

Karolinska Institutet
Department of Public Health
Division of International Health, IHCAR

Supervisor: Bo Simonsson

The ghost women

A study about undocumented pregnant women's needs and access to
antenatal care in Stockholm, Sweden

Master thesis international health 2009
Author: Karolina Höög

Abstract

Background: Irregular migration is increasing worldwide and the so-called undocumented migrants face serious problems in accessing health care. Little is known about the health of undocumented migrants and even less is known about pregnant undocumented migrants; their conditions in life and specific health problems. Living under the stress of being undocumented and pregnant, without access to antenatal care, probably makes the women the most vulnerable group in our society.

Aim and methods: The overall aim with this study was to outline a general framework for understanding the needs and access that pregnant undocumented migrants have to antenatal care and factors that affect that access. The specific objectives were to describe the group of undocumented pregnant women who seeks antenatal care through the Red Cross health clinic in Stockholm, Sweden and to deepen the understanding of their specific needs.

In the years 2006 and 2007, 55 women in need of antenatal care came to the Red Cross clinic. The records of these 55 women were retrospectively studied and basic demographic data was extracted. In 2008 nine of these 55 women participated in semi-structured interviews and the interview transcripts were analysed for content and categories and themes were identified.

Result: From the interviews a complex connection of factors evolved, which all of them together affect the access to antenatal care and forms a specific vulnerability of the pregnant undocumented women. Direct obstacles such as cost, fear, language barriers and identification problems were described by the women as obstacles that affect the access. In addition, the women emphasised other obstacles that had an indirect impact on the access to antenatal care. Alienation in society, due to their legal status was described. This influenced their social contacts in a negative direction and the pregnancy seemed to enhance the feeling of alienation, social isolation and loneliness. The women also witnessed of an increased dependency upon their partners, friends and volunteers from NGO's and churches. The dependency was expressed as a negative experience and provokes feelings of shame and guilt.

Conclusions: This study contributes to a deeper understanding of the complexity of the undocumented women's situation and how an already vulnerable situation is aggravated by a pregnancy and it suggests that undocumented pregnant women have a specific vulnerability and specific needs. Poor access to health care affects their health negatively and the health care system should procure access to antenatal care for these women to minimize health risks and to fulfil their sexual and reproductive health rights.

List of content

1. Introduction.....	4
2. Background.....	5
2.1 Migration.....	5
2.2 Undocumented migrants.....	5
2.3 The human rights perspective.....	7
2.4 The Swedish health care system.....	8
2.5 The Swedish model of antenatal care.....	8
2.6 NGO's.....	9
2.7 The Red Cross health clinic for undocumented migrants.....	9
2.8 Undocumented migrants and health.....	10
2.9 Undocumented pregnant women and health.....	10
3. Aim and objectives.....	11
4. Methods.....	12
4.1 Setting.....	12
4.2 Selection of participants and selection of method.....	12
4.3 Data collection.....	13
4.4 Analysis of data.....	13
4.5 Ethical concerns.....	14
5. Result.....	16
5.1 Total population of undocumented pregnant women.....	16
5.1.1 Country of origin.....	16
5.1.2 Legal status.....	16
5.1.3 Causes of seeking health care at the Red Cross clinic.....	16
5.1.4 Time in Sweden.....	16
5.1.5 Family composition.....	17
5.1.6 When did they seek help?.....	17
5.1.7 Where they finally got antenatal care.....	17
5.2 Study group.....	18
5.2.1 Alienation.....	18
5.2.2 Social isolation.....	19
5.2.3 Dependency.....	21
5.2.4 Not in control of reproduction.....	22
5.2.5 Access to antenatal care.....	24
5.2.6 Obstacles accessing antenatal care.....	25
5.2.7 Self perceived impact on health.....	27
5.2.8 Contact with the health system.....	28
6. Discussion.....	30
6.1 Method discussion.....	30
6.2 Result discussion.....	31
6.3 Conclusions and recommendations.....	34

1. Introduction

In Sweden today there is a group of people who are excluded from the health care system, the so-called undocumented migrants. Undocumented migrants are migrants without a residence permit authorizing them to regularly stay in the country of destination. There is a huge lack of knowledge about the group of undocumented migrants in Sweden and even scarcer is the specific knowledge about the undocumented women and their specific health needs. As a midwife I have been working with a project run by the Swedish Red Cross with the objective of providing health care to undocumented migrants in Stockholm. Around a thousand patients are registered at this clinic as they are excluded from the health care system. The undocumented migrants live in the outskirts of the society. They are at risk for exploitation on the labour market, have difficult living conditions and precarious housing situations and difficulties accessing health care, but there are specifically concerns for women.

Undocumented women are confronted with gender-based discrimination, the majority of them are domestic workers and there are reasons to believe that these women are more often vulnerable to sexual abuse. Approximately 2/3 of the patients coming to the Red Cross health clinic are women and around 30% have reproductive health related problems such as; need for antenatal care, abortions, gynaecological care and sexual transmitted infections. (1)

Living under the stress of being undocumented and pregnant, without access to antenatal care and health care in case of pregnancy related complications, makes the undocumented pregnant women probably the most vulnerable group in our society. I decided, therefore, to make the study on the undocumented pregnant women as to my knowledge there has been no similar study done in Sweden

2. Background

2.1 Migration

Migration is a natural phenomenon and has always existed. The process of globalization has enabled an expanding economy and better opportunities for life to many people. Today it is easier than it has ever been for people to move around and the number of international migrants has doubled in the past 25 years. There are various reasons why people migrate and the reasons include among others: political, economical, social and environmental factors.

Almost half of the migrating population is women. Women are to a wider extent entering the global labour market as breadwinners and increasingly leaving their families behind. It seems to be a persisting trend as the industrialised parts of the world demand larger workforce in markets that are traditionally linked to women, such as domestic work, nursing and personal care, manufacturing, entertainment and sex trade.

The lack of regular migration opportunities has contributed to an increasing number of irregular migrants i.e. migrants without a residence permits. Irregular migration is a complex phenomenon influenced by the living conditions in the countries of origin and an increasing demand of cheap and flexible workforce in the countries of destination. (2)

2.2 Undocumented migrants

In literature and media there are many different names for people who live in countries with irregular status. Some examples are; irregular migrants, undocumented migrants, illegal migrants, gömda (in Sweden), sans papier (in France) and so on. Not going into any further analysis of definitions, in this study they will be defined as undocumented migrants.

There are many different situations that can cause an individual to become undocumented and the group of undocumented migrants is not homogenous. The situation of being undocumented has nothing to do with the entrance in the country. There are as many different backgrounds, reasons of migration and causes of becoming undocumented as there are people within this group. Undocumented migrants could, for example, be: rejected asylum seekers, rejected candidates for

family reunification, tourists that have overstayed their visa, students who have overstayed their student visa, labour migrants without residence permit or migrant workers who lost their permit, embassy staff who lost their diplomatic status, victims of trafficking etc. (3)

Lately it has been a priority for EU member states to fight against undocumented migrants and to become more restrictive regarding access to public services and health services. (4) This has not stopped undocumented migrants to stay in Europe and there is no evidence that health care could be a push or a pull factor of migration. On the contrary there are other factors involved in the decision making of migration and their country of destination. A British study reported that there is rarely a detailed knowledge about the welfare system of the country of destination. In many cases there is no conscious choice at all, rather a random phenomenon depending on channels and contacts of agents. In cases where there is a choice of country of destination, factors such as; friends and relatives, former colonial connections and ability to speak the language influenced the decision making. (5)

Policy makers are interested of how many undocumented migrants there are in their respective country, but due to the circumstances that the undocumented migrants are forced to exist in, makes it difficult to estimate numbers, but there seems to be a consensus that they are increasing.

