



Health care seeking practices of undocumented migrants in the Netherlands: a qualitative exploration of health care seeking behaviour

Rosa Watjer¹, Prof. dr. Jos van Roosmalen¹, Linda Janmaat²

¹ VU University, Amsterdam, the Netherlands

² Médecins du Monde, Amsterdam, the Netherlands

Student

Research MSc. Global Health

m.r.watjer@student.vu.nl

+31640718733

Studentnumber: 2556517

Onsite supervisor

ljanmaat@doktersvandewereld.org

+31 (0) 20 465 28 66 / +31 6 284 448 05

Academic supervisor

j.j.m.van_roosmalen@lumc.nl

+31 (0) 20 598 70 31 (Athena Administrative Office)

BMJ Open Access

**Health care seeking practices of undocumented migrants in
the Netherlands: a qualitative exploration of health care
seeking behaviour.**

Rosa Watjer

2556517

MSc. Global Health

05-08-2016

Word count: 8088

Journal: BMJ Open Access

Abbreviations

Médecins du Monde, The Netherlands – MdM

General Practitioner(s) – GP(s)

Undocumented migrant(s) – UM(s)

Bed, bath and Bread- BBB

Index

Abstract	5
1.1 Introduction	6
1.2 Contextual background on the health care system in the Netherlands.	7
2. Research design and methodology.	
2.1 Research approach	7
2.2 Data collection	7
2.3 Ethics	10
2.4 Integration and analysing of results	10
2.5 Final dialogue phase	10
3. Results	
3.1 Contextual inquiries	11
3.2 General practitioner.	11
3.3 Undocumented migrants in the Netherlands	15
3.4 Final dialogue phase	22
4. Discussion	
4.1 Key findings	22
4.2 Discussing key findings	22
4.3. Strengths and limitations	24
5. Implications and recommendations for policymakers	25
6. Conclusions	26

Abstract

Objective: The aim of this study was to (1) explore health care seeking practices among undocumented migrants and (2) gain insight into factors influencing health care seeking behaviour among undocumented migrants.

Design: Qualitative study involving a transdisciplinary component, containing in-depth semi-structured interviews and a focus group discussion.

Participants: Sixteen undocumented migrants above the age of 18, varying in country of origin, sex and age were recruited through migrant organisation, Médecins du Monde the Netherlands and snow ball sampling. Eight general practitioners, varying in their experience with health care provision for undocumented patients, were recruited through convenience sampling.

Setting: Amsterdam, the Hague and Utrecht. The Netherlands

Results: Less than half of the undocumented migrants indicated to visit the general practitioner for health care issues. Among undocumented migrants the regular health care system utilization was perceived most favourable, as in their view it secures adequate health care. However, due to barriers non-attendance, delay to health care and utilisation of alternative form of health care practices are reported among undocumented migrants. Previous experiences with health practices and social network, as a support and information source, are considered an important factors determining health practices among UMs.

Conclusions: Health care seeking experiences of undocumented migrants are shaped by both political environment and health care system. This study recommends increased transparency and communication on the health care situation of undocumented migrants towards public to realize the health care right of undocumented migrants. Second, improving knowledge of both undocumented migrants and general practitioners on the health care right of undocumented migrants is suggested to tackle barriers undocumented migrants experience in accessing regular health care.

Strengths and limitation of this study

- A qualitative study containing transdisciplinary components was conducted for full understanding of health care seeking behaviour among UMs and generating informed recommendations.
- For a holistic account of the issue data was collected among both UMs and GPs.
- UMs who speak the language not profoundly were not included in the study due to practical considerations, which led to an underrepresentation of this group.
- The study was unable to recruit GPs who hold a resistant attitude towards providing health care to UMs.
- Extended involvement of participants throughout the design and analysis is recommended for future research.

1.1 Introduction

Within current globalization trends migration is increasing worldwide. Many countries are not prepared to deal with this demographic transition and attitudes and policies towards migration are hardening[1]. Various authors argue this political context has negative consequences for the health status of undocumented migrants (UMs) in the Netherlands [1][2]. In 2013, an estimated 22.881 to 48.179 UMs resided in the Netherlands[3]. The health of this particular group is poorer compared to the general population and other migrant populations, characterized by a higher risk of infectious diseases and psychological health problems [4][5][6]. Previous studies recognize the difficulties UMs face to maintain their health due to their low socio-economic status, poor living conditions and limited social network [7]. Although health care is considered a human right, limited institutional health care access and utilization is reported among UMs, and this group is inadequately reached by health promoting programs [8].

Multiple factors are presumed to exacerbate limited access to health care. First of all, within the context of Dutch immigration discouragement policies, in 1998 the 'Linkage law' came into force, which entails that undocumented migrants are not entitled to collective benefits, including financial support and health care insurance. It has been argued this exclusion from basic facilities results in poverty, dependency and limited access to health care facilities [9][10]. Secondly, many UMs lack knowledge of the Dutch health care system and their medical rights, which hampers utilization [11]. Consequently, social exclusion and ensuing limited health care access perpetuates the poor health status of undocumented migrants.

While previous studies have addressed the medical situation and determinants for health care utilization among UMs, they focus mainly on the use of registered institutional care [7][9]. However, limited attention has been devoted to the full process of illness response, including consultation of alternative forms of care that fall outside the regular Dutch health care system. Literature suggests that health care seeking behaviour differs between people, depending on diverse social contextual and personal factors [12]. More specific, individuals make decisions in relation to their health, as they weigh up potential risks or benefits of a particular health care seeking behaviour in context of their practical and social environment [12]. Accurate understanding of the health care seeking process is, thus, needed to explain and predict health care behaviours for a tailored response to meet the needs of UMs.

This study aimed at understanding health care practices of UMs in the Netherlands by exploring how they make health care seeking decisions in the context of their daily lives and the Dutch health care system. The aim of this study was twofold: (1) to explore health care seeking practices of UMs and (2) to gain insight into factors influencing health care seeking behaviour among UMs. In order to study health care seeking behaviour and provide informed recommendations, this study adopted a qualitative research approach, in which needs and

experiential knowledge of UMs obtained a central role. In addition, health care professional's (i.e. general practitioners) views were consulted to provide context to the perspectives of UMs.

1.2 Contextual background on the health care system in the Netherlands.

The Dutch health care system is based on a financing system operated by private insurance companies. All Dutch residents are required to purchase private health care insurance in order to receive entitlement to health care. However, UMs are excluded from health care insurance, when the Linkage law came into force. Nevertheless, as universal right to health is enshrined in the Dutch constitution the Dutch law guarantees medically necessary care for all people on the Dutch territory. This entails all medically necessary care included in the basic health care package, for all UMs. Accordingly, health care providers of UMs can seek reimbursement of 80-100% of the costs of medically necessary treatment at *Zorginstituut Nederland*, when UM patients are not financially able to pay for the costs themselves. Plannable care can only be reimbursed to institutions that have a contract with the reimbursement institute. Yet, costs for emergency care, and care related to pregnancy, can be reimbursed to all institutions. Dental care is only compensated for minors and special cases [13]

2. Research design and methodology.

2.1 Research approach

The study was commissioned by Médecins du Monde in the Netherlands (MdM), which is an international non-profit organisation, that among other things, aims at improving accessibility to health care for UMs. The study was conducted in the period March 2016 till August 2016 by a single female researcher. A qualitative study was undertaken based on in-depth interviews with both general practitioners (GPs) and UMs, and a focus group discussion with UMs. GPs were included in the study as they arose as an important stakeholder during the exploratory phase, as described below. In addition, participatory observations were conducted and an expert meeting with UMS for reflection was organised. The study adopted a transdisciplinary component by applying an iterative design for analysis and multi-stakeholder involvement. Furthermore, this component allowed for exploration of needs and possible solutions in collaboration with participants. Complementary to predetermined topics, issues addressed by the target population guided the study.

2.2 Data collection

2.2.1 Contextual inquiries

In order to prepare research activities with GPs and UMs informal face-to-face interviews were conducted with employees of MdM (n=7). This informal contact remained during the full

research process, as collected data was discussed for reflection. In addition, expert interviews (n=4) were conducted with founders of different migrant organisations and churches.

2.2.1.2 Participatory observation

Participatory observations were conducted during volunteer work at the office of MdM and health education programs on health care access for UMs (n=9), organised by MdM at community centres and migrant churches. Informal interviews were conducted with UMs and members of migrant organisations. In addition, participatory observations were conducted at a Ghanaian and Brazilian church service in Amsterdam, as church communities emerged as important sites throughout the data.

2.2.2 In-depth study

2.2.2.1 Study population and recruitment

During the study 27 GPs were selected based on already established contact with MdM and snow ball sampling. The researcher approached GPs by means of a letter send through E-mail or post, and, in addition, a telephone call. This letter contained information on the purpose and importance of the research project, and an introduction of the interviewer. In the end, eight GPs agreed to participate in the study. The foremost reason for not participating was lack of time.

This study included sixteen UMs, aged 18 or above. Respondents were recruited in Amsterdam (n=12) and The Hague (n=4), through support and migrant organizations (n=6) and MdM (n=7). UMs were purposively selected to ensure a diverse sample, including diversity in sex, age, nationality and length of stay in the Netherlands. Additionally, this study adopted a snow ball sampling method to recruit respondents (n=3) that were not engaged with support organisations. The researcher approached respondents face-to face or by phone to explain the study, invite them for participation and make appointments. Half of the participants approached responded to the request to participate in the study. In the end, five recruited respondents did not show-up for interview appointments. Four conducted interviews were excluded due to language barriers, mental health status, or reserved attitude of the participant in disclosing information.

Respondents of the focus group discussion were recruited through a single migrant organisation. Previous research indicates that members of existing groups feel more at ease as they are familiar with each other [14]. The expert meeting respondents were recruited by means of flyers at a community centre and an announcement on a local Amsterdam South-East Radio.

2.2.2.2 In-depth interviews.

An in-depth semi-structured interview method was applied to propose questions based on predetermined topics and allow respondents to address topics that the researcher did not anticipate [15]. Based on available literature on health care seeking theory and health care seeking practices among UMs a conceptual model was developed to inform the interview guides. Interviews with UMs included topics related to general living conditions, perceived health, health care seeking practices, health care seeking motives, experiences and expectation of care practices and factors influencing health care seeking considerations. Additionally, sociodemographic questions were included. Respondents were asked to reflect on their own experiences and fellow UMs. The duration of interviews with UMs ranged between 25 and 147 minutes. Interviews with GPs addressed topics related to their experiences with UM patients and lasted between 25 and 45 minutes. Details of the topic guides are demonstrated in Box 1. In addition to the topic guides, within each interview respondents were, based on the issues addressed in the interview, consulted on possible recommendations.

Box 1. Topic guide: in-depth interview with UMs and GPs	
<i>Interview with UM</i>	
Demographic features	<ul style="list-style-type: none"> - Age - Nationality - Migration history - Education/employment - Living condition - Social network (e.g. family/friends)
Perceived health	<ul style="list-style-type: none"> - Feel about one's health (health problems (current/past)) - Factors affecting one's health - Control over one's health
Health care seeking process	<ul style="list-style-type: none"> - Response to first symptoms - Time interval consulting care - Social contact in health seeking process - Forms of care consulted - Motives behind health seeking behaviour
Health care seeking experiences	<ul style="list-style-type: none"> - Attitude towards care practice - Expectations of care practice - Satisfaction of care practice
Usual practices	<ul style="list-style-type: none"> - Previous care practices in the Netherlands - Previous care practices in home country - Health seeking practices of social environment
Perceived behavioural control	<ul style="list-style-type: none"> - Comfortability seeking health care - Ability to find needed care
<i>Interview with GP</i>	
	<ul style="list-style-type: none"> - Practice procedures regarding care giving to UMs - Experiences with health care provision to UMs - Lifestyle of UMs - Health situation and health needs of UMs

2.2.2.3 Focus group discussion.

A focus group discussion with six UMs was conducted to discuss issues addressed in the interviews and generate recommendations. The focus group discussion was held at a Nigerian community organization and had a duration of 45 minutes.

2.3 Ethics

Participants were informed on the research purpose and procedure of the study. Additionally they were informed on the anonymous and voluntary nature of the study, the safety in which data will be processed, and their right to withdraw from the study and refuse answering any individual questions. Undocumented interview participants provided written informed consent. During the focus group discussion, expert meeting and interviews with GPs, participants agreed verbally. The board of MDM approved the study.

2.4 Integration and analysing of results

Most of the in-depth interviews with UMs (n=11) and GPs (n=8) were recorded and transcribed verbatim in the same language as the interview. Five UMs refused recording because of misgivings about the safety of disclosed information. With regard to these interviews written notations were made. During participatory observations and the focus group discussion observations were recorded by means of field notes. Data analysis started after the initial interviews, as part of a cyclic process of data collection – analysis – further data collection and analysis. Accordingly, material gained from analysis informed further data collection. Interviews were analysed line by line and coded by a single researcher by means of MAXQDA 12 software. Eventually, concepts were generated and subsequently categorised into a more defined scheme by relating different themes that appeared. All quotations were translated from Dutch to English when needed and identifying information removed from the quotes to ensure anonymity.

2.5 Final dialogue phase

2.5.1 Expert meeting

To reflect on the results of the study a feedback meeting with UMs (n=12) and two members of different non-profit organisations that support UMs was organized. The meeting provided the opportunity to establish active engagement of UMs in the formulation of recommendations tailored to their needs and wishes. The meeting lasted for 70 minutes.

2.5.2 Dissemination of information

According to recommendations provided by UMs an interview dialogue was developed and broadcasted on the local TV in Amsterdam South-East in collaboration with a TV producer and member of the Ghanaian community, targeting issues that derived from the results.

3. Results

3.1 Contextual inquiries

During an exploratory phase different stakeholders agreed upon the presence of limited access to health care for UMs. This was considered to result from the attitude and degree of knowledge of both health care providers (i.e GPs) and UMs. In specific, non-attendance and delay to regular health care was recognized as problematic among UMs.

3.2 General practitioner

GPs were interviewed at various sites in Amsterdam. In addition one GP from Utrecht was included (see Table 1). All GPs interviewed had experience with UM patients. Yet, the number of UM patients registered with a GP differed between respondents, ranging from 4 to 93 UM patients. The GPs were aware of the medical rights of the UMs and the regulations concerning health care provision for UMs. Nevertheless, GPs identified several bottlenecks in health care provision, related to treatment of health complaints of UMs, workload and distribution of UM patients.

Respondent	Practice area
1	Amsterdam South-East
2	Amsterdam South-East
3	Amsterdam South-East
4	Amsterdam South
5	Amsterdam New-West
6	Amsterdam West
7	Amsterdam North
8	Utrecht Lombok

3.2.1 Treatment of health complaints among UM patients

Most GPs recognized psycho-somatic complaints as more common among UM patients than non-UM patients. This was considered to result from their past history, current living situation and insecure future prospects. GPs felt these complaints are more complex to diagnose and treat among UMs. As one GP explained how the living situation of UMs hampers adequate treatment of psychological health complaints:

“Someone has to be in a stable situation, otherwise it does not make sense to start a PTSD treatment. Someone must have a place to stay for long, otherwise the only thing you can do is a bit of patching up the problem in the hope that better days will come. Only a little support you can offer, but no more than that. In these circumstances the condition of the person may develop.”
(GP6)

Providing treatment to UM patients was considered difficult for other complaints as well, as they may result from living and working conditions, which they are not able to alter. The following quote exemplifies this.

“ There was a man who came with a huge eczema, probably work related because he had to deal with all kinds of chemicals. But he didn’t have a leg to stand on towards his employer. The employer did not think about a solution and he also couldn’t leave the job. So the man was in a difficult situation and I could not do more than prescribe crème and recommend gloves. Then you experience that people have a hard time and get into working situations where they are being exploited.” (GP6)

In addition, GPs indicated that UM patients mostly visit their practice when complaints are more advanced.

