

# Seeking Health below the Radar: Undocumented People's access to healthcare in Two Dutch Cities

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## Abstract

This study sought answers to a puzzling paradox. Generally, formal legal health care rights for undocumented people in The Netherlands are relatively good, with some exceptions (like dentistry and mental health). Despite this, many undocumented people were found only to access health care services in the case of an emergency, and sometimes not even then. Why were undocumented people not fully making use of their legal rights to access health care? Was it due to discrimination? A lack of information? Or some other deterrents? This article presents findings from a project entitled: "Count Us In": Towards Realising Health Rights among Undocumented People in Two Dutch Global Cities", funded by the Rotterdam Global Health Initiative (RGHI). Using the Participatory Ethnographic Evaluation and Research (PEER) methodology, research was conducted in The Hague and Rotterdam between 2012 and 2015. The study found that those in work or socially embedded in support networks or NGOs, were more likely to claim their health rights in practice. Rejected asylum seekers, more isolated on the whole, tended to access health care only in extreme situations or emergencies. Both groups reported self-medication, which was found to be quite common. We also found that undocumented people exclude themselves from health care services, for fear of being detected, detained and even deported. We conclude with some modest suggestions to ensure that the future.

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*"The biggest wish is to get a residence permit. All misery comes from the lack thereof"* (interview Bernard (not real name) asylum-seeker from Guinea) (D46).<sup>1</sup>

*"My medicines are my wife"* (D01).<sup>2</sup>

### 1. Introduction

This study addresses a puzzling problem. Whilst formal legal health rights of 'undocumented' people in The Netherlands are relatively good, a range of research, which we consider here, suggests that significant numbers of undocumented people do not access the health care services to which they are entitled under law. One study on unaccompanied migrant children's health care in the Netherlands, by Staring and Aarts, reported that some undocumented children, especially those with mental health problems, were not having their health needs met (Staring and Aarts 2010: 156-161). Among the undocumented children they interviewed, for those who had serious psychological problems, these were compounded by difficulties accessing mental health care in the Netherlands. In spite of family, NGO and peer support, significant numbers of young undocumented people with serious psychological problems did not visit Dutch healthcare providers. Their main reason was their fear of being identified (Staring and Aarts 2010: 161). In 2012 the Dutch NGO, Dokters van de Wereld (Doctors of the World), estimated that almost one third (29%) of undocumented migrants in the Netherlands, did not receive the 'medically necessary' health care to which they were entitled (in Biswas et al 2012: 54). For undocumented adults also, these findings were confirmed by a 2013 Ombudsman Report on Asylum Seekers and Failed Asylum Seeker's access to health care, which found evidence that undocumented people avoided presenting themselves to medical care providers when ill, and would usually do so only in an emergency (De Nationale Ombudsman 2013). Another excellent study, by Pharos, documented in detail the problems with health care of failed asylum seekers in detention centres in The Netherlands (Pharos 2013).

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<sup>1</sup> These codes refer to the unique primary document in ATLAS.ti. All interviews were coded thematically as well as open.

<sup>2</sup> Omit. (Mijn medicijnen zijn mijn vrouw), Ali Z. born 20.11.1970 (Algerian) sought asylum October 1993 in The Netherlands; undocumented since 1999, imprisoned 2 months in 2006, and for a year 2011-2012.

This evidence corroborates the problem – undocumented people are not receiving and sometimes not seeking the health care services they are legally entitled to (Biswas et al 2012: 52). Even though formally speaking, Dutch law provides for ‘medically necessary’ health care for undocumented people, undocumented respondents in The Netherlands fail to benefit from these laws as much as might be expected. For instance, another study showed that compared with the situation in Belgium, undocumented people in The Netherlands were twice as likely to be excluded from health care through various forms of socio-economic violence. This is despite the legislation on undocumented people’s health rights in The Netherlands being more protective, on paper, than in Belgium (van Ginneken and Gray 2013: 347).

The study seeks to address one simple question: Why do undocumented people not manage to exercise their formal legal rights to ‘medically necessary’ health care, as defined in Dutch law? Is it because they are not informed of their legal rights? Is it because of their “fear of having to pay the bill” (Biswas et al: 53)? Or is it, as some studies suggest, more complicated. Could it be due to the fear of being detected through contact with health care institutions and providers? Could it be that health care providers discriminate or neglect undocumented migrants, because of prejudice or lack of being informed about the law (Biswas et al 2012)?

We explore all these possible explanations of why significant numbers of undocumented people are not receiving the health care service they are formally entitled to under Dutch law. Some problems are institutional, for example in relation to the national vaccination program. As has been reported, undocumented children who are not formally registered at the municipality, do not receive invitations to be inoculated, even though such children are legally entitled to free vaccinations under government schemes (Biswas et al 2012). There is some evidence of heavy pressure on a few doctors, GPs and other health care providers who treat undocumented people without filtering them out, which implies that other GPs, hospitals and clinics filter out or discriminate against the undocumented.

We use the term ‘undocumented’ quite broadly, to denote migrants who have entered irregularly, have failed their asylum claims, or have over-stayed after entering legally (Merlino and Parkin 2011: 3). Other terms like clandestine, unauthorized, irregular or illegal seem to blame those without legal status for their own predicament, so we prefer the term undocumented. In this study, we seek insights from undocumented people in particular, and focus on two Dutch ‘global cities’ - The Hague and Rotterdam. Based on a project funded by Rotterdam Global Health Initiative, entitled “Count Us

In: 'Towards Realising Health Rights among Undocumented People in Two Dutch Global Cities', this is our first discussion in print of an experimental pilot study conducted in 2012-15. The findings draw on almost sixty interviews with around fifty undocumented men and women, interviews conducted by a team of mostly undocumented researchers trained in the PEER (Participatory Ethnographic and Evaluation Research) methodology. The PEER approach is described in the third part of this article.

The 'liminal' status of undocumented people can be connected with the problem of their not effectively gaining access to health care. For this reason, we briefly discuss the question of liminality in the next section. We then explain how PEER methodologies were translated into practice in The Hague and Rotterdam contexts, before reporting on our findings from PEER interviews, regarding undocumented people in our sample, their health needs, their health-seeking behavior and their experiences of contacts with health-care providers. Issues arise including question of the 'knowledge and information about rights', and 'fear of detection' of undocumented people, and problems of 'racist and discriminatory attitudes' among health care service providers. Towards the end of the article, we also consider some examples of good practice.

## **2. Health Rights and Liminality: theorizing the Gap**

As a general principle, our starting point is that key principles of global health justice apply also to undocumented people, and also in The Netherlands. Effective access to health care should be possible for everyone in society, and only in this way can basic human rights to decent health be fulfilled. The International Covenant on Economic, Social and Cultural Rights (ICESCR), for example, stipulates that healthcare services should be accessible to everyone living within the jurisdiction of a state, without discrimination on any basis whatsoever, including on the basis of a person's legal status (Biswas et al. 2012: 54-56). The "right to protection of health" is also included in Article 11 of the (Revised) European Social Charter (Revised ESC). Like Article 12 of the ICESCR, this applies to all EU residents, whether legally resident or not. Article 24 of the Convention on the Rights of the Child (CRC) further grants: "...all women and children a right to health, without regard to legal status". Furthermore, these provisions are in line with:

"International human rights law recognizes that a right to health benefits everyone residing in a state's territory. Thus, undocumented migrants have a right to health care on a non-discriminatory basis. [...] In the Netherlands, undocumented migrants have access to a wider range of health care services; therefore, the Netherlands is, in principle, meeting its international obligations (Biswas et al 2012: 55)."

