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# Preventing the spread of Tuberculosis via refugees, asylum seekers and immigrants entering Sweden

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**A study of health communication, prevention strategies,  
policies and recommendations**

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## Sammanfattning

Sverige har under många decennier sett en minskning av tuberkulos (TBC), men infektionen har kontinuerligt ökat från 2003. Majoriteten av TBC-fallen är personer som är födda utanför Sverige. Hälsotillståndet har förbättrats i Sverige men det finns fortfarande problem. Kommunikationen mellan flyktingar och sjukvårdsspecialister är bristande idag, vilket resulterar att endast ett fåtal genomgår hälsokontroller. Detta kan leda till en ökning av infektioner och sjukdomar i Sverige.

Denna studie undersöker hur hälsokommunikationen idag fungerar mellan den svenska sjukvården, nyanlända immigranter, asylsökande och flyktingar, samt vilken typ av vård som finns tillgänglig för flyktingar med hög risk för att utveckla TBC. Specifikt syftar studien till att förstå på vilket sätt kommunikation brister på samt analysera vilka sätt det finns för att en reduktion av TBC i Sverige ska kunna ske och hur kommunikationen kan förbättras. Studien har genomförts med hjälp av både primära källor i form av intervjuer och sekundära källor.

Baserat på de intervjuer och sekundära källor som genomförts i studien dras slutsatsen att trots att den svenska sjukvården utvecklas positivt så finns det en hel del brister - hälsokommunikation är bristande idag mellan nyanlända flyktingar, sjukvårdspersonal och myndigheter. En av huvudorsakerna som informanterna i studien nämnt är språket, mycket av det som skrivs och sägs är på svenska. Det är viktigt att en mer välfungerad hälsokommunikation utvecklas mellan de nyanlända flyktingarna, sjukvårdspersonal och myndigheterna för att det ska kunna underlättas för flyktingar att söka vård och samarbeta med sjukvårdspersonal med deras arbete för att kunna förhindra spridning av TBC och andra sjukdomar och infektioner i Sverige.

**Nyckelord:** TBC, HCT, HC, Hälsokommunikation, Flyktingar, Sverige, Stockholm

## **Abstract**

Sweden has for many decades witnessed a decrease of the spread of tuberculosis (TB), but between the years of 2003-2012 a new pattern has emerged with refugees carrying TB entering the country and contributing to a situation where the infection has slowly begun to spread again. The communication between the refugees and the health professionals has been inefficient, which inevitably results in fewer refugees undergoing health examinations. This in turn can lead to an increase of infections and diseases.

The purpose of this study is to examine the current health communication between Swedish health professionals and immigrants, asylum seekers and refugees, and to give an overview of what type of health care currently exist for refugees with a high risk of TB. This is done to understand what is missing in the communication process, what has been done in order to improve the situation, and how it can be further improved in order to prevent TB. In order to fulfill the purpose of this study, a qualitative method has been used combining text analysis of interviews and secondary sources.

This study has shown based on the interviews and secondary sources that the Swedish prevention work regarding TB is developing positively in general, but the communication between newly arrived refugees, health professionals and authorities in Sweden is lacking due to the fact that most of what is written and said in this communication process is in Swedish. This makes it difficult for the refugees to understand what is communicated and is stated as one of the main reasons why many refugees do not undergo health examinations, combined with the lack of awareness. Therefore a better functioning health communication between refugees, authorities and health professionals is required to support refugees seeking health care, as well as co-operating with health professionals to prevent the spread of not only TB but other infections and diseases in Sweden.

**Key words:** TB, HCT, HC, Health communication, Refugees, Sweden, Stockholm

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## List of Abbreviations

HC	Health communication
HCT	Health communication theory
HIV	Human Immunodeficiency Virus
ILO	International Labour Organization
IOM	International Organization for Migration
MDR-TB	Multidrug-resistant Tuberculosis
SCC	Stockholm County Council (Stockholms läns landsting)
SMA	Swedish Medical Association (Läkartidningen, sveriges läkarförbund)
SMI	Swedish Institute of Infectious Disease Control (Smittskyddsinstitutet)
SCB	Statistics Sweden (Statistiska Centralbyrån)
SOSFS	Swedish National Board of Welfare and Health (Socialstyrelsen)
TB	Tuberculosis
TBC	Tuberkulos
PDD	Purified Protein Derivative
UN	United Nations
WHO	World Health Organization

# **1. INTRODUCTION**

Tuberculosis is the most widespread infectious disease in the world. It is estimated that a third of the world's population is suffering from latent TB. Each year there are almost nine million people affected with TB and two million people die (WHO 2012, p.2)

TB has been one of the most worrying diseases among immigration authorities in Europe for a long time. At the end of the 21st century, in 1993, TB was announced to be a global emergency with around ten million cases (Carballo 1998, et. al, p.936-937). In 2011, the number had decreased somewhat, with 5.8 million people diagnosed with TB (SMI 2011). It has been estimated that 60 percent of these cases occurred in South-East Asia and 24 percent in Africa, which also has the highest death rates per capita. In 2011, there were 5.8 million people diagnosed with TB Worldwide. Among them 40 percent of the patients infected also carried the infection HIV (Human Immunodeficiency Virus), and as many as 80 percent of the African patients affected with TB were also infected with HIV (WHO 2012, p. 2).

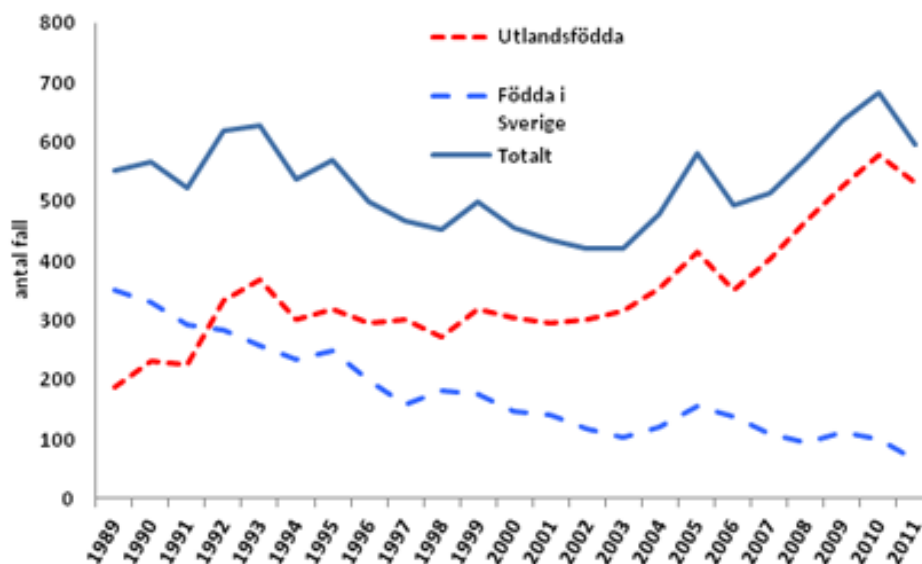
TB is a disease that typically occurs in low-income countries, and cause poverty. The countries that are mostly affected are countries with overcrowding, war- and civil conflicts, poor nutrition, inadequate housing, political instability, and where the population has limited access to education. Because of the wide spread poverty in low-income countries, there is limited access to health care and treatment for major parts of the population in these countries. Therefore it is more beneficial for people living in low-income countries to migrate to a high-income country to improve their rate of survival or safety (Carballo 1998, et. al, p. 936-937).

TB is an airborne infection, which is spread through sputum from patients with TB. TB mostly affects the lungs but sometimes also the larynx, the latter being the most infectious type of the diseases. There are many people infected both during childhood and as adolescents, with the risk of infection being the greatest during close and frequent contact indoors, such as in households and in crowds of different kinds. The incubation period of TB is difficult to define it can take several weeks or months

before a person has developed a primary infection stage. The risk of developing TB is highest during the first two years after infection, but persists throughout life (SMI 2011).