Furthermore, GPs considered diagnoses and treatment as more complex due to cultural differences. Most GPs suspected UM patients, similar to other patients with a different ethnic background, to use traditional forms of care. Although the importance of being informed about the use of these care practices is recognized as it may influence prescribed treatment, most GPs indicated to lack knowledge on the exact traditional health care practices applied by UM patients. In addition, with regard to ethnic differences, GPs contributed experiences with communication barriers related to language, jargon, expression of complaints and care demands to the complexity of health care provision for UMs.

3.2.2 Workload

Most GPs experienced care provision for UMs patients as more time consuming in comparison to regular patients. This was, as well, related to the complexity of the diagnoses and treatment of health complaints among UMs. Two GPs indicated to count two consults for UM patients as a standard procedure. One GP indicated to occasionally provide additional basic specialist care herself during consultation to prevent complications the UM patient may encounter when being referred to a hospital, related to payment or possible refusal. Moreover, as many UMs have limited knowledge of the Dutch health care system, explaining procedures adds up to the time involved. One GP having limited registered UM patients indicated that not dealing with UM patients frequently consumes more time to ascertain the procedures for processing payments, as compared to GPs who have UM patients regularly. All GPs indicated to have gathered general information on the health care provision procedures for UM patients themselves.

Furthermore, GPs considered appointment arrangements more complex and time consuming among UM patients. For instance, one GP stated to experience UM patients visiting the practice without appointment, while other GPs mentioned to record more no-shows among

UM patients as compared to other patients. One respondent explained noncompliance with appointments by UMs in the following quote:

"What you see more often are no-show of people who made an appointment. I do not consider this an attitude towards me, but more as an expression of their own problems. If they do not have money to come with the train or metro then they do not come. If they don't have credits to call they do not." (GP2)

Some GPs mentioned UM patients apply, what the respondents call, a "shopping" method, in which they consult different health providers. This leads to a situation in which the GP is not aware of the full medical history and the GP has to start from scratch with the patient, which contributes to a higher workload.

3.2.4 Distribution of UM patients.

The number of UM patients registered with a GP practice, differed tremendously among GPs in this research. The GPs interviewed considered this as a trend among different GP practices in Amsterdam. This was perceived problematic, as some GPs experience higher workload and receive lower payment for consultations as compared to others. As one of the GPs explained:

"If 5% of the total in the patient's data base is undocumented I consider it acceptable. However it should not be more, because that makes your business uncertain, it becomes un-controllable." (GP1)

Several explanations were provided by GPs for the differences in number of registered UM patients. First of all, the allocation of UM patients is partly influenced by variances in density of UMs at different sites in Amsterdam. Secondly, respondents pointed out that some GPs are resistant in including UM patients, leading to a situation in which more receiving GPs take on a higher number of UM patients. In addition, it was stated that GPs have different approaches to payment arrangements, which influences the registration of UM patients. Some respondents said to always seek reimbursement of the costs at *Zorginstituut Nederland*, while others indicated to assess the payment ability of the patient. GPs who seek reimbursement as a standard procedure explained that it is often difficult and time consuming to identify whether a UM patient is able to pay and they do not consider this as part of their professional tasks. In addition, two GPs indicated to not request for any payment or reimbursement, when it regards an occasional case, as they weigh the money and time involved arranging the reimbursement. Respondents stated that this inconsistency between GPs leads to a situation where some GPs are favoured by UMs and over-used compared to others that are under-used. One GPs exemplified this with the following quote:

“Last week there was someone from Suriname with another family member who wanted to register with us because she had to pay with her own family doctor and her cousin or something did not have to pay at our practice. That is difficult. Then you attract people to come to you. [...] It is understandable, but you shoot yourself in the foot.” (GP1)

Similar as this quote illustrates, GPs pointed out most UM patients reach their practice through social network (i.e. church and friends), followed by the pharmacy, or health care mediating organizations (i.e. MDM). Accordingly, differences in the attitude of GPs towards receiving UMs influences the registration behaviour of UMs, as UMs may share experiences with peers.

3.2.5 Recommendations provided by GPs

Several recommendations were provided in order to ease the workload of GPs that treat UM patients. Firstly, GPs recommended to develop a system which ensures an equal allocation of UM patients. Secondly, it is suggested to regularly disseminate up-to date information to GPs on the procedures of health care provision for UM migrants to ease the workload. A third recommendation was provided by GP7 who suggested to establish an additional GP located in a high UM density environments for only UM patients. In the opinion of this GP, this will both relieve workload of GPs and overcome UMs not being assisted due to resistance of health providers.

3.3 Undocumented migrants in the Netherlands

Sixteen UMs were interviewed in Amsterdam and The Hague. Overall, nine men and seven women were interviewed, with an age range of 28 - 60 years and from divers countries of origin (see Box 2). The participants' sociodemographic characteristics are represented in Table 2.

Table 2. Characteristics undocumented migrants (UMs)

General Characteristics	UMs (n=16)
Age (Years)	43.4 (mean) 28-60 (range)
Gender (n)	
Male	9
Female	7
Education level* (n)	
None	2
Primary	4
Secondary	4
Tertiary	4
Working at the moment **** (n)	6
Reason to come to the Netherlands (n)	
Political	3
Economic	13
Presence of family in the Netherlands (n)	
Yes	3
No	13
Housing (n)	
Own place	4
With friends	6
With family	2
In an shelter (i.e. BBB, Leger des Heils, Refugee action collective)	4
Homeless	0
Duration of residence in the Netherlands (Years)***	7.6 (mean) 1.5-23 (range)
Registered at a General Practitioners (n)	7

* Highest level of education accomplished.

** Distinction between economic reasons and political reasons for migration is made based on the interpretations of the story of the respondent.

*** The duration of stay in the Netherlands was for one respondent unknown.

**** Entails working on regular and irregular basis

Box 2. Country of origin of undocumented migrants (UMs)

<i>Interview</i>		<i>Focus group discussion</i>	
Egypt	(n=2)	Nigeria	(n=6)
Ghana	(n=3)		
Indonesia	(n=2)		
Morocco			
Philippines			
Tadzhikistan			
Zambia			
Nigeria			
Senegal			
Sierra Leone			
Brazil			
Ethiopia			

The analyses of the interview transcripts identified three major themes that describe 1) the health situation of UMs, 2) health care practices, including regular health care system utilization and alternative forms of health care practices, 3) factors influencing health care seeking behaviour among UMs. In this section, these themes are described accordingly.

3.3.1 Health situation

Insight into the health situation of UMs, meaning the absence or presence and severity of symptoms, provides context to the health care seeking intention among UMs. Seven respondents indicated to feel healthy at the moment of the interview. The remaining respondents noted to have some or more severe medical conditions and complaints, including high blood pressure (n=3), diabetes (n=2), kidney complications, medical complication due to surgery, coughing blood (diagnosis unknown), swollen leg (diagnosis unknown) and pressure on the chest (diagnosis unknown). In addition, the experience of stress was mentioned by almost all respondents (n=13). Respondents mentioned the term stress specifically or used terms related to “trauma”, “thinking too much”, “not able to sleep” and “worrying”. Some respondents recognized stress as the cause of other complaints and conditions as well, such as headache, sleeplessness and high blood pressure.

The majority of the respondents considered their current situation as a perpetuating factor affecting their physical and mental health status. Experiences with lack of financial means, and poor work and living conditions were discussed frequently by UMs in relation to their health. In addition, UMs contributed the following factors to their impaired emotional state: fear of being arrested and deported, worries about their family they left behind, uncertainties about their future, accommodation and availability of work, and passivity, meaning not being able to work or study. Three respondents related the experience of stress to their past history. The following quote exemplifies the effect of uncertainty and fear on the mental wellbeing of UMs:

“ We are not able to sleep. The other day, the police came to where we live. There was an undocumented lady, she had to leave the country. She was living where we were living. Some police, some giants, came from the immigration service. When you see them you collapse! It makes you scared! Just for this one undocumented lady so many police came, four giants! They are really serious. You never know when they come for you.” (Nigeria, female, focus group discussion)

3.3.2 Health care seeking practices.

3.3.2.1 Regular health care system

Less than half of the respondents (n=7) were registered with a GP, of which five UMs experienced one of the health complaints described above. All respondents registered with a GP indicated to have registered when they experienced a health problem, of which three indicated to have had advanced complications. Most of the respondents reached the GP through social

contact (i.e. church, friends) (n=4). Two respondents were guided to health care by the MDM organization and one respondent indicated to have found a GP on her own initiative. The time interval between experiencing pains and visiting the GP for the first time differed between the respondents. Most did not visit the GP immediately when they experienced symptoms and experienced delay. Similarly, during the focus group discussion delay in health care was identified as a common problem among UMs due to barriers discussed in a later section.

Five respondents indicated to have had dental problems, of which two reached a dentist with support from the MDM organization. One respondent searched a dentist himself and described his seeking process:

"I went to a Spanish dentist and he said to pay 700 euro. I told him I'm from Egypt, I don't have papers, money. He said okay 500 euro. Not possible for me. So I went to another address and explained my situation and asked what he can do. He said 300 euro. I said it is too much, then he told me 150 euro. So that was good. I like him, so somebody helped me and I want to help other with a similar case." (Egypt, man)

All respondents indicated to have had dental problems for a longer period of time, with a maximum of one year, before receiving care.

3.3.2.2 Alternative forms of health care practices.

When experiencing a health problem five respondents went to *Kruispost*, a non-profit organisation that provides ad hoc health care for persons without insurance in Amsterdam. This included complaints concerning dental, menstruation, sore throat, coughing blood and high blood pressure. Five respondents mentioned to use self-medication. Self-medication related to the use of traditional herbs (n=2), crèmes from the home country (n=2) and medication sharing (n=1). Also, in the focus group discussion it became apparent that self-medication by means of herbal medication is common practice in the African community. By three respondents undertaking activities to divert oneself was considered as a method to release stress (i.e. studying Dutch language, reading the bible, making music, participating in community activities, chatting with friends back home, socializing with friends, attending church, volunteer work). One respondent commented:

"I try to forget about thinking. I don't want to think too much. If I think too much is bad for me. So I try to be free.. just to get myself like a bird and fly. [...] I try to not get the stress much. It is there, but you have to try to avoid it."(Sierra Leone, man)

Four respondents mentioned religion as a manner to deal with stress and health complaints.

Five respondents mentioned God as a recourse and in relation to the fate of their health status.

During participatory observations in both church services, church attenders were summoned to

call on God when experiencing problems, as he has power of guidance. In both church services problems were related to legal status in specific.

3.3.3 Factors influencing health-care seeking behaviour

This section further elaborates on the factors influencing the health care seeking behaviour brought up by the respondents; personal ability to reach regular health care, previous experiences with health care forms and social network.

3.3.3.1 Personal ability to reach the regular health system

The nine respondents, not registered with a GP, stated their wish to be able to register. Respondents expressed worrisome feelings about becoming sick, as they do not know where to turn. One respondent stated to try to go back home when he becomes sick, as he felt there are no services that support him in the Netherlands. The following comment illustrates worrisome feelings expressed by one UMs:

“I: What would you do when you become sick?”

R: I don't want to think about it. Immediately when I will be thinking about this gives me stress. Too much thinking about imagination. If I'm sick, if I need something. If I get sick, I can't fix it. Better not too much thinking. What can I do now” (Indonesia, male).

At the time of the interview, lack of knowledge on the possibilities to utilize the regular health system was the foremost reason for respondents (n=7) for not being registered with a GP. This is illustrated in the following quote:

“I didn't have the knowledge about going to the family doctor before. I thought, a person without residence permit is a zero. I didn't know a family doctor would help people like me.” (Tadzhikistan, male)

In addition, two of the respondents mentioned explicitly to have or to have had fears for being arrested when going to the GP. As well, during the participatory observations at the health education programs of MdM questions were asked, in relation to safety at hospital admission and calling an ambulance. One respondent expressed her fears in the following quote:

“ Because I don't have any idea. How we, our people, talk about it: ‘when you don't have something, don't have documents, you cannot go forward’. So I was afraid. Maybe if I go and say ‘I'm sick’ and they (GP) say ‘where is your document’ and you don't have. You are here illegal you know.” (Ghana, female)

Similar to the previous quote, this comment illustrates how fear, induced by perceived limited rights in the Netherlands, hampers UMs to utilize the Dutch health care system. Accordingly,

from analysis emerged that feelings of fear derived mainly from the lack of knowledge on their medical rights and the professional secrecy of GPs.

3.3.3.2 Experiences with the regular health care system.

The interview respondents held positive feelings toward GPs and considered the regular health care system as most favourable. All respondents were familiar with the formal health care system in their home country. Overall, the interview respondents that were registered with a GP demonstrated to have had positive experiences with their GP, hold a grateful attitude and feel comfortable visiting their GP. In specific, respondents mentioned positive remarks, such as “taking good care”, “good doctor for following up to and checking with me” and “informed me I shouldn’t stay home, but come to the clinic”. Most respondents (n=6) indicated to not have paid for consultations at their GP, which was considered positive. One respondent indicated to have paid only for registration at the GP. The full price of medication at the pharmacy was paid by one respondents. This was experienced as a difficult situation, as the respondent indicated have limited financial means.

“At the moment I take medicine. But I’m not working, jobless. When I go to see the doctor they have to prescribe for me. Than I have to go pay it myself, but I don’t have the money. So it is difficult. It is not a joke! When I have the prescription I have to ask people to help me to buy my medicine.”

(Sierra Leone, male)

In informal interviews during participatory observations and the focus group discussion, attitudes towards the regular health care system were more divided. In the focus group discussion four of the six respondents experienced complications when seeking care at the GP, related to payment, refusal of registration and denial of care. Respondents agreed this problem not solely lies with the GP, but as well with the GP’s assistant. One respondent indicated to have stopped going to the GP, as she consider it “*embarrassing going there and being denied*” (Nigeria, female, focus group discussion). Another respondent expressed her wish to switch her GP as she felt that her GP did not take her condition seriously.

“He (GP) said I have psychological problem, because he doesn’t want to treat me. But I have pains. If I change my doctor, maybe my situation will change too” (Nigeria, female, focus group).

The respondents of the focus group discussion agreed that experiences differ between UMs due to the different approaches and attitudes of GPs.

Communicative barriers, related to language and jargon were not mentioned by the respondents explicitly. Yet, when reflecting on peers they did consider communication as a bottleneck for both gaining knowledge on the Dutch health care system and visiting the GP. In addition, the previous quote may indicate differences in perceptions of health complaints

between health care provider and patient, although it was not perceived as such by the respondent. Similar, differences in perceptions of medicines emerged during one interview. One respondent indicated to not mention the use of herbal medication to her doctor, as her story suggested that she did not consider it as remedy that is of interest for the doctor.

"I rushed to the hospital and they said 'you have to say the truth, did you take medication?' And I said 'no really, I did not take any'. He asked 'no?' This doctor came and looked with a camera and said 'he madam, have you taken any medication'. I said 'yes paracetamol'. They say 'no, not paracetamol'. So I was thinking what have I done, doctors don't want to help me. They said 'you have to say the truth, so they will know how to treat you.' Then I said ' ah yes a Ghanaian lady gave me'." (Ghana, female)

As these two cases indicate, differences in perceptions may lead to misunderstandings between GPs and UM patients and subsequently, as the first case illustrates, it may cause discontent and perceived denial of care among UMs. In this manner, experiences with the regular health system influences health care seeking behaviour of UMs.

