

How do Filipino au pairs mobilize a support system when becoming ill and undergoing treatment for tuberculosis (TB) in Norway?

The story of their rights, relations and illness experience.

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Tittel How do Filipino au pairs mobilize a support system when becoming ill and undergoing treatment for tuberculosis (TB) in Norway? The story of their rights, relations and illness experience.

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Abstract

Title: How do Filipino au pairs mobilize a support system when becoming ill and undergoing treatment for tuberculosis (TB) in Norway? The story of their rights, relations and illness experience.

Background: There has been an increase in au pairs from the Philippines with TB registered in Norway. The study's objective is to investigate 1) how this patient group is managing their TB treatment, 2) how the disease influences the host families they live with and 3) the relationship between au pairs and host families.

Design/Methods: The study is conducted over a two-year period. Methods include qualitative research methods in the form of semi-structured in-depth interviews, participant observation, questionnaires, group discussions, focus-groups and informal conversations.

Results: The study follows 5 au pairs undergoing TB treatment, their host families, health care workers, and NGOs. The au pair visa requires that they live with a host family as a culture exchange and perform household chores and child care for housing, food and a small salary. They are particularly vulnerable because their visa, social network in Norway, living arrangements and salary are all connected to their host family and the role they have as an au pair. Au pairs draw on multiple resources and negotiate their health and legal status in a precarious situation. They are followed up closely by health care workers, but cultural differences and misunderstanding when communicating seem to influence illness management. Middle class host families and au pairs often have diverging expectations to each other regarding the au pairs role and they often face social stigma around TB. While the stigma and illness management may strengthen ties between them, some au pairs also have their contract terminated due to the diagnosis.

Conclusions: The immigration status of au pairs determines their rights. Findings indicate that legal rights and status could be strengthened to ensure successful treatment. The information given to host families can be improved to avoid tensions, and to au pairs so that they understand and manage their illness better. Thus, the combination of this disease and au pair regulations has serious consequences for the au pairs, but also impacts on their host families and the relationship between them.

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Definitions and List of abbreviations

CDC	Centre for Disease Control (USA)
DOT	Directly Observed Treatment
DOTS	Directly Observed Treatment, Short course
EN	Enrolled Nurse
GP	General Practitioner
HCW	Health Care Worker
IGRA	Interferon-Gamma Release Assays (Blood test to diagnose TB infection)
IUATLD	International Union against Tuberculosis and Lung Disease
LHLi	Landsforeningen for Hjerte og Lungesyke; LHL International
LTBI	Latent Tuberculosis Infection
MDR TB	Multi Drug Resistance Tuberculosis
M. tuberculosis	Mycobacterium tuberculosis
NAV	Norges Arbeids- og Velferdsetat= Norwegian Labour and Welfare Service
NIPH (FHI)	Norwegian Institute of Public Health (Folkehelseinstituttet)
SSB	Statistisk Sentral Byrå= Statistics Norway
RN	Registered Nurse
TB	Tuberculosis
UDI	Utlendingsdirektoratet = The Norwegian Directorate of Immigration
WHO	World Health Organization

Introduction

I will start with an ethnographic example to illustrate how vulnerable the au pair is in the first meeting with the tuberculosis (TB) diagnose. This first chapter is an introduction to learn about the complexity surrounding the sick au pair and her host family. The au pairs are young people in a new country, they are often away from the protection of home for the first time and they have little or no social network on arrival in Norway. Their visa is linked to having a host family whom are supposed to treat them as part of their family. When becoming ill with a contagious disease like TB which comes with isolation, stigma, long treatment and physical and social strain this support is important and influence the way they cope with their disease. The chapter will explain my personal motivation for this study and introduce my research questions. Then the chapter will give background information and facts about TB. It will start with a short history of TB with focus on stigma, TB prevalence, explaining the disease and the system that regulates it. Since the system that screen, diagnose and treat TB is very complex I will give a short explanation of this to understand how this influence patients illness management. Then I will end the chapter by explaining the au pair program, history, prevalence and regulations.

An Ethnographic Example

A¹ young girl is admitted to hospital, isolated at the medical ward for infectious diseases. After dressing up in yellow clothes, gloves and facemask walking in through the locked door I meet a thin, pale girl that seems scared about the whole experience. She is in her twenties, from the Philippines, working as an au pair. She came directly from the Philippines to Norway, and has lived with the host family for about two weeks. She claims she has not felt ill, only had a slight cough and been a bit more tired than usual. She is worried about what her host family will say, and what will happen to the small children she has been caring for- has she infected them?

The host dad is furious! I try to calm him down on the phone; I have had many of these conversations before. He claims the au pair is “not trustworthy”, “she should have known she was sick” and “she has deceived us”. He says he does not want her to return to his family, because “she has ruined their life” and “his wife is only crying”. I keep trying to

¹ When writing the quotes I have decided to keep the language the way the au pairs speak English. For this reason, grammar and sentence structure will not always be correct.

calm him down, I know that in most cases this happens when the information is new and the families are in shock. They usually calm down after some time.

The next day, the au pair tells me later, the host dad visited her. He came with all her things, and had yelled at her and the hospital staff, so that the staff eventually had to make him leave. When I talk to her after this, she is shaking in tears and shock. This is very difficult for her. Not only has she just been given a very serious diagnose, she is isolated in a hospital in a foreign country, she has no network here, she has a bad consciousness about if she has infected anybody, she just lost her host family. On top of this she tells me her host dad has called the UDI and notified them about the terminated agreement, so her visa is then also terminated, he now wants to book her a ticket back to the Philippines...

[In the beginning, getting involved...](#)

What decides which topic one ends up writing about? Sometimes one is led to the topic over time in ways that are really interesting. As a newly educated nurse from Australia in 2000 coming home to work in Norway were I am from for the first time, I was convinced that I did not want to work in a ward in a big hospital. I did understand however, that I needed that experience to be able to get work in the field that I really wanted to work within; refugees and diverse populations. Yet, I got a job working in infections disease ward, a ward filled with germs that most people are afraid of, filled with vomit, diarrhoea and sputum...

After a year at home I moved to South Africa and did my Honours degree in Sociology and Anthropology. Having a nursing background and limited anthropological experience, I was uncertain about what to do my fieldwork on, but I knew it had to be within the field of medical anthropology. One of the small local Tuberculosis hospitals, located in the township was threatened of closure due to lack of funding even though the number of TB patients were rapidly increasing, TB and AIDS being *twin diseases* (Møller et al, 2009, USAID, 2014). One of the professors at my department, also a local politician, asked me if I would write my thesis on the implications such a closure would have for the patients using the hospital. This led me to do my fieldwork in a township in the Eastern Cape, South Africa. I followed seven patients who were treated for TB from the lower social economic class during their treatment for the disease. I learned how TB is still affecting the poorest people in this world, and it continues to be a structural and political disease (Erstad, 2006, Farmer, 2001, Farmer et al, 2004, Rytterager, 2002).

Returning to Norway in 2003 I returned to my previous job at the hospital I was asked if I wanted to work as a tuberculosis coordinator. The regulation on tuberculosis control which came in 2002, made it mandatory for every hospital which treated tuberculosis patients to employ a tuberculosis coordinator (Tuberkuloseforskriften §4-3, 2009). The head of my department had been looking for someone who had experience and interest in TB for a while and I was asked if I wanted the position. I accepted the offer and I got the *Tuberkuloseveilederen*² from NIPH in my hands and was told to “*make the position my own*”.

For 18 years I have worked with TB patients, not only as a tuberculosis coordinator but as a nurse doing screening in asylum reception centres, in the office for Infection Prevention and control in the local municipality³, as a nurse in the medical ward, as a teacher for nursing students and as an advisor at the Norwegian Institute of Public Health (NIPH) being part of writing the national guidelines on TB. I have been working and living in an area of Norway where the density of au pairs is particularly high. This is one reason why I have had a great number of them as my patients. When I came to choose my topic for this Master thesis, I knew I had to write about something that really interests me. Having experience with this patient group, as well as living in the same area, and having friends who are host families I hear both sides of their TB story. With my work experience from government and policy level down to the “ground floor” I knew the complexity of this special patient group and the challenges both them and those who work to help them face. This is their story.

Why do I want to tell their story?

This research takes moments of someone’s life as a point of departure. The focus is au pairs living in Norway, from the Philippines, their experience when diagnosed and receiving treatment for TB and the experiences of those living with them and the professionals who work around them during this time. I hope this thesis will show how this patient group is very

² *Tuberkuloseveilederen* from NIPH are Norway’s National Tuberculosis Guidelines; they can be read online on www.fhi.no. The National Tuberculosis Regulations came out in 2002, and they were updated in 2009. The National Guidelines are a detailed interpretation of the legislation and the national recommendations. The guidelines were updated according to the 2009 update in the regulations and were then made available only online. They are now updated on a regular basis according to national practice.

³ Norway is by law obligated to have an office in all municipalities dedicated to handle Communicable Diseases. In Norwegian these are called *Smittevernkontor*, I have chosen to call these local offices for; the office for Infection Prevention and Control in the local municipality in this text. These offices are responsible by law for the prevention and control of tuberculosis in the municipality, including screening au pairs for TB.

complex and vulnerable, but I also hope to give a voice to the host families and the struggles they too endure.

When an au pair is diagnosed with TB, there is a large system that is activated around the patient; one wants to avoid further transmission, to start treatment and to find a source to the initial transmission if this is possible. Many patients experience this as traumatic. Some might not even have symptoms, some may not recognize them if they have, and many do not believe they are ill at all, and suddenly they are isolated in a hospital and given medications with sometimes severe side effects. The shock from diagnose with quite serious disease, that many are scared of, is for most overwhelming.

The au pairs come on a special visa. The au pair visa requires that they have a host family to welcome them; they stay in the family as a culture exchange and shall perform a set of tasks like household chores and child care for housing, food and a small salary. When they arrive they have little or no social network, and they are often afraid to lose the network they do have. This makes the au pairs particularly vulnerable, because their visa, social network in Norway, living arrangements and salary are all connected to their host family and the role they have as an au pair and the fact that he or she can perform the tasks linked to this role. If their contract with a host family is terminated, and they do not find a new family within a set time, their visa is cancelled and they are at risk of having to return home. The balance of power is not evenly distributed between the au pair and the host family and relations between them are influenced by this.

Their host family is like an extended kin but they are also their employer. The au pairs also have different status within the Norwegian state system; they are in the country on a cultural exchange, it is a form of student visa, they pay taxes and with that come different rights like sick leave, holiday pay, and salary if their contract is terminated, but they cannot work for salary outside their host family. When diagnosed it depends on what status they then have within the system, and this in turn influence their rights in Norway. So, they have newly arrived in Norway, they are diagnosed with a disease associated with stigma and they are at risk of losing everything they came for in this new country; how do they cope?

[Research problems and objectives; Key questions asked](#)

To investigate how these au pairs were coping during their treatment for TB I have done a qualitative research study over a two year period. I have talked to five au pairs who were under treatment for TB while they were on an au pair visa in Norway. I have talked to four of

the five au pairs' host families and in addition one host family that had an au pair who was treated for a latent TB infection. I have spent some time in three families and focused my attention on one of them, following the whole treatment period. I have also interviewed and talked to au pairs who are not sick, host families who do not have sick au pairs, health care workers (HCWs), and different state organisations and NGOs. I have asked three main research questions, and some additional questions to support these further.

1) What do au pairs from the Philippines living in Norway perceive as their support system during their TB treatment?

Who are there to support them when diagnosed, and in the treatment period? How does this support affect the au pairs? Do they feel “on par” or a part of their host families, and receive support from them or do they see them as employees and they need to be healthy quickly? Do they tell friends in Norway about the disease, or are they afraid of being excluded from this small community that is so important in an already vulnerable situation? Do they tell their family at home about the disease? Do they feel support from HCWs at hospital during isolation and during treatment e.g. doctor, nurses TB coordinators and home care nurses and what felt supporting?

2) How do au pairs who are under TB treatment use their support system, and how do they feel that this network supported them?

How do these perceptions of a working/ non-working support systems impact their life and illness management as a whole; work, side effects, compliance and their relationships with the host family, friends, family and community?

3) How does being diagnosed with a serious disease like TB impact the au pairs and the host family and the dynamics between them?

What role does the au pair perceive they have within the family, a sister or a servant? Do the dynamics between the au pair and the host family change so much that it makes the family develop a closer relationship with the au pair or does it create a distance between them, and how does this change affect the daily life of the au pair? Do different expectations to the au pair role and tasks, power relations or a change in family dynamics create tensions and how does this impact them?

Thesis overview; What did I write about?

This work is situated within the field of social anthropology and focuses on interpersonal and intergroup relations and social relationships of au pairs in Norway while being sick with TB. This study addresses the way the welfare state and its regulations impact the everyday life of this patient group and those around the patient. The emphasis is put on the au pairs' and those who interact with them during their illness personal story.

The ethnographic example in the beginning of this chapter shows how vulnerable the au pair is in the first meeting with the TB diagnosis. Her experience and story made me realize that the world needs to hear her voice. The complexity surrounding the sick au pair and host family needs to be explained so they can be met where they are and supported towards becoming well. I have explained my personal motivation for this study and introduced my research questions and an overview to my thesis. Then the focus shifts to the background and facts on TB; the history, prevalence, the disease and how the system for TB is established in Norway. The chapter will also explain the history of au pairs, the prevalence of TB among au pairs in Norway and how the system of screening, diagnosis and treatment for TB are regulated and organised in Norway.

My theoretical framework and research methods will be introduced in chapter two. I have conducted a literature review regarding au pairs, with a main focus on roles and relations within the family and visa regulations and rights. I have discussed communication with Goffman's front- and backstage theory, introducing Kleinman's health care model and explaining the terms disease, illness and sickness. I have then discussed the term illness and stigma and looked at TB in a social and global perspective before I have given a short summary of how the au pairs scheme has been portrayed in Norwegian public and mass media. Then the focus shifts, I present my field work; my research methods and data collection. I will introduce my informants and my research field. I will discuss how I have done fieldwork at home and how I gained access to the field and informants, and I will discuss ethical challenges and limitations to the study throughout this chapter.

The empirical findings will be introduced in chapter three. I have divided the chapters into different phases of the treatment, starting with dealing with the diagnosis. The chapter will tell the story of how the au pairs included in this study experienced being screened for TB and what happened when they got the diagnosis. This is followed by a discussion of the

findings with focus on how their status when diagnosed has influenced their rights in Norway. Their stories also show how those around them supported them in different ways and how this influenced their illness management. The discussion will focus on where they could and did seek help to manage their situation and link it to Kleinman's health care model and Goffman's theory on stigma.

Chapter four focus on clinical interaction and communication. I will explore what information that was given to the au pairs and host families, and where they got that information. I will discuss these findings in relation to illness management. Through ethnographic examples of different attitudes health professionals have towards au pairs and host families the chapter will show how these attitudes can influence the care and information given.

Chapter five will discuss the support system around the au pair and the consequences the illness have had for them. The chapter will look in to what kind of relationships and kinships develops between the au pairs and their families, and what kind of support have they got from friends and health care workers will be discussed. I will end by summarizing their hopes and plans for the future.

Chapter six will summarize the research. Since the au pairs are such a complex patient group, with various statuses within the Norwegian state system, I hope this thesis can help those who work with this immigration group can use the information given here to navigate the system in such a way that it can help other au pairs in a similar situation.

History of Tuberculosis; The Struggles and Stigma

Tuberculosis, *Mycobacterium tuberculosis* has had many names before it was named by Johann Schonlein in 1834 (CDC, 2016). In the 1700s the disease was called the "the white plague", but the most known name for TB might have been "consumption", or "tæring" as it was called in Norwegian (CDC, 2016). There was no treatment and it could kill whole families and wipe out even small communities. TB can affect everybody in society but the disease is strongly linked to socioeconomic factors; the lack of good nutrition, poor housing or work conditions and crowded living conditions are all factors that impact the rise and spread of the disease (Farmer, 2001, WHO, 2018). This, combined with the fact that the disease is airborne, also meant that this disease has been and still is associated with death and

suffering and there is much negative stigma associated with TB (Farmer, 2001). The stories told in this thesis are proof of that.

“Until the discovery of antibiotics, treatment for TB was limited to warmth, rest, and good food” (CDC, 2016). People who were sick was often sent to sanatoriums to rest, in Norwegian they called it “kuring”, and it divided families and made a big impact on the society at the time, both economic and socially. In the Oslo area we find several places among them Dikemark Hospital, today used by Oslo University Hospital for patients with mental disorders as well as a asylum reception centre. The disease affected, and still do, mostly people from lower socio-economic backgrounds with the risk factors mentioned above. However, the state by trying to contain and stop the spread of infection suppressed these patients and their family even more by confining them to sanatoriums, sometimes under terrible conditions.

The concept “structural violence” shows how complex and overlapping factors can influence inequalities in health, in this case TB, and how societies can be a “social machinery of oppression” (Farmer, 2004: 307). An example in Norway was this way of containing people; the families came in worse situations, only one breadwinner, sometimes split up and the survivors of the sanatorium often suffered later in life (Norsk Teknisk Museum, 2012). The effect this had on families, made people not talk about it and led to much stigma associated with the disease.

On March 24, 1882, Dr. Robert Koch announced the discovery of *Mycobacterium tuberculosis*, the bacteria that cause tuberculosis. The discovery led to the development of vaccines, knowledge regarding infection and transmission, an introduction of laws and regulations and to the discovery of antibiotics, all which contributed to the decrease of TB in the Western world. However, the major factor and the one that had the biggest impact to reduce the disease was the general improvement in the populations living conditions which all became better during the 19th century. TB have declined in western societies, because of access to better healthcare together with improved living conditions and better lifestyle, while from a global perspective it is still the largest infectious disease in the world. Africa is the part of the world which has the highest number of cases, while Asia has most cases in total (FHI, 2018: 6).

The numbers; TB Prevalence

Tuberculosis is a global challenge and United Nations have made it one of their sustainable development goals to reduce the disease worldwide (www.un.org). “TB is one of the top 10 causes of death worldwide, and it is also the main cause of deaths related to antimicrobial resistance. In 2016, there were an estimated 10.4 million new (incident) TB cases worldwide and 1.7 million people died from TB. Seven countries accounted for 64% of the new cases: India, Indonesia, China, Philippines, Pakistan, Nigeria, and South Africa” (WHO, 2017: 1).

In 2017, 328 773 new TB patients were notified in the Philippines, the incidence rate of new TB cases were 554/ 100 000 (WHO, 2018: 200). So whilst the Philippines have one of the highest incidence rate in the world, Norway has one of the lowest incidence rates with 261 new patients being notified to the Norwegian Institute of Public Health (NIPH) in 2017, the lowest number per year since 2002 (FHI, 2018). The incidence rate for TB in Norway for 2017 was 5/100 000 (FHI, 2018:7). However, the incidence differs widely among different population groups in the country. Among the Norwegian-born population the incidence is one of the lowest in the world, being only 0,7/100 000 in 2017 making it pre-elimination stage according to the WHO (FHI, 2018:7).

Tuberculosis is a global disease as is evident in the incidence rates of TB in Norway. Norway has had a shift in type of immigration over the last 5-10 years. The country receives a lower number of asylum seekers from high incidence countries, and this may be one major reason that since 2013 there has been a steady decline in the number of new cases reported (FHI, 2018:5). The Global Tuberculosis Report from 2017 tells us that about 85% complete their treatment for TB in Norway, there is little TB that is Multi-drug resistance (MDR-TB), and the median age for getting sick with TB is around 30 (FHI, 2018, WHO, 2017).