Until the mid of the 1900s, TB was a widespread disease in Sweden with several thousands of deaths each year. Death statistics from 1911 onwards indicate a declining mortality rate from the beginning of the 1900s, and illness statistics from 1940 show a dramatically decreasing morbidity during the following decades. Since the mid-1980s, Sweden is one of the countries in the world with low incidence of TB, with only less than ten new cases of diagnosed TB per 100,000 inhabitants (SMI 2008, p.11).

Figure 1. Number of reported TB cases in Sweden 1989-2011 (SMI 2011).



SMI, 2011. *Liten minskning av antalet tuberkulosfall under (2011)* Available at: <http://www.smittskyddsinstytutet.se/nyhetsarkiv/2012/liten-minskning-av-antalet-tuberkulosfall-under-2011/>

Sweden has for many decades witnessed a decrease of TB, but between the years 2003-2012, globalization, refugees from countries with TB immigrating to Sweden have carried TB with them and the number of people infected has slowly begun to increase again.

Data from Statistics Sweden (SCB) shows that the immigration to Sweden has been high in recent years. A total of 96 467 people immigrated, 45 643 women and 50 824 men, representing 171 nationalities (SCB 2012). However, the majority of all TB

cases (89 percent) in Sweden originate from a limited number of nationalities, with a majority being people born in Somalia and Eritrea (SMI 2011). During the years 2000-2011, 29 500 Somalis sought asylum in Sweden. Though there were very few Somali asylum seekers at the beginning of the decade, only 260 in 2000 and 525 in 2001. The large increase occurred in 2007, when 3 349 Somalis sought asylum in Sweden. In 2011 a similar number of Somalis, 3 982, sought asylum and residence permits were granted in 91 % of the cases (Swedish Migration Board 2012). The background of this immigration is that Somalia has experienced war and conflicts since 1991. According to the United Nations (UN) Human Development Index the country is at the bottom in terms of development and prosperity, but at the top in regards to the presence and spread of TB. Out of 8,7 million inhabitants in Somalia it is estimated that 31,000 get sick of TB, and 22,000 get diagnosed, each year (SMA 2010).

### **1.1 Problem statement**

For the last few years there has been around 500 TB cases/year, most of these among the foreign-born population living in Sweden (SMI 2012). One common risk in Sweden is the low concern of TB because of the low TB rate. This can be a risk since knowledge and preparedness often do not exist in a society where TB is a rare infection. Lack of knowledge about TB among doctors can lead to delayed diagnosis and treatments, which in turn can lead to an increase of the infection or more serious disease processes, such as meningitis caused by the tubercle bacteria (The Swedish Heart-Lung Foundation 2010, p. 28).

There are several factors that can increase the risk to get TB-infected in Sweden: Weakened immune system, such as HIV and other viral infections, malnourishment and diabetes, as well as living in environments where TB exists (Larsson 2011 & The Swedish Heart-Lung Foundation 2010, p. 27). Risk groups among the population being infants, young adults and elderly people, which are at a higher risk to develop TB compared to other age groups, but also women just having experienced childbirth. The risk groups are extremely vulnerable to develop TB (Larsson 2011 & The Swedish Heart-Lung Foundation 2010, p. 27). A higher risk to get infected can also occur in certain professions of the health care system, in laboratories, etc. (The Swedish Heart-Lung Foundation 2010, p. 27).



Another problem is the multidrug-resistant tuberculosis (MDR-TB)<sup>1</sup> that has steadily increased in Sweden, from 4-8 cases/year in early 2000 to 18 cases/year in 2011. Most of the cases were foreign-born people, and though it is not a major public health problem, it can be problematic for infection clinics, as they often have to isolate infected individuals long periods so that the bacteria do not spread into the society (Ängeby 2011).

Recently a lack of communication has been noticed between health professionals and refugees. Hence it is important to understand the consequences of lacking communication between refugees coming from countries with a high prevalence of TB and health professionals. Awareness is important so that the refugees can be treated in time before the infection develops further (Rydberg 2011, p. 6).

## **1.2 Purpose and research questions**

The purpose of this thesis is to investigate the present health communication between Swedish health professionals and immigrants, asylum seekers and refugees in Sweden, particular Stockholm, and to give an overview of what type of health care currently exist for refugees with a high risk of TB. This is done to understand what is missing in the communication process, what has been done in order to improve this process, and how it can be even further improved in order to prevent TB. The following questions will be addressed:

- What is the opinion of refugees regarding the current health communication?
- Do the Swedish health communicators and health professionals think that the Swedish health care demonstrates a high level of health communication? What has been improved and what needs to be improved?
- What precautionary measures have been taken by Swedish authorities to prevent TB?

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<sup>1</sup> Multidrug-resistant TB is when the tubercle bacteria is resistant to all reserve drugs. For these people the TB situation is similar to the patients back in the 1900s when there was no curative medicine for TB (Larsson 2011).

### 1.3 Definitions

*Refugee*: UN's definition of a refugee is a person who has left his home and who can not return there because of fear of persecution based on ethnicity, nationality, membership of a particular social group, religious or political belief. Refugees are also those who had to leave their home country because of war (Red cross n.d.).

*Asylum seekers*: Are usually people who have migrated across borders to seek protection and who are awaiting a final response to their application of asylum (The Swedish Migration Board 2011).

*Immigrant*: A person who has migrated to, for example Sweden, from a foreign country. The government has established that this is a crude generalization which implies a group with common characteristics and a togetherness that is separate from the Swedish people. The term should therefore not be used in a way that reinforces a "we-and-them mentality". Furthermore, the Swedish government states that the SCB and the Swedish Migration Board together have designed assistance to change the use of the term in the context of statistical description (Regeringskansliet 2000, p. 8)

In this thesis the term *refugees* will be used as a summarizing word for "refugees, immigrants and asylum seekers." Therefore, the terms "immigrants" and "asylum seekers" will not be mentioned together with "refugee" every time.

## **2. THEORETICAL FRAMEWORK**

### **2.1 Previous studies**

Migration all over the world has had a major impact on the spread of TB. In the beginning of the 1900s there was a death rate of 25 % of TB cases in Western Europe, with most of the TB death cases being carried by refugees from south and East Asia, the Americas and Central Africa. In later years TB cases has decreased in high-income countries, but has still remained in large numbers in low-income countries (WHO 2007).

Many people around the world migrate to other countries, sometimes because of war or poverty, sometimes just to have a better life in general. Refugees and asylum seekers are forced migrants and often do not know the language of the country the seek refuge in, nor do they have knowledge about the Swedish health system of the new country which is common to have among other migrating groups (Wahoush 2009).

In recent years there have been reported TB cases in countries where the incidence is low in general, such as United Kingdom, Canada and New Zealand. The European Centre for Communicable Disease Control (ECCD) has reported that many of these affected countries have slowly re-emerging TB problems because of the migration patterns from countries where the TB prevalence is high. (Massey et.al. 2013 & Kulane et. al. 2010).

In several European countries, such as Sweden, Denmark, Norway and Switzerland, a 50 % increase of reported TB has forced the health care authorities to notice the epidemiological importance to address the problem. As a result screening test for TB of newly arrived refugees have begun to be implemented (Lillebaek et. al. 2002, p. 679). In Sweden TB became a noticeable problem the early years of 2000 as a result of the increase in the number of immigrants from Somalia where the TB prevalence is high, combined with a non-successful health communication. This is basically the root of why the increase started in a low-incidence country like Sweden (Kulane et. al. 2010).