3.3.3.3 Experience with alternative forms of care

Respondents indicated to have applied alternative forms of care as a result of absence of regular health care. All respondents (n=5) visiting the *Kruispost* demonstrated a grateful attitude towards the care provided at the *Kruispost*. However, three respondents considered the care as minimal in comparison to the regular health care system, with regard to services and equipment.

Although the respondents indicated to be familiar with traditional medication in their home country, its use was not considered favoured by the respondents. This was related to the uncertainty of the effect of the medication. One respondent indicated to have experienced negative consequences of drinking herbal medication, leading to hospital admission.

"It is like a boil (showing back of the throat). A Ghanaian lady gave me Ghanaian medication (herbs) for it. [...] That time I didn't know of the house doctor. So she said I have to try it and it will go. [...] Not knowing that when I do it, it entered the boil and it is swelling big and my head was, Bam Bam Bam! I rushed to the hospital." (Ghanaian, female)

The respondent indicated this experience thought her to never use herbal medication again. In addition, one respondent using medication from a friend, considered medication sharing as an unsafe practice, as she indicated that treatment needs to be different for each person.

"One day I was feeling like having a kidney problem [...] And one of my friends she had these kind of problems, but she has papers. So she went to doctor and got medicine and that is why I know these symptoms are from kidney, because of her having the same symptoms. Then she gave me her

medicine. So, I took like four times her medicine and then it stopped. [...] But we are different, so the treatment is also different. But I don't have any possibility to go to the doctor. I feel bad taking someone's medicine and being depended. So I really need a doctor. It is hard.” (Ethiopia, female)

Even though, the respondent was aware of the risks involved when applying self-medication, she felt compelled to apply the practice as she considered the regular health care system as unavailable for her.

Unlike, the alternative health care forms discussed above, religion and God was considered important in dealing with psychological health problems. Respondents spoke positively about religious practices and emphasised the therapeutic role of God in “gaining strength” and reducing stressful feelings. In this manner, God was considered a supportive and stable factor in one’s life.

3.3.3.4 Social network

Social contact was mentioned as an important means to gain knowledge. More specific, most respondents indicated to contact friends for advice when experiencing health problems. Friends advised on both alternative form of health care practices and regular health care. Nevertheless, two respondents indicated to experience boundaries to their social contact, as they felt that constant reliance on friends leads to loss of respect. In addition, one respondent indicated contacts in social networks often possess limited knowledge on the Dutch health system, as it comprises of mostly UMs or persons from the same ethnic background.

Most respondents mentioned church as an essential meeting point for social contact. In addition, the pastor was mentioned by three interview respondents as an important central figure for information and guidance. Also in the focus group discussion there was consensus on the guiding role of the pastor.

3.3.4 Recommendations provided by UMs

During the interviews and focus group discussion one prominent recommendation came forward. Establishing close contact with churches and mosques, including pastors, was considered essential for informing UMs about their rights. Secondly, during participatory observations at a health education program it was recommended to utilize local community radio and television as a means of communication to educate UMs on their rights. Thirdly, participants in the focus group discussion suggested a special family doctor or clinic for UMs providing the same care as a regular GP.

3.4 Final dialogue phase

Expert meeting

During the feedback meeting recommendations to improve knowledge dissemination were discussed by the participants. It was recognized most information is communicated from person to person within one's social network. Using social media, such as Facebook and WhatsApp was considered an important means of communication to reach a large group of UMs. The advantage of Facebook is the possibility to provide open access to non-static information on various subjects deriving from interaction with UMs and the possibility for instant translation. By means of WhatsApp, information can be spread to social networks by putting a chain of messages in motion. In addition, disseminating information at public spaces and informing possible future UMs at asylum centres was recommended. Lastly, engaging and educating key figures in the UM community to inform and guide other UMs to the regular health care system was proposed. Besides educating UMs, participants of the expert meeting mentioned providing guidelines for GPs as a means to overcome access barriers as well.

4. Discussion

4.1 Key findings

All UMs considered being undocumented as the core of their diminished health and their limited access to health care. Among UMs regular health care system utilization was perceived most favourable, as in their view it secures adequate health care. However, due to barriers non-attendance, delay in receiving health care and utilisation of alternative health care practices were reported among UMs. Previous experiences with health care practices and social network, as a support and information source, are important factors determining health practices among UMs. Improving knowledge about the Dutch health care system among UMs and providing guidelines for GPs was considered crucial by the respondents to overcome barriers to health care access.

4.2 Discussing key findings

This qualitative study, explored the health care seeking practices of UMs and examined factors determining their health care seeking choices. Prior studies have identified undocumented migrants as vulnerable populations [16][17]. This study stresses that limited access to the regular health care system induces this vulnerability. Regular health care system utilization considered as most favourable by UMs is a theme that constantly emerged throughout the data. Problems identified by UMs related mainly to the absence of the GP in their care practices. Factors that withheld or delayed UMs from visiting a GP could be categorized into four barriers; lack of knowledge concerning their right to health care, fear of being arrested and negative experiences with regular health care system (i.e. refusal of registration, denial of care, and

payment of care). These findings are concordant with previous studies conducted in the Netherlands among UMs [9][18][19]. The barriers to healthcare access and use of alternative health practices can be explained by multiple factors.

Firstly, political resistance towards UMs influences the possibilities of UMs to reach the regular health care system. Although, the human right to health is enshrined in Dutch law, Dutch politics do not feel accountable for those who enter the country without legal permit. Consequently, UMs are excluded from public services and denied from societal participation. The rationale behind these policies is the purported belief that welfare systems attract migrants [20]. This positioning has influence on health care seeking behaviour of UMs. A theory provided by Lukes (1974), who studied different forms of social power, aids to understand the effect of this influence. He stated that structural power in place can shape perceptions, cognition and preferences to the effect that subjects accept their position in the existing arrangements [21]. Accordingly, the findings of this study demonstrated that the attitude of UMs toward the regular health care system is influenced by the internalized social construction of their undesirability, assuming they naturally do not have the right to health care as they do not have the right to reside in the Netherlands.

Experiences with the regular health care system is an important facilitating factor for health care seeking behaviour. As UMs experience many insecurities, negative experiences with the regular health care system may have a discouraging effect on seeking health care. Safeguarding a positive interaction between GPs and UMs is essential. GPs find themselves in a position in which they have responsibility in ensuring human rights to health care. However, similar to previous studies among GPs, the findings of this study signals that care provision to UMs is accompanied by several aggravating labour intensive factors [8][18][22]. Furthermore, although the finding of this study did not illustrate this, it is suggested that the political climate may influence the GPs sense of responsibility towards UMs [22]. These factors result in a reluctant attitude of GPs towards including UM patients. Subsequently, this contributes to the experiences of limited regular health care accessibility of UMs.

The political environment has effect on the knowledge on medical rights and skills to reach regular health care among UMs as well. In accordance with previous studies, this study found that lack of knowledge among UMs about their health care rights influences their health care seeking behaviour [11][23][24]. The findings of this study indicate that limited knowledge contributes to feelings of fear and inability to seek care among UMs. The prominent role of social contact in health care seeking practices and as gateway to knowledge and access to regular health care is found most apparent in this study. However, a number of UM respondents considered social health of UMs, meaning type of contact and experience of support, as poor. UMs are limited to the social network they find themselves and the knowledge their contacts

possess. Most of the respondents indicated to have social contacts with the same ethnic background and or contact with persons who are in a similar undocumented situation. In this manner, social contacts of UMs can be considered as both a facilitator and barrier to access health care. Previous research explained limited social capital as a result of limited participation in society and integration outcomes [25][26][27]. The study by Kuo (2014), which analysed the relationship between acculturation and mental health status among migrants, indicated that adaptation to the host country leads to skills that can be applied in the host country [28]. In this view, limited participation and social capital among UMs may lead to an inability to gain knowledge and skills to make appropriate health care seeking decisions and access the regular health care system.

This study demonstrated, that lack of access to regular health care induces alternative forms of health care seeking practices. Conflicting with the expectations of the study, UMs did not explain traditional health care utilization from a cultural reasoning. Nevertheless, UMs did state their familiarity with traditional health care practices in their home country. Similar to prior research, personal religiosity and religious communities were mentioned as important coping mechanisms to deal with mental and emotional problems [29][30]. Folkman (1984), who described the mental process of stress, identified religion as a coping mechanism that intends to reduce emotional distress by avoiding events that causes stress or by changing the meaning of the event [31]. Yet, the author stated that eventually this health care practice does not eliminate the cause that triggers stress. Accordingly, Folkman (1984) described this coping mechanism as a recourse in the absence of one's ability to gain control over the situation [31]. In this manner, this coping mechanism can be considered as an expression of the limited societal skills among UMs. However, rather than passivity, the findings demonstrate that respondents consider praying to God and being in contact with church members as a means to gain strengths, security and practical knowledge. Interestingly, none of the respondents indicated to seek care for the experience of stress at the regular health care system themselves, even though some considered stress as the source for other complaints. Although the explanation for this did not emerge from the findings, previous research suggest this may be due to differences in cultural perceptions of complaints and treatments required [32].

4.3. Strengths and limitations

This study focussed on the health care seeking practices of UMs, which provided insights into a population that is hidden from society. Research on UMs is complex and challenging due to the clandestine nature of this group. This study provided the opportunity to record health care seeking practices and needs among UMs. In combination with data from UMs and GPs, the process prior to applied health care seeking practices of UMs could be understood in its holistic context. In addition, consulting participants about their wishes and best practice strategies aided

identifying practical recommendations.

This study recognized several limitations. First of all, the researcher identified herself as an intern at MDM, which may have led to socially desirable answers by the respondents. Secondly, recruitment of GPs could have attracted participants that have more affinity with UMs. This may have prevented providing representative data. Furthermore, only UM respondents speaking Dutch or English were included in the study, as they were able to communicate with the interviewer. The exact bias of this is unknown, however previous literature indicate that those who do not speak the language are less informed about their rights and experience more communicative barriers [33]. Another limitation relates to the absence of member checks. This is generally recommended, however, due to the unstable situation of UMs this was not feasible. By means of a focus group discussion a degree of verification existed. Due to time constraints this study did not allow for dialogue between the different relevant stakeholders and to generate more viable recommendations. Lastly, due to the heterogeneity of the UM group, the findings of this study are not generalisable. Similar, respondents were recruited in Amsterdam and The Hague only, which withholds one from making claims about a national level. Social structures regarding support organisation and migrant organisations and ethnic density may differ between cities. However, this is an exploratory study that does not aim to make general claims about health care seeking behaviour among UMs. The purpose of this study was merely to understand different practices and its determinants.

5. Implications and recommendations for policymakers

A broad multi-layered approach, in which multiple socio-economic factors that underlie one's health are addressed, is favourable to reduce structural health disparities of UMs compared to the national population. However, within the current political system there are limited possibilities for addressing these factors. This study aimed at providing recommendations that utilize current societal structures and behavioural patterns of UMs.

The Dutch welfare state is responsible for ensuring health care for UMs. However, this study illustrates a gap between policy and practice. Studies in this manner contribute to transparency on the health situation of UMs to the national public and policy and appeals to the responsibility of the government. This study pleads for developing an information system to educate both GPs and UMs about regulations concerning care provision for UMs.

Secondly, this research proposes extended cooperation between grassroots organisations, migrant organisations and churches in activities targeting access to health care and knowledge exchange. In addition, this study suggests improving the knowledge of UMs on their health care right by utilizing social networks for information dissemination in the form of peer education and social media. Previous studies propose peer education as an effective tool among hard-to-reach hidden populations and based on the finding of this study it is expected to

be suitable among UMs as well [34][35]. More research on UMs involvement in health promoting programs and best communication practices tailored to the circumstances and every day practices of UMs communities is needed.

Thirdly, with regard to concerns of GPs, there is a need for development and implementation of uniform guidelines to ensure accessibility of health care and equal distribution of UMs patients. Improved communication and cooperation between GPs is suggested. In addition, involving health care providers situated in different sections and levels of the health care system, including secondary care providers and GP assistants is suggested for future research.

6. Conclusions

This study demonstrated that UMs often do not reach the regular health system, experience delay and are compelled to utilize alternative forms of health care practices due to formal and informal access barriers. Lack of knowledge on health care rights and the Dutch health care system among UMs poses barriers to access the health care system. Furthermore, GPs encounter challenges in health care provision for UMs, which contributes to inadequate health care provision for UMs. This study demonstrates the challenge of improving the health care access of UMs and suggests further research that aims at establishing guidelines on health care provision procedures for UM patients for GPs and developing health programs aiming at knowledge improvement among UMs.

Author Affiliations - Faculty of Earth and Life sciences. VU University, Amsterdam, The Netherlands.

Contributors - Linda Janmaat and Jos van Roosmalen reviewed the draft article version and provided feedback on research design.

Funding - This study received no specific grant from any funding agency in the public, commercial or not-for-profit sectors.

Competing interests - The author reports no conflicts of interest. The author alone is responsible for the content of the article.

Data sharing statement - No additional data for sharing available.

Acknowledgement

I would like to express my appreciation to the employees of MdM for the opportunity conducting my internship at the organisation. I'm grateful for their guidance and all I have learned during the internship. Furthermore, I want to especially thank the participants of the research, without them there would have been no research. Last but not least I wish to extend my gratitude towards my academic supervisor Jos van Roosmalen for his guidance and expert advice.

References

1. Grit, K., den Otter, J., & Spreij, A. (2011). Access to health care for UMs: a comparative policy analysis of England and the Netherlands. *Journal of health politics, policy and law*, 1496011.
2. Dwyer, J. (2004). Illegal immigrants, health care, and social responsibility. *Hastings Center Report*, 34(1), 34-41.
3. van der Heijden, P. G., Cruyff, M. J. L. F., & van Gils, G. (2015). Schattingen illegaal in Nederland verblijvende vreemdelingen 2012-2013:(in opdracht van Ministerie van Veiligheid en Justitie).
4. World Health Organisation (WHO). (2003). International Migration, Health& Human Rights. In Health & Human Rights Publication Series Issue No.4
5. van Oostrum, I. E., Goosen, S., Uitenbroek, D. G., Koppenaal, H., & Stronks, K. (2011). Mortality and causes of death among asylum seekers in the Netherlands, 2002–2005. *Journal of epidemiology and community health*, 65(4), 376-383
6. van Hanegem, N., Miltenburg, A. S., Zwart, J. J., Bloemenkamp, K. W., & Van Roosmalen, J. O. S. (2011). Severe acute maternal morbidity in asylum seekers: a two-year nationwide cohort study in the Netherlands. *Acta obstetrica et gynecologica Scandinavica*, 90(9), 1010-1016.
7. Reijneveld, S. A. (2000). *Toegankelijk van zorg voor illegalen*. Leiden: TNO Preventie en Gezondheid
8. Rodríguez, M. A., Bustamante, A. V., & Ang, A. (2009). Perceived quality of care, receipt of preventive care, and usual source of health care among undocumented and other Latinos. *Journal of general internal medicine*, 24(3), 508-513.
9. Veenema, T., Wiegers, T., & Deville, W. (2009). *Toegankelijkheid van gezondheidszorg voor 'illegalen' in Nederland: een update*. Nivel.
10. Biswas, D., Toebes, B., Hjern, A., Ascher, H., & Nørredam, M. (2012). Access to health care for undocumented migrants from a human rights perspective: A comparative study of Denmark, Sweden and the Netherlands. *health and human rights*, 14(2).
11. Chauvin, P., Simonnot, N., Vanbiervliet, F, Vicart, M, Vuillermoz, C. (2015). Access to Health Care for people facing multiple health vulnerabilities: obstacles in access to care for children and pregnant women. Médecins du monde International Network
12. MacKian, S. (2003). A review of health seeking behaviour: problems and prospects. *Health Systems Development Programme*.
13. Cuadra, C. B. (2010). Policies on Health Care for UMs in EU27. Country Report UK, MIM/Health and Society.
14. Boulton, M. (1994). *Challenge and innovation: methodological advances in social research on HIV/AIDS*. Taylor & Francis.

