

Umeå University Medical Dissertations  
New Series No 1555, ISSN 0346-6612, ISBN 978-91-7459-570-3

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# **A world on the move**

## **Challenges and opportunities for HIV/AIDS/TB care and prevention among vulnerable migrant populations in Sweden**

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The cover image is adapted from the United Nations' wall chart on International Migration, 2006.

Produced and printed by Print & Media, Umeå University  
Umeå, Sweden 2013

*This thesis is dedicated to the memories  
of my father Pius Mutombo Saka Ngoy  
and my husband Symphorien Kazadi Musasa.  
I wish you were here to see the end of the story.*



*“In a world on the move, improving the health of migrants  
will ultimately improve the health of all.”*

*(International Organisation for Migration, 2004)*



# Abstract

**Background:** Migration is a global phenomenon that characterizes today's globalized world. Although, the relationship between migration and health in the host countries is not always negative, many countries, including Sweden, are concerned about the possible spread of infectious diseases of public health significance such as HIV/AIDS and tuberculosis (TB). Moreover, apart from disease profiles, migrants also have different socio-cultural backgrounds, which may challenge health care access and provision.

**Objectives:** To investigate, identify, and delineate potential challenges of relevance in the care and prevention of communicable diseases of public health significance in general and particularly HIV/AIDS and TB among migrants from countries where these infections are endemic, and eventually generate knowledge that could inform policies and practice.

**Methods:** Data for this thesis were collected in four of the five counties of the Northern region in Sweden. Quantitative and qualitative methods were used including a survey of 268 migrant students in two language schools (I & II); an interview study with 10 care providers caring for patients with migrant backgrounds and observations of care encounters (III) and an interview study with 15 care providers experienced in screening migrants (IV). Descriptive and logistic regression analyses were used to summarize survey data whereas a thematic analysis approach was applied to the qualitative data within the interpretive description framework.

**Results:** The students scored on average low on both HIV/AIDS and TB knowledge and displayed misconceptions and negative attitudes towards the two diseases and infected/sick persons. Knowledge level and attitude could be predicted by prior knowledge, years of previous education and geographic origin. In contrast, no association was found between being screened and the level of TB knowledge or attitude towards TB and infected/sick persons. However, fear of being deported appeared to be the main predictor of reluctance to seek HIV/AIDS care after controlling for socio-demographic factors, knowledge level, stigmatizing attitudes and fear of disclosure. Health care providers described complex and intertwined challenges that influenced both care delivery and receipt. The challenges described included language, the socio-cultural diversity within migrant groups and between migrants and the caregivers. These often resulted in divergent perceptions and expectations about care and caring. The participants highlighted the complexities of caring for diverse patients within different institutions with conflicting policies and frameworks. They also described the difficulties the migrants face in navigating the Swedish care system.

**Conclusions:** This thesis illuminates complex challenges in the care of migrants. The findings emphasize the need for multilevel strategies in order to remove identified barriers. This requires accommodating diversity by improving care providers' cultural competence and migrants' health literacy. It further requires policies and practices that emphasize health services responsiveness in order to provide equal access and equitable care. Finally, it entails revisiting existing policies and legislative frameworks to promote a change in ways of thinking about and approaching migration, HIV/AIDS and TB issues, to address the specific vulnerabilities of mobile populations in a world on the move.

**Keywords:** HIV/AIDS, Tuberculosis, Caregivers/caregiving, Culture/cultural competence, Discrimination, Diversity, Immigrants/migrants, Interpretive description, Language/linguistics, Interpreters, Thematic analysis, Screening, Sweden



# Sammanfattning på svenska

**Bakgrund:** Migration är ett globalt fenomen som kännetecknar dagens globaliserade värld. Även om förhållandet mellan migration och hälsa i värdländerna inte alltid är negativt så finns det en oro i många länder, däribland Sverige, över eventuell spridning av smittsamma sjukdomar som hiv/aids och tuberkulos (tbc). Migranter kan också ha en kulturell bakgrund som utmanar mötet med hälso- och sjukvården.

**Syfte:** Att undersöka, identifiera och beskriva eventuella problem som är relevanta i vård och förebyggande av smittsamma sjukdomar av betydelse för folkhälsan i allmänhet och i synnerhet hiv/aids och tuberkulos bland migranter från länder där dessa infektioner är endemiska, och slutligen generera kunskap som kan informera riktlinjer och praxis.

**Metoder:** Data för denna avhandling samlades i fyra av fem län i Norrland, Sverige. Kvantitativa och kvalitativa metoder användes och inkluderade en enkätundersökning av 268 migrantelever i två språkskolor (I & II), en intervjustudie med 10 vårdgivare som möter patienter med utländsk bakgrund samt observationer av vårdmöten (III) och en intervjustudie med 15 vårdgivare med erfarenhet av att utföra hälsoundersökningar av migranter (IV). Beskrivande och logistiska regressionsanalyser användes för att sammanfatta enkätdata medan en tematisk analys tillämpades på kvalitativa data inom ramen för tolkande beskrivning ("interpretive description").

**Resultat:** De studerande hade i genomsnitt låg kunskap av både hiv/aids och tuberkulos och uppvisade också missuppfattningar och negativa attityder gentemot de två infektionerna och infekterade/sjuka personer. Kunskaps- och attitydnivå var associerade med förkunskaper, utbildningsnivå och geografiskt ursprung. Inget samband kunde fastställas mellan att ha genomgått en hälsoundersökning och nivån av tbc-kunskap eller inställning till tbc och infekterade/sjuka personer. Rädsla för att bli deporterad verkade vara den viktigaste faktorn för ovilja att söka hiv/aids vård. Vårdgivare beskrev komplexa utmaningar som påverkade mötet med hälso- och sjukvården. De utmaningar som beskrevs inkluderade språk, socio-kulturell mångfald inom migrantgrupper och mellan migranter och vårdgivare. Dessa resulterade ofta i olika uppfattningar och förväntningar av vård och omsorg. Deltagarna betonade komplexiteten av att ta hand om olika patienter inom olika institutioner med motstridiga strategier och regelverk. De beskrev också de svårigheter som migranter möter när de navigerar det svenska sjukvårdssystemet.

**Slutsatser:** Denna avhandling belyser komplexa utmaningar i vården av migranter. Resultaten understryker behovet av strategier på olika nivåer för att undanröja hinder som identifierats. Detta kräver att möta mångfald genom att förbättra vårdgivares kulturella kompetens och migranternas hälsokunskap. Det krävs vidare riktlinjer och praxis som betonar vård på lika villkor. Slutligen innebär det en översyn av befintlig politik och rättsliga ramar för att främja en förändring av sättet att tänka och närma sig migration, hiv/aids och tbc, för att ta itu med mobila populationers sårbarheter i en värld i rörelse.

## Original papers

The thesis is based on the following papers:

I. Nkulu Kalengayi F, Hurtig AK, Ahlm C, Krantz I. (2010) Screening migrants for tuberculosis - a missed opportunity for improving knowledge and attitudes in high-risk groups: a cross-sectional study of Swedish language learners in Umeå, Sweden. *BMC Public Health*, 10:349.

II. Nkulu FK, Hurtig AK, Ahlm C, Krantz I. (2012). Fear of deportation may limit legal immigrants' access to HIV/AIDS-related care: a survey of Swedish language school students in Northern Sweden. *Journal of Immigrant and Minority Health*, 14(1):39-47.

III. Nkulu FK, Hurtig AK, Ahlm C, Ahlberg BM. (2012). "It is a challenge to do it the right way": an interpretive description of caregivers' experiences in caring for migrant patients in Northern Sweden. *BMC Health Services Research*, 12:433.

IV. Nkulu FK, Hurtig AK, Ahlm C, Ahlberg BM. Perspectives of caregivers on screening migrants: managing conflicting discourses, policies and practices. Manuscript.

The articles I-III have been published in open-access journals.

# Acronyms

<b>ECDC</b>	European Center for Disease prevention and Control
<b>EEA</b>	European Economic Area
<b>EU</b>	European Union
<b>FHI</b>	Family Health International
<b>HIV/AIDS</b>	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
<b>ID</b>	Interpretive Description
<b>IOM</b>	International Organization for Migration
<b>IVIK</b>	Introduktionkurs för nyanlända ungdomar inom det individuella programmet (the individual programme introductory course for newly arrived youths)
<b>KAP</b>	Knowledge, Attitudes and Practices
<b>LMA</b>	Lag om Mottagande av Asylsökande (Law on the reception of asylum seekers)
<b>MDR-TB</b>	Multi Drug Resistant-Tuberculosis
<b>NGO</b>	Non-Governmental Organization
<b>OBSSR</b>	The Office of Behavioral and Social Sciences Research
<b>OECD</b>	Organization for Economic Cooperation and Development
<b>PLWH</b>	People Living With HIV/AIDS
<b>SEM</b>	Socio-Ecological Model
<b>SFI</b>	Svenska För Invandrare (Swedish for immigrants)
<b>STI</b>	Sexually Transmitted Infections
<b>TB</b>	Tuberculosis
<b>UNAIDS</b>	Joint United Nations Programme on HIV/AIDS
<b>UNHCR</b>	United Nations High Commissioner for Refugees
<b>UNFPA</b>	United Nations Population Fund
<b>WHO</b>	World Health Organization
<b>WMA</b>	World Medical Association

# Table of contents

<b>Abstract</b>	<b>I</b>
<b>Sammanfattning på svenska</b>	<b>III</b>
<b>Original papers</b>	<b>V</b>
<b>Acronyms</b>	<b>VI</b>
<b>Table of contents</b>	<b>VII</b>
<b>Introduction</b>	<b>1</b>
HIV/AIDS, tuberculosis and migration: three major global challenges	1
Concepts and definitions: people on the move who are they?	3
An overview of migration to Sweden	5
An overview of migrants' health	7
HIV/AIDS and TB in Sweden	8
Control of HIV/AIDS and TB in Sweden	9
Medical screening of migrants	10
<b>Conceptual framework</b>	<b>12</b>
<b>Aims</b>	<b>14</b>
General aim	14
Specific aims	14
<b>Material and methods</b>	<b>15</b>
Research design: mixed methods and mixed methodology approach	15
<i>Quantitative research design</i>	16
<i>Qualitative research design</i>	16
Study settings	17
Study populations and sampling methods	19
<i>Survey sample (I, II)</i>	19
<i>Participants in the qualitative studies (III, IV)</i>	21
Data collection methods	22
<i>Quantitative data collection (I,II)</i>	22
<i>Qualitative data collection (III,IV)</i>	23
Data Analysis	26
<i>Quantitative analysis (I,II)</i>	26
<i>Qualitative analysis (III,IV)</i>	26
Validity and Trustworthiness	28
<i>Validity (I,II)</i>	28
<i>Trustworthiness (III,IV)</i>	29
The field researcher	30
Ethical considerations	31

<b>Results</b>	<b>33</b>
Quantitative/survey results	33
<i>Survey sample characteristics (I,II)</i>	33
<i>TB knowledge and attitudes, and their determinants (I)</i>	33
<i>Knowledge about different aspects of HIV/AIDS and expressions of stigma (II)</i>	34
<i>Predictors of reluctance to seek HIV/AIDS care (II)</i>	35
<i>Accessibility and availability of information related to HIV/AIDS and TB, and risk perception (I,II)</i>	35
Qualitative studies results/findings	35
<i>Socio-demographic characteristics of participants (III, IV)</i>	36
<i>Struggling to understand and manage diversity (III, IV)</i>	36
<i>Understanding structural barriers (III, IV)</i>	42
<i>Managing conflicting policy and practices (IV)</i>	44
<b>Discussion</b>	<b>49</b>
Language: a substantial challenge	49
Cultural diversity: a source of misunderstandings	51
Socio-demographic differences: a source of uncertainty	53
Discrimination and stigma: barriers to access and delivery of care	55
Low interest in migrant/diversity issues: a barrier to advocacy, policy development and capacity building	59
Finding opportunities: implications	60
<i>Accommodating diversity or the special needs of migrant groups</i>	60
<i>Changing paradigms: are migrants a risk or at risk?</i>	61
Conclusions	63
Suggestions for future research	64
<b>Acknowledgements</b>	<b>65</b>
<b>References</b>	<b>67</b>

# Introduction

## **HIV/AIDS, tuberculosis and migration: three major global challenges**

Migration, HIV/AIDS and tuberculosis (TB) are three major global phenomena that are challenging today's changing world. All three phenomena challenge public health on a massive scale and are global in their scope and impact (IOM, 2010, UNAIDS, 2012, WHO, 2012, UNFPA, 2006). Migration is a phenomenon that has always characterised human society and one that has probably always been associated with complex challenges. Today, it is not only a global issue on the increase, but also a vital component of economic development and demographic revitalisation (UNFPA, 2006, WHO, 2010). Population movement now involves almost all nations, whether as countries of origin, transit or destination. The number of international migrants which was estimated at 150 million in 2000 rose to 214 million in 2010 and could reach 405 million by 2050 (IOM, 2010). However, because the share of people moving from the so-called 'developing/low-income' countries to developed/high income, countries has increased over the past 50 years, migration has become controversial and is surrounded by political and social attitudes that make it a precarious process. Despite hard policies and attitudes to population movement and migration, they are unlikely to stop any time soon as inequities persist in the world (IOM, 2010, UNFPA, 2006, WHO, 2010, Carballo and Mboup, 2005). However, it is estimated that only 37% of international migrants move from developing to developed countries, while nearly 60% of international migrants move between developed countries or between developing countries, and 3% move from developed to developing countries (WHO, 2010).

The human immunodeficiency virus (HIV) epidemic is one of the greatest disasters the world has ever known. It causes acquired immune deficiency syndrome (AIDS), which remains one of the world's most serious health challenges. Despite the increase in the proportion of people who have access to antiretroviral therapy and the decreasing trend in new infection rates globally, at the national level, the epidemic continues to expand in many parts of the world (UNAIDS, 2012). At the end of 2011, it was estimated that up to 34 million people were living with HIV worldwide. However, the burden of the epidemic varies between countries and regions. Sub-Saharan African remains the worst affected area, with more than two thirds of the total number of people with HIV/AIDS, followed by the Caribbean, Eastern Europe and Central Asia, where 1.0% of adults were living with HIV in 2011. Nearly 5 million people are living with HIV in South, South-East and East Asia combined (UNAIDS, 2012). In Western Europe and North America, HIV/AIDS remains a major public health problem despite low prevalence. Recent data has pointed to increasing trends in the number of people

living with HIV (PLWH) in most countries since 2001 with shifts in affected populations and patterns of transmission (ECDC/WHO, 2011, UNAIDS, 2012).

In 2011, AIDS related diseases claimed an estimated 1, 7 million people world-wide, which represented a 24% decline in AIDS-related mortality compared with 2005, when AIDS related diseases claimed an estimated 2.3 million lives. However, this decline was also unequally distributed among different regions around the world. Some regions experienced significant declines whereas others, including Western and Central Europe and North America experienced moderate declines of about 1% during the same period. Some other regions even experienced significant increases in the proportion of deaths due to AIDS related diseases, and these regions included Eastern Europe and Central Asia (21%) and the Middle East and North Africa (17%) (UNAIDS, 2012).

The same holds true for TB, an infectious disease caused by the bacillus *Mycobacterium tuberculosis*, which remains one of the leading killers globally. It typically affects the lungs (pulmonary TB) but can affect other sites as well (extrapulmonary TB). The disease is spread in the air when people who are sick with pulmonary TB expel bacteria, for example by coughing (WHO, 2012).

Despite continuing progress towards global targets for reductions in TB cases and deaths, the global burden of TB remains enormous. In 2011, it was estimated that 8.7 million people became infected with TB, from which an estimated 1.4 million died. Among the new cases and deaths 13 % were people living with HIV/AIDS (PLWH). In addition, the response to multidrug resistant TB (MDR-TB) is still slow. It was estimated that 3.7 % of new cases and 20 % of previously treated cases had MDR-TB in 2011 (WHO, 2012).

Yet again, the distribution of burden is not equally shared. The highest burden of TB, both in terms of cases and deaths, is in Asia and Africa. The South-East Asia and Western Pacific regions accounted for 60%, whereas the African region accounted for 24 % of the world's TB cases in 2011. Countries in Eastern Europe and Central Asia had the highest proportions of cases of MDR-TB. However, India, China, the Russian Federation and South Africa together accounted for 60 % of the MDR-TB cases in 2011 (WHO, 2012). In Western Europe, research studies, surveillance activities and national reporting have identified the increasing importance of migration in the epidemiology of TB in most countries. Foreign-born people are overrepresented among the TB cases that are now being reported in these countries (WHO, 2012, ECDC/WHO, 2012, Davies, 2003, King, 2003).

The growing international migration is thought to be one of the factors that have contributed to the global failure in controlling HIV/AIDS and TB. Although often associated with new opportunities, migration can exacerbate existing



problems and generate complex challenges, including public health challenges (Carballo and Mboup, 2005, UNFPA, 2006, Coker, 2004). Population movement is believed to hamper public health responses to communicable diseases such as HIV/AIDS and TB both nationally and internationally. Migration not only increases movements of people with disease, or who are at risk of developing the disease, but also makes those who move more susceptible to both HIV and TB infections (Carballo and Mboup, 2005, Davies, 2003, Figueroa-Munoz and Ramon-Pardo, 2008, UNFPA, 2006, WHO, 2010). Not surprisingly, many high income countries have observed increases in the number of reported cases of HIV/AIDS and TB, which have partly reflected the influx of people from high-prevalence countries (ECDC/WHO, 2011, ECDC, 2012, UNAIDS, 2012, UNFPA, 2006, WHO, 2012). Although most of the cases are imported, post-migration infections are not uncommon (Figuera-Munoz and Ramon-Pardo, 2008, Kan et al., 2008, Smittskyddsinstitutet, 2010a, Smittskyddsinstitutet, 2010b, UNFPA, 2006).

### **Concepts and definitions: people on the move who are they?**

Migration refers to any process of population movement, either across an international border, or within a country, either permanently or on a temporary basis, whatever its causes (IOM, 2011). Short term visits, such as travel for the purpose of business, tourism or to visit relatives and friends are not considered migration and are thus excluded from this definition. The definition of migration used here involves different categories of people in regular and irregular situations, as well as asylum seekers, victims of trafficking, refugees, displaced persons, returnees and internal migrants (IOM, 2011). However, there is no universal agreement regarding the definition of migrant. Thus, each receiving country has its own definitions for how to categorise travellers and migrants whereas international regulations not only emphasise the difference between nationals and non-nationals e.g. citizens, aliens, immigrants, but also identify other specific groups e.g. refugees, asylum seekers and migrant workers (IOM, 2011). However, the focus of this thesis is population movement that involves crossing international borders and, for practical reasons, a broader interpretation will be applied to the term migrant to include all non-nationals who move to Sweden for different reasons and who have different legal status. Some definitions of selected commonly used terms in the field of migration that will be used throughout this thesis are given below. These definitions do not constitute standards or exhaustive lists of terms or source of definitions in the field of migration.