During the first half-year of 2012 208 cases of TB were reported in Sweden, which is virtually unchanged from 2011, when 595 cases were reported throughout the whole year. Though there is a small reduction of multi-drug resistant cases as only 6 cases were reported so far, compared to totally 17 cases in 2011. Among children under 15, 14 cases were reported, of which 11 are 7 years old or younger, and 3 are 14 years old. All the children were born in another country or have one parent born in a low-income country where the disease incidence is high. Three belonged to risk groups and were detected as a result of screening, and the others were discovered at the environmental survey of infectious cases they had come in contact with (SMI 2012).

Health communication has been lacking not only in Sweden but also worldwide. It mainly lacks a broad socio-economical, socio-ecological promotion approach, including an awareness of how cultural differences influence successful communication. Health inequalities have also been a major concern in the health care system. An ecological health promotion addresses the cultural, economical and social aspects that are necessary and required to make appropriate health decisions and create functioning health care for both parties, as well as being able to reach sustainable health care services (Mahmud et.al. 2013).

Many refugees all over the world are dissatisfied with the health care in the country they seek asylum in, mostly because of misunderstanding and lack of proper communication. Patients play an important role in the health care - they are an important source of information regarding incidents, sickness, and problems that can occur. The health information they can provide is necessary for further safety, quality and development. Many of the newly arrived refugees decide not to identify their illness because of fear of rejection, and in many cases there has been a lack of communication (as mentioned above), which causes misunderstanding, distrust, etc. Many of the newly arrived patients are not used to the technical health system in the new country, nor the health approach with its examinations, language, medication and diagnostic errors (Suurmond et. al. 2011).

Health communication and intercultural communication has become a necessary tool for developed countries to interact with newly arrived refugees. The migration process to another country can often cause language barriers, distrust, misunderstandings, etc. Therefore, a wider consideration of the refugees' cultural background and the way they think about health is required for a successful health care situation (Filippo et.al. 2013 p, 139).

Improving health care and health related communication is important among low-incidence countries where immigration and diseases rates are increasing. It is important to address different types of political and technical factors of managing the communication between refugees and health professionals. Global partnerships are required at national, regional and international levels (IOM 2006, p. 29). The International Organization for Migration (IOM), the International Labor Organization (ILO) and the World Health Organization (WHO) are some of the organizations that are currently working together to improve the communication between refugees, authorities and health professionals. International Migration of Health Care Workers: the supply side is another action program that is currently working on developing policies and strategies to attain functioning management practices to a functioning cooperation between authorities, health professionals and refugees (IOM 2006, p. 29-30).

## **2.2 Health communication theory**

The health communication theory (HCT) defines health communication as when information is delivered and shared between health professionals and patients. It is transferring the information between the transmitter and the receiver.

Communication is a way of sharing meanings and to be able to reach out with the transmitter's message. If the relevant information is not existent the person is not able to make an informed decision. Good communication is the key to effective health care, which may lead to positive results of care, while bad communication lead to negative effects for the receiver (Berry 2007, p. 1).

Wahoush (2009) argues that effective communication in health care is necessary:

- In order to promote ongoing care.
- In order to restore the health after any kind of treatment for sickness.

- In order to provide global health information (which has shown to be difficult) (Wahoush 2009).

The communication theory describes that *effective medical encounters* will depend on developing and upholding effective relationships, which in turn depend on effective communication between the different contributors. The HCT is used to inform patients to reduce doubt. Relationships are developed through steps of self-disclosure in which members gradually reveal information, feelings, behavior and attitudes through communication (Berry 2007, p. 40). Communication is vital for the effective delivery of health care, and therefore the most influential tool for effective health care, but the communication on a clinical level and a patients level has often lead to misunderstanding and distrust from the patients side. According to Berry and Weiss (2007) research, most of the patients, mostly refugees do not even understand the information that is given to them by health professionals. The lack of understanding has caused missed appointments with patients, medication errors, etc. (Barry and Weiss 2007, p. 6).

There is more than just ‘good health communication’. To achieve successful health messages in a community there has according to Jarlbro (1996) to be knowledge about the group of refugee patients who the message is targeting. The knowledge will make it possible to for the communication designer to choose specific health communication factors as well as communication channels that are suitable for the target. Jarlbro (1996) also describes that public health authorities often base their communication on the fact that they share the same outlook on risk as the general population (Jarlbro 1996, p. 25).

There are different health care encounters that have different communicative styles. Berry (2007) describes that according to a few researches it has been shown that individual health care providers vary in terms of how often they provide information. It has also been proven that health care professionals manages to adapt their style of contact in reliable ways, according to the nature of the patient, for example that health care professionals use a more serious manner where they focus more on technical and physical aspects, and prioritize patients that are more ill (Berry 2007, p.41).

Health communication and promotion has been concerned with ongoing healthy and risky behaviors of people. Organizations and communities focusing on policies, program and practices do according to Gilk (2007, p.34) improve health status and often banish health inequalities. Messages and communication campaigns can change awareness and health behaviors within the populations (Gilk 2007, p. 38). Gilk (2007) explains that here are two types of risk communications. *First* there is the crisis and risk communication, a functional essential to public health agencies, which can be seen as accurate and effective communication to diverse audiences in emergency situations such as natural disasters, disease epidemics, etc. The *second* one is the risk communication which explains information concerning caused by industrial, policies, and health risk generally (Gilk 2007, p. 34). Gilk (2007) further describes that public health agencies should be better prepared for the demand of risk communication during disease crisis, or the agencies could risk losing centralized control of the risk communication process (Gilk 2007, p .43).

Health communication campaigns play a significant part in disease prevention and health related factors. Usually the information is complex and technical which makes the communication a difficult task.

Apart from information campaigns there are other public ways to reach out to people, for example, Internet and other modes of communication. Internet has become a necessary tool over the years and a global network for people to be able to communicate all over the world in an easy way.

HC is necessary in order to provide a functioning health care and treatment - that is why good communication and social skills are important in people's lives. In the later years HC has been considered and recognized in health care in order to gain as effective treatment as possible. It has been concluded that health professionals who create a "friendship" with their patients have made more important difference for the patients health and wellbeing compared with health professionals being impersonal and conventional (Berry 2007, p. 7)

According to HCT it is important to reach out with the necessary messages to the patients. All of the authors agree that good communication is needed for an effective

health care. Information campaigns, the use of interpreters, and cultural understanding of the patients background are some of the important objectives that are required in order to be able to reach the patients with communication and build a relationship of trust which can lead to positive emotions. This in turn can lead to a functioning health care, where patients can trust the health professionals, are able to seek health care if needed and are able to and wants to co-operate with health professionals to prevent the spread of disease.



## **3. METHODOLOGICAL APPROACH**

### **3.1 Interviews**

In order to answer the questions interviews have been carried out with four refugees as representatives for the immigrant community, two health communicators and the medical head of unit at SCC representing the health establishment, and finally one senior medical officer at the Swedish Board of Welfare and Health. Eight structured interviews were carried out between 3rd-21st of May and August 19th 2013, with several health communicators and refugees of different ages to get a wider perspective. The informants were contacted by telephone where the purpose of this study was presented, followed by the questions. These categories were divided into two groups: refugees and health professionals. The selected refugees were students at high school level. The reason to select them was because they have not lived in Sweden for a long time and their experiences are beneficial for this study. The health professionals were defined as health communicators and worked at Stockholm County Council and at The National Board of Health and Welfare.

All of the interview questions were based on the lack of HC focusing on how the communication is currently working and on what in their opinion needs to be improved. The questions were formulated differently for the refugees and the health professionals, which will be referred at the end of this thesis (Appendix 1). Most of the interviews were conducted face-to-face, two of the interviews were conducted via telephone. Each interview was carried out for 10-20 min, with the same questions. The interviews were transcribed immediately on the computer after the interview in order to not forget any essential information. The choice of taking notes on the computer instead of recording the interviews was because of the time limit and also because the informants would feel more comfortable and relaxed.