15. Britten, N. (1995). Qualitative research: qualitative interviews in medical research. *Bmj*, 311(6999), 251-253.
16. Karl-Trummer, U., Novak-Zezula, S., & Metzler, B. (2010). Access to health care for undocumented migrants in the EU. *Eurohealth*, 16(1), 13.
17. Da Lomba, S. (2014). Vulnerability, Irregular Migrants' Health-Related Rights and the European Court of Human Rights. *European journal of health law*, 21(4), 339-364.
18. van Oort, M., Kulu-Glasgow, I., Weide, M. & de Bakker, D. (2001). *Gezondheidsklachten van illegalen. Een landelijk onderzoek onder huisartsen en spoedeisende hulpafdelingen*. Utrecht: Nivel
19. Wolswinkel, J. (2009). Ongedocumenteerde patiënten bij de huisarts. Onderzoek naar de morbiditeit van ongedocumenteerde patiënten en de daaraan gegeven zorg door Nederlandse huisartsen in enkele grote steden. Nijmegen: Radboud Universitair Medisch Centrum
20. Van der Leun, J. (2006). Excluding illegal migrants in the Netherlands: Between national policies and local implementation. *West European Politics*, 29(2), 310-326.
21. Lukes, S. (1974). *Power. A radical view*. Macmillan, London, New York.
22. Larchanché, S. (2012). Intangible obstacles: health implications of stigmatization, structural violence, and fear among undocumented immigrants in France. *Social science & medicine*, 74(6), 858-863.
23. Biswas, D., Kristiansen, M., Krasnik, A., & Norredam, M. (2011). Access to healthcare and alternative health-seeking strategies among undocumented migrants in Denmark. *BMC Public Health*, 11(1), 560.
24. Rechel, B., Mladovsky, P., Devillé, W. L. J. M., Rijks, B., Petrova-Benedict, R. & McKee, M. (2011). (Eds.). *Migration and health in the European Union*. Berkshire: McGraw-Hill
25. Dagevos, J. (2001). *Perspectief op integratie; over de sociaal-culturele en structurele integratie van etnische minderheden in Nederland*.
26. Engbersen, G. (2003). De armoede van sociaal kapitaal. *Economisch-Statistische Berichten*, 27, D12-D13.
27. van Tubergen, F. (2004) *The Integration of Immigrants in Cross-National Perspective: Origin, Destination, and Community Effects*. Utrecht: ICS.
28. Kuo, B. C. (2014). Coping, acculturation, and psychological adaptation among migrants: a theoretical and empirical review and synthesis of the literature. *Health Psychology and Behavioral Medicine: An Open Access Journal*, 2(1), 16-33.
29. Carpenter, T. P., Laney, T., & Mezulis, A. (2011). Religious Coping, Stress, and Depressive Symptoms Among Adolescents: A Prospective Study. *Psychology of Religion and Spirituality*. Advance online publication. doi: 10.1037/a0023155

30. Teunissen, E., Van Bavel, E., Van Den Driessen Mareeuw, F., Macfarlane, A., Van Weel-Baumgarten, E., Van Den Muijsenbergh, M., & Van Weel, C. (2015). Mental health problems of undocumented migrants in the Netherlands: A qualitative exploration of recognition, recording, and treatment by general practitioners. *Scandinavian journal of primary health care*, 33(2), 82-90.
31. Folkman, S. (1984). *Stress, appraisal, and coping*. Springer Publishing Company LLC.
32. Satcher, D. (2001). Mental health: Culture, race, and ethnicity—A supplement to mental health: A report of the surgeon general.
33. Hacker, K., Anies, M., Folb, B. L., & Zallman, L. (2015). Barriers to health care for undocumented immigrants: a literature review. *Risk management and healthcare policy*, 8, 175.
34. Turner, G., & Shepherd, J. (1999). A method in search of a theory: peer education and health promotion. *Health education research*, 14(2), 235-247.
35. Lazdane, G., & Lazarus, J. V. (2003). Does peer education work in Europe. *The European Magazine for Sexual and Reproductive Health*, 56.

PORTFOLIO

Healthcare seeking practices of undocumented migrants in the Netherlands: a qualitative exploration of healthcare seeking behaviour

Rosa Watjer

2556517

MSc. Global Health

Index

1. Scheme developed based on literature
2. Respondents recruitment: invitation for GPs
3. Informed consent
3. Interview Topic guide
 - Expert migrant organization
 - Undocumented migrants
 - General Practitioners
 - Focus Group discussion guide
5. Coding scheme
6. Invitation Expert meeting, feedback session.
7. Logbook: Activities during study process
8. Expert meeting: Flip-over results.
9. Journal requirements
10. Research proposal

Appendix 1. Scheme based on literature. Predetermined factors influencing healthcare seeking behavior among UMs based on literature to inform interview guide.

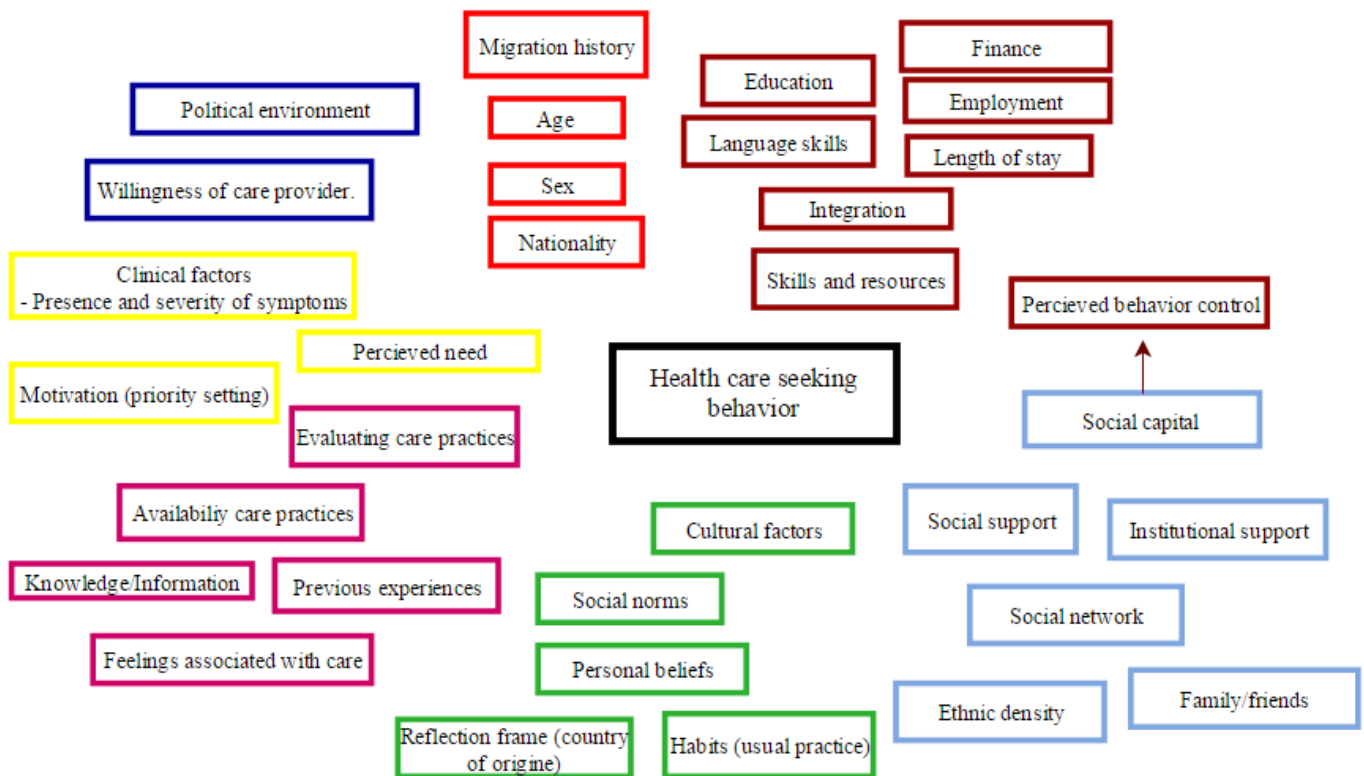


Figure 1. Overview of factors influencing healthcare seeking behaviour (developed by author).

Appendix 2. Invitation letter Interview. Recruitment General Practitioners.



Onderzoek Dokters van de Wereld

Ik stel u hierbij voor aan Fatosj Temizkan (BSc. Gezondheid en leven) en Rosa Watjer (MSc. Global Health). Zij lopen momenteel stage bij Dokters van de Wereld. Wij zouden willen vragen of u mee zou willen werken aan een onderzoek.

In opdracht van Dokters van de Wereld voeren zij een onderzoek uit naar de toegang tot zorg van ongedocumenteerde migranten en het zorg-zoekend gedrag van deze groep. Resultaten tot nu toe laten zien dat ongedocumenteerde migranten vaak de reguliere gezondheidszorg niet zelf kunnen bereiken. Dokters van de Wereld helpt bemiddelen tussen ongedocumenteerde cliënten en zorgverleners zodat deze groep de juiste zorg kan krijgen. Door middel van onderzoek kunnen aandachtspunten worden geïdentificeerd voor een gerichte aanpak om de zorg voor deze groep te waarborgen. Om dit te realiseren is het van belang meer inzicht te krijgen in de ervaringen van zorgverleners. Wij zouden u willen uitnodigen voor een interview van maximaal een half uur, waarin de volgende onderwerpen aanbod komen:

- Beleid in uw praktijk met betrekking tot zorg voor ongedocumenteerde patiënten
- Ervaringen met zorgverlening aan ongedocumenteerde patiënten
- Zorg-zoekend gedrag van ongedocumenteerde patiënten

We horen graag van u of u zou willen meewerken. Bij voorbaat dank.

U kunt ons bereiken op het email: zorgrecht@doktersvandewereld.org

Met vriendelijke groeten,

Linda Janmaat

Programmamanager Zorgrecht

Dokters van de Wereld / Médecins du Monde Netherlands

Nieuwe Herengracht 20 - 1018 DP Amsterdam

+31 (0) 20 465 28 66

www.doktersvandewereld.org

Appendix 3. Information leaflet and informed consent.



DOKTERS VAN DE WERELD

TITLE OF THE RESEARCH PROJECT:

Healthcare seeking behaviour among undocumented migrants

PRINCIPAL RESEARCHER: Rosa Watjer

CONTACT: RWatjer@doktersvandewereld.org
 020-465 2866

You are invited to take part in a research project. The information on this paper will explain the research project. Please ask the study staff any questions about any part of this project that you do not fully understand. It is very important that you fully understand the give information and the purpose of the research. Your participation is **entirely voluntary** and you are free to stop participating in the research at any moment. All information provided by you will be processed anonymously, meaning that your name and other identity revealing descriptions will not be linked to given information and used in publications.

What is this research study all about?

This research looks at the different health practices people undertake when they have a health problem. There are many different ways people take care of their health. Different practices can help in making you feel better or relief pain. In this research we would like to learn more about what you do when you have a health problem. Eventually this information will make it possible to inform and help others.

Are there risks involved in your taking part in this research?

To my knowledge, participating in this study would not have any risks to you.

Who will have access to the information?

All information provided by you will be confidential and participant will remain anonymous. Nobody except the researchers will have access to individual, personal information. The results may be used for publication in a scientific journal or for presentation at a university gathering, without disclosing your name or personal descriptions that may reveal your identity .

Will you be paid to take part in this study and are there any costs involved?

There will be no costs involved for you, if you do take part. For taking part in this research you receive a small contribution.

Is there anything else that you should know or do?

You can contact Rosa Watjer at 020-465 2866, if you have any further queries or encounter any problems.

Declaration by participant

By signing below, I agree to take part in a research study entitled Healthcare seeking behaviour among UMs

I declare that:

- I have read or had read to me this information and consent form and I understood the given information.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary**.
- I may choose to leave the study at any time.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) on (*date*) 2016.

To be filled in by executive staff

Declaration by researcher

I (*name*) declare that:

- I explained the information in this document to
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below*).
- I will treat all information as confidential and will not disclose any information to third persons.

Signed at (*place*) on (*date*) 2016.

Declaration by interpreter

I (*name*) declare that:

- I assisted the investigator (*name*) to explain the information in this document to (*name of participant*)
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.
- I will treat all information as confidential and will not disclose any information to third persons.

Signed at (*place*) on (*date*) 2016

Appendix 4. INTERVIEW GUIDE- ('experts', UMs, GPs) and Focus Group Discussion design.

4.1 Interview- EXPERT MIGRANT ORGNISATION

Purpose: Gain insight into the issue to prepare for research activities with UMs and GPs

Interview topics

- Can you tell something about your organisation and what you do?
- What activities are organised in the organisation?
- For who is the organisation?
- What is your experience with the UMs?
- What issues do you see among UMs?
- How does the lifestyle of undocumented migrant effect their health?
- How do people without residence permit take care of their health when they are sick?
- What problems do you see when they seek health care?
- Why do people without residence permit experience these problems?
- How does the organisation help people without residence permit?
- How can people without residence permit be helped more?
- What can Dokters van de Wereld do more for this population?

4.1 INTERVIEW GUIDE - UNDOCUMENTED MIGRANTS

Purpose

Gain detailed information about health seeking practices among UMs through personal narratives.

Introduction.

"First of all thank you for your time. I'm pleased you could be here today. So, to introduce myself: My name is Rosa, I'm a student at VU university and I'm an intern at Dokters van de Wereld. Do you know the organisation? (It is an organisation that helps people without residence permit and health insurance in finding their way to healthcare). I'm not a doctor or nurse, but I conduct (do) a research for the organisation to improve their services to help people without residence permit in getting the healthcare they need. This research looks at the different health practices people undertake when having a health problem. There are many different ways people take care of their health. Different practices can help in making you feel better or relief pain. In this research I would like to hear more about what you do when you have a health problem. This helps the organisation to inform and help others."

Personal and socio-demographic questions.

How old are you?

What is your country of nationality/in which country are you born?

For how long are you in the Netherlands?

For what reason did you come to the Netherlands?

What education did you have in your home country?

What job did you do in your home country?

Do you work/earn money at the moment?

Do you have a stable place you can stay at the moment?

Do you live with other people?

With who do you live?

Do you have a partner?

Do you have children?

Do they live in the Netherlands?

Are they born here?

Do have other family in the Netherlands?

Do you know many other people from.....(home country)?

Do you know many other people?

Healthcare seeking experiences: participants' illness response.

How would you say your health is?/ Do you feel healthy?

What things have made you weak/sick? / What things helped you in staying healthy?

Do you have the feeling you have control over your health?

What health problems have you experienced in the Netherlands?

Can you tell me about how that went when you experienced (health problem)?

(Probing for full story of illness episode)

What where the first symptoms?

What did you do when you first noticed the symptoms (so, the first thing you did)?

How long was this after noticing the symptoms?

Did you see someone?/ did you go some were for help?

Was this far from the place you were staying?

How do you feel about this care?
Did someone advice you? / Did someone accompany you?
Did you have to pay?
Did this care help for you?
What did you expect from this care?
Where you satisfied with this care?
Did you do other thing as well?
Why?
(repeat previous questions)

Is this similar for the other health problems? So, when you have a health problem what is it what you usually do?
Why?
To who do you usually go to?
Do you receive support from someone?
Do have advice from someone?
What did you expect from this care?
Are you satisfied with this care?

When going to GP/ hospital
Have you often been at the family doctor/ in hospital?
How do you experience the care of the family doctor/ in hospital?
Was the family doctor/care provider in hospital friendly to you?
Would you feel comfortable going there again?
Are you satisfied with the care from the family doctor/ care provider in hospital?