**Migrant:** There is no universally accepted definition of the term migrant. It is usually understood to cover all cases where the decision to migrate is taken freely by the individual concerned for reasons of personal convenience and without any coercive external factors (IOM, 2011).

**Immigrant:** A non-national who moves to a country for the purpose of settlement (IOM, 2011).

**Refugee:** A person who meets the eligibility criteria of the refugee definition provided by relevant international or regional refugee instruments, UNHCR's mandate, and/or national legislation. According to many of these instruments, a refugee is a person who cannot return to his/her country of origin owing to a well-founded fear of persecution or serious and indiscriminate threats to life, physical integrity or freedom (UNHCR, 2006).

**Resettlement refugee:** A person who is selected and transferred from a state in which they have sought protection to a third state, which has agreed to admit them as a refugee with permanent residence status. The status provided ensures protection against *refoulement* and provides a resettled refugee and his/her family or dependants with access to rights similar to those enjoyed by nationals. Resettlement also carries with it the opportunity to eventually become a naturalised citizen of the resettlement country (UNHCR, 2006).

**Migrant worker:** A person who is to be engaged, is engaged or has been engaged in a remunerated activity in a state of which he or she is not a national (Art. 2(1), International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, 1990) (IOM, 2011).

**Asylum-seeker:** An individual who is seeking international protection. In countries with individualised procedures, an asylum-seeker is someone whose claim has not yet been finally decided on by the country in which he or she has submitted it. Not every asylum-seeker will ultimately be recognised as a refugee, but every refugee in such countries is initially an asylum-seeker. If the application is rejected after consideration and after all possible appeals, the applicant's right to asylum is dismissed and the state usually tries to remove or deport them, sometimes after detention (IOM, 2011; UNHCR, 2006).

**Unaccompanied child:** A child who has been separated from both parents and other relatives and is not being cared for by an adult who, by law or custom, is responsible for doing so (UNHCR, 2006).

**Unofficial/illegal/undocumented /irregular migrant:** Someone who, owing to illegal entry or the expiry of his or her visa, lacks legal status in a transit or host country. The term applies to migrants who infringe a country's admission rules and any other person not authorised to remain in the host country. The preferred term is "migrant in an irregular situation" (IOM, 2011).

**Table 1.** Global estimates of different categories of international migrant populations

Category of migrant	Population estimates
Migrants	214 million worldwide (3.1 % of the world population) (2010)
International students	2.8 million (2007)
Refugees	15.4 million persons (2010)
Migrant workers	100 million (2009)
Asylum seekers	837, 100 applications in 2010
Resettlements/quota refugees	98,800 resettled />108,000 applications (2010)
Unaccompanied children	15,500 claims in 69 countries (2010)
Unofficial/illegal/undocumented/irregular migrants	30 million (2010)

**Source:** International Organization for Migration, United Nations High Commissioner for Refugees (2010).

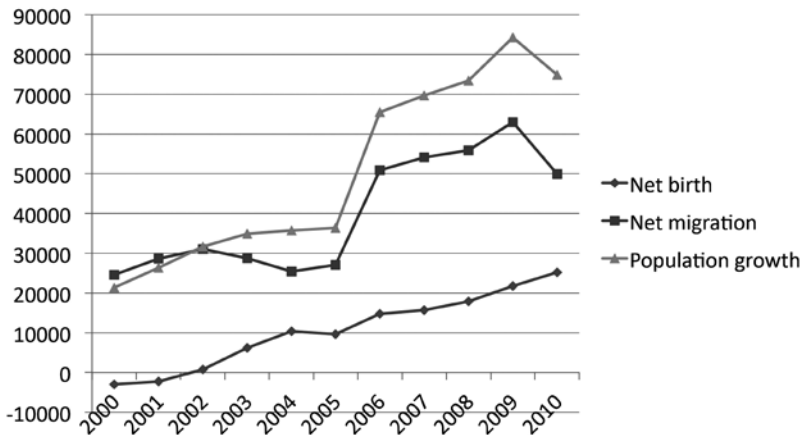
### **An overview of migration to Sweden**

Between 1850 and 1930, up to 1.4 million Swedes left Sweden; most of them moved to North America. During this period, immigration to Sweden was mainly dominated by returnees from America. However, between the 1930s and 1940s, the trend reversed and the proportion of foreign-born immigrants started to increase gradually; and Sweden, which was traditionally a country of emigration, shifted to being a country of immigration. Since then, population movement to Sweden has changed over time, depending on national policies and different events occurring around the world (Bevelander and Dahlstedt, 2012, Cuadra, 2010, Statistics Sweden 2012).

During the 1940s, most people who moved to Sweden were refugees from World War II. Thereafter, between the 1950s and 1960s, labour immigration from Nordic and other European countries (southern Europe and Turkey) took place in response to the rapid industrial and economic growth during that period. In the early 1970s, the lower rate of economic growth and increased unemployment led to a decline in demand for a foreign workforce, and there was a drastic decrease of labour migration as migration policy became tougher. Since then, immigration to Sweden has been dominated by refugees and family ties from Eastern Europe and other continents which experienced socio-political unrest and dictatorship during the 1970s (Chile, Poland and Turkey), in the 1980s (Chile, Ethiopia, Iran and other Middle Eastern countries) and the 1990s (Iraq, the former Yugoslavia and other Eastern European countries) (Bevelander and Dahlstedt, 2012, Cuadra, 2010, Statistics Sweden, 2012). This movement of people in need of protection continues today, with Iraqis, Iranians, people from the former Yugoslavia and Somalis being the largest groups. Migration from the European Union (EU) states has also increased during the last decade as a

result of new members joining the union. Consequently, immigration from other Nordic and European countries constitutes a significant share of foreign-born people living in Sweden (Statistics Sweden, 2012). Since the end of 2008, labour migration has started to increase again as a consequence of a new legislation that opened the Swedish labour market to migrants from outside the EU and the European Economic Area (EEA). On the other hand, the movement of students from countries outside the EU/EEA has drastically decreased since the autumn of 2011, when other new legislation introduced tuition fees for students from countries outside the EU/EEA (Statistics Sweden, 2012).

According to Statistics Sweden, the share of foreign-born immigrants, which was estimated at 11% in 1998, reached 15% of the population in 2011 and included citizens from almost 200 countries (Statistics Sweden, 2012). Net migration contributes significantly to the current population growth in Sweden (Figure 1).



**Figure 1.** Population growth in Sweden (2004–2010) showing the large contribution of net migration (Source Statistics Sweden, 2010).

Currently, it is estimated that around 19% of the working-age (25–64 years) population in Sweden are foreign born. This proportion is expected to increase and reach 25% of the Swedish population by 2030 (Statistics Sweden, 2011). However, these figures do not include all foreign-born people living in Sweden, implying that not all foreign-born people are considered migrants. In fact, while all foreign born persons are socially categorised as “invandrare”, meaning immigrant, Statistics Sweden defines an immigrant as a foreign-born person whose actual legal stay in Sweden has/will last for at least one year (Statistics Sweden, 2012). This definition is based on legal status and as a consequence asylum seekers who have an unknown status and undocumented migrants are automatically excluded from this definition. It also implies that all temporary migrants whose stay lasts less than 12 months are not included (Cuadra, 2010,

Statistics Sweden, 2012). This definition has implications for access to public services, including the health care services since all legal residents are registered by the Swedish National Tax Board and allocated a personal number that they use to access all public services including health services. Asylum seekers have limited access to care services as they are only entitled to care that “cannot wait”; when they seek care they are required to show a special personal card known as a LMA (*Lag om Mottagande av Asylsökande*; translation: the Law on the Reception of Asylum Seekers) card provided by the migration authorities. In contrast, undocumented migrants and other non-residents may also access care services, but they have to pay out of their own pockets (Cuadra, 2010).

### **An overview of migrants' health**

According to the National Institute of Public Health's report, migrants have a high risk of poor health compared to Swedes. However, there are also discrepancies between different groups of migrants. The disparities in health between native Swedes and migrants are believed to be due to socio-economic factors including lifestyle and the low social position that most migrants have regardless of their educational level and work experience (Statens Folkhälsoinstitut, 2002, Socialstyrelsen, 2009).

The health problems of migrants are as varied as their previous experiences and geographic origin, and range from communicable to non-communicable diseases, mental illness and reproductive health problems (Socialstyrelsen, 2009, Statens Folkhälsoinstitut, 2002). For instance, the risk of cardio-vascular diseases was found to be 15-40 % higher in some groups compared to Swedes, but lower in other groups. Migrants from Organization for Economic Cooperation and Development (OECD) countries had the same risk level for cardio vascular diseases as Swedes (Statens Folkhälsoinstitut, 2002).

Except for migrants from Finland and other OECD countries, the risk of cancer is reported to be lower among migrants, with lower mortality rates compared to Swedes. The prevalence of communicable diseases such as HIV/AIDS, TB and hepatitis mirrors the global epidemics with migrants from endemic countries being overrepresented among reported cases in Sweden. Mental health is worse for many groups compared to Swedes. Reproductive health problems include unwanted pregnancies, pregnancy related illnesses and low birth weight (Socialstyrelsen, 2009, Statens Folkhälsoinstitut, 2002).

### **HIV/AIDS and TB in Sweden**

Sweden is one of the countries with a low prevalence of both HIV/AIDS and TB. However, the prevalence of the two diseases is unequally distributed among the population. The current trends and patterns of both HIV/AIDS and TB bear witness to a connection between population movement and the epidemi-

ological picture of the two diseases in Sweden (Smittskyddsinstitutet, 2010a, Smittskyddsinstitutet, 2010b).

The HIV/AIDS situation in Sweden mirrors the global epidemic and trend in migration patterns, with a large number of reported cases being migrants from highly endemic areas (Smittskyddsinstitutet, 2010b). From 1985 to 2010, up to 9 400 HIV/AIDS cases were reported in Sweden. Among them, 5 000 are now living with HIV/AIDS (Smittskyddsinstitutet, 2010b). A large proportion of the increase in new HIV/AIDS cases that has been reported since 1990s are believed to be due to imported cases. For instance, in 2010, up to 56% of the 465 reported cases were migrants from high prevalence areas who were supposedly infected with HIV prior to their immigration to Sweden (Smittskyddsinstitutet, 2010b).

Although men who have sex with men remain the most affected group among Swedish residents, there has been a clear and persistent upward trend in the number of heterosexual migrants becoming infected after migration to Sweden since the year 2000 (Smittskyddsinstitutet, 2010b). These migrant residents have supposedly become infected through heterosexual contact with a fellow countryman, which indicates that migrants are more at risk of HIV infection than native Swedes. Moreover, although Swedish men represented the majority of residents who were reported to be infected heterosexually when travelling or staying abroad in 2010, this group also included migrants residing in Sweden who revisited their home countries (Smittskyddsinstitutet, 2010b). However, the data reported may only reflect the situation among people who come into contact with HIV/AIDS services, thus leaving out undocumented migrants, those who are unable to seek care, or those who are unaware of their HIV status. Nevertheless, certain groups of migrants are at a greater risk than others. According to the Swedish Institute for Communicable Disease Control, migrants from sub-Saharan countries and Thailand are over-represented among all migrants living with HIV/AIDS in Sweden (Smittskyddsinstitutet, 2010b)

Similarly, migrants to Sweden constitute an increasingly high share of the TB cases reported since 1992. The proportion of foreign-born cases, which in 1989 was 202 (34%) of 595 reported cases, had more than doubled and reached 85% of the 683 cases reported in 2010 whereas a declining trend was observed among native Swedes (Smittskyddsinstitutet, 2010a, Smittskyddsinstitutet, 2011a). Most of the foreign-born persons affected by TB were migrants from the horn of Africa, Asia, Eastern Europe, the Middle East, North Africa, and South- and Central America. Furthermore, the most affected age group among migrants is young adults (median age =30, 2008), whereas most native Swedes affected are over 65 years (Smittskyddsinstitutet, 2011a).

Regardless of whether infection is a result of an activation of an old infection, re-infection or a new infection in the host country, or through frequent visits to the home country, the risk of TB among migrants from highly endemic areas remains high many years after immigration. For instance, 106 (23%) of the 460 of foreign-born cases reported in 2008 had resided in Sweden for more than ten years (Smittskyddsinstitutet, 2010a). Likewise, most of the cases (82/102) in the five outbreaks of an identical Isoniazid resistant strain of *M. tuberculosis* that occurred in Sweden between 1996 and 2005 were young immigrants from sub-Saharan Africa who had migrated to Sweden more than five years earlier (Kan et al., 2008). Moreover, a cluster of TB cases was discovered at a reception centre for asylum seekers in Östergötland in 2010, and most of the cases were probably infected at the reception centre and not in their home country (Strand and Åkerlind, 2010).

### **Control of HIV/AIDS and TB in Sweden**

Communicable disease control in Sweden involves different types of preventive activities that aim at reducing infection risk, preventing individuals who have been exposed to infection from becoming ill and preventing an infected individual from passing on the infection to others. The Swedish Communicable Disease Act (2004:168) classifies HIV/AIDS and TB as public health threats in Sweden and thus notifiable infections/diseases. However, latent TB infection is not notifiable (Government Offices of Sweden, 2004, Socialstyrelsen, 2007).

According to this act, contact tracing should be done for each new case and anyone who suspects being infected is urged to consult a physician without delay for diagnosis and treatment, to assist clinicians in contact tracing, and to protect others from the risk of infection, including by disclosing one's HIV status to those at risk (Government Offices of Sweden, 2004, Socialstyrelsen, 2007). The index case/patient is required to provide information about their contacts, who are required to be examined. A county medical officer (infectious disease control doctor), who has an overall responsibility for control activities within the county area, should ensure that all necessary measures are taken to identify the source of the infection and the people who may have been exposed to risk of infection (Government Offices of Sweden, 2004, Socialstyrelsen, 2007, Socialstyrelsen, 2012). For example, he/she may request from the administrative court a compulsory examination of a person suspected of being infected, but who has refused to undergo medical examination. In addition, he/she may request compulsory isolation of an infectious person who exposes others to the risk of infection, and who does not follow the necessary measures taken to prevent the spread of infection. Finally, this act stipulates that all treatment and investigations of diseases classified as public health threats should not involve any cost to the individual (Government Offices of Sweden, 2004, Socialstyrelsen, 2007, Socialstyrelsen, 2012).

Due to the low prevalence of the two diseases in the general population, control activities mainly focus on high-risk groups or individuals for early detection, treatment and prevention through contact tracing, medical screening and vaccination (only for TB) (Socialstyrelsen, 2007). Targeted health assessments may also be offered to specific groups with increased risk of TB such as those being treated with immunosuppressive drugs, HIV/AIDS patients, and those who work in an environment that might expose them to the risk of TB (Socialstyrelsen, 2007, Socialstyrelsen, 2012). The National Strategy against HIV/AIDS recommends medical screening even for residents returning from travel abroad to countries or regions where infection is widespread, but it is unclear how and whether this recommendation is implemented (Smittskyddsinstitutet, 2010c, Socialstyrelsen, 2007).

### **Medical screening of migrants**

Migrants in general, and those from high-prevalence countries in particular are one of the high-risk groups that are prioritised for specific, targeted, preventative interventions against HIV/AIDS, TB and other communicable diseases of public health significance in Sweden. One of the interventions is medical screening of newly arrived migrants from countries with a higher risk of such diseases (Smittskyddsinstitutet, 2010a, Socialstyrelsen, 2011). According to the National Board of Health and Welfare's regulations and recommendations, all children and adult migrants should be offered an individual health assessment as soon as possible after their arrival in Sweden. These regulations and recommendations also emphasise that the offer of medical screening shall specify: (a) information about the purpose of screening, (b) that screening is voluntary, (c) that an interpreter will be hired if necessary, and (d) contact information of the health care provider who will perform medical screening. Also emphasised is the importance of providing this information in a language that the recipient/client understands, and to remind them at least once if they has declined or do not show up at the appointed time (Socialstyrelsen, 2011).

Medical screening aims at assessing the medical need for care that can be offered in accordance with the law on care for asylum seekers (2008:344) and other migrants as well as the need to provide advice, support or apply other measures in accordance with the Communicable Diseases Act (2004:168)(Socialstyrelsen, 2011). Medical screening should include a complete medical history of the subject's health, with respect to both the past and present physical and mental health status. It should also indicate if the client's health status has been influenced by their psychosocial situation or by any traumatic experiences to which they have been exposed. This initial consultation should also include questions about the subject's vaccination status, their exposure to risk of infection, as well as the other information that may be needed from a communicable disease control standpoint (Socialstyrelsen, 2011). Medical screening should be tailored to the

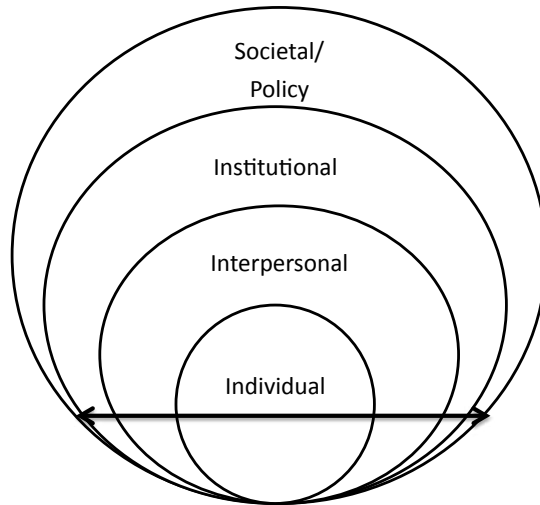


epidemiological situation in the specific places where the patient/client has been staying before coming to Sweden. Medical screening should also include a physical examination and tests that are based on the needs identified during consultation (Socialstyrelsen, 2011). The county council should offer all newly arrived asylum seekers medical screening unless it is clearly unnecessary. The county council can thereafter apply for reimbursement for completed medical screening from the Swedish Migration Board, which can grant it in accordance with § § 35-36 of the regulation (1990:927) regarding state compensation for reception of refugees and other migrants (Socialstyrelsen, 2011).