1) The first informant used in this study was Sofie Bäärnhjelm, 57 years old, working as a consultant and psychiatrist at Transkulturellt centrum, Stockholms läns Sjukvårdsområde. The interview took place via telephone. 2) My second informant was a girl from Somalia, Fatima, 16 years old, who had just arrived to Sweden. She

could not understand Swedish, so my friend Mona interpreted for me during the interview at Fatima's house in Spånga. 3) My third informant was a newly arrived boy from Afghanistan, Hussein Asadi 16 years old. He could understand and speak Urdu, and since Urdu is my mother tongue, there was not a problem to communicate with him. The interview took place at Upplands-Bro Senior High School. 4) The fourth informant was a Somali girl named Zarah, who was 18 years old and who just like Fatima did not want her last name to be mentioned in this thesis. Zarah came to Sweden three years ago, and it was not a problem to communicate in Swedish when we met at her house. 5) The fifth informant was a lady called Marukh Babar, who was 82 years old. She could not understand Swedish but could understand and speak Urdu. The interview took place at Marukhs house in Märsta. 6) The sixth informant was Nadia Toma, licensed nurse and health communicator at Transkulturellt centrum, Stockholms läns Sjukvårdsområde. The interview took place via telephone. The interview proceeded in Swedish. 7) The seventh informant was Haibe Hussein, a 51-year-old coordinator and health communicator at Transkulturellt centrum, Stockholms läns Sjukvårdsområde, who was interviewed via telephone. 8) My last interview was held by phone with Inger Andersson von Rosen, a 58-year-old physician at the National Board of Health and Welfare (Socialstyrelsen) at the Department of Communicable Disease Prevention and Control.

### **3.2 Choice of method**

At one hand this thesis is based on eight structured interviews, performed to give the study necessary empirical data. At the other hand it contains secondary data consisting of peer-reviewed scientific reports, used in order to widen its empirical base and give theoretical arguments for carrying out the analysis. Most of the reports and articles used in this thesis are collected from the data banks of SMIs (<http://www.smittskyddsinstitutet.se/>), SOSFSs (<http://www.socialstyrelsen.se/>), Swedish Heart-Lung foundations (<http://www.hjart-lungfonden.se/>), and SCCs (<http://www.sll.se/>) at their websites and from the Internet: BioMedCentral (BMC Public Health: <http://www.biomedcentral.com/>), Google scholar (<http://scholar.google.se/>), PubMed (<http://www.ncbi.nlm.nih.gov/pubmed>), Web of science (<http://wokinfo.com/>) and other scientific websites such as and SöderScholar (<http://webappl.web.sh.se/>). The keywords that were used to find peer-reviewed articles and reports were: tuberculosis, tuberkulos, health communication,

hälsokommunikation, Sweden, Sverige and migration. The main focus has been on recent information from SMI's, Swedish Heart-Lung foundation's, SOSFS's, SCC's and SMA's websites.

The selected data concerning regulations and practices were mostly used from SMI, since SMI is a reliable source. The data was selected after its relevance regarding lacking health communication between health professionals and refugees who migrate to Sweden from countries with a high burden of TB issue and therefore SMI's website, peer-reviewed reports and articles will be used. SMI is a national knowledge authority responsible for infection disease control issues with a broad public health perspective. However, to achieve a well-performed method and thesis it is still important to be critically of the sources - peer-reviewed or not.

SMI monitors analyzes the development of infectious diseases, as well as build a communicate knowledge to the health sector and other stakeholders in disease control area. The government statute regulates SMIs activities through the *Infectious Disease Act* (SFS 2010, p.604) and in the annual appropriation. SMI and the disease control units place emphasis on epidemiological surveillance of more than sixty diseases that are modifiable under the Communicable Diseases Act, the Communicable Diseases Regulation, and the Board's rules of application of Diseases Act. SMI is reliable and therefore it is relevant for this thesis to use SMI as a main source (SMI 2011). Other websites that will effectively be used are SOSFS and SCC.

SOSFS is a government agency that highlights health, welfare and equal access to good health care, and SCC is a county council, which is responsible for certain collective functions within a county, such as: it is controlled by politicians who are elected directly by the Swedish citizens of the county, and it has the right to levy taxes. Google Scholar, Söder Scholar has been effectively used for this thesis with a search for scientific literature. BioMedCentral has also been a huge benefit to this thesis with recent peer-reviewed data about TB.

### **3.2 Validity and criticism of sources**

The structured interviews gave this study a deeper perspective. The interviews have demonstrated validity due to that the informants opened up about their experiences. Based on the interviews the informants experienced real life situations with information based on personal information that made this thesis more recent and reliable. However the interviews were few and if it was not because of the time limit, more interviews could have been performed in order to make the thesis stronger.

Overall the interviews proceeded smoothly. The structured interviews were however not recorded. Taking notes and not recording the interviews is a weakness as information easily gets lost. It was also difficulties to book time with the health communicators and refugees to match their schedules. For that reason there were no face-to-face interviews with the health communicators, which could have been more valuable. The interview that was probably easiest to write down was the e-mail interview, which made it possible to read it through over and over again. The interpreter was of great help for this study since that made it possible for me to communicate with one of my informants. The differences in method, telephone, mail and face-to-face represents an uncertainty interview in the material. More informants could have been used and for further studies a recorder would be helpful.

Another obstacle has been to find up-to date information about the Parliament's and the government of Sweden's actions due to the low concern of the TB problem in the country and lack of HC. It has also been some difficulties to find information about preparedness and changes of TB between the years of 2003-2013, since SMIs reports focus more on statistics. The main obstacle for this study has been the limited recent sources, which made this study weak. Further, some sources are not scientific such as information from The Swedish Heart-Lung Foundation, ILO (<http://www.ilo.org/global/lang--en/index.htm>), IOM (<http://www.iom.int/cms/en/sites/iom/home.html>), WHO (<http://www.who.int/en/>), and UN (<http://www.un.org/>), but the sources have been investigated and carefully considered; these organizations often use peer-reviewed scientific information like

statistics and calculations when they make their decisions, however the WHO and UN sources have been carefully observed.

There are sources of information available that address the health communication in Sweden, the screening process of newly arrived refugees, and the TB problem between 2003 until today. Most of the sources that are used in this thesis are Swedish sources, and most of the used statistics and information are from SMI's research. Many of the sources were secondary sources such as information taken from SOSFS and SCC websites.

## **4. FINDINGS**

### **4.1 Refugees' experiences**

The Swedish Communicable Disease Act defines TB as a public health concern. Therefore screening of TB patients is extremely important. The main thing about screening is to acknowledge asymptomatic or symptomatic patients suitable for preventive or curative treatment and to be able to stop further transmission. In Sweden TB is controlled by screening and contact tracing - this practice describes whether TB has been spread through earlier contacts. Contact tracing is used to decrease the burden of TB. Screening foreign-born people for TB has widely been used in low-income countries to face the challenge in countries where the TB prevalence is high. As foreign-born people are at a higher risk to develop TB in Sweden than native Swedes, the Swedish health care system now offers refugees routine TB checks and screening (Nkulu et.al. 2010, p. 2). In Sweden, the law (2008:344) health care for refugees has been established and therefore a health examination will be carried out as soon as possible after the arrival to Sweden (Swedish Parliament 2008).

During the recent years Sweden has received and still receives a large number of refugees mostly from Somalia and Afghanistan. As mentioned in the introduction chapter the migration patterns from Somalia initially resulted in an increase of TB in Sweden, followed by a drastic decrease in 2010-2011. The reason could be that Somali citizens went from being the largest immigrant group in 2010, to the sixth largest group in 2011. The reason why this migrating group decreased is because it has become much more difficult for citizens of Somalia to obtain a residence permit in Sweden to reunite with a relative, as there is no government approved of Sweden to issue identity documents (SCB 2011).