International norms are thus reasonably well reflected in provisions of Dutch law, and this implies that in The Netherlands, undocumented people do have a recognized right to ‘medically necessary’ healthcare. Unfortunately, detailed information about undocumented people’s health is no longer being collected, collated or disseminated in The Netherlands. This reinforces the marginality and liminality of undocumented people’s status in Dutch society. Since 2015, data estimating the number of undocumented people in The Netherlands, no longer seems to be available, indicating that researchers or perhaps the Dutch government may no longer wish to have this information publicly known or at least presented in an accessible form (. This also means that the health conditions and questions of access of the undocumented population will come to be unknown or un surveilled, raising issues of how to advocate for better health care for the undocumented (Hintjens 2013). The lack of data testifies to a certain officially-sanctioned neglect, a sense of which was in part what motivated us to carry out the study on which this article was based. Since data is not sought, collated, disaggregated or disseminated, this reflects the low priority and liminal status of undocumented people, who in recent years have been pushed even further down ‘below the radar’ of health care planning and provision.

Liminality, as defined by Victor Turner, can help to explain undocumented people’s fear of the authorities, since:

“The attributes of liminality or of liminal *personae* (‘threshold people’) are...neither here nor there...betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial” (Turner, 1969: 95; see also Jackson, 2005: 333).<sup>3</sup>

Fears of being detected, of being reported by medical staff, are all possible factors explaining the reluctance to access health care service providers. Being confined ‘to the margins’, and excluded from full entitlement, undocumented people feel, in Arendt’s words, they do not have ‘the right to have rights’ (Babha 2009). Living liminally, out of sight, they find it difficult to present themselves, and to assert their rights to medical treatment.

Fearing the authorities, and even experiencing paranoia, need not be irrational emotions when immigration police can legally turn up at your door one morning, ‘catch’ you, detain and deport you.

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<sup>3</sup> In-text citation: Victor Turner (1969). *Liminality and Communitas*. In *The Ritual Process*. Pp. 94- 130. Ithaca, NY: Cornell University Press, p. 95 cited in Jean E. Jackson (2005) “Stigma, Liminality and Chronic Pain: Mind-Body Borderlands”, *American Ethnologist*, Vol. 32, No. 3: 332-353, p. 333.

When you live under such conditions, fear can play a debilitating role in people's daily lives. Its negative effects can spill and become an obstacle to accessing health care services. Like many EU governments, the Dutch government has sought to make undocumented status a criminal offence. This reinforces distrust and fear among undocumented people whose perspective is that public institutions of all kinds can be used to detect and apprehend them. Strongly 'deterrent' public policy approaches may even lead some health care providers to feel that undocumented people are 'undeserving'.

Overall, liminal status encourages some undocumented people to exclude themselves from accessing health care provision. Examples presented later in the article draw on our findings, confirming what previous studies have shown, namely that undocumented people's fear deters many from seeking health care or redress even in situations where they may very much in need. Under such conditions, their main priority will be to avoid contacts which could lead to detection and being 'flushed out' from below the radar. Many undocumented people living in Dutch cities keep a fairly low profile, and are quite cautious in extending trust to others (Staring & Aarts, 2010).

The number of undocumented non-European migrants in The Netherlands has been estimated at around 41,835 in 2009, with lower and higher estimates of between 20,654 and 63,015 (Heijden et al, 2011). According to a more recent estimate for July 2012 to July 2013, the estimates varied from 22,881 undocumented people to 48,179, an average of 35.530. If these figures are at all accurate, this trend represented a decline in the number of people living without legal status in the country, of around fifteen percent (Heijden et al 2015: ii; Heijden et al 2006: 12). However, one advocacy NGO, LOS (Landelijke Ongedocumenteerde Stichting – National Association of the Undocumented) estimates that the true figure in 2015 was as high as 100,000, so it is not even clear if the numbers of undocumented has been falling or growing.

According to the most recent estimation based on the 'capture recapture method' the number of undocumented migrants living in the Rotterdam area is estimated at 7,547, and in The Hague the number is estimated at 3,188 (Heijden et al, 2015: 1). Irrespective of the precise numbers, this study considers the relationship between undocumented migrants' health and the health-care providing institutions, in practice rather than in theory. We did not seek to obtain a representative sample of undocumented migrants in the two cities of The Hague and Rotterdam. Instead we sought the perspective of around fifty undocumented men and women. They spoke to two teams of PEER interviewers, trained on the basis of an approach we now briefly account for.

### **3. Justifying the PEER Approach**

By integrating qualitative, ethnographic and trust-based interviewing, the PEER approach has been used as a methodological tool before in migration research, especially in relation to undocumented people (Crawley, Hennings and Price 2011; Hintjens and Guemar 2012). The PEER approach was specifically selected for this study because of its potential for generating valid and previously unknown data about various ‘invisibilised’ groups of people, in a liminal position. Perhaps the most fundamental idea of the PEER methodology, as used in this study, is the idea of trust. Price and Hawkins, explain that the PEER approach is an:

“...ethnographic approach used by anthropologists [which] is based on the premise that what people say about social life and behaviour changes according to the level of familiarity and trust established between the researcher and researched” (Price & Hawkins, 2002: 1328).

In the best tradition of action research, this approach simultaneously brings undocumented migrants’ own issues into the research agenda and raises awareness among professionals of undocumented people’s situation, their problems and the solutions they propose. When it works well, the PEER approach can create a participatory and valid data base that can inform future healthcare decisions affecting undocumented migrants.

An atmosphere of trust is arguably vital to any successful qualitative research. What was significant in this study was that most PEER-trained researchers, who were all volunteers, were undocumented themselves. A couple had worked with undocumented people. The PEER researchers in The Hague and Rotterdam brought their own understandings of the significance of interview data to both the interview process and the analysis of findings. We are very much indebted to them for their interviewing skills, their hard work and for sharing their insights with us. Under different circumstances, we would have liked to include them all as co-authors. Given the need to protect their confidentiality, this proved impossible.

In the past, the PEER method has been used for monitoring, for example by DFID (the UK Department for International Development) in Nepal (Rolfe, 2006). Researchers who pioneered the PEER approach hoped to get: ‘...beyond the surface’ of sensitive issues, especially in relation to health (Price and Hawkins 2002). Most PEER studies have focused on liminal and stigmatised social groups, who may be vilified or ignored by the wider society, such as HIV/AIDS sufferers, Roma in Europe, sex workers, refugees and undocumented people as well as a range of other controversial topics London (Hawkins, Nsengiyuma & Williamson, 2005; Price and Hawkins 2002; Norman,

Hemmings, Hussein & Otoo-Oyortey, 2009; Hintjens and Guemar 2012). For stigmatized or vulnerable groups, PEER methods based on trust can mitigate the likely overwhelming power imbalances between researchers and interviewees. In this way, the PEER approach can lower risks of skewed responses, and can make frank disclosure more likely (Cunningham and Diversi 2012).

Originally, we had hoped to combine qualitative and quantitative elements in one set of questions (Tashakkori and Creswell, 2007: 207). In the end, the data actually gathered by our PEER researchers was almost entirely qualitative, reflecting the informality and trust-based quality of most of the interviews (Price and Hawkins, 2002: 1329). In other migration-related PEER studies, what comes across is the quality of the interviews, and how frankly people speak about issues that concern them. As the authors of one report claim:

“...tapping into established relationships of trust between peer researchers and their friends, PEER rapidly generates rich narrative data that provide insight into how people view their world, conceptualise their behaviour and experiences, and make decisions on key issues” (Crawley, Hemmings and Price 2011: 12-13).

In our study too, some new and revealing insights emerged from the PEER interviews. Crucial to making this approach work, were the training events. We brought together two teams of PEER researchers, one in each city, most of whom were undocumented. The following description fits our PEER training workshops quite well:

During the workshop, the peer researchers spent time...defining their own research questions based on what they considered to be the most important issues. The peer researchers also developed interviewing skills, and practised introducing the study to potential participants and asking for their informed consent to participate (Crawley, Hemmings and Price 2011: 13).