The disease; What are we dealing with?

Tuberculosis is contagious and airborne, and the disease most often affects the lungs, but can affect all organs in the body. It is transmitted through air when a person who is sick breaths or cough and someone else breaths in air with the bacteria in.



Picture credit; LHL

Usually this would happen to persons with close contact with the sick person, those who live in the same household, work or go to school together, but since it is airborne; *anybody can get it*. When the TB bacteria enter our body, it is transferred with the white blood cells, but instead of being destroyed, the macrophage becomes a host cell. The bacteria ‘go to sleep’, it becomes dormant and one has become infected with the TB bacteria but one is not sick with the disease. This stage is called a Latent TB infection (LTBI), and one cannot infect anybody. The WHO estimates that one fourth of the world’s population has a Latent tuberculosis infection (FHI, 2018:6). The risk of developing disease during one’s lifetime when infected is about 5-10%. The risk of developing disease is highest the first few years after infection, and this is especially true for children and those with reduced immune system that are more vulnerable to the disease than others (FHI, 2018:6). A weak immune system, caused by disease or stress, can wake the dormant TB bacteria that start to multiply and grow, causing the disease to become active. However, TB bacteria grow very slowly, which is also the reason that it takes so long to diagnose the disease. This is frustrating, not only for the patients, but also for those who have been exposed to the disease, and need to be screened for the bacteria. The recommendation is that one should wait 8-10 weeks from the last exposure of the disease before testing, because it takes so long to have an immune response. It can also take up to 8-10 weeks to get the diagnose from sputum tests. During this time the au pair who has been screened live and work within the family.

The System; Norwegian regulations

Screening

Upon arrival in Norway all au pairs are by law required to undergo TB screening; chest x-ray and IGRA⁵ blood testing. This is the host families' legal responsibility, and it is to be done before they start caring for the children in a family, and should be done as soon as possible after arrival (FHI, 2017). The regulations are there because potential transmission can be avoided if the x-ray is negative. Many host families take this responsibility seriously and follow these regulations. When an au pair is registered with UDI and local police, the municipality health office gets a notification that the au pair is living in the area. The municipality health office will then send a letter to the host family/ au pair and inform about the screening. Most municipalities and hospitals have drop in for this screening on specific days, to make it as flexible as possible. From my work experience in the local municipality and within the hospital I know that many host families are not aware of this responsibility. There are also those host families that do not see the importance of this screening, saying "they do not have time" to make sure the au pair meet at the screening facilities. When they are asked to come, the au pairs sometimes say they do not get time off to come, or it is difficult for them to find their way, when just arrived in the country and the family does not follow them to the screening. Health care staff included in this study explained that this is a major delay in TB screening in this group. It is also very time consuming for HCW to locate the patients and get them to come to screening. There is no statistics on this, however when talking about the issue in various settings it is a reoccurring problem discussed. Finding better solutions to reduce this screening delay has been to: inform the public in media, offering information meetings for host families and au pairs, including the information in web sites and produce written information about the au pair arrangement (see examples of this on these web pages; Caritas, FHI, LHL, UDI, Bærum kommune).

There has been a discussion on who has the formal responsibility for the screening of au pairs. Since they are on a cultural exchange, the host families are not employers in a formal sense, but they do pay employee tax so the au pair should get rights at the same level as an employee if she or he should become sick. At the same time the au pairs are registered in the system as both working and students in visa statistics. When unforeseen things happen to the au pairs, like becoming sick with TB and in some cases get their contracts terminated, they

⁵ IGRA is a diagnostic tool, a blood test and is short for *Interferon-gamma release assays* that can tell us if one has been infected with the tuberculosis bacteria, having latent TB. IGRA cannot distinguish between latent infection and active tuberculosis (TB) disease.

fall outside the system; they fit into more than one category or in none at all. Findings in this study will show how this complexity makes it difficult for the au pairs, especially during diagnosis but also during and after treatment. These stress factors make the process of sickness and healing more challenging, not only for the patient; the au pairs, but for those around them, including host families and health care workers.

Diagnoses

All patients who are diagnosed with TB in the lungs are admitted in an isolation ward while they are contagious. Normally one is not contagious after two weeks on antibiotics, however for some it might take longer. When in isolation, one stays in a single room, with private bath and to enter and exit the room one has to go through a room with extra ventilation system of different pressured air to avoid infection. All visitors have to wear gloves, mask and yellow dresses. This is very scary for many and some state they feel like outcasts.



Picture credit; Vestre Viken HF, MINF

Treatment and follow up

Treatment is compulsory when sick with TB, by law and has to be given as DOT (Directly Observed Treatment) by health care workers (HCWs) daily for a minimum of six months (FHI, 2010). This means that a HCW need to observe every tablet taken during treatment. During admission to hospital, nurses at the ward do this, when discharged an individual plan is made that state who gives the medication. Most often this is the local home care nurse (HCN), and it is not recommended that it is done by the host family. Standard treatment regime is to give four types of drugs, and this 4-drug cocktail does not come without side effects. For those who are asymptomatic when diagnosed, and get side effects, the treatment seems even more of a burden and for some even unnecessary as explained some do not

believe they even have the TB diagnosis. An individual plan is made for all TB patients and they are all followed by a TB coordinator during the treatment and follow up period. Giving the medication as DOT is not only meant as a control and reminder to take the medication, but also as a physiological support around the patient. Research has shown that support is important when undergoing treatment for a serious disease over a long period of time (Husain et al, 2008, Rytterager, 2002). Furthermore, factors like depression and anxiety are associated with an increase in the number of symptoms reported, more serious perceived consequences and less control over the illness (Husain et al, 2008). This is important because these factors may contribute to poor compliance with TB medication. All screening and treatment for TB is free of charge for the patient, including all appointments, tests, and medication (Tuberkuloseforskriften § 4-9, 2009, FHI, 2010). While on TB treatment Norwegian law has been regulated so that one can stay in Norway and get a visa extension for the whole treatment period and in some cases until checkups are done (Utledningsforskriften § 17-14, 2009). After completing treatment, checkups are done after, two weeks, two, six and twelve months, but usually the patients go for checkups every month, and sometimes this is also extended (FHI, 2010). So from the first screening to the last check up, the patient has usually been in the health care system for two years. Au pairs only get a maximum of two year visa. What happens to them when treatment is completed differs and I have had experience in those who get their visa extended, those who go to another European country and they follow up there, those who go to another European country and return to Norway for checkups and those who go back to the Philippines and do follow up there. The uncertainty of what will happen in this period until the last check-up is completed is stressful for some.

[History of the au pair programme](#)

History tells us that young women in Northwestern Europe as early as from the sixteenth century worked as so called 'life style servants', in families between puberty and marriage as a transient phase (Anderson, 2009:417). The elite might not have sent as many as those in the middle-class, however relations were familiar and the young women would be regarded as junior members or integral within the family they worked, performing tasks of housework and childcare (Anderson, 2009:418). Formally, the au pair system is said to have started in Switzerland in the late nineteenth century, when young middle-class German-speaking women were placed in French-speaking families to learn how to run a household. They would learn a new language as well as French cuisine in return for childcare from women of

their own social standing (Bikova, 2017: 6, Boer, 1987 cited in Dalgas & Olwig, 2015:471). “The period abroad was intended as a preparation for adult life and particularly marriage as the young middle-class women were expected to learn how to run a household and set up their own homes”(Bikova, 2017:6). It soon became popular across Europe for young women of all classes, and concerns about this unregulated movement and to protect their rights the European Council passed the ‘European Agreement on Au Pair Placement’ in 1969, also called the “Strasbourg Agreement” (Dalgas & Olwig, 2015:471, Bikova, 2017:6).

The Strasbourg Agreement defines the au pair placement as follows:

The temporary reception by families, in exchange for certain services, of young foreigners who come to improve their linguistic and possibly professional knowledge as well as their general culture by acquiring a better knowledge of the country where they are received (Council of Europe 1969, Article 2).

English speaking countries such as England, Australia and the USA have been popular destinations among Norwegians au pairs going abroad. However, Norway had a shift around 2000 when the country went from being primarily an au pair- sending country, developing into a receiving country for au pairs, from all over the world, and especially from Eastern Europe and Asia (Bikova, 2017:8).

The Philippines are the nation that has a long tradition of travel and working overseas and in many communities it is almost expected of them to go abroad to work and then send remittances back home to their families (Bikova, 2017). A huge part of the economy is dependent on these remittances. Filipinos have been participating in the au pair program since the 1990s (CFO, 2014).

Statistics on au pairs in Norway

Norway has about 3000 au pairs and received 887 au pairs in 2018; about 90% are from the Philippines. There is a small decline in all immigration to Norway, including au pairs. The table below shows the number of au pairs registered in Norway, and how many of those who were from the Philippines 2014-2018.

	2018	2017	2016	2015	2014
Total au pairs to Norway	887	963	1182	1336	1481
From the Philippines	781	854	1009	1163	1270

(UDI, 2019)

There has been a shift over the last decade, from mostly getting young people from western countries to register as au pairs to almost exclusively receiving them from the Global south, poor countries outside of the EU, like the Philippines. In 2006 Norway received 1243 au pairs, but then only 587 of them were from the Philippines. This shift of an increase of au pairs coming from countries outside of Europe, like the Philippines has not only been seen in Norway, but in Denmark and UK as well (Cox, 2007, Dalgas, 2015, Dalgas & Olwig, 2015, Hess and Puckhaber, 2004). Socio-economic changes in the western industrialized societies like “women’s entrance into the paid labour force and the growth of the dual-earner family model that, at the face of men’s reluctance to take their share of the household chores has created the need for someone else – most often a woman, and increasingly a migrant woman, to take over the domestic and care work” (Bikova, 2017:2) It has been argued that this shift has consequences for the au pair program because it is becoming a form of domestic work with quite similar working and living conditions to that of live-in migrant domestic workers instead of the cultural exchange program it is intended to be (Hess & Puckhaber, 2004:65). At least that is how some eastern and southern parts of the world see the program, and this together with stories of abuse led the Philippine Department of Foreign Affairs (DFA) impose a ban on deployment of Filipino au pairs to Europe in 1998, but it was lifted in 2010 (Bikova, 2017, CFO, 2012, The Philippine Department of Foreign Affairs, 1998). However, this increase happened despite the ban which is an interesting development (Bikova, 2017:4). There have been studies on why host families chose to get au pairs from the Philippines and theories have been that there is reputation about this nationality as hard working and “good with handling children” (Cox, 2007).

This shift has new challenges; in the 10-year period from 2008-2017 a total of 77 au pairs were registered as having TB and of those 47 were registered in the past five years (MSIS; FHI, 2017/2018:11). This number is probably higher since the MSIS⁶ registration system do not have an option to categorize au pairs as a group, and those sick might be recorded under other visa options like student, working, temporary or visitor’s visa. In 2017, 42 of the 261 people who were sick with TB were registered with a working visa in Norway, and 6 were registered as being au pairs (FHI, 2018: 11).

⁶ MSIS is the Norwegian Surveillance System for Communicable Diseases (MSIS). Microbiological laboratories analyzing specimens from humans, and all doctors in Norway, are required by law to notify cases of certain diseases to the MSIS central unit at Norwegian Institute of Public Health. (www.fhi.no).

What is an au pair?

“Au pair” means “on a par” in French or “equal to”. Participants in the au pair scheme are intended to be treated as an equal member of the family to gain knowledge about a foreign culture and language in exchange for light household chores and childcare. To become an au pair in Norway one needs to be between 18 and 30 years old, one cannot have children and it must be likely that you are to return to your home country after your stay in Norway (UDI, 2012). The program is a cultural exchange program and the UDI regulations should be followed. The au pair has to live with a host family to learn language and customs of the country and the host family cannot be relatives of the au pair nor can a host family have more than one au pair at the time. The au pair shall have an own room and will get free board and lodging and a small amount of pocket money, the au pair shall in return perform tasks like housework and childcare. To not be exploited there are regulations regarding these tasks; the au pair should not work more than 5 hours per day, maximum of 30 hours per week and have at least one day a week off, is entitled to 25 days a year holiday leave. To ensure that the au pair does not come here “only to work” and they cannot work for other than the host family nor can they work more hours for extra pay and the host family shall cover cost for language courses and travel expenses to return home (UDI, 2012).

The system; Visa rules and regulations and impact on au pairs rights in Norway

The Norwegian state system is complicated, and au pairs are a group that falls in under different categories in this system. This can affect their everyday life and decision making. It also affects those around them, and those working within the system, since the regulations that control these categories are open for interpretation. This section will give a short introduction to this in regard to literature, but a discussion with examples from the findings will come in the next chapter.

Many young people who travel to European countries, “shop around” so they can stay as long as they are allowed as an au pair. Au pair visas are commonly limited to a one year period; however in some countries it is possible to get an extension. This is the case for France, the UK, Denmark and Norway which permit up to two years au pair visa (www.aupairworld.com). For this reason, Norway is a popular destination. According to CFO (2014) “Denmark, Norway and the Netherlands are the top destinations for Filipino au pairs”. The rumor among the au pairs is also that you are well treated in Norway compared to many other countries. Other countries have the same regulations regarding e.g. working hours and

salary, however Norway has implemented methods of enforcing these regulations. If regulations are not followed, the au pair can report it and UDI can impose a disqualification period on the host family (UDI, 2014). This way of implementing regulations was introduced in 2013, and in 2016 29 host families got put in a disqualification period and 21 in 2017 for breaking the rules, according to UDI.

The NGO Caritas also run Au Pair Centers in major cities in Norway. They arrange information meetings about regulations regarding the au pair scheme for both host families and au pairs. They have a legal advisor that helps au pairs with different issues including help to report abuse; this service is free of charge. They also arrange social events once a week for the au pairs. Caritas is a Catholic NGO, and in Norway they work to better integrate foreign nationals through offering help with job seeking and Norwegian language classes (Caritas, 2019).

When leaving the Philippines to travel as au pair they have to have a valid au pair visa as well as a certificate from the Commission on Filipinos Overseas (CFO) in order to demonstrate that they have completed a country familiarization seminar (CFO, 2012). When the ban existed to become an au pair one needed an exit permit from the Philippine Overseas Employment Administration (POEA), which is no longer required “because they are no longer considered overseas Filipino workers (OFWs)” (CFO, 2012). The ‘European Agreement on Au Pair Placement’ also places them in a special category as they are neither students nor workers (Council of Europe, 1969), however they are a category with characteristics of both.

When the au pair arrives in Norway they already have a valid visa. However, they also need to register at the local police station upon arrival to get a valid residence permit. It is only when they have completed this registration and they are granted a valid residence permit that they automatically becomes a member of the Norwegian National Insurance scheme⁷. Until this registration is done, they are not covered by the Norwegian National Insurance scheme, which means they have no rights when becoming ill. This happened to one of the au pairs in this study and will be discussed in the next chapter.

⁷ If you intend to live in Norway for at least 12 months, you are as a general rule a member of the National Insurance Scheme. Membership in the National Insurance Scheme, or *Folketrygden* in Norwegian, is the key to eligibility for rights to services from NAV.

Theoretical framework and Research methods

My theoretical framework will be introduced this chapter, starting with a short literature review which focuses on roles and relations within the family. This is followed by a discussion about communication through the use of Goffman's front- and backstage theory. The chapter then moves into explaining the terms of disease, illness and sickness before moving into theory about illness and stigma regarding TB. The chapter gives a short summary of how the au pairs scheme has been portrayed in Norwegian public and mass media. The fieldwork is presented by explaining my research methods and data collection, how I got access to the field sites and informants. The informants are introduced and ethical challenges and limitations to the study are discussed throughout the chapter.

Literature review

Research done in Norway has traditionally the same findings as in the rest of Europe, and has mainly been investigating issues related to au pairs and their relations to host families and society; gender issues, power struggles within the host family, exploitation of the au pairs, house rules and regulations, issues regarding care work and reproduction labour, media and agencies' portrayal of au pairs, immigration and so on (see f.ex. Anderson, 2009, Cox, 2007, Cox & Narula, 2003, Due, 2011, Hess & Puckhaber, 2004, Hovdan, 2005, Kristensen, 2015, Mellini et al, 2007, Sollund, 2010).

Roles; au pair, domestic worker, student

Literature on au pairs often discusses the problem of the different roles they are ascribed, what status they have in their host family with regard to their visa status, and how this can influence forming their identity. All au pairs should have a valid au pair visa upon arrival in Norway. However, in the UDI system they are registered as working visa holders. The fact that they are registered as one status in government systems, but actually have another illustrates the complexity of the status for au pairs because they do not fit into one category in the 'system'. As Cox (2007: 282) writes; "They are migrant workers who are constructed by official discourses as neither workers nor migrants but as participants in a cultural exchange... Their labour is not considered to be labour but the natural activity of any other family member". She continues to argue that housework and childcare is not considered 'work' and that this hides the value of work that au pairs do (Cox, 2015). The consequence of this kind of labour being devalued is also discussed by Ragnhild Sollerud (2010) and Guro Korsnes Kristensen (2015), the latter who argues that the au pair scheme is challenging the

Norwegian norms of social and gender equality as “Norway’s main strategies for achieving gender equality have been to strengthen women’s economic independence through increasing their labour market participation, and to normalise men’s involvement in care work and housework” (Kristensen, 2015: 204). Kristensen (2015) continues to argue that to be able to manage two full time careers with having children and running a household, more middle-class families hire domestic help, like au pairs. This study investigates how people then attach value to paid and unpaid work, and how the practice of au pairs can claim to destabilize the Nordic model of gender equality with symmetrical gender relations. When talking to informants, mainly host parents, I heard comments that in some instances were the same as in the articles mentioned above, i.e. where the nature of gender relations was questioned. However, even if I will discuss these comments I have chosen not to focus on the gender equality issues in this thesis.

Elisabeth Stubberud (2015) did a PhD on the au pair arrangement in Norway and discusses the dual role of au pairs. She highlights the fact that they are not working immigrants but are working and they are not students, but still they are here to study the language and culture illustrates this duality (Stubberud, 2015). In an interview done in the Journal (2018b) she is questioning why they are to learn Norwegian as they are supposed to return to their country of origin— after all they are never going to use this language upon returning to the Philippines. The reality is also the fact that the au pairs in Norway often speak English within the host families and with the kids, and that this is a wish of the family as well. The host parents wish for their children to learn English and the au pair become better in a language they do get to use later in life. However, I would argue that the value of learning a new language whether or not you will use it in the future is high, and is definitely part of being on a cultural exchange as this exchange partly is mediated through language.