While the need for health care is large, there is often distrust in the health care according to the refugees (Baker and Alleback 2012, p. 4). Stockholm County Council explains that it is necessary to provide refugees with optimal conditions to help them establish socially in the Swedish society, which is the main goal of the

municipal induction program (SCC 2003). SCC (2003) offers newly arrived asylum seekers, refugees and immigrants medical examinations. During the asylum period the asylum seekers are entitled to emergency care. Refugees with residence permits and asylum-seeking people have the same right to health care as other Swedish residents. Many refugees have experienced difficult and traumatic situations before their arrival to Sweden and they are in need of extensive contacts with health care or psychiatry. Many refugees have such poor health that it impedes the introduction (SCC 2003).

According to Rydberg (2011) the general health status of Swedish residents is improving, but this improvement does not include everyone. Although most groups in Sweden have better health status than earlier there are still differences, especially between the people who are foreign-born and the Swedish born. Rydberg (2011) argues that in order to fully remedy the unequal differences improvements have to be made on several fronts - An accessible care in socially and economically disadvantaged areas and choice for patients, and zero tolerance of discrimination. She also explains that it is important to reach out to newly arrived refugees and asylum seekers through functioning communication, to explain the Nordic conditions to them, how to seek health care and other important social functions in Sweden (Rydberg 2011, p. 6).

Today the Swedish health care system is developing positively but there has been a lack of health communication between refugees, authorities and health professionals, mostly because of the Swedish language. This directly cause that fewer refugees (who carry a disease) undergoes health examination which in turn cause the spread of the infection (Bågenhom 2011, p. 10). When asking the foreign-born informants about how they feel about the Swedish health care system, both Fatima and Zarah mentioned that they had difficulties understanding it, especially when it come to the health examination guidelines of how to seek health care.

One common problem is the lack of economic possibilities and transport –i.e. the distance to health care clinics. Zarah commented further by adding that the extended use of specialist social workers and classes on healthcare provision in Sweden could help foreign-born individuals to better understand the health care system and the services provided by them. Fatima held the opinion that interpreters alone are not

capable of providing the required assistance in the matter of healthcare and that the problem can be tackled through other means, for example literature and 24 hour advice helplines. Although the incapability of interpreters is a very rare case and it is not a major concern.

Husain experienced difficulty with the Swedish language, which has caused misunderstanding and distrust due to that he could not understand the importance of health examinations if needed and other health care guidelines. Although every newly arrived refugee has the right to an interpreter, the three informants, Fatima, Husain and Zarah, experienced lack of understanding of the Swedish health care system and health thinking approach. Alternative measures should be applied by the local authority or city council to spread awareness of the rights that foreign-born individuals have in Sweden in terms of medical care. When interviewing the three informants, a clear pattern emerged in which they were overall content with the level of medical treatment, but were not satisfied with how the administration dealt with enquiries. Where a certain issue needed to be discussed or resolved, because administration could not fully understand the issue, a communication gap was developed and certain issues were left unresolved leaving the patients feeling worried and anxious (Asadi, informant, Fatima, informant, Zarah, informant).

Zarah can understand and speak Swedish today, but she said that there was a problem with the communication three years ago when she had newly arrived. Zarah was infected with TB when she arrived in Sweden, but it was not a serious case and although she was treated immediately after arriving she explained that she had problems understanding the underlying factors of the TB-treatment even though she had access to an interpreter (Zara, informant). The first phase of TB can be treated with antibiotics, and it is not seen as a high concern compared to for example HIV. Zarah did not understand this.

*“I had an interpreter when I was infected with TB but I still did not understand how dangerous TB could develop or what medicines I needed. It was very confusing and I did not really have the money to have access to internet so I could not Google about TB. The only help I had was from the doctors and my interpreter, but the communication was not enough to completely understand the whole TB situation. I*



*was scared and confused and I prayed that it was not a major problem, I really hoped that I was not going to die. After a few conversations with the doctors they told me that it was not anything serious and that it was good that I had been able to treat TB in time before it developed into anything serious which I did not know much about. I am happy that I got the help I needed but if the communication was better I could have known more about the infection health examination policies, etc. “ (Zarah, informant).*

One of my informants opened up about the lack of communication when it comes to the cultural misunderstandings. She wished for a female nurse when she was going to undergo a health examination but got a male nurse even though she tried to explain through her interpreter that she felt uncomfortable with a male nurse. She felt very uncomfortable and had to accept to get checked up by a male nurse even though she was not used to it and made her feel uncomfortable. Interpreters were involved to help aid her along her treatment and provide the healthcare she needed, but as her request to have access to a female nurse was being rejected it left her feeling vulnerable, humiliated and misunderstood. She did not want to seek health care anymore and made her feel as though her voice was not being heard, even though the government was providing her with a high level of healthcare.

*“I did not like the service at all! I asked for a female nurse but still got a male nurse because they claimed that they did not have the access of a female nurse at the moment. I feel like the health professionals did not take my culture seriously or maybe they just ignored or did not care because the Swedish culture is very different from my own. I felt humiliated and very uncomfortable, which is not right. Every patient have the right to feel safe and the professionals should satisfy the needs of each patience for the best service and have understanding for each patients unique background, which clearly is lacking because of ignorance and lack of communication” (Babar, informant).*

Babar (2013) describes that cultural differences have been an issue in the Swedish health care, it has been discussed by the author Ekblad (1996) as well. He argues that the understanding of this dimension plays an important role.

This demands to the health care system to understand each patient’s unique

background, expectations and knowledge and to find new ways to meet the patients need of proper care on equal terms (Baker and Alleback 2012, p.4). Most of all stakeholders agree the ability to communicate and convey a message is as important as the specific medical knowledge (Baker and Alleback 2012, p. 33). SCC's report has presented that refugees are dissatisfied with the Swedish health care, mostly because of bad communication between the health professionals and the refugees. Different cultures have different ways of interpreting disease and pain. Factors such as history, environment, social structure, and religion have continually shaped different perceptions. The human body is different and therefore human bodies react different. The same disease can be treated in different ways in different countries (Ekblad et.al. 1996).

The refugees often feel like they are not taken seriously. Hussein (2013) explained that the migration process can be complex, factors like: norms, culture, values etc., can have a negative impact on the communication between the refugees and health professionals, especially when it comes to newly arrived refugees. However, Hussein was quite satisfied with the Swedish healthcare and the interpreter he got, though he said that the main obstacle was the financial barriers like paying for the transport to the health center, the depth of information given to patients, and the medical assistance delivered in terms of administration issues that he had encountered but was unable to deal with because of his weak Swedish (Asadi, informant).

Although not mentioned by the informants, fear of expulsion from the country because of TB symptoms has been mentioned in the literature as a reason for lack of health communication. Many of the refugees often fear the contact tracing process as they fear that their asylum application will be rejected if there are any signs of active TB – this can also be a the reason TB-infected refugees do not want to undergo health examinations, which in turn cause the spread of the infection (Kulane et.al. 2010, p. 27).

As mentioned by Bäärnhielm (2013), the experiences the individuals carry with them from their home country differs and the immigrants' expectations from the doctors and health care system differs, which can create both disappointment and misunderstanding. Therefore the health care system has a huge responsibility to

inform how and why newly arrived immigrants need to undergo health examination, and it is important that migrants get informed of the different perceptions of illness and health (SCC 2003).

Fioretos (2009) describes that refugees are more dissatisfied with the health care than Swedish people. The refugees often feel like they are not taken seriously. When it comes to the primary care, health professionals have experienced difficulties with patients expressing their suffering in both physical and emotional terms simultaneously. Many times it is difficult to distinguish between life problems and illnesses (Fioretos 2009, p. 36).