In Europe it has been estimated by the Organization for Economic Cooperation and Development (OECD) that there may be 5-8 million of undocumented migrants and larger numbers are estimated in other parts of the world. (2)

In Sweden there are no reliable data available so far. The only statistics that exists is the list of rejected asylum seekers that are object of removal orders but cannot be located. According to the Swedish National Police Board 7500 persons were missing in 2007. No one knows how many of these persons still remain in the country, they might have moved to other countries. (6)

There are no data or statistics available for other groups either.

2.3 The human rights perspective

The essence of the human rights perspective is that every individual has the right to a life free from discrimination and poverty. Sweden has ratified a range of international human right treaties recognising the right to health and other health-related rights. The Covenant on Economic, Social and Cultural Rights (7) clearly states the right to health declaring:

“the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”

(Article 12 of the Convention on Economic, Social and Cultural Rights, UN 1966)

Sweden has recently been heavily criticised by UN’s Special Rapporteur on everyone’s right to health, Paul Hunt. The undocumented migrants are identified as one of the most vulnerable groups in the society and Paul Hunt emphasised that they should access health care with the same conditions as Swedish citizens for humanitarian and human rights reason, but also with a perspective of public health issues. He also pointed out that specifically for these people human rights were created and were meant to protect. (8)

Sexual and reproductive health and rights (SRHR) are fundamental for women. SRHR is regulated implicitly and explicitly in various international conventions such as; the Universal Declaration of Human Rights (9), the Covenant on Economic, Social and Cultural Rights (7), the Convention on the Elimination of All Forms of Discrimination against Women (10) and the Convention on the Rights of the Child (11).

In article 24 of the Convention on the Rights of the Child it is clearly stated that states shall:

“ensure appropriate pre-natal and post-natal health care for mothers”

(Article 24:2d of the Convention on the Rights of the Child, UN 1989)

Article 12 of the Convention on the Elimination of All Forms of Discrimination against women states that:

“1. States Parties shall take all appropriate measures to eliminate discrimination against women in the field of health care in order to ensure, on a basis of equality of men and women, access to health care services, including those related to family planning.

2. *Notwithstanding the provisions of paragraph I of this article, States Parties shall ensure to women appropriate services in connection with pregnancy, confinement and the post-natal period, granting free services where necessary, as well as adequate nutrition during pregnancy and lactation. “*

(Article 12 of the Convention on the Elimination of All Forms of Discrimination against women,

UN 1979)

2.4 The Swedish health care system

Sweden has a compulsory, predominantly tax-based health care system covering the entire population but undocumented migrants are not entitled to subsidised medical care or subsidised medicines from the national public health system. According to the Swedish Health and Medical Services Act local County Councils are obliged to offer “immediate health care” to everyone present in Sweden. (12) There is no definition of “immediate healthcare” so practically it is up to each health care provider to decide in each case and the undocumented migrants are obliged to pay the full cost for receiving care even in cases of emergency. In practice this results in extreme difficulties for the undocumented migrants when they are in need for health care.

Regulations concerning health care for undocumented migrants look different in other EU countries. A recent overview of 11 West European countries shows that Sweden and Austria are the most restrictive countries in terms of health care for undocumented migrants. (13)

Nevertheless, in 2000, the Swedish Association of Local Authorities and Regions (Sveriges Kommuner och Landsting) and the State reached an agreement on subsidized health care for undocumented children. Since then the undocumented children have access to health care, and in 2008 this agreement became a law. (14)

2.5 The Swedish model of antenatal care

The Swedish model of antenatal care, with midwives monitoring pregnancies, identifying risks pregnancies and referring them to gynaecologists when needed, is internationally well known and seen as a success model. The system of antenatal care and the high level of coverage are probably, besides qualified delivery services, one of the major reasons why Sweden has one of the lowest maternal and infant mortality in the world.

The overall objective of the maternal health care in Sweden is to provide a good reproductive and sexual health for the whole population. To achieve the overall objective the antenatal clinics provide services such as; basic antenatal care program,

screening program for infectious disease in pregnant women (HIV, rubella, lues, hepatitis and TB). Also provided are foetal diagnostics, psychosocial support, parents education, health education, STI prevention and treatment, advice regarding family planning, prevention of unintended pregnancies, advice regarding abortions and screening program for cervical cancer. There is a consensus that providing these services is cost effective. (15) .

When it comes to undocumented pregnant women in need of antenatal care it is usually not seen as “immediate health care”. Practically this means that the woman has to pay the full price of antenatal care in advance. The current cost is 500 SEK for each visit to the midwife. When it comes to delivery services it is usually considered as “immediate health care” and the woman can pay the full price after receiving proper care at the delivery unit. Currently a normal delivery in the hospital costs approximately 25 000 SEK and can go up in case of complications. (16)

2.6 NGO's

With the current system in Sweden it is clear that the health care needs of undocumented migrants is not met. Presently there are a few non governmental organisations (NGO's) and individual health care staff that provide health services for these patients on a voluntary basis. The NGOs are relying on few professionals with limited resources which obviously make it difficult to cover all health needs. Currently there are four NGO's providing health care to undocumented migrants in Sweden; Médecins du Monde (MDM) and the Red Cross in Stockholm, Rosengrenska Foundation in Göteborg and Delta Foundation in Malmö.

2.7 The Red Cross health clinic for undocumented migrants

The data for this study was collected at the Red Cross health clinic and the methods will be further described in the method's chapter. The project was started in 2004 by Médecins Sans Frontieres (MSF) and handed over to the Swedish Red Cross in 2006. The Red Cross clinic has two fulltime nurses mainly operating as a link; putting patients in contact with health care professionals who are volunteers and parts of a network connected to the Red Cross clinic. The volunteers counsel and treat undocumented migrants free of charge at their own clinics. When a woman seeks help with antenatal care at the clinic the first thing that is done is to call the public

antenatal clinic in the area where the woman lives. At present there are 72 public antenatal clinics in the County Council of Stockholm. In some cases, they receive the woman under the same conditions as a woman with residence permit. In cases where it is not possible contact with one of the five voluntary midwives in the Red Cross voluntary network is established.

The Red Cross also acts at the structural level to convince the Swedish government to change the law. The Red Cross demands that the government creates a regulation which provides all people, regardless of their legal status, access to health care in order to address their medical needs.

2.8 Undocumented migrants and health

There are few studies done on undocumented migrants and health and to my knowledge only one done in the Swedish context. The study is a questionnaires survey that includes 102 undocumented migrants at the MSF health clinic in Stockholm. In addition a mental health questionnaire of 23 undocumented migrants was carried out. The participants were diagnosed with a variety of health disorders including chronic and severe diseases. The study results showed a deterioration of both physical and mental health while living in Sweden as undocumented migrant and a high prevalence of depression and anxiety disorders was reported. The study participants also reported a number of barriers accessing health care such as; high costs or being refused health care due to lack of documents and fear. Fear that the health care staff would call the police or the Migration Board and therefore being arrested and deported. (16) However the anonymity of all patients is regulated by Swedish law that covers everyone including undocumented migrants. (17)

2.9 Undocumented pregnant women and health

If little is known about the health of undocumented migrants, in general, even less is known about pregnant undocumented migrants, their conditions in life and specific health problems. Little research has been done to address these issues and the results are contradictory. In the United States some studies have shown a lower prevalence of low birth weight among undocumented foreign born Latinas compared to US-born Latinas. It has also been shown that migrant women (not specifically undocumented) generally have a better birth outcome than US-born women from similar socio-economic background. This has been explained to some extent with the theory of

“healthy migrant effect” which implies a selection of the fittest during the process of migration. (18, 19)

Other North American studies have shown similar results with lower rates of preterm deliveries and low birth weight among undocumented migrants. But the same studies indicates higher rates of pregnancy related risk factors (such as anaemia, less likely to gain weight and less likely to receive satisfactory antenatal care), and higher rates of labour complications such as; excessive bleeding and foetal distress. (20,21).