## Conceptual framework

In Sweden, despite the wide recognition of migrants as being particularly vulnerable to HIV/AIDS and TB, very little is known about their knowledge of, beliefs about and attitudes towards TB, all of which may influence health-seeking behaviours. In addition, despite the availability of care services, early diagnosis and treatment of HIV/AIDS and TB among migrants, challenges remain. Most analysts acknowledge that care, treatment and prevention of HIV/AIDS and TB in migrants are influenced by a wide range of social, cultural and political factors (ECDC, 2009, Amon and Todrys, 2008, Solskone and Shtarkshall, 2002). Migrants have not only different disease profiles, but also various socio-demographic and cultural backgrounds, which may impact their health-seeking behaviour and challenge policy makers and caregivers. Moreover, both HIV/AIDS and TB are highly stigmatised conditions, which may result in the sick/infected migrants being reluctant to disclose their HIV status or TB diagnosis if they expect stigmatisation and prejudice from their own/host community; consequently, care and prevention activities among migrants may be compromised (Amon and Todrys, 2008, Bhattacharya, 2004, Maman and Medley, 2003, Fakoya et al., 2008). Finally, it would be difficult, if not impossible, to reach failed asylum seekers or undocumented migrants, who have no access to health care services and fear being reported to the migration authorities (Amon and Todrys, 2008).

The above underlines the influence of multiple factors and the need for multi-faceted approaches in order to identify and explain common barriers to HIV/AIDS and TB care and prevention among vulnerable migrant groups living in Sweden. A socio-ecological model (SEM) was therefore applied to this research project, as it fit this purpose well (Figure 2). The SEM emphasises the relevance of social contexts and the intertwined relationship between individuals and their social environment (community norms and values, regulations and policies) (Bronfenbrenner, 1989, Liburd and Snizek, 2007). Additionally, the model suggests that factors at different levels may not only impact on individual behaviour, but also may impact on or modify each other as illustrated in Figure 2 (Liburd and Snizek, 2007, Shtarkshall et al., 2009). The rationale behind the use of the model is the need to identify and describe different factors at individual, interpersonal, institutional, and societal levels, as well as their influences on HIV/AIDS and TB care and prevention services among vulnerable migrant groups in Sweden.



**Figure 2.** An illustration of the different levels of the socio-ecological model. The arrow extending throughout the four levels indicates that factors at different levels overlap and interact with each other. The individual level represents individual characteristics, knowledge, attitude and behaviour; the interpersonal level represents the relationships between different actors involved in the medical encounter; the institutional level represents factors related to the organization and practices within the health care setting and the societal/policy level represents cultural factors, different policies and regulations at the local and national levels. (Adapted from Liburd LC & Sniezek JE, 2007)

## **Aims**

### **General aim**

The overall aim of this project was to investigate, identify, and delineate potential barriers of relevance in the care and prevention of communicable diseases of public health significance in general and particularly HIV/AIDS and TB among migrants from countries where these infections are endemic, and eventually generate knowledge that could inform policies and practice.

### **Specific aims**

The specific aims were to:

- document and gauge the general knowledge and beliefs of migrants concerning HIV/TB transmission, prevention, and treatment and their attitudes towards these diseases and infected or sick people (I,II),
- assess the relationships between knowledge, attitudes, and socio-demographic characteristics (I,II),
- explore healthcare providers' experiences of caring for patients with migrant backgrounds (III),
- explore healthcare professionals' experiences of screening patients with migrant backgrounds for communicable diseases of public health significance (IV).

# Material and methods

## Research design: mixed methods and mixed methodology approach

The research design used in this project consisted of different components, where emerging questions from one component formed the basis for the design of the next. This is a key feature of qualitative research also known as the emergent design, where the research design emerges as a result of the increased understanding that the researcher gains through the research process. Quantitative projects may be designed in the same way, each sub-study generating insights useful for developing the next sub-study. In contrast, however, to a qualitative design that follows a circular path, the quantitative design takes a linear path (Dahlgren et al., 2004). The research design of this project matched what Creswell described as a 'mixed methodology design' that combines both quantitative and qualitative methods to address different questions that emerge at various stages of the research process (Johnstone, 2004). In other words, decisions about a planned study were preceded by the analysis of the results of a previous study and formulation of new questions. Subsequently, the choice of specific research method was guided by the type of research question to be answered.

Despite being little documented, the mixed methodology strategy is an increasingly accepted approach used to investigate and improve health services research because of the complexity of research questions to be answered (Clark, 2000, Johnstone, 2004). Other scholars have labelled this strategy 'the situationalist perspective' and stressed that qualitative and quantitative methodologies can be used to complement each other as they are appropriate for different purposes. They have, however, pointed out the necessity of observing sampling strategy and techniques within each methodology to obtain high-quality data (Dahlgren et al., 2004). Traditionally, the two methodologies adhere to different theoretical paradigms that guide research design and the data collection methods within each methodology (Dahlgren et al., 2004). The two methodologies were combined to allow the project to benefit from their complementary strengths and the diverse perspectives provided by each method for better understanding of the complex processes, structures and outcomes of migrant health care. Although the project started with a quantitative study, we did not adopt the Priority Sequence Model developed by Morgan (1998) for combining quantitative and qualitative methodologies in the situationalist manner as both methodologies carried equal weight in the project (Clark, 2000, Dahlgren et al., 2004, Morgan, 1998).

## **Quantitative research design**

### *A cross-sectional design (I, II)*

A cross-sectional design was applied to the quantitative study to assess migrants' knowledge and attitudes towards HIV/AIDS and TB according to their socio-demographic characteristics and also to allow comparison among subgroups of migrants. The dictionary of epidemiology defines a cross-sectional study as a study that examines the relationships between a health-related event and other variables of interest as they exist in a population at a particular time (Last, 1988). Cross-sectional studies provide a basis not only for health planning and provision of services, but also for identifying high risk groups for prevention purposes and evaluation of care needs, as well as generating and testing hypotheses (Persson and Wall, 2000, Szklo and Nieto, 2007). One application of cross-sectional studies in healthcare planning is to determine the prevalence of risk factors for an event in a population and tailor interventions accordingly. Thus, the quantitative study aimed at assessing migrant students' knowledge of and attitudes towards TB and HIV/AIDS as well as infected and sick people, and their determinants, in order to adapt care and interventions to the health needs of migrant groups.

## **Qualitative research design**

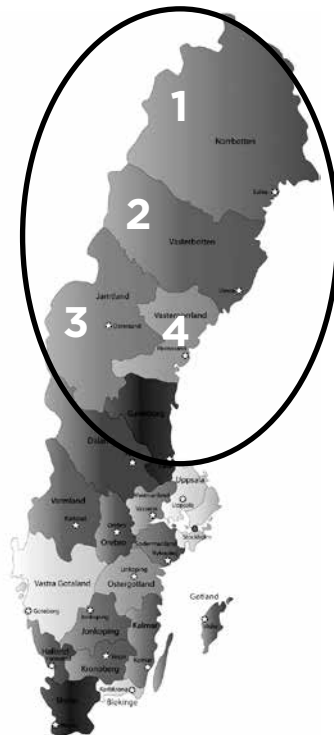
### *Interpretive description approach (III, IV)*

In general, qualitative research seeks to explore the interpretations and experiences of different individuals and groups in particular social contexts and over time to gain a better understanding of the social phenomena in question and/or generate hypotheses (Clark, 2000, Dahlgren et al., 2004). Much qualitative research in applied health disciplines has been carried out according to the three dominant qualitative methodologies developed within the disciplines of sociology, anthropology, and philosophy (Thorne, 2008). Many scholars, however, argue that sometimes researchers within applied health disciplines claim to use these traditional qualitative methodologies although their research design and products depart from their stated methodological choices. Rather than methodological allegiance, it is the practice orientation of the research questions that should influence the research design in applied health disciplines (Hunt, 2009, Thorne, 2008). As a result, Thorne and colleagues developed a non-categorical methodological approach that they identified as 'interpretive description' (ID) in response to this call for an alternative way of generating grounded knowledge relevant for the clinical context of applied health disciplines (Hunt, 2009, Thorne et al., 2004, Thorne, 2008, Thorne, 2011.). Adopters of this approach reject methodological orthodoxy in favour of a less prescriptive approach that allows them to draw on a variety of research techniques and traditions to explore questions related to applied health disciplines and yield knowledge that could advance disciplinary knowledge and inform practice (Hunt, 2009, Thorne et al., 2004, Thorne, 2008, Thorne, 2011). Thorne and

colleagues have argued that rather than theory development or general qualitative description, health researchers study problems primarily in order to solve them (Thorne et al., 2004, Thorne, 2008, Thorne, 2011). Thus, an ID approach was used as the sensitizing framework for the qualitative inquiry to explore and illustrate practical problems in caring for patients with migrant backgrounds within the Swedish context, with the goal of generating knowledge that could inform and improve clinical practice, and advance knowledge within the field of migrant health care.

### Study settings

The studies included in this thesis were conducted in four of the five counties (Jämtland, Norrbotten, Västerbotten and Västernorrland) of Northern Sweden (Norrland Regionen) (Figure 3). The quantitative study was carried out in the school settings in one of the four counties whereas qualitative studies include participants from different healthcare settings in all four counties involved in the project.



**Figure 3.** Map of Sweden showing the Northern region and the four study settings (1= Norrbotten, 2= Västerbotten, 3= Jämtland and 4= Västernorrland).

**Source:** <http://www.freeworldmaps.net/europe/sweden/sweden-map-political.gif>

The region constitutes nearly 60% of Sweden's total landmass, but is home to only about 1.2 million inhabitants. Its most striking features are a sparsely populated area with spectacular countryside dominated by mighty rivers, lakes, forests, and mountains (Regionfakta, 2012). The majority of the population lives in the counties' main cities (Sundsvall, Östersund, Umeå, Skellefteå and Luleå). The demographic characteristics mirror those of the Swedish general population with around 70% of the population aged 50 years or over. Life expectancy varies between 78 and 79 years for men and 82 and 83 years for women (Table 2).

**Table 2.** Demographic indicators for Sweden, Northern Region and the four counties, 2011.

<b>Indicator</b>	<b>Jämt-land</b>	<b>Norr-botten</b>	<b>Väster-botten</b>	<b>Väster-norrland</b>	<b>Norrland</b>	<b>Sweden</b>
<b>Total population</b>	126 299	248 545	259 667	242 155	1 152 796	9 482 855
<b>0-15 years (%)</b>	16.6	16.1	16.8	16.8	16.5	17.8
<b>16-64 years (%)</b>	62.7	62.3	63.7	60.8	62.1	63.4
<b>65 years or older (%)</b>	21.7	21.6	19.5	22.4	21.4	18.8
<b>Life expectancy (years)</b>						
<b>Men</b>	79	78.2	79.3	78.1	78.7	79.4
<b>Women</b>	83	82.8	83.3	82.7	82.9	83.4
<b>Foreignborn people (%)</b>						
<b>Men</b>	6.1	7.8	7.6	7.4	7.7	14.7
<b>Women</b>	7	10.7	8	7.9	8.8	15.4
<b>Net migration</b>	508	1 322	1 290	971	4 986	45 288
<b>Population growth rates (2010-2011)</b>	-0.3	0	0.1	-0.2	-0.1	0.7

**Source:** Statistics Sweden, 2011

More than half of deaths are owed to cardiovascular diseases and cancers; however, infections and parasites are among the top ten causes of deaths. Similar patterns are seen at the national level. The foreign-born population represents on average 7% of the population compared with 14.7% at the national level and mirrors the diversity of the general population in terms of geographic origin (Table 3).



**Table 3.** The proportion of migrants in Sweden and Northern Region by geographic origin, 2011.

<b>Geographic origin</b>	<b>Northern</b>	<b>Sweden/country</b>
<b>Returned Swedes</b>	26.5	10.4
<b>Nordic countries</b>	30.3	31.4
Denmark	17.8	21.4
Finland	4.5	2.4
Islands	4.3	2.8
Norway	3.7	4.8
<b>Other European countries</b>		
Great Britain & Northern Ireland	1.9	2.7
Poland	2.2	2.3
Germany	1.9	2.1
Romania	2.1	2.2
<b>North America</b>	1.4	4.6
<b>South America</b>	1.3	1.9
<b>Africa</b>	1.4	2.1
<b>Asia</b>		
Turkey	1.7	2
India	1	3.3
Iraq	0.8	1.7
Iran	0.8	2.3
China	0.8	1.8
Pakistan	0.6	0.9
Thailand	0.2	0.4
<b>Oceania</b>	0.2	0.8
<b>Other countries</b>	23.9	26.1
<b>Stateless</b>	0.8	1.3
<b>Unknown</b>	0.3	0.3

**Source:** Statistics Sweden, 2011

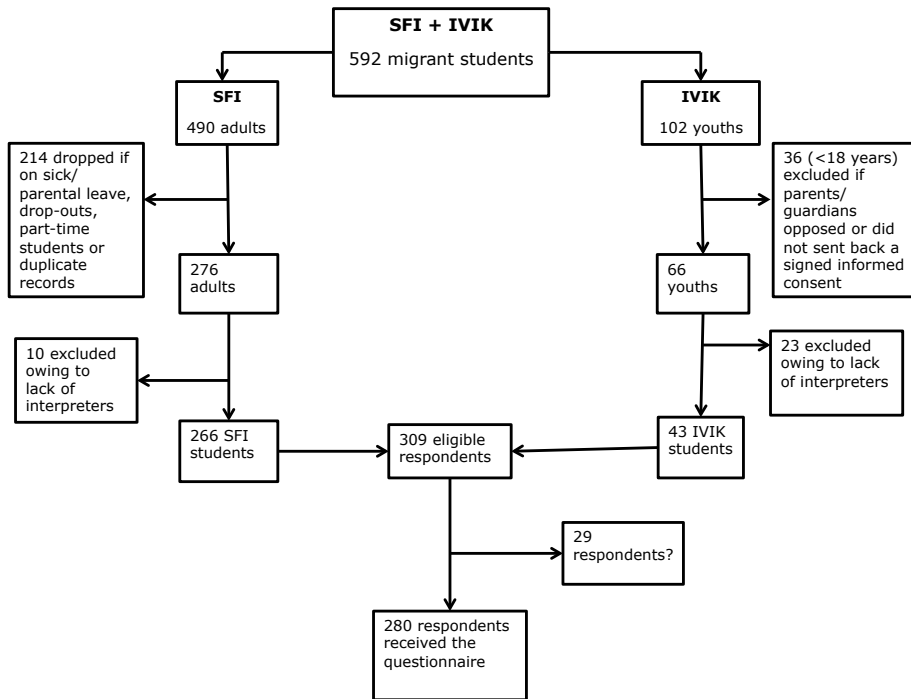
### **Study populations and sampling methods**

The study populations comprised migrants (students) enrolled at two public Swedish language schools in the city of Umeå in the county of Västerbotten between October 2007 and September 2008, and healthcare professionals with experience in caring for patients with migrant backgrounds in the four counties in the study area. The sampling procedures for each study are described below.

#### **Survey sample (I, II)**

Participants in the cross-sectional survey were selected by convenience sampling of migrant students aged 16 or over at two municipal schools in Umeå in

Västerbotten. One of the schools was the SFI (*svenska för invandrare*: Swedish for immigrants) school which is intended for newly arrived immigrants aged 18 or over, and the second was the IVIK (*introduktionkurs för nyanlända ungdomar inom det individuella programmet*: the individual programme introductory course for newly arrived youths) school for youths aged 16 to 20. The two schools were selected because they had the highest numbers of both students with migrant backgrounds and students enrolled throughout the year. The survey was initially targeted at migrants from sub-Saharan African countries; but the target group was revised later on to include all students enrolled at the time of the study. Gathering data from all students prevented some groups of students from feeling that they were being singled out, as both HIV/AIDS and TB are sensitive issues. Eligible participants were selected on the basis of two criteria. The first criterion was being registered as a full-time student at one of the selected schools and the second was speaking a language spoken by at least three other students. The school register records showed a total of 592 migrant students, of whom 102 youth and 490 adult immigrants were formally registered as students at the IVIK and SFI schools respectively in the study period. Two hundred and fourteen students were excluded as they were drop-outs, duplicate records, part-time students (evening classes) or unable to attend classes during the study period, and the latter included those on sick or maternity leave. No more than 378 attendees remained, of whom 276 were regular attendees at SFI classes (N=276) and 102 youths were enrolled on the individual programme introductory course at one of the municipal high schools (N=102) in the study period. Of the 102 youths, 36 minors (< 18 years) were excluded because of difficulties in obtaining parental/guardians' informed consent. Either the parent or guardian did not send back a signed informed consent after being contacted (33) or they withdrew their children (three) from the study. Of the remaining 276 adults and 66 youths, ten SFI and 23 IVIK students respectively could not participate owing to the unavailability of interpreters on the day of the survey. Of the remaining 309, some students might have voluntarily chosen not to participate, but unfortunately teachers failed to provide attendance lists for data collection days, which made the estimation of non-respondents difficult. The reason why 29 students failed to participate could not, therefore, be ascertained. Thus, the sample consisted of 280 students.



**Figure 4.** Flowchart illustrating the selection of the survey sample from two schools in the city of Umeå.

### Participants in the qualitative studies (III, IV)

By means of a purposive sampling approach and a criterion sampling strategy, a total of 25 healthcare professionals performing different roles within hospital or primary care and with different levels of experience in caring for migrant patients were selected for the two consecutive interview studies. The general principle of purposive sampling is to identify a person, place or situation that has the greatest potential for advancing the researcher's understanding of the phenomena under study. A criterion sampling strategy involves searching for cases or individuals who meet a certain criterion such as a disease or a life experience (Palys, 2008). The inclusion criterion for this study was experience in caring for migrant patients. In the first round interviews (III), a total of ten health providers representing different professional categories (doctors, nurses, social workers, and public health officers) of different ages and sexes were purposively selected after being identified by the researcher who worked as a trained interpreter within the healthcare setting. The ten participants were hospital staff, mainly from infectious disease clinics, primary care and county councils.

Participants in the second qualitative study (IV) were 15 purposively selected district nurses with experience in screening recently arrived migrants, identified by the researcher with the help of county council staff through what is known

as the Northern HIV/STI knowledge network (*Kunskapsnätverk Hiv/STI Norr*). Except for one, all participants were employed by the county councils. There was some reluctance on the part of those employed in the private sector to participate in the study.

