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Experiences of occupational therapy among first generation immigrant women with physical dysfunctions

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Bachelors Thesis

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Abstract

Background: As the conflict crisis in the Middle East and West Asia has elevated, simultaneously has Sweden seen a higher level of immigration. Among these groups of people are women who are both physically and emotionally affected. Integrating their old cultural values into the new cultural values often creates problems. However, at present there are not many studies showing how these women experience occupational therapy. Thus, I wanted to investigate these first generation immigrant women's experiences regarding occupational therapy.

Aim: The aim of this study is to investigate how first generation immigrant women with physical dysfunctions experience occupational therapy.

Method: A qualitative study was conducted with three participants from the Middle East using semi structured interviews. Content analysis was used in analyzing the interviews in order to get the manifest meaning.

Result: The result showed two themes: "Knowledge about occupational therapy" and "Trust and confidence in the therapist". Additionally, five subthemes appeared: Issues related to language, being unfamiliar with occupational therapy in the native country, the interaction between the therapist and the patient, the occupational therapist's cultural awareness and sensitivity, and the occupational therapist´s intervention and practice.

Conclusion: It is necessary that occupational therapists have cultural competency and knowledge about other cultures in order to give the best therapy to immigrant women.

Keywords: Physical health, occupational therapy, culture, immigrant women, cultural encounter

Bachelor thesis

Department of Health Sciences, Occupational Therapy and Gerontology Box 157, S-221 00 Lund.

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Arbetsterapi program

2016-01-15

Upplevelser av arbetsterapi av första generation invandrarkvinnor med fysiska funktionsnedsättningar

Fatima Sadat

Abstrakt

Bakgrund: Samtidigt som konflikten i Mellanöstern och Västra Asien ökats, har Sverige sett en ökad invandring av människor från dessa områden. Inom denna grupp av människor finns kvinnor som är både fysiskt och känslomässigt påverkade. Att integrera sina egna gamla kulturella värderingar med det nya kulturella värderingarna skapar ofta problem. Men för närvarande finns det inte många studier som visar hur dessa kvinnor upplever arbetsterapi. Därför ville jag undersöka första generationens invandrarkvinnors erfarenheter av arbetsterapi.

Syfte: Syftet med denna studie är att undersöka hur första generationens invandrarkvinnor med fysiska dysfunktioner upplever arbetsterapi.

Metod: En kvalitativ studie genomfördes med tre deltagare från Mellanöstern med hjälp av semistrukturerade intervjuer. Innehållsanalys användes för att analysera intervjuerna och få fram den manifesta meningen.

Resultat: Resultatet visade på två huvudteman: kunskap om arbetsterapi och förtroende för arbetsterapeuten samt fem underteman: Frågor som rör språket, vara obekanta med arbetsterapi i hemlandet, interaktionen mellan arbetsterapeut och patient, arbetsterapeutens kulturella medvetenhet och känslighet samt arbetsterapeutens intervention och praktik.

Slutsats: Det är nödvändigt att arbetsterapeuter har kulturell kompetens och kunskap om andra kulturer för att ge den bästa behandlingen för invandrarkvinnor.

Nyckelord: Fysisk hälsa, arbetsterapi, kultur, invandrar kvinnor, kulturella bemötande

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Preface

I would like to start with thanking the participants who participated in this study. I would also like to give a heartful thanks to my supervisor Parvin Pooremamali for her help and guidence during the process of writing the thesis and to Mona Eklund for her advice and help in the final phase.

Furthermore, I would like to give my deepest gratitude and love to my family who has supported me and shown understanding during this period.