In Europe to my knowledge only two studies have been done, both in Geneva, among undocumented pregnant women. There were no significant differences in birth weight or complications during pregnancy, delivery or post-partum but a slightly higher, but not significant, rate of pre-term delivery among the undocumented women in comparison with a control group consisting of pregnant women from the general population of Geneva, Switzerland. Nevertheless the two European studies identify a significant higher proportion of unintended pregnancies, underutilization of preventive measures such as cervical smear test and immunization of rubella and delayed antenatal care among the undocumented pregnant women. The undocumented pregnant women were also significantly more exposed to violence during pregnancy. These studies suggest that not having a legal residence permit is a particular vulnerability for pregnant women. (22, 23)

Delayed antenatal care is also reported in a study from London, were 44% of the undocumented women came to antenatal care after 23 weeks of gestation. (24)

3. Aim and objectives

The aim of this study is to outline a general framework for understanding of the needs and access that pregnant undocumented migrants have to healthcare and factors that affect that access.

Objectives

1. To describe the undocumented pregnant women who seek health care through the Red Cross in Stockholm.
2. To deepen the understanding of their self-perceived health situation and specific needs.

4. Methods

4.1 Setting

The data was collected at the Red Cross clinic for undocumented migrants in Stockholm, where I was employed at the time of the study. All patients seeking health care at the clinic are routinely interviewed with a number of questions regarding age, country of origin, legal status, time in Sweden, family composition, health problems etc (see appendix 1).

The information is registered in a data base and the medical records are stored in an archive. The database was created in 2006, when the Swedish Red Cross took over the project from MSF.

All people who do not have access to subsidised health care because of their legal status are welcome to the clinic. The clinic is visited by several categories of undocumented migrants such as rejected asylum seekers, overstayers of different kind of visas and people who have been rejected residence permit for family reunification. There is one group of people not having access to subsidised health care but not necessarily undocumented who also visit the clinic. This group is people who have applied for residence permit for family reunification but are still waiting for a decision. While in this process the person is not granted subsidised health care and has to pay the full price herself.

4.2 Selection of participants and selection of method

A search in the database was done for pregnant women seeking the clinic in need of antenatal care, during the years of 2006 and 2007, which resulted in 55 women. All general demographic information about these women was extracted from the database and after that the 55 medical files from the archive were retrospectively studied for complementary information such as; week of gestation and where they finally got antenatal care.

Of the 55 women in need of antenatal care 24 were selected as possible candidates for in-depth interviews or focus group discussions. The selection criteria were that they should have given birth in 2007 or being in their third trimester of pregnancy at the time of selection (October 2007). Because of language limitations and lack of resources to pay for translators, the women had to be able to be interviewed in

Swedish, English or Spanish. There were also problems to locate the women. At first the study was planned to be conducted through focus group discussions but there were problems in finding women who wanted to participate. The reasons are unknown but will be discussed later. Out of the 24 selected women four of them initially said yes to participate but were later unable to reach. Three of them said they wanted to think about it and could not be reached later. For another three the phone numbers no longer exist. One had moved to another country, one had moved to another city in Sweden and one said clearly that she didn't want to participate. The nine remaining women who wanted to participate, but at this time the study was presented to be conducted through in-depth interviews. The nine selected women had different background and different reasons for being in Sweden. They were from South America, Central America, former Soviet Union, Asia and Africa. Some were primipara and some multipara, some singles and some married. Six had given birth at the time of the interview and three were pregnant in the third trimester.

4.3 Data collection

The interviews took place either at the Red Cross clinic or in the homes of the women, wherever they had preferred. As the interviews were semi-structured they have been performed as a conversation, but guided by some themes with questions to keep track of the conversation for the interviewer (see appendix 2). Every interview lasted between 45 to 80 minutes and was tape recorded. Each interview were transcribed in the original language and after that translated into Swedish.

The interviews were carried out during a period of four months, from November 2007 to February 2008.

4.4 Analysis of data

The data from the interviews were analyzed using qualitative content analysis. The transcribed interviews were read through several times to grasp the material in its entirety. Later on, each interview was divided and mixed with the others, sorting after the themes and questions following the interview guide. The analysis started with extracting meaning units from this material. The meaning units were further on condensed without losing its meaning. The condensed meaning units were organised in sub-categories and the sub-categories formed categories. At this point the process

of analysis was focused at the concrete and “visible” components of the text, referred to as the “manifest content” (25). An example of analysis is presented in the table 1.

Table 1

Category	Obstacles accessing antenatal care				
Sub-category	Cost	Fear	Language barriers	Identification Problems	Lack of Knowledge
Condensed meaning units	Costs much, not affordable, you must pay a lot, expensive, staff ask for money you must go home	Staff calls the police, get caught, be sent back, questioned by staff, denied care, feeling shame, anger from staff , insulted	Not speaking language, not being able to express yourself, if you don't speak the language they won't receive you	No id-card, can not identify myself, not having a complete personal number, can not prove who I am	I can not access ANC unless it is through someone else, must go to NGO, can not buy drugs at the pharmacy

It was clear that the transcribed text consisted of other type of information as well. This type of information was much more subtle, containing an underlying meaning of the text and were not linked to direct answers to the questions. This has been referred to as the “latent content” in the literature. (25)

The interviews were read through again and the “latent content” were also organized in categories which formed the themes. The latent content gave the result a framework of interpretation, showed in table 2 on page 17 Other researchers have read the interview material and the analysis has been discussed through out the process.

4.5 Ethical concerns

Research involving impoverished and marginalized people is a concern of research ethics as they are to a higher extent susceptible to exploitation. The first step to address this vulnerability is to recognise that the vulnerability actually exists.

When conducting a study among vulnerable population there is a need to pay special attention to the unequal power of relationships between the researcher and the studied population. In related literature, some issues have been highlighted as specific for research among vulnerable populations and thus consideration is necessary for the

credibility and trustworthiness of the study. Some issues described as of special attention in vulnerable population and that has to be taken into account are; the possible distrust in society and in the health care system, the use of incentives could serve as coercion, fear of telling their true opinions and reluctance to refuse participation because of dependency upon the researcher. Dealing with these issues calls for individual treatment according to the circumstances of the study group and sensitivity to their reality. (26, 27, 28)

Some of the ethical issues and strategies of this study are;

(i) At first the study was planned to be conducted through focus group discussions. However, soon it became clear that recruiting women who wanted to participate was impossible. I can only speculate in the reasons and to the fact that there could exist subgroups and internal hierarchies within the group that are not known to me. (ii) There could also be fear and stigma in sharing sensitive information with others. After realizing the problem the method of data collection was changed into individual interviews and recruitment became easier. (iii) Another issue is the women's dependence to the Red Cross clinic and that could cause reluctance to refuse participation in the interviews. All participants were informed of confidentiality and that participating was voluntary. Further it was also clarified that participating in the study would not in any way influence the possibilities of getting help with health care through the Red Cross clinic in the future. All women who wanted to participate were given time to change their minds. A second phone call was done the day before the interview to repeat the purpose of the study and to reinforce the message of voluntarism and that refusing wasn't going to affect their possibilities to get assistance from the clinic in the future.

