Views, attitudes and experiences about childhood vaccination among undocumented migrants in Sweden - a qualitative study

Karina Godoy Ramirez

Master of Public Health

MPH 2014:6
Master of Public Health
– Thesis –

Title and subtitle of the thesis
Views, attitudes and experiences about childhood vaccination among undocumented migrants in Sweden - a qualitative study

Author
Karina Godoy Ramirez

Author's position and address
Investigator/Immunologist, Public Health Agency of Sweden, Nobels väg 18, 171 82 Solna.

Date of approval
09.05.2014

Supervisor NHV/External
Asli Kulane, Ass. Professor, Karolinska Institutet
Henry Ascher, Professor, Göteborgs Universitet

No. of pages
37

Language – thesis
English

Language – abstract
English

ISSN-no
1104-5701

ISBN-no
978-91-86739-71-3

Abstract

**Background:** WHO/Europe remains committed to eliminating measles and rubella by 2015. Overall, vaccine coverage in Sweden is good. However, recurrent outbreaks of measles and rubella highlight the fact that the vaccination program does not reach everyone. Pockets of individuals susceptible to measles, rubella, and other vaccine-preventable diseases may exist. Importantly, current knowledge about the immunization status of undocumented immigrant children is scant.

**Aim:** This study explored the views, perceptions, attitudes, and experiences of undocumented immigrants regarding childhood immunization and investigated their access to vaccination and health care.

**Methods:** This qualitative study used exploration and individual interviews. Seven undocumented parents with pre-school children were recruited in close collaboration with nongovernmental clinics serving undocumented immigrants in Stockholm and Gothenburg, Sweden, and also with three nurses at Child Welfare Centres having a high immigrant population.

**Results:** Many of the parents in this study expressed a strong fear of being asked for immigration documents at healthcare centers. Frequent mobility among immigrants may limit access because vaccinations require several healthcare visits. Undocumented parents indicated that they mistrust healthcare providers and avoid health facilities, further delaying children’s access to health care, including vaccination services.

**Conclusions:** Undocumented immigrant parents know that every child is entitled to health services in Sweden, and show high compliance with childhood vaccinations. Improving access for undocumented immigrants requires additional and specific efforts to restore trust in the health system.

Key words
undocumented, children, hard-to-reach, vaccination, sweden
TABLE OF CONTENT

1 INTRODUCTION .................................................................................................................. 5
  1.1 BACKGROUND ............................................................................................................. 5
  1.2 PUBLIC HEALTH PERSPECTIVE ............................................................................... 6
  1.3 NORDIC PERSPECTIVE ............................................................................................ 6
  1.4 VACCINE COVERAGE ............................................................................................... 7
      1.4.1 In Europe ............................................................................................................. 7
      1.4.2 In Sweden .......................................................................................................... 7
  1.5 THE MIGRANT COMMUNITY ...................................................................................... 8
      1.5.1 The undocumented community ......................................................................... 9
      1.5.2 Undocumented children ..................................................................................... 9
  1.6 ACCESS TO HEALTH CARE AND RIGHT TO HEALTH ............................................. 10
      1.6.1 In Europe .......................................................................................................... 10
      1.6.2 In Sweden .......................................................................................................... 11

2 AIM AND RESEARCH QUESTION ....................................................................................... 12

3 METHODS .......................................................................................................................... 12
  3.1 STUDY DESIGN AND SETTING ............................................................................... 12
  3.2 PARTICIPANTS AND RECRUITMENT ....................................................................... 13
  3.3 DATA COLLECTION ................................................................................................... 15
  3.4 DATA ANALYSIS ....................................................................................................... 15
  3.5 ETHICAL CONSIDERATIONS ...................................................................................... 16

4 RESULTS ............................................................................................................................. 16

5 DISCUSSION ......................................................................................................................... 22
  5.1 DISCUSSION OF FINDINGS ...................................................................................... 22
  5.2 METHODOLOGICAL CONSIDERATIONS ................................................................ 25
      5.2.1 Trustworthiness ................................................................................................. 25
  5.3 IMPLICATIONS OF THE STUDY ................................................................................. 26

6 CONCLUSION ......................................................................................................................... 27

7 ACKNOWLEDGEMENT ........................................................................................................ 27

8 REFERENCES ......................................................................................................................... 29

9 APPENDIX ............................................................................................................................ 34
  9.1 APPENDIX I - INTERVIEW GUIDE FOR PARENTS .................................................. 34
  9.2 APPENDIX II - INTERVIEW GUIDE FOR KEY INFORMANTS .................................. 36
1 INTRODUCTION

1.1 Background

Vaccination is frequently cited as one of the most efficient, low-cost and high-impact public health measures for preventing disease. Although many of the vaccine-preventable diseases (VPD) have the potential to be eliminated, globally they still represent a major cause of illness and mortality among children, adolescents and adults. An estimated 2.1 million people around the world died in 2002 of diseases that are otherwise preventable by widely use of vaccines (1). Among these, 1.4 million children were under the age of five, and over 500 000 of these childhood deaths were caused by measles. In Europe more than 100 000 cases of measles (2) and 30 000 cases of rubella (3) have been reported in the last four years.

Although all European countries have implemented vaccination programs for children overall in the region, an estimated 700 000 –1 000 000 infants born each year do not receive all of the scheduled vaccinations. Based on vaccination coverage data reported to the World Health Organization (WHO) between 2000 and 2010, close to 5 million children aged 2-12 years in the European Union (EU) had not received measles, mumps and rubella (MMR) vaccination (4). Thus, pockets of low immunization coverage for childhood vaccines have been documented across the European region (5).

Sweden has in general had a good vaccination coverage rate for many years, which is above the herd immunity threshold of 95% recommended by WHO. However, during the last years several outbreaks of imported measles and rubella have been reported, pointing to the presence of pockets of susceptible populations and the fact that the immunization program does not reach all people in the population. In 2012, there were 30 cases of measles (6) and 50 cases of rubella (7) reported in Sweden. This trend poses a serious threat to reaching the WHO European Region’s goal to eliminate measles and rubella by 2015 (8). Elimination refers to cessation of endemic transmission (no new cases) in a country or region, while eradication is reached when there are no new cases worldwide and vaccination can be ended (9).

WHO/Europe have recently developed a new methodology, called the Tailoring Immunization Programmes (TIP) for mapping underserved populations concerning vaccinations coverage, to be able to tailor specific interventions according to the needs of the specific groups. In collaboration with WHO Europe, the European Centre for Disease Control (ECDC) and Karolinska Institute, The Public Health Agency of Sweden (formerly Swedish Institute for Communicable Disease Control, SMI) launched a project 2013 to explore views, attitudes and experiences among hard-to-reach groups. The groups identified in Sweden to be most at risk of outbreaks based on national and regional vaccination coverage statistics and current knowledge, are the Somali community in Northern Stockholm, the anthroposophic community in Järna in the south of Stockholm, and the more diverse group of newly arrived migrants in Sweden. This qualitative study is part if the main TIP project and focuses on irregular (undocumented) migrants in Stockholm and Gothenburg.
1.2 Public health perspective

Vaccination is considered to be one of the greatest achievements of public health. It has greatly reduced the mortality and morbidity of various infectious diseases (10). WHO estimates that immunization saves more than 2.5 million lives worldwide each year (11,12). Thus, maintaining high vaccination coverage is necessary in order to control vaccine-preventable diseases.