Bridget Anderson (2009) studied au pairs and domestic workers in the UK, two groups that perform the same tasks, but who are different visa holders. Even though the same tasks are performed, Andersen shows how different these tasks are imagined and how they produce different relationships with the families they live with and work for, for the two groups of visa holders. These differences influence social and legal construction of identity, and raise questions like what count as work and what count as family? When one is a worker in Norway one is protected by the law, when staying as an au pair what protects them is UDI regulations regarding au pairs. A domestic worker is employed whereas an au pair is “part of the family”; this difference influences the way one is treated in one’s everyday life and hence

influence how one create an identity. Anderson (2009: 407) explores how a nation-state, through visa regulations, protects national interests and how nations “produce workers with certain types of relations to the labour market, and residents with certain types of relations to citizens and social institutions”. She argues that the state controls the visas through sorting mechanisms based on national interests. Norway regulates this by allowing young people to enter the country on au pair visa but does not grant domestic workers work visas. These regulations are always open to negotiation depending on who has the political power at any given time, and what kind of immigration that can pose a “threat” to the country. Some might argue that the au pair agreement is a way of helping women in Norway on a way to more equal rights by giving them an opportunity to pursue a career at the same time as having children, while others will argue that the au pair agreement might pose a threat to the equality within the family as gender relations within the family remains at a status quo. Researches have argued how nations can grant different visas for the same work and how this influences the way they shape their identity. However looking into how this difference in visa might influence their rights when becoming ill would be an interesting topic for further research.

Recent literature in Denmark and Norway has made a shift, looking at au pairs from the Philippines in a wider perspective, including transnational relations and the making of kinship and relations. Dalgas (2015) and Bikova (2017) have both looked at au pairs in a Global Care Chain; how they create different forms of kinships with their host families as well as transnational family bounds mostly back in the Philippines. They have looked at how being an au pair have intended outcomes of self-transformation, and how upon return to the Philippines they have gained respect and new responsibilities after having sent money home during their time abroad (Dalgas, 2015, Bikova, 2017). Media has also covered some of the “success stories” (Kilden, 2017, Dagsavisen, 2015, DN, 2015). These success stories, I argue, illustrate the ways in whic the au pair programme is intended: au pairs have experienced adventure, they have learned about a new culture, they were treated like family. Finally their experience opened up new doors to their future either in Europe or when returning to the Phillippines.

My research does not aim to investigate any of the issues directly, however they can all influence how a person perceives their support system to actually be supportive, and thus are relevant perspectives to keep in mind throughout this thesis. I will discuss some of these topics here and include some of them in my further discussions.

While the above-mentioned contributions have covered many aspects related to au pairs and their relations to host families and society, we know little about what happens to the au pairs when they get sick with TB and the effect this has on the families and the au pairs. There is a knowledge gap here to be filled, which this thesis aims to address.

Communication; front stage, back stage

“Front stage” and “back stage” are concepts of social interaction developed by the Canadian-American sociologist Erving Goffman. Many of his theories are relevant to my study, looking at the micro-society of everyday life around au pairs during their illness, and their social interaction within their host family, with friends and HCWs. In his first book *The Presentation of Self in Everyday Life* (1959) Goffman tried to explain this in the way we organise and make sense of our interaction with each other and how we manage to make our interactions strategic. Goffman used the metaphor of the theatre to explain social interaction and understanding human interaction and everyday behavior, hence the terms for social life as a “performance” either “front stage”, “back stage”. When we communicate one’s role in the conversation, the way the one acts and the setting the conversation takes place all influence the “performance”. I argue that au pairs especially when newly arrived want to make a good impression with their new host family and hence, feel they have to act as on “front stage” when they are in their own “home” where they should be able to act “back stage”. Au pairs in this study have told me about how they control the information they share about themselves and their disease in their social network including their host families. They do this because they want to protect their own role as a care person and family member and to protect and control the impression others get of them during the “performance”. That is why I have chosen to use Goffman’s theories in my discussion. Goffman (1959) argues that all social interaction is shaped by the time and place in which it occurs, but also the “audience”. The communication is also shaped by the values, norms, beliefs, and common cultural practices of the social group within where it occurs.

Front Stage Behaviour—The World is a Stage

According to Goffman (1959), “front stage” behavior is how we behave and interact when we know that others are watching us, when we have an audience. When we communicate front stage our behavior reflects norms and values in the society and we act the way that is expected of us in a given setting and what role we believe we have in that setting. One can act intentionally and planned but it can also be subconsciously. But this front stage way of acting often follows a learned social script shaped by cultural norms, and we are aware of how others

perceive us and what they expect of us. This knowledge in turn shapes how we behave, but it also shape how others view us, what they expect of us, and how they behave toward us. The front stage is then typically in public, at work or school and with people we do not know or have a professional relationship to.

Back Stage Behaviour—What We Do When No One's Looking

We are back stage when we are at home or with family and friends whom we have a close relationship with, what we do when we are relaxed and comfortable. We are able to be what we consider as our "true" selves, because back stage we can behave as no one's looking, or when we think no one is looking. Here we do not have any expectations. However, there are of course elements of how to behave here as well, unwritten norms that we are always aware of, and that influence our thoughts. We do also interact with people back stage, like family members and close friends, but the rules and norms might differ from front stage.

However, life is not a stage, and we do not have a manuscript to follow all the time. Critique of the model has been that that it does not really show the reality of life, since we cannot compare life in the theater with real life in society. We do not always have the choices in front of us, we have to improvise and react to those around us. In a way we meet people and situations with “white sheets of paper” and we can write our own history. We also tend to move on and off stage at the same time moving between them.

This critique is in a way very relevant for the position in which the au pairs are in most of the time. When they are here as an au pair they are living with a family they have never met before and may feel that they have to live up to certain expectations. They have often sacrificed a lot to come to Europe; this is for many the first time away from home, taking a chance in the world to get a better life. They want to make a good impression on their family, they want to be a part of a family, but are also afraid to “fail”, to be sent out of the country. I will give an example of this way of acting from the perspective of a mother in a host family.

“When she (the au pair) came to our house, she went up at six o'clock in the morning. She kept asking us how we wanted our coffee and what she needed to prepare for us in the morning. She is not our servant! She is supposed to be part of our family, I tried to tell her this but she kept wanting to make us coffee. I want to make my own coffee! I think she gets it now, but I had to sit down and have a serious talk to her about our expectations. I wonder

how the last family treated her since she keeps acting like this? Maybe she is afraid that if we do not like how she is, we throw her out like the previous family did. We won't do that. But I have to control my feelings so I do not get angry and upset her... I cannot live with a servant in my house! That is not why I got an au pair. We need some help around the house, but with the kids getting older, she needs to be a part of our family to make this work in a positive way. ... I am sure this will work out, I just have to get to know her better. "

Here the au pair tries to make a good impression, afraid that this new family would not like her. Further, she may be concerned that they would terminate her contract, as her previous family did. However, the new family was not looking for a servant, they wanted her to relax and do as the others, to be a part of the family. When this au pair had stayed in the family for a while and they got to know each other better she started to let her guard down, allowing herself a back stage. The host mother and au pair found daily routines that suited both; the family normally got up early and had breakfast before school and work, while the au pair – who actually liked sleeping in - often got up after the family had left the house. Acting the way the au pair did in the beginning, going up early serving coffee and breakfast must have been very tiring and stressful for her; her wish to show the family her best side “playing on a scene” not being able to relax “off stage” when she was in a house that she was to call home for the next two years of her life could have impacted her healing time. It is known that stress can have an impact on the immune system, infections and the healing of them (Klein, 1993). Also, by giving an impression front stage that she is more well than what she is, she might work harder than what she should do, considering her TB, as one of the host parents said during a conversation:

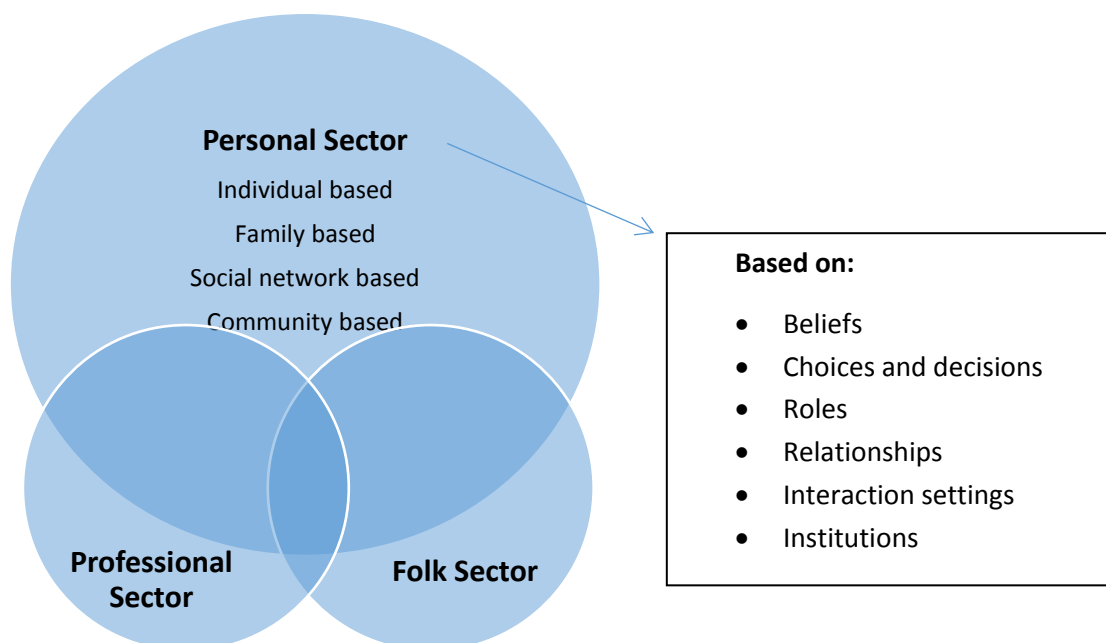
“It was this story about the coffee; you know the one I told you. About her getting up in the morning and wanting the house to be perfect before we got up. The poor girl, she was so sick in the beginning, she was so tired and she needed sleep. I think it lasted for about six months. She was so tired. She did the best she could, she worked hard and she tried so hard to pretend not to be ill and act as if everything was normal. We did not understand this at once, since we did not know her. We only understood it when she was back to her own self, working full speed how sick she had really been and how much she had worked to please us and pretend that everything was fine. She must have been terrified that we would let her go if she was not good enough, like the first family had when they found out that she was sick. ”

This can also be explained that the au pair are front stage because she is afraid or feel shame in regard to her TB diagnose, stigma and acts in this way. Herald Eidheim had similar findings among the Sámi people of Norway; they would speak in Norwegian in public and Sami when they were together with other Sámi people, thus negotiating language and identity in and between places (Cited in Sajjad, 2011:548). According to Goffman people may control the information they give to others about themselves to avoid stigmatization from society and the consequences thereof. In this study the au pairs hide their illness in fear of being “expelled” from the family. Stigmatization is a complex social process, and disease stigma is often understood as problem of fear and blame rather than ignorance (Møller et al, 2009:219), as this example also indicate.

Model of health care sectors

Arthur Kleinman came up with an explanatory model, that explain three interconnecting sectors of health care; the *folk sector*, the *professional sector* and the *popular sector*, called the *personal sector* in the model Tishelman (1993) has constructed based on Kleinman’s terms (Figure 1).

Figure 1. Kleinman’s model of local health care systems



(Professional and folk sectors may or may not overlap in different settings)

According to Kleinman “each sector has its own ways of explaining and treating ill health, defining who the healer is and who the patient is, and specifying how healer and patient should interact in their therapeutic encounter” (cited in Helman, 2007: 82). The model of the sectors helps us understand how people respond to sickness experiences in their daily life with or without engaging professionals to manage their condition (Belqaid et al., 2018).

The folk sector is composed of ‘non-professional’ health care specialists, often without a biomedical background, like herbalists but also the use of alternative medicine such as natural products e.g. vitamins, minerals and herbs, or mind and body practices e.g. yoga, meditation and acupuncture (Belqaid et al., 2018). In the Scandinavian context there is very little overlap between the folk sector and *the professional sector* which consists of organized health care professionals, whose practice is regulated by structures in society, regulations and politics. These health care professionals possess social power, as they have the authority to legitimize illness by determining diagnoses and to offer treatment alternatives, and they are commonly responsible for treatment and management of disease (Belqaid et al., 2018). The patients are expected to comply with treatment recommendations. From my professional experience most patients will comply with treatment, even if they do not agree or believe in the TB diagnose given. As this quote from one of my informants confirms:

“But in the back of my mind that time, I was a bit reluctant to have this medication so I asked so many questions to the doctor if I do really have TB, because I did not believe it (that she had the disease).”

This au pair was not the only one in this study who did not believe in the TB diagnose given by the health care professionals; from the professional sector of Kleinman’s exploratory model. She did however, take the medication prescribed to her and completed her treatment, or so she said she did. So the au pair do not believe the TB diagnose given her from the professional sector, however she claim to follow the guidelines and recommendations about treatment regime. She believes in healing so she is willing to comply with the treatment, but do not believe the TB diagnose. It is a bit contradicting because she had told me before that her mum and grandmother had both been treated for TB when she was young, back in the Philippines. She knew the TB disease. When asked how she perceived her health before she received the TB diagnoses she said:

“I used to have bad health, I got sick very easily. Especially when I was stressed, I had a very weak immune system, and I got tired very easily. I am less tired now than before. I have much better health here in Europe”.

For me as a health professional it is hard to believe that she does not see the link between her perception of her “bad health” and link these symptoms to the fact that she has got the TB diagnose. Since she had experience of the disease in close relatives and were highly educated I would think that her health literacy is high. However, as a researcher I would argue that she in her illness management do not have the perception that her “bad health” are symptoms of TB. She did not tell me, however this might indicate that she finds help also outside her personal sector; in the folk sector where she is explaining her “bad health “ and dealing with her illness. She has chosen though, not to take a chance or gamble with her health, so she is taking her medication as prescribed to make sure that she is healed. Also having in mind that she has experience of her relatives who were cured for TB from treatment received from the professional sector.

The personal sector consists of lay, non-professional and non-specialist health care, that is family and friends, the patient’s social network and the community. Kleinman (cited in Belqaid et al., 2018) argues that the majority of efforts at health assessment, maintenance, and treatment take place in the personal sector and may occur on the inter- related levels of the individual, family, social networks, and communities. How the patient manage the experience of being sick will be “influenced by the cultural context and social relationships around the sick individual, in terms of health beliefs, roles, and relationships” (Belqaid et al., 2018). This is true for most of us and is very relevant in understanding the ways in which the au pairs deal with their illness. This patient group might be scared of losing a contract, to be expelled from the host family or even Norway in addition to being afraid of being diagnosed with a serious illness. The au pairs move between the sectors and having different roles in different sector.

Kleinman’s model can help to structure and interpret the findings I present in this thesis. The model distinguishes between the strategies and resources based in participants’ daily lives and can help us explain how they use these in their illness management and experience. The model can also give us the au pairs descriptions of health care professionals’ role in their TB management as Belqaid et al., (2018) also did in their study.

Disease, Illness and Sickness

In medical anthropology the terms *disease* and *illness* have different meanings. The term *disease* is most often used within bio-medicine by health care professionals to describe the (to them) objective reason that something is wrong within the biology or psychology of humans. Professionals will diagnose and put a name on what is wrong, confirm that the disease exist, start treatment and by doing so legitimize to the society that a person is sick (Sachs cited in Magelssen, 2008:41). What the health care worker and the patient focus on in regard to the disease often differ. While the health care worker is often most interested in the pathology of the disease the patient is often interested in the symptoms and reason for disease (Magelssen, 2008:41). Treatment and cure is a common interest of both.

The term *illness* often reflects the person's perspective of being sick and the subjective experience of being unwell and what meaning the person put into it (Magelssen, 2008:42). The individual and personal is important but so are the cultural reactions to and understandings of the diagnose. This in turn will shape the illness experience. The term illness thus, is not only individual but socially constructed and potentially experienced (Magelssen, 2008:42). This is important because when a diagnose like TB manifests itself as an illness it does not only affect the patient but those around him or her. Both those ill and those around the patient aim to understand the illness, give it meaning, touch and feel it, communicate with it, adapt to it, protect oneself from it and so on, and these reactions from the environment will deeply influence how the patient manage him or her illness (Magelssen, 2008:42). When a host family considers ending a contract due to an au pair's diagnosis, the ways in which she actually perceives this diagnosis as an illness will influence her management of it and her interpretation of the situation. In some instances like for two of the informants in this study the host family had a need try to protect themselves from the disease and hence did not let the au pair back in their house. In my experience au pairs affected by this decision negotiated the advice and treatment regime given by HCWs and incorporate it to her life when finding a new family. When the TB diagnose comes without symptoms, or the patient have other explanations to the symptoms than the actually disease, like; those who think weight loss or lack of appetite comes from their newly arrival in a new country with new food and culture rather than being a classic symptom of TB. This will be addressed and discussed in more detail later in the thesis.

According to Kleinman, whether we understand a condition as disease or illness, models of these are used to explain five topics; cause of the disease, the outbreak of the symptoms, the pathophysiology, the duration of the disease and the treatment (Magelssen, 2008:43). The explanatory models are influenced by history, sociopolitical and cultural situations and linked to values, beliefs and actions of individuals. It has therefore been important to include chapters discussing these issues in the thesis to try and see the bigger picture of the au pair's illness management from their experience but also from the host families' view. Trying seeing it from different sides can help all involved to cooperate about the patient's treatment outcome and reduce non-compliance. This is relevant for the au pair/ host family relationship but also the health care profession towards both au pairs and host families.

The term *curing* is understood as the effect of treatment for a disease, either physically or physically. The term *healing* is understood as creating personal and social meaning in relation to those life problems that comes with illness (Kleinman cited in Magelssen, 2008:46). Traditionally healing has been associated with traditional medicine by those in bio-medicine, however, it is now widely accepted that to be able to deliver holistic health care to the patient, healing is an important part of that. Both curing and healing can be seen as having an equal outcome; making a sick person well.

However, there are critiques to Kleinman's explanatory model. Transactions between the models should not only be about the HCW transferring knowledge to the patient but rather an exchange and sharing of information. For the model to work it should be an equal relationship between the HCW and patient, there should be a symmetry of power between them. However, the power relationship is not equal between the HCW and the patient; the meetings are between the helper and the helped, ethnic majority and ethnic minority, those with high status and those with low status, man and women, those educated and those with no education those who speak a language and those who do not and so on. As Young argues, the model has too much focus on the individual level and less on the social and political aspects, and too little emphasis on how diseases can be distributed unevenly in society (in Magelssen, 2008:45) introduced a third term *sickness* that is the process that makes the terms disease and illness into a social phenomenon or the social process that surrounds the disease and illness. TB is a good example to illustrate this phenomenon with its history, social stigma, and how social as well as political issues influence its spread in the world.

Illness and Stigma

Stigma is a term that comes from Greek, and was used to describe a sign or mark on the body that was burnt or cut in to the skin to mark a person who was a slave, criminal, traitor, or was seen to have bad moral. The purpose was to show that these persons were different in a negative way from others in society and should be avoided, especially in public places (Goffman, 1963). Goffman (cited in Sajjad, 2011: 547) describes the term stigma as it is used today as related to the feeling of shame associated with this mark rather than the bodily marks itself. Social stigma is disapproval or discrimination against a person because of characteristics that distinguish them from other members of the society. It can either be a physical characteristic, like a disability or a group characteristic like ethnic background or religion (Goffman, cited in Sajjad, 2011:547). What is perceived as stigmatic by one person or a society might not be so by another, as this is influenced by norms, values, culture, and religion. Stigma can lead to either social isolation or a feeling of shame by the bearer of the stigma. Both these consequences of stigma have been experienced by my informants in this study; the feeling of shame and fear of exclusion from social networks and actually being excluded from friends or host family.