### **Data collection methods**

Both quantitative and qualitative methods were used during the data collection process. Quantitative and qualitative research paradigms are traditionally opposed as regards their epistemological and methodological orientations (Dahlgren et al., 2004). The quantitative research assumes the researcher is independent from what is being researched and approaches the research process in a value-free and unbiased manner. In contrast, the qualitative paradigm presumes that the researcher interacts with what is being researched and that research is context-bound, meaning that the same individuals might answer the same questions differently whether they are approached individually or in a group, or when they are approached in a different setting (Clark, 2000, Dahlgren et al., 2004). The quantitative method was used when the aim was to collect numerical data to predict the phenomena of interest (knowledge and attitudes about HIV/AIDS and TB and diseased people). Qualitative methods were chosen when the aim was to collect narrative data and observations of events to gain deeper insights into the phenomena of interest and answer the questions how and why.

### **Quantitative data collection**

#### *Structured survey interviews*

A survey is a quantitative data collection tool that emphasizes the standardization of the data collection process with a standard structure (order and wording) for questions to maximize the reliability and validity of measurement and ensure generalizability of the results. It is designed to answer a set of clearly specified research questions and can be divided into two different categories: the questionnaire and the interview. Questionnaires are usually handed out to the respondent who completes them whereas interviews are completed by the interviewer according to what the respondent says (Trochim, 2006). In this study, the survey method selected was based on the sample literacy skills and language issues. The personal interview technique was used for less literate respondents. Literate respondents were assembled on the basis of their native language then each respondent was handed the questionnaire to complete. This is also known as a group administered questionnaire (Trochim, 2006). Data collection was carried out with the assistance of interpreters or translators.

#### *Survey instrument*

A standard question set was developed by the researcher based on other knowledge, attitudes and practices (KAP) surveys on HIV/AIDS and TB (FHI, 2000, Larsson, 2007, Policy Project, 2003, Population Council, 2006, TB Alert, 2004).

The survey instrument included questions that addressed different aspects of knowledge and beliefs about HIV/AIDS and TB knowledge as well as attitudes towards the diseases and diseased people. The questionnaire comprised three sections: the first section included a set of socio-demographic items and a series of questions related to perceived risk of contracting HIV infection and TB, the seriousness of the two diseases, and their control in Sweden. The second section included 80 knowledge and 15 attitudinal items regarding TB (I) and the last section was a set of 69 items concerning knowledge and beliefs about different aspects of HIV/AIDS, 17 items concerning attitudes towards PLWH, and five items regarding fear of disclosure of HIV status (II). Each knowledge item was placed in one of the following categories: causes, mode of transmission, high-risk groups, symptoms, diagnosis, latent infection, and treatment and prevention. Attitudinal items were grouped under two topics: attitude towards the disease (which included statements about how participants might react if they had TB or HIV/AIDS), and attitude towards diseased people (where the statements were about how participants might react if they had a close relative or friend with TB or HIV/AIDS). The response options were 'Yes', 'No', and 'Don't Know' for knowledge items and 'Agree', 'Disagree', and 'No Opinion' for attitudinal items.

#### *Survey procedure*

The survey was anonymously administered to all 280 migrant students enrolled at one of the two selected schools between October 2007 and September 2008 on six separate occasions (two at the youth school and four at the adult school) to allow for the inclusion of newcomers. To overcome language and literacy barriers, interpreters and master's students in public health were hired to assist the researcher in administering the survey. They received the survey questionnaire a few days before for translation. On the survey days they were coached on how to proceed and given the opportunity to ask questions about the questionnaire and the process. The students were split into different groups and put in different classrooms with respect to language. Of the 280 respondents who participated, six were fluent in Amharic, 71 in Arabic, 38 in Badinani, nine in Chinese, three in Dari, 28 in English, 22 in French, three in Japanese, 13 in Persian, 23 in Somali, four in Sorani, 13 in Spanish, eight in Swahili, 23 in Thai, and four in Tigriny. In each classroom, the interviewer read the questionnaire aloud to respondents in their vernacular and then the latter ticked the appropriate response options. Face-to-face interviews were used to assist 17 respondents who could not fill in the questionnaire by themselves.

#### **Qualitative data collection**

The ID approach allows the use of multiple data sources. By so doing, it provides triangulation of data sources and methods and contributes to the trustworthiness of the generated findings (Thorne, 2008). Semi-structured interviews and participant observation were the predominant data collection methods used to

collect qualitative data in this project. Collateral documentary sources were also included for a better understanding and broader view of care providers' experiences, as recommended in interpretive description (Hunt, 2009, Thorne, 2008).

#### *Individual semi-structured interviews (III,IV)*

Interviews are the predominant source of data in many fields of clinical qualitative inquiry. The two types of interviewing in qualitative research are unstructured and semi-structured interviews. Whereas unstructured interviewing tends to be similar to a guided conversation, the semi-structured interviewing approach involves using an interview guide that contains a list of questions or specific topics to be covered (Dahlgren et al., 2004, DiCicco-Bloom and Crabtree, 2006). Unlike highly structured quantitative interviewing, the two types of qualitative interviewing tend to be flexible and responsive to significant issues that emerge in the course of the data collection process. For instance, in semi-structured interviews the interviewer may depart from the interview guide by varying the order and wording of questions, dropping unnecessary questions, and even asking new questions that pick up on things said by interviewees to gain insights into what they see as relevant and important (Dahlgren et al., 2004, DiCicco-Bloom and Crabtree, 2006). The choice of one or the other type of interviewing is likely to be influenced by a number of factors. The semi-structured interview was preferred in this project because the research focus was fairly clear from the beginning; addressing specific issues in caring for patients with diverse backgrounds. In this project, individual interviews were appropriate because the basic research question was essentially focused on migrant care so that a relatively homogeneous group of caregivers could share their experiences about the topic (caring and screening migrants) with the researcher (could be interviewed individually).

Individual interviews were the primary data source in the qualitative inquiry and comprised a series of face-to-face semi-structured interviews conducted with each participant by the author of this thesis. This type of interview is effective for probing personal experiences and perceptions on a specific research topic, something difficult to achieve with group interviews which focus on general opinion rather than personal experience. This technique is widely used by healthcare researchers to collect information about perceptions and experiences of health and healthcare delivery events from the target audience for programme planning and evaluation (DiCicco-Bloom and Crabtree, 2006).

Altogether 25 individual interviews were conducted with caregivers in order to explore and understand their shared perceptions and experiences of caring for migrants and generate knowledge that could inform policy and clinical practice. The interviews were performed in two rounds. In the first round, the 10 interviews that resulted in paper III were based on themes that emerged from results of the survey study on knowledge and attitudes towards HIV/AIDS and

tuberculosis among migrants attending language schools. The experience of the author of this thesis as an interpreter was particularly useful here as it helped to refine the interviews based on the observations recorded.

After completion of the survey and first interview studies, it was evident that medical screening, which often constitutes the first encounter between migrant patients and Swedish caregivers, was of considerable importance not only for the control of communicable diseases of public health significance but also for future care delivery and use. Consequently, 15 more interviews (IV) were performed to probe particularly issues surrounding medical screening in order to generate knowledge that could inform policy and clinical practice.

The interview sessions were carried out at the participants' offices or another convenient location and lasted one to two hours. Each interview was recorded with a Dictaphone. Only one participant asked to be interviewed in English; all other participants were interviewed in Swedish. The sample size was evaluated on an ongoing basis to identify when saturation was reached (Dahlgren et al., 2004, DiCicco-Bloom and Crabtree, 2006).

#### *Participant observation (III)*

Participant observation was also used for collecting data in the qualitative inquiry. The aim of observation was to get a better understanding of the organized routines of migrant care, answer questions that emerged from the survey study (health information behaviour), uncover unexpected topics and issues that participants might be unable or unwilling to share, and use them as source of questions to be addressed with participants in subsequent interviews. Unlike interviews, participant observation allows researchers prolonged immersion in the study setting and to become part of the group being studied while observing their behaviour and participating in their activities. In addition, participant observation enables the researcher to confront members of a social setting in their natural environment and observe their behaviour rather than just rely on what is said (Cooper et al., 2004, Dahlgren et al., 2004).

Working as an interpreter provided the researcher and author of this thesis with an opportunity to enter the field, and observe and participate in care encounters, thus becoming a participant observer. Using an observer-as-participant approach, the researcher did not participate as a regular worker within any of these settings, but simply made a number of key observations on the encounter. She noticed (observed and heard) what was going on during the encounters between patients with migrant backgrounds and care providers, and the ways in which they interacted while on interpreting duties as in-house or phone interpreter in different care settings.

The researcher interpreted oral and/or written communications between healthcare professionals and migrant clients/patients with limited Swedish proficiency whose first languages were French, Swahili, or Lingala. Interpreting assignments/duties were exercised with migrants from African countries where Swahili and Lingala are spoken and migrants from other parts of the world which use French as the official or a second language. The researcher's professional background in medicine allowed frequent interpreting tasks and trust to be established between the researcher, clients/patients, the interpreter agency and healthcare professionals. The observation process was also supported by the first-round interviews as participants' insights guided the decision on what to observe. The observation data thus consist of reflective memos of the author's professional experience as an interpreter and health professional.

### **Data analysis**

The two types of data were dealt with separately because of the differences in analytical strategies used to analyse each type.

#### **Quantitative analysis (I,II)**

After being checked for accuracy and completeness, 12 questionnaires were disregarded as they were not fully completed. Thus, the survey analysis was based on 268 complete questionnaires. The response rate, however, was estimated at 71% (268) of the 378 (SFI= 276 and IVIK= 102) eligible participants. Thereafter, the 268 questionnaires were entered into the computer by means of the Statistical Package of Social Science (SPSS Inc, Chicago, IL) software for Windows version 15.0, transformed and documented into a database structure that integrated the various measures/variables of interest. The same software was used throughout the analysis process.

Descriptive analyses were used to describe the basic features of survey data and provide summaries about the sample and the measures. Standard statistical methods were used with a 95% confidence interval to summarize data according to the study objectives. A p-value of 0.05 was considered statistically significant. Logistic regression analyses were therefore performed to compare different groups and assess the relationships among variables of interest, and adjust for confounders.

#### **Qualitative analysis (III,IV)**

The aim of qualitative analysis was to identify and describe common patterns and themes about caregivers' experiences in caring for migrants, and generate knowledge about how and why things appear as they do within the Swedish context. In qualitative research, data collection and analysis processes ideally occur concurrently so that new analytic steps can inform the process of additional data collection and new data can inform the analytic processes



(Dahlgren et al., 2004, DiCicco-Bloom and Crabtree, 2006, Johnstone, 2004, Thorne, 2000). In this project, qualitative analysis was initiated immediately after each interview or observation, with the researcher transcribing verbatim and reading through each interview and writing field notes and preliminary analytical notes to inform the ongoing data collection process and focus the interviews and observations (Green et al., 2007, Hunt, 2009, Thorne, 2000, Thorne, 2008). This process is referred to as iterative and ultimately leads to a point where no new information (categories or themes) emerges. This is also known as saturation point and indicates that data collection is complete (Dahlgren et al., 2004, DiCicco-Bloom and Crabtree, 2006, Thorne, 2000). Transcription of the first-round interviews was carried out by the researcher. The second-round interviews were transcribed by a Swedish-speaking research assistant and then checked for accuracy against the original audio recordings by the author of this thesis.

#### *Constant comparative analysis*

The following step of the qualitative analysis process consists in using a specific analytical strategy/technique to conceptually interpret a data set as a whole and transform the raw data into meaningful findings that coherently depict the phenomenon under study (Green et al., 2007, Thorne, 2000, Thorne, 2008). Interpretive description is one of the qualitative approaches that rely on constant comparative analysis strategy. This technique involves comparing every piece of data (an interview, a statement, a theme) from participants with similar experiences with all others to identify the differences and similarities among them, and develop conceptualizations of the possible relationships between various pieces of data (Green et al., 2007, Thorne, 2000).

#### *Thematic analysis*

In interpretive description analysis, detailed line-by-line coding is avoided in favour of asking broad questions so that the researcher can bring together a group of data that might be thematically related or not (Hunt, 2009, Thorne, 2008). This analytical approach is consistent with thematic analysis, which therefore seems to be appropriate for the analysis of transcripts and field notes in this inquiry. Like interpretive description, applied thematic analysis derives from a broad range of traditional theoretical and methodological perspectives, relies on constant comparative analysis strategy, and is suitable for solving real-world problems (Guest et al., 2012, Thorne, 2008).

After completion of transcriptions and proofreadings, there was no need to translate the interview transcripts as all members of the research team were bilingual. Thus, using a constant comparative technique, the author of this thesis and another senior researcher with a background in sociology, both with migrant backgrounds, read and reread the transcripts separately to identify

patterns and linkages in the data and labelled chunks/pieces that contained information relating to each particular point made. After these familiarization and coding phases, the two researchers met to search for potential themes by comparing and discussing the meaning of codes and emerging patterns to reach agreement. Thereafter, the codes were sorted into potential themes and all relevant coded data extracts were collated within identified themes following the process used in thematic analysis (Braun and Clarke, 2006, Guest et al., 2012).

The other two members of the research team who participated in the analysis were a senior public health researcher within the field of healthcare systems and a senior consultant in infectious diseases. They read the interviews and had debriefing sessions with the author of this thesis throughout the research process.

Thematic analysis of the two rounds of interviews focused on challenges in cross-cultural care and conceptual themes were, therefore, inductively derived from analysis among and between interviews as well as the relationships among and between codes and themes, and between different levels of themes. This phase ended with the collection of candidate themes and sub-themes to form a preliminary analytic structure that identified and explored commonalities and differences among and between the experiences of participants. In the next phase of analysis, themes and sub-themes were reviewed and refined according to the socio-ecological model (III); this consisted in identifying factors that, within each theme, had the potential to affect care delivery, health-seeking behaviour and the medical encounter at different levels of the model. The provisional findings based on observation notes and survey results were also scrutinized. At the end of this phase, the themes and sub-themes were either collapsed into each other when they fitted together or separated when they did not. Finally, the main themes and sub-themes that captured different aspects of the data were developed and presented in publication III and manuscript IV.

### **Validity and Trustworthiness**

The studies included in this thesis have both qualitative and quantitative features, and, therefore, address both qualitative and quantitative criteria for assessing the validity and trustworthiness of research findings. Although the criteria depict similar issues within the two traditions, they have names that indicate the differences in applications and interpretations (Dahlgren et al., 2004). Therefore, quantitative and qualitative findings are assessed independently of each other.

#### **Validity (I,II)**

Validity issues could be raised in the quantitative study owing to the convenient sampling, the unknown validity of the survey instrument, and the use of different techniques and interpreters in the data collection procedure. Different strategies were employed, however, to enhance the validity of the quantitative results.

Despite being based on a non-probability sampling method, the convenience sample was likely to be representative of the target population in terms of demographic characteristics as it reflected the heterogeneity of migrant groups. Different ages, geographic origins, levels of education, religions, migration statuses, and duration of stay were represented, which could increase the generalizability of the results. Interpreters and face-to-face interviews were used during data collection to overcome linguistic and literacy barriers in order to enhance the response rate and reach representativeness. Thus, the non-response bias was estimated at 29% (110/378) of eligible respondents.

The following strategies were employed to establish the validity and reliability of the research instrument. First, the questionnaire covered different themes regarding both HIV/AIDS and TB, including attitudes towards the diseases and infected/sick people. Second, bilingual researchers with backgrounds in medicine (infectious diseases and public health) participated in the construction and translation of questions. Third, the questionnaire was pilot-tested and refined by the opinions of the target group to reduce measurement error. Fourth, possible imbalance owing to the differences in the number of questions addressing each theme was reduced by computing a single summary score for each theme that was obtained by summing the number of correct responses and dividing the total by the number of items in that specific theme. Finally, multivariate analysis was used to adjust for confounders.

To reduce bias from the unavoidable use of interpreters, the latter were given the questionnaire beforehand for translation and then coached on the survey day. Additionally, the use of two different methods to administer the questionnaire certainly added variability to the data, but it is unlikely that it affected the average performance of the sample. Moreover, the questionnaire showed a logical/coherent relationship between variables of interest and a reasonable distinction between different categories of respondents (e.g. low/high educated, sub-Saharan Africa/Middle East) in terms of responses as hypothesized. Finally, the survey study was complemented by interviews and observations to neutralize any bias inherent in quantitative data source, investigators, or methods and enhance the validity and credibility of the results.

### **Trustworthiness (III,IV)**

Different strategies were used to satisfy different criteria of rigour in qualitative inquiry and ensure trustworthiness. The author of this thesis spent more than three years in the field making observations and having informal conversations with the study participants, both caregivers and clients/patients with migrant backgrounds, on different occasions. Different data sources, data collection methods, and research methodologies were used to provide triangulation, reduce investigator bias, and contribute to the trustworthiness of the generated findings.

Furthermore, the other three members of the research team who participated in the planning, interpretation, and report writing of the qualitative inquiry had different professional and cultural backgrounds and represented both insiders' and outsiders' perspectives. They also added inputs to the research process through debriefing sessions with the main investigator during the study. Later on, preliminary findings were presented and discussed in seminars with other providers caring for migrants in other parts of Sweden whose feedback was incorporated in the final report.

Qualitative research is context-bound, so sufficient detail of the context of the fieldwork is provided to allow readers to assess the transferability of the findings to similar settings or situations. The research process and its implementation are documented in the form of notes and reflective memos written by the researcher during the fieldwork and the whole study period. Finally, the field researcher's multiple and varied positions, roles, and identities were valuable for accurate interpretation and validation of the experiences.

### **The field researcher**

The personhood of the researcher, including his or her membership status in relation to those participating in the research, is an essential and ever-present aspect of the investigation regardless of whether he/she is inside or outside the group studied (Dwyer and Buckle, 2009). Besides my past experience as a hospital doctor at home in the Democratic Republic of Congo, as the thesis author and fieldworker for the project, I became involved with the delivery of care to immigrant patients as an insider without being a provider when I took on the interpreter's role to provide interpreting/translating services for patients with limited Swedish proficiency and healthcare staff during consultations and other care encounters in different care settings. I shared a professional background with the care providers and a socio-cultural background with the patients. Obviously, I conducted this research not only in my role as an academic and researcher but also in my roles as an immigrant and healthcare professional. Any or all of these roles might have influenced and shaped my way of being in terms of the assumptions and biases that I brought to the inquiry.