Efficacious vaccines not only protect the immunized population, but can also reduce disease among unimmunized individuals in the community through “indirect effects” or so-called herd immunity, when a sufficient proportion of the group is immune. In general a high level of vaccine coverage is required to achieve elimination although due to herd immunity, some diseases can be eliminated without 100% immunization coverage.

The overall aim of the Swedish public health policy is ”To create social conditions to ensure good health on equal terms for the entire population” (13). Based on this, Sweden has identified 11 different areas of public health where "protection against communicable diseases" constitutes a specific target. It is also stated that vulnerable groups such as children, elderly and immigrants are particularly important target groups for preventive health care.

In general Sweden is in a favourable position regarding communicable diseases, mainly due to effective preventative measures such as vaccination programs. However, these national rates may hide clusters of under-vaccinated individuals, the so-called hard to-reach (HTR) populations. One such group are the newly migrated, and for this reason it is needed to collect more information about these individuals regarding risk of contracting vaccine-preventable diseases.

1.3 Nordic perspective

The foreign-born proportion of the population has increased steadily in all the Nordic countries since 1990 (14). The incidence of communicable diseases is similar between the Nordic countries as well as the National Immunisation Programs and vaccine strategies (15).

Each Nordic country has an authority equivalent to the Public Health Agency of Sweden that oversees and monitors communicable diseases and vaccination coverage. However, none of the Nordic countries monitor vaccine coverage among immigrants in a systematic way. Thus, there are opportunities for Nordic collaboration projects in monitoring of vaccination programs and of combating infectious diseases, in close collaboration with WHO, EU and ECDC.
1.4 Vaccine coverage

Assessment of vaccination coverage is one of the key parameters for monitoring the successes and difficulties in the implementation as well as for improving the quality and effectiveness of vaccinations programs (16). A high overall vaccination coverage in a specific country or geographic area is very important, but it is also necessary to have a high coverage on the local level. All EU countries collect and assess vaccination coverage data on a regular basis; however, the methods used vary widely (16). Moreover, the national immunization programs and strategies vary notably among European countries (16). Thus, there is still room for improvements in the immunization programs and for closer collaboration within the region.

1.4.1 In Europe

Estimated current immunization coverage rates in the WHO European Region are not sufficient to ensure herd immunity and stop the spread of VPDs in the Region. In some countries with previously high coverage, the rates have now fallen well below the 95% threshold recommended by WHO.

In general, at the European level there is little information on vaccination coverage among hard-to-reach/serve populations. The reported data is commonly based on surveys or data collected during outbreaks. A recent report from ECDC shows that vaccination coverage for different underserved groups is in general low with great variability: 7-46% among religious groups, 0.6-65% among anthroposophic communities and 0-82% for nomadic groups (Travellers and Roma) (5). Further, the report suggests that in some countries the childhood vaccine uptake is lower among migrants than in the indigenous population (17,18).

The undocumented communities were, however, not addressed in this ECDC report. Research on undocumented migrants’ vaccination coverage as well as their views, attitudes and experience of vaccination facilities is more or less non-existing. The Promovax project has explored policies, legislation and practices in regard to migrant immunization in some EU countries (19). One of the general findings was that the majority of the countries lack specific national laws and regulations on migrant immunization. In addition, there is no body assigned with the mission of monitoring immunization in the migrant population (19).

1.4.2 In Sweden

The Public Health Agency of Sweden is responsible for surveillance and prevention of communicable diseases. The agency works closely with regional health agencies and County Medical Officers to improve and sustain high immunization coverage of VPDs. The Swedish national immunization program (NIP) is offered free of charge and the county councils and municipalities are responsible for implementing the NIP through
the Child Welfare Centers (CWC) and school health systems (Pupil Health Care - Elevhälsan) that carry out the immunizations (20).

Despite a good vaccination coverage rate, during the last years there have been several outbreaks of imported measles and rubella. In 2012, there were 30 cases of measles (6) and 50 cases of rubella (7) reported in Sweden. These outbreaks point to the presence of pockets of susceptible populations. Local immunization statistics show areas of low MMR coverage in Sweden, within specific communities.

Migrant communities, particularly undocumented groups, are also potential pockets of susceptibility, due to their vulnerable situation and limited access to health care. In 2011 Sweden reported its first case of congenital rubella since 1985. It was an unvaccinated migrant woman from Vietnam, who arrived in Sweden at the age of 17 years and was not reached by complementary vaccination against rubella. Later during a visit to Vietnam she contracted rubella in early pregnancy (21).

A seroprevalence study performed at SMI showed that children born abroad, aged 14-16 years, have in general good levels of protection against vaccine preventable diseases (22). However, the study had certain limitations in terms of lack of representation of different migrant groups, sample size, high dropout rate and lack of information on children below six years.

There is scarce research and knowledge regarding the vaccination status among regular and undocumented migrants in Sweden. More information is needed about whether or not the group of newly migrated individuals are at risk of contracting vaccine-preventable diseases, both children and adults.

1.5 The migrant community

There is no uniformly agreed upon definition of migrants due to the diversity of the population, consisting of many different subgroups. However, the United Nations (UN) defines a migrant as “an individual who has resided in a foreign country for more than one year irrespective of the causes”. According to the International Organization for Migration (IOM) every 30th person today is an international migrant. Migration to the European countries has increased since 2000 (23) and an estimated 72 million migrants and of which 8 million undocumented migrants are living in the WHO European region (24).

Over the past two decades the issue of migration has been a top public concern across Europe and in all industrialised countries. A series of studies have been presented on migrants’ access to and use of health care services in Europe (25-28). Some of the studies are mainly focused on problems of accessing care, while other address the migrants’ experience of unequalex access to care and the complexity of health care entitlements. An analysis of migrant health status conducted by the ECDC found a lack of comprehensive information in most EU countries in relation to infectious diseases
and migration (29). In a series of papers on Migration and Health in the European Region, Rechel et al., have brought together key aspects of health and migration, pointing out legal entitlements as the main barrier to access of health facilities (24,30). Across Europe, there is evidence that migrant of all categories and status face significant barriers in attempting to access health care. Further, within the European region the legal barriers vary greatly for undocumented migrants (31).

About 20% of the population in Sweden has a foreign background i.e. foreign born persons (15%) and native-born persons with two foreign born parents (5%) (14). Each year Sweden grants residence permits to about 95 000 immigrants, more than 30% on grounds of family reunification. In 2011, 30 000 applied for asylum and a third of the seekers were granted residence permit. All asylum seekers are offered a free health screening including an evaluation of their vaccination status. However, due to weaknesses in the system, only four out of ten adult asylum seekers and two out of ten children below six years actually go through this health screening. By law, child health care services and school health are obliged to give complementary vaccinations to children up to 18 years old. The best link in this chain of events are probably the schools where eventually all children turn up and where vaccine coverage rates are fine. The Public Health Agency of Sweden is currently conducting a EU-supported project to increase the number of asylum seekers to undergo a health screening.

1.5.1 The undocumented community

Undocumented migrants are an increasing and vulnerable group consisting of individuals with different backgrounds, legal status and origin. It is estimated that 120 000-500 000 people enter the EU every year. Undocumented refers to third-country nationals without a valid permit authorizing them to reside in the EU Member States, including: i) rejected asylum seekers - those who have been rejected in the asylum procedure; ii) overstayers - overstayed the visas due to for instance family reunification; iii) entered the country illegally.