Since TB is one of the infectious diseases that kills most people in the world each year the WHO has increased their attention to the disease. This has helped and for the first time TB was on a decline in 2018. According to Helman (2007: 440) among others “attempts to treat TB and control its spread have encountered a number of social and cultural problems”. He argues that the two main barriers to successful control are a delay in seeking treatment and the abandonment of treatment before it becomes effective (Rubel & Garro cited in Helman 2007:440).

TB; a social and a global disease

The reasons for the first barrier, the delay in seeking treatment are many; among them is the stigma that exists around the disease. People often associate the disease with other social problems like drug or alcohol abuse, poor housing or poverty or diseases like HIV and AIDS (Møller et al, 2009, Erstad, 2006). People do not want to be associated with any of these “problems” in fear of being excluded from friends, work or society. People’s fear of this stigma together with fear that they might have an even more serious disease like cancer that might not be cured are some known reasons for treatment delay. This was briefly mentioned in the chapter about the history of TB. TB has a strong association with poverty and social

inequalities, and these inequalities are a risk in itself in developing diseases like tuberculosis (Farmer, 2004). These inequalities like poor housing, poor work conditions or poor nutrition as well as access to health-care are all major contributors to the high burden of TB. As previously mentioned, TB is a stigmatized disease, which research has explored in the context of Goffman's theories of social stigma (Møller et al, 2009). Møller et al (2009:219) found that if persons have several discreditable attributes they would "cover" the dominant stigma with a less damaging one. An example would be that for those with a co infection with TB and HIV, they would often prefer to be open about their TB diagnose because it was seen to be less stigmatizing than the HIV infection (Møller et al, 2009:219).

Illness and treatment management

The second barrier that Helman (2007) cites; the abandonment of treatment before it becomes effective are the main reason for drug resistance. Norway supports the WHO guidelines regarding treatment and recommend it be done by DOT, explained earlier.

"Since successful completion of treatment is associated with good social support from the family, the stigma associated with the disease may be one reason why attempts to control it can fail. Other reason for failure relates to the health care system itself, and the ways that TB clinics are organized." (Helman, 2007:441).

The organisation of screening in Norway is not the major problem. Systems are in place and the government have means to enforce the regulations. Health care workers do however complain of the screening delay of au pairs; the barrier mentioned in the previous part. This was discussed in chapter 2.4.1. about screening. However, the social support from family and friends are also argued to be important. Since the support system upon arrival is limited for most au pairs, how they are able to construct one that helps them manage the TB treatment is fascinating. All families whom the sick au pairs stayed with during their treatment period took care of them as they would a family member, maybe with the exception of one family that I did not talk with. One au pair said this about her family;

"In my opinion I found the most wonderful family, they respect me- I respect them. They are very kind, calm and understanding. I have never heard them shout unless they watch a very good sports competition."

This is a story of an au pair being treated as she should. However, this same girl had endured difficult relationships and assignments from previous host families and was not so positive toward the au pair program in itself. The fact that au pairs do get their contract terminated when diagnosed with TB on a regular basis is terrible. This study it happened to two out of five. There is no statistics on this, but when I asked TB coordinators working in Norway, several reported that the au pairs they had cared for had to move from their host families due to their TB diagnose. As the stories in this thesis will show, this is extremely stressful and does have an impact in illness management if not treatment outcome. Other ways of treatment management will be discussed in chapter four.

Media and public discourse on au pairs in Norway

I briefly turn to Norwegian media and public discourse on au pairs. Scandinavia and Norway in particular, differs from other European countries because of its advanced welfare system, with state-sponsored childcare policies, “including financial support for families and child care benefits and” (Mellini et. al., 2007:49). The consequence of this is that host families most often need help with housework and not childcare, and for many this is different than they expected or they have done in other countries before coming to Norway (Kristensen, 2015). Sollund (2010: 143) argues that the au pair arrangement may serve to re-establish a practice of domestic help that in Norway became extinct in the 1950s. This introduction of the ‘new servant’ as some call au pairs is often debated in Norway, and the au pair program is often discussed in public media and the program has been evaluated by the government regularly, last in June 2017 (Stortinget, 2017). Then the recommendation was to terminate the program in Norway, however this was not the outcome and the program continues.

There is also an ongoing political discussion in Norway about how the au pair scheme has changed over the years and many argue to discontinue this practice. The media has covered this in many angles over the last decade, however only few mentions TB among au pairs (VG, 2017, Aftenposten, 2015, VG, 2015, Aftenposten, 2014, Dagsavisen, 2013, 2012, VG, 2011, Dagbladet 2009, Aftenposten 2007). These articles debate that au pairs are cheap labour, young girls being exploited by middle-class families, often with references to research done in Norway in recent years by others like Sollund (2010), Kristensen (2015), and Øien (2009).

The stories of those au pairs who endure abuse and exploitation are most often written about in the media, and the NGO’s and politicians are quick to tell these stories with headlines like “Workers union about the au pair program: West side slavery”, “Au pair or house-slave?”,

“Au pairs in Norway: the underpaid servants”, *“Exploitation of au pairs in Norway continues,”* and *“Call them maids!”* (VG, 2017, Aftenposten, 2015, Aftenposten, 2014, Dagsavisen, 2013, Aftenposten, 2006). There are those who have been treated badly, like three of the informants in this study. However in my experience I have seen most of those families who follow the rules and au pairs that are happy and content with their host family and assignments they get. In this thesis, I aim to provide a broader and more complex picture of the experiences and dilemmas of au pairs and their host families than what the media portrays.

Research Methods and Data Collection

The study used qualitative research methods in the form of semi-structured in depth interviews, participant observation, questionnaires, group discussions, focus-groups as well as informal conversations. The last method was not described in my research proposal, but became a large way of collecting data during the study. The research time frame has been from August 2017 to December 2018.

Interviews

I have used an interview guide for each interview, when the questions were not relevant, I left them out. I used the interview guide from Bikova (2017) as a guide, and added questions relevant for my research. The reason for this is that I would be able to compare my findings with her study in my analysis and discussion. Written notes were taken during the interview, no recordings have been done. The reason for this is that in my experience, people talk more freely when not recorded. Interviews were transcribed on my computer shortly after they were conducted. If things were unclear, I have been able to discuss this with informants when we met again. I also got the au pairs to read through my written material and add comments so that what I had written is actually what they meant to tell me. This was actually very helpful as they added information that I could use in the discussion.

Participant Observation

Participant observations have been conducted at a number of different sites. However doing field work in an institution like a hospital has been more challenging than I had foreseen. According to Vike, (2003) the use of a method like participant observation can be challenging within a formal institution (Vike, 2003). The reason for this is that the formal organization they have in the hospital and strict rules around confidentiality makes this challenging to use a method of observation. This has been my experience as well; however, I

was able to observe a few of the sick au pairs during check-ups at hospital. I met the informants there; the au pairs, medical officers and nurses and other health professionals like TB coordinators. I was invited to come in during consultations, and I participated in some of them with my main informant. However, I chose not to participate in others because I wanted them to have privacy during this time. Knowing the limited time the au pairs get with the medical officer, but also knowing that information regarding their health is shared in these consultations that were not relevant for my study I made a decision not to participate.

Questionnaires

Questionnaires have been handed out to all 32 TB coordinators in Norway. The questionnaires was handed out in person and filled in on paper, handed back without name to make sure it was anonymous. However, as some coordinators work in the same hospital, with the same statistics and experience with the patient group they handed in only one questionnaire. The total forms collected were therefore 26. This is a quantitative method, not commonly used in social anthropology, however it has helped me collect statistics needed that FHI cannot give me. It also could tell me if the au pairs are more common in certain areas and what experience the different co-ordinator have around the country. As these questionnaires were handed out early in the field work period it helped me recruit informants, both au pairs and TB coordinators that I would talk to during the study.

Questionnaires have been handed out to au pairs who are not sick or have an unknown TB status to get information that they might not give me in person. The aims of the questionnaires were to find out what the knowledge of the disease is among some au pairs as well if there is stigma around the disease. I wanted to get this information from those who were not directly connected to a TB diagnose. They were asked about TB in general, about knowledge and attitudes towards TB.

Focus-groups

I had two formal focus groups with nurses from the Philippines working in medical wards caring for patients with TB. During these group meetings we talked about cultural topics new to me as well as language differences that I was not aware of. This was all relevant for my study. I also learned how au pairs use social media like Facebook and WhatsApp to communicate and help each other during their stay in Norway. They have secret groups that for instance rate host families, they are recommended or not and they have their own “black list” of host families. Knowing that UDI has made an official black list of host families this

last year and put around 30 families in quarantine (UDI, 2016, DN, 2018) made this information very useful. I will discuss this further in the chapter about public discussion.

Consent

I obtained ethical approval from REK (Regional Committees for Medical and Health Research Ethics) as well an approval from NSD (Data Protection Official) for this research project. REK handle applications if the research is regarded as medical and health research and includes personal health information for participants, and NSD handle applications for storage of personal information. I contacted both agencies in the spring of 2017 to plan for my research, because I knew it could take some time to get informants. The conclusion from both agencies was that no application was needed since I was not to store personal information like name and social security number. So I started conducting field work that did not need any kind of approval, like having informal conversations and discussions and observations with collages, friends and at arenas like the Au Pair Centre. When talking to people I was clear that my role was as a student and not as a professional nurse. I got an oral consent from participants unless they were recruited through other professionals, then I would get a written. Since I normally have a role as a professional HCW, I was very clear about my role as a student and researcher when issues related to my study was discussed. When I spent time at my work place, I was not comfortable that a formal approval was not obtained, and this proved evident when I wanted to recruit informants from other professionals. The informants needed to sign a consent form that the professionals could recruit them for this research. A research approval was then obtained from NSD and REK

The Field; Doing fieldwork at Home;

I now move onto introducing my field site and discuss some challenges and advantages of doing fieldwork at home. I have used Raymond Madden's definition of the ethnographic field and discuss his theories in relation to my own field site. Doing research in your own backyard has both limitations and challenges but it also gives the researcher advantages and access in a unique way, that I will give some examples of in this chapter. I have discussed some of Signe Howells critique against doing field work at home. The chapter ends with addressing some ethical implications for my study; that doing research at home can have and the different roles I have to undertake.

The field sites

The field work has mainly taken place in and around the greater Oslo area. In addition, I have conducted a trip to Kirkenes in Finnmark and Murmansk in Russia on a National TB

congress with TB co-ordinators from all regions in Norway, NGOs and staff from FHI. The field site has been in different locations including; home visits to au pairs and their families, local hospitals, local health arenas in the municipalities, at the Caritas Au Pair Centre in Oslo, at the LHL International office, different seminars and conferences sites, public and private arenas where au pairs or host families are, as well as conversations with friends, family and colleagues.

Recruitment and Getting Access to the field

The informants were recruited in different ways, but mostly through my work as a TB coordinator. Health care workers were mainly collages; medical officers, nurses and TB coordinators at hospitals mainly in the greater Oslo area, municipalities and home care nurses offices, or through agencies that I would normally collaborate with through my work, like FHI, LHL and Caritas Au Pair Centre. They were asked personally if they wanted to participate, and given information regarding the study in a written letter with the information that they could withdraw at any time during the study. I also sent out an email regarding my study to different people that I expected to talk to before I started my field work with the same written information. In this way they knew I was a student in the set time frame of the study, and that when we talked about the subject of au pairs and TB it was as a researcher, not as a colleague. My main informant was recruited through people I knew and I spent a lot of time with the family on a personal level, alone as well as with my own family. We would eat dinner together, my kids would play with their kids and the au pair would also watch my kids in period of the study, we went on short trips together, celebrated birthdays and other occasions. In this way I could spend time with them as one might have done if living in the field site in a foreign place, this is one of issues that Signe Howell mentions in her article from 2001, when she critique doing field work at home. She argues that it is difficult to spend time close to a family like a “classical anthropological methodology“, or like “commandments” given by Malinowski; to live with those one study, talk the local language, participate in activities of everyday life, thought different situations (Howell, 2001: 18). I would argue that I got to do this at least partly in my field work. I would argue that I got to spend time with the family in various settings, from every day “stress” situations with getting kids to activities and eat dinner as well as social settings, I had access to situations both with and without the au pair present and talked to everyone in the family. I met them at work, at home, in their home environment as well as in the hospital. I have also used knowledge from the society in literature, mass media and social media, history, public information and

political discussions. These additional sources of information become important when doing fieldwork at home (Howell, 2011:22).

The other au pairs were recruited through other TB coordinator who would ask patients under treatment if they would participate. They got the written information, and signed the consent form so the HCW could give their contact information to me and I would call them and arrange a meeting. I then asked the au pair if I could interview the family and spend time with them. I spent some time with two of the families and interviewed one family only once.

Since I am a nurse, and work as a tuberculosis coordinator at a hospital in the region, I did not struggle to get access to health care workers in the TB field. I discussed the topic with several of my colleagues at FHI, the local municipality and at the hospital before finalizing my research topic. I also discussed it with people I know well and who live in my neighbourhood that have au pairs, those who were sick and those who were not infected. I got positive feedback, and it helped me finally decide on this topic. I took two years leave from my work to do the Master's degree, and in this way I did not recruit my own patients. Nor did I put my colleagues in a difficult position; I wanted them to choose if they wanted to participate in the study and knowing I was talking to them as a researcher in the time frame that the fieldwork was undergoing. I did my best to make sure they could participate in the study without the pressure of feeling they had to because we were colleagues.

I also wanted to do this independently from my position, not telling those I talked to that I usually worked as a TB coordinator to avoid informants to tell me what they might think I wanted to hear. Most informants got to know my position at a stage in our conversations, but this mostly happened during informal talks at the end of my research period. I got to know many of my informants quite well and I felt as if they did not keep any information away from me, and many have also got to read sections of the paper to make sure that what I have written is what they meant to say. This because I did not record any conversations or interviews, all information was collected as written notes. Things that I was unsure about, I have asked about again, one of the positive things about doing field work at home is that the informants are close by, and the research seems never ending.

Research in my own backyard

Traditionally anthropologist went off to do field work in "exotic" places and study the lives of "primitive" people (MacClancy, et al, 2002, Madden, 2010). There were some kinds of

presumptions that “pre-existing ethnographic fields are out there awaiting discovery, all one has to do is walk into them” (Madden, 2010: 46). When choosing a topic I wanted to do something that really interests me, a topic that I was engaged in and something that made me excited and curious. My experience came mostly from work, but having friends with au pairs and living in an area with many au pairs, I suddenly had chosen a field in my own backyard. Therefore I am happy that there has been a shift within the field anthropology, and doing fieldwork in more urban settings, in the western part of the world, or at “home” has become accepted. Madden (2010: 47) has defined the ethnographic field as a part geographical, part social and part mental construct and explained it like this:

“So, an ethnographic field is not equivalent to a simple geographic or social space, nor is it a simple mental construct of the ethnographer, but it does require both these elements. It is the synthesis of concrete space and investigative space that defines the ethnographic field and gives it its reason for being- it exists to describe, to interrogate, to question, to problematize, to theorise and to attempt to solve questions about the human condition.”

He continues to write that it is impossible to separate the researcher as a person from his/her account of other people, and this becomes even more difficult at home because “the familiarity of home has a way of disarming one’s sense of being ethnographic. It’s difficult at times to maintain an ethnographic perspective in a familiar setting” (Madden, 2010: 52). This is also Signe Howell’s critique of doing field work in one’s own back yard; she argues that it is difficult to relate to everyday situations as something marvelous when these situations take place in known environments (Howell, 2001: 21). I can relate to this, and I have struggled to make boundaries within my fieldwork, as it is not a new arena within my home area. My fieldwork has been conducted where I work, live and spend time, among colleagues, friends and family. I did meet new people of course, and spent time observing, interviewing and talking to strangers, however it has been done in familiar setting within my home environment. Madden (2010: 54) defines home as “...a mixture of geographical, emotional, social, and cultural components, which are brought together under the rubric of familiar”. I found the familiar in my culture and the un-familiar among the au pairs. This can be challenging because it is easy to see the culture that is “different” from one’s own, and harder to see one’s own cultural background and analyze it.

Ethical Considerations

Locations for the study have been different health care facilities, from local and regional hospitals, to home care nurse office, and the infection control offices in the municipalities. I have worked at several of these institutions and it has made access to staff easy because people like to discuss the topic of Au pairs and their experience with this patient group with me. They already trust me, and know me as a colleague or friend.

This also poses a potential ethical dilemma; do they talk to me as a co-worker or as a researcher? I have tried to distinguish my roles during the research period, and repeated the fact that informal talks and discussion with them is how I collect my research data. In the beginning of my research period I sent out emails to institutions and colleagues with information regarding the study, and when doing more formal data collection like discussion groups I have handed out the information /consent form in paper as well (Appendix 1). At seminars and conferences I have presented my presence as a student doing research. Access has also been easy in these settings as well, since those attending are working within the TB field. Many know me and my involvement in this patient group, so the interest and willingness to answer questions and discuss the topic with me has been high. More often than not people have contacted me and asked me about the study, rather than me finding someone to ask questions to. I have handed out questionnaires, one to all the TB coordinator in the country, another to au pairs who have not been sick or infected with TB. The response has been good on all the questionnaires. So the access has been easy however the conditions that the access is gained can be argued because of my role as a health care worker. In all these settings I have been able to set boundaries. It has been challenging for the reasons mentioned, being a co-worker and colleague, I have to wear the right hat at any given time.

Moving the field work to my local area has been most challenging. Doing observations within homes sometimes where I know the host parents, have been blurred. This was also Howell's experience; "My distance to the field became blurred" (Howell, 2001:21). However, they have all given consent and are fully aware of the extension of the study. Here again the access is easy, because they are not afraid to open up to me, because they trust me. The ethical question I have asked myself is; are they telling me more than they would like to be exposed? How can I tell their story and make sure everybody is anonymous? What information can I share? These questions are not unique to me. Anthropological researchers has become close to their subjects before. However, most like Madden (2010) look into

subjects in their home that they are not familiar with. I have chosen a topic and a group that live around me and whom I socialize with in my everyday life. I have suddenly discussed the topic with someone at the 17th May celebrations at my children's school or at home with friends or at friends' houses. The positive side is that my field site is accessible to me, I can navigate it, and finding informants in this group have been easy. I speak the language; I know the norms and the culture which I live in, at least among the host families. But as Howell (2001: 23) also experienced, accepting that these informal conversations are field work has sometimes been hard to apprehend. I will conclude as Madden (2010: 57) does that ...” the process of socially knowing people, was probably as important to the ongoing viability of my fieldwork as any other event.”