As I was working at the clinic at the time of the study there was a certain amount of trust in the study group and familiarity to their situation. The trust is one of the strengths in this study but also one of the weaknesses. Trust and confidence reduce fear of being identified and could also affect the willingness to share information. On the other hand, trusting the organisation or me as a person could also result in a tendency to express what they think I expect to hear and not telling their true views.

Incentives were not used for this study, but travel expenses were reimbursed when needed. Almost all women revealed information during the interview that was needed further attention. It was therefore, after consent, documented in the medical file and handled, within the regular activity at the clinic.

5. Result

5.1 Total population of undocumented pregnant women

In total, 55 women came to Red Cross to get help with antenatal care, during the two-year period 2006-2007, 21 in 2006 and 34 in 2007.

The average age was 27, 8 years with a range between 17-43 years.

5.1.1 Country of origin

The 55 pregnant women had their origin in 26 different countries. Divided in geographical regions the result shows the following; 25 women (45%), were from South America followed by eleven (20%) from the former Soviet Union and six women (11%) from Africa. Five (9%) were from East Asia, three (5%) were from Central America, two (4%) were from South west Asia/Middle east, two (4%) had unknown country of origin and one (2%) was from Europe.

5.1.2 Legal status

Twenty-one (38%) women came to Sweden with a visa and then overstayed the time of expiry and 19 (35%) had applied for asylum but were rejected. Nine (16%) had applied for residence permit due to family reunification. Four (7%) had unknown status, one (2%) was rejected residence permit for family reunification and one (2%) was an EU-member.

5.1.3 Causes of seeking health care at the Red Cross clinic

Nineteen (34%) of the pregnant women said the reason for seeking antenatal care at the Red Cross clinic was because of the cost, they knew they couldn't afford paying the midwife at the public health centre and 18 (33%) said the fear was the reason not seeking help at the public antenatal clinic. Eleven (20%) of the women said they tried to get antenatal care at the public health centre but were rejected by the staff. For five (9%) women the reason is unknown and two (4%) reported a lack of knowledge about the health system and their rights.

5.1.4 Time in Sweden

The mean time the 55 pregnant women had been in Sweden was 1-2 years, with a range from less than 6 months up to 10 years.

5.1.5 Family composition

34 women (62%) were married or co-living with their partners in Sweden, 14 (25%) were singles and two (4%) were married but their husbands were not in Sweden. In five women (9%) data was missing.

34 women (61%) were primipara, twelve (22%) had children who lived with them in Sweden, and seven women (12%) had children but had left their children in their home countries. In two women (4%) data was missing.

5.1.6 When did they seek help?

25 (45%) came to the Red Cross clinic in the first trimester of the pregnancy and 19 women (35%) came in the second trimester. In seven cases (13%) there were no data and four (7%) came in the third trimester.

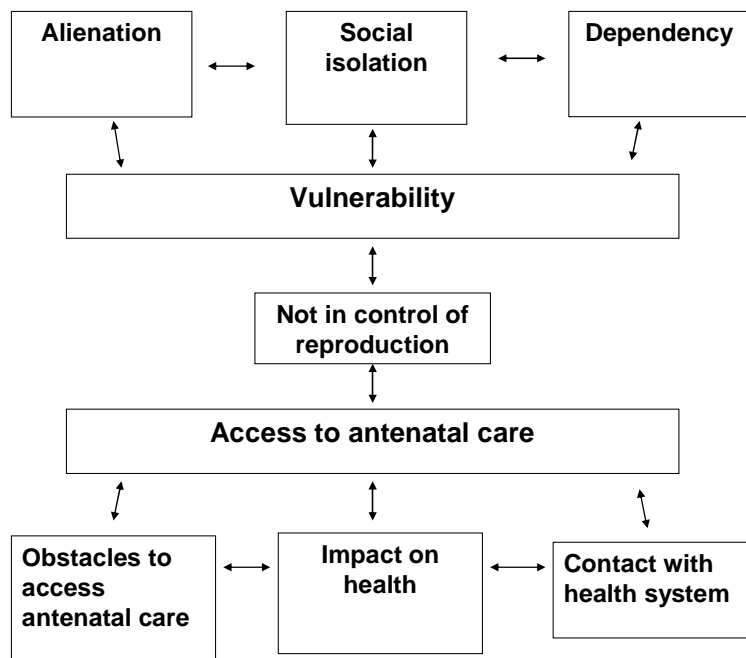
5.1.7 Where they finally got antenatal care

25 women (42%) got antenatal care at public antenatal clinics after the Red Cross had contacted them, 22 (40%) got antenatal care through the Red Cross voluntary network of midwives. Three (6%) women got help from other NGO and three (6%) had a miscarriage/premature stillbirth before getting in contact with any antenatal clinic. Two (3%) decided to go to the public antenatal clinic and pay the full price themselves and of two (3%) women data is missing.

5.2 Study group

Table 2 below illustrates a summary of the results. When the themes and categories evolved from the in-depth interviews it became clear they could not be interpreted as isolated courses. They all interfere and influence each other in a complex context. The table is meant to serve as a tool for interpretation and to illustrate their mutual connection.

Table 2



5.2.1 Alienation

The group of participants in this study is heterogeneous but they have some things in common, they are, or are soon becoming mothers and they live alienated in the society. No matter where in the world they come from or from what background, or for what reasons they have come to Sweden, they all experience a feeling of exclusion and a lack of the feeling of connection and context. They strive to be normal and to have a normal life, a wish of being included and to belong, but above all being seen

as, and accepted as human beings and not being categorised according to legal status. One woman expressed:

"You can not be accepted as a normal human being, as you were from another caste. You become different but you only want to live in a normal situation"

Being accepted and a wish to belong are universal feelings; nevertheless these women are not protected by the Swedish society and are therefore excluded from rights and resources. The women described feelings of not having any rights, not being seen, not being heard, having no voice in society and not being able to protest. The lack of rights and the lack of being seen as a human being above all have been expressed as follows:

"I said I am also a human being. It doesn't matter if I am an asylum seeker or a citizen here; I am also a human being"

"I feel like a ghost in Sweden...if you are undocumented you have no rights at all nor you have a voice...you can not make yourself heard.....nothing..."

The alienation and exclusion the women are experiencing also has an impact on their ego and self-esteem. The women witness of being insecure and feeling sadness of not being appreciated, being nobody, the lowest caste in society, not even being an asylum seeker are things the women witness of. The alienation is a repeated theme through out the interviews and seems to have an impact on the behaviour, way of thinking and ways of decision making.

5.2.2 Social isolation

Many of the women mentioned they were feeling lonely. This loneliness mentioned is basically related to their legal status. The loneliness is strongly linked to the feeling of none existence and the feeling of not belonging as presented in the chapter of alienation. But it seems that the pregnancy, in some cases, increases the loneliness and social isolation. This is expressed by several women in different ways and it affects relations to friends, partners and other people around them. Social isolation, loneliness and what it leads to will be presented in the two following chapters.

Some of the women were abandoned by their partners in the beginning of the pregnancy. They said that the pregnancy itself was the cause of being left alone, the partner couldn't handle the responsibility and left when the woman decided to keep the pregnancy. In these cases the dependency to others increased. Dependency will be further explored in the next chapter.