When you had a health problem in your home country, what would you do?
How is this different from here?
What kind of care do your peers (friends) often practice (do)? (What do you see among other UMs?)
Where do your peers (friends) usually go to?
Who do they see?
Do you do other things now when you experience health problems, then when you just arrived in the Netherlands?
How comfortable do you feel looking for healthcare [and other services]?
Next time, when you experience some health problems, what would you do?
Why?

4.2 INTERVIEW GUIDE - GENERAL PRACTITIONER

Purpose

Gain knowledge on the experiences of General Practitioners (GPs) in relation to care provision for UMs. This will provide full insight into the context of health seeking practices of UMs. In the Netherlands GP's are considered the regular care providers and UMs take this form of care into account in healthcare seeking considerations. Experiences of GP's as well reflect the experiences of undocumented clients that consult the regular health facilities. These experiences influence healthcare seeking practices.

Introduction

"In this interview I would like to learn more about your experiences with healthcare provision for UMs. Would like to emphasize here that it is not about personal patient data. Furthermore, I would like to ask whether I can record the interview. This is only used for processing the information for the research, and not for other purposes. The data will be processed anonymously."

Does your practice treat undocumented patients?

Questionnaire for general practitioner who treats undocumented patients

Could you estimate how many patients have been treated (in total/on a monthly basis)?

For how long has your practice treated undocumented patients?

What happens when a patient without a residence permit signs in for your practice?

Could you describe the steps that are conducted in such a case (when an undocumented patient signs in)?

How is the payment arranged? (To which extent do you test if the patient is able to pay for a consult?)

Did you ever receive information about healthcare for UMs before? (For instance in university/meetings/NGOs)

How do you experience the care provision for irregular migrants?

How do you experience the contact with irregular migrants?

How do you experience the administration for irregular migrants?

How do you experience the attitude of the patient towards the provided care?

What was your expectation when you accepted undocumented patients?

Did the reality meet these expectations?

Do you know how the patients came in contact with your practice?

What do you know about the lifestyle of undocumented patients?

To what extent do you have insight on whether undocumented patients make use of alternative practices?

To what extent do you agree with the statement: 'People without a residence permit have the right to medical healthcare, even when they are not able to afford it.'?

Is there anything you would like to add?

Do you have any other questions for us?

Questionnaire for general practitioner who does not treat undocumented patients

How would you explain the fact that your practice does not treat/has never treated patients without a residence permit? (Have you ever had undocumented patients who did want to apply to your practice?)

What happens in your practice when an undocumented patient wishes to sign in?

What do you expect of providing care to undocumented patients?

What do you expect of the contact with undocumented patients?

What do you expect of the administration for undocumented patients?

What do you know about the lifestyle of patients without a residence permit?

To what extent do you agree with the statement: 'People without a residence permit have the right to medical healthcare, even when they are not able to afford it.'?

4.4 FOCUS GROUP DISCUSSION – UNDOCUMENTED MIGRANTS

Purpose

To assess the healthcare seeking practices and motives among the participants

Internal aim

To unravel the structure of people's behaviours, perceptions and values regarding healthcare practices. Thereby it will give insight into group dynamics and how healthcare practices are discussed in interaction.

Focus group approach

The focus group discussion was held with a small group of 6 participants. The participants were recruited through a migrant organization. The focus group discussion was homogenous with regard to nationality and sex. This increased comfortability among the participants to share their views, as they share similar background and experiences (Morgan, 1992; Ashury, 1995; Krueger and Casey, 2000). The location of the focus group discussion was determined in contact with their representative. A comfortable environment that is easy to locate is essential for participants to feel at ease and prevent delay or drop outs. The set-up of the focus group discussion was arranged in such a manner that the participants were able to face each other.

Focus group design

The focus group discussion had the following structure:

- Before starting the focus group discussion, small talk was important to make participants feel more at ease. Thereby, it sets the tone for the focus group discussion. This gave an indication of the relationships between the participants.

- Starting the discussion by welcoming the participants, and introducing the MdM organization. This was followed by an introduction of the topic and purpose of the focus group discussion.

“Good Afternoon everyone. I’m very pleased you could all be here today, so thank you for coming!. My name is Rosa and I conduct a study for Dokters van de Wereld. (Dokters van de Wereld is an organisation that helps people without residence permit and health insurance in finding their way to healthcare) This study is about different healthcare practices of people. There are many different ways of taking care of your health, which can all help in pain relief or just make you feel better. This can simply start from speaking with people in your environment, who can give support or give you information.. There are many different ways in how people seek care to make their health better. And people have different reasons why they seek certain care. We would like to learn more about all the different forms of care and why this care is used. In this focus group discussion, I hope we can learn from each other by sharing our experiences and ideas.”

- The introduction is followed by presenting the ‘rules’ for the focus group discussion.

“ This focus group will take around 1 hour.. To have good discussion about this topic, it will be good one person at a time speaks, so we can all hear the person well. In this discussion it is important to respect each other’s ideas. Thereby it is important to note that everything that we discuss today in this group will stay in the group. And mostly remember there are no wrong answers. All answers are of importance!”

Creating a dialogue

This session was based on in-depth interviews. Following topics were discussed:

- Healthcare seeking practices
- Motives for applying a healthcare seeking practice
- Barriers to the regular healthcare system.
- Knowledge on their legal right and right to healthcare.

Additional topics brought up by the participants led the discussion.

Participants as advisors

In the last activity participants will be consulted on their experiences and recommendations. This helped to inform activities and work of MDM.

"Imagine you are a consultant and you give advice to organisations. What would you advise MDM to help people without insurance to get access to healthcare. (You can think about for instance education programmes topics, or any other activities)." (suggestions only given when needed to overcome reserved attitudes)

Closing the discussion

Participants are thanked for their contribution.

"Hereby, I want to close the discussion. I wish to thank you all for participating. I felt it was a very fruitful discussion. Your contribution was very important for this study and will help Dokters van de Wereld to help people without residence permit. So thank you very much! I enjoyed our discussion and I hope you did as well. If you have any more questions you can come to me. If you later on have any more question, you can always contact Dokters van de Wereld. I will give you an information sheet of Dokters van de Wereld."

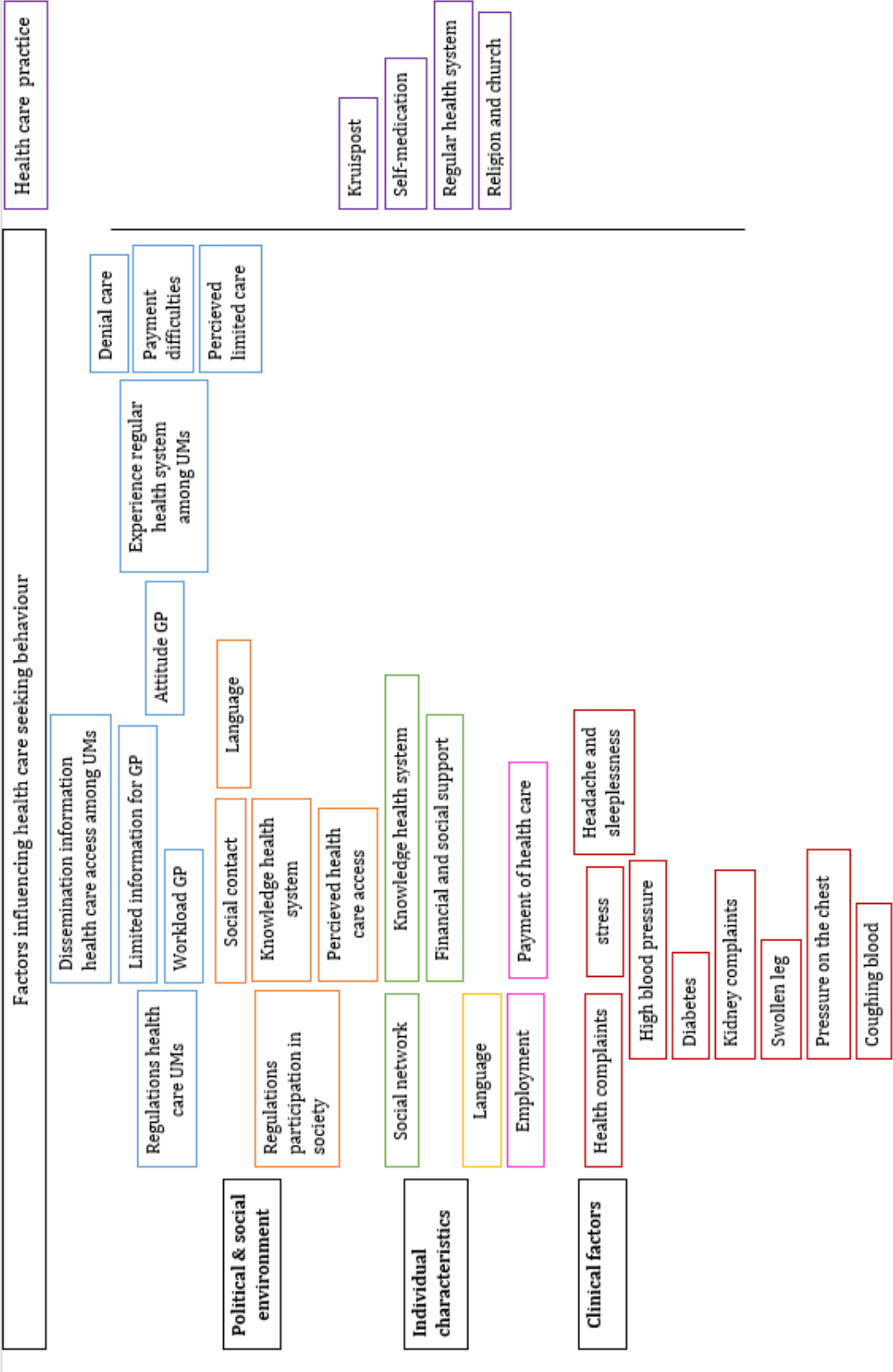
Reference

Asbury, J. E. (1995). Overview of focus group research. *Qualitative health research*, 5(4), 414-420.

Krueger, R. A., & Casey, M. A. (2014). *Focus groups: A practical guide for applied research*. Sage publications

Morgan, D. L. (1992). Designing focus group research. *Tools for primary care research*, 2, 177-93.

5. Appendix. Data analysis: Coding scheme.



EXPERT MEETING

What would you recommend Dokters van de Wereld?

Help Dokters van de Wereld to Help people without residence permits to get into healthcare.

Do you have a good idea on what Dokters van de Wereld can improve or you would like to share experiences and think with us on how people without residence permit can be helped better, **JOIN** the expert meeting!

WHEN

MONDAG 18 JULY

17.30 Expert meeting

18.30 Diner

WHERE

WERELDHUIS

Nieuwe Herengracht 20



If you like to join you can leave your name at the Wereldhuis or Dokters van de Wereld office. We appreciate your contribution!

HEALTH CARE IS A HUMAN RIGHT!

7. Appendix. LOGBOOK: Research process and activities.

11 March, Health education Program at Turkish community Mosque

Access to healthcare for undocumented migrants and high blood pressure

6 April, Congress for General Practitioners, Utrecht

Congress on cultural sensitive care. Congress provided opportunity to get in contact with GPs for recruitment.

7 April, Dutch National Health Congress (*Nederlands congress volksgezondheid*), Rotterdam

Congress on various health inequality topics. Different organisations, health professionals and other professionals came together. Provided opportunity to get in contact with GPs for recruitment.

15 April- Interview not included

Interview with a man with psychological problems not included due to psychological health problems. Within this interview it was difficult to gain focus on the interview question. Interview is not included in the study.

21 April Participation market Amsterdam South-East. (Community house Anansi)

During this day local/neighbourhood organisation came together to learn from each other's existence and activities. During this day, contact has been made with different organisations (i.e. community organisation, mental health organisations, organisations that focus on health and sport). Besides members of organisations, people from the neighbourhood are present. During this day it was possible to get in contact with organisations that possibly have contact with persons without residence permit. Information on the study is given to people interested in MdM. Few people are approached with the question whether they know someone who would be willing to participate in the study. They could contact me when someone wants to participate. Resulted in no respondents

23 April, National women day celebration, Amsterdam South- East (No limit)

On this day different women organisations (Refugee women, African Women Perspective) came together to celebrate women day. On this day I spoke with different women in the organisation. Opportunity to establish contact for recruitment of respondents.

23 April, diner cafe (Women without residence permit organisation)

Evening for women without residence permits to come together and have diner, funded by the organisation. Social activity for women to relax. During this evening two contacts are established for an interview.

29 April, accompanied the mobile carebus of MdM.

Bed Bad en Brood (BBB) was already closed and people left due to bad weather

29 April, Telephone contact with *Service Punt Emancipatie Amsterdam (SPE)*

This is an organisation that is in contact with many women's organisations. Purpose of this contact is to gain information on organisations that have contact with undocumented migrants. This resulted in an information text in the newsletter of SPE about MdM.

1 May, IMWU (Indonesia Migrant Workers Union) celebration.

Undocumented Indonesian domestic workers came together to celebrate the existence of the organisation. A video is displayed and there was a discussion among the participants (In English and local Indonesian language). Afterwards there was a diner organised by the organisation at

the *Wereldhuis*. Through this event I got in contact with the Amsterdam coordinator. Contact resulted in an health education programme on pregnancy services in the Netherlands developed by myself and another MdM volunteer.

2 May, Interview with a lady from Nigeria.

The lady didn't show up for the interview. I called few times.

3 May, HO-Yin Chinese women organisation

Email contact to inform whether they are interested in the activities of MdM. However, within the organisation there is limited knowledge on the Chinese undocumented migrant population.

4 may, Visited Brazilian Catholic church in Amsterdam West

Many migrants, mainly from Brazil, visit the church. Among the church members there are many without a residents permit. The church community is interested in the education programs of MdM. This contact did not result in respondents. Arrangements were made to attend the church service.

4 May, Visited Ghanaian church in Amsterdam South-East

The pastor has experience with supporting and guiding undocumented migrants. The church is interested in education programs of MdM and will help in finding people for interview. Eventually, this contact did not result in respondents. Arrangements were made to attend the church service.

4 May, interview with a man from Togo

This interview is not included in the research. He was suspicious and didn't want to disclose information

12 and 30 May, 1 and 2 of June visit community home Assadaaka, Amerdam oost

This is a local community organisation that organises different activities to improve participation of people in the neighbourhood. They are interested in the activities of MdM. Flyers of healthcare access in different languages are provided. Spoken with a community worker, with knowledge on the concerns of undocumented migrants. Most of the people do not speak English or Dutch. Contact resulted in one interview respondent.

14 May, Visit the church service in the Ghanaian church.

Participatory observation.

17 May, Appointment with couple from Iran and Morocco for an interview|

Couple did not show up for the interview.

17 May, Health education program at community centre Holendrecht (Amsterdam South-East)

Health education program on Access to healthcare and High blood pressure. A small group of women came together. Unknown about their status. Asked for participants, but resulted in no respondents.

18 May, email contact with Veronica van der Kamp, founder of GAM TV, a local TV program which targets social and health issues in the African community.

For MdM it is of interest to reach a larger group of people. The data of the study indicated many undocumented migrants have limited knowledge on their rights to healthcare. During the interview it came forward, the local TV and Radio is an important means of communication.

22 May, Visited Brazilian church service.

Participatory observation. To establish contacts with people within the church. Within this church many people do not have a residence permit and mostly only speak Portuguese.

26 May, Interview at Stap Verder (community centre, Amsterdam South-East)

Interview respondent cancelled due to health problems.

26 May, visited a clinic in Amsterdam South East, mentioned in an interview with a GP in Amsterdam South East.

This was a clinic where many Ghanaians come for a 'health check'. It is an alternative healthcare practice. The owner did not know whether people without residence permit come to her.