[Some limitations to the study](#)

Finally, I discuss home visits to families that I did not know, and those who were recruited through other co-workers. Getting the trust from the au pairs has to some extent been challenging. Three of the au pairs who have been asked to participate declined the offer, and one left the country before I could recruit her for the study. The last one was also a girl who had her contract terminated when her diagnosis was known to her host family. The municipality took care of her housing but she was not able to find a new host family and decided to try her luck somewhere else in Europe. All host families asked were positive to contribute, even if the au pairs thought “they were too busy to participate”. I have talked to four of the five families that had a sick Au pair, and one family that had an au pair that was treated with a latent infection for TB, but who was not actually sick. I have been invited to all homes to which the au pairs lived and conducted interviews and informal talks. Sometimes the children have also been at home. I have talked to the families alone and together with the au pair, so I have been able to observe social interactions within the families. This is true for all, but two families were I talked to the parties separately. I could identify with the families, being a mum of three, working and studying, having a house, living in the area; I was one of them. I did participant observation and spent much time with the family of my main informant. However, asking to visit to observe the other families was difficult for me. It was partly the case of not having that time in the given time frame of this master study, but also because it felt very intruding to ask! I had an expectation that it would be easy for me to get this access, since I am in the same situation as most host families; living in the same area, being a mum of three small children, working full time and pursuing a two parent career. The access was there, and the similarities, however this made me realize how

difficult it was to ask to spend time with them. Everyone seemed happy to talk to me, and participate in the study. However, knowing how time is a limited resource, those who get an au pair are those who already have difficulties finding enough hours in the day. Asking if I could come into their home and observe and “drink coffee” with them on a regular basis over a time, does not feel culturally accepted. So to be able to get the information needed to do the research I adopted my methods to the field I was in; I did not spend so much time in the households doing participant observation as would have liked to; however I spent a lot of time with my informants in other settings outside the home. Another issue that became clearer to me was the issue regarding the children in these families who have not agreed on participation in the study. I did not ask them any questions, and I have not included descriptions of observations including the children involved. Thus, children have been present in the field, but not subjects of study.

I am glad that I did my research at home, and I hope as Madden (2010: 60) do that, “...anthropology ought to muster the same enthusiasm for representing and translating the familiar as it does for the representation of the exotic”.

[An Introduction to my Informants](#)

[Au pairs](#)

The au pairs stories vary widely; from those who live in a supportive host family that embrace the au pairs and regard them as part of the family, often going beyond the formal responsibilities that they have, to those stories where the girls have been thrown out from the families when the diagnose of TB has become known. During my field work, I have been in contact with five au pairs who were or had been treated for tuberculosis. Two of the girls were initially kicked out of their host family, but fortunately they both found new families that took them in and treated them as part of the family. I had very different contact with the five au pairs. One of the au pairs has been my main informant. I have been in contact with her over a period of three years; from she arrived in Norway until she left to live in another European country. She was initially one of the reasons I choose this topic, and I got to know her and the family she lived with very well. The other au pairs I have been in contact with over a period of six months in 2018. I have met them in various settings, mostly at home, both alone and with their host family, but also in hospital. We had informal talks over a cup of coffee, while waiting for appointments as well as more formal in-depth interviews.

I have also spent several hours with au pairs who are not sick, or whom I did not know their TB status. I spent many hours at the au pair centre in Oslo, owned and managed by Caritas, a Catholic Non-Government Organisation. Since I am surrounded by au pairs in my daily life with three small children, I have also got to talk to many au pairs in informal daily settings. My family does not have an au pair in our house, however many of our friends or our kids friends family does. So in my everyday life I meet au pairs when spending time at friends' neighbours or picking up the kids from friends. Some becomes part of the family in many ways, like joining when we have dinner together, go out on picnics, and meet at the beach or in the park or talk together at social arrangements in school and kindergarten. I have often discussed my research, and people tend to be positive and interested in the subject. I find this a bit strange since I know that there is a lot of stigma surrounding the disease, but the curiosity and interest may indicate that this is changing. I have handed out questionnaires to these au pairs also, (Appendix) to get information that they might not tell me in a more public setting. These questionnaires were handed out through those au pairs I know personally, and then they got their friends to fill them in, so that it was anonyms.

Host Families

I have talked to the host families of all the informants in this study. I have had various type of contact with the families and with both host parents, in at least three of the families. I have had the opportunity to visit those three homes and spend some time with them. One family has been my main informants, and I have spent a lot of time in this family, having long and frequent conversations regarding the topic of this study, alone with the host mum or dad as well as with the au pair present. The conversations and observations done in this family have been done over time, and have been more informal than the interviews have been.

Two families signed contracts with the au pair after diagnosis. The au pairs had been kicked out from their previous family when they were admitted to hospital. One host family was looking for an au pair and found her through an agency; the two other families were connected to the au pairs through accountancies/friends. All families reported to have a strong and positive connection with their au pair. Four of the five au pairs I talked to did not have their own apartment or "hybel", but their own bedroom and access to their own bathroom. Since none of them had their own kitchen, most meals that was eaten together when at home at the same time. All felt that the au pairs were an integrated part of the family. They had all come with the family on short trips like to the cabin or abroad, and had the choice to be with them when they felt like it. Despite having many friends they often spent

time with the family in the evenings and weekends, and joined all social arrangements like birthdays, Christmas, 17th of May, or special days like confirmations and baptisms. Three of the host families had decided to get an au pair when they had their third child, one family when they had two children and one when because he got divorced and he and his wife had one child each. None of the families was new to having an au pair when they had one that was or became ill during the stay.

I have talked to other host families who have au pairs who are not ill, including a family who have had an au pair on preventative treatment for TB. This treatment is for those infected who are not yet developed active TB, it is the same medication however less and for only three months. These families have been included because I have found their stories relevant to describe the complexity regarding the au pair scheme. The information has been collected through informal conversations with host families in various settings.

Other informants; Health Care Workers and NGO's

I have spent several hours talking with colleagues regarding my study. I have also discussed the topic with healthcare workers on different conferences and seminars I have attended during the past year. When I have told people what my research topic is, the comments I have got have been very varied! Most comments are positive and most health care workers find the topic very interesting and important. Many are curious, especially about the number of au pairs affected with TB, even within the small environments that work with this patient group. I have visited the local municipality and talked to the primary health care nurses and medical officers that conduct the screening, trace investigations and give information to the au pairs and host families in most issues regarding TB. I have talked to and conducted semi structured interviews with several medical officers and nurses working within infection medicine in both local and regional hospitals. I had the opportunity to talk to all the medical officers who had been responsible for the au pairs who were treated for TB in the study, and I got to be a participant observer on consultations with two of them.

Dealing with the Diagnosis

In this chapter I will tell the story of how the au pairs experienced being screened for TB and what happened when they got the TB diagnosis. Their stories tell us who they spoke to, were they found help and support in these first few weeks after diagnose. The way in which they use the little network they have and turn the situation into something positive in spite of challenges faces it remarkable. For two of the girls the TB diagnose was a major shift in their

status as their contract with their host families was terminated. This influenced their visa status, but in two different ways; one got diagnosed within 24 hours of arrival in Norway so she had few rights, and the other got diagnosed after a few months which meant she had more rights when her contract was terminated. These differences will be discussed in more detail, also looking at how this experience influenced their illness management. The other three au pairs included in this study had very supportive families when becoming ill. Even if their stories tell us about fear of transmission within own family and suddenly having an au pair to care for instead of getting help from, the stories still show compassion and responsibility towards the au pair the way the agreement is intended to work. The stories have similarities, however, they differ widely!

Joe

Joe has been an au pair in Denmark for two years. She is 24 years old and does not want to return home, so she has got a host family in Norway and is moving north. The new family in Norway does not need her until after the summer holiday, so she decides to go home for the summer and spend some quality time with her family in the Philippines before starting a new adventure in Norway. It is a Sunday evening in August, the Norwegian host family meets her at the airport and they travel together in their car to the house. It is quite late, and dark outside so she cannot see much. Even if it's late she gets to meet the children, and have some late evening snacks before retreating to her room after a long journey. The next morning her host mum drives her to the office for Infection Prevention and Control in the local municipality to screen for tuberculosis, which is compulsory in Norway. The test consists of a blood test, taken at this local office. She gets information regarding the test, as well as a pamphlet and a referring to do a chest x-ray, to be conducted at the local hospital the same Monday morning. The host mum has planned her arrival, so that she could be screened immediately after arrival, before taking care of their kids, the youngest under a year old.

“She (the host mum) did not ask me to rest or anything. She just takes me straight to the hospital. I was really tired and jet-lagged. At the hospital they found something on my x-ray, and they admitted me directly. I was put in an isolation room. All the nurses were wearing yellow suits and masks. I was scared. I cried a lot at night. I was upset I did not have a Wi-Fi code so I could use the internet and contact my family in the Philippines and my sister in Denmark. They (the hospital staff) did not get me the code until after a few days. My host family texted their ex au pair, and she contacted my sister because they are friends. They (the host family) also contacted my ex host family (in Denmark) and told them about me having

TB. I am not sure how they communicated, but it made me a little bit angry that they told them, I was not able to talk to them. I think it would be better if I was the one telling them about my TB. I was afraid they would be angry with me. A couple of days later they (the host family in Norway) terminated my contract. Good that you have Filipino nurses at hospital, they helped me. At least I had someone to talk to. After five days I got internet, and I could contact my family and sister in Denmark.”

Communication is central to illness management and dealing with the diagnosis. I will discuss more of this in the next chapter, but mention it also here because this, for this au pair, is central to her possibility to deal with the diagnosis. It was clear that this added stress on top of the fact that she just got a serious diagnose and had her contract terminated; the fact that she senses that people talk about her and her stigmatised disease makes the disease harder for her to deal with. Without a Wi-Fi connection she also has no way of communicating for the first days in isolation, this enhances the feeling of isolation. Joe had severe cavities in her lungs, indicating that the disease is quite serious and she is very contagious. Normally one is isolated for two weeks before returning home. Joe stays in isolation for six weeks. She was worried, depressed. When the family terminates her contract, UDI regulation states that she has six weeks to find a new host family, or her visa is terminated, meaning she needs to return to her country of origin. She needs to meet in person at the local police station first to inform of her arrival so the au pair visa can be activated, and then to report her changed status and hand in an application to stay with a new host family, but she cannot leave the hospital. She registers at an au pair agency; however conducting interviews is difficult when in isolation. When she is let out of isolation, the hospital lets her stay a few days longer since she needs daily medicine given as DOT (Directly Observed Treatment, meaning that healthcare workers need to observe all tables taken) and she does not have anywhere to go. The municipality has the legal responsibility to give shelter to those who need medical treatment, however shelter is not so easily obtained, and the que for one is long. The local support system is activated. The TB coordinator talks to UDI and the police and explain so her visa is extended until she can meet at the station. The Oslo Au Pair Centre is contacted. The centre is run by *Norsk Folkehjelp*, and Joe gets in contact with the lawyer who works there and gives legal advice to au pairs free of charge. Arrangements are made for alternative housing, paid for by the municipality and NAV. Despite serious illness and a rough welcome to Norway Joe is resourceful. She organizes interviews, and finally she gets a new host family through her contact network she obtains in the hospital. She has no social

network in Norway, but she adapts to the situation and uses the resources she has available; the support system in the professional sector. So then the professional sector becomes part of her personal sector where she finds support; with the TB coordinator and the nurses who are from the Philippines and work at the ward she is admitted. They all help her navigate the Norwegian system. The new host family gets information regarding her TB diagnose and what implications her disease might have for the family and their everyday life. They welcome her and embrace her as part of their family.

Jay

Jay is 21 years old. She has been a year in Sweden as an au pair. Her host family has a Filipino network, and she's got a boyfriend in Sweden. She wants to stay close to him and she gets an au pair contract in Norway. She arrives on a Friday. Her new host family lives in a beautiful place, but it is in a small town, being from a large city on the Philippines, she described it as the countryside. It is far from Oslo and further from Sweden than she had expected, it took hours to get here from Oslo. The following Monday her host mum takes her to the local municipality health clinic to do the compulsory TB screening. She takes the blood test, then she is taken to the local hospital to take chest x-rays. The x-ray is negative. She is the host family's first au pair, and quickly gets a good connection with the family. The blood test results do not arrive until after four weeks. It is positive. She gets an appointment at the local hospital. She is informed about TB, and she has to spit in a glass, the sputum test is sent to be analysed, the results will not be ready for at least another four weeks. It normally takes two to eight weeks for the bacteria to grow in the lab and for the result to come back. She likes her new family and does not think too much about what the result will be. She does not feel sick. She does not cough or feel tired. She has lost some weight, but that is expected when undergoing the stress around moving to a new country, getting a new host family, and she also miss her former host family as well as her boyfriend. She finds it a bit difficult to live in this small town; she comes from a large city at home, lived in a large city in Sweden, and she is the only au pair the area. She does not have any friends there so she spends a lot of time with the family and feels at home. The test results come back positive. She has to be admitted to the hospital to be isolated for two weeks. Two months after arriving to Norway she is admitted to a local hospital, isolated, no symptoms, alone. Her host mum comes and visits her in the hospital. The kids in the family ask after her. The family invites her for dinner when she is discharged but they have decided to terminate her contract. They like her, but cannot overcome the fear of the disease. A disease that a hundred years ago killed

thousands of people in Norway, sometimes even whole families. The local support system is activated.

“I was depressed. How could I be an au pair and take care of others when I felt so weak. I was worried. I was alone in the room and I feels like everybody hates me. Nobody want to be in the room, the isolate with me. Everyone is wearing masks and yellow suits, and they do not talk too much with me. They, like... uh... hurry to get out of the room. The TB coordinator visit me every day when I was in the hospital. She talks to me like I was a normal person. We were talking, but not about my sickness. The nurses were very positive. There were some from the Philippines, it was nice to talk to them....if this had happened to me when I was younger, it would have been different. Now it has just made me stronger.”

Here two things are important to discuss; how she use the network she gets while in Norway and how she feels that she cannot live up to the role that is expected of her. It is for Jay as it was for Joe, she uses part of the professional sector; the TB coordinator and the Filipino nurses to support her and help her navigate the Norwegian system in the time after diagnose. This illustrates how the support network spans across boundaries and overlap each other from the professional to the private sector. Health care professionals become a part of her personal sector, because she have limited personal support network, Filipino in particular.

Her contract was terminated, but when she was discharged from hospital, the family invited her for dinner. The kids kept asking when she was returning. They were all sad, but too afraid to keep her with them. Jay keeps in touch with her former host family and is planning to visit when she has finished her treatment, and gets a statement from the hospital that she is cured. When discharged, the local municipality and NAV arranged for an apartment for Jay. This was possible because she had a Membership in the National Insurance Scheme. This shows how the state or nation influences her illness management almost like a surveillance state, but here it did so in a positive way.

She lived in the small town for almost three months. It was hard for her, she felt that everyone was looking when she walked down the street and she felt that everyone was talking about her. There were not many non-Norwegians in town, making it very transparent. This might have been a contribution to why the family felt it was difficult to keep her with them. Even if not everyone knew about the TB diagnose, they were still afraid of stigmatisation from the small community; being afraid of exclusion. Living in small communities in Norway, one is dependent on being a part of the network that exists. Having children also add a factor of the need to protect them against potential seclusion from friends.

The au pair said during interviews that information regarding her disease had been told to her host mum's work place, so "everybody knew". I do not know if this is correct, or how they "all knew", however if this is true it could have made an additional pressure on the family to end the contract. Having Goffmans (1963) explanation of stigma in mind, and how people act in fear of being stigmatized is actually what happens here. I would argue that the decision to end a contract with a young girl that the family have a good relationship with and that keep in touch with the au pair after this is very complex indeed, and would need further research to be understood.

Jay registered at an au pair agency, she was open about having a medical condition, but did not tell about the TB diagnose until the interviews. Many host families turned her down because of this. Finally, she found a new family closer to Oslo. They accepted her and made her very welcome into their family.

Keeping in touch or breaking the bond

Both these girls had their contract terminated when the TB diagnose was known. The major difference is that one kept in touch with her former host family, the other family does not want to talk with the au pair again. The reason might be the time spent with the family, and initially having negative test results. But in both families the fear of the disease and the thought putting their own family in danger of being infected is stronger than the feeling of responsibility of the au pair as a person. A person they have in some way employed and helped come to the other side of the world.

However, one shall not believe that this is always done with a cold heart. During my career I have had many conversations with host parents, very upset about the situation, crying and being frustrated with the fact that they have to make this difficult decision. Many meet the au pairs with anger, as this is often the first response. This was illustrated in the example in the beginning of the thesis. Very often they have told me they feel that the au pairs have "tricked them", that they "have kept information regarding their health a secret" and comments like "she must have known that she was sick" are not uncommon. However, when the initial response has calmed down, they are often filled with regret, sadness, worry and a very bad conscience. This is often a very hard decision to make, and the need to protect their own family will always be their first priority. If the au pair is diagnosed with active lung TB and has spent more than 8 hours with the host family, as is the case in most circumstances, the whole family needs to be screened for TB to check that they have not been infected. This includes check-ups and blood tests from the children and an additional chest x-ray from those

over 15 years old living in the family. This is done within the first week after diagnosis has been made, and if tests are negative have to be repeated after 10 weeks. If the tests are positive, meaning they most likely have been infected they are recommended to start preventative treatment to prevent becoming sick with active TB. If there are children under 2 years old, they are recommended to start treatment regardless, because of their age and high risk of developing active TB if infected. This screening, the time to wait for test results and in some cases treatment of the small children is straining on most families. No one wants to give antibiotics to children, let them take blood samples and go for medical check-ups unless absolutely necessary. The families often report guilt and it is normal to ask oneself many questions. For some this together with the responsibility of a young au pair that needs support is just too much to handle. Joe's host mum was like that. The host mum said something to me that made an impression;

"I will go around being angry with myself for having exposed my children to the risk of this disease, and having to watch them undergo this screening. I am not angry with her (the au pair), it is not her fault, but I cannot look behind my feelings, at least not at this point! It is not fair to her if my guilt is transferred to her through my words or actions, even if it is not my intention. Because when I see her around the house, she will remind me of what the children had to go through and it will stir my emotions around, regardless if I want it or not. It will take me a long time to get a grip on these feelings, and that is not fair to her! She is supposed to be a part of our family, but my emotions will in some way get in the way of that."

I find this reflection honest, not in the way that she is telling the truth, but in a way she reflects upon her feelings and are able to express them. One could say that for her blood is thicker than water, but the host mum finds this challenging and stands in a complex moral juncture. Finding ways to cope with the information regarding the TB diagnose and negotiate ways of dealing with this as a host family is challenging. For her, the host mum, she felt that she was doing everything right in protecting her family against TB, following all the regulations, still she had put her new-born baby at risk of being infected. When a host family decide to get an au pair it takes quite some investment; both economically in that there are fees and costs that they have to cover for the au pair to come to Norway, the time of finding a person they think would fit into their family and emotionally because the whole family is involved preparing the children and so on. There is a built up of excitement before the arrival, and a hope that this person that they will bring into their family, that are going to live with them, take care of their children, and see their most private sphere will be a person they can

embrace in to their lives. Even if Joe had her contract terminated, and that was difficult to handle, it could be argued that it is a fair thing to do. Had the family not terminated her contract, taken her home and experienced what the host mum stated, it would probably have led to a dynamic within the host family that would have been challenging to live with. Here the host mum recognize the fact that stigma is present, actually the fear of the disease itself. Since the au pair would not return to the family until after she was no longer contagious it would not cause a treat to the family. I would argue that it is a stigma against the disease and the person who has the TB disease. This is so embedded in the host mum as a person, she admit that she cannot see beyond these feelings even if she wants to. I would argue; that with her, as with the other families it is the fear of the family being excluded from social networks, school, friends, and activities and so on, that makes her act on the fear of future stigmatisation, like a prophesy as also seen in other studies (Goffman, 1963, Møller et al, 2007). I would argue that this behaviour increase the stigma against the TB disease, and more information and close follow up of host families could prevent this from happening. I will end this discussion by arguing that the built up of excitement around the arrival and the sudden diagnose of TB are stirring emotions around, that might influence the decision making process of the family to terminate the contract. This together with the fact that they have not yet formed a close relationship with the au pair makes her more replaceable?