The undocumented community in Sweden is growing, currently estimated to 10.000-50.000 people (29). The undocumented population constitutes a heterogeneous group but is mainly composed of rejected asylum seekers. The exact number of people who never seek asylum and live in Sweden, as undocumented, is unknown. The undocumented migrants are an extremely vulnerable group (29) often living under precarious conditions with limited access to health care.

1.5.2 Undocumented children

Undocumented children in Europe are also a diverse group, including children to rejected asylum seekers, those who entered the country with relatives in a irregular way, children born in Europe but whose parents are undocumented; or minors arriving in Europe alone or to be reunited with their family (32). Undocumented children are in a position of extra vulnerability as children, migrants, and as irregular migrants.
Access to health care for children is of special concern given the knowledge that improper care has long lasting consequences on the development of the child (33). Further, under-utilization of preventive care has been associated with poorer health outcomes and higher mortality rates (34,35).

A report presented by the Platform for International Cooperation on Undocumented Migrants (PICUM) on health rights for undocumented children (32) shows that children are often subjected to the same immigration control measures as their parents, independently of the children’s entitlements. Thus, parents’ undocumented status hinders efforts to obtain proper health care for the children, in many cases being limited to urgent care services. Another report addresses the gap between the State obligations according to human rights law and the disparate local implementation in different European countries (33). The Health for Undocumented Migrants and Asylum seekers Network (HUMA Network) has recently presented a very comprehensive report on the legislation of access to health care for undocumented migrants and asylum seekers in four European countries. The authors discuss cases of missed vaccinations among newborns in Poland and Romania, and issues of cost for vaccination and fear of being reported when vaccinating a newborn (36).

Thus, there are several important practical obstacles that prevent undocumented children from accessing health care services, even if entitled. Access to health care in practice differs greatly from legal entitlements in many European countries. Particularly challenges encountered in relation to health care for undocumented children. In Sweden, the undocumented population of children is estimated to 2000-3000.

1.6 Access to health care and right to health

1.6.1 In Europe

The undocumented population constitutes a heterogeneous group and in many European countries their migratory status decides whether they have access to health care or not. Legal access to care for undocumented is different in different countries and entitlements often difficult to understand. Thus, several groups have attempted to clarify the complex situation of access to care for undocumented (33,37,38). A recent report showed that there are major discrepancies in relation to access and human rights law (39). Thus, health agencies and health care workers (HCW) need to cope with different challenges in different groups of undocumented who experience many difficulties in accessing health care (40-43).

Although increasing, existing literature on health and access to care of undocumented migrants in the EU is limited in terms of focus and quality. Woodward et al., have recently published a scoping review on undocumented migrant’s health and access to health services in the European Region (Eu27) (44). Barriers faced by undocumented migrants to access and use of health care services in the European region have been
identified and presented from different perspectives: the patient perspective (37,45,46) the legal perspective; the health professionals perspective (47); and from the children’s perspective (32). However, research addressing health care related challenges encountered by both the undocumented community and the health care professionals, is very scarce (48).

1.6.2 In Sweden

Sweden has a primarily tax-based decentralised health care system that provides universal access to residents holding a personal identification number (37,39,49). The responsibility for health care is divided between the government, the 21 county councils at a regional level and municipalities at a local level, with considerable freedom regarding organisation of health services. Patients can seek health care anywhere in the country on the same terms as in their county council of residence. Adults contribute to a minor part of the cost (out-of-pocket fee) while children below 18 years have health care services for free as well as women who need ante- and postnatal care.

Adults

In 2008, the act on Health and Medical Care for Asylum Seekers and Others was adopted (50). This law emphasizes the county council's obligation to provide health care for asylum seekers. However, adult asylum seekers are entitled, free of charge, only to “immediate care” and “care that cannot be deferred”, beside antenatal care, abortions and contraceptive counselling. However, no clear definition of the term “care that cannot be deferred” is provided.

Undocumented migrants were, in May 2008, for the first time referred to in relation to health legislation. From then on they have been explicitly excluded from subsidized health care, i.e. undocumented adults are entitled to “immediate/emergency care” only. However, the county councils may require them to pay the full cost, often at a much higher price than for Swedish citizens (37). In addition, administrative routines are often very complex. Persistent efforts and dedication from voluntary organisations and health professionals have prevented the authorities from issuing a law that formally prohibited provision of health care to undocumented migrants. Furthermore, some county councils allow access to pre-natal care service for undocumented pregnant women, and others have decided to grant rejected asylum seekers the same health coverage as asylum seekers.

Children

In 2000 a new legislation passed, granting the asylum-seeking children the same rights to medical and dental care as resident children in Sweden. To prove entitlement patients have to show their LMA-card, provided by the Migration board when applying for asylum. In Stockholm the asylum seekers are referred to two specific health centers that receive only asylum seekers.

Undocumented children, who were formerly asylum seekers, are entitled to free health and dental care on the same terms as resident children. However, undocumented
children, who have not been asylum-seekers, have no entitlement to subsidized health care. In view of the restricted legal entitlements to access health care for asylum seekers and undocumented migrants, Sweden has been heavily criticized for being inconsistent with international human rights law and treaties (51).

A new law was passed in July 2013 (52) that was extended to also include different groups of undocumented migrants, adults and children. The law should facilitate increased access to health care services.

2 AIM AND RESEARCH QUESTION

The general aim of this research project was to explore views, perceptions, attitudes and experiences of undocumented migrants, regarding their child’s immunization and access to vaccination and healthcare.

Specific aims were:

- To understand the availability and accessibility of vaccine services for the undocumented.
- To explore the views of health care providers and undocumented parents on childhood vaccination.

Research question

What are the experiences of undocumented parents on factors influencing them to vaccinate their children against vaccine-preventable diseases? How do nurses perceive parents experience on access to and use of vaccination services?

3 METHODS

3.1 Study design and setting

A collaborative pilot project between The Public Health Agency of Sweden, WHO/Europe, ECDC and Karolinska Institute was conducted in 2013. The main project “Measles and Rubella Vaccination in Hard-to-Reach Communities” in Sweden aims to understand barriers and facilitators for vaccinations in underserved groups and to find the most suitable and specific interventions to increase vaccination coverage and access to primary health care services in these groups. The collaborative project consists of three sub-studies targeting the anthroposophic community in Järna, the Somali community in Tensta/Rinkeby and undocumented immigrants in Stockholm and Gothenburg. The present study focuses only on the undocumented community.
This was an exploratory qualitative study carried out in Stockholm and Gothenburg, Sweden. An exploratory study design is appropriate since no previous information exists on childhood immunization among undocumented migrants in Sweden. We opted for qualitative in-depth interviews using semi-structured interview guides to obtain empirical and conceptual knowledge and to understand experiences from the informant’s point of view (53).

Study site

The study sites represent different health care facilities that provide services to undocumented communities in Stockholm and Gothenburg, including both public health facilities such as Child Welfare Center (CWC) and Non-Governmental Organization (NGO) driven facilities.

The three NGO clinics are non-profit independent charity facilities consisting of medical staff and health professionals offering health services to migrants (undocumented migrants, hidden refugees or rejected asylum seekers), who don’t have access to the regular public health care system. The clinics are hosted by the Red Cross and Läkare i Världen (Medecins du Monde) in Stockholm and the Red Cross/Rosengrenska foundation in Gothenburg.