#### **4.2 Health communicators view on health communication**

The health care in Sweden, particularly in Stockholm is improving positively but there are still concerns. The communication between newly arrived refugees, authorities and the health care system in Sweden is poor because of the linguistic barriers - most of what is written and said is in Swedish. Another obstacle is the financial issues and distance to the clinics where the refugees can undergo health examinations. People migrating from low-income countries often lack experience of preventive health thinking and approach. Therefore, there are very few refugees who undergo preventive health examination because of lack of awareness, despite the presence of hidden infections is common (Bågenholm 2011, p. 10 and Rydberg 2011, p. 6).

*“It is important that the staff is competent and has a good understanding of “intercultural communication” (Hussein, informant).*

Dr. Bäärnhielm mentioned in the interview that even if the health care situation is developing positively in Sweden there are a few things that need to be improved. When people with different cultures and backgrounds migrate to Sweden it is important to make awareness on an individual level as well as on an organizational level and be able to understand the cultural differences. It is also important to respect and try to fulfill the needs of the newly arrived refugees. One of the difficulties that can occur is the difficulty to understand the language, but that can be solved with an interpreter which every immigrant has access to. One of the main obstacles is the

financial issue, which has been mentioned above. In order to improve the system it is important to highlight this issue. Written information should be available in several other languages, and it should be made sure that every immigrant and refugee has access to an interpreter (Bäärnhielm, informant, Hussein, informant). Another obstacle for the refugees is the Swedish health care system, which is very new for them and different from their home countries health care systems. They are not used to wait for a doctor if it is urgent. In many cases they expect to receive a doctor immediately in the emergency room, and many immigrants, refugees and asylum seekers from Arabic countries do not trust nurses as much as doctors (Toma, informant).

*“As a health communicator I can say that the communication has become better, many of the refugees are very happy with the given information”* (Toma, informant).

It is necessary to have access to an interpreter to be able to communicate with the newly arrived refugees. A patient’s requirement can sometimes not be satisfied - factors like disease and stigma around certain diseases can be difficult to define - two factors to consider from a cultural perspective when speaking to refugees with a different culture and background (Hussein, informant).

The migration process can be complex, and factors like norms, culture and values can have a negative impact on the communication between the refugees and health professionals especially when it comes to newly arrived refugees (Hussein, informant).

#### **4.3 Practices, policies and preventive measures taken by Swedish authorities**

The strategy for preventing and combatting TB is similar in all countries where TB is a public health concern. Apart from a general desire to raise the living standard and level of knowledge of people, the authorities are trying to apply simple and safe methods to prevent TB in Sweden. The authorities’ goal is to give all patients with TB an effective treatment, and to ensure that patients follow the treatment long enough to be free from infection (The Swedish Heart-Lung Foundation 2010, p. 29).

The professionals who are responsible for TB in Sweden should, according to SOSFS

(2012), make sure that the refugees are well informed of how to seek health care if any signs of TB occur. It is the health care professional's responsibility to find people who are ill and arrange procedures to reduce the risk of infection. The medical professionals have the responsibility to protect their employees if the work carries an increased risk of infection, and the National Board has a responsibility to develop recommendations and solutions for this work to be carried out and to ensure that it is implemented (SOSFS 2012).

People who migrate to Sweden from areas where TB prevalence is high are recommended to undergo a health examination (SOSFS 2012). However, health examinations of TB have led to problems when it comes to sampling. Sputum sample is sent to the laboratory for microscopic examination but the tubercle bacteria grow very slowly. It takes up to 7-8 weeks before you get the response (Larsson 2011). As the Swedish Parliament and SOSFS suggests it is important that refugees get advice about the Swedish health care system at arrival. It is also important that they get proper information about symptoms of TB, and where to turn in the case of suspicion of active TB (SOSFS 2012, p.19).

*“In Sweden there are no mandatory health examinations. However, there is a concern that way too few actually are made aware of this legal right, and some believe it should be compulsory to be consulted by our health care at the point of entry”* (Andersson von Rosen, informant).

People who migrate to Sweden have a legal right to be offered health conversations quickly and the necessary investigations. A reason for this is that those who may carry a TB infection – also people without any TB-symptoms – should know how to contact the health care if there are any signs of the infection to develop any further (SOSFS, 2012 and Andersson von Rosen, informant). It is essential to intervene as early as possible to be able to handle the infection as well as reduce the risk for the transmission of TB (Andersson von Rosen, informant).

SMI (2011) underlines the importance to offering new arrivals a health examination early after arrival to Sweden, something that is also recommended by SOSFS and the Swedish Parliament (SMI 2011).

TB can be treated differently depending on which stage of TB the patient is in. For instance, patients with infectious TB must be hospitalized, but for patients in an earlier stage the entire treatment can be performed in outpatient care, provided the patient is cooperative and does not have other diseases that require hospital care. TB is treated primarily with antibiotics. It can be necessary to combine two or more drugs to reduce the risk of bacteria developing resistance (Heart-Lung foundation 2010). This is important information that many refugees miss, mostly because of the lacking communication between them and the health professionals.

Today, in Sweden there are vaccinations and treatment against TB so it has less priority as HIV, which today has no cure. TB screening tests are not mandatory in Sweden because of the low concern in the country and growing samples take a very long time. Today it is more up to the doctors to decide whether the refugee or immigrant should undergo a health examination or not. However, the Communicable Disease Act requires a person to undergo a health examination if there are any signs of active TB.

A health examination is required of new arrivals from countries where the TB prevalence is high, such as Somalia, to whom it is particularly important to provide information to about symptoms of active TB and the importance of seeking medical attention if these symptoms occur (Winstrand et.al 2010). Today, doctors and nurses who are responsible for a person with infectious TB offer him/her a contact tracing, which means a mapping of the contacts the sick people had before they got infected. The Communicable Diseases Act require of people to agree to get a TB tests if the person has any sign of infectious TB that can develop into active TB (Larsson 2011).

According to Berggren (2006) mandatory controls should be required, but you can do a lot to influence attitudes. It is also important to note that in Sweden there are groups without foreign background among whom an increasing TB prevalence could take hold (Morner 2006). Berggren also explains from experience that it can be difficult to identify and reach the people who were exposed. The old tuberculin<sup>2</sup> test is not

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<sup>2</sup> Tuberculin, Purified Protein Derivative (PPD) test is one of several steps to determine whether a person is infected with TB or not. The test can show if the person ever in their life has come into contact with other TB patients and then become infected. The

completely reliable for assessing for contamination and must be interpreted. Nor can the test predict which of the infected will become sick. Berggren (2006) stated the importance to address a latent infection. Only 5-10 % of infected people develops TB some time during their lives, though the greatest risk is within 2 years of infection (Morner 2006).

The Stockholm County Council started a project in 2010-2011 - *Health Communicators in Stockholm County 2010*, where the purpose of the project was

*“To promote health and prevent ill health associated with migration, asylum and municipality received refugees and subsidiary protection of people by strengthening health promotion and prevention in primary care with multilingual health communicators that can reach a group which cannot usually be reached by primary health care”* (Baker and Alleback 2012, p.2).

The idea of the health communicator is to build a bridge between the refugee reception and primary care, by both supporting asylum seekers and newly arrived refugees contacts with primary care and by facilitating primacy care staff working with these groups. The reception and introduction of newly arrived refugees human health should be seen and is an increasingly important part (Baker and Alleback 2012, p.5).

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test can also find out if the person has been vaccinated against TB. If the tuberculin test does not show any reaction, it is often because the person is not infected with TB (Larsson 2011).

## **5. ANALYSIS**

In this study the following three questions have been studied:

- 1) What is the opinion of refugees regarding the current health communication?
- 2) Do the Swedish health communicators and health professionals think that the Swedish health care demonstrates a high level of health communication? What has been improved and what needs to be improved?
- 3) What precautionary measures have been taken by Swedish authorities to prevent TB?