Different rights

Another factor that is different with these stories and that have a serious effect on the au pairs' rights within the Norwegian welfare system is the time frame. Both families took the au pair to be screened immediately after arrival, before starting work, which is recommended by the National guidelines (FHI, 2009). The screening performed was the same, blood tests and chest x-rays. However, Joe was diagnosed because her chest x-ray was positive; she was admitted to hospital the day after her arrival. Jay had a normal chest x-ray, and had to wait for her blood tests to come back positive, and to be referred to the hospital for sputum tests that takes up to eight to ten weeks to analyse. She was only diagnosed after almost four months after her arrival. Still this is not a long delay but the time it takes to get the results. So why does this matter?

As for Joe who was diagnosed the day after arrival she had almost no rights in Norway when becoming ill. First, she had not had the time to register at the local police office, so that she did not have a valid residence permit and was not a member of the Norwegian National Insurance scheme. She could have risked having to pay for her hospital bill and other health

expenses, this could have added up to be very expensive. However being TB it is always free of charge for the patient. Registration at the police should be done within 14 days of arrival in Norway. Second, she had not worked for 14 days, and received a “salary” or pocket money. All au pairs pay tax and when doing so are eligible to salary when becoming sick. This is to be paid by NAV and not the host family, so even if her contract would be terminated she would have had the right to receive enough money to live in Norway. When she got the TB diagnose before register at the police and before earning any money and paying tax, she had few rights. She was not a member of the Norwegian National Insurance scheme, and could not claim the benefits of the system. However, Joe was very resourceful and that and with the help of the support system; TB coordinator, municipality, NAV, UDI, police and the Au pair Centre all worked together to extend her visa and help her get a new family. I talked to the TB coordinator about what happened:

I visited her several times during her stay in hospital, almost every day. She was crying a lot, her situation was desperate. The first I had to do was to send a fax to UDI and inform them about her TB diagnose, so they can use the law to grant her a visa so she would not be expelled from Norway until her treatment was completed. This is a standard procedure. But at the time I did not know she was not covered by the Norwegian National Insurance scheme, because I was not aware that the au pairs had to register at the police to get the residence permit. I used several days to find the right person at UDI and the police to explain the situation so that they could actually make her visa valid. They wanted her to come to the police station and I tried to explain that she was very contagious and that we could not send her in a taxi with a mask on. The fact that she was very contagious and spent six weeks in the isolation room did not make it easier. The only positive thing about that was that it gave her time to find a new host family. My colleagues and me used our network to help her out, asked around if anybody needed an au pair. In this area, there are always families that are looking for au pairs. But we were running out of time. I talked to NAV to help find her a place to live but in this municipality the que for that is long, people have been on waiting list for several months, it was difficult to argue for her to skip the que.... In her instance a lawyer was contacted at the Au pair Centre, and in the municipality to make sure she got the benefits she was entitled to. When she was ready to be discharged from hospital she still had no host family, but the municipality had arranged for accommodation for a week, in a hostel, and hoped she would be able to have interviews and get a new host family within that time. It took many phone calls and a huge effort from the municipality to make that happen. The municipality health officer was positive to find a solution, which saved her. The police was notified about the situation, and that granted her an extension and UDI granted her a

temporary visa. She found a new host family a few days before her discharge, through her network. She informed them about her diagnose and I met with them to inform about the illness and what way it might impact their life. The family was very easy going and compassionate, she was lucky.

This statement supports the fact that the system, the professional sector, the health care workers becomes the support network and safety net for the au pairs in the first few weeks after diagnose, especially if they have little or no personal network in Norway. The au pair cannot manage to navigate the complex Norwegian system without the professional sector with the professionals to build a support network around the patient. In this way the regulations can work well in favor of the au pair also; having a TB coordinator to coordinate within the system, building up around the patient in the time after diagnose. When this works, and all sectors involved, like the health sector, both regional and local, UDI, NGOs and so on work together for the best of the patient I would argue it is a good support system. Thus I will continue to argue that this demand professionals who also know how to navigate the system in the best interest for the patient when they belong to a marginalized group with special limited rights in the system. When an au pair applies for a visa or want to change a host family, the host family is checked to find out if they are in a disqualification period. This is done to protect the au pairs against families that have broken the rule earlier. To complicate the situation further, the au pair when applying to change host family, has to pay a fee. This is almost equaling to a month of pocket money (5300,- NOK in fee and 5900,-NOK is pocket money) and is to be paid by the au pair, unless they can make a deal with the new family to pay the fee. They also have to meet in person at the local police office to hand in the application to change host family (UDI, 2019). There have been suggested that an au pair visa should not be linked to a host family, but rather be linked to the au pair itself (Stortinget, 2017). This have been discussed in parliament, however, wish to protect the au pair from potential abuse is stronger than coverage of certain rights (Stortinget, 2017). Journalen (2018a) a newspaper for Oslo-Met University tells a story of an au pair who changed host families and waited for her application to go through and by the time UDI had processed the application, they found out the family was in a disqualification period. From the time she had left her first host family until she got the notification she had been without a valid host family for too long and hence lost her visa rights and she had to leave the country (Journalen, 2018a). This story can be compared to Joes' story because she also was at risk of having to leave the country, since she was admitted to hospital for a longer period than permitted by the

UDI to obtain new host family that would make her visa valid. She was not able to meet at the police station to get her residence permit or to hand in a new application until she was discharged from hospital. Neither was she able to conduct interviews with potentially new host families, while in isolation. She had no money as she had not yet stayed with her original host family and she did not have the money to pay for a fee to register with a new family. However in the end she got a family and negotiated for the fees to be paid by them. She got help from the TB coordinator to extend her visa and a network consisting of both the personal sector, as well as the professional sector from Kleinman's exploratory model (Belqaid et al., 2018). TB is the only diagnose covered in the Norwegian law system that allows a person who are under treatment to stay in the country until treatment is finished and the patient is regarded cured (Utlendingsforskriften §17-14, 2009). If she had suffered from another serious disease like cancer, or infections that would also have her admitted in isolation she would not have been able to stay in Norway. What also helped Joe being able to stay in Norway was having the TB diagnose which activated a support system around the patient such as a TB coordinator, who would draw help from a team of health care workers and other professionals from the professional sector (Belqaid et al., 2018). I would argue that this window of being unprotected from the benefits that are supposed to help them should be evaluated and discussed further.

As for Jay, she had been in the country for almost four months when diagnosed with TB. She had become a member of the Norwegian National Insurance scheme, she had earned money and payed her taxes so the local municipality and NAV could support her, she got help from mainly from the professional sector of Kleinman's exploratory model. She got an apartment, and they paid for her living expenses so she could look for a new family. She was discharged after two weeks, and her family did not terminate her contract until after this. That gave her time, the six weeks needed to find a new family before her visa as an au pair was no longer valid. She had the opportunity to contact the police and UDI and get a visa extension and time to find a new family.

Looking at both stories in regard to the first research question; "*What do au pairs from the Philippines living in Norway perceive as their support system during their TB treatment?*" the two stories have similarities but differ. In answering one sub question; *who are there so support them when diagnosed, and in the treatment period?* Joe had no relation to her first host family which she met for less than 24 hours. They terminated her contract within the first week, and she never saw them again after she was admitted to the isolation ward. But her

second host family was very supportive. They were not scared of TB; the host dad even told me his father had TB when he was young. Having grown up knowing someone who had the disease and became well from it might have impacted the way they handled the situation as well. Jay on the other hand got support from the host family when diagnosed and when in hospital. The host mum came and visited her in hospital and she was invited to the family's house after discharge too. However, they could not cope with the disease, and choose to terminate the contract with Jay. This might have had several reasons, being a small town where everybody knew about the TB diagnose. They might have been afraid of stigma from the small community.

The second sub questions; *How does this support affect the au pairs?* The way these two girls did not get support from their first host family in the way that they both got their contract terminated had major consequences for them in the first phase of their illness. It was hard for both to manage the disease. Getting diagnosed with TB, being ill and isolated is a huge stress factor in itself, having to figure out your future in top of that is very difficult. They both used the word depressed about the period they were admitted to hospital, and talked about crying a lot. Stress is not a contributing factor to illness management so this factor did not help healing. One could wonder if this was a contributing factor to being infectious for so long together with the physical fact that Joe had a major cavity that normally takes a long time not to be contagious.

The last sub question I would discuss is; *do they feel support from health care workers (HCW) at hospital during isolation and during treatment e.g. doctor, nurses TB coordinators and home care nurses and what felt supporting?* Both au pairs got their main support when diagnosed from the professional sector, from health care workers that could navigate them through the system. Both found great comfort in talking to the Pilipino nurses working in the hospital. Having something familiar in a very unfamiliar situation was very important to them both. Joe had no internet so she was not able to connect to her family abroad, this was very hard for her to handle. Belqaid et al (2018) argues that "With the diagnosis of a disease, the individual's role as part of families, social networks and communities in the personal sector may be altered, depending on the course of events in the professional sector and how the cultural context and social networks view the disease". This is illustrated well in both the stories told here. Jay was uncomfortable about the strict regime for the visitors, wearing the gloves, masks and coats. She felt alienated. They both found support from the TB coordinators. This role is mentioned by all interviewed in this study as an important success factor for managing the period of diagnose, hospitalization and settling in when discharged.

But these two au pairs talked about the TB coordinators in a very positive way, smiling when mentioning them indicating that they might have been a major support person in their initial phase of illness management.

When one of the political parties wanted to ban the au pair agreement and this was discussed in the Norwegian parliament in 2017, it was suggested for parliament that the au pairs should be protected by the Working Environment Act (Arbeidsmiljøloven, 2006), however this was not passed, because they argued that the regulations from UDI should cover the rights needed when being an au pair in Norway (Stortinget, 2017). I would argue that these rights are a good protection, and they are adjusted to the situation that the au pairs are in, that are different from a person in a work situation. However, there are still gaps in these regulations that do not cover the au pairs in all situations that the AML would have done if they were covered by this law as well. The au pairs in Norway do pay tax for the income received, so the AML should also cover them in my opinion. The examples regarding Jay's lack of certain rights are an example.

However, the laws state that if you arrive in Norway on a valid visa you are entitled to stay in the country until your TB treatment is complete (Utledningsforskriften § 17-14, 2009). The municipality that you live in must ensure you can receive this treatment, but also benefits to be able to receive it, like housing and money for daily living (Helse- og omsorgstjenesteloven, 2011). However, most laws are open for interpretation and lawyers within the system have different ways of doing this.

Cat

Cat is 23 years old. She is an au pair in a family, which previously had her aunt as an au pair. She spends most time at home, and enjoys being together with her host family. She feels part of the family, like a "big sister", or "little sister, since I am so small" she giggles under our conversation. When she arrived to Norway she did not have a resident card, so the screening was not done immediately upon arrival, but within a few weeks she recalls. She went to the local municipality health office to take the blood test, and got a referral to do a chest x-ray the same day at the local hospital. Her aunt took her to the different places, her x-ray was normal. After a few weeks she was informed that her blood tests came back positive and she got an appointment at the hospital, but not until about three months after her arrival in Norway. She was informed about TB and she had to spit in a glass, the sputum tests were sent in for analyses. Three months later she was called and told to go to the hospital immediately,

because they had found something in her sputum and she had to be admitted. She got very frightened; she called her host dad who came home from work and drove her to hospital. She was transferred from the local hospital to a regional one since they had found some bacteria that were resistant. She was isolated in the hospital for three weeks. She got information from the doctor, but was very afraid to tell her host family because she was afraid they would “let her go”. Her host dad who drove her to the hospital was informed by healthcare staff and herself, and he was very supportive. During her hospitalization they came to visit and brought her food and magazines. Her aunt also visited regularly. She had three friends who also came and visited her; they were not afraid of the disease. One was even a nurse, and she talked a lot to her. She felt sad and depressed during the isolation time in hospital “...but most of all I was bored” she smiles. Before her diagnosis she had no symptoms, and she states she still does not believe that she is sick. The side effects from the treatment make her sicker than the disease. She is often dizzy, nauseous and even vomits a lot which has caused her to lose weight. She also has to sleep more during the day, in the beginning she slept at least two hours after her medication. The family is very supportive, and she feels very welcome.

The host parent had this experience from the time of diagnosis;

“She (the Au pair) called me at work. She was really upset. She told me they had called her from the hospital and asked her to come there straight away, and that she would have to be admitted for a few days. Of course I drove her there. We were met at the entrance by health care workers with masks dressed in yellow clothes. They just took her away. It felt very overwhelming. I got to talk with staff in the hospital, but it was not really clear to me if she had TB or if it was just a high risk of her getting TB. I went to visit her in hospital and brought her food. I was not prepared for the equipment that I had to dress up with; mask, gloves and yellow clothes. One day she lived with us, the next day I had to dress up to see her. After a few days we found out we could meet outside. Then we would sit there and talk and I did not need all the protection gear.”

The host dad told me they never considered terminating the au pairs contract when she was diagnosed with TB. They (both host parents) said they were in shock when learning about the disease, and found it uncomfortable to think about that their children could have contracted TB. However, even if they were worried for their children’s health they were also worried for Cat. When asked if they ever considered terminating her contract due to the TB diagnose they both instantly said no during the interview. None of them could imagine that someone would throw someone out of their house because of it. It had” never crossed their mind” the fact that the host dad came to visit her almost every day, brought food he knew she liked and spent

time talking to her confirms this. To take the time in a very often hectic lifestyle, working in a demanding job within finance, having three children taking the time to give the au pair support in this way is quite remarkable in my experience. Knowing how most people find it very terrifying and scary to come to the infection ward, having to dress up when visiting and still taking the effort to do so in a hectic day show the way this au pair truly was a part of their family. The host dad was excited when he told about how they have found a way to meet outside, so that he did not need to dress up when he visited. This family's former au pair was this au pair's aunt. They had already formed a good relationship with the aunt, and when the niece, the newly diagnosed au pair, came to live with them, they already had a connection. This connection and the fact that she had already lived with the family for almost six months when the TB diagnosis was made, makes the ties and bond between the au pair and her host family stronger and therefore less likely that they would terminate the contract due to the disease.

Mary

Mary is 28 years old, she is highly educated with a bachelor degree in Arts and English and 2 years work experience in a Japanese firm in the Philippines. She used to love her work, but the salary was not very good. She wanted to travel and see the world, and her aunt had been an au pair in Europe and convinced her to try it out. Mary has not been home for 5 years now; she has been an au pair for two years in Denmark and one year in the Netherlands before she came to Norway. She took a CT scan to look for TB in the Philippines before coming to Europe. In Denmark they did not screen for TB. However, in the Netherlands she had to take two chest x-rays to screen for TB. She knew a lot of people with TB in the Philippines, it is very common there. Her mother and grandmother had both been on treatment for TB when she was younger, and she knew many who were sick when she was in high school back home. When she arrived in Norway she got a letter in the mail with information about the compulsory TB screening with a place and date to do it. It was very easy to go there, she took a blood test and a chest x-ray at the same time and place. The chest x-ray was normal but her blood test came back positive after a few weeks. I went for check-ups at the hospital, but nothing more. My host family did not mind me going to screening or hospital, but they did not go with me. They think I am an adult, and they trust me to tell them if anything is not normal or if I need help from them. When she was in Denmark she was not home sick, she felt she was part of her host family. They were wonderful; they made it easy for her to be

there. Her aunt had been an au pair there before. When she arrived in Norway, it was different, she was a bit stressed.

“My host family had two children, and even if the family was nice I could not manage the children. I felt stressed; I could not sleep at night. I felt alone, dealing with everything alone. It was just too much for me to handle. So after about six months I decided to find a new family. When I had lived with my new host family for a while my lymph nodes started to grow. I was feeling very tired all the time and I was worried because I did not know what was wrong with me and I thought that I had something serious like cancer. I went to the host family’s house doctor (GP). He was reluctant to do a biopsy but I was referred to the regional hospital. They took a biopsy that came back positive for TB. I was not admitted to hospital because I was not infectious. I was worried that my host family would be upset when I told them about my diagnosis, but they were very supportive, and that was a big relief for me.”

Mary use her personal sector to take charge over own health. She understands that her stress level is too much and aside from crying and feeling depressed, she now has swelling on her lymph nodes that are coming and going on her neck. She needs to do something, and she takes charge of her own illness management. She understands that in order to be healed she needs a different support network and home environment. She is able to use her personal network to find a new host family, conduct interviews, terminate her contract and apply for a new family. Her new host family was a divorced man with two children, one child lives with the mum overseas and he lives with a teenage son. He has remarried and his new wife and children also spend time in the household but not all the time as they go to school in another area. They spend most of the time as a family in the weekends. He travels a lot with work and then the au pair is home, which makes her feel like a big sister or almost like a “mother” to the boy she says. She felt very supported when diagnosed:

“I sat down and told them about my TB diagnose, and how they had search for the bacteria and found it. And I told them I was not contagious. But when I told them they were very supportive and it was a relief when they were so supportive towards me. And they did not treat me like a sick one but helped me a lot and let me rest most of the time when I was having my medication. They were also cautious that I do not handle food when necessary, especially when my lymph node is leaking. The family did not make me feel like I am kind of dirty (laughing)”.

This au pair has a very good relationship with her host dad and the new family. She was worried to tell them about the TB diagnosis, here again the fear of stigma comes through. Her host dad explained that he arranged for an appointment with the family doctor, but did not go there with her. She was referred to the regional hospital, and all tests were done there as an out-patient. When she got the TB diagnosis she told him, and she had an information letter from the doctor with information about the disease and that she was not contagious. When asked if when her symptoms had appeared, he said they did not manifest itself until she moved in with his family. When her lymph nodes started to grow, they made an appointment.

Noe

Noe is 24 years old; she has been in Norway for about six months. She is the youngest of three siblings. Her brother is a police officer and his best friend has been an au pair in Norway. Her visa is about to expire, and she wants Noe to come and be an au pair in the family where she is. Noe says she did not really choose where to go, this was her chance if she wanted to travel and earn some money overseas as an au pair. She came to the family in a busy city; they live in a huge house and have two children. Her days are busy, and she has a lot to do during evenings as well. After about two months in Norway she got a letter in the mail informing her that she needed to go for a TB screening; she did the blood test and chest x-ray at the same time and place. They could see something on the x-ray, so she had a CT scan too. After about a month her blood test results came back positive and after three weeks she took sputum tests. They called her after 2 weeks because they had found TB bacteria and she was admitted to an isolation ward in the hospital.

"I had no symptoms of the disease, and I did not feel sick; still I had to stay in isolation. I got very depressed in the hospital. I was upset and I was thinking: where did I get this? They were nice to me in the hospital I got a lot of information. I only had to stay there for six days, because I was not so contagious. I was very worried that I could have infected the children. The whole family had to be screened too! But they were all negative. I felt a lot better when the doctor explained everything to them. They have been very supportive. My host mum said to me: "we are not mad at you; we understand that this is not your fault." They always offer to come with me to the hospital, but I go alone. I feel this is very private."