Through role play and group reflection, the PEER researchers we worked with learned how to conduct non-directive interviews, how to make interviewees feel comfortable and informed, and the importance of maximizing trust and open-ended question. It was agreed with PEER researchers that they would seek information about (a) undocumented women and men’s perceived health issues; (b) their health-seeking behavior; (c) obstacles experienced in seeking healthcare, and (d) how health care services could be improved. Some simple questions formulated with the first group of PEER researchers in The Hague, in an August 2013 workshop were first tested out through role plays during the training. Finally, agreed questions about undocumented people’s general situation, and



their specific health situation and health needs, were reworked with PEER researchers, the trainer Joanne Hemmings, and the three of us. The final questions used for the interviews are provided in [Appendix 1](#).

The questions and a 12-page guideline for PEER researchers were then translated into French, Dutch, English, Spanish, Chinese and Portuguese. The questions were translated into Indonesian Bahasa. All questions were designed as semi-structured and non-directive, and interviews lasted from 15 to 45 minutes. Compared with more usual structured interviews, the findings of the PEER interviews, described in more detail later in this article, were intended to dig deep for narratives and stories that might usually remain hidden to outsider social researchers (see Guemar and Hintjens, 2012: 2 for more on the PEER methodology). We thus hoped new insights and lessons might arise from the process of reflection. In both Rotterdam and The Hague, we had consulted municipal health officials, some time before starting the study and asked them about their priorities. We tried to take these into account, without prioritizing their concerns over those of the mostly undocumented PEER researchers. Finally, we sought to shed light on some existing good practices, whenever these emerged from PEER interviews.

Our PEER researcher teams in The Hague and Rotterdam included both working undocumented people – labour migrants – as well as failed asylum seekers, most of whom were not working. There were also four people trained who had legal status. The others either had an asylum background, or were ‘migrant workers’ who had never sought asylum. The PEER researchers were from the Philippines, Indonesia, Myanmar, Angola, Tanzania, Pakistan, DRC (Democratic Republic of Congo) among others. All but two of the interviews conducted were recorded, transcribed and included in an Atlas TI database. The interviewees included young adults and the elderly, from countries including Philippines, Indonesia, Bangladesh, Uganda, Myanmar, Angola, Tanzania, Burundi, Cameroon, India, Morocco and Suriname. Some interviewees were in regular employment, and sent home money home. Other were not working and lived on handouts and charity; most of these were failed asylum seekers.

Of twelve or so PEER researchers originally trained, 8 continued with PEER interviews in The Hague. PEER training in Rotterdam was then conducted by the three of us, with a group of 8 or so, of whom four went on to actively interview. Since the PEER researcher group in Rotterdam joined later, questions were already set for them, and they were trained using materials generated in the first PEER workshop in The Hague. Reflection was part of the process, which made it possible, indeed

desirable, for PEER interviewers to adjust the questions asked, so they could be comfortable in interviewing undocumented people. As in an earlier project that used the PEER methodology for studying children coming out of care:

“The peer researchers suggested topics and questions to be included in the survey and interview guides and highlighted areas that they felt were important to explore in the context of the aims of the evaluations. There was full transparency with peer researchers over the likelihood that topics and questions might be re-framed and re-ordered to facilitate the flow of the interviews. This is the same iterative process used in other research whereby drafts are developed, reviewed and refined to ensure that the data collection tools created obtain information that will answer the main research questions” (Lushey and Munro 2014: 527).

Most of our PEER interviewers spoke first with people familiar to them from their existing social networks. This then led to other introductions to people in similar situations. The hope remains that this has made for more robust and reliable findings. Our PEER teams showed themselves not only enthusiastic but also highly skilled in different ways. The PEER-trained researchers first conducted one, or sometimes two, open-ended and semi-structured interview(s) with individuals from their own social networks PEER researchers fully collaborated in formulating questions, did the interviewing, and then helped with initial analysis of findings. Eventually, PEER researchers in The Hague interviewed 31 undocumented people, 20 women and 11 men. In Rotterdam, PEER researchers interviewed 21 documented migrants, 13 men and 8 women. Of this total of 51 people interviewed, all but one, who had recently been regularized, were undocumented. In later workshops, PEER researchers in The Hague reflected on some common myths about healthcare and undocumented people, resulting in a document used for discussion with policy makers (see Appendix 2).

The PEER approach is not the only way to research those in a precarious situation on a sensitive topic. Another approach pioneered in recent work by researchers based in Belgium, is to study undocumented people’s experiences of sexual violence through what is termed a Community-Based Participatory research approach. As they explain:

“[...] we adopted a qualitative and collaborative approach organised around the notion of Community-Based Participatory Research...[which] focuses on inequalities and aims to improve the health and well-being of community members by integrating knowledge in action, including social and policy change” (Keyngaert et al., 2012: 507).

We also noticed that a similar tendency towards advocating for the health of undocumented people frequently arose with the PEER researchers in this project. To work well, the PEER methodology requires rapport-building between PEER researchers and interviewees, in this case undocumented people in the research locality (in our case in The Hague and Rotterdam). This is to enable interviewees to report on daily and lived experiences, without fear that their identity will be

disclosed. Interviews may be conducted in the third person, if the person interviewed prefers to talk of ‘a friend’ or ‘my neighbour’, rather than in the first person. Interviews with people with whom the PEER researcher already had a good relationship of trust, based on shared friendships and common language, are easier than those with people they have never met. Knowing one’s interviewees also proved useful later when in the follow-up workshops to analyse key findings from interviews.

#### **4. Health Care Systems and Undocumented People**

Only four European countries (France, the Netherlands, Portugal, and Switzerland) currently entitle undocumented migrants full access to health care. Four other countries (Belgium, Italy, Norway, and the United Kingdom) allow partial access, in case of emergencies (source). Undocumented migrant women and children should enjoy special protection on the basis of the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) and Article 24 of the Convention on the Rights of the Child (CRC). They grant all women and children a right to health, without regard to legal status. At the level of the European Union, the Charter of Fundamental Rights of the European Union recognizes a right to preventive and medical services for “everyone”. The Netherlands has ratified all of these human rights treaties and are therefore legally bound by the mentioned provisions (Biswas et al. 2012: 54-56). However, ultimately the law is impotent in the face of public attitudes, often encouraged by the same government that has ratified international laws protecting human rights. In this respect, to realise the right to access ‘medically necessary’ health services, perhaps “(t)he most challenging aspect to influence is...staff attitudes, which may be linked to personal experiences as much as the wider societal context” (Priebe, Sandhu and Dias 2011: 11).

Since 2009, health care providers under Article 122a of the Dutch Health Insurance Act, can seek reimbursement for up to 80% of the cost of providing health care for ‘uninsurable’ people, including the undocumented.<sup>4</sup> Some treatment costs, like those resulting from pregnancy and child-birth, are covered to 100 per cent. To receive the reimbursement, the health care providers must prove they first attempted to collect the money owed from the undocumented patient they treated. CAK, the ‘central administrative organ’, would take over running the scheme from the Zorginstituut Nederland (Dutch Health Care Institute), a decision that came into effect in March 2018, but otherwise the scheme introduced in 2009 would remain unchanged (Lampion 2018). Still, for ‘uninsurable’

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<sup>4</sup> The provisions (in Dutch only) can be found here: <https://www.hetcak.nl/zakelijk/regelingen/onverzekerbare-vreemdelingen>.

foreigners, including undocumented people, if they cannot afford their medical bills, then medical staff and suppliers can claim back costs from the government.

“Nonetheless, undocumented migrants encounter several formal and informal barriers when seeking access to health care, including the financial barriers for general access to health care services, the reported unwillingness of some health care providers to treat undocumented migrants, and the lack of access to acute dental care” (Biswas et al., 2012: 56).