In order to answer the questions interviews have been carried out with four refugees as representatives for the immigrant community, two health communicators and the medical head of unit at SCC representing the health establishment, and finally one senior medical officer at the Swedish Board of Welfare and Health.

Theories on health communication argues that the lack of communication between refugees and the local health establishments, both worldwide and in Sweden, is a result of a) language barriers, b) cultural differences, c) fear of expulsion, and d) financial problems. They also claim that inequalities in the health care system are a major concern. Many newly arrived refugees are dissatisfied with the Swedish health care mostly because of misunderstanding and lack of proper communication.

According to Suurmond et. al. (2011) many refugees globally are dissatisfied with the health care as a result of communication problems and misunderstandings. In the interviews with the Swedish refugees the first question asked was “How do you feel about the Swedish health care today?” According to all of the informants Husain, Zahra and Fatima they have had problems understanding the Swedish health care system, how to seek health care, how to go about in order to have a vaccination, as well as receiving dangerous infections and other diseases. This supports Suurmond et. al’s arguments that refugees have a problem understanding the health care they meet as refugees.



Filippo et. al. (2013) argue that skills in intercultural communication has become a necessary tool for developed countries to reach out to refugees. Language barriers have caused a problem with the health communication between refugees and health professionals, which has led to distrust, and misunderstandings between them. Therefore it requires a wider consideration with the refugees' unique cultural background when communicating about health. The second and the third questions asked was "What do you think about the communication, do feel that you have been given correct information to be able to seek health care if needed?" and "Have you ever felt lack of understanding or distrust for the Swedish health care? If yes, explain why?" All of the informants had experienced misunderstandings due to the language barriers, which had enabled them to seek health care and not provided them with enough knowledge about how health examinations are carried out. Another problematic aspect according to Ekblad (1996) can be the cultural differences between refugees and health officers in the receiving country, which need to be carefully considered. Baker and Alleback (2012) agree and further argue that this demand of the health care system to understand each patient's unique background, expectations and knowledge. Hence, new ways to meet the patients' need of proper care on equal terms are necessary to develop. The informant Marukh Babar gave a good example of cultural misunderstandings. She explained that she had experienced disrespect from the health care when she wished to be examined by a female nurse, but got a male nurse instead as there were no female nurses available at the moment. This misunderstanding lead to a situation where Marukh avoided seeking health care in the future when she needed to, because she did not believe that the health officers would offer her a female nurse if she asked for it. Marukh's case clearly shows a lack of cultural understanding because women from certain cultures are not used to be examined by a male nurse without feeling very uncomfortable.

According to Suurmond and the interviewed refugee informants health communication is clearly lacking in Sweden (Suurmond et. al 2011). Improving health care and communication is important among low-incidence countries where immigration and diseases are increasing. It is important to address different types of political and technical factors of managing the communication between refugees and health professionals (IOM). The first question asked to the health professionals was "What are your thoughts regarding the communication between refugees and health

professionals? How do you think the communication is currently working? " All of the health professional informants agreed that the communication currently is lacking and Bäärnhielm explained that the health care is developing positively but there are a few things that need to improve. She also said that when people from different cultures and backgrounds immigrate to Sweden it is important to raise awareness on an individual level as well as on an organizational level that it is important to be able to understand cultural differences. Hussein (2013) also explain that the migration process can be complex due to factors such as norms, culture and values which can have a negative impact on the communication between the groups. However Toma (2013) explained that many of the refugees today are very happy and thankful with the given information. Although according Bäärnhielm's and Hussein's statements this study shows that cultural differences should be carefully considered and understood in order to achieve understanding and a good communication between the groups.

Wahoush (2009) argues that when refugees migrate to another country some of the main obstacles can be the language and other knowledge about the health care system. The second question asked was "What do you think is the main obstacle - what can lead to lack of communication between health professionals and refugees?" As my health professional informants said, one of the difficulties that can occur is the language, but that can be handled with an interpreter, which every immigrant has access to. One of the other main obstacles is the financial issues, which is mentioned above. Toma (2013) described that many refugees are not used to the health care system and refugees from Arabic countries do not trust nurses as much as they trust doctors. Another obstacle is that many refugees are scared of expulsion of the country if they talk about their infections.

According to IOM (2006) improving health care and communication is important among low-incidence countries where migration and diseases are increasing. Therefore it is important to address different types of technical and political factors of managing health communication between refugees and health professionals. The third question asked was "How do you think lack of communication between these groups can be improved?" Bäärnhielm (2013) explained that in order to improve the system it is important to highlight the issue, specifically what strategies can be used to improve

the health communication in Sweden. Written information should be available in several other languages, and it is important to make sure that every immigrant and refugee has access to an interpreter. Hussein (2013) mentioned that it is important that the staff is competent and has a good understanding of intercultural communication and it is also necessary to have access to an interpreter to be able to communicate with the newly arrived refugees. The patient requirement can sometimes not be satisfied - factors like disease and stigma around certain diseases can be difficult to define - two factors to consider from a cultural perspective when speaking to refugees with a different culture and background. Therefore it is extremely important that this problem is highlighted and that SCC's researches about HC between refugees and health professionals keep continue in order to achieve improvement.

The professionals who are responsible for TB in Sweden should according to SOSFS (2012) make sure that the refugees are well informed of how to seek health care if they develop any signs of TB. It is the professional's responsibility to find people who are ill and arrange procedures to reduce the risk of infection. People who migrate to Sweden from areas where TB prevalence is high are recommended to undergo a health examination (SOSFS 2012). However, health examinations of TB have led to problems when it comes to sampling. Lastly, the third question asked was "What policies have been made regarding health information/conversations and health examinations for newly arrived refugees?" As Larsson (2011) demonstrate and according to Andersson von Rosen (2013) health examinations in Sweden are not mandatory. However, she said, there is a concern that way too few actually are aware of this legal right, and some believe it should be compulsory to be consulted by the health care at the point of entry. People who immigrate to Sweden have a legal right to be offered quick health conversations and necessary check-ups. It is essential to intervene as early as possible to be able to handle the infection as well as reduce the risk for the transmission of TB.

In the case of health communicators background and expertise in Stockholm county most of all stakeholders agree that the ability to communicate and convey a message is very important as the specific medical knowledge (Baker and Alleback 2012, p. 33). SCC's report have been experiencing some difficulties when it comes to the Swedish health care, which is mostly because of lacking communication between the health

professionals and the refugees which causes distrusts. However Toma (2013) explained that the communication today has been better and that many of the refugees are thankful for the information that is given.

After studying the applicability and the potential added value of the HCT that was used in this thesis, the theoretical framework, previous studies and the informants has shown an important link between health professionals and patients, as mentioned above there have been some complications between newly arrived refugees and health professionals - without proper communication the treatment for TB or other diseases cannot be cured effectively. Berry (2007) explains that health communication is used to inform others to reduce doubt, which means in this case that people arriving to Sweden with a high burden of TB should be screened if there are any signs of active TB. Berry (2007) also describes that relationships are developed through steps of self-disclosure in which members gradually reveal information, feelings, behavior and attitudes through communication. Berry is absolutely correct on that statement where the health professionals should receive information from the patients, where they explain their experiences, and their present traumatic experiences, medical illness history if they had any. As Ekblad (1996) explained people migrating to Sweden are not used to the healthcare system of the country, and therefore it is important that they are aware of how to seek health care. As both Gilk (2007) and Monahan (1995) explain in the HCT patients must receive important information through the health professionals so that the patients can seek health care if needed and can co-operate with health officials to minimize the spread of TB, in order to be able to achieve the most effective health care.