The CWCs are located in areas housing a high percentage of immigrant population from different countries: Flemingsberg (Stockholm), Vantör (Stockholm) and Bergsjön (Gothenburg). Flemingsberg is a southern suburb of Stockholm with 12 000 inhabitants. The CWC in Flemingsberg has approximately 1000 registered children and around 98% of them are either foreign born or native born with foreign-born parents. In 2011, the MMR vaccine coverage at the age of two years was 88.8%. Vantör is a suburb in the southern part of Stockholm. The CWC in Vantör has in total 800 registered children. Vaccination data from the Public Health Agency of Sweden showed that in 2011 the MMR vaccine coverage at age two years was 95.9%. The CWC in Bergsjön with approximately 1500 registered children is located in the eastern part of Gothenburg, with approximately 16 000 habitants. As of 2011, there were over 140 nationalities represented in the district and more than 75% of the inhabitants were foreign-born or had parents born abroad. The Bergsjön CWC has around 1600 registered children. In 2011, the MMR vaccine coverage at age two years was 94.8%. However, we suspected that subpopulations within these communities had even lower vaccine coverage.

3.2 Participants and recruitment

The participants were recruited using purposive sampling in order to include appropriate informants (54). In addition, emergent design was applied throughout the study and changes were made in order to adapt the research process as new information was gained or problems encountered (54). The study population consisted of CWC nurses and undocumented parents.
Nurses

Three female CWC nurses with extensive experience in pediatric health services, working at CWCs based in Bergsjön, Flemingsberg and Vantör were recruited. They responded to information about the study that was sent to the Child Health Consultants in Stockholm and Gothenburg, who are in charge of the implementation and monitoring of the National Immunization Program at a regional level. The information sent out asked for assistance to get in contact with paediatricians and CWC nurses, particularly in areas with a high proportion of immigrants.

Undocumented Parents

The interviewed parents were undocumented migrants with children at preschool age (<7y), visiting the CWCs. The parents, six females and two males, had a mean age of around 30 years. They were from six different countries, representing different regions in the world. Most of the parents were former asylum seekers being undocumented for less than three years. These parents were recruited through the NGO clinics. In close cooperation and dialogue with health professionals, we decided to start approaching the parents with a written invitation to participate. Information about the study and the invitation to participate was then translated to relevant languages: English, Spanish, Mongolian, Dari and Russian, and posted in the waiting room at the Red Cross clinic in Stockholm. Parents were asked to contact the author or the health care providers at the Red Cross, if they were interested in participating or if they wanted to know more about the study.

Table 1. Characteristics of the parents

<table>
<thead>
<tr>
<th>Study Nr</th>
<th>Sex</th>
<th>Region of origin</th>
<th>Time as undocumented</th>
</tr>
</thead>
<tbody>
<tr>
<td>P-1</td>
<td>F</td>
<td>Middle East</td>
<td>2y</td>
</tr>
<tr>
<td>P-2</td>
<td>F</td>
<td>Africa Former Soviet Union</td>
<td>1,5y</td>
</tr>
<tr>
<td>P-3</td>
<td>F</td>
<td>Former Soviet Union</td>
<td>3y</td>
</tr>
<tr>
<td>P-4</td>
<td>F</td>
<td>South America</td>
<td>&gt;5y</td>
</tr>
<tr>
<td>P-5</td>
<td>M</td>
<td>Former Soviet union</td>
<td>3y</td>
</tr>
<tr>
<td>P-6/7</td>
<td>F and M</td>
<td>Middle East</td>
<td>1,5y</td>
</tr>
</tbody>
</table>

Due to a low number of interested parents we also used a more proactive approach where the staff at the Red Cross actively presented the information about the study and asked parents with pre-school children if they where interested in participating. In addition, the author participated in weekly drop-in activities in order to interact with
parents and asked directly if they would be interested in participating in the study. The latter approach was the only approach used at the Rosengrenska Clinic in Gothenburg. One mother whom we approached declined to participate due to inconvenient timing since she was close to delivery.

Thus, the parents were recruited either through announcement in pamphlets, by direct invitation by the health care providers or by the author, assisted by a volunteer at the NGO clinics.

3.3 Data collection

Data were collected from May to August 2013 by the author. A total of nine (3 nurses and 7 parents) in-depth interviews with ten participants were conducted using a semi-structured interview guide until saturation was reached (55) meaning that additional data collection (interviews) would not yield new relevant information. One interview was carried out with two participants (parents) at the same time.

Data were collected using two different semi-structured interview guides. The interview guide for data collection among nurses explored their views and information on undocumented migrants’ access to health, so called entry/exit points (Appendix I). The interview guide for the parents explored vaccination experience, attitudes and access to health (Appendix II).

The interviews were audio-recorded and ranged between 35-60 minutes. All interviews with CWC nurses were held in Swedish. Interviews with the parents were, except for two interviews, conducted with interpreters. All interpreters were professionals, except for one who was a volunteer at the NGO clinic. In total interviews were conducted in six different languages. Convenient time and place for the venues were decided by the participants in order to make them feel comfortable.

3.4 Data analysis

The interviews with CWC nurses and undocumented parents were transcribed verbatim, reviewed and analysed using content analysis, a widely used qualitative research approach for studying the content of communication such as interviews (53,56). The interviews with CWC nurses and the parents were analysed separately by the same analytical approach, using both Excel software to facilitate the initial coding of the texts and post-it notes at a later stage of the analysis.

Following transcription of each interview, the texts were read through several times by the author to obtain a sense of the material. The data was analysed using Swedish and English: the initial coding was done in Swedish, except for one interview that was conducted in English. The texts were labelled with codes and related to different topics. Thereafter, the author read together with the main supervisor, and the codes were
further discussed and adjusted. At this stage the texts were orally translated and the codes written in English to facilitate a continued joint analysis. Coded data within the same content areas were grouped and compared for similarities and differences. Codes with similarities were then gathered into sub-categories, which subsequently supported the constructed categories. A second round of discussion and reflection took place wherein the latent content of the categories, representing more abstract levels of the meaning, was interpreted into themes. Relevant quotes were translated from Swedish or Spanish into English by the author.

3.5 Ethical considerations

The study participants were informed about the study in writing and further explanations were given orally. They were also informed that participation was voluntary and could be interrupted at any time. It was also emphasized, especially for the parents, that the information would only be accessible to the research team and that answers would be processed anonymously. Consent to participation was obtained by every interviewee before participation, either written or orally. The informants received no economic reward or other incentive.

Recruiting undocumented migrants and conducting research in this vulnerable community is very sensitive. Participant safety and anonymity of the families in question must be guaranteed. Therefore, the study is conducted in close collaboration with the health care providers with thorough experience of undocumented individuals. The content and the detailed information regarding the interviewees presented were carefully reviewed for potential harm before included in the final report.

The study received ethical approval from the Regional Ethics Committee in Stockholm, Sweden, Dnr 2013/678-31/3.

4 RESULTS

The data from this study revealed two main themes; parental acceptability of child vaccines and parental fear of been questioned (Table 2). The latter theme consists of three categories that focus on challenges faced by undocumented parents when seeking vaccination care for their children. The problem lies at the utilization level rather than accessing the service, where fear of being asked for documents was strongly expressed. The immunization program requires several visits in a child’s life. This poses a problem for undocumented parents’ high frequency of mobility. Despite knowing that every child has a right to health services in Sweden, undocumented parents express mistrust towards health care providers, thus avoiding the health facility.

