenteren we de bevindingen van semi-gestructureerde interviews met 12 huisartsen uit Kreta, Griekenland over de psychologische zorg bij OM. Griekenland is één van de partners van het RESTORE project en heeft een ander gezondheidszorgsysteem waarbij OM alleen recht hebben op spoedzorg bij levensbedreigende situaties. Uit ons onderzoek komt naar voren dat Griekse huisartsen, net als Nederlandse huisartsen, zeer betrokken zijn in het zo goed mogelijk voorzien van adequate psychologische zorg voor OM, maar dat zij nog grotere problemen ondervinden bij het verlenen van deze zorg. De meeste barrières worden ook door de Nederlandse huisartsen benoemd: gebrek aan kennis van OM over hun rechten, gebrek aan middelen van OM om toegang te krijgen tot zorg, angst van OM om aangegeven te worden bij de politie, en een gebrek aan vertrouwen in gezondheidsprofessionals. Specifieke barrières voor de Griekse context zijn de verplichte eigen bijdrage voor consulten, de werkgevers die de OM vaak vergezellen tijdens het consult en de grote invloed van de bezuinigingen op de toegankelijkheid en kwaliteit van de huisartsengeneeskundige zorg in Griekenland. Daarnaast ervaren huisartsen dat de economische crisis de maatschappelijke weerstand tegen OM heeft vergroot en noemen ze diverse overheidsmaatregelen gericht op het criminaliseren van OM. Griekse huisartsen noemen diverse creatieve oplossingen om deze barrières te overbruggen: ze vragen geen eigen bijdrage of vragen de werkgevers om deze te betalen voor de OM, vragen niet naar de identiteit van de OM en schrijven gratis medicatie voor. De problemen in de verwijzing naar de GGZ worden overbrugd door gebruik te maken van lokale faciliteiten in de gemeenschap, zoals maatschappelijk werkers. Deze bevindingen leiden tot de volgende aanbevelingen: meer privacy voor OMs in de spreekkamer, een betere inbedding van bestaande psychologische zorg in de eerstelijn, het opzetten van een actieve samenwerking tussen huisartsen, GGZ en gemeenten, en een betere registratie van psychische problemen van OM in huisartsen dossiers.

Strategieën voor het verbeteren van de communicatie, via richtlijnen en trainingsprogramma’s, met migranten in de eerstelijn en de evaluatie van de implementatie (RESTORE)

In Hoofdstuk 6 beschrijven we de evaluatie van de implementatie van richtlijnen en trainingen gericht op het verbeteren van de interculturele communicatie in de huisartsenpraktijk (RESTORE). Vijfenzestig deelnemers (migranten, huisartsen, praktijkondersteuners, doktersassistentes, praktijkmanagers, medewerkers universiteiten, tolken en beleidsmakers) uit vijf landen (Engeland, Griekenland, Nederland, Ierland en Oostenrijk) zijn betrokken bij de implementatie en evaluatie.
In drie settings betreft het een trainingsprogramma gericht op het verbeteren van de culturele competenties en in twee settings betreft het een richtlijn voor het invoeren van een tolkentelefoon. Normalisatie Proces Theorie is gebruikt als analytisch raamwerk, en een participatierichting onderzoeksmethode PLA als methode om de deelnemers te betrekken in de implementatie. Het blijkt dat de ingevoerde trainingsprogramma's een positieve invloed hebben op de kwaliteit van de praktijkorganisatie en resulteren in een meer positieve houding ten opzichte van migranten en een effectiever manier van communiceren, die meer gericht is op de behoeften van de migrant. Het implementeren van de tolkentelefoon in de deelnemende huisartsenpraktijken is moeilijker te realiseren, voornamelijk door het gebrek aan financiële middelen. Maar indien de tolkentelefoon toch gebruikt wordt, heeft de migrant meer vertrouwen in de gestelde diagnoses van de huisarts en krijgen huisartsen een beter overzicht van de klachten van de migrant. Migranten noemen barrières waar in eerste instantie niet aan werd gedacht, zoals de angst dat de tolkentelefoon hen geld kost en dat zij hun eigen mobiele telefoon moeten gebruiken. Wij komen tot conclusie dat migranten, huisartsen en andere deelnemers goed in staat zijn om gemeenschappelijk de training of richtlijn te evalueren, en dat deze evaluatie leidt tot nieuwe informatie die bijdraagt een duurzame invoering van trainingen en richtlijnen in de dagelijkse praktijk.