Although taking on a role as an interpreter allowed me more complete access to the healthcare setting that might otherwise be impossible or denied, I was also aware of the fact that being an insider was not without challenges. Some experiences were recognizable to me as a field researcher from a shared profession whereas others were unique to healthcare staff caring for culturally and linguistically diverse patients. For instance, I was frustrated when healthcare professionals used medical jargon such as hepatitis or tuberculosis when inquiring about the immigrants' medical history, because, back in the country of origin, healthcare professionals tend to ask about symptoms such as yellowness

of the palms for hepatitis or a long-lasting cough with noticeable weight loss or night sweats for TB. On another occasion, I hesitated before stepping in and telling one caregiver to stop searching for TB vaccination evidence (scar) on the patient's upper arm and to look instead at the forearm. This time, the caregiver was happy when she finally found the scar on the forearm and told me that she had learned something new. Equally, a discussion could ensue wherein my role was questioned. On the other hand, I also recognize experiences coming from a shared social (immigrant) status with patients who might each have unique experiences of the Swedish healthcare services. I was frustrated in my role as an interpreter for HIV/AIDS or TB patients from my own community who were suspicious or reluctant to perceive and trust me as a professional because of the HIV/AIDS/TB- related stigma widely spread within the community. At the same time, it was difficult to explain why I kept referring them to the caregivers and could not give them any medical advice despite my professional background and past experience.

Dwyer and Buckle (2009) argued that although a shared status can be beneficial to access and acceptance, it can raise the issue of undue influence if the researcher's perceptions are clouded by personal experience, leading to a tendency to respond to the participants or analyse data from a perspective other than that of a researcher. Yet being an outsider does not create immunity to the influence of personal perspective. It is obvious that there are both positive and negative aspects of insider or outsider status that the researcher must be aware of in relation to their particular status and they should be carefully assessed (Dwyer and Buckle, 2009). Therefore, I could not fully occupy one or the other of these statuses, but the space between, and use reflexivity to critically question my assumptions in order to deal with biases. Nevertheless, it should not be forgotten that my perspective was also shaped by my position as a researcher, including the literature used and academic conferences on the research topic. As Dwyer and Buckle (2009) posited, my personal and professional roles added to the research, and through the research I learned what I might never have learned through my personal and professional experience.

### **Ethical considerations**

This project was conducted in accordance with the Helsinki declaration (WMA, 2008). The project received approval from the regional ethical committee at Umeå University. Permission to conduct the study was also obtained from relevant authorities after clarification of the study and its purposes. Parents/guardians of those under legal age (<18 years) were given the opportunity to withdraw their youths from the study if they were opposed to it. In addition, oral or written informed consent was obtained from all participants prior to the survey and semi-structured interviews after clarification of the purpose, the voluntary nature of the study, issues of confidentiality, and the importance

of honesty in responses. Participants were also told that they could withdraw from the study at any time without any consequence. For the observation study, however, informed consent was not obtained because the study was not planned; rather, opportunities presented themselves. It was, therefore, difficult to identify potential participants before starting each interpreting service and clarify the purpose of the research and ask for informed consent. Moreover, the constantly shifting working environment and restricted time for each service, where I came across different health service staff and migrant patients in every field trip, had the potential to result in reactive effects and make the researched people behave less naturally (Dahlgren et al., 2004). Nevertheless, like health professionals, interpreters have a code of conduct that also emphasises confidentiality. In addition, all findings from the project were reported anonymously and access to the data was limited to the research team in order to protect participants' confidentiality. Finally, generated knowledge carries potential benefits not only for participants, but for care providers and migrants in general.

## Results

In the following section, a summary of the main findings is presented. Full details are given in papers I to III and manuscript IV.

### **Quantitative/survey results**

The following is a summary of the quantitative results and is mainly based on the analysis of data from the survey conducted with migrant students on their knowledge, opinions, and attitudes regarding different aspects of HIV/AIDS and TB and infected or sick people. The students on average scored low on both HIV/AIDS and TB knowledge and displayed misconceptions and negative attitudes towards the two diseases and infected/sick people. Knowledge level and attitude could be predicted by prior knowledge, years of previous education, and geographic origin. In contrast, no association was found between being screened and the level of TB knowledge or attitude toward TB and infected/sick people. Fear of being deported, however, appeared to be the main predictor of reluctance to seek HIV/AIDS care after controlling for socio-demographic factors, knowledge level, stigmatizing attitudes and fear of disclosure

### **Survey sample characteristics (I,II)**

The sample represented 133 different countries and 25 different languages and dialects. Ninety-five per cent of the 268 respondents originated from low- and middle-income countries, also classified as high HIV/AIDS and/or TB burden/risk countries. The majority (80%) were recent migrants who had resided in Sweden for fewer than four years. Their ages ranged from 16 to 63 years (mean 30). Only 10% were aged 45 or older. Male and female respondents represented 55 and 45% respectively. The majority had attended school for more than six years and there was no gender gap in terms of educational attainment. Half of the respondents were married or living as couples, one-third were single and the remaining 17% were divorced, separated, or widowed. Most respondents (72%) were refugees and their relatives, about 16% were related to Swedes, 4% were either students or migrant workers, and 8% did not specify their immigration or legal status. Nearly half the group were Muslim, one-quarter was Christian and the rest were either atheist or had another religion.

### **TB knowledge and attitudes, and their determinants (I)**

Both average scores for TB knowledge (mean =  $2.7 \pm 1.3$ ), (maximum = 8) and attitudes score ( $5.1 \pm 3.3$ ), (maximum = 12) were low, meaning that most respondents held misconceptions and negative attitudes towards TB and infected/sick people.

The key determinants of TB knowledge level were years of previous education and prior knowledge. Those with more than 12 years of educational attainment and those who were informed about TB before migration were likely to have higher levels of TB knowledge than those who did not. Educational attainment was also an important determinant of level of attitudes towards TB and infected/sick people. It appeared that attitude was likely to be low among those with fewer than 12 years of previous education than those with more. Other determinants of attitude were being informed about the Swedish Communicable Disease Act and originating from the Middle East. Although having heard about the Communicable Disease Act was associated with a positive attitude towards TB and infected/sick people, being from the Middle East was associated with a negative attitude towards TB and infected/sick people with reference to being from a high-income country. Undergoing medical screening and being exposed to TB information in Sweden were not determinants of knowledge level or attitude.

### **Knowledge about different aspects of HIV/AIDS and expressions of stigma (II)**

Overall, the mean HIV knowledge score for the sample was 4.9 (maximum =9). Most respondents knew of HIV/AIDS, and knew that it was a sexually transmitted infection. A number of respondents, however, had misconceptions about other modes of transmission, causes, the difference between HIV and AIDS, the meaning of a positive or a negative HIV test result, risk factors, and anti-retroviral treatment. Logistic regression analyses showed that level of education and geographic origin were significant statistical predictors of level of knowledge. Being from the Middle East and having  $\leq 12$  years of education increased the likelihood of poor knowledge.

Respondents also had different opinions about effective measures to prevent the spread of HIV, but most of them did not make their position/opinion clear or supported coercive measures and forced disclosure, which engendered stigmatizing attitudes towards people living with HIV/AIDS in the form of rejection, violation of rights, moral judgment, and attribution of blame. Multivariate regression analyses indicated that being from the Middle East and having  $\leq 12$  years of previous education increased the likelihood of negative attitudes towards people living with HIV/AIDS. At the same time, the majority of respondents said that they were afraid to be stigmatized because of HIV/AIDS and thus expressed fear or uncertainty about disclosure of their own or a relative's HIV status. More than half stated that they would disclose their HIV status to their partners (78%), parents (76.1%), or children (55.6%) rather than to other relatives (47%), religious leaders (41.4%), and friends (40.3%). Being a woman, having  $\leq 12$  years of previous education, and being from the Middle East increased the likelihood of fear of disclosure. Respondents were also aware about the vulnerability of HIV-infected people to TB infection (61.9%), disease



(63.1%) and increased death risk (58.6%). Yet more than half (54%) did not know that TB was treatable and curable in people with dual infection.

### **Predictors of reluctance to seek HIV/AIDS care (II)**

Bivariate analyses indicated that young age (16-24 years), less than seven years of previous education, being from the Middle East, poor HIV/AIDS knowledge, expressing stigmatizing attitudes, fearing disclosure of HIV status and deportation significantly increased the reluctance seek medical attention if one suspected being infected or sick. In the multivariate analyses educational attainment of respondents; medical screening; fear of disclosure and fear of deportation appeared to be the most important predictors of reluctance to seek care. Fear of deportation, less than seven years of education and fear of disclosure decreased the likelihood to seek care. In contrast, being screened increased the likelihood to seek care.

### **Accessibility and availability of information related to HIV/AIDS and TB, and risk perception (I,II)**

Descriptive analyses showed as well that the majority of respondents (72%) underwent medical screening. Besides, almost similar proportions of respondents reported having heard about TB (53%) and HIV/AIDS (51%) before migration. However, only 29% affirmed that they got such information after migration to Sweden. In addition, up to 67% of respondents claimed they did not know where to find health information and most (71%) respondents expressed the need to receive HIV/AIDS and TB information in their vernacular. Moreover, up to 60% of respondents affirmed that they did not know where to go if they wished to test for HIV or TB. One in five people (20%) believed that HIV testing was compulsory only for immigrants, but nearly three in ten (28%) said it was compulsory for everyone. Yet knowledge about the Swedish Communicable Disease Act and its legal implications was very poor. Approximately one in four respondents (23%) answered that they had heard about it. Consequently, only a few respondents were aware of the legal consequences of knowingly exposing others to the risk of HIV infection such as forced isolation (35%), imprisonment (28%) or damages (21%). There was a difference in the proportion of respondents who believed that a person living in Sweden was at some risk of contracting or dying from HIV/AIDS or TB if infected/sick. Whereas only 30% believed that such risks existed for contracting or dying from TB, more than that proportion believed that there was risk of contracting (40%) or dying from HIV/AIDS (53%) while living in Sweden.

### **Qualitative studies results/findings**

In the qualitative studies, the interplay of individual, cultural, and structural factors was described as complex and affected not only delivery but also access to and receipt of care. It was made obvious that these factors often resulted in

barriers to access and use, and divergent perceptions and expectations about care and caring, which in turn affected delivery and receipt of care as well as the interactions between caregivers and migrants. In addition, the complexities of caring for diverse patients within different institutions with conflicting discourses, policies, and frameworks were highlighted. In what follows, the healthcare providers' comments are used to illustrate these different aspects.

### **Socio-demographic characteristics of participants (III, IV)**

The 25 study participants comprised healthcare professionals who have regularly been responsible for migrant care, infectious disease control, and screening of migrants. They had different professions and varied experiences. The youngest participant was 27 and the oldest 65. Only three were men. The majority were district nurses (15). Of the remainder, four were doctors, another four public health officers and two social workers. Most of the participants were Swedes (21) and only four had migrant backgrounds.

### **Struggling to understand and manage diversity (III, IV)**

Overall, the caregivers described how they struggled to understand the differences in socio-cultural backgrounds among migrants and cope with the differences between their own and migrants' backgrounds as they affected perceptions and expectations about clinical realities.

#### *Understanding diversity among migrants*

The caregivers described being challenged by the heterogeneity of migrant groups, which consisted of individuals from different geographical regions, with different cultural and educational backgrounds as well as migration histories and statuses. They explained that individual characteristics resulted in differences in knowledge levels, attitudes towards health issues, care needs, and entitlements to care, which had implications for care approaches. For instance, level of education and geographical origin were said to influence the nature of knowledge and attitudes towards diseases. The caregivers explained that knowledge differed not only between people from different countries but even among people from the same country depending on their educational levels. One infectious disease specialist commented:

*So the term 'immigrant' is of course ... so in a way I would perhaps say that one should be aware of the subtle nuances of the meaning of this word... I have currently an immigrant here. He is a visiting doctoral student from Eastern Europe. His views differ greatly from those of women from Africa; even the knowledge is quite different as well among them.*

The attitudes of migrants towards diseases were moreover said to differ and often illustrated the general attitudes in their country of origin. For instance,

the caregivers argued that it was easier to talk about HIV/AIDS with migrants from African countries than with other migrants who originated from countries where this topic was still rare or taboo.

Another challenge described was the difficulty of identifying individual health needs and adapting care approaches accordingly. It was emphasized that the 'one size fits all' approach did not work all the time because of the differences in pre-migration histories or past exposures, particularly for those who experienced traumatic events before or during migration.

Religious diversity among migrants was also reported to be a challenge as it resulted in different perceptions of and attitudes towards clinical realities. Migrants were said to react differently to the diagnosis of a life-threatening condition on the basis of their religious affiliation. One doctor explained:

*One of the two patients was a Muslim from an African country and a strong believer, the other was a Christian from another African country... Their personalities were also quite different. The first one, the Muslim, he barely reacted and said, "Yeah, okay, Inch Allah ... It is God's will ... uhm, it's God's will" and was like very tough. The second, he got a crisis reaction the first time I met him... Once he got the diagnosis and he had to be admitted to the hospital because of his anxiety reaction and he had never really recovered, he never got back to work he had a chronic crisis...*

The need to train caregivers in migrants' issues was also emphasized, especially for those who do not care for migrants on a regular basis. The participants argued that other care staff, including doctors, failed to distinguish between different categories of migrants although this has implications for health and care approaches. One district nurse said:

*Actually, there is great lack of knowledge about this in general, and I think that it has always been so all the time, and I don't think it's getting any better. So, it is very important in basic education, nursing education... raise issues concerning values, some ethical aspects as well ...It's really important, all nursing programmes, but medical training too. The doctors do not actually know the difference between asylum seekers and refugees...*

#### *Managing diversity*

It was reported that the difficulties in screening and caring for migrants stemmed from socio-cultural differences. The incompatibilities between caregivers' own socio-cultural backgrounds and those of migrants were believed to result in different perceptions and expectations about clinical realities that created problems during medical encounters. Migrants' socio-cultural backgrounds

and past experiences were reported to influence their perceptions about health, illness, and care, which in turn influenced their expectations about care, health-seeking behaviour, and attitudes towards the caregivers. Details were given on how differences in educational backgrounds and religious or health beliefs and practices affected the encounters and became grounds for communication difficulties, misunderstandings, and dissatisfaction on both sides. For instance, patriarchal structures and gender segregation, which were believed to be a corollary of religious beliefs, were described as substantial challenges. They resulted in undue interferences in care from male relatives, requests to have caregivers of the same sex, and negative attitudes towards providers of the opposite sex. This behaviour was described as a frustration because it was in contradiction with the Swedish guidelines and standards which emphasize patient autonomy and gender equality. Accounts of strategies used to cope with these interferences from male relatives while dealing with female patients were also given. A district nurse explained:

*...Usually, I pretend to be very naïve and say, well, you can sit outside the door but this is the way we do things here. You can sit in the waiting room or if you want you can sit outside... I want to see your wife and you can sit outside because there is some form of control about it. Some people do not want me to talk about contraception. And even if the husband comes in with his wife, I can see that he gets quite annoyed. I said this is part of my profession, this is what I have the obligation... to inform both you and your wife about women's rights in Sweden, about the right to contraception and if she wants it or not. I think I get on my high horse because of my profession; I have the right to give this information to anyone.*

Some religious beliefs and practices that were perceived as unrealistic and had negative interferences in care included fasting, belief in supernatural powers, fatalism, travelling back home for religious rituals, and refusing drugs assumed to contain taboo ingredients. Dealing with such beliefs or practices was said to be frustrating. A specialist nurse explained:

*...some patients... fast sometimes, like Ramadan or other types of fasting for religious reasons and it may be a bit difficult with medication that should be taken with food at specific times.*

The case of one patient was narrated by one infectious disease specialist:

*...because he was on antiretroviral drugs, then went to Africa. During the time he was there he stopped taking his drugs. He never told anyone about it. Then he was a very strong Muslim believer and also fasted ... and then he became very ill and it turned out that he had tuberculosis bacilli then we found out*

*that he had stopped taking medication and... It's a little hard to understand that way of thinking. Really! It's a little bit religious and... a little deeper supernatural belief.*

One more challenge described was the difficulty of knowing how much migrants knew about health issues and how they adapted health information to meet their needs. It was suggested that conveying complex information and explaining things, especially to low educated migrants, was challenging. A district nurse said:

*It may well be that they do not know about the issues. Like, they do not know what a vaccination is; they do not know what TB is... often, they say that they do not know. And one should try to explain what something actually is, what a vaccination is ... Then it may be that some of them are illiterate... It may also be things that are totally new, that they do not have any idea about.*

An infectious disease specialist explained this challenge in the following way:

*...I often suspect that they might not know so much about the human body, how it works and some maybe know a lot about it but it's hard to know how much. If I sit and talk about the immune system, does the person in front of me understand what I mean? I do not know every time if they do, and how can I express myself? I think this is very difficult.*

It was also argued that migrants' perceptions about diseases were mainly based on their past experiences. For instance, it was easy to explain diseases that migrants were familiar with such as HIV/AIDS because possibly they had seen people suffer or die from it or heard about it in their home countries. It was difficult, however, to ascertain whether they possessed the correct knowledge or not. Misconceptions about HIV/AIDS were said often to lead to unfounded fears of casual transmission and stigmatization of affected community members as well as fear of disclosure of HIV/AIDS diagnosis among those affected. A district nurse explained:

*...I was thinking of cases of discrimination from their own countrymen that if you have HIV and they don't want to have any more contact with these people because they can give you HIV by being in the same room with you or drinking from the same glass of water.*

In contrast to HIV/AIDS, explaining unfamiliar diseases such as hepatitis was considered challenging even though it was a common health problem among migrants.

*... There is a difference between HIV and hepatitis... Hepatitis is a bit more a hidden disease; people do not get as much information, I mean not in the same ways as HIV. ...I think it may be that one does not really know that hepatitis also can be a deadly disease...*

It was particularly difficult to explain the diagnoses of asymptomatic diseases/infections after screening or consultations to those with poor knowledge about health issues, who always associated infection/disease with symptoms and thus perceived themselves as healthy. This was said to lead to conflicts with those who could not imagine being sick/infected without having symptoms and who argued that they were given the disease in Sweden. An infectious disease specialist said:

*...We have, had these types of reactions: 'When I was in my home country, I was healthy and then I fled to Sweden and here you make me sick'... Like, there is a man that I was talking about ...he claims that it is we who have produced/created the disease. Really! Just because he has been healthy in the past...*

This was said to lead to a situation where some migrants required to be treated immediately even for latent infections since they could not understand why they were given a diagnosis for which they were not given treatment. A nurse explained:

*Then, many actually want to start with drugs quite early when they have been told the diagnosis. They believe that it is better but it is not true. One starts taking drugs when the time comes, so to speak, when the immune system is affected to some extent. It's not that a diagnosis means that you should start treatment immediately. And it's a bit strange for some that they cannot then start medication immediately.*

This led to the conclusion that migrants did not fully understand the meaning of screening and other health promotion initiatives. This could negatively impact on caregivers' clinical management of chronic or infectious diseases because, in the absence of symptoms, migrants would be unlikely to seek care or comply with treatment and preventative measures.

