

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

Erik Teunissen,¹ Jamilah Sherally,¹ Maria van den Muijsenbergh,^{1,2} Chris Dowrick,³ Evelyn van Weel-Baumgarten,¹ Chris van Weel^{1,4}

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For numbered affiliations see end of article.

Correspondence to

Dr E Teunissen; Erik.Teunissen@radboudumc.nl

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 semistructured 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: 4 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 healthcare, 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 a good practice.

Conclusions: 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 healthcare 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

Strengths and limitations of this study

- A qualitative study containing interviews with 15 undocumented migrants (UMs) of varying age, region of stay and educational background, representing the main non-Western migrant nationalities and with varying duration of and reason for stay in the Netherlands.
- A good participation of UMs by using stakeholders from different organisations to recruit participants.
- The fact that in this study the group of UMs without access to general practice is under-represented and UMs who could not communicate without help of an interpreter are not represented at all.
- Reflection of the participants on the coding and thematic review, which is generally recommended, could not be achieved due to time limitations of the study.

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 healthcare services may impede adequate treatment of these problems by healthcare providers, usually general practitioners (GPs) who are in the Netherlands their first contact with healthcare.^{3–5}

Accessibility problems

In 1998 a Dutch law named Linking Act was passed making it impossible for UMs to obtain healthcare 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 to 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 UM 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 (eg, 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 healthcare 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 healthcare 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 healthcare 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.⁹ 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.¹⁰ Several of these practices do not keep patient records of UMs which hampers continuity of care and adequate registration of medical histories.¹⁰

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.¹¹ Various studies have shown that a large percentage of migrants are unaware of their medical rights and lack knowledge of the Dutch healthcare system.^{9 11} These problems are not exclusive to the Netherlands and have been reported in other countries as well.²

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.^{12 13} Language barriers and cultural differences add to the risk of inequity in healthcare access and quality.^{11 13} Studies on the accessibility of healthcare with a focus on UMs with mental health problems are scarce. Literature does exist on the perceptions of mental health, healthcare utilisation and accessibility of mental healthcare services at both national as well as international level but these concentrate on migrants in general and often exclude UMs.^{14–18}

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.^{19 20} In turn, concordant with international literature asylum seekers report more health problems than refugees who have been granted asylum.²¹

Among studies reporting health status of UMs in the European Union, psychological issues appear most widespread.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.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*³ 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,²² it is unclear from primary healthcare data to what extent professional care is responding to these needs.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 healthcare 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 UM 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 UM to inform the trusted representative if they agreed to participate. If so, the representative asked the UM 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 problems 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.

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 online 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.²⁴

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.^{25 26} 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 categorised 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.

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, 3 reported their general health as *good* ('good' or 'very good'), 6 as *moderate* and 6 as *poor* ('bad' or 'very bad'). After the interviewer explained what was meant by mental health problems, the question whether

Table 1 General characteristics undocumented migrants (UMs)

General characteristics	UMs (n=15)
Age (years)*	40.3 (mean) 21–73 (range)
Gender	
Male	9
Female	6
Education	
None	2
Primary	5
Secondary	5
Tertiary	3
Reason to come to the Netherlands	
Political	8
Economic	7
Presence of family in the Netherlands	
Yes	3
No	12
Housing	
With friends	8
With family†	2
In organisation‡	3
Homeless	2
Duration of residence in the Netherlands (years)	8.9 (mean) <1–23 (range)
Duration of undocumented residence (years)	6.6 (mean)§ <1–23 (range)

*One respondent did not know her age.

†With husband and/or children.

‡Shared housing provided by migrant organisation.

§For one respondent the length of the undocumented residence was unclear.

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

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 UM. 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 traumatising 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, chicken-pox), skin problems (eg, wounds, acne) and respiratory problems (eg, cough and lung problems). Only 2 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 on 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.^{27 26} 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 emphasised 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.

R: The reason why he asked me those questions, maybe its like he thought like for example I'm an immigrant or maybe I don't have a paper. That's it. I'm 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 UMs 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 healthcare

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 healthcare.

General barriers

Lack of knowledge about the right to medical healthcare 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 'hmpf'. (R8, female, the Philippines)

Having said this however, most UMs did state that in their experiences GPs did not treat 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 healthcare

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 know 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 UM 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 everyday 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 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 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 emphasised 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 practise, 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.^{3 22} 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 UM. 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 well-being as better than expected based on an earlier study with 100 undocumented women in the Netherlands in which 65% rated their health as 'poor'.³ Possible explanations for this disparity include the different rating scales used (Schoevers *et al*³ 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 healthcare.

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 stigmatisation 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 UMs 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 UMs 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 UMs from visiting a GP when confronted with mental distress could be categorised 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 healthcare; 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.^{9 11–13} 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 UMs that showed that language was a main obstacle to access primary healthcare, and often a main barrier to discuss mental health problems with a GP.^{11 13} 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.^{15–17 34}

These factors might explain why UMs 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 UMs 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.³⁵

Initial access to healthcare 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.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 healthcare 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.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.³⁷

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 healthcare 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 healthcare systems.^{4 38 39}

The recruitment method, using stakeholders from many different organisations to recruit participants resulted in a good representation of the different subgroups 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 UM participants. This is generally recommended but was not possible in the timeframe of a 3-month student research project.⁴⁰

Implications for policymakers 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 healthcare organisations and advocacy groups.

Second, we suggest that primary care organisations make the problems around (mental) healthcare 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.

Author affiliations

¹Department of Primary and Community Care (Radboudumc), Radboud University Medical Center, Nijmegen, The Netherlands

²Centre of Expertise on Health Disparities, Pharos Utrecht, Utrecht, The Netherlands

³Department of Psychological Sciences, B121 Waterhouse Buildings University of Liverpool, Liverpool, UK

⁴Australian Primary Health Care Research Institute, Australian National University, Canberra, Australia

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