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1. Background

1.1 Migration

Humans have always been on the run from violence, war or trying to find a better place for themselves to live in (Norberg & Segerfeldt, 2012). Migration in Sweden has considerably increased in the last few years (Migrationboard, 2014). There are several explanations as to why people migrate to another country. According to Norberg and Segerfeldt (2012) it is mostly about people wanting to move away from war, violence or because they want to live in a better place. Furthermore, the Red Cross (2015) says that people migrate because of persecution or serious violation. According to Ruist and Sarnecki (2015) in reports from Migrationsinfo, migration is divided into three different phases: phase one was during and after the Second World War around 1945-1960 when a large part of these people were running away because of the war or other crisis. The second phase started during the end of 1960 and beginning of 1970 when labor migration was very high. The third phase started around 1980 and has continued up till today. The majority of the immigrants are refugees from countries outside of Europe.
During 2014, 650 000 people migrated to the European Union and 81 000 of these migrated to Sweden. In 2013, 15.9 percent of Sweden's population was foreign born, a percentage that is equivalent to 1.5 million people. Furthermore between the years 2000 to 2013 there was an increase of foreign born women with about 250 000. Also it was found that during 2012, 123 272 women who were born in Middle East migrated to Sweden. Of these 123 272 women, 58918 were from Iraq, 31247 were from Iran, 20182 were from Turkey and 12925 were from Syria (Statistiska Centralbyrån, 2013).

Currently there is a high percentage of immigration to Sweden from Middle East and some from East Asia (Migrationsboard, 2014). For the first generation immigrant women, migration is not just about moving from one country to another but also about trying to find a better life with better living conditions and an everyday safety (Berry, 1997).
According to Berry (1997) acculturation means changes during a clash of two different cultures, meaning the individual´s own culture and the new culture. Acculturation may occur along for different routes and these are assimilation, separation, integration and marginalization. Assimilation means that the individual accepts the new culture and discards the old one; separation means keeping the old culture and discarding the new one: integration means keeping both and mixing them and marginalization means not accepting any of the cultures (Berry, 1997). In a study by Martins and Reid (2007) where women between the ages 20 to 50

were interviewed, the results showed that personal and emotional factors played a role when the women tried to integrate using both the original cultural values and the new cultural values. To adapt to a foreign culture can be and is difficult, the immigrants often experience a kind of stress called acculturative stress. According to Devylder et al. (2013) acculturative stress occurs when you have an increased sensitivity to ongoing stress in relation to a new culture.

1.2 Culture

The word culture is grounded in the Latin language word Cultura which means to cultivate or grow (Ringquist, 2005). Culture is a complex concept and is defined differently according to different perspectives such as anthropology, sociology or psychology. For example Kielhofner (2007) defined culture as a group of individuals' common rules, values and way of living while others argue that religion is a big part of the cultural aspects and views (Ringquist, 2005). According to Pooremamali (2012) "Culture is a dynamic and creative process, some features which are changeable and some features which are not changeable" (p. 70). Investigating culture is a continuing concern within occupational therapy as it is often that occupational therapists meet individuals with different cultural backgrounds. As a result, a clash of different views in cultural orientation based on the patients collectivistic and the occupational therapists individualistic worldviews may occur when there is a lack of cultural knowledge on both parts (Pooremamali, Eklund, Östman & Persson, 2012; Pooremamali, Persson & Eklund, 2011).

Pooremamali et al. (2012) demonstrated how the occupational therapists´ individualistic worldview, embracing values such as autonomy, independence in daily life, self- efficacy, mastering one's own life, clashed with that of the clients who held an collectivistic worldview in term of the desire to be cared for, group tied, interpersonal relationships, independence and balance into a body-mind-spirit unity. Cultural discrepancy and clashes seem to occur in occupational therapy in the areas of communication and interaction, views on illness and treatment and view on occupation (Black & Wells, 2007; Pooremamali et al., 2012). There are a lot of patients in the health care system who speak different languages. Often health care professionals do not understand these languages which creates a lot of problems, mainly in giving information and receiving information (Fioretos, 2002). According to Black and Wells (2007), poor integration of cultural knowledge into practice often leads to difficulties in providing services that meet the diverse needs of ethnic minority clients.