Expects this is not the case, as people mostly come with health insurance.

1 June, Health education program at Brazilian community church

Health education program on High blood pressure and access to healthcare.

2 June, MOC (*Multicultureel Ontmoetings Centrum*) in Den Haag.

5 interviews were planned by phone. 2 respondents did not show up.

7 June, Meeting organised by the GGD with migrant organisations about establishing behavioural change by means of activities and health education programs.

Establish contact with different migrant organizations and exchanged experiences.

8 June, Meeting with the coordinator of AWP (*African Women Perspective*).

Discussing the activities of MdM and AWP, and the possibility to organize a health education program and focus group discussion. Although plans were made, there was no follow up.

9 June, email contact with the coordinator of the organization ProFor (contact was exchanged on the GGD evening)

The coordinator was interested in the activities of MdM and participating in the study.

9 June, meeting with Veronica van der Kamp, founder of GAM TV.

Discussed problems related to healthcare access for undocumented migrants. In collaboration with Veronica van der Kamp an interview 'access to healthcare' was organized. This interview developed targeted questions and problems that undocumented people within the community experience. The study results guided the interview dialogue.

9 June, Health education program at *Wereldhuis*

Health education program on nutrition and health.

11 June, meeting with Nigerian pastor, founder of the *Vrouwen Empowerment Center (VEC)* in Amsterdam South-East

VEC aims for more participation in society and avoid isolation. Focus group discussion with women in the organization. Additional interview with the pastor.

17 June, meeting with the coordinator of ProFor organization.

Expert interview on the experiences with undocumented migrants in the organization. The ProFor organization provides social support for different migrant groups, with special attention to Spanish speaking populations.

18 June, Health education program at IMWU

Health education on pregnancy services in the Netherlands. Only three people showed up, but provided opportunity to discuss access to healthcare.

23 June, Health education program at Suriname community church Amsterdam-East.
Health education program on access to healthcare.

28 June, Interview local Ghanaian Amsterdam TV. Veronica van der Kamp, GAM TV
The interview for GAM TV is recorded. Was broadcasted June 20th on Salto TV

2 June, PCC, Health is your Wealth conference by AMC, GGD and 50 Ghanaian churches
Event on health issues (i.e hypertension, diabetes, cardio vascular disease) among the Ghanaian population. Presentations and discussions were held. During this event MdM was here to speak about right to health for undocumented migrants. During the event questions were asked about access and payment regarding healthcare for undocumented migrants. It was noted by the community that this is a vulnerable group, with limited resources to take care of their health. Delay in health seeking was mentioned as a prominent issue among the Ghanaian community.

27 of May, 2 and 11 of June, Appointment with African women perspective to speak with a group of women for Focus group discussion
All appointments did not go through.

18 of July, Expert meeting with Ums

In collaboration with the *Wereldhuis* an expert meeting was organized to discuss study results and recommendations of undocumented migrants. Participation of undocumented migrants in improving healthcare access took a central role.

8.1 Appendix. Expert meeting

Expert Meeting 18 juni-2016

Setting: Wereldhuis (Circle with chairs)

Tools: Flipover

Introduction: research DvdW.

Thank you all for being here today. My name is Rosa Watjer. I'm a Master student at the Vu university and I'm currently an intern at Dokters van de Wereld. For Dokters van de Wereld I did a research on how people without residence permit take care of their health and on what factors influences the way people take care of their health by means of interviews. To inform Dokters van de Wereld on how they can help people better.

We noticed that most people still have limited knowledge on their rights, medical, social and juridical. Many do not know they have the right to go to a family doctor for instance. As a consequence many do not reach the regular health care system while do have the right to go.

Therefor we organized this meeting today to think with you about possible solutions.

To start, we would like to hear more from you about hoe people get information on their rights and going to family doctor.

- What are your experiences? How do you get your information?
- What do you consider/see as a good means to spread information?
- Who should be involved in spreading information? (Organizations/people)
- What is important information to spread? What are issues that need more attention?
 - Questions you have yourself you would like more information about?
 - What is still unclear? (experiences of others?)
- Are there other things you would advise Dokters van de Wereld?

8.2 Appendix. Results Expert meeting

how do you get your information?

- offer info in different languages (phone)
[dvdw]
- by people (networks, groups)
- social media / website

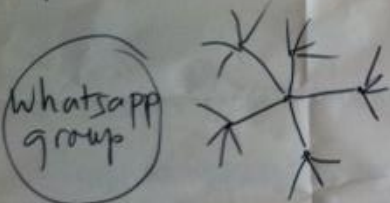
TRANSLATE OPTIONS

- PREVENTION TOPICS (MEETINGS)
- FOLDERS (DISTRIBUTE AT MOSQUES, CHURCHES etc)
- MEDECINS DU MONDE / DOCTERS VAN DE WERELD
↳ verschil → in NL mediators
- PAYMENT SITUATIONS (ZINL)
emergency
- WHATSAPP GROUP (EXPERTS+ORGANISATIONS)
- HANDLEIDING VOOR GP'S

Regeringsgroep (0)

COA (^{bekend} dvdw → internationaal logo)

Folders at trainstations, shops,
50, 51, 53, 54, Kelylaan, → ADS in metro, gvb



Whatsapp group

youtube - medical & basic rights

9. JOURNAL REQUIREMENTS - BMJ Open Access: Instructions for authors.

<http://bmjopen.bmj.com/site/about/guidelines.xhtml>

Points for inclusion according to BMJ open Access

Research articles

Research submissions should have a clear, justified research question.

All articles should include the following.

- The article title should include the research question and the study design. Titles should not declare the results of the study.
- A structured abstract (max. 300 words) including all the following where appropriate (please note that for RCTs there is a specific CONSORT extension for abstracts):
 - objectives: clear statement of main study aim and major hypothesis/research question
 - design: e.g. prospective, randomised, blinded, case control
 - setting: level of care e.g. primary, secondary; number of participating centres. Generalise; don't use the name of a specific centre, but give geographical location if important
 - participants: numbers entering and completing the study; sex and ethnic group if appropriate. Clear definitions of selection, entry and exclusion criteria
 - interventions: what, how, when and how long (this can be deleted if there were no interventions)
 - primary and secondary outcome measures: planned (i.e. in the protocol) and those finally measured (if different, explain why) - for quantitative studies only
 - results: main results with (for quantitative studies) 95% confidence intervals and, where appropriate, the exact level of statistical significance and the number need to treat/harm. Whenever possible, state absolute rather than relative risks
 - conclusions: primary conclusions and their implications, suggest areas for further research if appropriate. Do not go beyond the data in the article
 - where applicable, trial registration: registry and number (for clinical trials and, if available, for observational studies and systematic reviews)
- An 'Article summary' section consisting of the heading: '**Strengths and limitations of this study**', and containing up to five short bullet points, no longer than one sentence each, that relate specifically to the methods of the study reported. They should not include the results of the study and should be placed after the abstract.
- The original protocol for the study, where one exists, as a supplementary file.
- A funding statement, preferably worded as follows. Either: 'This work was supported by [name of funder] grant number [xxx]' or 'This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors'. You must ensure that the full, correct details of your funder(s) and any relevant grant numbers are included.

- A competing interests statement. See [this advice](#) from the BMJ on what to include.
- Articles should list each author's contribution individually at the end; this section may also include contributors who do not qualify as authors. Please visit the [ICMJE](#) website for more information on authorship.
- Any checklist and flow diagram for the appropriate reporting statement, e.g. STROBE (see below).
- Any article that contains personal medical information about an identifiable living individual requires the patient's explicit consent before we can publish it. We will need the patient to sign our [consent form](#), which requires the patient to have read the article. This form is available in multiple languages.
- Please provide a data sharing statement such as: "Technical appendix, statistical code, and dataset available from the Dryad repository, DOI: [include DOI for dataset here]."

We recommend your article does not exceed 4000 words (VU INTERNSHIP IS MAXIMUM OF 10.000), with up to five figures and tables. This is flexible, but exceeding this will impact upon the paper's 'readability'. Supplementary and raw data can be placed online alongside the article although we prefer raw data to be made publicly available and linked to in a suitable repository (e.g. Dryad, FigShare). We may request that you separate out some material into supplementary data files to make the main manuscript clearer for readers.

We also recommend, but do not insist, that the discussion section is no longer than five paragraphs and follows this overall structure (you do not need to use these as subheadings): a statement of the principal findings; strengths and weaknesses of the study; strengths and weaknesses in relation to other studies, discussing important differences in results; the meaning of the study: possible explanations and implications for clinicians and policymakers; and unanswered questions and future research.

Authors are encouraged to submit figures and images in colour - there are no colour charges.

At upload you will be asked to choose one general subject area that applies to your article - it will be published under this banner on the main table of contents. You will also be asked to select further subject headings to be used for the 'Browse by topic' section, and specific keywords for help with identifying reviewers.

10. RESEARCH PROPOSAL- HEALTH CARE SEEKING BEHAVIOUR AMONG UMS

Index

1. Introduction

1.1 Societal and political relevance

1.2 Research questions

2. Background

2.1 Target population

2.2 Health situation of Undocumented migrants

2.3. Health care provision for undocumented migrants in Dutch context

3.Theoretical framework

3.1 Process of health care seeking behaviour

4. Research design and methodology.

4.1 Research approach

4.2 Methodology

4.2.1 Phase 1: exploratory phase

4.2.2 Phase 2: in-depth study

4.2.3 Phase 3: integration and analysing of results

4.3 Possible limitations this research needs to overcome

Abbreviations:

DvdW- Dokters van de Wereld

MdM- Médecins du Monde

UMs – Undocumented migrants

GP- General Practitioner

1. Introduction

Within the current globalization trends, migration is increasing all over the world. Many countries are not prepared to deal with this demographic transition and policies and attitudes towards migration are hardening. This political context has negative consequences for the health status of UMs in the Netherlands (Grit, den Otter & Spreij, 2011; Dwyer, 2004). In 2013, an estimated 22.881 to 48.179 undocumented migrants (UMs) resided in the Netherlands (van der Heijden, *et al.*, 2015). Persons who do not request a valid permit to stay or get rejected when requesting become undocumented (Meerens, 2006). This is a vulnerable and marginalized group with limited resources. The health of this particular group is poorer than that of the general population and other migrant populations, characterized by a higher risk of infectious diseases and psychological health problems (Rechel, *et al.*, 2011; WHO, 2003; Van Oostrum, *et al.*, 2011). Several studies recognize the difficulties UMs face to maintain their health, due to socio-economic vulnerabilities, poor living conditions and limited social network (Reijneveld, *et al.*, 2001; Rechel, *et al.*, 2011). Although health care is considered a right for all human beings, it is noted that there is limited institutional health care access and utilization among UMs, and this group is inadequately reached by health promoting programs (Rodríguez, Bustamante & Ang, 2009). Multiple factors are presumed to exacerbate limited access to health care. First of all, within the context of Dutch immigration discouragement policies, the “Linkage law” came into force in 1998, which entails that UMs are not entitled to collective benefits, including financial support and health insurance. This exclusion from basic facilities results in poverty, dependency, fear, and limited access to health care facilities. Secondly, many UMs lack knowledge of the Dutch health care system and their medical rights, which hampers utilization (Chauvin, *et al.*, 2015). Consequently, social exclusion and ensuing limited health care perpetuates the poor health status of UMs.

While previous studies have addressed the medical situation and the determinants for health care utilization among UMs, they focus mainly on the use of formal institutional care. However, limited attention has been devoted to the full process of illness response, including consultation of other forms of care. Health seeking considerations and actions differ between persons, depending on diverse social contextual and personal factors (MacKian, 2003). Individuals make decisions in relation to their health, as they weigh up the potential risks or benefits of a particular health care seeking behaviour. Though, as MacKain (2003) indicated, they do so in a way that is mediated by their immediate practical and social environment. Accurate understanding of the health care seeking process is needed to explain and predict health behaviours for an tailored response to meet the needs of UMs.

In this study I propose to understand health care practices of UMs in the Netherlands by exploring how they make health care seeking decisions in the context of their daily, socially and

culturally embedded lives and in context of the health care system. The aim of this study is therefore to (1) assess health care seeking behaviour practices among UMs and (2) assess factors influencing health care seeking practices.³ In order to study health care seeking behaviour, this study adopts a qualitative research approach, in which perspectives of UMs obtain a central role.

1.1 Societal and political relevance

This study is developed from a human rights approach, which entails that all humans beings should have the opportunity to reach their full potential for health. The undocumented status is accompanied by vulnerabilities leading to higher risk of developing health ailments. The societal burden of health disparities manifests itself in various ways. Poorer health leads to social and economic costs, due to increase of costly diseases. Attention to vulnerable groups is essential, as they are generally not able to defend their own interests. Knowledge gained on health care seeking behaviour among UMs can be employed in policies and inform health promotion strategies, to eventually contribute to the improvement of health of UMs.

1.2. Research question and sub research questions

Research Questions

How do undocumented in the Netherlands seek health care?

Research sub-questions:

- What health care seeking actions do undocumented migrants apply?
- What individual factors influence health care seeking behaviour?
- Which structural conditions have an influence on the health care seeking behaviour of undocumented migrants?
- What actors (relationships) are important in health care seeking behaviour decisions of undocumented migrants?

2. Background

2.1 Target group.

The target group of this study is the UMs population, which entails persons without residence permit for the EU-country they live in. The UM population is highly heterogeneous, as there is great diversity in work and living situations, nationalities⁴ and reasons for being in the

³ This study is commissioned by Dokters van de Wereld (DvdW).

⁴ DvdW recorded that 54.6 % of the undocumented migrant patients had a sub-Saharan African descent, 3.4% a European descent, 4.2 % are from Near and Middle East and 8.4% from Maghreb area, 14.3% had a Asia descent and 15.1% a Americas descent (Chauvin, et al., 2015).

Netherlands. According to Dokters van de Wereld (DvdW), in 2013 the foremost reason for being in the Netherlands was economic (36.8%), followed by political including religious, ethnic or sexual orientation related conflicts (26.3%), reuniting with family(14.9%) and to escape family conflict (12.3%)(Chauvin, *et al.*, 2015)

Undocumented persons live in an unstable and vulnerable situation and are dependent on external support. According to documentation of Médecins du Monde (MdM), in 2015 91.3% of the UMs in the European network lived below poverty threshold (Chauvin, *et al.*, 2015). UMs are not entitled to financial support from the Dutch government and have limited possibilities to find housing and employment. Many UMs live with relatives, sleep in charity homes or at their workplace. Most employment is unofficial with little assurance and high competition between employers. The jobs are often physically demanding, which has impact on their health condition (Meerens, 2006: Chauvin, Drouot, Parizot, Simonnot, Tomasino, 2007). Besides this, the earnings are often not enough for their living costs, which makes them often dependent on support of their social environment (PICUM:2010). Even though, many UMs may have unregistered jobs and a place of residence, it remains difficult to live a secure life. To illustrate this, UMs in the Netherlands can be arrested and detained in immigrant detention for no reason for a maximum period of 18 months. In addition, UMs have no access to health insurance and saving possibilities on a bank account (Staring en Aarts, 2010). UMs often have a limited social network besides their relatives and friends, who are often in the same situation. This may be partly due to limited participation in society, as a result of employment restrictions and linguistic- and cultural barriers that UMs encounter (Staring en Aarts, 2010). In need of shelter and financial resources, undocumented immigrants may engage in risk full practices. These conditions impede the possibility for UMs to escape their vulnerable position.