The system thus contains financial and practical hurdles; the shortage of GPs willing to cooperate; the reported distrust of some healthcare providers in the integrity of the system; the refusal to treat certain undocumented patients, for example those with mental health problems or who need physiotherapy (Lampion 2018). Although the: “...system has a very low threshold for access. This is how it should be, since otherwise undocumented patients will not dare to present themselves” (Lampion 2018: 10). For this reason, however, when medical providers suspect fraud, this can result in obstacles being placed in the way of undocumented people’s access to health care without payment.

The referral system from primary to secondary care is not optimal, due to financial obstacles for health care providers (80% reimbursement for most treatments, 100 per cent for maternity-related health care). In the Dutch medical system, effective access to health care generally requires either insurance or cash payments. Accordingly:

“The Dutch health care system requires all residents to purchase private health insurance. Undocumented migrants, however, have been excluded from health insurance since 1998, when the country adopted the Linkage Act connecting the right to social services with administrative status” (Biswas et al. 2012: 52).

Even after the Linkage Act, however, undocumented migrants remain entitled to ‘medically necessary’ health care, a rather vague definition that is administrative rather than medically precise. Most ‘normal’ medical treatment is covered, and reimbursement is only possible if the health care provider can show that they have tried to secure payment from the person involved. Since undocumented people cannot obtain health insurance, due to not having legal residence, they are not allowed to insure themselves. As INLIA (the International Network of Local Initiatives with Asylum Seekers) explains, the new scheme distinguishes “directly accessible” services like general practitioners (GPs), midwives, and dental care up to age 18, from “not directly accessible” services such as non-emergency hospital care, nursing homes and ambulances. Services deemed “not directly

accessible” require a referral, usually from the GP.<sup>5</sup> As a result of this scheme, a wide range of services is available, in principle, to undocumented migrants in the Netherlands.

Another problem can be that the existence of this fund – which needs to be applied for – may not be equally well known to all health care providers. Fear, stress and the very sober attitude of Dutch medical practitioners may further increase the risk of medical treatment coming too late for many undocumented people, who are often afraid to go to the doctor until their condition is very serious indeed, or even life-threatening. Undocumented people’s fears include the obvious ones of detention and deportation. They fear getting others around them into trouble, for instance by seeking medical care or reporting abuses to the police. In our findings section we address these fears more fully.

Recently, Grit et al. (2012) analysed access to healthcare for undocumented migrants from an institutional perspective. Their focus was on regulation, on policies and on institutions. In contrast to our pilot study, they do not appear to consider migrants’ own healthcare needs, and their health-seeking behaviors as central. Schoevers’ (2011) study, for instance, identified gynecological and psychological illnesses as particular problems for undocumented women in the Netherlands. Surprisingly, the same study also found a lack of facilities for diagnosis and treatment of Tuberculosis (TB), even though this is clearly a public health priority. Undocumented people often report that they do not contact medical professionals, because of feelings of shame, fear or a lack of information about what healthcare they are entitled to.

The Keygnaert et al. study mentioned earlier also has food for thought for The Netherlands’ image as a generous country in relation to health care (2012: 512). Another interesting finding of their study was that young undocumented men and boys were more vulnerable to sexual violence than had been expected (Keygnaert et al. 2012: 515).

## **5. Seeking Health under the Radar**

At the start of this article we referred to the daily lives of undocumented migrants in The Netherlands as characterized by liminality, or living “betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial” (Turner, 1969: 95). We added that for the undocumented migrants liminality centres on feelings of insecurity and fear which can lead to (self)

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<sup>5</sup> This is explained in the following page of the INLIA website: <http://www.inlia.nl/news/show/ehrm-ook-toegankelijkheid-medische-zorg-moet-worden-onderzocht>

exclusion from accessing health care, and disorientation and a feeling of ‘not knowing’. These characteristics of a life lived in limbo also influence the health needs of undocumented people and shape obstacles they encounter whilst navigating their access to health care. R. was interviewed in November 2013 in The Hague by T., a male PEER researcher, and her case illustrates how insecurity and stress can influence and enlarge the health problems of undocumented migrants. During the short interview, R. explains why someone she knows would not go to the hospital, even if she were really unwell. Talking in the third person, she reports that:

“...there is a woman I know. She is sick but she will not go to the doctor. She does not know what may happen to her if once they ask for her papers.... She thinks maybe...the doctor she works for IND and she was very afraid. She leads a life of stress, she has sore heads, insomnia ... she do not know how to go out or to submit to doctor and his [her] situation becomes more serious” D0 with interviewer T. from DRC).

In this section we now review reported health needs of undocumented informants, the obstacles they faced, including fear and economic obstacles, and then move onto a section that suggests some means of overcoming such obstacles in future.

### *Perceived Health Needs*

A majority of undocumented people describe their health status as poor, and yet tend not to visit medical practitioners because of their lack of health insurance, their fear of identification, their inability to pay, or their lack of awareness of their legal healthcare entitlements. One of the many examples given is from a Rotterdam interviewee, also a PEER researcher from Tanzania, who answered:

“People who have a paper, they have *verzekering* [health insurance], so when they get sick, they know where to go. But if you don’t have a paper, then you don’t know where to go. So you just hope that the sickness goes away, if you’re worse, you have no choice. You have to go to hospital...” (D39).

The longer the duration of their stay in the Netherlands, the more psychological problems the undocumented tend to experience. A. has been in the Netherlands for decades, since the mid-1990s, and is now very sick indeed, with high blood pressure, heart problems and severe psychiatric problems, including psychotic episodes. He thinks constantly of self-harm and suicide. He is unusual in that he says he has no problem getting access to the doctor or seeking medical help. Many organisations are willing to help him, it seems, including the municipal mental health service, the GGZ (Geestelijke Gezondheids Zorg). Talking to a PEER interviewer in The Hague, A. explains: “For my own safety, I have my medicines with me every day, so that everyone can see what is wrong

with me. And I can simply go to the doctor. I can just go right there” (D01).<sup>6</sup> Perhaps the reason he can walk in to the mental health clinic is that his case concerns a public health issue since he is at risk of self-harm. He will therefore be considered a priority case, in terms of public safety as well as mental health.

Many long-term failed asylum seekers are single men like A., who live alone without family. Those with children worry about their children’s future instead (Van den Muijsenbergh and Schoevers 2009: 61). During one interview by a Hague-based PEER researcher, one male undocumented worker, stated that: “for us who do not have permission to live here and...have children here, it is also a problem for us if our children are sick” (D12, PEER interview, December 2013).

Under the law, undocumented children are more protected than adults, yet they may not receive proper healthcare either, if their parents’ fear being detected by the authorities. In practice, this places restrictions on parents’ willingness to take their (fully entitled) children to see the GP, for example, in case of detection. Fear thus acts as a strong deterrent element in efforts by the undocumented to access health care. This can also apply to landlords and employers, who fear becoming involved with undocumented people in case they are targeted by police and even fined. As S. said about his landlord when interviewed by Yvette (not her real name) a Hague-based female PEER interviewer, in December 2013:

“The people who we live at their home [i.e. the landlord] are afraid because they keep undocumented people. They are afraid to get any fine or anything. They are afraid [to go to the hospital or GP with us because] of dealing with the police” (D17).

The obstacles that undocumented migrants in their search for health care encounter, have many different faces as is expressed in the following extensive quote from a conversation with one of the Rotterdam based undocumented migrants who was interviewed in November 2014 by a PEER researcher from Burma:

“They come to me and they ask me and they are really crying and sometimes you go sit there. They fear to go to hospital because they don’t have a passport or they don’t have papers and they will be crying. Or maybe they even have an accident and they don’t know; they cannot go to hospital to heal their wounds and everything. So they don’t know anything about where to go. Because of fear the police will catch them or the doctor will give the bad medicine and

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<sup>6</sup> Interview with A. conducted by Ahmed Pouri and transcribed by Fredy Winters, December 2013. “Ik heb ter veiligheid iedere dag mijn medicijnen bij me, iedereen kan dan zien wat er met mij aan de hand is. Ik kan gewoon naar een dokter gaan. Ik kan daar rechtstreeks heen”.

everything. But I've been able to talk to some of them, until not to get scared, because they are humans, if they are sick, go and get treated. But the thing is they don't know where to be treated, that is it" (D27).