1.3 Physical Dysfunctions

The change of environment, way of living and adapting oneself to newfound aspects of the new life, may result in health problems, both physical and cognitive (Melle, 2006). A study by Bennett, Sconaiencki, Brzozowski, and Magalhaes (2012) showed that immigration can have a negative effect on immigrants' health and wellbeing, especially when it comes to their roles, routines and habits. Furthermore another study by Müllersdorf, Zander and Eriksson (2011) demonstrated that women from minority ethnical groups have generally worse health compared to the women in the majority ethnical groups. Furthermore, they concluded that most of these women have illness condition such as pain in the shoulder, neck, back and joints.

Physical disabilities often create problems in everyday occupations and affect an individual in every aspect of life, from personal and social aspects to performance in daily activities (Turner, Foster & Johnson, 2002). The most common conditions among immigrant women from Middle East and West Asia are pain, osteoarthritis and rheumatoid arthritis (RA) (Akhavan, Bildt & Wamala, 2007).

1.3.1 Rheumatologic diseases

There are different types of rheumatologic diseases and one of them is for example osteoarthritis. Osteoarthritis is an inflammatory joint disease and is observed by collapsing joint function where the joint cartilage is continually damaged (Petersson, Roos & Thorstensson, 2011). The disease appears roughly from the age of 30 years and forward. The common symptoms for osteoarthritis are cartilage and bone changes as a consequence of the inflammations reaction as well as depressed muscle force. As a result pain is felt when the cartilage is pressed and can be helped by training the joint. The beginning symptoms are an increased feeling of heat gain in the area, increased liquid substance and pain in the joint.

To suffer from osteoarthritis can lead to health difficulties. An important factor that can prevent suffering from osteoarthritis is to exercise and doing physical activities. Rheumatic diseases such as osteoarthritis can lead to significant disabilities both in work and leisure if not treated (Petersson et al., 2011). Osteoarthritis is most often found in women over the age of 55 years and is developed in joints such as knees, hips, spine and hands (Brittberg, 2014). Women are more often negatively affected by the disease than men in general (Persson, 2008). A study by Zhang and Verhoef (2002) showed that strategies related to osteoarthritis are often connected to personal and cultural values. An important aspect of osteoarthritis is that pain is the most common symptom and affects women in different ways depending on the location of osteoarthritis in the body.

1.3.2 Pain

According to International Association for the Study of Pain [IASP] (2012) pain is "An unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage." (p. 1).

Pain is found in different forms such as chronic pain which is a painful condition that remains more than six months of an expected healing of tissue damage. Acute pain is found in a more extensive tissue damage, which is temporary and usually disappears after the tissue injury has healed (Werner & Leden, 2010). All of these types of pain are commonly found in immigrant women (Müllersdorf et al., 2011).

According to Warner and Leden (2010) the acute pain is often associated with various traumas, tumors, surgeries and certain rheumatic diseases. Transient pain is a short-term pain that occurs for example, at a biopsy or a gynecological examination. The most common chronic pain conditions are osteoarthritis, headache and low back pain.

Pain is experienced differently depending on which culture or religion the individual belongs to (Lasch, 2000). According to a study done by Lovering (2006) "… the meaning and expression of pain and suffering is socially learned and has cultural significance. Culture is the conditioning influence in forming the individual's patterns of responding to and expressing pain" (p. 2). Culture also influences on how people behave when ill, how and if they seek help and how much receptivity they have for medical care interventions (Lasch, 2000). According to Müllersdorf et al. (2011) "Physical complaints such as pain in the shoulder, neck, back or joints, reduced mobility and mental ailments such as insomnia, anxiety, agitation, feelings of abandonment and loneliness are suffered most by people from dispersed ethnic populations" (p. 1). Pain is also affected by different issues such as socio-economic conditions, past experiences and other factors (Müllersdorf et al., 2011).

According to Helman (2007) conveying the pain in different forms and responses from the environment relies on social, cultural and psychological factors. A majority of people with different ethnic backgrounds tend to rely on methods of treatment of pain that differ from the scientific medical treatment (Lovering, 2006).