The other theme parental acceptability of childhood vaccines is based on two rather positive categories where parents illustrate high knowledge of benefits of vaccination in
general and have shown acceptability to uptake vaccines for their children when legal issues are overcome.

Table 2. Summary of themes and categories

<table>
<thead>
<tr>
<th>Theme</th>
<th>Parental fear of been questioned</th>
<th>Parental acceptability of childhood vaccines</th>
</tr>
</thead>
<tbody>
<tr>
<td>Category</td>
<td>Fear of being detected</td>
<td>Difficulties in immunization on follow-up</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Distrust overriding the knowledge of rights</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Vaccine acceptance</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Knowledge of importance of vaccines</td>
</tr>
</tbody>
</table>

**Parental fear of been questioned**

_Fear of being detected_

Fear of being asked or being detected is always present, affecting the everyday life of the undocumented families and children. Parents expressed a strong sense of fear of disclosure when seeking health care for either their children or themselves. Some of the parents had personal experience of having been in contact with regular health care services for adults. Others had never dared to seek health care as undocumented.

_I'm so scared and so ashamed that I don’t have a residence permit. It's difficult to seek health care. I'm always so scared because I have no address, I'm afraid of what will happen and I feel constant fear of being discovered._ (Parent)

The CWC nurses commented that many of the undocumented families are very afraid of visiting a health care facility even if they know that primary health centers would receive them. This is grounded in not having confidence in the health staff they meet at a regular health facility.

One of the nurses commented that sometimes it takes several visits before the families dare to tell that they are undocumented. The parents often told the nurses that they are waiting for their papers or gave different reasons for not having documents. The nurses tried to be very clear from their first encounter:

_You know, whether you’re waiting for a residence permit or are undocumented, you are allowed to visit a CWC. Everyone has the right to come. We do not care about it (the status) and we'll try to help you and your child._ (Nurse)

However, the nurses pointed out that it is very important to tread carefully. They cannot ask too many questions at once. They have to probe the situation. The nurses
approaches the families carefully since they want the parents to come back to the CWC in order to assist and serve them. The parents mentioned different ways of keeping the children healthy to try to avoid attending health care clinics. One mother tried to avoid seeking care for what she thought were minor complaints from her undocumented child, such as seasonal flu or gastroenteritis. She used homemade herbal remedies instead. Another coping mechanism mentioned by several parents was to teach the children good hygiene, or to prevent the children from playing with water and get wet, or simply to pray for the children.

*I try to keep an eye on them so they don’t get sick. I teach them good hygiene; it should be clean so they don’t get germs.* (Parent)

**Difficulties in immunization follow-up**

Movements within the country due to their legal status complicate the follow-up at the CWC. Common for undocumented families is that they often move from one place to another due to the illegal status. The previously established contacts with health care are then broken, and new appointments must be made. This situation ultimately might delay the monitoring of children's development and immunization. The CWC staff works hard to get the parents to come back to the CWC. The nurses reasoned that if the undocumented parents have a good experience of a CWC, they might be less reluctant to visit another child health center when they move.

In general, the parents who maintain contact with the CWC often complete the vaccination schedule. The nurses acknowledged that if possible, some parents choose to travel far to visit the same CWC where they feel safe. However, some of the families just move around.

*Suddenly we cannot get hold of the family or they might say that they are going home, they can’t stay here...* (Nurse)

Parents have in general no detailed knowledge of the immunization program or schedule, but they try to follow the scheme and trust the health professionals’ guidance. All of the interviewed parents mentioned that their children had been vaccinated, either in their home countries or transit countries. Some parents had more detailed information on what type of vaccines the children had received.

*I know they have received vaccines against measles, rubella and hepatitis in country X.* (Parent)

Other parents just knew that the children were vaccinated and had received what they needed according to a schedule.

The biggest challenge for the health care providers at CWCs was to get the undocumented parents to continue coming to the centers. The same applied for the asylum seeking families.
The nurses reasoned that as long as the parents bring the children to the CWC, the staff could assist them with health related issues. Most of the families often need help with so many other things in the everyday life situation, but the CWC staff cannot help them with all issues. Support is needed from many other sources for economic and legal issues.

*We can try to help them to put the focus on the child, helping them to see their children’s needs.* (Nurse)

As the nurses expressed, sometimes it is difficult to raise other childhood related issues when they know that the family does not even know where to stay or sleep the next day.

The nurses felt that there was a lot of tinkering and changing in the individual vaccine schedule. Not because the parents deliberately want to postpone the vaccination schedule, but merely because they are traveling with the children at an early age. Some families are away for a long time. This can alter the whole vaccination scheme, impeding completion. In addition, there must be a certain period of time between the immunizations.

The nurses can only advise and give recommendations to the parents, but they cannot prohibit the parents to travel with small children. After all, it is the parents’ responsibility.

*I often say quite clearly to all parents: when the child is 18 months, then it’s ready for a journey. Before that, the child has not sufficient vaccination coverage. Then it’s up to the parents.* (Nurse)

*Distrust overriding the knowledge of rights*

Children are entitled to health care, but sometimes due to the parents’ life situation the rights cannot be fulfilled. The interviewed nurses commented on the undocumented parents’ lack of awareness of their entitlements regarding health care for the children. The entitlements are different depending on where they are in the asylum seeking process, which contributes to some confusion.

The parents might have the knowledge but mistrust the information due to previous experiences or rumours.

A nurse expressed it as:

*They hear what you tell them but they don’t really trust that it is right. They know that their children are supposed to receive health care, but they don’t dare to trust that the health care professionals will not contact the police or the authorities.* (Nurse)

Contrary to the nurse’s opinion, most of the parents expressed that they are aware of their children’s entitlement to health care. However, they were also well aware of the barriers despite the entitlements:
The children have the right to go to the hospital for treatments even if they don’t have the permit or a phone number. But if I go to the hospital, they tell me to bring an ID. (Parent)

The interviews revealed an important observation: there seemed to be a certain confusion among the parents regarding the differences between the health care services provided by the CWC and regular health center and hospital. It was not fully clear for the parents that the CWCs provide preventive care for children, while the primary health centers provide curative care for children and adults. Thus, if the parents have once been turned away from a primary care center they might be afraid of seeking a CWC later on.

In general the NGO clinics refers children to the regular health care, either to a CWC or a primary health center. Anyhow, quite often parents need assistance with at least the first appointment at a regular health facility.

**Parental acceptability of childhood vaccines**

*Vaccine acceptance*

All interviewed parents had a positive attitude towards vaccinations. They were keen to get the children vaccinated since they perceived vaccination as a means to keep children healthy. The nurses reinforced this attitude: they were consistent in their opinion that the undocumented parents visiting the CWC had a very positive attitude towards vaccinations. Either they came from countries where there are more dangerous diseases and more frequently occurring, or they came from countries where vaccination is compulsory.

The nurses believed that parents see vaccination as an important benefit they were offered, and that they also trusted that the vaccines had been tested and were good. When asked if the parents have concerns about vaccines, a nurse put it like this:

> All parents, regardless of where they come from are caring for their children and would not like to expose them to unnecessary things. But they do hesitate to vaccinate. (Nurse)

Some parents were worried that the sting from the injection would hurt the child. But above all, parents were worried that the children would get very high fever after immunization. This may be due to the fear of having to seek medical care for the children if they get ill. All interviewed parents expressed gratitude toward access to child vaccination. They gladly accepted news as well as complementary vaccines referring to the benefit.