This single quote addresses central issues as fear for the police, the medical world and even the fear for being unequally treated and 'experimented' with by getting 'old' or 'bad' medicines as the respondent explains. The quote also stresses the lack of knowledge by the undocumented people on fundamental health issues as where to be treated for what. Whereas fear and knowledge deficiencies tend to polarize and reinforce social exclusion, the idea of 'being human' underscores a vision of common and equal humanity. Many Rotterdam interviewees asserted simply 'we are human beings'. This reverberates in many protests by those with 'illegal' status, asserting their humanity and their right as human beings to proper medical treatment. In the following sections we elaborate on some of the obstacles undocumented people face in their search for their human right to health care.

#### *Obstacles: fear, distrust, stigma*

Perhaps our single most notable finding was that fear of the authorities combined with a lack of knowledge and networks, combined with unwilling and incompetent health care providers were the central reasons why undocumented people often preferred to keep away from doctors and hospitals in their search for health care. Those who avoided accessing health care did so in spite of the relatively 'good' formal legal provisions for undocumented people to access "medically necessary care", as well as GP care, in the Dutch context.

Most respondents simply did not trust the authorities. There was much obvious distrust of the police in particular. Many undocumented people fear apprehension and forced deportation to their home country, if they are arrested. Simultaneously, most of those interviewed suspected medical-police cooperation as an outcome of the 1998 Koppelingswet (Linking Act) that made access to basic services, including health insurance, education over 18 and housing, dependent on valid residence, identity and national insurance documents (Engbersen and van der Leun 2001: 66). Data-sharing across government departments was viewed as a form of control exercised over undocumented people in particular. This may explain why one of the Rotterdam interviewees from Burma stated that "sometime the people really complain, that is, thinking they go to the doctor, doctor maybe call the police, or something." (D37) Self-exclusion was reported by respondents, as well as self-medication. Those who knew about their rights, through contact with NGOs such as *Dokters van de Wereld* (Doctors of the World), still hesitated to report illness or accidents at work, for example, for fear of prosecution for themselves or their employers. In line with other research (Biswas et al 2012:



56) we found undocumented people lacked access to dental care – both acute and routine - in both Rotterdam and The Hague.

Such fears of detection may not be completely unrealistic. There is no direct evidence from our discussions with medical staff that they ever report undocumented people to the police. Yet as Van der Leun and Ilies (2008: 12) and others (Engbersen, Van der Leun, De Boom, 2007) have noted, sharing information is an integral part of the ‘Linking Law’. Cross-departmental data sharing should respect patient confidentiality, and yet this principle clashes with the Netherlands government’s explicit “discouragement policy” towards illegal residence, which requires that:

“[t]he control and enforcement of law against irregular residence is delegated to officers and professionals working in the public service sector, namely health institutions, schools and housing agencies. Data registered by these bodies, as well as immigration service registration files, census bureau data, fiscal identification agency data, and social security and social assistance information can be crosschecked to verify the validity of immigrants’ residence and work status, therefore the name of the “Linking” Act” (Engbersen et al., 2007).

The basic idea of the Dutch government is that since people without residence permits do not belong to the Netherlands, they should be excluded from all provisions offered by the modern welfare state. Health care is one notable exception, as the provision of funding for this purpose confirms. Here the implications are potentially serious, since according to one Ministry of Justice report: “the health problems suffered by illegal aliens are more serious, i.e. life-threatening, than those suffered by regular patients” (2005: 33). In a densely-populated country like The Netherlands, for the sake of public health, all migrants, including the undocumented, need to be able to access health care services.

One problem is that fear drives rumours, creating a shared sense of vulnerability that reinforces the disorientation characteristic of those who live without legal documents. Among our interviewees, for example, there were some who believed undocumented people were deliberately given second-class medical treatment, or were even being experimented on in Dutch hospitals and clinics:

“Because the doctors, if they know [that you are an] illegal people, they sometimes do not help so good. [...] Even, I heard something that some people said, illegal people go to hospital, the doctor get the person to a student. A student takes the operation, so it is really, really painful. [...] They get a treatment, but not so good.” (D26)

The same person also expressed the view that doctors were likely to administer experimental medications and treatments to undocumented people, rather than the regular treatments reserved for

native Dutch. In general, there were many expressions of such fears about the integrity of the medical establishment, seen as ambivalent at best, and discriminatory and stigmatizing at worst. This kind of response conveys the sense of being in a position of ambivalence, within the system but not of it. In many cases, they appeared to feel lost:

“in a kind of no-man's land between the real and the imaginary, and between innocence and irresponsibility...Their condition requires them to deal with the consequences of inhabiting a space that is both mental and physical and both guilty and innocent” (Jackson 2005: 346).

Many interviewees felt it was the lack of papers that made all the difference. This was the cause, they believe, of their being stigmatized and treated as second-class when it came to accessing health care in The Netherlands. This tempted one Rotterdam interviewee from Burundi to make the following cynical statement: “[we are] human beings, we need...things, but [these]...people they don’t care about that. They only care about their animals” (D35). In asserting that they were “human beings”, a few interviewees who made these kinds of comments were asserting their right to be treated as other residents of The Netherlands. Whether claims of experimentation and unequal treatment are factual or not, what emerges from these narratives are very high levels of distrust towards health care providers as institutions of the Dutch state. Many respondents avoided accessing healthcare wherever possible, because of their fear of being arrested, detained and even deported.

#### *Obstacle: lack of economic means*

A serious lack of financial resources for food, living costs and transport, means that very few undocumented people can pay for medical treatment or medicines. This too keeps undocumented people from seeking treatment. Undocumented people’s employment status plays an ambiguous role in mediating this financial obstacle to accessing health care. Employment is the means to obtain the much-needed financial resources that enable a person to make a living, yet work also exposes undocumented workers in particular to health problems and risks related to their job. In addition, the necessity of working long hours, since they lack any social protection, leads migrant workers to neglect their health problems. This ambiguity of work comes out in interviews with undocumented men and women, especially in The Hague. Whilst work gives them a sense of greater control over their lives, and the cash income necessary to cover health expenditure, it also results in health problems and safety issues that adversely affected undocumented people’s well-being. As one Filipina pointed out:

“[...] the most [common] problem of undocumented here is, since our job is cleaning, we have always this back problems or shoulder problems or... how do you call this now...hands we cannot fold in the morning” (D09).

Similarly, Benseddik and Bijl (2004: 139, 147-149) show that back, neck and shoulder pain are all common among undocumented workers in greenhouses close to The Hague. Labour migrants not only are compelled to make a living for themselves, but normally also support family members at home, and this too can impose expenses that hinder their access to healthcare. Labour inspection is unlikely to reduce risks for occupational safety and risks. Benseddik and Bijl (2004: 139) report the case of an undocumented worker in a glasshouse who lost two fingers due to high work pressure. In conditions of legal liminality, the supposedly ‘protective’ bodies responsible for labour inspection can take on the task of surveillance of immigration status. When the researchers contacted labour inspectors, the confirmed that they would report this person (who had lost two fingers) to the immigration and naturalisation service (IND).