A good way to an effective health care can be possible if health professionals and agencies take into consideration the following factors when creating awareness of the impact of TB and the spread of the infection:

- The importance of building a good relationship with the refugees; a sense of trust and security.
- How to inform the refugees and immigrants in a way so that they can understand TB, the cause, the diagnosis and treatment.
- How TB affects society and how to confidentially report cases of TB that are

not recorded.

- The importance of health information campaigns. As mentioned by the HCT effective planned messages and communication campaigns can change awareness and health behaviors within the populations.

According to SMI and SOSFS the research findings also show that it is extremely important that refugees and immigrants can be screened if there is any sign of active TB, and that immigrants coming to Sweden have the opportunity to undergo a health examination as soon as possible after arrival into the country. However, the health examinations can be problematic due to the fact that the sputum sample can take up to 7-8 weeks to give results.

*“Health examinations must be undertaken if the refugees and immigrants suspect any sign of symptoms that can lead to active TB” (Larsson 2011).*

This is reasonable because even though the testing process takes a long time, only screened individuals should be able to travel outside of their country. Treating TB in the early stages is advisable as it can be controlled and treated. Awareness is vital so individuals know how to seek for health care if there is any sign of TB.

There are plenty of risk factors. One common risk in Sweden is the low concern of TB because of the low TB rate, this can be a risk due to that preparedness may not exist in a society where TB is a rare infection. Lack of knowledge among doctors about TB can lead to a delayed diagnosis and treatment, which in turn can lead to increased infection or more serious disease processes. Another serious concern is the financial issues and distance to the clinics for the refugees to undergo health examinations. People migrating from low income countries often lack experience of preventive health thinking and approach. Therefore, there are very few refugees who undergo health examination because lack of awareness. Today the TB symptoms can be seen in early stages and be treated with antibiotics, but one concerning problem is the MDR-TB problem, that has steadily increased in Sweden.

This study has shown that according to the informants the health status in Sweden is improving even if there are concerns that has to be improved: the health

communication is lacking which all of the informants agreed on, refugees feel distrust and there are plenty of misunderstandings when it comes to the cultural differences. Even though the refugees have the access to an interpreter they feel like the given information is not enough. To improve this problem it is important to understand each refugees unique cultural background but also for the refugees to understand the Swedish culture. To achieve functioning communication it is important that the refugees are given both oral and written communication in several languages

This study has found that a number of factors need to be improved in order to control TB that has already entered the country via refugees:

- Refugees need to be provided with awareness to be able to seek help at healthcare facilities by themselves, including tests and treatments.
- Refugees need to be counseled so that they feel a sense of security and confide in health professionals, especially if they suspect any unreported cases of TB.
- Creating a sense of awareness of the importance of treating TB through understandable proper health communication, hire an interpreter if needed.
- Asylum seekers, refugees and immigrants should see it as their obligation to seek health care if there is any sign of active TB.

As mentioned in the research findings HIV tests of newly arrived refugees are mandatory. According to Rydberg (2011) Sweden has today shown that health communication is lacking and that there has been distrust between patients and health professionals in the Stockholm county area, but which cannot be clearly clarified because of lack of information. However, the communication plays an important role to get as effective care as possible and therefore the communication has to be confirmed.

## **6. DISCUSSION**

In this thesis the health communication between refugees and health professionals has been investigated, particularly the situation in Stockholm. This study has clearly shown based on both primary and secondary sources that there is a lack of communication between health professionals and refugees in Sweden, similar to what has been observed in many countries all over the world. Many refugees migrating to other countries are dissatisfied with the health care they meet, mostly because of the same main reasons as was forwarded by the refugee informants in this study – the language barriers, fear of expulsion, financial issues and cultural differences. The health communicator informants mentioned that although the health care situation is improving there are several factors that need to be carefully considered when it comes to the communication with the refugees. These facts are not only supported by the interviews but also the secondary literature that was used in this study.

However, this study has also shown that Swedish authorities have taken quite a few measures already in order to tackle TB in Sweden and to improve the health communication according to SCCs project (2012), SMI, Andersson von Rosen (2013) and SOSFS. Awareness is vital so the refugees know how to seek health care if any signs of TB, and this important information can only be reached if there is proper health communication between the health professionals and patients. In line with this SLL have implemented reports regarding health communication and how to improve the issue, and SOSFS and The Swedish Communicable Disease Act have implemented guidelines for the newly arrived refugees – how to seek healthcare and be screened tested if needed.

It is of great importance for the health information to be given in several languages and maybe to get more employed health professionals with foreign origin who has a wider understanding of refugees from their particular countries.

If authorities, related departments and organization continue to contribute to achieve better communication and health service it might be possible to make refugees

more satisfied with the Swedish health care. The SCC's work and studies are extremely important in order to contribute to the improvement of the lacking communication and further investigation on how the communication currently is working, and what factors that need to be extra carefully considered such as the cultural differences and the refugees health approach thinking. Another thing that Bäärnhielm (2013) mentioned is to improve the issue and highlight the problem, discuss it and be able to cooperate and interact with each other in a functioning way.



## **7. CONCLUSION**

The authorities goal is to give all persons in need of treatment an effective drug reservoir action, and to ensure that patients follow the treatment long enough to be rid of their infection. Some of the policies that has been made, and policies in progress are:

- The law (2008:344) health care for refugees has been determined, and therefore health examination will be prepared as soon as possible after the arrival to Sweden. People who migrate to Sweden from areas where the TB burden is high is recommended to undergo a health examination, and the people who have been in Sweden for a longer time resided abroad in a highly endemic area do not need to undergo health examinations.
- Today, foreign-born people coming to Sweden have the opportunity to undergo a health examination, however it is not mandatory.

The health professionals claimed that even if the health care is developing positively in Sweden there are a few things that need to be improved:

- One of the difficulties that can occur is the language barrier. This is today handled with an interpreter, which every immigrant has access to. Misunderstandings still occur so the quality of interpreters needs to be improved.
- Another obstacle for the refugees is that they have a different health approach in their country compared with the Swedish health care system and it is important to be able to try to fulfill their requirements and understand their unique cultural background and their health approach thinking.

The informants who recently arrived to Sweden experienced lack of understanding sometimes even with an interpreter, especially when it comes to:

- The health examination guidelines, how to seek for health care. Another common problem is the lack of communication, which is clearly lacking according to the newly arrived informants.

- Another obstacle is financial possibilities and the distance to the health care clinics. Many of the refugees do not have the access to immediate financially support which can cause difficulties and cultural misunderstandings, which clearly needs to improve with more cultural knowledge and understanding.
- Refugees should be offered quick health conversations, and any investigation required.

Based on the informants and previous studies this study has shown that there is a lack of communication due to language barriers, which cause a situation where fewer refugees seek health care. The best way for the health professionals and authorities to reach out to these patients is through functioning health communication, which can only be achieved with proper understanding and respect. To achieve a functioning communication it is important that every refugee, immigrant or asylum seeker has access to an interpreter. This study has shown that health communication between patients and health professionals is extremely important so that the patients can seek health care if needed and can co-operate with health officials to minimize the spread of TB.

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# **APPENDIX 1 - INTERVIEW QUESTIONS**

## **Interview questions for the health professionals:**

- 1) What are your thoughts regarding the communication between refugees and health professionals? How do you think the communication is currently working?
- 2) What do you think is the main obstacle that can lead to the lack of communication between health professionals and refugees?
- 3) How do you think lack of communication between these groups can be improved?
- 4) What policies have been made regarding health information/conversations and health examinations for newly arrived refugees?

## **Interview questions for the foreign-born refugees/immigrants/asylum seekers:**

- 1) How do you feel about the Swedish health care today?
- 2) What do you think about the communication? Do you feel that you have been given correct information to be able to seek health care if needed?
- 3) Have you ever felt lack of understanding or distrust for the Swedish health care? If yes, explain why?