When the au pair is dealing with the diagnosis, many questions arise. Like; Where did I get this? How could this happen? The situation is challenging, but even more so when in

isolation from the world. They have a lot of time to think when in the isolation, and for some this is very frustrating and even depressing. When informing the patient about the diagnose, the HCW is most interesting in informing about the disease, however the patients are often most interested in knowing how they were able to contract TB and how those around them will react to them being sick (Sachs cited in Magelssen, 2008:41). This is something I have come across often in my career but also in this study. Hearing what the medical officer is informing the patient about her diagnose, however, the patients are not listening. They are in a state of mind that is not ready to take in this information. They have different ways of expressing uncomfortable situations, pain and illness. The information given is often good, I have been there, heard the same, however if your mind is not there to take it in it does not matter how good the information is given. I will discuss this further in the next chapter about communication. Also the patient might not really be concerned about their own diagnose. Like Noe who had no symptoms, they cannot believe they have something so serious without having any symptoms. Their concern might be about, for them, other pressing issues. Kleinman also discuss this in his exploratory models, how one are concerned about different things in different, therefor the effort of being cured or heled might be put on different things. In a way many are in denial of being sick, they do not believe it. This denial can take the focus away from getting well and disturbing their illness management. This au pair was diagnosed only a month before I talked to her, she had not in a mindset to look back and evaluate her situation as well as the other informants. None the less she felt supported by her host family and friends she already got in Norway.

Three stories of supportive host families

Cat, Mary and Noe all had the experience of support from their host families. None of the host families considered terminating the contract with their au pairs when they got diagnosed with TB. Joe and Jay also came to host families that supported them managing their illness and TB treatment. They were all very clear and in agreement that this support was important for their recovery. When the families gave them support and compassion as a family at home would it was less stressful for the au pairs.

Clinical interactions

This Chapter focus on clinical interaction and communication. What information did au pairs and host families receive? Ethnographic examples will be used to illustrate different attitudes

HCW have had towards au pairs and host families and show how these can influence the care and information given. I will discuss how and what information the au pairs share with the host family, and show how this might have influenced the relations within the host family and between host family and the au pair.

Attitudes toward host families, do they matter?

In all the years I have had this patient group the discussion regarding cheap labour and use of words like servants for the middle class comes up as a topic to argue about. There are always two sides; those who see them as servants for the middle class and those who defend the au pair programme. Those who defend the program can be divided as well into those who see this as the cultural exchange program it is supposed to be and those who have a bit different attitude. I will start with a story with an example of that. I experienced this early in my field work and it made quite an impression on me. The person said this after I had explained why I did the study, and explained how some au pairs got their contract terminated while admitted to hospital.

“If the au pair is admitted for many weeks in hospital, the host family have to get a new au pair to work for them! When she is admitted she cannot work. The family have got an au pair because they have a need for assistance around the house. They need help... and if she (the au pair) can no longer preform her duties, then the family cannot be expected to wait for her to be discharged....”

The lack of understanding and empathy for the au pair is quite shocking to me in this statement. This is a classic example of people who sees au pairs as maids and certainly not young people on a cultural exchange in a system created for them to be taken care of as part of their foreign family. Research discussed earlier in this thesis done on au pairs have written about these attitudes among host families as well, however I have med few that has this attitude myself during this research (Hess & Puckhaber, 2004, Sollund, 2010).

One of my informants had similar experiences with her first host family:

What expectations did you have about being an au pair and is your experience different than your expectations, if yes in what ways? Do you feel that you are part of a cultural exchange, is that your goal for being an Au Pair?

I was 20 something when I arrived in Europe. I was young and scared. I was expecting it to be difficult. I had to get used to a new culture and family. I do feel it is a cultural exchange, but maybe 50/50 also as a domestic worker.

Can you explain more why you feel like this?

I feel this way because I worked like one. I have to clean toilets, mop floor and do most of the entire household task and also taking care of the child and walking the dog and grocery shopping, dinner etc. And it was kind of expected of me to do. When I applied at the embassy from the Philippines I know all the rules (what to do and not to do) but, every time the host family asked me to do this and that, I feel so afraid to argue since I am living inside their house and scared to be deported back to Philippines. Maybe they also thought that is ok with me doing what they asked since I do not complain but that, I do not know. I have no Idea what could have happened if I did complained, if things will change or something but I guess it will. I once told them that I was so tired thinking what to make for dinner every evening and also doing the shopping. The family understood and the next day they are the ones who decides what we are having for dinner. What if I told them about all the cleaning?

Obviously the au pair felt she had too many chores and was too afraid to communicate this with the family. She does question what would have happened if she had told them how she felt. When she told them about the shopping they seemed to understand and shared the responsibility with her. This happened just before she moved to a new family and before she got diagnosed. Could one argue that she was tired due to her disease and the household chores seemed overwhelming for her in a period of time? Communication between them might have solved the situation. Also what kind of expectations did they have to her and what assignments needed to be done and what she had expected to do probably differed as well? The issue of power relations is also evident here, Sollund (2010) in her study that au pairs work load was often more than the agreement and this was difficult to set the boundaries because the au pair live within the family, and “they work all the time”. I argue that this was this au pairs experience as well. This au pair did say she was happy she had experienced this, she was now very happy in her current host family.

During conversations with medical doctors in hospitals that are responsible for screening, admission, treatment and follow up consultations of the au pairs, but also host families if needed I met a lot of frustration. Many are personally against the au pair scheme as they see it as exploiting young girls, using them as maids. However, the attitudes they often meet among host parents are often shocking. When au pairs are under examination or treatment the medical doctor is most concerned about the au pair; the patient. They expect them to inform the host families with the information they get, and share what they are comfortable with, and they are not obligated to share any information. The healthcare system is responsible to

inform persons around the patient if needed, like regarding infection and transmission. The comments that I have received during the study, is however that the au pairs seldom share much information with the host family regarding their disease. Sometimes the reason for this is fear of losing their contract, but more importantly because it is often difficult for them to grasp the information they get regarding themselves in the first place, trying to explain it to another is difficult if not impossible for many. So the host families often feel that the information given is non-existing, many are scared of TB, few know much about the disease as it is today. In this fear or lack of seeing how their attitudes and behaviours are seen by others they behave rude and inappropriate. One story told by a medical officer is quoted here, sadly this is not a single occurrence.

“Last week while I was writing in the journal after an appointment seeing one of my patients who is an au pair, the door burst open and a man stormed into my office. He looked very upset, he was screaming that he wanted to be informed regarding and demanded to know what was happening to her! He did not tell me his name, he did not knock on the door, nor was he talking to me in a polite or calm manner. I was shocked, and quite honest I got a bit upset and irritated with him. I calmly showed him out of my office, explaining to him that if he wanted to talk with me he would have to make an appointment with the front office like everybody else, and that he could not just burst into my office and act the way he did. Of course I understood who he was referring to and what information he wanted, but I do not tolerate such an inappropriate behaviour! Who does he think he is? What if I was in the middle of a consultation or on the phone? I do understand the need for him to get information, but he cannot behave like that. If he had knocked on the door and asked me if I could see him for a few minutes, of course I would have given him that. I just get upset about the way some of these host parents act as they own the poor girls and the world, and have the right to get everyone’s attention at the moment that suits them.”

The reaction this host parent have towards the medical officer and the system is not very polite. However, I would argue that it is understandable in some ways. It is driven by frustration and fear for a disease that historically is associated with death, and the need for information and protection of the family make one act not rational. Boundaries that most people would normally keep, are crossed. As stated earlier, many au pairs are not able to give host parents the information they need to be assured that it is no danger for them. It is the HCWs responsibility to inform the host family, but it is a shared responsibility. This is something that can be systematized in a better way to ensure that information is given in a

way that reassures and calms the host families. Unfortunately, many host parents have not thought about the risk of disease imported with au pairs from countries that have a higher incidence of infectious diseases.

One of the host dads from this study was very content with the information he got when the au pair living there got diagnosed. He got a letter from the hospital with information regarding the au pair's diagnosis and he was offered an appointment to come and talk to the medical officer at the hospital he did not feel the need for this, as he had found the written information good enough. He had also contacted the families' house doctor to be screened privately, and he had been contacted by phone from the municipality. They had talked to him on the phone and offered an appointment however he also declined this offer. He felt taken care of by the professional sector. So the information given varies and the need for information also varies, but it should be routine to at least offer a conversation with the host family.

My argument to offer information is that host parents that do not know get worried. When they are worried they get scared, and the relationship between the host family and au pair could change as the need for information grows. This can in worst case lead to them ending a contract because they would feel that the au pair is withholding information. I would argue that in some instances this might be true; however I do not mean that the host family should get personal health information, but general information regarding TB.

Communication good communication is a prerequisite for successful treatment

The written information is available in many languages, including Tagalog (FHI, 2019). However feedback received in this study indicates that the Tagalog version is the hardest to read and understand, because of the many dialects in the Philippines which make translation difficult. This feedback came from LHL who have produced much of this patient information, as well as from TB coordinators and nurses who have given it to patients.

In Norway the screening for TB is compulsory, however if the screening is negative on a chest x-ray and symptoms occur, seeking health care might not be done right away. This was the case for one of the au pairs in this study. The cause for initial treatment delay was according to her:

“When I was with my former host I had no idea that I have TB. Only I was so tired and stressed with the family and having a lymph node growing and then disappearing in my neck made it even more stressful. I think I had cancer, I was afraid of that... they (the host family) were always arguing about the kids and I had too many chorus. I was tired but ...I feel so afraid to argue, since I am living inside their house and scared to be deported back to the Philippines...”

She changed family. When her new host family found out about her growing lymph nodes they immediately made an appointment for her to be checked out. If she had not changed family, and she had not sought help, it could potentially have developed into a contagious lung TB as well. The reason for not seeking help was the fear of losing her contract to the host family, and in worse case losing her visa. However, she did not think the diagnosis was TB, so the stigma to the disease is not the factor here.

Communication is in my experience often a cause of misunderstandings that can lead to actions that interrupt or deviate from treatment. This can have serious consequences for patients who are sick, but also for others since TB is an infectious disease and interruption in treatment can lead to the patient being infectious again. This example told by a medical officer give an example of this.

“There was this au pair I was treating for tuberculosis in the lungs, she moved from one municipality to another. When she was in the last few months of treatment I decided that it was not necessary to give her the treatment as DOT anymore. She told me she felt very restricted by the DOT regime; the nurses coming at different times, and constrains in weekends when she often wanted to stay with friends. She spoke good English, communicated well, and in my opinion was very able to administer the medication by her own. So when she moved to a new area, and the treatment was in the last phase, it was natural to go over to give her a medicine-box for self-administration. I had not informed the new TB coordinator of this change. I got a phone call from her, she was very upset. The TB coordinator had called the girl after she moved to check up on her medication and to ask how the DOT regime was doing. The au pair told her on the phone she did not take her medication any more. When asked why this was, she replied that I had told her on the last appointment: “That all her tests were ok, and she was doing fine”. So when the TB coordinator called me, quite angry and asked me if it was correct, that I had stopped medication, since all standard treatment for TB is at least six months, no exceptions. I told the TB coordinator that the au pair was not to

have stopped medication. That I felt that she was responsible enough and seemed to understand information given, so I had decided not to give her the medication as DOT, but to let her administrate the medication by her own. The au pair was put back on medication, this time as DOT and her treatment was extended for the same period as she had stopped the medication”.

So what went wrong? The information that the doctor had given to the au pair, was indeed correct. Her blood tests that during TB treatment is done every month to check that her body can handle the medications were all ok, and she was indeed tolerating the medication well and in that meaning “doing fine”. However, the doctor did not say she could stop her medication, and she did not mean that her treatment was to come to an end even if she was “doing fine”. So the au pair had even after being given information regarding standard treatment for TB, both orally and written fully understood this. The au pair was highly educated and spoke fluent English, so how is that? It can be many reasons for why this information was misunderstood. For many hearing “they are ok”, and “doing fine” might mean the same as “you are cured”. And together with the desire to stop medications that might give one side effects and discomfort, one wants to hear that one can stop taking the medication. With none to follow up on information given during long periods of treatments this can easily happen. This is backed up in research, by Kleinmann (1980) who also point out that treatment results often depend on the quality of the clinical communication.

One of the sick au pairs in this study also told me something that was quite surprising to me. She did not have any symptoms before she got diagnosed. She was not very contagious, but had a resistant strain of bacteria so her treatment period was extended and the medication she took was more extensive than a normal regime. She experienced quite a lot of side effects, and was very much looking forward to her treatment period to end.

“When I first arrived from the Philippines I lost some weight, but it was because of stress and in the beginning I did not like the food too much...laughing... But now I eat more, I have gotten used to it (the food)... at least most of it...laughing. When I started the treatment I got very sick. I vomited and felt sick all the time. I have headache every day, and I get very tired. I have to sleep two hours in the middle of the day, about half an hour to an hour after I take the tablets. I have to lie down and sleep. I cannot do the work that is expected of me...

What kind of TB do you have?

I am not sure... they find the bacteria only in my blood.

But that is not possible, are you sure they did not take a test from your lungs or other part of your body? Like a spitting test?

I did spitting test, but they did not find bacteria there. I am not sure where they find it.

Do you actually think that you are sick with TB?

(Thinking, looking down). No, I do not think I have TB, but I take my medication as the doctor tells me to. “

During the interview I explained the importance for her to understand where in her body the disease is. It was important for her to see the test results on paper, being explained once more what kind of TB she had had what kind of medications she was on, as she did not know that either. When we met later, she wanted me to come with her to a checkup, and talk with the doctor with her. We decided to meet at the clinic for our next meeting. He was actually quite surprised when I told him she did not know, and he explained her situation for her again. He also promised her to give her a statement in English on completing of her treatment with a summary of her records.

It is important for all patients with TB to understand the disease, what tests have been done, where bacteria have been found and what treatment they have been on. This can be important in the future, because once one has been sick with TB the IGRA blood test will remain positive for the rest of your life, and having TB in the lungs can result in scarring that can show on an x-ray. This is important to know if you have to undergo TB screening later in life, and if not explained can have consequences.

I have had similar episodes happen before, and I see the need for regular checkups by health care workers. When the regulations regarding DOT treatment came in 2003, the regime was quite strict. Everybody was to get medication as DOT. However, many doctors saw this as too strict and very intruding on patients and their private life. Studies have been done on patients experience with the DOT regime, among them Sagbakken (2010) and Stridbeck (2007), and they all conclude that it is very important with individual treatment plans. Sagbakken (2010) would even argue that for some patients the DOT regime was more of a burden than the disease itself, and this is not the intention of the regulations in place. So 15 years on, FHI changed the guidelines again in January 2019. The new guidelines now states that one can make more personal treatment options. Uncomplicated patients and treatments can get medication boxes and self-administrate the medication after the initial treatment

phase of two months. So instead of DOT on every dose taken, a box with medication for one week is delivered to the patient each week. I believe that this option is good for many patients; however, one has to remember that communication is not always straight forward. Asking control questions and getting the patients to come “back stage” in the way that they open up and tell health workers what is happening around them during their disease is essential. According to this study, even among highly educated and those who communicate well, misunderstandings happen.

However getting the information to the au pair is also important. One of the Filipino nurses explained that many of the au pairs she had talked to when admitted to the ward she works as felt that Norway was a cold country. Not only physical but psychosocially;

“When one becomes sick in the Philippines, your family would come and visit you in the hospital, they will bring food, and spend time with you. Here in Norway the au pairs are put into isolation when admitted with TB. The information they get about TB before admission is almost non-existent in my experience. The admission to hospital is mentally straining and they feel frustrated and depressed. They receive few if any visitors, they are alone and scared. They feel the culture-shock as they are admitted. When they get the Wi-Fi code and have a phone or computer they skype with friends and family around the clock. But they tell few or none of their friends in Norway about their TB diagnose.”

So the information given to the au pairs can be better in all levels of the health care system and misunderstandings and lack of communication happens everywhere. Here the Filipino nurse see the problem from a culture sensitive side. She also observes something else; the stigma and the act of controlling information to the social network. So they would share to those who are far away and that will not exclude them socially at this given time. However they chose not to share the information about their TB diagnose to those friends in the close network in Norway. They seem afraid that the stigma of the disease will affect them. I would argue that with good information this should not happen however I have had experience in those who have had friends who do no longer want to spend time with them or come over. This was the case among one of the informants in this study too.

The expectations toward the au pair also differ widely. It might differ with different experience, like if you have had an au pair before or not. All host mums compared having an

au pair in the house with having a teenager. This example show how one can have some role expectations from what experience we have with young girls within our own culture, in this example depending on what age you are.

“There is never anything serious. Everything is always ok. They (the au pairs) always have a nice appearance, always looking well dressed. However, the knowledge gap is present in some areas, especially regarding health. I got a wake-up call when she (the au pair) had just started her treatment. One evening I found her in our bathroom going through our bathroom cabinet, looking for medicine. She had a high fever and was only looking for some Paracetamol. This scared me because my husband is on medication for a chronic disease, and taking his medication could have fatal consequences for one who does not need them. I drove her to hospital where she got some antibiotics. I did not go with her into the consultation. When she came to Norway she was over twenty years old, we (her husband and her) regarded her as an adult and treated her like that. If I knew how little she knew I would have explained more to her upon arrival, like about the health system, the climate, the unwritten rules and so on. So after this experience I kept a closer eye on her. I knew that she needed to be looked after, more like a teenager.”

The host mum also said it was strange that she would not just ask for a Paracetamol, because they had a very open relationship;

“I felt like we (the au pair and host mum) had a very good relationship. We would do things together, like go shopping or eat lunch. I was home with my youngest child who was under a year old, and we spent a lot of time together. She would tell me everything, like personal stuff like when she had her period. However, when it came down to the TB treatment she was very secretive. She told us she went for check-ups, and that she was being treated for Latent TB, but no more than that. I did not ask questions, because I respected her privacy and decision about what information she wanted to share with me. And I trusted the system, so I expect that if we needed to know more; about infection and so on a health care worker would contact us”.

I asked the tuberculosis coordinator who was responsible for this patient, if information had been given the host family when the au pair was put on preventative treatment. She replied that standard information about Latent TB and treatment in the form of the pamphlet form LHL and standard letters from FHI had been given the au pair in an envelope to give to the

family. The envelope also had the contact information to the TB coordinator so that they could call her if needed or if they had question. The au pair never handed this information over to the family. I have had similar experience in the past. Information to be given to host families is not handed over. Once I was to have a meeting with au pair and host mum, this was important because the au pair had a resistant form of TB, her treatment was complicated and expected to last for at least one year, and the all parts involved in the treatment regime had reported difficulties. I arrived to do a home visit and the only one there was the au pair. I got a bit annoyed because she told me that she had given the information, to the host mum, and she did not prioritize the meeting. When I called the host mum, she had a different story, she had never been informed and she very much wanted to have a meeting.

These examples show how important it can be to include the host families more, and make sure the information reach them.

This relates to my research question regarding how they under treatment use their support system. The stories from the nurse about those who do not tell their friends in Norway about their TB diagnose do not get the support they could have had from those who are here. I do understand the fear of losing friends and host families but they lose the support they need to manage their illness. The fact that they tell those back home is also my experience. No one in this study had withheld information to family back in the Philippines.

Support network and consequences of the illness

This chapter will explore the support system around the au pair further, and look at the consequences the illness have had for them. I will look at the expectation au pairs and host families have to the scheme and discuss how this can included illness management. What kind of relationships and kind of kinships develops between the au pairs and their families, and what kind of support have they got from friends and health care workers will be discussed. All patients who are on TB medications are recommended to get this as DOT. This treatment form can feel very intrusive, restrictive and controlling for many patients, but also for the host family, even if they are not the ones who are sick.