Studies show that pain effects daily life. A study by Michaelis, Norredam and Kristiansen (2015) showed negative effects of pain on well-being, daily life activities and mental health in

immigrant women in Denmark. Furthermore it showed a high probability that individuals who suffer from chronic pain also suffer from, among many other things, depression, sleeplessness, low self-esteem and emotional distress. The experience of pain affects the ability to work, do household chores and be engaged in social activities. This in turn affects social and family relationships (Michaelis et al., 2015).

1.4 Occupational Therapy and Culture

In occupational therapy, different models have linked culture with occupation and established that link as an important part of the human being. Models such as Model of Human Occupation and Canadian Model of Occupational Performance and Engagement stress the importance of cultural values related to activity performance and the cultural differences between individuals (Kielhofner, 2007 & Turpin & Iwama, 2011). Furthermore, the Value and Meaning in Occupations model stresses the importance of socio-symbolic activity value and its relation to culture (Erlandsson & Persson, 2014). On the other hand, Iwama, Thomson and Macdonald (2009) argue that western occupational models such as Model of Human Occupation and Canadian Model of Performance and Engagement are more focused on the individual and that separating the individual from the environment creates two different entities. They argue that recognizing the multidimensional challenges that culture presents increases the need for an alternative model and theory that is not grounded in the western life style and can help clarify the cultural dimensions of rehabilitation theory and help occupational therapists in their work (Iwama et al., 2009). They created a new conceptual model of occupation named KAWA – a model that focuses on how the individuals look at themselves, and their connection with the environment. In this model, the individual and the environment interconnect and affect one another and compose an entity.

Occupation can be defined as an activity that the individual does during a day or a lifetime and an activity is then defined as doing something meaningful in a special time and place (Christiansen, Baum & Bass, 2015). Townsend and Wilcock (2004) argue that individuals have different values and lifestyles and so they also have different needs. In order to be able to meet these unique needs of these individuals, occupational therapists have to keep an open mind and work in accordance with occupational justice. Occupational justice occurs according to Townsend and Wilcook (2000) when individuals have the right to opportunities and social and environmental resources in order to engage in different occupations that are personally and

culturally meaningful to the individual.

Another important issue according to Lovering (2006) is keeping in mind that culture and language are valuable when creating interventions and long-term rehabilitation for individuals with immigrant backgrounds as much is conveyed in the language. It also depends on whether the individual understands the language spoken or not, since it is important that he or she understands the underlying reason for the intervention to work. The majority of older immigrants are often socially excluded in the society because they do not understand the language of the host country (Lovering, 2006). This does create problems in communications between the occupational therapist and the client (Denktas, Koopmans, Birnie, Foets & Bonsel, 2009).

A large part of the first generation immigrant women in Sweden originating from the Middle East and West Asia have been housewives and thus family, their homes and activities circling around family life may be more important for them compared to working women. These preferences are not mainstream nowadays, which sometimes creates problems between the therapist and the patient due to the fact that western occupational therapists often take for granted that payed work is a huge part of a woman's day-to-day life (Pooremamali et al., 2012). However, on the other hand, one thing that is common to both groups is the need for some sort of occupation, whether that is payed work, leisure or a family oriented occupation. Occupational therapists have so far chosen to focus on how the physical health problems are affecting these individuals and not chosen to focus on the cultural differences that may be present (Hammell, 2013). Currently there is some research done in the area of immigrants and health, especially focusing on the second generation individuals and health, both in the occupational therapy area and in health sciences in general. However, research focusing on first generation immigrants, and especially women, is sadly lacking to the best of my knowledge. This brings forth an important issue regarding how first generation immigrant women with physical dysfunctions experience occupational therapy, if and how occupational therapy helped them in their everyday life and what they generally feel about occupational therapists from a cultural perspective.

2. Aim

The aim of this study is to investigate how first generation immigrant women with physical dysfunctions experience occupational therapy.