Een kritische reflectie van onze ervaringen wat betreft het betrekken van migranten, en met name kwetsbare migranten, in onderzoeksprojecten

In Hoofdstuk 7 wordt een praktische gids gepresenteerd hoe op een succesvolle manier kwetsbare groepen migranten, zoals OM, te betrekken in gezondheidszorgonderzoek. We bespreken de volgende punten: welke studiemethode werkt het beste om deelname te garanderen, hoe kun je op succesvolle wijze migranten benaderen, wat kun je doen om selectie bias te minimaliseren en hoe moet je omgaan met dilemma's zoals informed consent (toestemming geven aan deelname aan onderzoek). Andere meer praktische zaken, zoals de locatie van de onderzoeksbijeenkomsten, tijd en financiële aspecten, het gebruik van tolken en member check (navragen bij deelnemers of de gepresenteerde data kloppen) worden ook besproken. We komen tot de conclusie dat het gebruik van elementen van deze gids kan bijdragen om kwetsbare migranten in onderzoek te betrekken en hen een stem te geven, en bijdraagt tot een betere gezondheidszorg.
In het laatste Hoofdstuk 8 bespreken we de meest markante bevindingen van dit proefschrift en hoe deze in verhouding staan tot de kernwaarden van de huisartsgeneeskunde. Het eindigt met een conclusie en aanbevelingen voor interventies en toekomstig onderzoek. Een van de belangrijkste bevindingen van dit proefschrift is dat het mogelijk is om zelfs de meest kwetsbare migranten zoals OM te betrekken in alle stadia van de implementatie van een training of richtlijn in de huisartsenpraktijk. Dit wordt mogelijk gemaakt door het gebruik van PLA. Wij komen tot de conclusie dat de combinatie van PLA met NPT een veelbelovende strategie is om voor kwetsbare groepen een betere gezondheidszorg te creëren, en dat deze methode in lijn is met de kernwaarden van de huisartsgeneeskunde (generalistische, patiëntgerichte en continue zorg). We adviseren om NPT/PLA ook te gaan gebruiken in andere huisartsgeneeskundige onderzoeksprojecten en stellen voor om verder implementatieonderzoek te verrichten hoe NPT/PLA toepasbaar te maken voor de dagelijkse praktijk van de huisarts.

Een andere markante bevinding is dat de meerderheid van de huisartsen het tot stand brengen van een vertrouwensrelatie als belangrijkste oplossing zien om psychische zorg te kunnen verlenen aan OM, en dat zij zoveel mogelijk proberen om voor deze kwetsbare groep de kernwaarden van de huisartsgeneeskunde te bewaken. Wij adviseren (financiële) prikkels om huisartsen te belonen voor het leveren van meer continuïteit van zorg voor deze groep, niet alleen in Nederland maar ook in andere landen, omdat dit een van de beste strategieën blijkt om gepaste zorg te leveren en ongepaste zorg te vermijden.
Dankwoord

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Dank!

In 2011 was het dan zover, de start van mijn promotie. Ik zou mij verdiepen in iets wat ik persoonlijk erg belangrijk vind: het verbeteren van de kwaliteit van de huisartsgeneeskundige zorg voor kwetsbare groepen. Vijf jaar later is het af en de tijd lijkt voorbij gevlogen. Wat zijn er veel leuke dingen gebeurd: een prachtige zoon gekregen, onderzoek doen in waar mijn interesses liggen, in een nieuwe stad gaan wonen, waarnemen als huisarts, internationale congressen, artikelen publiceren en samenwerken met onderzoekers uit heel Europa. Maar er waren ook zorgen: over de gezondheid van directe familieleden, en hoe privé, promotie en werk als huisarts te combineren. Dit alles maakt de afronding van dit proefschrift een afsluiting van een turbulent en boeiende periode in mijn leven. De steun van de volgende mensen is hierbij heel belangrijk geweest.

_Chris van Weel_

_Maria van den Muijsenbergh_
Maria, iedere huisarts noemt jouw naam als ik aangeef onderzoek te doen naar zorg voor kwetsbare migranten. Ongelooflijk wat jij op dit gebied allemaal betekent. Je vrolijke lach, bevlogenheid, werklust en gevoel voor humor maken het een feest om met je te werken. Dank je wel voor onze samenwerking, ik ben er trots op dat je mijn copromotor bent.

_Evelyn van Weel-Baumgarten_
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_Francine van den Driessen Mareeuw_
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Members RESTORE
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Beoordelingscommissie
Geachte leden, hartelijk dank voor uw inspanning om mijn proefschrift te evalueren. Ik zie uit naar een vruchtbare discussie tijdens de verdediging.