The women who lived with their partners expressed loneliness and isolation within the relation. They said that the pregnancy and problems related to it, such as no access to care, stress, worries of an extra mouth to feed etc led to heavy arguments and affected the relation negatively.

Some women expressed that they had become lonelier within the relation to their partners since they became pregnant. The partners had become more silent and distant and the women felt difficulties to share their thoughts.

Some women expressed feelings of being lonely because they were far away from their families and longing for their families became stronger when being pregnant. For one woman, her pregnancy was certainly a factor of isolation. She became pregnant after being raped and her friends judged her of making the wrong decision to keep the baby. They suspected she was a prostitute and stopped calling her. They didn't even want to touch the baby.

Other women explained that they consciously isolated themselves because of difficulties to have friends or close relations to others because they moved around a lot and were feeling so ashamed of their situation and were scared to reveal the truth of their life to others.

Other women confirmed that by expressing that friends or other people around them actually judged or strongly questioned them, as for example being a single mother not taking responsibility to protect herself.

Some women also mentioned isolation and limitations in daily life. For example, one woman had problems with her three years old daughter who wanted to play with other children but she could not get a place at a day care centre and the mother didn't know anyone with whom the child could play.

The women also talked about the limitations of not being able to move around where they wanted in the city because of the risk of being caught by the police, for example

they avoided crowded places such as shopping centres. Another woman was homeless during the first five months of the pregnancy and collected bottles and cans to buy food..

5.2.3 Dependency

Dependency on others is a big part of these women's lives. All of them are dependant on others in one way or another. The stories of the women witness of how the pregnancy itself and the worries around it affects their already difficult life situation into an even more vulnerable situation with an increased dependency on others. Again, in the light of a gender perspective, the women become more vulnerable being undocumented and pregnant. Some topics that have come forward in the interviews will be presented in the following chapter.

The women who lived with their partners witnessed of an increased dependency upon him. No one expressed directly that their partners abused them but they expressed worries for other women in the same situation. They said that men could take advantage of undocumented women and their vulnerable situation. They could easily abuse them knowing that they couldn't go to the police and wouldn't leave them because they wouldn't have anywhere else to go.

Other women in the study expressed an increased dependency on the husband because of economical problems connected to the pregnancy. As undocumented persons in general have to work on the black market and they have no economical or social benefits. Therefore a pregnancy is a huge loss of income for a family. In the later parts of the pregnancy the woman can not work anymore and when the child is born she needs to stay at home taking care of the child and without day care or someone who can baby sit she is not able to work for many years. This means she has to stay with the man as he is the breadwinner.

One woman explains the dependency on her partner as a catastrophe:

“We came back home and I had started to think about suicide. I thought...I will go to a bridge with my children and jump...I had enough....enough of always being strong, but I never said anything to my husband. He just knew I felt bad. I cried the whole day but I couldn't tell my husband what I was thinking. He didn't know what I was thinking...he didn't know anything...he didn't know anything about my life...and I just felt I was dependent on him...it was a catastrophe”

The women who were alone described an increased dependency to others. Some were taken care of, for example, families or people they had got to know in Sweden. They were helped with a room, food, taught the language etc. They were also dependent on NGO's and churches. These women express many positive things with people who helped them but they also talked about dependency as a negative aspect. Asking for help provoked feelings of shame and feelings of guilt.

”So in all that sorrow I have had people who supported me ...even giving me food and a little bit of money. I felt happy for that...but at the same time I felt shame. I have never asked for help earlier but at that time I really needed to do that”

5.2.4 Not in control of reproduction

Among the participants there is knowledge about contraceptive methods. All women mentioned the pills and IUD when talking about contraception, some also mentioned condoms. All women witness a problem of accessing contraceptive methods caused by obstacles that will be further explored in this study. As a result of not having access to conventional contraceptive methods some women described using the natural rhythm or praying to God as alternatives. Some of the women express feelings of not being in power or control of their reproduction, not having the possibility or even the right to decide whether to get pregnant or not. They describe it as a worry and a stress factor. The situation of not being in control or power of their reproduction is also expressed as problematic and having negative influence in the relation to their partners. One woman expressed the powerlessness as follows:

"When you are together with your partner and don't have a method to protect yourself you live day by day. Always with the stress...maybe I am pregnant, maybe not...and you just wait for your period. Constantly you live with that stress in your head...did I get pregnant this time? It means every day you ask yourself that question. And the day when the period comes you think this time I managed...this time I managed. A woman who does not have access to health care must protect herself with the rhythm, a method which is taught all over the world.

I. And the men, do they accept that sometimes it is too risky to have sexual intercourse?

No it is difficult, it often ends with trouble with your partner or you take the risk it is a continuous struggle...a struggle with your partner and a struggle with yourself. It is just something that happens and I don't believe I am the only one in this situation".

The participants can roughly be divided in two groups when it comes to the decision making concerning having a child. One group has planned to get pregnant and expressed human, universal feelings and reasons of having a child. Four of the nine participants expressed that the pregnancy was planned or almost planned.. All of them lived with their partners at the time of conception.

One woman said that she and her husband had started to talk about having a child, she became pregnant quicker than she had believed but the pregnancy was welcome.

Another woman expressed that her age (30 years) made her think she couldn't wait any more, she didn't want to wait for a solution for her legal status because she might get to old to become a mother before it can be solved.

A third woman had a ten year period of infertility together with her husband and both of them believed they couldn't have children. They had both longed for a child and suddenly she becomes pregnant and both of them were very happy despite of the problematic legal situation.

A fourth woman talked about an indescribable power that came to her when she longed for a child. The couple planned having a child together but she was later on in the pregnancy abandoned by her partner.

The other group, five of the nine participants, expressed less control and had not planned the pregnancy.

One woman expressed she had dreamed of being married before having children but she became pregnant after being raped by an unknown man. She expressed she had a lot of doubts and worries. She was at the time homeless and she didn't have a job, but wanted to have the baby as a reason to keep living.

Another woman expressed a lack of contraception methods and became pregnant with her partner but was abandoned when she told him about the pregnancy. She expressed that having the child was a reason to keep on with her life.

The third one expressed lack of access to contraceptive methods and became accidentally pregnant with her husband. She said she thought it would be easier accessing health care when being pregnant.

The fourth woman also became pregnant with her husband and expressed a lack of contraceptive method and sudden irregular menstruation. She expressed feelings of being desperate and worried about an extra mouth to feed. But she also says "I became pregnant and now there is no return".

The fifth woman in this group also became pregnant with her husband due to failure of contraceptive method.

All these women, no matter if the pregnancy was planned or not, expressed worry after getting the pregnancy confirmed. They described concerns as problems to access antenatal care, economical problems, problems of housing, and problems of being far from their families and relatives and problems in their relations.

" In one way I felt happy about the pregnancy but in another way I felt bad and worried because you never know if you will get health care".

5.2.5 Access to antenatal care

According to all participants of the study there are a number of things affecting the access to antenatal and delivery care. All the women expressed worries and considered they were in need of antenatal care but all of them mentioned a variety of barriers, both direct and indirect. In this chapter three categories related to lack of access will be presented; obstacles to access antenatal care, self perceived health consequences of access and perception of contact with the health system.

Eight of the women had not attempted to get help from public antenatal clinics before coming in contact with the Red Cross clinic. One had tried but was rejected by the staff.

5.2.6 Obstacles accessing antenatal care

The fear the participants expressed is mainly concerning two things. First, the fear that the health care staff will contact the police or Migration Board resulting in deportation and secondly, fear of being denied health care and rejected by the staff.