3. Method

A qualitative design was used, which governed the gathering and analysis of data. According to Kvale (2008) qualitative methods are unique, powerful and sensitive to capturing subjective experiences in the participant's everyday life. Content analysis was used as the data processing method in order to examine, analyze and interpret the transcribed data (Granskär & Höglund-Nielsen, 2012).

3.1 Participants

In order to find women to participate in the study, occupational therapists working in the primary health care centers and hospitals in Sweden were used as gatekeepers. The occupational therapists agreed to contacting individuals who could fit the inclusion criteria from their group of patients.

The recruitment of participants followed these inclusion criteria;

1. First generation immigrant women with some form of physical dysfunction such as pain, osteoarthritis, rheumatoid arthritis and/or swelling.
2. The women would be in the ages between 20 to 75 years old.
3. They would originate from the Middle East or West Asia.
4. They would have had contact for at least two weeks with an occupational therapist and have gotten some kind of intervention.

An exclusion criterion was that these women would not have any kind of cognitive or psychological impairment.

An attempt was made to follow the plan of getting in contact with participants through occupational therapists. Twelve occupational therapists were contacted via email and phone. The author requested their help in finding participants that fitted the inclusion criteria for this study. Out of these twelve different occupational therapists, four consented to help, six did not answer back on phone calls and emails, two declined to help giving reasons such as being busy or not working in the field where they had contact with immigrant women. From the four occupational therapists that consented to help the author, none found a participant that fitted the criteria and wanted to participate during the timeframe that was set for the data collection.

The snowballing method (Trost, 2012) was then used as an alternative strategy for finding women who wanted to participate in the study and who fit the criteria, starting with an acquaintance of the author. The women were identified by this method and all agreed to participate. All the women were born outside of Sweden and had lived in Sweden for a varying number of years, the shortest time was four and halve years and the longest time was 27 years. They were between the ages of 47 to 61 years old. These women were from Afghanistan and Iraq. Two of the women were fulltime housewives while the third was unemployed at the moment. All of them lived with their families consisting of a husband and at least 2 children. Other characteristics were that these women spoke several languages such as; Swedish, Norwegian, Dari, Kurdish, Pashto and Farsi. The women had different types of problems and symptoms such as pain and osteoarthritis. Further details are presented in Table 1.

Table 1: Description of the study group

Participants	**A**	**B**	**C**
Gender	*Female*	*Female*	*Female*
Age	*47*	*54*	*61*
Living Conditions	*Husband and two children*	*Husband and two children*	*Two children*
Activity/ work	*Housewife*	*Housewife/ unemployed*	*Sick leave*
Education	*Sixth grade education*	*High school*	*Uneducated*
Language	*Kurdish, Arabic, Swedish , Farsi and Norwegian*	*Dari, Swedish and Pashto*	*Dari*
Disorder/medical history	*Chronic pain and swollenness*	*Osteoarthritis and chronic pain*	*Osteoarthritis Chronic pain*
Years in Sweden	*27 years*	*13 years*	*4 1/2years*

3.2 Data Collection

Data was collected with the help of the interview guide presented in the appendix, where the first questions on background are specific but the rest open up for a discussion. Themes central to the study aim were covered in the guide, which according to Dalen (2011) is important in

semi-structured interviews. Individual qualitative interviews were seen as a relevant method to enable the participants to talk freely about their experiences (Malterud, 2014). The author was aware that she needed to keep an open mind during the interviews to get new information that she otherwise would not notice. Different types of questions were asked such as what kind of problems the participants had, how the problems had started, if it had brought changes in their daily life activities, how they experienced communication and interaction with the occupational therapists, and their opinions regarding the treatment and intervention they got.

The intention behind the interviews was to get the phenomenological perspective where the participants would give their subjective perspective of their reality (Kvale, 1997). It was also considered important that the participants would feel safe during the interview in order to be able to speak freely and this was ensured by having the interview in a secure and calm place where there was no other person around. The author was attentive during the interview to any changes in the participant´s reactions and attitudes and adapted her interviewing if relevant. According to Kvale (1997), this is very important in order to keep a good cooperative relationship between the participant and the researcher. The interviews lasted from 30 minutes up to 60 minutes.