2.2. Health situation of UMs

There is inadequate information on the health situation of UMs compared to other population groups due to scarce health statistics and research among this population (Engbersen, *et al.*, 2002). However, it is recognized that an undocumented status has negative impact on health (Kuehne, Huschke & Bullinger, 2015). Chauvin, Parizot and Simonnot (2009) noted in their study that unhygienic living conditions and frequent house moves adversely affects physical and mental health of undocumented migrants. Specifically, health complaints related to psychological problems, such as depression and stress, (psycho) somatic complaints (i.e. high blood pressure, digestive disorders, headaches and musculoskeletal conditions) and infectious diseases are found more common among undocumented population as compared to other migrant populations and the general population (Chauvin, *et al.*, 2015: Rechel, *et al.*, 2011: Erkens and Pot, 1999). Due to limited resources, health care is often not considered the first priority among UMs (Schoevers, Loeffen, van den Muijsenbergh & Largo-Jansen, 2010). Delay in

health seeking practices leads to advanced and severe complications, and further spread of infectious diseases (Kuehne, Huschke & Bullinger, 2015; Rechel, *et al.*, 2011). For instance, a Danish study by Ehmsen, *et al* (2014) indicates that undocumented pregnant women do not seek health care till a late stage, and often do not return for infant care after birth. These conditions contribute to the poorer health status of UMs.

2.3. Health care provision for UMs in Dutch context

The Dutch health care system is based on a financing system operated by private insurance companies. All residents are required to purchase a private health insurance to be entitled to health care. However, UMs are excluded from health insurance since 1998, when the *Linkage law* came into force. The *Linkage law* is enforced with a view on tightening the immigration policies by depriving people who are not legitimate to stay in the Netherlands the right to social security, including health insurance (Veenema, Wieggers, & Deville, 2009; Biswas, Toebe, Hjern, Ascher & Nørredam, 2012). According to Entzinger and Meer (2004) 'Shielding the welfare state because of fear of abuse or overuse of the social system' elucidates the social exclusion of UMs. In this manner, citizenship is a requirement to claim rights in the Netherlands, including protection from the state and the right to participate in the political sphere (van Houdt, 2008).

Nevertheless, the universal right to health is enshrined in the Dutch constitution and applies to all people on Dutch territory. Non-discrimination is an important principle in human right and entails that health care needs to be accessible to all layers of the populations (Veenema, Wieggers & Deville, 2009). Therefore, the Dutch law guarantees medically necessary care, which is included in the basic health care package, for all UMs. According to Article 122a of the Dutch Health Insurance Act, health care providers of UMs can seek reimbursement of 80-100% of the costs of medically necessary treatment, when undocumented migrants are not financially able to pay for the costs themselves. However, not all care provided by all care institutes can be reimbursed. Emergency care costs can be reimbursed by all institutions. Yet, plannable care can only be reimbursed at institutions that have a contract with the reimbursement institute. Though, some plannable or elective care costs, such as care related to pregnancy and delivery can be reimbursed at all hospitals, including those without a contract. Dental care is only compensated for minors, and special cases (Cuadra, 2010).

The Dutch health care system arrangements with regard to health care provision for UMs limits access to care for this population, which has a tremendous impact on health. Accordingly, Kleinman and van der Geest (2009), critically note that the Dutch health care system is based on a capitalist and bureaucratic structure that undermines the moral idea of care giving. Although, in Netherlands in theory UMs are entitled to necessary health care, UMs often experience obstacles regarding access to regular health care (Chauvin, Parizot & Simonnot, 2009). This may include problems related to refusal of health care or administrative obstacles due to often

inadequate knowledge among health care providers and UM patients. There is substantial gap between the official policies and the practical experiences of undocumented migrants, health professionals and public officials, due to limited legal clarity of entitlements of undocumented migrants. Access to information and its correct distribution is fundamental. NGO's are therefore often active actors in providing and mediating health care in Europe (Chauvin, Parizot & Simonnot, 2009).

3.Theoretical framework

3.1 Process of health care seeking behaviour
3.1 Process of healthcare seeking behaviour

Healthcare seeking behaviour refers to the manner in which people actively seek care to maintain or improve their health. This may include care seeking activities at registered care providers and informal care forms, such as traditional healers or self-medication (MacKian, 2003). Individuals may consult different actors and channels during healthcare seeking practices. The healthcare seeking behaviour has influence on the personal health condition. This study aims for a full overview of healthcare seeking considerations and actions of UMs. Healthcare seeking behaviour is complex and it is important to understand underlying processes that determine healthcare seeking behaviour to ensure a tailored response to needs of UMs.

Healthcare seeking process is determined by personal considerations, that are in turn influenced by the social, economic and political context, individual characteristics and clinical factors. Currently, several theorists have developed models that aim to capture healthcare seeking behaviour of individuals. Based on the theoretical basis of these models and literature on care seeking behaviour among UMs, a theoretical model is developed and was employed in the study.

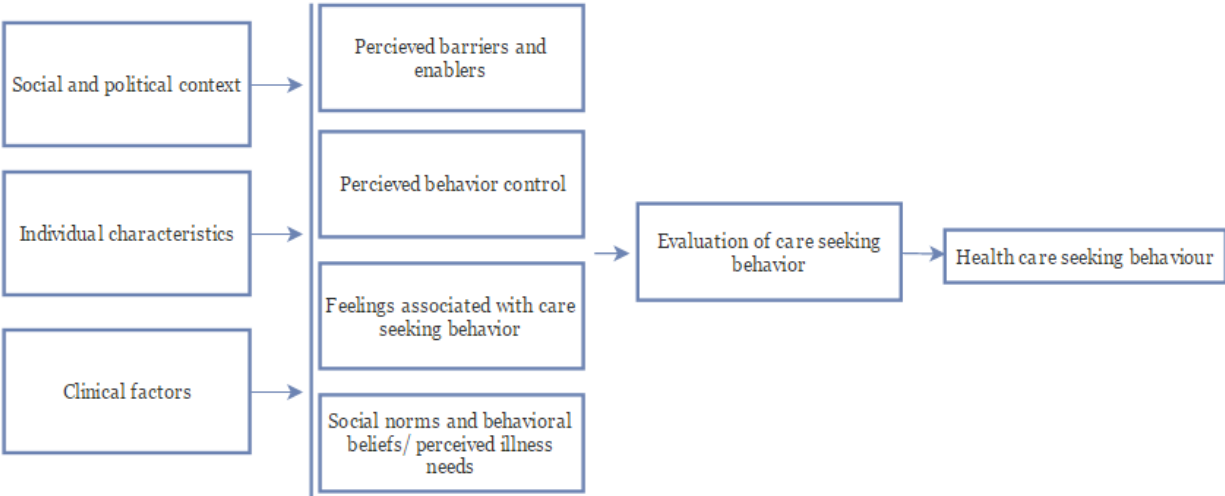


Figure 1. Healthcare seeking behaviour process and its influencing factors (developed by the author).

According to this model healthcare seeking behaviour is first of all influenced by predisposing factors; the socio-political context, individual characteristics and clinical factors. The socio-political context refers to external determinants, such as regulations, healthcare possibilities, health information distribution and the ethnic social network in the country. Individual characteristics include for instance age, educational background, employment, religiosity and country of origin. Clinical factors relate to the presence and severity of symptoms, and the history prior to the related problems. These predisposing factors, in turn, influence personal healthcare seeking considerations (Bandura, 2000; Munro, et al., 2007).

Individuals make health decisions based on different considerations. Firstly, perceived barriers and enablers, such as healthcare availability and access has influence on healthcare seeking decisions (Becker et al., 1979). Secondly, perceived behavioural control, which refers to one's ability to perform a given behaviour, also influences healthcare seeking behaviour. This is often determined by, among others, one's skills, resources and social capital (Rosenstock, Strecher, & Becker, 1988; Strecher & Rosenstock, 1997; Munro et al., 2007). Thirdly, feelings associated with care influences healthcare intentions. This may include emotions, such as shame, insecurity or fear. Emotions may be induced by past experiences or by someone's familiarity with healthcare practices. Thereby expected outcomes may as well trigger certain emotions towards healthcare practice (Gebhardt & Maes, 2001; Stroebe, 2000). In turn, expectations are as well influenced by social norms and beliefs. Social norms and beliefs within a community are identified as the last influencing factors. Norms and beliefs, including cultural meanings, with regard to health and care determines the accepted healthcare behaviour, which in turn shapes personal perceived healthcare needs and healthcare seeking practices (Ajzen, 1991). Finally, based on these different factors individuals evaluate healthcare possibilities and decide upon healthcare behaviours. This conceptual model does not exclude multiple different healthcare seeking actions in healthcare seeking behaviour.

4. Research design and methodology.

4.1 Research approach

The proposed research is exploratory and involves different phases. The following methods will be included: a literature search, participatory observation, in-depth semi-structured interviews and focus group discussions. Although, the phases are described in a linear manner, the study adopts an emergent design, as processes occur within the research phases. Specific, indicators, stakeholders and instruments will occur during the research process. Accordingly, issues addressed by the target population will guide the research. The combination of activities will enable an in-depth understanding of the issue and a solid basis for recommendations for health promoting programs.

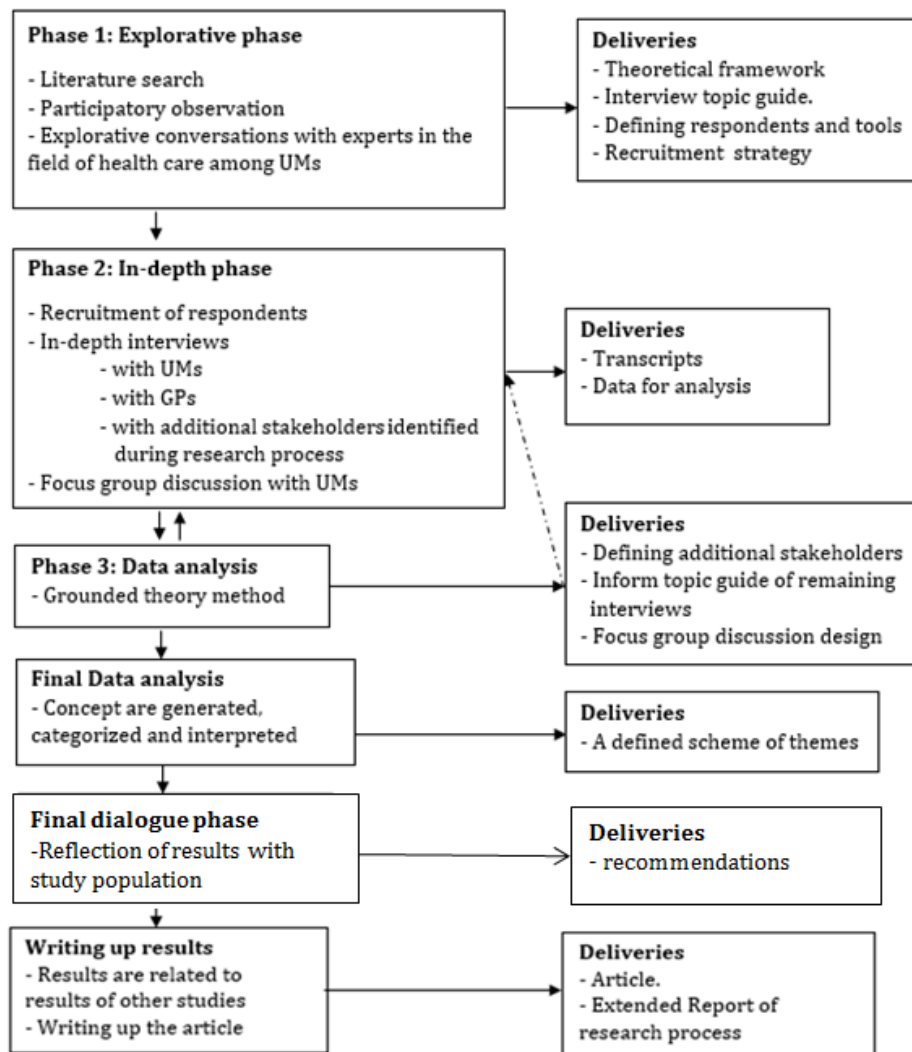


Figure 2. Research process graphic

4.2 Methodology

4.2.1 Phase 1: exploratory phase

The study will start with a literature search, participatory observation at DvdW and explorative conversations with experts in the field of health care among UMs. This will aid gaining an overview on the available research in relation to the topic, help defining the conceptual model and yield appropriate indicators for data collection and recruitment strategies. The literature search will cover a variety of literature types, including technical literature (i.e current guidelines for health care provision among undocumented migrants), grey literature and academic articles addressing health, health provision and health seeking behaviour among UMs. Explorative informal conversation will be conducted with members of DvdW to gain practical knowledge on health care for UMs. This organization is an international NGO, which among other things, aims at making health care accessible for vulnerable populations. Participatory observations will be conducted at consultation hours, help desk activities and outreach activities

in Amsterdam centre, Amsterdam South-East and The Hague. By means of these activities DvdW provides information on medical issues and possibilities of receiving health for UMs. In addition, during these activities DvdW mediates in events of problems with access to regular healthcare.

4.2.2 Phase 2: in-depth study

This stage entails in-depth semi-structured interviews and focus group discussions with initially UMs and structured interviews with General Practitioners (GPs). In context of this study, the combination of in-depth interviews and focus group discussions tools with UMs will generate the opportunity to explore thoughts and experiences of both individuals and groups, which will aid gaining further understanding of their health care seeking behaviour. Results from the in-depth interviews will inform focus group discussions design. Through interviews with GPs knowledge will be gained on their experiences in relation to health care provision for UMs. GPs, whose referral is key to access the entire health system, are considered important stakeholders in determining access to care and subsequently influencing the health care seeking practices of UMs. Interviews with GPs will provide full insight into the context of health seeking practices of UMs. Based on the interviews and focus group discussion additional stakeholders may be included in the study.

4.2.2.1 Recruitment strategy

Preliminary identified participants will be first generation UMs, aged 18 or above. Respondents will initially be recruited in Amsterdam and The Hague, according to purposive sampling method. To come in contact with UMs is challenging due to their living situation and their attitude towards reporting personal information. In this study various support organizations and migrant organizations that maintain structural contact with UMs will be consulted. In specific, DvdW will provide an entry to recruit respondents. By means of a database, in which DvdW keeps track of their clients, respondents can be purposively selected. This manner ensures a diverse and more representative sample, including diversity in sex, age, nationality and length of stay in the Netherlands. This study aims to include the most common nationalities⁵ of undocumented migrants in the Netherlands and represent the population in age and sex. Research indicated that nearly one third of the undocumented migrants are men (71%) and have an age below forty (78%) (van der Heijden, Cruyff & van Gils, 2015). Snow ball sampling method will be adopted to recruit respondents that are not engaged with support organisations. It is expected that their health care seeking practices may differ from those receiving support in

⁵ Due to the nature of the undocumented migrant population it is impossible to have an exact insight into the distribution of nationalities. According to a report of *Zorginstituut Nederland (2015)*, the following nationalities were most common in receiving medication in 2014: Ghana, Nigeria, Suriname, Morocco, Brazil, China, Sierra Leone, Turkey, Somalia and Iraq. This study is aware of the limitations basing the distribution of nationalities on medicine claims. Nevertheless, it provides an indication of the most common nationalities in the Netherlands.

reaching health care. In total fifteen interviews with UMs will be conducted. Respondents for the focus group discussions will mainly be recruited through religious and migrants organisation. This study aims to identify existing groups for focus group participation. Although members of an existing groups may be more subjected to social rules, this study expects the respondents may feel more at ease when being familiar with each other (Boulton, 1994). This study proposes to conduct four focus group discussions.

GPs, without regard to their experience with undocumented patient, will be recruited through purpose sampling and snowball sampling. Firstly, by attending conferences for health care providers this study aims for establishing contact with GPs. Secondly, GPs will be recruited through the network of DvdW and visiting various health care centres⁶. This study aims to conduct five interviews with GPs.