Among the women there is a prevailing fear that the staff actually will report them and that is one of the major reasons mentioned not to dare seeking antenatal care. One woman expressed this fear as follows:

” I have never sought health care because of fear, fear of being rejected...that they will not receive me”.

I. Can you tell a bit more about that fear?

Fear because I am here illegal, fear that they will send me back to my country. That’s why I never dared to seek health care...they can get mad at me and send me back...that is what people say.

I. Who says that?

The same people...the illegal people. They say the caregivers call the Migration Board. Just because of that I have never sought health care or even entered a pharmacy”.

Another fear expressed by some of the women is the fear of being denied care or rejected by the staff. It was expressed as a fear of being insulted or not welcomed. Some explained that it was no idea to try to go to the antenatal clinic because they knew they wouldn’t get help. One woman expressed that as follows;

” I know from the beginning they will not do anything for me...if I say I am illegal I don’t know their reaction, but I am afraid of it. They will not help me and you don’t want to end up in such situation...it doesn’t feel good”.

According to the current fees of antenatal care in public health centers one visit to the midwife costs 500 SEK and an obstetric ultrasound costs 1500-2000 SEK. The women described this as not affordable for them and a direct obstacle for them to access antenatal care. One woman said:

”First they ask you for your personal number, if you don’t have any personal number they say you have to pay and it is expensive, it is a lot of money. So you must go back home again”.

Some women described a language barrier. The difficulty to express themselves in Swedish or English and explain their situation made them not wanting to approach the health care centre. Several women said that if they were not able to speak the language they would not be received by the midwife.

The majority of the women expressed problems of not being able to identify themselves. When they can not verify their identity they said they can not get health care. Some believed that the right to seek health care is connected with the Swedish identification number and if you don’t have identification card you have no access to health care. Some women also expressed a worry of how to explain their situation when being questioned by the staff. One woman said:

” I have no papers. I can not identify myself. It is difficult. When you are here without documents it is always a stress, you feel a bit ashamed. You always wait that they will ask you. Who are you? You just wait for that question. Who are you, you don’t have any papers?”

Some women did spontaneously tell about strategies they had, or had heard of, coming around these barriers. One told that in her first pregnancy she waited to present herself at the antenatal clinic until six months of pregnancy because she had been informed that in late pregnancy there is no possibility to be transported by airplane back to her home country.

Another woman said that the only option she had during the pregnancy was to apply for asylum although she knew she would be rejected after a few months. Anyway she

didn't think she had another choice because she couldn't afford antenatal care and delivery care.

Another woman talked about a friend who was pregnant and desperate. She couldn't afford the abortion so she borrowed an id-card of someone else and presented herself at the hospital.

5.2.7 Self perceived impact on health

This chapter will highlight what the women themselves perceived as health risks and consequences of not accessing antenatal care.

All the women seemed to consider that it was dangerous not to have access to antenatal care. All of them considered they were forced to take risks both with their own health and with their expected children's health. But due to fear and other mentioned obstacles of access, they preferred to wait to seek health care up to the last minute.

All women mentioned the stress and worry of not accessing antenatal care during pregnancy as having major impact on their health. Staying at home and hoping they would not get sick was part of their lives. Some women talked about desperation of not knowing what to do and that had a major impact on their mental health. One woman expressed as follows:

"I think a person who worries a lot can die. To be worried and have no clue where you can find an answer or a solution...that causes diseases like depression and that can in the long run cause death".

They also expressed worries about how that would affect their unborn children. All women believed that if they were worried and nervous it would have a negative impact of the health of the unborn child. Some also expressed worries of not knowing what they could do to improve the health of the child, for example not knowing what food to eat or not eat, or what vitamins to take etc. One woman believed that was a higher risk for malformations of the child. Other women believed that worry could affect their physical health and lead to miscarriage or premature birth.

One of the women participating in the study never got any antenatal care. She contacted the Red Cross clinic but no one in the clinic at that time was able to find a midwife for antenatal check-ups for her. She expressed her worries at that time as follows:

“I got crazy, not only desperate but I got crazy before I got help at the hospital. I couldn’t even have peace with my husband ...you know I looked like someone who is mad. You know I was sitting here, I had my baby inside me, I didn’t have any help, no money, no papers....so it was not easy. It affected me whole life at that time”

Around 30 weeks of pregnancy she was feeling so sick that her partner brought her to the emergency room at one of the hospitals in Stockholm. She was diagnosed with pre-eclampsia and deep vein thrombosis and the child suffered from severe intra uterine growth retardation. She was immediately brought to the operating theatre and delivered a boy with a caesarean section. The mother stayed at the hospital for ten days and the boy needed six weeks of intensive care at the neonatal ward.

5.2.8 Contact with the health system

In the following chapter the women’s experience with the health system will be explored. Both the contact with the midwife at the antenatal clinic and the contact with the hospital at the time of delivery.

All the women said they had been very well treated by the midwife at the antenatal care clinic. They were very thankful to her and the help she gave and described that the midwife became an important person for them during their pregnancy. They experienced the contact with the midwife as a relief, and as a person who took away their worries and that they had great confidence in her. The midwife at the antenatal care clinic also seemed to have a positive impact on the women’s feeling of alienation when receiving them. Some women described that the midwife “was a person who saw me”, “she listened to me”, and “she treated me seriously”.

One woman said she had missed the ultra sound, another woman missed parenthood training and another one said she had some language problems and missed that she

couldn't express herself as she wanted when talking to the midwife. But overall they were all very positive to the good care they received.

When the date of delivery came closer, the women described new worries again. Another new barrier had to be seized. Worries of the contact with the delivery ward at the hospital. Some doubted they would be received at the time for delivery. Some expressed they were nervous to present themselves at the hospital. Some didn't know if they had the right to deliver at the hospital and if they would be taken care of. The same worries that have been described before in this study such as; fear, cost, language barriers and identification problems were brought up again.

Finally at the delivery ward, again all women who had given birth at the time of the interview described they were all taken good care of and were well treated at the hospital. Again expressions as "they cared for me" and "they saw me as a person and not as an illegal" were brought up. Again it seemed like being visible and being someone was a positive experience, breaking the alienation for a while.

"Later when I was at the maternity ward they were very nice too. They were nice and when they told me I could leave the hospital I said I didn't want to, because there I was like a Swedish woman. I promise. They asked me everything. They asked how I was feeling and how it was with my baby. When I dressed her they all came and gave me a hug and wished me good luck. They were very nice".

Some women, even if they expressed they were very well treated, also described worries of cost and fear of being reported during the stay at the hospital. One woman said:

"They say they are different groups...that the hospitals don't have anything to do with the police and the police doesn't have anything to do with the Migration Board...I think. But in situations like this you think everybody works together. You think they all know about you and that everybody is against you".

In some cases the staff never talked to the women about their situation as undocumented. The women themselves didn't want to express their worries and

therefore reveal their situation, even if they thought the staff knew about it. In some cases this confusion seemed to increase the worries of the women. One woman described the situation at the maternity ward as follows:

"I thought...what do I do know? I am here illegally and what do I do now? I thought about what was going to happen when I would leave the hospital...if I would have to pay then. How will I do...I have no money. How much will it cost? I will not be able to pay and they will not let me take my child with me when I leave the hospital".

All women in this study have given birth at the hospital. No one could tell of someone they knew or heard of anyone who had given birth at home. They couldn't tell of any other parallel systems of antenatal care, either. The only possibilities of getting antenatal care in Stockholm according to the women participating in this study was to turn to an NGO or pay full price at the public health centres or paying a private doctor for controls. All women who had given birth attended the child health care centre with their children.