In order to keep the participants own words the interviews were recorded using a dictaphone and according to Dalen (2011) this will give reliable interview information. One interview was carried out in Kurdish with an interpreter present who interpreted into Swedish; the second interview was carried out in Dari and the third in Pashto, both without an interpreter. Transcribing method was used in order to enable the author to represent the participant's views fairly and correctly. All interviews were later translated during the transcription and written down in English. A trial interview was done in order ensure that the interview guide had reliable and good questions and also to test the dictaphone (Dalen, 2011).

3.3 Procedure

The three participants were contacted by phone by the author and asked if they wanted to participate in the study. They were given information both verbally via phone and later in written in person. A verbal consent was given via phone and a time and a place for a meeting was scheduled. The choice of place was left up to the participants because that was assumed to make them at ease during the interviews. All of them chose their own homes for the interview.

Before the interviews began the consent forms were signed and they were once again informed that they could decide to stop participating at any moment during the study. They were informed that they would remain anonymous to everyone but the author and their information would be kept confidentially until the study was completed. Then all the information would be destroyed. When this information was given, the author started the interviews.

3.4 Data analysis method

Qualitative content analysis focuses on interpretation of texts. It is applicable on different texts and because the interpretation can be carried out on different levels it is very valuable and useful in qualitative research (Granskär & Höglund-Nielsen, 2012). The methodological approach could be both inductive and deductive. The inductive approach, applied in the current thesis, means an unconditional analysis of data based on individuals' personal experiences. The focus in content analysis is to describe variations by identifying differences and similarities in a text. The differences and similarities manifest in categories and themes on different interpretation levels. In every text there is a manifest content and a latent message. The manifest content is expressed in descriptive levels in categories. The latent message is about the underlying hidden message and is expressed on an interpretive level. Qualitative content analysis was chosen in order to get a view of the participants' personal perspectives on their situation.

3.4.1 Data analysis

In order to analyze the data and get a good perspective of what the participants said, the interviews were read through and listened to twice. Then the sentences and paragraphs that were important and had a connection to the aim were highlighted. These were read through twice again in order to be sure of the selection of relevant information. After this all text that illuminated the study aim was copied to another document. This text was thereafter read again and sentences and passages that formed meaning units were identified.

In the next step, these meaning units were summarized into condensed sentences. And then after that these condensed sentences were given reflective codes that best described what the sentences meant. In the fourth step, the reflective codes were aggregated into categories that best described them. These initial steps were done separately for all the three interviews.

Table 2; Example showing how the analysis was carried out from sentence units to categories

Interview text Sentence Unit	Condensed sentence	Reflective Code	Category
when I went to them, they gave me good advice, helped me to overcome my fears and my mind got settled	Getting help to overcome fears, getting advice that settled my mind	Overcoming fears and being soothed	Emotional support

In the end, all the categories were condensed into larger preliminary units. Thereafter the text was read again to check whether all relevant content was captured by these larger preliminary units, which were reconsidered accordingly. This lead to the identification of six subthemes which were seen as forming two themes.

3.5 Ethical Consideration

According to Dalen (2011) researchers have always an ethical responsibility to get their study approved by the Ethical Science Committee before the study is conducted. A VEN application was written by the author and approved by the author's supervisor but it was not deemed necessary to send it to the ethical committee.

A consent form was signed by the participants before the interview (Dalen, 2011). A verbal consent to the study was given by the participants before they met the author in person. Furthermore to keep them well informed they were given both a written information letter and verbal information. They were informed that they could withdraw from the study at any time without giving a reason and that their information would be held confidentially (Codex, 2013). They were also informed that the recorded interviews would be deleted after the study was completed. During the study, information was given by the participants and in order to keep this information confidential, all the raw data was decoded and locked away when it was not used by the researchers. The participant's integrity was protected by respecting their wishes during the interviews (Codex, 2013).