*Communicating in different languages/Dealing with language barriers*  
Language was considered as the most important barrier to effective communication. For instance, it was difficult to reach, communicate, or interact with migrant patients/clients because of language barriers. The Swedish routine of communicating and making contact with patients over the telephone, through the internet, or post was said to be problematic because of language barriers and poor literacy skills among some migrant groups. Although working with

interpreters was acknowledged as crucial, it was also described as complex as it involved many issues that arose in triadic communication and increased the potential for misunderstandings and conflicts. One issue discussed was the difficulty of persuading worried patients who distrusted interpreters from their own communities that the interpreter, too, was bound by secrecy. To avoid this, telephone interpreters were preferred to in-house interpreters as it was believed to guarantee confidentiality to those who wanted to be anonymous. Telephone interpreters were seen as the best alternative for worried patients from small communities, especially when talking about sensitive issues or stigmatized conditions such as HIV/AIDS and TB. Even for caregivers who found it disturbing to have a third person in the room telephone interpreters were seen as a good option. Accounts of drawbacks in working with interpreters on the phone were also given, however, and included the inability to control information transfer through body language, bad equipment, and the interpreter's poor working environment. A nurse explained:

*...What may be the advantage of telephone interpreter is that you do not feel that there is one more person present, it seems more like it's just a conversation between two people, the downside may well be for example, wrong equipment, that makes the sound in the speakerphone a bit poor, it sparks and crackles a little bit, sometimes you hear a ringing cell phone where the telephone interpreter is or there is a child screaming in the background...*

Another issue discussed was lack of competence and unprofessional conduct on the part of interpreters who were not only unable to translate terminologies properly but who also sometimes took over and interfered in medical encounters by engaging in personal conversations with patients. A doctor said:

*...Sometimes ...you can almost feel the need to educate both the interpreter and the patient. We try to avoid it, but sometimes it can be really frustrating. I think it's very common that, so to speak, one misunderstands the interpreter job, then the patient sits and talks to the interpreter. Instead, I would like that you and I talk and the interpreter is there and kind of just translating, but often it does not work like that...*

One more issue in working with interpreters was the difficulty of matching patients' and interpreters' age, accent, gender, dialects, and political opinions as it depended on the availability of interpreters and the agency which decided which one to send. In such cases, it was difficult to interact with patients.

Lack of interpreters for some languages was described as a major problem because it was impossible to communicate without interpreters. Divergent views were, however, expressed regarding the use of relatives or friends to cope with

the lack of interpreters. Some explained that they had no option even though they were aware that it raised the issue of confidentiality and that information transfer could not be guaranteed, but they also added that they faced difficulty in preventing relatives from acting as interpreters because there were no guidelines.

*... If one has no one else it's better than nothing... So, it is difficult for me to say you cannot interpret. It's really hard to say that they cannot. But I usually try to avoid it... Because one must treat the patient with respect but still one has to somehow find a way to deal with it and it is not always so easy...*

Other caregivers, however, argued that they would never let family members act as interpreters. They explained that they were aware that this might just be a way to control the other family member. Second, with regard to the family structure it might be inappropriate to tell children or other family members to ask about intimate matters. Third, they added that what these ad hoc interpreters might wrongly translate could threaten the patient's life.

### **Understanding structural barriers (III, IV)**

*Coping with migrants' difficulties in understanding and navigating the Swedish healthcare system (III, IV)*

Apart from the language barrier discussed above, it was stressed that migrants' expectations about healthcare services and caring were grounded on their past experiences in their home countries. Thus, lack of knowledge and unfamiliarity with the structures and organization of health care in Sweden were reported to cause difficulties in care delivery and receipt as well as the medical encounter. One more barrier that was said to prevent migrants from accessing and using available services was the use of distant information technology that required not only general literacy but also computer literacy skills. All these were said to affect migrants' ability to use available services effectively and to lead to poor health literacy, delay in seeking care and failure to attend important appointments, inability to navigate the healthcare system, and increased likelihood of seeking care as drop-in patients.

*They could not reach us, because we are actually only available on this kind of phone with keys that you must press in codes and how you do ... but it happens sometimes that they actually do not come at the appointed time, but it's of course because they have not been able to inform us, for they have no opportunity to call us by phone so easily, we are pretty inaccessible...*

It was challenging to deal with lack of information about the organization of care, the mistrust of nurses, poor health literacy, knowing how much to tell, and how authoritarian to be to meet migrants' expectations. This sometimes



resulted in misunderstandings and conflicts, with language barriers adding to the problems. A nurse explained:

*Perhaps it is to do with the language as well, then they do not understand the Swedish healthcare system too, some are actually very demanding in that ‘ We should see a doctor, we should go to the doctor just for ...’, for little things, which we call self-care in Sweden or that a nurse can take care of... Well, I’ve been working with this, so I, I’ve come to know that, I know how to deal with them so that they do not get offended...*

It was argued that migrants’ feelings of being discriminated against stemmed from their lack of information and the differences in healthcare systems and care practices between Sweden and their countries of origin. One migrant doctor stated:

*Maybe if one has to wait a while until he gets to his turn then he experiences this as discrimination because of his background... Certainly, it is so, yeah. It is very hard. People must work more so that these people understand what it means to come here, as well as how to adjust and acculturate to the society.*

#### *Understanding the complexities of caring for migrants ( IV)*

The caregivers indicated that they provided care to migrants in an environment with complex interactions among many factors including the influence from other institutions, poor staffing resources, heavy workloads, and inadequate training and policies. The working environment was depicted as stressful and characterized by overwhelming time pressure. For instance, it was highlighted that caring for migrants involved collaborating with other migrant-serving agencies and social institutions. This was described as causing difficulties in reaching migrants with timely information, heavy workloads, and long waiting time for consultations. In addition, collecting and sharing information with different institutions was said to be time-consuming and difficult as the source of information differed according to legal status. Moreover, it was difficult if not impossible to reach migrants who were not asylum seekers or refugees with timely information about care because there was no official source of information about them. A nurse explained:

*... It is clear that it is a lot of work... it’s a lot of things, it is cumbersome at times, and you play detective if you have to find out different things-from the different municipalities, schools and elsewhere..., it is perhaps, but if you only have time for that, then I think it will be nice*

Even when the sources were available, in some cases the caregivers reported it was difficult to get correct information because the received information varied

from one source to another. Sometimes migrants failed to attend important appointments because the invitation/notice did not go to the correct address or they had overlapping appointments at different institutions. Another nurse said:

*...They have concurrent appointments at the Migration Board and the lawyer and sometimes they have moved to another city, and they have changed accommodation and mailbox number, then the letter is returned, and yes it is like that.*

Lack of appropriate training in caring for diverse populations was said to make it difficult, for example, to take medical history about sexual health or care for patients who experienced trauma so that learning from one's own mistakes was the only option. Moreover, unhelpful and insensitive colleagues with negative attitudes towards migrant patients were described as a challenge believed to stem from lack of knowledge about migrants' issues and inadequate skills in caring for diverse patients.

*Many people complain that they are ..., open racism definitely unfortunately. 'No, but it is so hard. No, calling and booking an interpreter! – Oh, I did not understand what they meant'... it's hard to imagine oneself in their situation. So, it can be like that unfortunately...*

Despite all these challenges, the caregivers showed devotion to their job and described it as inspiring and enriching. It was also suggested that even if it is not the same as meeting a countryman/woman, it was all about caring for human beings and that was the most important thing. A nurse stated:

*I think it ...takes a lot of time. But, it is really funny, it's really interesting and it gives back a lot. It challenges you in a completely different way as a nurse than other nursing jobs do.*

#### **Managing conflicting policy and practices (IV)**

##### *Balancing migration control laws against public health laws*

Keeping the balance between migration control laws and public health laws was considered a struggle. For instance, migration laws made it difficult to reach or follow up migrants with infectious diseases of public health significance. It was reported that some migration staff refused to disclose important information about migrants to caregivers, arguing they were bound by secrecy which caused problems for caregivers who attempted to reach migrants. The restrictive entitlement policy that emphasizes legal status for migrants' access to care was said to make matters worse as it conflicted with medical ethics, the law on equal access to care, and the Communicable Disease Act. The ethico-legal issues were highlighted by several examples. First, it was difficult to apply

the Communicable Disease Act and follow up failed asylum seekers and other undocumented migrants who were not only denied access to care but also hid themselves from migration authorities owing to the fear of deportation. This was reported to make migrants and in particular asylum seekers mistakenly confuse the role of care providers with that of migration authorities/staff and suspected collaboration between the two institutions that could lead to their repatriation or believe that caregivers or test results could influence decisions about asylum applications. Migrants, therefore, became reluctant to disclose certain information. An infectious disease specialist commented:

*...If this should work well, it is important to provide appropriate information in order to get an acceptance so that they realize that it is not really for repressive purposes that we do it ... Possibly remove misunderstanding that is like if one is discovered with HIV so one will be thrown out of the country. It's actually the opposite.*

Second, applying the concept of 'care that cannot wait' to some categories of migrants was said to be challenging. Accounts of frustrations were given and included being unable to provide appropriate care because of migration laws. A nurse explained:

*If somebody wants help with something ...they will not get help with it, I think it can be hard sometimes to explain that this is not really included in acute care that we provide to asylum seekers. It can be a dilemma.*

It was also reported to be frustrating to see the poor being required to pay for received care, when some migrants were denied appropriate care after being screened because of their legal status or when they were repatriated before they had been treated properly.

*...They may not have this magnetic card from the Migration Board; they get a bill in their mailbox later on after the consultation. Asylum-seeking women who delivered they can get a bill for many, I do not know ten thousand, twelve thousand or twenty, I do not know how much but it is too much. And as an asylum seeker then you have no money, but once you get the residence permit then you start your Swedish life in debt...*

There were also accounts of the struggle to circumvent migration laws and give treatment, which in some cases resulted in forced disclosure of health conditions to the lawyer. In some cases, conflicts arose with asylum seekers who required care that they were not entitled to and thus felt discriminated against. Additionally, it was argued that the Migration Board's dispersal and housing policy

had implications for the care of asylum seekers and had the potential to impede the control of communicable diseases among these vulnerable populations.

*...the problem is that it is the Migration Board that decides when it comes to those who still do not have a residence permit, it is the Migration Board that determines where they should stay and live... so that the Migration Board can move people from one place to another place and then it affects my work because it might be more difficult for them to come here. Maybe move a person from one county suddenly to another or vice versa and then you have to change doctors and get another infection clinic.*

Moreover, the housing policy resulted in overcrowded conditions with an increased risk of disclosure of stigmatized conditions such as HIV/AIDS and TB. Both the researcher and the caregivers reported a constant fear of disclosure for HIV/AIDS and TB. It was stressed that it would be hard to be discreet about one's status when sharing accommodation. As a result, those affected would try to avoid disclosure by hiding their diagnosis or drugs and not follow preventative and curative recommendations, which might have negative consequences for the control of communicable diseases. A social worker explained:

*They are afraid that the letter might be read by people they live with, when they have the status of asylum seeker ...They are afraid when they are treated with drugs that drugs will help others understand that there is now someone who has got HIV...*

Finally, the dispersal policy was said to impede the delivery of care to asylum seekers who lived at long distances from healthcare facilities where they were referred and the language barrier made it difficult to interact with them over the telephone.

#### *Balancing individual rights against community needs*

There was a general view that it was difficult to strike a balance between individual rights and the need to protect the community against infectious diseases of public health significance. Two divergent views emerged about the rationale for screening migrants for these infectious diseases. One view put more emphasis on the public health goal which aims at protecting community health by screening migrants who come from high prevalence countries to identify and treat diseases of public health significance and stop its spread. It was argued that community needs outweighed individual rights.

In contrast, another view emphasized the human right or ethical goal. Here, it was argued that the idea should be to help people in need and identify diseases

that need to be taken care of, and in that process of doing good one can achieve public health goals. The selective screening policy was criticized as it only focused on infectious diseases without paying attention to individual health needs. It was therefore suggested that if it has to be called medical screening it should encompass a wide range of tests that actually assess individuals' health needs. One nurse expressed her opinion thus:

*...My personal opinion is that one is just checking ...infectious diseases. -It's no health assessment in my eyes - I'd like a bit more than that. ...Because if it should be called health assessment then I would like to take urine samples, blood pressure. Yes, this basic stuff, anyway. But we do not do that. And it is actually infectious disease control doctors who have decided that it should be HIV, hepatitis B and syphilis, and these kind of tests ... One should adjust health assessment to the needs...*

The ethics of screening asylum seekers was even questioned because their access to care was limited as they were denied appropriate treatment after screening or repatriated after they had started treatment. A public health officer commented:

*...A negative consequence may be that someone is detected with a disease in Sweden and gets treatment and then is forced to move to another country where he or she cannot get treatment.*

#### *Balancing infectious disease control against discriminatory practices*

The strict regulations and practices applied to control the spread of certain infectious diseases were also criticized by the caregivers as it might be difficult to balance fear of infection and discriminatory practices. It was highlighted that laws and practices make a drama out of certain infectious diseases with the risk of portraying migrants as disease vectors. It was argued that it is the practices or guidelines to prevent contagion that told the insider /care provider that a person was dangerous. For instance, in some counties migrant children were not allowed to go to school until they were screened.

These practices, according to the caregivers in this study, had the potential for stigmatization and discrimination of those affected as they increased fear of contagion, particularly outside the infectious disease clinics where the staff might be more aware of the laws and guidelines than the disease itself.

Moreover, it was suggested that these strict regulations to control the spread of certain infectious diseases including obligatory notification, criminalization of HIV transmission, and forced disclosure also reinforced fear of disclosure and stigma among those affected. A public health officer highlighted some of the restrictive rules that applied to people living with HIV/AIDS:

*We have a law ...and I have to work according to the law. So there are 31 diseases in Sweden that are considered public health threats and therefore a person cannot behave as he or she wants, ..., for example, if a person who has been exposed to the infection and refuses to take the test: 'I do not want to take the test.'. I can make sure that such a person gets tested... And if a person continues to spread infection I can also request that the person be isolated and treated. But, that person is locked up; it's a form of police action.*

The referral of people living with HIV/AIDS to the infectious disease clinic for any kind of illness was questioned. It was underlined not only that this practice might be perceived as discriminatory by patients but it also had the potential to reinforce fear of disclosure and stigma as it resulted in unintended disclosure.

Another view expressed about HIV infection was, however, that it was also dramatized by the patients themselves who were afraid of being seen in the infectious disease clinic by their countrymen and women as they associated the infectious disease clinic with HIV infection. According to caregivers, patients assumed that anyone who saw them at the infectious disease clinic would automatically conclude that they were infected. One staff member at the infectious disease commented:

*They are afraid when they come that they will be seen in the waiting room or meet someone here that might gossip further. In general, they are afraid that their HIV status will be known to someone who does not have anything to do with it. I think it is the most difficult... ..it's like they think it is visible that they have HIV.*

## Discussion

It appears there are numerous challenges in the care and prevention of HIV/AIDS and TB among migrants in Sweden. From a socio ecological theoretical perspective, these challenges involve factors at various levels, including the micro-level (individual factors), meso-level (interpersonal factors), exo-level (institutional factors) as well as macro-level (cultural and/or societal factors and policies), factors that directly or indirectly influence the health care of migrants in general and HIV/AIDS and TB control in particular. This section discusses how these factors influence care-seeking by migrants for HIV/AIDS and TB and their encounters with caregivers. The factors are explored and discussed in an attempt to clarify their role and how they affect migrant care, specifically with regard to HIV/AIDS and TB control.

At the micro-level, individual factors such as educational level, religion, knowledge, attitudes and migration status were described as barriers for migrants to access health care services, which also affected medical encounters and compliance with treatment. For caregivers, individual factors including lack of training and skills in caring for patients with diverse backgrounds, as well as some negative attitudes towards migrants and a fear of infectious diseases were said to adversely affect the delivery of care and their interactions with migrants. At the interpersonal level, language was reported to alter the relationships between caregivers and migrants due to the involvement of interpreters. In addition, family members were also said to interfere in care delivery and how care was received. The structure and organisation of the health care system including the use of distant communication technology are institutional factors said to affect access, use, and delivery of care and disease management. At the macro-level, cultural factors such as gender norms and family dynamics, community attitudes towards diseases and those affected, misconceptions about HIV/AIDS and TB as well as past experiences of the health care system were reported to affect health-seeking behaviours and the interactions between migrants and the caregivers. Additionally, conflicting policies and regulations that exacerbated stigma and discrimination were described as impediments to care and prevention. Understanding the nature of these challenges can help to improve care and develop integrated prevention programs.

### **Language: a substantial challenge**

Although multiple and complex factors explain the disparities in access, utilisation patterns and delivery of care among migrants, the clinician/patient relationship constitutes an important contributing and potentially mitigating factor. Effective clinician-patient communication is widely perceived as key in the process of health care delivery and use (Koehn, 2006). In this study,

most of the perceived challenges during medical encounters largely reflected socio-cultural and linguistic differences. Language was, however, described as the primary barrier to health care access, use, delivery and how information was received. The caregivers reported that they were heavily dependent on interpreters in their communication and interaction with migrant patients who had limited skills in the Swedish language. The language barrier is referred to in many studies as a major problem in delivering relevant care to ethnically diverse patients (Goth and Berg, 2011, Greena et al., 2006, Hadziabdic et al., 2011, Hultsjö et al., 2011, Pergert, 2008, Shahnava and Ekblad, 2007, Svenberg, 2011). Although language can be addressed with the use of interpreters whose availability is mandated by law in Sweden, dealing with unavailability of interpreters and complex issues related to the involvement of a third person in the care encounter was described as “complicated” (Goth and Berg, 2011, Hultsjö et al., 2011, Hadziabdic et al., 2010). For instance, it was difficult to deal with feelings of insecurity when using an interpreter from the patient’s own community, especially for those who suffered from highly stigmatised conditions such as HIV/AIDS and TB. Misinterpretations of medical terminology and professional misconduct were also described as being common. In some cases, family members were used as interpreters to cope with a lack of interpreters on relatives or patients requests. Similar findings have been reported in other studies (Goth and Berg, 2011, Greena et al., 2006). All these factors carry the potential to harm the medical encounter and ultimately the medical outcome, as they might result in mistrust, misunderstandings, errors in diagnoses and treatment. Studies have indicated that the use of professional interpreters was associated with improved clinical care, decreased communication errors, improved patient comprehension and improved clinical outcome. In contrast, the use of family members or other ad-hoc interpreters was associated with increased risk of misinterpretation, poor quality of care, more adverse events and other undesired medical outcomes (Hadziabdic et al., 2010).