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Dear colleagues from Crete, thank you for your openness to talk about the care for undocumented migrants in Greece. I am proud to have colleagues who provide free care for undocumented migrants, even when it is against the regulations. Keep up your excellent work.
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Afdeling ELG

Secretariaat ELG
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Medewerkers en patiënten asielzoekerscentrum Schalkhaar
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Studenten Geneeskunde
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List of publications
**Peer reviewed**

Late effects of chemotherapy compared to bone marrow transplantation in the treatment of pediatric acute myeloid leukemia and myelodysplasia.
Leahey AM, **Teunissen H**, Friedman DL, Moshang T, Lange BJ, Meadows AT.  

Bellse parese.
**Teunissen E**, Eekhof JAH, Knuistingh Neven A, Opstelten W.  

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De NHG-standaard ‘Perifere aangezichtsverlamming’: samenvatting.
Klomp MA, Verdaasdonk AL, Striekwold MP, **Teunissen H**, Opstelten W, Goudswaard AN.  
*Ned Tijdschr Geneeskd* 2010; 154:A2439.

NHG-Standaard Perifere aangezichtsverlamming.
Klomp MA, Striekwold MP, **Teunissen H**, Verdaasdonk AL.  

REsearch into implementation STrategies to support patients of different ORigins and language background in a variety of European primary care settings (RESTORE): study protocol.

Enhancing the use of theory in practice: A qualitative study of Normalisation Process Theory training and support in cross-country implementation research.
*Submitted*
**Thesis**

Mental health problems in undocumented and documented migrants: a survey study.

**Teunissen E**, van den Bosch L, van Bavel E, van den Driessen Mareeuw F, van den Muijsenbergh M, van Weel-Baumgarten E, van Weel C.


Mental health problems of undocumented migrants (UMs) in the Netherlands: a qualitative exploration of help-seeking behaviour and experiences with primary care.

**Teunissen E**, Sherally J, van den Muijsenbergh M, Dowrick C, van Weel-Baumgarten E, van Weel C.


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Van den Muijsenbergh M, **Teunissen E**, van Weel-Baumgarten E, van Weel C.


**Non-peer reviewed**

News.

**Teunissen E**.

List of publications


**Teunissen E.**

Vasco da Gama Movement: Achievements and future plans.

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Editors: Eekhof JAH, Knuistingh Neven A, Opstelten W.

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WHO Regional Office for Europe, Copenhagen 2012.

**Abstracts**

Late effects of chemotherapy compared to bone marrow transplantation in the treatment of pediatric acute myeloid leukemia and myelodysplasia.
Leahey AM, **Teunissen H**, Friedman DL, Moshang T, Lange BJ, Meadows AT.
Poster presentation.
*The tenth annual meeting of the American Society of Haematology/Oncology of Pediatrics 1997, San Francisco, USA.*

Late effects of chemotherapy compared to bone marrow transplantation in the treatment of pediatric acute myeloid leukemia and myelodysplasia.
Leahey AM, **Teunissen H**, Friedman DL, Moshang T, Lange BJ, Meadows AT.
Poster presentation.
Professional Development for young General Practitioners.  
_{Teunissen E, Knutsen M, Novac M, Peters-Klimm F, van Leeuwen Y.}
Workshop.  
*European Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians* (WONCA Europe 2006), Florence, Italy.

Young and future family doctor in a global perspective. Vasco da Gama Movement.  
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Workshop.  
*World Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians* (WONCA World 2007), Singapore.

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Van Leeuwen Y, _Teunissen E_.  
Oral presentation (key-note).  
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Succession policy in health care organizations.  
Wieringa S, _Teunissen E_.  
Oral presentation.  
4th Congress *European Alliance of Medical Managers* (2011), Rome, Italy.

Mental health problems of undocumented migrants in the Netherlands.  
_{Teunissen E, van den Bosch L, van Bavel E, van Weel-Baumgarten E, van den Muijsenbergh M.}
Oral Presentation.  
*European Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians* (WONCA Europe 2012), Vienna, Austria.

Research in the most difficult to reach. Understanding the context of primary health care helps.  
_{Teunissen E, van Weel-Baumgarten E, van den Driessen Mareeuw F, van den Muijsenbergh M, van Weel C.}
Oral Presentation.  
*North American Primary Care Research Group (NAPCGR), annual meeting* 2013, Ottawa (Canada).
Mental health problems in undocumented and documented migrants in the Netherlands: a comparison study.

Teunissen E, van den Bosch L, van Bavel E, van Weel-Baumgarten E, van den Muijsenbergh M, van Weel C.
Poster presentation.

North American Primary Care Research Group (NAPCGR), annual meeting 2013, Ottawa (Canada).

Master of Science, courses and teaching activities

2005-2009
Dissertation: ‘Improving primary care for battered women in shelters: a quality development project.’