Widespread fear of apprehension, detention and even deportation has the effect of controlling undocumented migrants. Their contributions to the Dutch economy and society are considerable, and yet they are in unsafe, often harmful working conditions. Rather than report their work-related health problems to labour inspection services, such undocumented workers prefer to avoid the authorities altogether. To other fears already mentioned, we can add their fear of losing their jobs, through their employer fearing the fines imposed for employing undocumented people. Verbal work contracts are the norm for those without status, and this means they:

“can always be cancelled, for example, if illegal workers or tenants are not submissive enough or violate certain rules of conduct. Labour and housing conflicts are then settled by firing or evicting the illegal immigrants or by simply refusing to pay them for the work they have done” (Engbersen and van der Leun 2001: 63).

This precarious work situation can be dangerous for health and safety. An example is Hague interviewee S. from Indonesia who works in a factory together with other undocumented migrants. They also sleep in their workplace. He narrates how a leaking gas heater resulted in vomiting and fainting for himself and several colleagues. Fearing the police, they did not dare call anyone for help. Later, workers demanded the gas heater be replaced. S. added:

“Just like we told our boss, we said to him that we would not work if it was not replaced. Because the boss does not want to know since we are the ones who work. He said if...something happens here, it would be our own risk and if we are dead, it is our destiny from God. The boss is from here. I do not know with Dutch people, but the people at my work do not really care about that, the important [thing] is that you work and you are paid. Well, [the] risks [are] for undocumented.” (D17 interviewed by Y. December 2013).

*Obstacle: unwilling medical health care providers*

Is it valid to conclude, as Van den Muijsenbergh and Schoevers (2009: 62) did, that undocumented people's failure to access healthcare in the Netherlands is mainly due to obstacles on the side of the undocumented? Our findings suggest this is a one-sided conclusion and quite unrealistic, at least based on available evidence. In one of our workshops with PEER researchers, we considered some common myths about healthcare and undocumented people, including this one (see Appendix 2).

As the Health for Undocumented Migrants and Asylum Seekers (HUMA) Network notes: "Undocumented migrants can only access care considered by doctors on a case by case basis as 'medically necessary'. The rule is that they will have to pay for it unless it is proven they cannot pay. If this is the case, health care providers, hospitals and pharmacies will provide care or treatment and then ask for reimbursement to the specific public fund" (2009: 15). An often business-like attitude of Dutch health providers can result in informal blocking of access, since patients are expected to be insured, and to be able to identify themselves. If they fail to do either, they are expected and told that they must pay. Undocumented people generally cannot identify themselves, yet very few can afford to pay. Sometimes, care and compassion appear to be lacking at the point of first contact with medical and health care service providers, and not only in The Netherlands. As a recent study of medical staff attitudes towards migrants across Europe, found:

"The majority of respondents (74%) asserted that, in general, treatment for migrants after the initial contact would not differ from that for non-migrant patients. When specifically asked in case vignettes about different further pathways depending on the immigration status, for the labour migrant vignette over two-thirds (147 participants) explicitly said that there would be no difference in further treatment pathways. However, for refugees and undocumented migrants only one or two participants respectively reported no difference in further treatment pathways" (Priebe et al. 2011: 4).

Frictions start with language and with cultural miscommunication and bad attitudes, including at reception. As an undocumented person presents herself to the staff of a GP clinic or hospital, the first question asked will be to verify their identity. Our interviews confirmed that some medical and administrative staff in Dutch public hospitals, for example, seem to believe that undocumented people are receiving 'special' treatment'. Since undocumented people only pay if they can afford to, legal residents resent being compelled to pay high monthly insurance bills. The fact undocumented people are not allowed to pay insurance, does not prevent such pre-conceptions from being reported in PEER interviews.

For instance, although some undocumented people exclude themselves from health care services, this may result from previous experiences. With the rise of intolerant attitudes towards migrants in general makes it more likely that undocumented people may be treated harshly or with indifference at reception or by the doctor. This may even amount to stigmatisation, where:

“Quite often the stigmatizers realize that the evidence available does not justify their negative reactions and come to see some of the process as arbitrary. When this happens, guilt and sympathy mingle with the primary feelings of aversion or revulsion, and another very common feature of stigma - ambivalence – appears” (Jackson 2005: 339).

When S. a Filipina woman, is interviewed by J. a male Filipino PEER researcher, towards the end of the interview, she starts to clarify a few things about the ins and outs of health care funding as it works in practice in hospitals in The Netherlands. She explains that the first time she had to have treatment, she first needed to get help from a Dutch woman. This Dutch woman phoned up the hospital administration and told them S. could not pay. Then S. fell sick a second time. Again, the Dutch woman phoned up and informed the hospital administration that S. could not pay. This time things went less smoothly than the first time:

“...the second time... when M..... called they just closed their mouth. They just keep quiet, saying ok I received this letter, I got a call it's ok. But I know that not all of them were happy with that situation because you could see their faces, you can see their... the way they approach you, the way they talked to you” (DO8, October 2013).

Attitudes of medical and hospital staff could vary from neglect, to active hostility towards undocumented people. However, as we saw for a few, not necessarily lucky, undocumented people access to medical professionals and drugs were relatively easy, especially where public health issues, like serious mental health problems, were involved.

## **6. Coping with fear and distrust**

As a result of the existing fear and insecurity, the lack of knowledge on where to go to, the necessity of making a living and negative experiences with unwilling or incompetent health care professionals, two dominant strategies can be distinguished. The first involves living a healthy life as much as possible. For some undocumented migrants, this implies eating healthy food and trying to maintain a level of physical fitness through exercise and sport. Health and weather are sometimes connected, as when D. claimed that his “body has no resistance for the cold weather, because I used to stay in the tropical weather” (D41). The PEER researchers asks D. how he manages to maintain his health in the Dutch weather, to which he replies:

“Yeah, that is a good question. Every day, I wake up in the morning, I, used to do sit-ups and push-ups. Sit-ups are very important for people. Because, in this area [point at the belly], we

have the power [...] In our belly we have this power to resist the cold. And I don't smoke, I don't drink, I don't use marijuana, don't do drugs. Only sometimes, some people have fiesta, I drink beer or something or wine. And number two is, we...eat cheese every day." (D41)

Whether eating cheese on an everyday basis is a recipe for a long and healthy life is not as important as the fact that D. here expresses a conscious way of living that other undocumented migrants adopt when faced with possible apprehension, detention and/or and deportation. In addition to physical exercise, and eating healthily, R., an interviewee from Cape Verde stated:

"Okay, but what apart fitness and exercise, what do you do to keep healthy yourself." R: "Food. Food. I don't eat too much, I drink water every day, one litre every day. Before I leave house and when I come, every day, one litre, minimal. And not, like I told, don't eat too much. And get if you eat fish, not too much other kind of food and then you will be good." (D34, Rotterdam May 2014).

Another significant strategy among undocumented interviewees was self-medication and self-treatment. One of the most frequently used references to medicine in the sixty or so interviews was the term 'paracetamol'. This basic medication, very cheap to obtain, is used by most undocumented people for minor ailments as well as for quite severe pain. One of the PEER researchers asked his interviewee what kind of medicine he would use if he had a medical problems. The interviewee, as many others, replied "my medicine is, just medicine... paracetamol, yes paracetamol [...] You can buy it in the supermarket, in Lidl, or Ibuprofen" (D27). One of the Rotterdam interviewees reflected on what happened to a friend looking for a dentist:

"One day, my friend had tooth pain, she's is feeling so [much] pain in her...She can't sleep the whole night and she don't know where to go. So she looks for a dentist here and a dentist there. They tell her they cannot treat her because she has no papers, so she just been taking paracetamol and not working and hoping [but] that can't help her to get the pain away. So I know so many people who get sick and don't have anywhere to go to hospital. That's very sad." (D24)

Paracetamol, however is also referred to in a rather cynical way by some undocumented migrants who view being prescribed this medicine as part of the low quality, cheap and easy health care they encounter and the unequal medical treatment they receive from Dutch health providers. Thus R. explained:

"Well, if the police come there, it's not all right. Police putting you in jail, so is not a good place." Interviewer (I) : "Yeah, but if they put you in jail, they will give you some medicine over there in jail? R: "Oh, yeah. They give you paracetamol!" I: "Only paracetamol? But depends on which kind of sickness you have?" R: "They don't give any medicines, only paracetamol " (D37, Rotterdam May 2014).