4.2.2.2 Ethics

UMs live an insecure life in which they are often confronted with situations that are perceived threatening to them. This population group is not able to claim their rights and they face the possibility of being denounced to authorities. Within this study effort will be made to ensure participants understand the voluntary and anonymous nature of the study. Written informed consent will be obtained from the undocumented participants⁷. Among GPs verbal informed consent will be obtained due to expected time constrains.

4.2.2.3 In-depth interviews

The semi-structured interviews will be guided by an interview topic list, which is developed by the researcher in consultations with members of DvdW. The aim of the interviews with UMs is to capture personal narratives with regard to the following topics: general living conditions, perceived health, health care seeking practices, health care seeking motives, experiences and expectation of care practices, and factors influencing health care seeking considerations. Additional to the theme list, sociodemographic questions are included⁸. Details of the interview topic guide is demonstrated in Box 1. The interview was semi-structured in nature, allowing for flexible exploration of topics addressed by the respondent. The interviews will have a duration of approximately one hour and will be conducted by one interviewee. Interviews with GPs will address the following topics: experiences with care provision, communication and administrative, knowledge on health care regulations for UMs, living situation of the UMs and alternative health practices among UMs. The interviews with GPs will have a maximum duration of thirty minutes and will be conducted by two interviewees⁹. During the interview process

important issues may be addressed by the respondents, which will subsequently be included in the following interview guide.

Box 1. Topic guide: in-depth interview with UMs and GPs	
<i>Interview with UM</i> Demographic features	<ul style="list-style-type: none"> - Age - Nationality - Migration history - Education/employment - Living condition - Social network (e.g. family/friends)
Perceived health	<ul style="list-style-type: none"> - Feel about one's health (health problems (current/past)) - Factors affecting one's health - Control over one's health
Health care seeking process	<ul style="list-style-type: none"> - Response to first symptoms - Time interval consulting care - Social contact in health seeking process - Forms of care consulted - Motives behind health seeking behaviour
Health care seeking experiences	<ul style="list-style-type: none"> - Attitude towards care practice - Expectations of care practice - Satisfaction of care practice
Usual practices	<ul style="list-style-type: none"> - Previous care practices in the Netherlands - Previous care practices in home country - Health seeking practices of social environment
Perceived behavioural control	<ul style="list-style-type: none"> - Comfortability seeking health care - Ability to find needed care
<i>Interview with GP</i>	<ul style="list-style-type: none"> - Practice procedures regarding care giving to UMs - Experiences with health care provision to UMs - Lifestyle of UMs - Health situation and health needs of UMs

4.2.2.4 Focus group discussion

Focus group discussions will be adopted to explore social, cultural and political influences on health care seeking behaviour among UMs. Sociologists have proven the importance of networks in shaping individuals' behaviour (Scott & Carrington, 2011; Gochman, 2013). By observing interactions between participants in focus group discussions, the social context influencing health care seeking behaviour can be better understood. In this manner, this study moves away from the conceptualization of health care seeking behaviour as the product of an individual decision. Within the focus groups different health seeking practices and motives will be discussed. Thereby, topics addressed in the interviews can be confirmed and discussed more broadly. In addition, there is aimed at actively involving the participants by consulting their experiences and recommendations. They possess expertise with regard to their unique personal experiences (e.g. disease, recovery knowledge, skills) and their social environment, which provides a solid evaluation of the current situation and aids defining the needs of the

undocumented population. The focus group discussions will be held in an informal context and will have a duration of around 60 minutes¹⁰.

4.2.3. Phase 3: integration and analysing of results

The interviews and focus group discussions will be recorded and transcribed verbatim in the same language as the interview. The analysis will be conducted according to the grounded theory method. The analyses will be established in different phases. Firstly, the first conducted interviews will be read and re-read to gain an overall impression of the data. Subsequently, the interviews are analysed line by line and coded. Material gained from this first analysis informs the design of the following interviews, which will be analysed in the same manner and in turn informs the remaining interviews and the focus group discussions design (Figure 2).

Accordingly, new issues that are raised by respondents will be included in the interviews guide. Eventually, a list of concepts will be generated and interpreted in collaboration with team members of DvdW. Subsequently, the concepts will be categorised into a more defined scheme by relating different themes that appear. Lastly, the results are related to results from other studies.

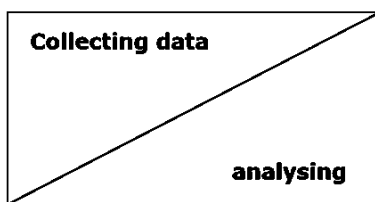


Figure 3. The data collection and analysis will be established in a parallel manner. According to this method, the analysis of the initial data will inform the remaining data collection (i.e tools, indicators, respondents).

4.2.4 Final dialogue phase

To ensure well informed recommendation and increase empowerment among the study population a feedback meeting with UMs is organized to reflect on the results of the study.

4.4. Possible limitations this research needs to overcome

First of all, my position as an intern at DvdW may influence respondents in their disclosure of information. DvdW mediates between UM client and care providers in the regular health care sector. Yet, this research not solely focuses on the regular health care utilization, but aims to gain an overview of the full illness response, including alternative forms of care and healing.

Respondents may tend to narrow their answers due to the assumption that alternative forms of healing is not of interest for the organization. To overcome this limitation, the purpose of the

interview will be well emphasised by providing a clear introduction. In addition, it is expected that being a member of DvdW brings feelings of trust among the respondents, which aid recruiting respondents and creating an environment in which the respondent feels at ease to speak freely.

Secondly, related to my position as an intern at DvdW, I expect that the respondents have expectations with regard to aid with medical problems. It is important to clearly inform about my non-medical background and purpose of the study to guide the interview in a favourable direction and prevent a change of focus. In addition, when questions regarding health problems may arise, the respondent is made attentive on the purpose of the interview and directed to the consultation hours at DvdW.

Thirdly, this research may be subjected to a number of practical issues. It is expected that planning appointments with the respondents may come with difficulties due to their irregular lifestyle. Besides this, communication difficulties may hamper setting appointments as well. Nevertheless, this process illustrates the difficulties UMs face when engaging in the Dutch health care system and may therefor provide valid data. To ensure a proper process, the respondents will receive a confirmation call on the day of the interview or day before depending on the time of the interview.

Linguistic and other communication barriers are also expected to arise when conducting the interviews. Interpretation frames may be different leading to misunderstanding between interviewee and respondent. Thereby, speaking about health issues in another language than the first language may hamper understanding from both sides. Being aware of these difficulties, I aim to overcome this by being patient, ask for further explanation and repeat the answer in my own understanding for confirmation. Thereby, the interviews and informed consent will adopt common language to ensure sound understanding. An interpreter is employed when the respondent in question does not speak Dutch or English sufficiently. Initially, inquiries will be made whether the respondent in question knows someone that can accompany to translate. This study is aware of the potential response bias due to the presence of an informal translator. When this appears to be by no means possible, the network of DvdW will be consulted.

Recruiting respondents through migrant organisations is accompanied by complex communication and approaching methods. According to a research conducted by The association of National Undocumented Support (Stichting Landelijk Ongedocumenteerde Steunpunt (LOS) (2011), migrant organisations are often wary in revealing their contacts with UMs and disclosing information to official institutions. This is often induced by fear of losing allowances from the government when their support for UMs is exposed. Besides this, previous experiences have learned that migrant organisation often encounter 'data grabbing' practices by research projects, in which solely one party profits from the relationship. Thereby, migrant

organisations are difficult to reach, as they are often self-organised and not public (LOS, 2011). To overcome these barriers, the work of DvdW will first of all be explained explicitly. Secondly, in combination with the focus group discussion, an educative presentation on access to care will be provided after the focus group discussion, to ensure a mutual relationship. Thereby the relationship with the migrant organisation will be maintained within DvdW for further collaboration.

Lastly, due to the heterogeneous nature of the UM group, making generalisations about health seeking practices is not feasible. Thereby, the respondents are recruited solely in Amsterdam and Den Hague which withholds making claims about a National level. Social structures regarding support organisation, migrant organisations and ethnic network may differ between cities. Nevertheless, it is expected that the findings of this study may as well account for other sites in the Netherlands. Furthermore, this is an explorative study that does not aim to make general claims about health seeking behaviour among UMs. The purpose of this study is merely to gain insight into the different practices and its determinants.

Reference

- Ajzen, I. (1991). The theory of planned behavior. *Organizational Behaviour and Social Human Decision Processes*, 50, 179-211.
- Asbury, J. E. (1995). Overview of focus group research. *Qualitative health research*, 5(4), 414-420.
- Bandura, A. (2000). Health promotion from the perspective of social cognitive theory. In P. Norman, C. Abraham & M. Conner (Eds.), *Understanding and changing health behaviour: from health belief to self-regulation* (pp. 299-339). Amsterdam: Harwood Academic.
- Becker, M. H. (1974). The health belief model and sick-role behaviour. *Health Education Monographs*, 2, 409-419.
- Biswas, D., Toebes, B., Hjern, A., Ascher, H., & Nørredam, M. (2012). Access to health care for UMs from a human rights perspective: A comparative study of Denmark, Sweden and the Netherlands. *health and human rights*, 14(2).
- Boulton, M. (1994). *Challenge and innovation: methodological advances in social research on HIV/AIDS*. Taylor & Francis.
- Chauvin, P., Parizot, I., Drouot, N., Tomasino, A., & Simonnot, N. (2007). European survey on UM's access to health care.
- Chauvin, P., Parizot, I., & Simonnot, N. (2009). Access to healthcare for UMs in 11 European countries. Médecins du Monde European observatory on access to healthcare. *M'edecins du Monde*.
- Chauvin, P., Simonnot, N., Vanbiervliet, F., Vicart, M., Vuillermoz, C. (2015). Access to Health Care for people facing multiple health vulnerabilities: obstacles in access to care for children and pregnant women. Médecins du monde International Network
- Cuadra, C. B. (2010). Policies on Health Care for UMs in EU27. Country Report UK, MIM/Health and Society.
- Dwyer, J. (2004). Illegal immigrants, health care, and social responsibility. *Hastings Center Report*, 34(1), 34-41.
- Ehmsen, B. K., Biswas, D., Jensen, N. K., Krasnik, A., & Norredam, M. (2014). UMs have diverse health problems. *Danish medical journal*, 61(9), 1-4.
- Engbersen, G., Staring, R., van der Leun, J., de Boom, J., van der Heijden, P., & Cruijff, M. (2002). Illegale vreemdelingen in Nederland: omvang, overkomst, verblijf en uitzetting.
- Entzinger, H., & Van der Meer, J. (2004). Grenzeloze solidariteit. *Amsterdam: De Balie*.
- Gochman, D. S. (Ed.). (2013). *Handbook of health behavior research II: Provider determinants*. Springer Science & Business Media.
- Gonzalez, L. (2008). *Health-care seeking behaviors of Puerto Ricans with diabetes mellitus who live in South Florida: an exploratory study*. University of Central Florida.
- Grit, K., den Otter, J., & Spreij, A. (2011). Access to health care for UMs: a comparative policy analysis of England and the Netherlands. *Journal of health politics, policy and law*, 1496011.

- van Houdt, F. (2008). Citizenship as an instrument of bio-power: Identifying changes in the functioning of citizenship in the Netherlands in Times of Glocalization and Culturistic Discourse. In *Inclusion and Exclusion in Contemporary European Societies Conference*, April (Vol. 14).
- van der Heijden, P. G., Cruyff, M. J. L. F., & van Gils, G. (2015). Schattingen illegaal in Nederland verblijvende vreemdelingen 2012-2013:(in opdracht van Ministerie van Veiligheid en Justitie).
- MacKian, S. (2003). A review of health seeking behaviour: problems and prospects. *Health Systems Development Programme*.
- Meerens. B. (2006). *Onverzekerde zorgen*. Amsterdam: University van Amsterdam
- Kleinman, A., S. van der Geest (2009) "'Care' in health care. Remaking the moral world of medicine". *Medische Antropologie*. 21(1): 159-168
- Krueger, R. A., & Casey, M. A. (2014). *Focus groups: A practical guide for applied research*. Sage publications.
- Kuehne, A., Huschke, S., & Bullinger, M. (2015). Subjective health of UMs in Germany—a mixed methods approach. *BMC public health*, 15(1), 1.
- Morgan, D. L. (1992). Designing focus group research. *Tools for primary care research*, 2, 177-93.
- Stichting Landelijk Ongedocumenteerden Steunpunt (LOS) (2011). Verantwoording van het project Migrantengroepen en ongedocumenteerde hulpvragers. Eindrapportage Migrantengroepen en ongedocumenteerde hulpvragers. Retrieved from <http://www.stichtinglos.nl/content/projecten> (accessed 5 April, 2016)
- Munro, S., Lewin, S., Swart, T., & Volmink, J. (2007). A review of health behaviour theories: how useful are these for developing interventions to promote long-term medication adherence for TB and HIV/AIDS? *BMC Public Health*, 7, 104.
- Van Oostrum, I. E., Goosen, S., Uitenbroek, D. G., Koppenaal, H., & Stronks, K. (2011). Mortality and causes of death among asylum seekers in the Netherlands, 2002–2005. *Journal of epidemiology and community health*, 65(4), 376-383.
- PICUM (2010) Country Report The Netherlands, Workpackage No. 6 : The Voice of UMs from Migration and Health in Nowhereland.
- Rechel, B., Mladovsky, P., Devillé, W., Rijks, B., Petrova-Benedict, R., & McKee, M. (2011). *Migration and health in the European Union*. Mc Graw-Hill Education (UK)
- Rodríguez, M. A., Bustamante, A. V., & Ang, A. (2009). Perceived quality of care, receipt of preventive care, and usual source of health care among undocumented and other Latinos. *Journal of general internal medicine*, 24(3), 508-513.
- Rosenstock, I. M., Strecher, V. J., & Becker, M. H. (1988). Social learning theory and the health belief model. *Health education Quarterly*, 15, 175-183.
- Schoevers, M. A., Loeffen, M. J., van den Muijsenbergh, M. E., & Lagro-Janssen, A. L. (2010). Health care utilisation and problems in accessing health care of female undocumented immigrants in the Netherlands. *International journal of public health*, 55(5), 421-428
- Scott, J., & Carrington, P. J. (2011). *The SAGE handbook of social network analysis*. SAGE publications.

Staring, R., & Aarts, J. (2010). Jong en illegaal in Nederland: Een beschrijvende studie naar de komst en het verblijf van onrechtmatig verblijvende (voormalige) alleenstaande minderjarige vreemdelingen en hun visie op de toekomst.

Strecher, V., & Rosenstock, I. (1997). The health belief model. In A. Baum, S. Newman, J. Weinman, R. West & C. McManus (Eds.), *Cambridge handbook of psychology, health and medicine* (pp. 113-116). Cambridge: Cambridge University Press.

Stroebe, W. (2000). *Social psychology and health* (2nd ed.). Buntingford: Open University Press

Veenema, T., Wiegers, T., & Deville, W. (2009). *Toegankelijkheid van gezondheidszorg voor 'illegalen' in Nederland: een update*. Nivel.

World Health Organisation (WHO). (2003). International Migration, Health & Human Rights. In *Health & Human Rights Publication Series Issue No.4*

Zorg Instituut Nederland. (2015). 9e monitor Regeling financiering zorg onverzekerbare vreemdelingen. Retrieved from:
<https://www.zorginstituutnederland.nl/binaries/content/documents/zinl-www/documenten/publicaties/rapporten-en-standpunten/2015/1510-9e-monitor-regeling-financiering-zorg-onverzekerbare-vreemdelingen/9e+monitor+Regeling+financiering+zorg+onverzekerbare+vreemdelingen.pdf>