Language was also shown to prevent migrants from accessing available information and services, receiving information from caregivers, booking or cancelling appointments, and participating in health education and health promotion activities, all which require a good command of Swedish. Apart from caregivers’ opinions, migrants themselves also mentioned language as a barrier, and requested health information in their mother tongues. A study in Norway found scanty and incorrect knowledge about the Norwegian health care system among migrants (Goth and Berg, 2011). This was said to be the result of sending routine information about the health care system in Norwegian, without regard to migrants’ proficiency in Norwegian and health literacy skills (Goth and Berg, 2011). In this study, language may also explain why a large proportion of survey participants stated they did not know where to find HIV/AIDS or TB information or where to get tested. Additionally, language may



prevent migrants from participating in surveys that are used to develop and prioritise public health policies. As a result, their perspectives and care needs often remain unidentified and unmet. Some migrants are also dependent on interpreters to communicate with caregivers; a study in Denmark showed that 15% of migrants who participated in the study expressed a need for an interpreter after seven years of residence (Harpelund et al., 2012). Language problems often result in poor knowledge of health issues and the health care system, as well as miscommunication between patients and caregivers, which in turn lead to delay in diagnosis, errors in diagnoses and treatment regimens, poor adherence, misunderstandings, failure to attend important appointments, dissatisfaction with care, reluctance to seek care and inappropriate use of available services (Goth and Berg, 2011, Greena et al., 2006, Pergert, 2008, Svenberg, 2011).

### **Cultural diversity: a source of misunderstandings**

This study illustrated moreover, that communication was not just about speaking different languages. As argued in many studies even with accurate translation, communication problems persist in cross-cultural medical encounters (Jensen et al., 2013, Goth and Berg, 2011, Greena et al., 2006, Hadziabdic et al., 2010, Pergert, 2008, Shahnavaz and Ekblad, 2007, Svenberg, 2011). It was also obvious in this study that language fuelled communication problems that stemmed from migrants' socio-cultural backgrounds such as low educational level, poor health literacy, past trauma and previous experience with care, but also from the differences in values and beliefs between patients and their caregivers. Apart from linguistic barriers, Schouten and Meeuwesen (2006) identify four more predictors of culture-related communication problems in their literature review. These include cultural differences in explanatory models of health and illness, differences in cultural values, cultural differences in patients' preferences for doctor-patient relationships, racism and perpetual bias (Schouten and Meeuwesen, 2006). Likewise, this study indicated that communication problems actually stemmed from differences in educational levels, religious beliefs, different cultural values and approaches to health and care practices, and in particular the conception of the authority and the roles of different clinicians that often resulted in divergent expectations about care and often led to misunderstandings. Other studies have also reported tensions that often arise in cross-cultural medical encounters when patients' beliefs and values differ from those of caregivers, or when caregivers' lack of understanding of patients' culture and spirituality challenge the ways care is provided (Jensen et al., 2013, Greena et al., 2006, Pergert, 2008, Shahnavaz and Ekblad, 2007, Svenberg, 2011). Equally, tensions described in this study were said to be due to cultural and religious rules and practices that were at odds with Swedish guidelines and standards and that affect provision of care and compliance with treatment. For instance, while the caregivers perceived themselves as neutral and professional, migrant women did not trust them because of cultural rules

prohibiting them from being treated by male caregivers. Although emphasising cultural differences is believed to result in stereotypes, the tendency of health care professionals to represent themselves as neutral has also been criticised and is said to result in a culture-blind and ethnocentric approach (Beagan and Kumas-Tan, 2009, Shahnavaaz and Ekblad, 2007). The focus on cultural characteristics has also been criticised because it overlooks the complexity of perspectives and behaviours that exist within diverse ethnic groups due to varied social origins, behavioural inclinations and exposure to different experiences (Koehn, 2006, Shahnavaaz and Ekblad, 2007).

Gender segregation issues have been discussed in others studies, which have also shown that preference for providers of the same sex was more common among Muslim women than women with other religious backgrounds (Feldmann, 2006, Goth and Berg, 2011, Svenberg, 2011). However, some researchers have warned against simplistic generalisations about gender preferences in care. There are contrary opinions that sex preference might not be necessarily based on religious conviction; their recommendation is that caregivers should approach these patients individually and ask them openly and respectfully about their preferences, which according to them might clear the atmosphere and allow good communication (Feldmann, 2006). This might be possible in Sweden, but migrants are often unaware of their rights. Another source of tension was the cultural rules that dictated who within the family should receive medical information, since this was in contradiction to the Swedish guidelines that stipulate the caregiver should only talk to the patient directly. Tensions often arose when men wanted to act on behalf of the family and involved themselves in the care of their spouses or children. In this study, it is argued that this was a way for men to control their partners and limit their access to information. A gender inequality in access to information between boys and girls was also reported. Inequitable access to health care and health information for women and girls has been identified as a strong driver of the HIV/AIDS and TB epidemics (Maman and Medley, 2003).

Competing religious beliefs and practices were said to interfere with care and resulted in poor adherence to treatment. For instance, fasting and beliefs in super natural or spiritual healing were believed to result in poor compliance and discontinuation of treatment that could be fatal in some cases. A previous study about the influence of religion on HIV prevention activities among Africans in Sweden suggested that religion could impede preventative work through faith and beliefs that it is fate or God who determines who should get infected with HIV, and that HIV is a punishment for sins. In addition, the importance of children and family among Africans prevented condom use and thus increased vulnerability to HIV (Steel et al., 2002). Other studies have also emphasised the role of religion in HIV/AIDS care and prevention. However, some studies

have suggested that most people suffering from chronic diseases, as well as those living with HIV/AIDS, use religion to cope with their illness (Cotton et al., 2006, Pergert, 2008, Svenberg, 2011). It is, however, also emphasised that, like understandings of and responses to health and illness, care delivery is also culturally determined because it is provided according to the Western bio-medical paradigm that does not always fit migrants' belief systems (Beagan and Kumas-Tan, 2009). This mismatch between belief systems is considered to be a cause of misunderstanding that leads to dissatisfaction with the medical encounter for both patients and caregivers. Another study found that patients' ethnicity affects physician satisfaction with clinical encounters, particularly in the delivery of preventative care and chronic disease management (Kamath et al., 2003). Nevertheless, cultural and/or ethnic differences might be used as an excuse for care providers who failed to communicate with patients and provide adequate care (Jirwe et al., 2010, Shahnavaz and Ekblad, 2007). Likewise, communication problems described in this study might as well express uncertainty due to lack of training and routines in caring for patients with diverse backgrounds that result in a struggle about how best to address diversity. Participants in this study stressed the need to improve caregivers understanding of migrant issues and diseases such as HIV/AIDS and TB that affect migrants most. Moreover, the screening staff explained that they lack appropriate training and thus, felt uncomfortable to take medical history about sexual health. This may prevent them from identifying and discussing sexual risk behaviours with migrants, or delivering appropriate prevention messages.

### **Socio-demographic differences: a source of uncertainty**

The complex interaction between socio-demographic factors such as geographical origin, sex, age and, levels of education, knowledge, attitudes and behaviours, was also a source of uncertainty that challenged the caregivers in their attempt to understand and care for migrant patients. The heterogeneity of migrants who participated in the survey study generated intergroup and intragroup variations that resulted in discrepancies in perceptions and attitudes towards HIV/AIDS and TB due to the factors identified above. Furthermore, the caregivers stressed that, even when people originated from the same country, they had different perspectives and attitudes towards health issues based on their educational background or past experiences. Except for migrants from the Middle East, the survey results also showed that educational level was a better predictor of knowledge and attitudes than was geographical origin. Therefore, it was difficult for caregivers to know how much an individual knew in order to adapt health information to match the patient. However, the way the information is made available in Sweden, it seems it is taken for granted that everyone can access, read and process it. The lack of association between knowledge level and undergoing medical screening or having received HIV/AIDS or TB information in Sweden reported in the survey study is an indication that migrants face

problems in accessing available information. Although medical screening offers an opportunity for health education, it appeared that caregivers had failed to make the most of it in this regard. This could partly be explained by the overwhelming time pressure reported by the screening staff, or the way in which the information was provided, which made it inaccessible, incomprehensible and unacceptable to migrants. Ensuring that necessary information is both available and understood by diverse communities is important especially for communicable diseases of public health significance such as HIV and TB that are regulated by law and thus involve legal consequences.

The caregivers also felt powerless when poor education was coupled with misconceptions about health issues and limited knowledge of available services, which resulted in divergent expectations about care. Although better knowledge does not necessarily lead to behavioural change, basic knowledge is an essential prerequisite to good communication, early diagnosis, treatment and prevention. This study identified a positive relationship between a high level of education and health knowledge and positive attitudes towards HIV/AIDS and TB and those affected by them. In contrast, the negative attitudes, low risk perception, and fear of deportation and disclosure reported in this study were associated with a low level of education and misconceptions, and were described as impediments for testing, care, prevention and management of HIV/AIDS and TB in migrants. A study of African migrants living in Sweden concluded that low educational level was associated with multiple sex partners, while poor knowledge about HIV was associated with a high number of occasional or casual sex partners (Steel et al., 2004). Knowing what causes a disease and how it is transmitted may increase awareness and improve attitudes towards the disease and those affected by it. Moreover, knowing where to get tested and that a positive test result does not lead to deportation may positively impact on willingness to seek care and contribute to early diagnosis and treatment that could help stop further transmission. Finally, knowing the difference between an infection and a disease, or that one can be infected/infectious even in the absence of symptoms, may help avoid denial of diagnosis, late presentation and legal consequences, and actually improve adherence to treatment of latent infections and compliance with preventive measures. Late presentation has often been reported among some migrant groups diagnosed with HIV/AIDS (Arco et al., 2012, ECDC, 2011, Venters and Gany, 2011). In Sweden, 60% of all HIV/AIDS cases reported in 2011 were diagnosed at a late stage, when the infection has already had such an impact on the immune system that HIV treatment was immediately recommended. Although late diagnosis also occurred among native Swedes, the majority of those diagnosed late were immigrants who had been infected heterosexually before they moved to Sweden (Smittskyddsinstytutet, 2011).

**Discrimination and stigma: barriers to access and delivery of care**

The Oxford English Dictionary defines discrimination as “the practice of treating a person or a particular group in society less fairly than others especially on the ground of race, sex, age or ethnicity” (Hornby, 2003). Discrimination may also be a consequence of stigma related to conditions such as HIV/AIDS or TB. Stigma is described as an attribute associated with a particular illness or behaviour that significantly ‘discredits’ an individual in the eyes of others within particular culture and setting (Policy Project, 2003). As a result, people may express negative attitudes towards such individuals or may discriminate against them by treating them differently. Stigma may have different consequences depending on whether it manifests itself internally or externally. External stigma refers to actual experience of discrimination whereas internal stigma is the shame associated with the attribute (HIV/AIDS or TB in this case) and the affected individual’s fear of being discriminated against (Policy Project, 2003). Discrimination is described as a key issue in understanding problems associated with diversity and may be manifested at different levels within a society including, at the individual, institutional and structural levels (Pincus, 2000). Thus HIV/AIDS- and TB-related stigma and discrimination associated with migrants is often overlaid upon existing social inequalities, and produces and reproduces relations of power and control in social systems and manifests itself at all levels in the society (Logie et al., 2013, Policy Project, 2003). Because both HIV/AIDS and TB are stigmatised conditions, having such a condition and being a migrant becomes, therefore, a dual ‘misfortune’ that may result in greater marginalisation and discrimination.

In this study, migrants represented the non-dominant group or a minority group because they lack power in Swedish society and do not control social institutions as they are not often involved in decision and policy-making (ECDC, 2009b, Pincus, 2000). Discrimination against migrants and those affected by health conditions of public health significance was identified at all three levels in this study, and it has the potential to jeopardise HIV/AIDS and TB care, prevention and control. At the individual level, there were accounts of negative attitudes towards migrants among caregivers because of their HIV/AIDS status, or because of the high prevalence of HIV/AIDS and TB in their countries of origin, particularly among those working outside of infectious disease clinics. This may result in mistrust of caregivers, reluctance to get tested or to seek care, denial of diagnosis and an increased risk of poor adherence to treatment regimens. However, the negative attitudes towards HIV/AIDS and TB and those affected that were reported among migrant language students imply that those affected by these two diseases could isolate themselves due to fear of stigma and discrimination from their own community members. Other studies have revealed that both HIV and TB were associated with high levels of stigma as well as a reluctance to seek both screening and care among certain migrant groups (Arco

et al., 2012, ECDC, 2011, Venters and Gany, 2011). Moreover, the caregivers interviewed in this study reported a constant fear among migrant patients of being seen at infectious disease clinics. Migrants may refrain from seeking care or attending important appointments out of fear of being identified and exposed to stigma and discrimination from fellow community members. This could also explain the mistrust of interpreters within their own communities, who they suspected might disclose their status to others. Evidence suggests that stigma and discrimination increase the vulnerability of migrants to HIV/AIDS and TB by increasing social isolation, hampering access to prevention and testing services and constituting barriers to treatment, care and support for those affected (Arco et al., 2012, ECDC, 2009b, ECDC, 2011, Logie et al., 2013).

It was found that institutional discrimination includes policies and laws that reinforce prejudices against migrants and prevent them from accessing available services and receiving appropriate care. There was a general perception in this study that the Swedish policies regulating entitlement to care for migrants conflicted with medical ethics (which is to provide care to all regardless of individual socio-demographic characteristics) and reinforced migrants' precarious access to health care and public services. The caregivers in this study were frustrated over these institutional policies and tried to circumvent them as they believed they violated migrants' basic rights and constituted an ethical dilemma in their profession. They were frustrated at having to be the ones to determine who was entitled to care or not. This was also illustrated in another study in Denmark (Jensen et al., 2011). In addition, it was also suggested in this study that some caregivers faced difficulties in distinguishing different categories of migrants and their entitlement to care. The caregivers were, for instance, frustrated to see asylum seekers who live below the subsistence level being required to pay when they received services to which they were not freely entitled according to the law. They also argued that undocumented migrants might refrain from seeking care because they had to disclose their status at the reception desk, which may prevent them from receiving adequate medical attention in due time. This problem is not unique to Sweden, as it has also been reported in other high-income countries that are trying to control the movement of foreign-born people across their national borders (Magalhaes et al., 2010, Rousseau et al., 2008, WHO, 2010, Arco et al., 2012, ECDC, 2011, Jensen et al., 2011). Even though the Swedish Communicable Disease Act gives asylum seekers and undocumented migrants, the right to be treated free of charge for communicable diseases of public health significance such as HIV/AIDS and TB, the survey results suggested that most migrants are unaware of this act and its implications (Government Offices of Sweden, 2004). In addition, fear of deportation may prevent undocumented migrants from seeking care. The recent recommendation from the government to remove all illegal migrants from Sweden, which allows the police to search for them in public places, adds to the problem because it will prevent these people

from accessing treatment made available by non-governmental organisations (Lindberg, 2013). Compliance with treatment regimens is an integral factor in the success of both TB treatment and antiretroviral therapy. Discontinuation of treatment increases the risk of development of drug resistance, thereby reducing treatment options not only for the individuals, but also for other people that they might subsequently infect. Migrants who are sent back home after starting treatment in Sweden carry the potential to fuel global epidemics with drug-resistant strains because access and treatment options are often limited in their home countries. Moreover, the fact that some migrants have been sentenced to deportation for intentionally transmitting HIV to other persons may reinforce the belief that a positive test may lead to deportation (Åberg, 2011). All these factors may delay care and increase the severity of the disease, lead to mortality and, in some cases, perpetuate transmission and contribute to the proliferation of drug resistant strains.

Other regulations, such as those of the National Board of Health and Welfare that regulate screening of HIV and TB targeting migrants, may heighten misconceptions and prejudices against migrants among care providers and the wider society (ECDC, 2009a, ECDC, 2009b, Socialstyrelsen, 2011). The selective screening policy that focuses on infectious diseases among migrants from specific countries was reported to potentially reinforce discrimination against migrants both within and outside the health care setting. These laws and policies might actually exacerbate discrimination against migrants, particularly against those from the so-called 'high-risk countries' as they might be perceived as a danger or threat to public health. On the other hand, despite evidence that Swedish residents who travel to such countries are also at increased risk of HIV infection, they are not systematically offered medical screening when they return home. A recent article in a newspaper reported a conflict between the school authorities and one of Västerbotten county's municipalities, following an anonymous complaint about the requirement for children from some countries to be screened before starting school. In the complaint, it was argued that the screening was voluntary and that the health care staff was bound by secrecy, and thus did not have the right to disclose children's health status to the staff at schools. In its response to the school authorities, the municipality referred to a case where a child started school before being screened, but happened to have an infectious disease that was transmitted to other children. This led to mass-vaccination and anger among parents. According to the school authorities, all children have the right to attend school, regardless of whether they undergo medical screening or not (Wallin and Johansson, 2011.). Apparently, the school authorities acted out of fear of infection and not in accordance with the law. The main issue here is that medical screening might be perceived as an excuse for discriminating against children from specific countries. This confusion illustrates misperceptions of the goals of medical screening and a lack

of standardisation in policies that apply to migrant populations. As a result, the motives for screening might be questioned if they give the impression that they are being used for furthering unrelated goals; their effectiveness will be compromised as a consequence.