The parents did not think of the option of not vaccinating the children. Most of the interviewed parents were familiar with the terms of mandatory National Immunization Programs in their home country and were used to receiving a call for vaccination of the children. Thus, the question whether to vaccinate or not was never raised.
Participants said that they would consult their CWC medical staff for guidance should they require more information on vaccines.

*It is the doctor who knows which vaccines to give my child. I wouldn’t know what vaccines to choose.* (Parent)

The parents expressed that in Sweden the CWC nurses were engaged and keen to giving good health services to the children. The perception of having their children ‘well looked after’ was mentioned by several parents.

Parents also mentioned that they had received proper information at the time of immunization.

*They explained that the vaccination was for preventing diseases, such as TB and cholera.* (Parent)

Reassurance regarding the health of the children was frequently cited as a motivation for having the children vaccinated.

**Knowledge of importance of vaccines**

Many participants were aware of the importance of vaccination, although a major topic was to keep the children healthy in order to avoid disease thereby avoiding seeking health care. The parents had a general knowledge that vaccines protect against childhood diseases. Some of the parents were also aware of the risks associated with childhood diseases.

*In the past when there were no vaccines, many got measles and died. With vaccines they get a milder disease.* (Parent)

According to the nurses many families come from countries where they know someone who has died in various childhood diseases so they know the importance of vaccines. Families from such countries are more eager to have the children vaccinated.

According to the CWC nurses, awareness and knowledge of the importance of vaccination to prevent child disease among undocumented migrants is high. However, many undocumented families have large difficulties in their everyday lives, so CWC visits are not something they prioritize, especially if the child is 2-3 years old, suggesting that the visit frequency declined as infants grew older.

*If they have an infant, they are probably thinking more on CWC visits and vaccinations, otherwise CWC is not their first priority. It is to pass the day, to have food for the day and so on.* (Nurse)
5 DISCUSSION

5.1 Discussion of findings

The purpose of this study was to explore views, and experiences in accessing child health care and attitudes towards childhood vaccination among undocumented parents. To our knowledge, this is the first qualitative study in Sweden by in-depth interviews of undocumented parents and health care workers regarding childhood vaccination.

We found that undocumented parents had a positive view and attitude towards childhood vaccinations. Parents did not question or decline immunization; on the contrary they were grateful for the service since they considered vaccination as an important measure to keep their children healthy, thus avoiding to seek health care for sick children.

Literature and data on vaccination coverage among migrants and children of migrants in the EU, including Sweden, is scarce. Data on undocumented migrants’ vaccination coverage or attitudes and experience of vaccination is even more limited. It is important to note the temporary and transient feature of immigration statuses. For instance, many migrants may migrate regularly, lose their status becoming “undocumented” at one point or another in the process of seeking asylum, and later have the opportunity to regularize their status again within a short period of time. Thus, what applies for regular immigrants may also apply for the undocumented community. The complex process of regularity/irregularity contributes to confusion regarding entitlements for children and adults.

A positive attitude toward immunization is essential for vaccine uptake. A review of grey literature identifies that the major determinants of child under-vaccination are related to immunization services and to parental knowledge and attitudes (57). The findings in our study show that undocumented parents have a positive attitude to vaccination - parents believe that vaccination is good for their child’s health and prevents various diseases. In addition, a positive relationship between health staff and parents, making the parents feel comfortable, may influence continuity of care. Several studies across Europe have shown that healthcare providers ranked first among most used and most trusted sources of information on vaccines (58). This corroborates our findings where parents exhibited a high degree of trust in paediatric-care providers at the CWC facilities. In addition the interaction between patients and providers is the cornerstone of maintaining confidence in vaccination.

Our findings demonstrate that there are problems in accessing healthcare for undocumented migrants, which is also supported by previous reports (40,59). Issues regarding fear of seeking health care due to lack of personal identification and permanent address, as well as requests for full payment have also been highlighted in other reports (37). In our study parents describe experiences of being rejected or questioned at health facilities for adults and children, including vaccination services.
However, no reports of proved missed opportunities of vaccination, as those discussed in the report by the network HUMA, have being reported in Sweden (36). The network, reports of an asylum seeker’s newborn that was never vaccinated, although there should have been access to health coverage, which also included vaccination. Moreover, several undocumented mothers had to pay for having the newborns vaccinated. Furthermore, a mother opted for not vaccinating her child, as she didn't want to take the risk of being reported.

Also, the role of the NGO clinics and organisations in assisting undocumented migrants to access health care has been highlighted (37,60). In our study access to vaccination services were facilitated and improved by the assistance of health care workers at the NGO clinics, the Red Cross and Médecins du Monde. A survey conducted in 2008 by Médecins du Monde Sweden in Stockholm (61) showed that the majority of interviewed undocumented migrants never went to the public health centers because of the fear of being reported. This agrees with the findings of this current study, where several parents described negative experiences encountering regular health care providers with whom they did not feel welcome and were asked for identification. Some of the interviewed parents would never seek health care for themselves due to fear of disclosure. Similar findings have been presented in other studies (62,63).

In a review of migrant health in the EU, entitlement issues were mentioned as a major barrier for access to health services (64). Studies of migrants in the European community show that migrants are reluctant to reveal information about their migrant status due to fear of denunciation and deportation (65,66). Beside the restricted legal entitlements to health services and the administrative obstacles, the migrants are particularly affected by the user fees (67). One of the barriers expressed by the interviewed parents is the request for payment at regular health care facilities. Direct and indirect costs of accessing health services are important determinants of sub-optimal vaccine uptake.

Until recently, undocumented migrants in Sweden, including children (other than children of rejected asylum seekers), pregnant women, or persons in emergency situations or with serious infectious diseases did not have any access to health care free of charge and had great difficulties paying the high costs of the health services. However, there is no formal prohibition to provide care to undocumented migrants, so some county councils and public hospitals have adopted initiatives to provide some health care to this very marginalized social group (49).

Recent publications have been looking at factors associated with vaccination acceptance, refusal or hesitancy (68,69) in developing countries and some of them have focused on parental decision-making toward different childhood vaccines (63,70). Decision-making among undocumented parents in our study is not an issue, since the option of not vaccinating is never considered by them. An important observation in our study is that the parents were confused regarding the difference between preventive health care provided by the CWC and curative health
care provided by regular health care facilities. Lack of understanding of the health care system as a barrier to access to health care has also been reported by others (60,71).

Other barriers include unfamiliarity with rights, entitlements, and the overall health system as also reported by others (30,64). One study (28) suggests that knowledge of the health care system and awareness is crucial. In the report from PICUM it is stated that, if families are not aware of their child’s right to health care, they will not go to a doctor except under extreme circumstances. In our study we found that parents seemed to be aware of their child’s entitlement, but they did not trust the system.

A systematic review has recently been presented regarding the importance of health workers attitudes to vaccination, concluding that the existing studies show associations between health care workers’ knowledge, beliefs and attitudes and their intentions to vaccinate the populations they serve (72). The CWC nurses in our study were all pro-vaccines, expressing that it would be difficult to work at a CWC being against vaccines.

Although this study has focused on the CWC facilities, other reports have shown that undocumented migrants may come across problems earlier in the system, for instance at the encounter with administrators at the hospital or at curative health care centers (37,48). Thus, this confirms the complexity of undocumented migrants access to health facilities for both, children and adults, suggesting barriers at different levels of the health care system.