As shown in the example of the Dutch woman writing on behalf of an undocumented woman, an important factor that emerged from the PEER interviews, was the support of social networks of

friends, self-help through NGOs and support from other professional organisations. Such networks are a critical factor in helping undocumented people cope with and control their fear of seeking medical treatment in the early stages of an illness or injury. It was within these networks that interviewees reported learning about where to go for medical attention, and what they could do in case they faced health problems or obstacles to accessing health care.

One problem is how social networks shrink as someone moves below the radar, because of their undocumented status. J. moved to the Netherlands five years before being interviewed in 2014, and had lost her residence permit in 2011. She reported how she had become very cautious in choosing his friends, after she lost her legal status and residency rights:

J: “If you are undocumented you have to be aware of everything...for example, we have to choose the people, we have to choose our friends”.

Q: “Can you explain what you mean, being aware of what? Your surroundings, the people you are dealing with? Is that what you mean?”

J. Yes, sometimes, we don’t know...who we are talking about, or who are we dealing with so you have to be aware what kind of people these are, are they your friends, your true friends?” (D07 interviewed by J. October 2013).

Although J. was from the Philippines, she no longer mixed much with the Filipino community. She was afraid someone might betray her undocumented status to others. It seemed safer for her to have fewer friends than before. A similar concern was shared by L. from Egypt, who explained her hesitation in consulting medical practitioners in this way: “in general undocumented people don’t go that often to the doctor. We don’t have many friends, and our social life is very restricted”<sup>7</sup> (D49 interviewed by A., January 2014). Another failed asylum seeker described how her friends helped her to consult a medical doctor when she got dizzy spells. Trade unions could also encourage greater awareness by providing training in relation to health rights, but it was not clear that getting such information served to reduce the fear of accessing healthcare. For some, friends were crucial both to provide them with information, and to accompany them to the doctors or the hospital (D11, Interviewed by A, The Hague January 2014).

NGOs and other professional organisations whose goal is to support of undocumented people have the advantage of accurate information about health rights. Such NGOs can sometimes provide material and financial support. Yet one drawback of professional support organisations is that they

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<sup>7</sup> Original quote in Dutch: “In het algemeen gaan illegalen niet vaak naar de dokter. We hebben niet veel vrienden, het sociale leven is zeer beperkt.”

must give generic and carefully specified support, rather than personal support and accompaniment. This may be what the following statement from a failed asylum seeker from Guinea is hinting at: “sometimes you cannot wait till a specific date when others have time for you. Sometimes it is already too late for medical attention” (D46, Interview B., Rotterdam March 2014).<sup>8</sup>

Organising information evenings is one way to reach isolated undocumented people who may fear going anywhere near a medical facility, GP or hospital. However, even this is not unproblematic, as one of the first PEER interviews suggested. A woman J. explains to J., PEER researcher and a man, that although the government does not seem to recognize this fact, she is convinced migrants workers have the right to respect and basic rights, whether they are documented or not. J. asks J. about experiences among other people she knows. She explains that the undocumented people she knows do need to know they have rights to healthcare. However, she admits given fears that are often well-founded, and the use of the ‘Linkage Law’ that involves sharing information among government departments, distrust remains. As J. mentions:

“I mean, like us, we undocumented, some undocumented even though the government is giving them a chance like for example there is an orientation or there is an awareness, but most of the undocumented they prefer not to show, not to go because they are thinking, oh this is a... maybe this a way of catching us or tracing us so every negative thinking on the... that’s what they think, that’s why they don’t bother to show or they don’t bother to go to this kind of program” (D07, Interviewed in The Hague, August 2013).

Quite often, when a GP refers someone to a specialist, and if that person is undocumented, then the individual fails to show up at the hospital or may start, but not continue with the treatment. This is irritating for service providers in the health sector (Lampion 2018). However, it is far from clear whether this failure to continue treatment is because undocumented patients do not follow-up their healthcare treatment, or because health care providers are reluctant to provide longer-term treatment for undocumented patients. In the case of GPs there is also evidence of less-than-professional record keeping. For example, B. was sick one time and went to a doctor in The Hague and got a prescription. She reports that the doctor said if she were still ill two weeks later, she should come back. As she says:

“When we came back, we were asked again, our name, what is the complaint. She [i.e. the doctor] forgot. So they have no data about the patients”. Y: “Is it because you’re

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<sup>8</sup> “[...] je kunt soms niet wachten tot een bepaalde datum dat anderen tijd voor je hebben. Soms ben je al te laat voor de hulp”.



undocumented?” B.: “Well I do not know, the doctor just said that she had no data in her computer. If I go to the hospital, when I come there, they have all my records. Everything is recorded.” Y: “The patient and the treatment should be recorded. You must pay in cash, right, well, it means the money you have paid is not recorded. It goes directly to her own pocket. Though this helps the undocumented and it does not mean the doctor does black work. But if she does not record your data, or your payment, then she is working ‘in the black’...She’s like me - doing black work.” (D21 interviewed by Y. December 2013).

In this case, during the PEER interview, which progresses more like a normal conversation than a series of questions and answers, both B. and Y. come to the ironic conclusion that illegality may be embedded within the Dutch health care system itself. Some studies, in contrast with this one (Grit et al., 2012; Kulu Glasgow et al. 2000) focus on the supply side of healthcare rather than the demand side. As a result, they fail to notice some or the salient information about undocumented migrants that *do not* find their way to healthcare providers and are *unable* to overcome whatever barriers may prevent their access to basic healthcare in Dutch cities (ibid: 72). Kulu Glasgow et al. do confirm what our PEER researchers heard several times in interviews - that undocumented migrants often postpone visits to GPs and other healthcare providers. Psychological and psycho-somatic problems are also common among most of those who claim asylum, and are rarely treated (Kulu Glasgow et al. 2000).

According to one major review study, conducted in 2009, and “...drawing on 181 surveys with 81,900 refugees and other conflict-affected people” (Silove, Ventevogel & Rees, 2017: 131), the prevalence of PTSD and depression among the undocumented was around 30 per cent. Exposure to torture and the total number of trauma events experienced emerged as the strongest predictors of PTSD and depression, respectively. A study by PICUM (2007: 65) points to another problem that may be more institutionalized, namely the lack of awareness about relevant legal frameworks and policies among healthcare providers and health administrators, rather than among migrants.

The entitlements of undocumented migrants to a basic ‘necessary’ package of healthcare may not be appreciated or fully understood by all health care professionals in Rotterdam or The Hague. Their own ignorance of the provisions can be an obstacle that studies not taking the perspective of the ‘end-users’ will tend to ignore. Although more research is needed on this kind of supply-side obstacle, some undocumented PEER interviewees appeared not to have made it past Reception, as it were.

## **7. Forward-looking Conclusions**

From the perspective of marginalized groups in society, formal rights mean little unless they can be accessed and realized. Among the member states of the EU, none “provide universal health coverage for nationals, few offer migrants equal coverage. In Germany or Sweden, for instance, migrants in the country illegally can only access emergency services” (Wudan 2016). Globally, the EU lags behind some much poorer countries in terms of provision. In Thailand undocumented people are allowed to access health insurance on the same basis as citizens, refugees and other legal migrants (Wudan 2016).