6. Discussion

6.1 Method discussion

In qualitative research generalisability is not used as in quantitative research, rather the term transferability is used that means to what extent the results can be transferred to other settings. The qualitative research is always subjective and results are not facts but can contribute to the understanding of feelings, beliefs and experiences of, in this case, the undocumented women's needs, obstacles and self-perceived health situation. There is such little knowledge about this hard to reach population and the women included in this study can not represent all undocumented pregnant women. They could be the tip of an iceberg and they could represent a specific group of women with a certain way of handling the situation of being undocumented and pregnant. The selected nine participants to the in-depth interviews had great differences in country of origin, cause of being undocumented, age, parity, civil status and that gives as broad perspective as possible to the study questions in the existing circumstances.

In qualitative research among vulnerable groups there are some ethical dilemmas and issues that deserve special attention. These issues have been presented in the part of ethic considerations but it is of importance to be aware of these issues when drawing conclusions of the study as well. The trust is one of the strengths in this study but also one of its weaknesses. Trust and confidence reduce fear of being identified and could also increase the willingness to share information. As I was working at the clinic at the time of the study there was a certain amount of trust in the study group and familiarity to their situation which certainly contributed to a relaxed conversation and an opportunity for the women to express themselves and to be listened to which is probably rare in their daily lives. On the other hand, there can be a reluctance to assertion their true views but rather what they think they are expected to say.

An example of this could be when talking about parallel health systems. At the Red Cross clinic there has been at least one case of a woman who delivered at home assisted by non skilled staff because she was frightened to present herself at the hospital and two other cases of women trying to induce abortions at home for the same reason. When talking to the participants on this topic it is not a common knowledge to them. It could be that it is such rare phenomena that they have never heard about it but it could also depend on their reluctance to talk about it to a representative of the Red Cross clinic.

6.2 Result discussion

The majority of the women coming to the Red Cross clinic who are in need of antenatal care were Latin Americans. It might not be representative of the population of undocumented migrants, which is by nature unknown. The most common reason for not accessing ANC was the cost, secondly women reported fear as the reason. This fear was in the interviews expressed as fear of being reported to police or Migration Board but also a fear of being questioned or rejected by staff. Being rejected seems to be a real problem as 20% reported they had been rejected and therefore sought help at the Red Cross clinic. 40% of the women were denied ANC from public health services after staff from the Red Cross has called them and explained the situation and 40% got accepted. This is by experience pure arbitrariness depending on who is answering the phone call and who the responsible midwife at the centre is. This is a

result of not having any legislation or policy for taking care of these women, putting the individual health worker into an ethical dilemma.

35% sought help with ANC in second trimester and 7% in third trimester. Delayed ANC has been identified in other studies as well (21, 23, 24) and is a major health risk for mother and child.

From the interviews a complex connection of factors evolved, which all of them together affects the access to antenatal care and forms a specific vulnerability of the pregnant undocumented women. The women experienced alienation in society, due to their legal status, which influences their social contacts in a negative direction and the pregnancy seemed to enhance the feeling of alienation, social isolation and loneliness. The women also witnessed of an increased dependency upon their partners, friends and volunteers in NGO's and churches. The dependency is expressed as a negative experience and provokes feelings of shame and guilt. Increased dependency on the partner is expressed by one woman as a direct risk of abuse. As earlier studies have shown that undocumented pregnant women are to a higher extent exposed to violence (22) it is of utmost importance to keep this in mind when caring for these women. A common perception is, by experience, that women living with their partner are less vulnerable than the single women. One reflection is that it could be the contrary, especially in the cases of a residence permit due to family reunification. Women are probably less likely to leave a violent relation when the relation itself is the key for a residence permit. Another worrying problem expressed by the women is the lack of control of reproduction direct related to lack of access to contraceptive advice and modern contraceptive methods. This is confirmed in an earlier study from Geneva (21) where undocumented women reported a significant higher proportion of unintended pregnancies, which is an important public health issue. Seen in the light of a gender perspective, not having access to contraceptive methods and therefore not being in control of reproduction is a violation of sexual and reproductive health and rights.

Furthermore the women describe several obstacles to access antenatal care. No specific obstacles for pregnant women has come forward in the interviews but there seem to be the same direct and indirect obstacles as for the whole group of undocumented people as earlier reported by MSF. (16)

The cost was reported as a major obstacle of access. Regarding the cost there is an urgent need for regulations and legislation for subsidised preventive care, antenatal

care and delivery care for undocumented women. It is possible to reach agreements and regulations concerning subsidised antenatal care. The agreement and later the legislation for subsidised health care regarding undocumented children is a good example showing that it is possible if there is a political will. At the moment (January 2009) there are ongoing discussions within the County Council of Stockholm to subsidize antenatal care for undocumented women. If this becomes a reality it will be a very important step in the process of securing access to care. Nevertheless the question needs to be solved nationally.

Another obstacle reported was fear and the fear can be divided in two parts. First the fear of being reported to authorities by the health care professionals and secondly fear of being rejected or denied health care and therefore feel insulted. In Sweden the Secrecy Act strictly regulates the protection of confidentiality concerning patients in the health care system. It is of utmost importance to inform all undocumented migrants about this legislation and to reinforce the knowledge of current legislation among midwives, other health care professionals and administrative staff to be able to guarantee the protection of this group of patients. The undocumented women will hardly be likely to contact the antenatal clinic or the hospital if they continue to fear being reported to the police or being maltreated by the caregivers. Furthermore there is a need of creative solutions and flexibility to address the other obstacles such as; minimising language barriers by using language competencies of health care professionals, reduce fear of identification problems and misconceptions that a personal id-number is connected to the right to health care. As the system works now it is encouraging to use false ID cards to access care and to avoid the high costs. Borrowing someone's personal ID card has been described as one strategy to access care and is a dangerous strategy when it comes to medical safety.

The women described a feeling of relief when they finally got antenatal care and the midwife became a very important person to them. The midwife probably plays a far more important role to the undocumented women than for their other patients. It seemed like "only" by listening, supporting and having an interest in the women's situation the midwife reduced feelings of alienation, isolation and loneliness. It is definitely encouraging and important to know that with small means we can achieve a lot.

The women reported about the health risks that they were taking during pregnancy and how connected it was with the obstacles of access. The stressful situation affected

their mental health that also affected their relations negatively and increased their vulnerability. Again, reducing the obstacles would be needed to reach these women in early pregnancy to minimise the risks.

Another interesting finding was that when the delivery came closer the same worries, which had temporarily been reduced by accessing antenatal care, became reality again. The women were worried about if and how they would be received at the delivery ward and the same obstacles such as; fear, cost, identification problems, language barriers etc were repeated. In order to reduce fear and confusion at the time of delivery and post partum care it seems important to talk openly to the women about their situation. When the women overcame the barriers again they were very satisfied with the care and they experienced they were well treated. Again the hospital stay was a positive experience and seemed to reduce feelings of alienation and loneliness.

6.3 Conclusions and recommendations

This study contributes to a deeper understanding of the complexity of the undocumented women's situation and how an already vulnerable situation is aggravated by a pregnancy and it suggests that undocumented pregnant women have a specific vulnerability and specific needs. The study could theoretically serve as a tool for better understanding when meeting undocumented women in the health care system.