4. Results

The results of this study showed that the interviewed first generation immigrant women's views differed regarding their experiences of occupational therapy and what they thought about

occupational therapy. The most prominent issues that split these women, regarding their views, were the interaction between the occupational therapist and the women and the trust between them. Another issue that came up was that there was a lack of basic knowledge about occupational therapy before the women met an occupational therapist and in two cases even after they had met an occupational therapist. Due to language difficulties communication was also referred to as a problem between the therapist and the participants.

The result of the analysis showed two themes each with several subthemes. These themes were: "**Knowledge about occupational therapy**" with its subthemes: "*Issues related to language"* and *"Being unfamiliar with occupational therapy in the native country"*. **"Trust and confidence in the occupational therapist"** with its subthemes: "*The interaction between the therapist and the patient", "The occupational therapist's cultural awareness and sensitivity"* and *"The occupational therapist´s intervention and practice*".

Selected citations are given below to exemplify the issues reflected in the subthemes. In order to discern the different views, the participants are given the fictitious names Amina, Behnaz and Sara.

4.1 Knowledge about occupational therapy

Not having previous knowledge about occupational therapy created problems regarding how the participants viewed occupational therapy and what it meant. The participants said they had difficulties in communicating with their occupational therapists due to the fact that they did not understand Swedish well enough. In two of the three cases the participants often used interpreters during the meetings.

4.1.1 Issues related to language

The most common issue pointed out by all the participants was the language problems. The level of understanding Swedish varied between the participants. Amina could talk a bit in Swedish but not enough to communicate without interpreter and Behnaz was able to communicate enough in Swedish but she was not fluent. Sara on the other hand could not communicate in Swedish at all. The participants stressed that they had not understood their occupational therapists and had not been able to communicate what they wanted or needed. Even though they had an interpreter, expressing their wishes was the hard part and this was not because it was not being forwarded to the occupational therapists.

For example Sara expressed that:

> *"The problem lies with me; I don't know how to tell them."* (Sara)

The participant expressed that the problems were caused to an extent because she did not know how to explain her problems since she had just recently met an occupational therapist and did not know how she could get help from her. Not being able to understand what the occupational therapist said also created hardships for them. One of the participants described that:

> *"Maybe they have given me [Instructions] and I have not understood it."* (Sara)

In order to communicate they used interpreters and this created problems for the participants which according to them contributed to several problems such as mistrust in the occupational therapist. One participant described the dialogue between her and her occupational therapist as:

> "*She did not explain to me why I should use them [orthosis], or how I should use them, and was very negative about it, blaming me for what had happened."* (Amina)

According to the participant, this session had been interpreted by her daughter and the daughter had expressed to her mother that she had perceived the occupational therapist as being rude and unthoughtful. The participant argued that because her daughter had experienced this and she trusted her daughter, she felt negative towards the occupational therapist.

4.1.2 Being unfamiliar with occupational therapy in the native country

All of the participants expressed their lack of knowledge of occupational therapy in their native country and they conveyed that it was completely new to them. Everyone gave different opinions as to why they had not seen occupational therapy earlier in their countries. One of them expressed that she had not seen occupational therapy in her country because:

> *"No, I have not seen it in my country but it is because we were born in an era of war and we lived in an era of war."* (Behnaz)

Behnaz argued that since in her country a war was being raged at the time she lived there, the access to even medical aid was hard to get and thus rehabilitating aids were impossible to get. She saw war as the basic reason for not encountering occupational therapy in her home country. Sara on the other hand argued that the hospital staff was very corrupted in her country and thus access was limited to those who had money and prestige. Even the knowledge that something like this existed was limited to those who were rich and could pay the fees. She expressed that bribery was the main problem and not everyone was able to spend a lot of money to get the help since the economy in her country was not very good and there were a lot of poor people who could not access medical rehabilitating.
She expressed that:

> *"No, there is just a lot of bribery going on, until you have not bribed someone they will not let you even stretch your hands to a doctor."* (Sara)

Amina didn't give any reason but did say she had not encountered it in her native country.