In Sweden a new law was passed in July 2013 (52), increasing health care entitlements to cover all undocumented children regardless of their previous legal status. Free child health care is to be provided, both preventative including vaccination services, and curative and also dental care under the same conditions as residents/nationals in Sweden. The new law is also extended to all adult undocumented migrants, regardless of their previous legal status, to allow their access to emergency care and "health care that can not be deferred‖, although, the health care seekers may be requested to pay the full cost.

However, legal entitlements do not necessarily correspond with access to health services since children’s right are often overridden by the fact that their parents do not have the same entitlements. In accordance with the principles proclaimed in the United Nations Convention on the Rights of the Child (UNCRC) (73) all children have the same rights. Furthermore, article 24 states that children have the right to good quality health care – the best health care possible. Moreover, the right to health includes access to health services i.e. the right to timely access appropriate health services. The right to health also involves prevention and awareness campaigns. Prevention plays an essential role in maintaining public health, particularly children’s health. In fact, immunization coverage is often used as an indicator to assess health system capacity and primary health.

Sweden has ratified a number of international human rights treaties (39), including the UNC (73) that contain a right of access to health care services. Such human rights apply, in principle, to all residents in a country, regardless of citizenship or migratory
The WHO promotes the core message that the immunization of every child is vital to prevent diseases and protect life. Immunization is not only an effective intervention to reduce disease and death; it can be used as a strategy to help reduce inequalities in the delivery of primary health care. Thus, access to immunization is considered positive not only from a human rights perspective but also of public health benefit.

5.2 Methodological considerations

5.2.1 Trustworthiness

The choice of a qualitative approach for data collection and analysis was motivated by the explorative nature of the study due to lack of previous information on vaccination among undocumented migrants in Sweden. The methodology has been considered in order to achieve trustworthiness through the research process considering the three most commonly proposed components: credibility, dependability and transferability (56).

Credibility refers to confidence in how well data and analysis address the intended focus of the research. Research on undocumented migrants is a very sensitive issue. The research team regularly raised ethical issues and implications of the study objectives, data collection and reporting. The research is also complex and challenging due to the apprehensive and clandestine nature of undocumented migrants. Therefore, meetings and discussions with medical staff and volunteers at the NGO clinics as pre-interview fieldwork were valuable to increase the understanding and knowledge about the undocumented community.

The inclusion of both undocumented parents and key informants (CWC nurses) in the study provides a holistic overview addressing views and issues of barriers and motivators to childhood vaccination from both the undocumented parents and the health care providers’ perspective.

When conducting research on ethically sensitive topics or groups, such as undocumented children, there is a risk of social desirability bias i.e. health professionals may withhold information that can discredit their work or profession while parents may have been influenced by perceived social desirability. However, childhood immunization is a topic of high interest and concern for both parents and healthcare professionals. Thus, the general impression was that the participants - both nurses and parents - freely engaged in the interviews, generously wanting to share their views and experience. The interviewer, assisted by NGO volunteers regarding parents, made every possible effort to provide a comfortable interview environment and secure anonymity throughout the study.

Throughout the analysis process, data was discussed within the research team consisting of individuals with different cultural and professional background to strengthen the
dependability. In addition, to ensure reflexivity, transcripts were read several times, data was discussed, and supervisors were consulted. In addition, after data collection and analysis, a workshop was conducted assisted by consultants from WHO/Europe, to further discuss the findings according to the TIP approach.

For obvious reasons it very difficult to assess the size of the undocumented population and estimate the proportions of the undocumented parents who do visit any health facility or NGO clinic for further referral to a CWC. We do not know about their attitudes and experience of vaccination - they might have a different attitude towards health care and thereby to vaccination. Thus, the findings of this study may not be generalizable for the whole population of undocumented children. Detailed information about the context of the fieldwork of this study has been provided in order to facilitate other researchers to decide whether the findings can be applied to other settings.

In the case of the participants who were interviewed through interpreters, the quotes chosen are the interpretation of the original translation of the interpreter, subsequently translated to English. Thus, the extracts used are the translator´s best attempt at straight transmission of concepts from the participant’s statement (74).

One of the interviews was conducted with a married couple. The spouse had a more active participation in the interview while the wife mostly agreed by nodding.

These findings are based on interviews with seven parents from six different countries; even though we reached saturation with the questions asked to seven parents, it would have been interesting to find a larger group from each country.

To summarize, the study has a number of strengths: a) The findings are based on data from different settings in Stockholm and Gothenburg; b) the parents are from different countries with different background and histories of immigration; c) the interview scheme was more specific, targeting views and access to vaccination services rather than the more often studied issues of access to regular health care.

The are, however, also several limitations: a) the interviewed nurses were self-selected which may have introduced a bias, e.g. nurses with a particular interest in the undocumented community or with specifically positive/critical view; b) interviewed parents were those who visited a health care facilities, thus, we do not know about the attitude and experience of vaccination of the non-visiting parents; c) statements and answers, in particular from the parents, may have been influenced by perceived social desirability; d) by the use of interpreters for interviews, information may have been lost or not perceived by the author.

5.3 Implications of the study

This study should be viewed as an exploration of a complex social and legal phenomenon, potentially affecting the health of undocumented children in the long run. The study highlights the need of accurate estimates of the number of undocumented
families that actually seek health services, particularly at the CWC facilities. In addition, there is a poor knowledge of vaccination coverage and immunity status among migrants, particularly in the undocumented community. A seroprevalence study targeting the migrant community and newly arrived needs to be conducted.

The findings can serve as a basis for further analysis of sources and channels of information and communication about childhood vaccines and vaccination services and for interventions to improve the access to CWC for undocumented parents and completion of the vaccine schedule. Furthermore, the findings in this study are important from a public health perspective in Sweden and other Nordic and European countries. The community of undocumented with different legal status is increasing in most European countries. Understanding how undocumented parents, a vulnerable group, are reasoning and coping with the access to health care and childhood vaccination is essential so that measures can be tailored to facilitate the access.

Future studies are needed to obtain a complete picture and understanding of how parents in the undocumented community reason regarding vaccinations and access to health care. In this study we have recruited parents through NGO clinics and thereby only targeted the parents who seek health care for their children. However, it would be valuable to understand the reasoning of parents who do not seek for or do not have access to health care for their children.

6 CONCLUSION

The study informs that undocumented parents are aware of their child’s rights to receive vaccinations but fear of revealing their illegal status overrides their willingness to vaccinate their child. Thus, additional and specific efforts to restore trust in the health care system are needed.

7 ACKNOWLEDGEMENT

My sincere thanks to;

The study participants and key informants for invaluable contribution to this thesis:

The undocumented parents, that generously shared their experiences, difficulties and struggles in their everyday lives, wishing a better future for their children - the most precious thing they have.

The CWC-nurses and Child Health Consultants, the staff and volunteers at the NGO clinics for undocumented migrants in Stockholm (Röda korset, Läkare i Världen, the Antenal clinic in Rosenlund) and Gothenburg (Rosengrensko) - for letting me take part of their views, great knowledge and experience with the undocumented community and all assistance despite their hectic schedule.
Rigmor Thorstensson - former head of the Dept. of Immunology and my Mentor - for unlimited support and encouragement to pursue further studies in Public health; Ann Lindstrand for inviting me to participate in the Hard-to-Reach project, always with genuine interest in my work, enthusiastic support and great input.