There are a number of obstacles that in a complex way influence each other and are hindering these women to access antenatal care that has a negative impact on their health. It is clear that undocumented women should have access to preventive care, antenatal care, delivery care and post partum care to be able to fulfil their sexual and reproductive health rights and their right to health. Despite the Swedish engagement in human rights work internationally, there seems to be a discrepancy of how we are willing to follow international human rights law in our own country when it comes to health care for undocumented migrants, which undermines the work that is done internationally. For a number of reasons and arguments, it is simply not justifiable to exclude these women from their rights, when they also belong to a specifically vulnerable group that is in most need and to whom the human rights were created to protect. It is of utmost importance not making this a question of migration politics but

the right to health care must be seen with a humanitarian-, public health-, socio economic- and ethical perspective.

Further research is needed to be able to reach this group, to implement effective solutions and to be able to deal with a probable rising number of undocumented pregnant women. The subject has drawn some attention in Swedish media lately and there are certainly a great amount of questions left to be answered. Both quantitative and qualitative research is needed as for example; on birth outcomes and risk factors. Other questions to be answered are what happens to the undocumented children after birth, is the attitudes among health care providers towards this group an obstacle to access and to what extent is trafficking playing a role within this group?

Reference list

1. Röda Korsets vårdförmedling för irreguljära migranter, Årsrapport, Röda Korset 2007.
2. Global Commission. Report of the Global Commission on International Migration, Migration in an interconnected world: New directions for action. Global Commission 2005.
3. Platform for International Cooperation on Undocumented Migrants (PICUM). Book of Solidarity. Providing assistance to undocumented migrants in Sweden, Denmark and Austria. PICUM Volume/03, 2003.
4. Romero-Ortuno, R Access to health care for illegal immigrants in the EU: should we be concerned? European Journal of Health Law 11:245-272, 2004.
5. Robinson, V and Segrott, J. Understanding the decision-making of asylum seekers. Migration Unit, Department of Geography University of Wales, Swansea. Home office research, 2002.
6. Personal communication with Hans Rosenqvist, Swedish National Police Board, april 2008.
7. Article 12 of the Covenant on Economic, Social and Cultural Rights (UN 1966)
8. Hunt, P. Report of the Special Rapporteur on the right to everyone to enjoyment of the highest attainable standard of physical and mental health. Human Rights Council, UN 2006.
9. Article 25 of the Universal Declaration of Human Rights (UN 1948),
10. Article 12 Convention on the Elimination of All Forms of Discrimination against Women (UN 1979).
11. Article 24 of the Convention on the Rights of the Child (UN1989).
12. Swedish Health and Medical Services Act (Hälso- och sjukvårdslagen) 1982:763, section 4.
13. Platform for International Cooperation on Undocumented Migrants (PICUM). Access to health care for undocumented migrants in Europe. PICUM 2007.
14. Hälso- och sjukvård åt asylsökande mfl 2008:344
15. SOS-rapport 1996:7, Hälsovård före under och efter graviditet, Socialstyrelsen 1996.

16. Medecins Sans Frontieres). Experiences of Gömnda in Sweden: exclusion from health care for immigrants living without legal status. MSF 2005.
17. The Secrecy Act (Sekretesslag) 1980:100.
18. Kelaher, M and Jessop, DJ. Differences in low birth weight among documented and undocumented foreign born and US-born Latinas. *Social Science and Medicine*, 2002, 55 (12), p 2171-2175.
- 19 Winegate, MS and Alexander,GR. The healthy migrant theory: variations in pregnancy outcomes among US-born Latinas. *Social Science and Medicine*, 2006, 62 (2), p 491-498.
20. Haas, JS et al . The effect of providing health coverage to poor uninsured pregnant women in Massachusetts. *Journal of the American Medical Association* 1993: 269, p 87-91.
21. Reed, MM et al. Birth outcomes in Colorado's undocumented immigrant population. *BMC Public Health*, 2005, 5:100.
22. Wolff, H et al. Health care and illegality: a survey of undocumented pregnant immigrants in Geneva. *Social Science and Medicine* 2005, 60, p 2149-2154.
23. Wolff, H et al. Undocumented migrants lack access to pregnancy care and prevention. *BMC Public Health*, 2008, 8:93.
24. Médecins du Monde. Helping vulnerable people to access health care. Project London. Report 2006.
25. Granheim UH and Lundman, B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today* 2004, 24, p 105-112.
26. J.P Lott. Vulnerable/special participant populations. *DevelopingWorld Bioethics* ISSN 1471-8731, volume 5 Number 1 2005.
27. Heaman. M Conducting Health Research with Vulnerable Women: Issues and Strategies. *Canadian Journal of Nursing Research*, 2001, Vol 33, No 3, p 81-86.
28. Jacobsen. K and Landau.L.B. The Dual Imperative in Refugee Research: Some methodological and Ethical Considerations in Social Science Research on Forced Migration. *Disasters*, 2003, 27 (3): p185-206.

Appendix 1

PATIENTUPPGIFTER

DATUM:

ALLMÄNNA PERSONUPPGIFTER

RESERVNUMMER.....
.....

ID: LMA-kort Giltigt till:..... ANNAT.....

FÖDELSEÅR/ MÅNAD /DAG:.....

ÅLDER..... KÖN.....

NAMN:.....
.....

LAND:.....SPRÅK:.....
.....

BOSTADSOMRÅDE:.....
.....

BEHOV AV

TOLK:.....
.....

FAMILJ/GIFT:.....
.....

BARN ≤ 18 år i Sverige ≤ 18 år i annat land
Vuxna

VARIT I SVERIGE SEDAN:.....HAR TIDIGARE SÖKT
ASYL/UT:.....

LEVT GÖMD

SEDAN:.....

ORSAK

MIGRATION:.....
.....

HAR DU JOBB: Ja Nej EV., Vad?

.....

TELEFONNUMMER:.....
.....

Kontaktsak (fri text):

.....

.....

.....

.....

.....

.....

.....

.....

.....

.....

Aktuella läkemedel:

.....

.....

.....

Tidigare medicinska problem:

.....

.....

.....

.....

Överkänslighet:.....

.....

Andra vårdgivare i Sverige:.....

Om ej sökt offentlig vård: Orsak
- RÄDSLÅ / KOSTNAD / NEKAD VÅRD / INFO BRIST

Appendix 2 Interview guide

Beginning of the pregnancy, before contact with the Red Cross

1. When you understood you were pregnant – what did you think?
How did you think it would be, being undocumented and pregnant in Sweden?
Is there a choice of getting pregnant or not? – was it planned or not planned?

Access to health care

1. What obstacles is there getting access to health care?
Did you try to contact some healthcare centre or hospital?
2. Did you ever think that a pregnancy could be a risk and that you would need health care during the pregnancy? What did you think about that?
3. What do you think about the consequences not accessing health care?
Does that affect the health?
If the Red Cross wouldn't have had the possibility the help with antenatal care, what would you have done? What alternatives are there?

Pregnancy

1. What help did you receive during pregnancy?
Is there anything you missed?
Has there been any problems and in that case what?
Did somebody tell you about danger signs and where to go in case of that?
2. How did the midwife at the antenatal clinic treat you?
3. What reactions have people in your surrounding had?

Delivery and post partum

1. When the delivery started, did you know what to do?
Did you know when it was time to go to the hospital and did you know where to go?
Were there any concerns to go to the hospital?
2. How did they treat you at the hospital?
Did you receive a bill?
Did you receive any information about your where to go for further care for you and your child?
Do you know of/ have ever heard of someone who has not delivered at the hospital?

Do you go to the child health care centre?

Is there anything else you want to add or discuss?