Another policy that negatively affects migrants is the housing and dispersal policy for asylum seekers. For instance, the housing policy for asylum seekers leads to overcrowded conditions with an increased risk of transmission of communicable diseases such as TB. The outbreak of TB that was reported at one reception centre for asylum seekers is illustrative of how migration policies can conflict with public health goals (Strand and Åkerlind, 2010). The housing policy also exposed HIV/AIDS and TB patients to stigmatisation and discrimination from within their own communities as sharing accommodation often results in forced disclosure of their health status. This can lead to poor compliance with treatment regimens, as those affected try to hide drugs to avoid disclosure of their TB or HIV status. Moreover, it was also emphasised that the dispersal policy often resulted in the Migration Board housing asylum seekers far from health care facilities, thus compromising the management of HIV/AIDS and tuberculosis care among migrants. Another challenge related to migration housing policy was the difficulty of reaching migrants when the Migration Board moved asylum seekers from one place to another without notifying the caregivers. In some cases they refused to disclose details, arguing they were bound by secrecy. This was said to negatively impact care delivery and access, and delay diagnosis and care, which resulted in inadequate treatment, poor follow-up and compliance, as well as increased morbidity and risk of drug resistance.

At the structural level, the use of the Swedish language and distant communication technology within the health care setting are good examples of policies that are intended to be neutral, but which have a differential and/or harmful effect on migrants in terms of unequal access to, and use of, care services. Despite being modernised, the Swedish health care system might actually be inaccessible to migrants with limited language, and computer literacy skills. These are substantial barriers to access screening and care services, as well as the support services provided through hotlines for people living with HIV/AIDS. For instance, the invitation letters for screening and most of the other correspondence from caregivers are often written in Swedish. The caregivers who participated in this study acknowledged that this practice was wrong, but surprisingly they argued that migrants could rely on friends or people from their country to read the letters. However, as indicated above, relying on friends or people from their own country sometimes resulted in disclosure of sensitive information related to individual health status that, in cases of HIV/AIDS and TB, subsequently exposed affected persons to stigmatisation and discrimination. Migrants might also fail to grasp the meaning of the letter by themselves due to



poor literacy skills. Or they might also be confused by conflicting accounts from friends and others helping them to read, thus missing important appointments and information. At the same time, they might be unable to call and check with caregivers, as caregivers are only available on the telephone at restricted times or via the internet. All these factors may result in failure to attend important appointments, including screening and follow up appointments, errors in treatment and social isolation. Missing appointments also often involves costs for the health care system, especially when interpreters are involved, which may fuel negative attitudes towards migrants as they might be perceived as an economic burden for the health care system.

### **Low interest in migrant/diversity issues: a barrier to advocacy, policy development and capacity building**

The current legislation is not adapted to the challenges of an increasingly multicultural society. The current economic crisis forces many receiving countries, including Sweden towards restrictive policies (IOM, 2010, WHO, 2010). Within the health care system, the current policy framework for healthcare provision results in legal paradoxes, conflicting with the ultimate goal to ensure “the entire population a good health care on equal terms”. The systematic control of migration within the country, through the personal identity number, makes it difficult for undocumented migrants or failed asylum seekers to access health care services (Cuadra, 2010). As a result, the responsibility of providing care to undocumented migrants falls on a few NGO’s and advocacy groups that are willing to fight for the rights of this vulnerable group to access good health care. Such initiatives to advocate for access to care for undocumented migrants are limited and vary from one county to another (Cuadra, 2010).

Despite some attempts to make the health care system more culturally sensitive through initiatives such as language assistance, the promotion of multicultural staff, as well as the integration of migrant issues in the medical education curriculum, this study shows that there is still room for more improvement (Cuadra, 2010). For instance, provision of language assistance alone does not guarantee the availability and quality of interpreters. Most of the challenges identified in this study underscore the need for changes in approach to migrant issues as well as new policies and legal frameworks. In addition, the paucity of data also makes it difficult to identify migrants’ health and care needs and adapt interventions and policies to adequately meet them. According to a 2009 ECDC report, migration and HIV issues are given either low or no priority at all on the agenda of many EU states members (ECDC, 2009b). Equally, in this study, the caregivers depicted migrant care as characterized by shortage of staff and time, and a lack of training and national guidelines, which often resulted in different routines and practices within and between counties. Lack of culturally sensitive information in relevant languages, suitably trained

professionals and services tailored to the specific needs of migrants were identified in the ECDC reports as barriers to HIV/AIDS testing, prevention, care and support among migrants in the EU member states) (ECDC, 2011, ECDC, 2009b). The low interest in migrant issues among political leaders or policy makers may lead to misconceptions about migrants among caregivers, and to a low interest in advocating for them (Arco et al., 2012). Furthermore, concerns about social cohesion were described as the underlying cause of reluctance to fund specific services for migrants (ECDC, 2009b). Similarly, in this study the closure of migrant screening clinics was justified by concerns about social cohesion. However, the integration of screening units in mainstream primary care centres has worsened the working conditions for screening staff, imposing a heavy workload, resulting in poor quality of care and long waiting times for screening and the subsequent delays in care and prevention.

### **Finding opportunities: implications**

#### **Accommodating diversity or the special needs of migrant groups**

In order to remove barriers to good communication between migrants and caregivers, there is a need to improve caregivers' cultural competence and skills in identifying the special circumstances surrounding and defining individual care needs as well as the medical encounter (Betancourt et al., 2005, Devillé et al., 2011, Koehn, 2006, Shahnavaaz and Ekblad, 2007, WHO, 2010). Cultural competence is regarded as the ability for caregivers to identify and challenge their own cultural assumptions, values and beliefs and to incorporate relevant knowledge and interpersonal skills related to the care of patients from different cultural backgrounds (Betancourt et al., 2005, WHO, 2010). This implies more than cultural awareness or sensitivity, since it involves action and accountability, whereas being aware or sensitive to cultural differences does not necessarily guarantee changes in clinical practice (Stewart, 2006). Another aspect of cultural competence is the notion of reciprocity, which emphasises a two-sided learning process between care providers and migrants to develop cultural competence. With this perspective, the views of migrants are not ignored; rather, they are treated as an essential source of expertise and experiential insight (Betancourt et al., 2005, Koehn, 2006, Shahnavaaz and Ekblad, 2007).

On the other hand, there is a need to improve migrants' health literacy through health education to avoid misunderstandings like those described in this study. According to the Swedish National Board of Health and Welfare's guidelines, migrants should be informed about their rights and the functioning of the health care system during the screening consultation (Socialstyrelsen, 2011). However, the overwhelming time pressure described by the screening staff makes it difficult, if not impossible, to provide this information during this one-off occasion. Furthermore, the problematic collaboration between health care services and the Migration Board due to conflicting interests also adds to

the problems. The Migration Board staff expected to provide information about the offer of screening might not really understand the goals of screening. This emphasises the need to strengthen collaboration between these two services through the continuing education of both migration and care staff to deal with the misunderstandings that affect care delivery and use. Alternative ways of providing timely health information and health education to migrants should be reinforced and standardised. Initiatives such as outreach interventions involving care providers, trained interpreters and migrant health professionals in group sessions with migrants sharing a common language, at venues such as Swedish language schools, churches, migrant associations or NGO's supporting migrants should be promoted. In addition, health education and health promotion messages should take into account the heterogeneity of migrant groups and their cultural diversity, and adapt education material accordingly (Devillé et al., 2011, WHO, 2010). For instance, if websites and written information are adapted for the highly educated, visual materials may be used for the low educated. Group sessions are preferable for the low educated as the group dynamic might allow discussions that can help clear up misconceptions.

At the institutional level, there is also a need for policies that emphasise health services, responsiveness to the needs of diverse patients in order to provide equal access to equal care. For instance, addressing issues related to the unavailability and lack of competence of interpreters may help improve access and quality of care. Other options, such as the use of on-site interpreters within health care settings, should be evaluated. Caregivers' uncertainty, and divergent views regarding the use of family members as interpreters, indicated a lack of clear guidelines. Moreover, the issue of interpreters' competence needs to be looked into. The interpreters' agencies should not only guarantee to make interpreters available, but they should also guarantee their competence.

It should, however, be pointed out that the findings from this project are being used for improving the medical screening of migrants through continuing education of the screening staff in northern Sweden in collaboration with the Northern HIV/STI's knowledge network. It is only fair to mention that the knowledge and awareness about caring for patients from different cultural backgrounds have increased considerably within the network.

### **Changing paradigms: are migrants a risk or at risk?**

At the societal level, there is a lot of misinformation, misunderstanding and stigmatisation around the issues of migration, HIV/AIDS and TB that reflect the myths surrounding migration, which fuel discrimination and bolster xenophobia (Arco et al., 2012, UNFPA, 2006, WHO, 2010). Migration is a sensitive issue in most host countries, where migrants are often presented as a threat or risk to cultural integrity, national identity and physical security (crime, economic

burden for the welfare system) and public health (disease) and potentially to the future of host nations (IOM, 2010, Marrujo, 2003, WHO, 2010). From this perspective, host countries become victims of the danger that migrants represent and adopt restrictive policies to protect national interests (IOM, 2010, UNFPA, 2006, WHO, 2010). In this case, it is about protecting residents against the economic burden of migrants and the threat of communicable diseases such as HIV/AIDS, TB, hepatitis and other infections identified as threat to public health. Similarly, the caregivers explained that medical screening mainly focuses on infectious diseases rather than individual needs. This view is common in most high-income countries and justifies the selective screening that focuses on infectious diseases by classifying certain infectious diseases as ‘public health threats’ and targeting migrants from countries with high prevalences of these diseases (IOM, 2010, UNFPA, 2006, WHO, 2010). From an epidemiological perspective, it is likely that the prevalence of these diseases among migrants will be high because they have been exposed to greater risk in their home countries as illustrated by the number of cases that are being diagnosed in many high-income countries (Arco et al., 2012, ECDC, 2011, Gushulak et al., 2010, UNFPA, 2006, WHO, 2010). However, it is also argued that migrants are overrepresented among estimated cases in host countries because they are more tested than native people (UNFPA, 2006). In addition, there is evidence even in Sweden that in some cases infection occurred after migration and in other cases it is difficult to determine if the infection occurred before migration, in the host country or during a return visit (ECDC, 2011, Strand and Åkerlind, 2010, UNFPA, 2006). Despite this opponents of migration sometimes blame migrants for bringing dangerous diseases to the host country (UNFPA, 2006). Paradoxically, the same people identified as high-risk groups are exposed to conditions that can increase the risk of transmission and result in more cases through restrictive policies (entitlement, housing) that are aimed at making migration unattractive. This conflation of migration control and infectious disease control is counterproductive for public health goals at both national and global levels (Gushulak et al., 2010, WHO, 2010).

Despite stereotypes and widely held beliefs, neither migrants nor migration increases the risks of HIV transmission. Rather, it is the conditions and hardship associated, with migration that make migrants vulnerable to HIV infection. Migrants are at risk of poor health in general, and are particularly at risk of HIV and TB because they frequently confront social deprivations (isolation, marginalisation, segregation, and discrimination), health risks along with barriers (linguistic, cultural, legal) to accessing healthcare and social services in host countries, all of which are associated with increased susceptibility to and spread of both communicable and non-communicable diseases (Arco et al., 2012, ECDC, 2011, Figueroa-Munoz and Ramon-Pardo, 2008, Koehn, 2006, UNFPA, 2006, WHO, 2010). Thus, migrants are *at risk* and not *a risk*.

Consequently, there is a need to promote a change in thinking and approach to migration, and to infectious diseases of public health significance in general, in order to address the specific vulnerabilities of people on the move. Policy-makers in host countries need to revisit existing policies and establish new policies that will benefit migrants, the health care system and the host society as a whole (Arco et al., 2012, Devillé et al., 2011, Gushulak et al., 2010, WHO, 2010). This approach should emphasize this vulnerability, as opposed to the disease threat framework that has been traditionally used, which often results in a mismatch between people's needs and the available facilities. This view situates migrant care within the framework of human rights and focuses on the complex and multiple factors that increase the vulnerability of migrants and avoids the dichotomies that often arise in discourses that present migrants as a risk or threat (Marrujo, 2003, WHO, 2010). From this perspective, population movement is looked at through the lens of human rights beyond the boundaries of a country and considers human beings as equal. Changing the paradigm will not only benefit migrants, but also host societies as it will result in a successful integration of migrants and an improvement in public opinion towards migrants. Finally, in terms of public health, a human rights perspective results in early diagnosis and treatment of all potential cases of communicable infections, as well as the mitigation of transmission and advanced disease, and its subsequent costs (WHO, 2010).

### **Conclusions**

The current demographic statistics show that the Swedish population comprises people from almost 200 countries with different backgrounds and languages. This trend is expected to continue over the next decades. The changing demography and increasing population diversity generate complex challenges, including how to provide care services that are responsive to the needs of this diverse population. The first step in meeting these challenges is identifying them and understanding how they interact with care provision and use. This thesis identifies multiple challenges and illustrates their complexities and influences on the provision and use of appropriate, timely, high-quality care and prevention services. These challenges include language barriers and the diversity in socio-cultural backgrounds among and between migrants and caregivers that result in different perspectives on and expectations of health and medical care, which may lead to poorer quality of care and health outcomes. The use of distant communication technology within the health care system may impede access to and delivery of care and prevention services. Caregivers and migrants are also faced with conflicting policies and regulations to control both migration and infectious diseases.

These findings emphasise the need for multi-level strategies in order to remove identified barriers at all levels (individual, interpersonal, institutional,

political and societal) and replace the current exclusionary and one-size-fits-all approach with a system more responsive to individual needs. This requires accommodating diversity by improving care providers' cultural competence and migrants' health literacy. It further requires policies and practices that emphasise health services, responsiveness to the needs of patients with diverse socio-cultural backgrounds in order to provide equal access and equitable care. Finally, it entails revisiting existing policies and legislative frameworks to promote a change in ways of thinking about and approaching migration, and infectious diseases of public health significance in order to address the specific vulnerabilities of mobile populations in a world on the move. Achieving the above could improve communication between migrants and caregivers and thus reduce delays in seeking care, diagnosis and treatment, which may result in better compliance with treatment regimens, better attendance at screenings or follow-up appointments and more satisfied users and providers. Conversely, failure to do so may have significant social and health consequences for migrant groups in particular and the society as a whole.

### **Suggestions for future research**

1. Study of health and risk factors among migrants to identify the health and care needs of different groups.
2. Study of migrants' access to and perceptions about the health care system: although we could assess migrants' knowledge and attitudes in this study, it is important to investigate issues of access and use from the perspectives of those migrants who seek and receive care. There is a need for surveys and qualitative studies on migrants' use and satisfaction with health care to facilitate improvement.
3. Study of interpreters' experiences within the health care setting: it is important to hear the voice of the people who serve as interpreters for migrants and caregivers to better understand the issues that arise during the medical encounters.
4. Study to evaluate the efficacy of medical screening: it is important to know how effective medical screening is used as a tool for early diagnosis, care and prevention.
5. Outreach interventions that aim to improve health literacy need to be evaluated

## Acknowledgements

I wish to express my sincere gratitude to all those who in one way or another contributed to the accomplishment of this thesis. My deepest gratitude goes first and foremost to the Lord Almighty, for blessing me in so many ways, guiding me and always giving me the strength to face improbable events. My gratitude also goes to our pastor Håkan Gabrielsson and his family, and the big family of Bjökstakyrkan in Umeå who have supported me with prayers that have enabled me to face and overcome various difficulties.

I am also deeply indebted to all participants and representatives for their invaluable contribution without which this project would not have been possible. My gratitude also goes to all funding bodies that showed interest in this work through financial support: The Swedish Institute for Infectious Disease Control (SMI) (Grant number 640/2010/183), The European Refugee Fund (Grant number E85-292:51-2011- 12792) and The Swedish Council for Working Life and Social Research (FAS) within the Center for Global Health Research (Grant number 2006–1512), The Regional Federation of Northern County Councils (Visare Norr), The Medical Faculty of Umeå University and the County Council of Västerbotten.

Special thanks go to the “Kunskapsnätverk HIV/STI Norr”: Annika Nordstrand, Eva-Britt Carlsten, Anna- Karin and all the nurses within the network. I appreciated your support and collaboration. We learned together.

I would like to express my sincere gratitude to my supervisors, Prof. Anna-Karin Hurtig, Beth Maina Ahlberg, Clas Ahlm and Ingela Krantz for their valuable advices, guidances and encouragement throughout the course of this work. Together, they have taken much trouble and a lot of their private time for my sake by going through the drafts in order to bring the thesis to what it has become. Without all their support and consideration, this thesis would not have reached its completion.

I am equally grateful to all the staff of the division of Epidemiology and Global Health for their support and assistance in diverse ways, which have contributed immensely to the completion of this thesis. Special thanks go to Professor Stig Wall, who believed in my capacity and supported me in my ambition. Thanks also go to Professors Lars Weinehall and Elleinor Ädelroth for the stimulating work environment and support, and for giving me the opportunity to carry out my research project. Special thanks go to my roommates, Fredrik, Ann, Lena and Elisabeth for their support and encouragement during the tough time. I would also like to express my thanks to the administrative staff for their assis-

tance and support during my time as a student at the unit. Special thanks go to Birgitta, Karin and Lena. My gratitude is extended to the PhD students for their company and support. I wish you all the best.

Thank you to Sonja Nordström for the splendid work you did in editing, formatting and giving this work a “face”.

I am greatly indebted to the support and legal assistance provided by Lena Isaksson to my family. It was a great help in a most difficult time and it came just when we needed it most.

I am also very thankful to my friends Tatiana Igiraneza, Åsa Nordberg, Betty Lizwa, Vicky Kobota and all of you that I have not mentioned for your support and encouragement. Besides, I am grateful to my cousin Danny Mwepu who always believed in my capacity to achieve this work and encouraged me.

A special gratitude and love goes to my beloved mother, the woman who inspired me a lot and whose belief in my ability encouraged me to overcome obstacles and continue to reach the best. Special thanks and love also go to my brothers, sisters and my in-laws for your unconditional love and support and for looking after my children in my absence. I am deeply appreciative for the love and support provided by my sisters Marie Claire Nkulu, Mady Nkulu, Solange Nkulu and Brigitte Tshibangu and my brothers Jean Marc Kasongo Nkulu, Jacques Ilunga and Abbé Kasongo Mbuyu.

Thanks to Franck who was watching me while I was working. You do no longer need to worry, I have survived.

I want to sincerely express my gratitude to Raoul. Words will not be enough to express my gratitude. Thank you for motivating and supporting me through the difficult times. It is your love and support that have always encouraged me to stick on to this work. You gave me hope when I thought hope was gone.

Lastly, I wish to convey my everlasting love and special thanks to my beloved children: Kevin (my beloved), Mike (my guardian angel) and Tracy (my trace) whose patient love has enabled me to complete this work. They have tolerated my absence and showed understanding and love. I must say to them: I did it for you because I love you.



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