Asli Kulane (main supervisor) for introducing me to the Qualitative world and for excellent support and guidance throughout the thesis process; Henry Ascher (co-supervisor) for great knowledge and being a big source of inspiration from the very first moment at NHV, giving my public health studies an invaluable human rights perspective.

The TIP-research team; for good collaboration in the Hard-to-Reach project, particularly Nathalie Likhite and Robb Butler for excellent guidance and support during the TIP workshops and planning of the study.

My new NHV-friends and classmates - especially Margareta - for support, good study collaboration and nice study environment that made it a lot easier to be away from my family; the administrative staff at NHV- especially Susanne and Cecilia - for greatly appreciated technical support, and Lene for meticulous and dedicated work as the examiner.

Special thanks to my family: Juan Carlos, my dear husband and greatest supporter, for patiently taking care of the family and all practical issues during my endless trips to Gothenburg. To my beautiful sons Leandro and Andreas, and my extra sons Mauricio, Roberto and Herman, for love and joy; last but not least my dear parents and sisters with her families - you have all contributed a great deal to my studies.
8 REFERENCES

(9) CDC. The Principles of Disease Elimination and Eradication . 1999; Available at: http://www.cdc.gov/mmwr/preview/mmwrhtml/su48a7.htm.


(23) Herm A. Recent migration trends: citizens of EU-27 Member States become ever more mobile while EU remains attractive to non-EU citizens. Eurostat-Statistics in Focus 2008.


(34) Hadley J. Sicker and poorer—The consequences of being uninsured: A review of the research on the relationship between health insurance, medical care use, health, work, and income. Medical Care Research and Review 2003;60(2 suppl):3S-75S.


(36) HUMA network. Access to healthcare and living conditions of asylum seekers and undocumented migrants in Cyprus, Malta, Poland and Romania. 2011.


(45) Chauvin P, Parizot I, Drouot N. European Observatory on access to health care European Survey on undocumented migrants' access to health care 2007.


(65) Gushulak BD, MacPherson DW. The basic principles of migration health: population mobility and gaps in disease prevalence. Emerging themes i epidemiology 2006;3:3-14.


http://digitalcommons.ilr.cornell.edu/child/8

9 APPENDIX

9.1 Appendix I - Interview guide for Parents

Background information

- **Respondent**: Age, sex, education, country of origin, time spent in Sweden, time as undocumented, reason for being undocumented.

- **The family**: Family members with them in Sweden, number of children in Sweden, age and sex of the children, do the children attend a day care center or school?, do you/other adults have access to health care?, do the children have access to health care through the day care center or school?, do the children participate in other activities outside day care center or school?.

A. Child well-being and parental care

- What is like being a parent today? What are the biggest problems that you are facing as a parent of small children?
- What about the child health? What do you do to keep your children in good health?
- What health matters of your child are of most concern to you? With whom do you discuss these health matters of your children?
- What would your children need for well-being?
- When it comes to medical treatment of the child, whom do you trust?

B. Access to health care – (entry/exit points)

- What do you do when your child is ill?
- Can you tell me about the last time you sought medical attention for your child?
- How did you find out about the clinic/health facility?
- How often do you visit the clinic? For what? Purpose? Type of health care?
- How do you experience your visit at the health facility?
- Would you like to have/need other type of health care for your child than that offered at the clinic? What type?
- Have your child been offered a health screening in Sweden or in another country?

C. Childhood vaccination - diseases, benefits and dangers

- When you hear: “childhood diseases”, what comes to your minds?, can you give example of childhood disease, have your children had any childhood disease?
- Can you give example of dangerous childhood diseases? Describe the symptoms? Know of anyone close to you who has experienced a dangerous childhood disease? What happened?)
- Have your child been vaccinated?
- What are the benefits of vaccination against child diseases?
What are the risks of vaccination against child diseases?
At what age should children be vaccinated?
At what age should children be vaccinated and when should children NOT be vaccinated?

D. Parental decisions and experiences with childhood vaccination and acceptance
- With whom do you discuss the decision to vaccinate your child?
- How do you know when to vaccinate or not vaccinate your child?
- Where do you get/find information about vaccination when you need it?
- Are you familiar with the Swedish childhood vaccination schedule?
- Do you have any concerns do you have regarding vaccination of your child?
- Do you have any concerns do you have regarding accessing health care for your child?
- If concerned, what is needed to get rid of or at least diminish your concerns/fear?
- If you or a family member were in need of supplementary immunization and the clinic could provide that, would you accept vaccination?
- If vaccinated - Please describe what satisfies you and what does not with the level of information provided to you by the doctor before or during the vaccination session?
- If you would like to have more information about vaccines and the schedule/program, how would you like to receive that information?

E. Recommendations and Closing
- What recommendations do you have to improve the provision of vaccination services for the undocumented parents?
- What are the best ways for undocumented parents to receive information on vaccination?
- What can be done to strengthen the parents in their decisions to vaccinate their children?
9.2 Appendix II - Interview guide for Key informants

Background information - All key informants
- Please describe your role, position and responsibility area within the health center.
- Can you describe the way you proceed when you meet a family for the first time at the center. Please describe the procedure.
- What type of patients (migrants/undocumented) comes to the center? Socio-demographic information
- What type of health care do they look for?
- How do they find out about the clinic or center?

A. Access to health care (entry/exit points) - (All key informants)
- How do you get in contact with undocumented children? Which are their entry points to the health care system?
- Have the parents being in contact with paediatric health care before they become undocumented? Do they keep/loose that contact point after becoming undocumented? (Exit point?)
- Do you know if the parents are aware of their entitlement to access to health care?
- If so, what prevents them to seek for regular/mainstream health care?

B. Informants views/perception about vaccination and immunization service - (mainly CWC staff)

Information and access
- Do you have any vaccination service at the center? What does the service include?
- What do you think about the service? If no service, is there a need for that?
- What do you know about migrant’s vaccination status (regular and undocumented)?

Perception, attitude, need
- What is your personal opinion about vaccinations or vaccines? why?
- Are you familiar with and what do you think about the national immunization program (NIP) in Sweden?
- Is there any reason for not vaccinating a child? Other than contraindications?
- Where do you find information about vaccines?
- Do you feel you have knowledge and skills enough about vaccines?

C. Community views/perceptions about vaccination and the immunization service - (mainly CWC staff)
• Is there any specific attitude or perception towards vaccination? To health care? (Any specific group of patients? Differences between the groups?)
• Do parents ask specifically for vaccination for their children? (Which group, what reason, proportions?)
• Are there parents who do not want to vaccinate, do not complete or delay vaccination for their children? (Any specific group? reasons? proportions?)
• Do you try to convince them? If so, how do you proceed?
• Do you think parents have concerns regarding childhood vaccines? Any example?
• If any, what possible barriers to access vaccination service are there among the undocumented?
• Who is making the decision to vaccinate children in the family? Why?
• Do you have any suggestions or recommendation for improvement of information and vaccination service in order to encourage parents to vaccinate their children?

D. Immunization information to the migrants - (mainly CWC staff)

• Which is the most effective way of to inform families and parents about the advantages of vaccinating children? And encourage them to seek health care and the CWC.

E. Recommendations and Closing - (All key informants)

• Any additional suggestion or recommendation to improve the undocumented community access to or acceptance of vaccination?
• Is there something else you want to bring up?