Broadening access to health is part of wider social justice goals, and is central to an actor-oriented perspective that asserts ‘the right to have rights’ of socially excluded and invisible populations living among citizens (Pettit and Wheeler, 2005: 3). Findings in this study tend to show that the liminal position of undocumented people, at least in these two cities in The Netherlands, is not only a matter of legal rights, but of attitudes and health-seeking behaviour. Being ‘below the radar’ and ‘on the margins’, makes it rational for undocumented people to avoid presenting themselves to formal health care institutions and providers, unless it is an emergency. Towards the end of our research in The Hague, it emerged that covert surveillance had been active in the city centre for some time to ‘catch’ undocumented people who were regularly going to work, which is against the law. This police operation resulted in some undocumented migrant workers being arrested in their homes, detained and deported to The Philippines and Indonesia. When this happened, it proved very traumatic for our PEER researchers, some of whom were close to those targeted, arrested and deported.

Made invisible in the statistics, undocumented people can still find themselves targeted with intense scrutiny and surveillance in their daily lives. Their liminal position makes it all the more important to incorporate their perspectives into policy-making. The PEER approach was not always as easy as we had imagined. It cannot be fully operationalized in a climate where undocumented people are subjected to arbitrary arrest and are stigmatized. As pointed out by other scholars:

“...by minimising power imbalances between researchers and participants [PEER methods may reduce] bias and contributing to children and young people’s voices being heard, enhancing understanding. However these benefits are not automatic” (Lushey and Munro 2014: 533).

One problem with this study’s findings is that it is based on a fairly small sample, far from random or representative. This means our insights and key findings are not generalizable. Even so, we hope they may provide some insights for policy-makers about how to improve the Dutch health care system by tailoring it to fit in better with the priorities and concerns of undocumented people.

Towards the end of the research process, a few key myths that governed policy and media framings were identified together with PEER researchers, and were spelled out in a short document (see Appendix 2). Overall, the hope remains that relations of trust that emerged through the PEER approach will continue to generate opportunities for collaboration in future. Such ties:

“...may foster supportive peer relationships that endure beyond the life of the group program. Preliminary research suggests [this]...has the dual effect of increasing civic participation (and hence social capital) and improving participants’ mental health” (Silove, Ventevogel and Rees, 2017: 136).

Another practical suggestion in line with other studies, is that the health care funding scheme in place since 2009, updated and taken over by a new public body in 2018, is still not that well-understood by many Dutch health professionals and staff.

“Individual caregivers as well as institutions still are not aware of the regulation, and therefore undocumented migrants run the risk of being refused by these aforementioned caregivers” (HUMA Network, 2009: 118).

Other research supports our contention that health service providers can be part of the problem. And attitudes matter, whether in the GP practice, in hospital or in psychiatric care, youth health, and screening and treatment for HIV and other infectious diseases. The attitudes and training of medical staff of vital concern. With this in mind, the Johannes Wier Foundation (Stichting), an Amsterdam-based NGO dedicated to health and human rights, recently designed an on-line accredited training course to inform health professionals about the rights of undocumented people to health care.<sup>9</sup> This is certainly a useful and important resource that could enable health care professionals to become more aware of their potential contributions.

Even more fundamental reform is needed, especially given the finding that fear is an intended, not an incidental, outcomes of refugee policies across the EU and in The Netherlands. Recent research has exposed the impact of post-flight living conditions on the mental (and therefore presumably also on the physical) health of refugees and asylum seekers. As a 2017 study noted the:

“Growing number of studies in recipient countries [*which*] found that imposed conditions of adversity, including prolonged detention, insecure residency status, challenging refugee determination procedures, restricted access to services, and lack of opportunities to work or study, combined in a way that compounded the effects of past traumas in exacerbating symptoms of PTSD and depression” (Silove, Ventevogel and Rees, 2017: 132).

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<sup>9</sup> E-learning course on Health Care for the Undocumented (in Dutch) at: <https://www.johannes-wier.nl/documentatie/e-cursus-gezondheidszorg-voor-ongedocumenteerden/>

As one of the opening quotations explained: “My medicines are my wife”, implying that between this undocumented person and extreme distress and loneliness, come his medicines, which perhaps make his life more bearable. In any case, as he would be with a wife, he is highly dependent on his medicines emotionally and physically. Since 2016, undocumented people have for the first time been able to safely report crimes to the police, without fear of being detained. They can do this at any police station in the Netherlands. If municipalities – and/or the national government - extended this right to include reporting violations of health rights, and perhaps also labour rights, then many of the fears of undocumented people in accessing healthcare institutions could be reduced. Finally, Dutch health care providers might need to change their attitudes towards undocumented people, before the latter are able to trust in the confidentiality and transparency of the Dutch health care system. If undocumented people were willing to access health-care institutions and practitioners, without fearing that they could be reported to other branches of government, such as the immigration authorities, this would go a long way to help them secure their rights to health care.

**Text: 11,420 words excluding abstract and references**

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## APPENDIX 1: Questions Agreed with PEER Researchers for Interviews

### APPENDIX 2: Policy Brief

#### Box 1 Five Common Myths about Health Care and Undocumented People

##### **1. Undocumented people have no right to health care since they are illegal**

It is not correct to say that undocumented people have no rights to health care. Indeed, undocumented people have the right to obtain 'medically necessary' medical treatment. This is not charity; it is common sense. Otherwise, risks for public health will grow from untreated illnesses. Nobody wants TB, HIV or other infectious diseases. Nobody wants untreated mental illness. Medically necessary health care should continue for the undocumented, as this is the only way to avoid real risks for public health, and for the Dutch population too. Public health requires that health be better monitored. Overwhelmingly, undocumented people are found to be fearful of presenting themselves at medical institutions, until their symptoms are very advanced.

##### **2. They should be asked to pay, just like everyone else, through health insurance**

Schemes to enable undocumented people to pay for health insurance were attempted by one Dutch trade union, FNV. After an initial phase, the experiment was dropped. Since undocumented people cannot work legally, and have no BSN or residency rights, health insurance companies are not willing to have them as customers. So, some other provisions need to be in place for the undocumented. Some support organisations issue 'health passports' that help identify someone as undocumented. These 'passports' can help when presented to those who filter access to medical personnel, for example at Receptions in hospitals or GP clinics.

##### **3. If the undocumented cannot pay, they should ask families and friends to pay**

Research found that this is already happening. The trouble is that it can generate a great strain upon relationships that are already fragile. Debts and obligations can result, and with narrow social networks, undocumented people are not in a strong position to ask others to pay their medical bills. The fear of incurring bills may lead undocumented people to avoid accessing health services in future. Then medical treatment may come too late. Many working undocumented people would like to pay for health insurance. They are not allowed to do so. For destitute, homeless and insecurely housed people, asking others for help can expose them to further exploitation and abuse.

##### **4. Doctors who are busy should not have to fill in forms in order to be paid**

Doctors do complain about time-consuming form-filling. To get paid, they have first to demand payment from the person treated. By explaining that they cannot pay, patients trigger the doctor to fill in forms to reclaim a high proportion (around 80 per cent) of the costs of medical treatment. This money comes from a fund provided specifically for this purpose. In this way, doctors fulfil their professional responsibilities and can treat patients, regardless of legal status, knowing they will eventually be paid. Filling in forms is a small price to pay for this principle. At modest additional cost, the good health of undocumented people, and general public health, can be better assured.

##### **5. These are difficult times, we are in economic crisis, so only emergency care is affordable**

At first, this sounds fair. Everyone has to economise. However, this is short-sighted. Public health problems like TB, infectious diseases including STDs and serious mental illnesses, would all go

undetected if only emergency care were provided. Already, in countries like France only emergency health care is provided, and it is now proving a false economy. Treating someone in an emergency is often extremely costly, compared to treating someone in the early stages of an illness. More, not less, money needs to be spent on prevention, detection and early treatment of health problems among the undocumented. Health scares also undermine public confidence in health services, and this ends up costing governments a lot in financial and human terms, in the longer-term.