2012
Course Qualitative research.
Course Academic writing.

2012-2015
Participatory Learning and Action Training.
Training Normalisation Process Theory.

2015
Basic course on Regulations and Organisation for clinical investigators.

2012-2016
Journal Club, Department Primary and Community Care.

Teaching activities

2011
Facilitator pre-conference meeting junior doctors WONCA Europe, Warschau, Poland.

2012
Supervision research internship Laura van den Bosch and Eric van Bavel.
2013
Supervision research internship Jamilah Sherally, Alexandra Tsparas and Marleen Willemars. Facilitator pre-conference meeting junior doctors WONCA Europe, Prague, Czechoslovakia.

2014
Facilitator pre-conference meeting junior doctors WONCA Europe, Lisbon, Portugal.
Curriculum Vitae
Erik Teunissen was born on February 6th 1972 in Doetinchem (the Netherlands) as the son of Arie and Willemien Teunissen. He grew up with his two sisters Ria and Ans in Hengelo Gelderland. After completing his secondary school education at the Ulenhof College in Doetinchem, he studied political sciences at the Radboud University in Nijmegen. During his first year he decided to become a doctor, and studied chemistry and physics to enter medical school. He fulfilled his military services and entered medical school at the University of Groningen in 1992.

In 1996 he conducted a research project at the Children’s Hospital of Philadelphia, USA. After graduation medical school, Erik worked as a clinical house officer on the Department of Internal Medicine at hospital Gooi Noord in Blaricum and on the closed ward of the psychiatric hospital GGZ Delfland in Schiedam.

In 2001 he started general practice (GP) residency training at the Utrecht Medical Centre Utrecht and worked as a GP resident in the practices of Peter Geerts (Sleeuwijk) and Gert Slob (Uddel). During this period he was the regional representative of LOVAH, the National Association of GP-trainees, and member of the Advisory Board of the medical journal ‘Medisch Contact’.

In 2003, Erik became a member of the congress committee of the ‘Junior Doctor Program’ of WONCA Europe, the European Organization of National Colleges, Academies and Academic Associations of General Practitioners/Family Physicians. Together with Fons Sips and Ingrid van der Heijden he founded the Vasco da Gama Movement, the WONCA European Working Group for Young and Future General Practitioners. For three years, he was the Dutch representative and member of the board.

In 2004 Erik started to work as a GP in the practice of Marguerite Bunge (Utrecht) and in the practice of Hilco and Anneke Nijdam (Utrecht). He combined this with an appointment as academic teacher at the Department of General Practice at the Erasmus University in Rotterdam (2005-2009). During these years, he was member of the assessment committee of ‘Stichting Verenigde Universitaire Huisartsenopleidingen’ and of the guideline committees ‘Bell’s palsy’ and ‘Sleeping disorders and hypnotics’ of the Dutch College of General Practitioners (NHG). In 2005 Erik started a Master of Science ‘International Primary Health Care’ at the University College of London. Under supervision of Trisha Greenhalgh, he studied the modules Academic study of primary care, Research methods for primary care and International comparisons in primary care. This study was finalized with a dissertation called: ‘Improving primary care for battered women in shelters: a quality development project.’
In 2010 Erik combined his work as a GP with research activities at the Netherlands Institute for Health Services Research. Under supervision of Wienke Boerma, he investigated the quality of primary care of countries in transition like Romania and Slovakia. During that year, he presented with Yvonne van Leeuwen a key-note lecture at the WONCA Europe Congress in Malaga.

From 2010 to 2012, Erik was member of the Authorization Committee of NHG and from 2011 he is a member of the Member Council of NHG. In 2010, Erik moved to Deventer and started to work as a GP in different practices in and around Deventer area. He combined his work as a GP with this PhD project at the Radboud University Medical Centre. After his PhD defence, Erik will work as a GP in the practice of Pim van der Torre, and in 2017 he will become the practice owner of this practice. Erik lives happily together with Charlotte Vanstiphout, who works as a rehabilitation specialist at Deventer Hospital. They are the proud parents of two sons named Gilles and Stef and one daughter named Stella.
Involving migrants in shaping their primary care

Erik Teunissen

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Parkweg 5
7411 SG Deventer
erikteunissen2003@yahoo.com

Paranimfen:
Richèl Lubbers
06-18117759
richel@bytr.nl

Sander Nijenhuis
06-55327568
sander@fortes.nl

Uitnodiging
Voor het bijwonen van de openbare verdediging van het proefschrift Involving migrants in shaping their primary care op dinsdag 22 november 2016 om 12.30 uur in de aula van de Radboud Universiteit Nijmegen Comeniuslaan 2 te Nijmegen.

Aansluitend is er een receptie ter plaatse.