Expectations to the Au Pair Experience and reality that meet them

The expectations that the au pairs have to the program differ widely. As have been discussed earlier the mass media have often talk about the arrangement as a way for middle class

families to be able to have cheap “servants” in their home so that both parents can pursue a career at the same time as having small children and running a household (Sollund, 2010). Sollund (2010: 150) argues that because many of the Filipina au pairs send money home, this “underlines that they are migrant workers who have not come to Norway for a cultural exchange”. This is true for some. However only one of the au pairs in this study said she sent money home on a regular basis and that this was important for her family’s economy back in the Philippines. One said she saved all the money for herself and her future and the three others sent money home occasionally. All five au pairs had college degrees and they had jobs in the Philippines before coming to Europe. None of them *had* to go Europe to work, earn money and send home. In my experience within this patient group, the majority of au pairs from the Philippines fall into this category, this seems to be a new trend. They seem to come for the adventure, this I would argue is positive since this is the way the au pair program is intended to be. So how is this relevant for this study? I would argue that it is relevant in the way that these au pairs often are resourceful and what some call “street smart”. This I would argue is a factor to success, also in management of their illness because they are then able to use the network available to them. I have tried to illustrate this in the examples given in chapter three, how they are to find new families despite their limited resources in a new country. So where is this argument going? Back to the expectations these au pairs have had to the program before arrival and what they their experience here actually is. Hess and Puckhaber (2004) wrote about what expectations Slovenian girls had before coming to Eastern Europe as au pairs. They had heard rumors about negative experiences but hoped to be treated like a member of the family and not a housemaid (Hess & Puckhaber, 2004). This was also the case for the five au pairs in this study. They all had expectations of being part of a family. As for one who came to the family were her aunt had been before, her expectations were met, and she really felt like part of the family and spent much of her free time with them, even went on holiday trips and hang out on the couch in front of the TV in the evenings.

Social life and support

Both au pairs who had their initial contract terminated are very social girls. They were very socially active while in Norway, outgoing and spent a lot of time with their friends. They were offered to spend free time with their host families, and did so on a regular basis, like going to the family’s summer houses or cabin in the mountains as well as travelling abroad with them. All the au pairs interviewed also took part of the families’ regular life celebrating

birthdays and special occasions like baptisms and confirmations, as well as holidays like Christmas, Easter and 17th of May. They all expressed that they enjoyed spending time with their host families but rather preferred to stay at home to spend time with friends or family they have in Norway or former countries they stayed as au pairs, like Denmark or Sweden, and travelled there as often as they could. They reported to have a lot of friends and went to the church or other social events to meet them, or they would stay over at friends or family's houses, usually other au pairs in the area. This was also confirmed by the host parents during interviews. However, none of them were particularly open regarding their TB disease. They had told some friends, but confessed that they did not talk about it much and only maybe one or two knew, a handful at the most. This was the case for all the sick au pairs I talked to, and has been my experience from my work as well. I have heard through my work, stories from au pairs who have told me that their friends had turned their back on them when they heard about them being sick with TB. This had happened to au pairs who have had their contract terminated also, so not only do they have to find a new family but their lost friends too. In these cases, they lost all the little support system they had, so I was very curious if any in this study had the same experience and how this would affect them. None of the au pairs in this study reported to having this experience, but they were not comfortable about being open about the disease. Even if they did not tell many about TB, the one they did confess to seemed to be important support persons for them. Some of them even visited the au pairs while isolated in hospital. This is in some way surprising, since it for many is uncomfortable because of the strict dressing regime including masks, gloves and coats that has to be worn at all times during visiting hours, and therefore it scares many away. They all state the host families to be the most important support in daily life, but friends are those they confine to. However, when asked if they discussed the disease with their friends, they all stated that they seldom did. When they had questions they most likely would discuss it with HCWs, or some cases the host family. The findings still support the fact that this is still a disease with stigma, people know little about it and they are afraid of it. The unwillingness to be open about TB confirms this.

All host families had told close family and friends about the au pairs diagnose, but how open they were differed widely. One family had many conversations with health care staff regarding how open they should be. The recommendations given were that they should inform those around them that it was natural to share the information with. However, they were advised to be a bit cautious so that it would not be discussed at school or kindergarden,

this way they would avoid unnecessary rumours which could lead to talk that could exclude the children or family in any way. The host family told me they appreciated the advice given which they had followed, and they had no negative experiences regarding the au pairs diagnose. Another host family told me they had chosen to be very open regarding the au pairs diagnose. The host family told me she had expressed that she was a bit uncomfortable that people knew about her diagnose, but she had accepted that the family wanted to be open about it. The family felt comfortable with the decision to be open regarding this and felt it was important, not only for the family but also as a responsibility for the community to inform people. They had experienced negative attitudes and comments regarding their choice to let an au pair with TB move in, however by answering many questions from friends who had little knowledge regarding the disease most had become more informed and positive towards the decision they had made. When I asked if they had any friends who had stopped visiting their house, or in other way avoided them, the host mum took a pause to think, then she explained that one friend of the family had been very sceptical, negative and afraid.

...” when I think about it, she has not really been her since ... moved in. I have not thought about that... uhmm...she was not very positive towards the idea that we would let a person with TB live in our house, yet alone take care of our children. She did not agree with our decision, but we have not discussed it lately. She is very busy, so she might just haven't had the time to come by... uhmm... but she usually comes around often.”

This conform the fact that stigma exists also among those well educated, and inn all parts of our society from around the host parents who can lose contact with friends and the au pairs.

[Roles and power relations, the use of space and power over assignments](#)

The way the host families do small things can help the au pairs fell welcome and part of the family. The ways things are organized within the family influence what roles they seem to get and how the family and the au pairs see themselves (Cox & Narula, 2003, Mellini, Yodanis & Godenzi, 2007) The roles and power relations that are created around the au pairs not only influence the way they see themselves but how they shape their identity.

During an interview I asked these question:

How does the au pair live within the house? Why have you chosen this arrangement?

“She (the au pair) have her own room in the basement. She has her own bathroom, but the family also accesses and uses this bathroom. She use all the common rooms with us. The two

first au pairs who stayed with us had their own small bedroom next to the kitchen /living room and shared the family bathroom. But then we renovated, and made a more separate space downstairs.”

How come you did not make a flat for the au pair when you did the renovation? Or do you wish she had her own flat, and then you would have your own private space?

“We had the opposite in mind; we want her to be integrated and a part of our family, then she has to share the same rooms with us. She has got her own room, the same as all the children in our family. We treat them all the same. She does not watch TV so much, none of them (The Au pairs) do, they use the internet. So upon arrival they have all received their own PC or iPad, and of course their own cellphone. They have all been very grateful for this. They are a little like teenagers, so it is important to make their rooms nice and homely, that includes having access to TV and telephones.”

This host mum was the only one I talked to during this study that let the Au pairs who stayed with them decide which duties they perform when staying with the family;

“All things (Household chores) needs to be done within the house.... You know, like ironing, dusting, cleaning, washing clothes, prepare food... I do not mind who does what, we all have to do something. So I let her decide which chores she would like to do. All the au pairs we had preferred different chores, so it is better they do the things they like the most. It does not matter for me what I do as long as everything gets done.”

I would argue that having this attitude of shared responsibility for household chores among all members of the family, help the au pair feel as an equal member of the family. She has choices, but she can decide over her everyday life assignments. This is an empowering action, and help young adults grow. I would argue that most families that I know having au pairs have set assignments and household chores they would like to be done by them. In my experience it differs widely how this is done from strict lists with certain days things need to be done to flexible arrangements. This influence the au pairs everyday life of course, and also their feeling of freedom. How the work is planned for and with them impact how the patients in this study cope with the stress and burden of being sick.

[Side effects and work, power to decide](#)

All five of the au pairs asked in the study said to have some kind of side effects of the medication that affected their life of some sort. One reported that it was a little in the initial

phase of the treatment, but it did not really affect her more than that she needing a bit more rest the first few weeks. One was not working as an au pair when her side effects were most noticeable. Her contract was terminated and she was living by herself, looking for a new host family in the initial phase of her treatment when she needed rest and was not feeling too good. When she finally found a new family, most of the side effects had passed. One had some side effects, she needed more rest, but could manage them since they mostly occurred the first few hours after taking the medication, and since this was in the morning/day time so she could rest without feeling it influencing her work too much. One was very burden by side effects throughout the whole treatment period. She was the one on a different treatment regime due to the resistant bacteria. She was very relaxed towards her Host family and even thought she needed to rest quite a lot during the day she did not seem to be too worried that this would affect her role or work as an au pair. She was of course bothered by the fact that she had quite severe side effects; feeling nausea, loss of appetite, tired, headache and fatigue. And she felt her treatment was more of an issue than actually having a TB diagnose. She was in fact the one that did not really think she was sick, it was the medication that made her ill. But getting support and trust from the host family, and feeling part of that family helped her cope, it seemed. Her aunt had been an au pair in the family previously and she was still in the country, so she and the host family were the ones the au pair socialized with. She was the only one not reporting to spend much time with friends apart from her aunt. This was confirmed by the host family who said during interviews that she spends most of her time at home with us (the family), except when she is at her aunt's house. The last au pair was quite ill. She was admitted straight away due to positive results on the x-ray. She was hospitalized for over six weeks and when discharged she got a new host family since her initial one had terminated her contract before she had even lived with them.

The au pairs often get the exploited labor force label, and unfortunately this is true for some, but not for all. Some of the au pairs in this study had their original contract terminated, mostly due to fear of infection and illness. It might be argued that this is exploitation on a power relation, since the family can choose to do this to a young vulnerable person; however, the way these girls came out of the situation and made them stronger persons had a happy ending after all. There was only one of the au pairs that reported that she was not happy with some of the work load she was expected to perform. She was often asked to work evenings and take care of the children in the family for more hours than in her contract. However,

when I talked to her and at the time when interviews were conducted she was still fairly new in the family. In my experience it takes some months before expectations of each other are clarified and good routines are established, and this girl was planning to talk with the host mum to clarify how she felt about the situation. She was a bit uneasy about it, because she was afraid it would cause tension to talk about this issue, but she told me her relationship with the Host mum was good, and she hoped to be met in a positive way.

Earlier research on au pairs have had focus on power relations between the au pairs and host parents, mostly host mums, and roles they get as well as roles they feel they have themselves (Cox, 2015). I wanted to find out if the girls in this study felt the same way, and one of the questions that I asked them was; *What role they felt they had within the host family; a “big sister” and part of the family of as a “domestic worker” an employed?* (Check question ref appendix no) All but one stated they felt like the “big sister” in the family. Three said it with a slight laugh, answering without thinking and giving examples of how this was. Either in the way they took care of the children in the family, how they felt they were treated by the host parents, or how the children in the family looked up to them as “sister”. One was not so spontaneous in her answer. She seemed to think a little about the question before she answered that she felt like a big sister rather than a worker. When I tried to requisition and discuss the subject with her with examples; she stood strong in her opinion that she felt like part of the family. She was using arguments that were good, and similar to the other three girls who answered quickly. However, I still felt like she might want to say that she also felt like domestic worker or employed by the family. This was the only au pair that had only one child to look after in the family, at least at the time as the family was composed of host parents that had divorced, and was living with new partner and had one child staying with them all the time, and the other children only part time. The fifth au pair also thought about the question before answering. She said it was a bit of both. Maybe most like a “Big sister”. Many factors might contribute or influence her answer and the way she felt. She was the only one that was distant from the family in the sense that she had her own apartment or small “hybel” inside the house. Knowing how the sharing of space and meals can influence how the Au pairs feels like one of the family this can have influenced her. Dalgas (2015) also look into these issues of the use of space to define roles within the family.

The family had also said that she was welcome to have friends over, but they had to come to her “hybel”. She was not allowed to bring anyone into their part of the house without permission, or at any time really. They wanted her to have guests in her own space, not in theirs. She did not seem to have a problem with that and respected the families wishes, however this decision about “protecting their space” created a distance that seemed to make the au pair feel more of a worker and less part of the family. So the role she was getting within her host family was influenced not only by her own actions but by the rules that the family had set in the house. These findings are the same as Dalgas (2015) who see the importance of sharing space especially mealtimes together to form family bond with the au pair.

Getting well and planning for the future

Joe moved on to another European country. She wanted to continue travel and stay in different countries being an au pair as long as she is allowed according to her age. She found a new au pair position, looking after small children. After a short period there she has now fallen in love, and is hoping to settle down with him, starting a new life in Europe. When asked *How has this experience changed your life?* She answered;

“At some point I think I feel strong. It changed my life because I met my host family and some friends that I still have now”.

She keeps in touch with her friends and host family here in Norway, and they chat, skype and call each other on a regular basis. I would argue that from meeting a “girl” who was alone and afraid and very sick, to the woman she is now, independent and outgoing the experience not only from being ill but from the au pair scheme has shaped her into who she is today. The fact that she during her stay with her host family got to take control over her everyday life, in choosing what assignments to do, when it was best to do them, have helped her grow independent. But having the choice to decide within the supported frame of the family and household, living with them, eating with them and sharing everyday life has also made her confident. She believes in herself and has high hopes for the future in Europe;” My dream is to one day be able to open a coffee shop, have a boyfriend and get married, to stay in Europe”.

Jay is still with her host family in Norway, but is hoping to settle down in Sweden with her boyfriend. Her relationship with her host family from Sweden is strong, and she goes there

and visits as often as she has enough time and money to travel. When asked *How has this experience changed your life?* She answered;

“Before I came here I was very different. Before I was very shy! Now I have boyfriend and friends, I drink wine, I go to see concerts and I go skiing.”

Cat is also still living with her host family in Norway, and she is hoping to settle down here in Norway. Her aunt lives her too. But now she now goes to Bible school, and she is no longer here on an au pair visa. She lives with the family in exchange for helping around the house, but most of the time she is at school. She still feels like part of the family. When asked *How has this experience changed your life, and wat are your plans for the future?* She answered;

“Yes, it has made me stronger! When my visa expires, I want to go to language course and be better in Norwegian and then I want to go to nursing school and become a nurse and stay in Norway. If I cannot stay in Norway I want to go to another country in Europe and continue being an au pair. It will not be something new. Just a new country “I am still an au pair”.

The hopes for the future is the same for all they wanted to stay in Europe. This was also argued by Bikova (2017:97):

“That au pairs are strategically using their time in Norway to learn Norwegian and find a job after the au pair period is over is a finding consistent with Seeberg and Sollund’s (2010) study of Filipino au pairs and nurses in Norway”.

None of the five au pairs included in this study had plans to return to the Philippines in the near future unless it was to go and visit family and friends on holiday.

Conclusions

Au pairs that are infected with the TB bacteria are identified upon arrival in Norway. Some are admitted directly if there are findings on the x-ray, but many are not diagnosed until the sputum test results come back, which can take up to 8-10 weeks. Some of these patients may be asymptomatic; they have no typical symptoms of being actively sick with TB. They do not believe they are sick, and even if they might have had some symptoms, they explain it with the move to a new country and so on. Explaining to them that they have a very serious disease is difficult, and some are in denial the whole treatment period as this study also confirms. This denial is natural if symptoms is non- existing, however even when test results exists, some do not believe when the TB diagnose given to them from HCWs. The reason for

this was not uncovered in the scope of this research, however one could wonder if they believe in causes of illness outside the bio-medical or professional sector and believe to find answers within the folk sector for instance. I have tried to illustrate how the au pairs explain their illness within Kleinman's exploratory model, and how the three sectors overlap. The stories show how they mobilize a support system among friends and family in the personal sector and health care professionals in the professional sector.

The au pairs are such a complex patient group, with various statuses within the Norwegian state system. The two cases who had their contract terminated show how different status within the state system give them different rights, however if one know the system well the professional sector are able to mobilise forces and help the au pairs who might not be covered. The system would need guidelines to handle this special group to make sure they are protected by the laws that were made to do so. This needs personnel who have experience within this patient group and the knowledge to know how to use the laws and regulations in a way that helps the au pairs and the families it affect.

The immigration status of au pairs determines their rights. Findings indicate that legal rights and status could be strengthened to ensure successful treatment. The information given to host families can be improved to avoid tensions, and to au pairs so that they understand and manage their illness better.

I will not give specific recommendations; however I hope some of my findings can contribute towards changing attitudes towards what information is needed to give au pairs and host families at different stages of the process of being sick and coping with TB.

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Appendix

Consent form



UiO : Universitetet i Oslo

invitation to participate in a research project

How do Au Pairs from the Philippines mobilize a support system when becoming ill and undergoing treatment for tuberculosis (TB) in Norway? Does this have an effect on treatment outcome?

You are invited to participate in a research project that want to explore how Au Pairs coming from the Philippines to Norway mobilize/ construct a support system when they are sick from tuberculosis and are under treatment. What dynamics change within a host family when the Au Pair get sick with an infectious and quite serious disease like TB? And in what ways can this influence and impact the treatment outcome for the patients? You have been invited to participate in this study because you are an Au Pair with TB. The research project is part of a Master degree in Social Anthropology at the University of Oslo to be completed by June 2019.

What IS THE STUDY ABOUT?

To the Au Pair with TB:

The study aims to talk with you, to learn about your experience of being sick with TB, and the social situation that has been affected by your disease. This can be your relationship with your host mum, your friends and family or your relationship with Healthcare workers. The study does not need any medical information about you, other than your TB diagnose. What you share is up you. The study does not need access to medical records, but you have been asked to participate because you have TB and have been chosen from a TB register. The study will do interviews, but mostly informal talks. The study would also like to talk with your host family (Parents) regarding your disease. If you and your host family approve, the study would like to visit your home and observe your relationship and communication within the host family. The study might talk to your friends or other persons you regard as supportive during your illness, but only with your permission. These people may be health care workers. No recordings will be done, only written notes.

What will happen to YOUR HEALTH information?

The information that is recorded about you will only be used as described in the purpose of the study. You have the right to access which information is recorded about you and the right to stipulate that any error in the information that is recorded is corrected.

All information will be processed and used without your name or personal identification number, or any other information that is directly identifiable to you.

The Project Manager has the responsibility for the daily operations/running of the Research Project and that any information about you will be handled in a secure manner. Information about you will be anonymised or deleted a maximum of 5 years after the project has ended.

Voluntary participation and the possibility to withdraw consent (Opt-out)

Participation in the study is voluntary. If you wish to take part, you will need to sign the declaration of consent on the last page. You can, at any given time and without reason withdraw your consent. This will not have any consequences for any future treatment if you are a TB patient. If you decide to withdraw participation in the project, you can demand that all personal health data be deleted, unless however, the personal health data have already been used in scientific publications. If you at a later point, wish to withdraw consent or have questions regarding the project, you can contact:

Camilla Rytterager Ingvaldsen cell: 41044685, e-mail: rytterager@hotmail.com

Approval

The Project is approved by the Regional Committee for Medical and Health Research Ethics, reference number from REC (2018/191) and from NSD (Norsk Senter for Forskningsdata AS) The Data Protection Official for Research Norwegian Centre for Research Data, reference number 60403.

consent for participating in the research project

i am willing to participate in the research project

I give permission of a Health Care Worker to give my contact details to the study for them to contact me.

Date

Participant's Signature

Participant's Name (in BLOCK LETTERS)

I confirm that I have given information about the research project

Place and date

Signature

Role in the research project