4.2 Trust and confidence in the occupational therapist

According to the participants, trust was important for them all and two of the participants expressed happiness about their interaction with their occupational therapists. According to these two having trust in their occupational therapist helped them become more involved in the therapeutic interventions. They meant that their occupational therapists had respected them and made a difference in their everyday life which in turn made them trust the occupational therapists and their interventions.
For example one of the participants said:

> *"They have not done anything bad or disrespectful, they are nice."* (Sara)

Moreover, this participant stated how the occupational therapist's way of making interventions helped her not only to feel better but also to improve her ability to manage her pain when nothing else could help her. She also said:

> *"Exactly this [occupational therapy interventions] helped, actually only this helped."* (Sara)

As a result, this participant tried to demonstrate her gratefulness by accepting what her occupational therapist recommended.

> *"I have told them: "As you wish and as you know best." If they have said something I have said ok, I left the choices up to them."* (Sara)

Another participant said that what the occupational therapist had told her worked and made her manage her pain and everyday life better. She also meant that by following the therapist´s advices, she saw a difference and thus she started to trust her occupational therapist´s instructions.
For example the participant expressed that:

> *"They said to take it easy in the beginning and they have given good advice."…"The training they gave me worked, I feel much better after that."* (Behnaz)

Amina had very negative experiences regarding her occupational therapist. She had felt that she had been blamed for what had happened to her hand. She had also felt that the occupational therapist had been blaming her cultural background. The participant also expressed a feeling of being offended when her occupational therapist repeatedly reminded her of the missing welfare resources in her native country. She meant that the occupational therapist gave hints to indirectly remind her that she should be grateful for such treatment, which she would have never received in her native country.

> *"The occupational therapist was reminding me all the time that I live here, this country is modern, and you cannot do this. You live in Sweden."* (Amina)

According to Amina, this affected her very negatively which resulted in that she lost her confidence in the occupational therapist and she then felt that there was no point in going there again. According to her it affected her training and her situation had stagnated.

4.2.1 The interaction between the therapist and the patient

What the participants thought about their interaction with their occupational therapists varied. Behnaz and Sara had positive views of their occupational therapists because of the fact that

their therapists had listened to them and showed compassion and understanding during the meetings, which they emphasized was important to them. As a result they also felt trust and confidence in their occupational therapists and their work.
For example one of the participants expressed that:

> *"According to me it is good, here they have compassion for people, they help everyone….their approach is very nice according to me."* (Sara)

Amina on the other hand had experienced a negative interaction and had negative thoughts about her meetings with her occupational therapist. This was according to her because her therapist had shown no compassion, no sympathy, and had been very rude to her. She then expressed that she had not been met by the occupational therapist in a professional way and she had felt insulted by the way her therapist had behaved towards her during their meetings. This participant had a lack of trust in her occupational therapist due to lack of interaction between them and thus her impression of occupational therapy and the therapist was negative.
This participant expressed that:

> *"It felt like she did not want us to be there … the third time I did not go there because I felt bad."* (Amina)

Two of the participants expressed that their occupational therapists had listened to them and been kind to them. The occupational therapists had listened to them talking about other stuff even though that was not something they could help them with. They expressed that having the moment to talk about other things played a larger role than the intervention itself for their way to recovery. They meant that when their occupational therapists showed compassion, empathy and understanding by listening to them, it helped them overcome their fears and calm their minds.
For example Behnaz expressed that:

> *"The hour I spent talking with her has helped, it has calmed me down, my mind is calmer now, and now I know that what I thought earlier [negative thoughts] was wrong, and now I do as they tell me."* (Behnaz)

Furthermore, this participant said that her occupational therapists´ empathy helped her manage her anxiety regarding her losing control in daily life because of her disability. According to Behnaz her therapist gave her new hope in getting better and recover.

4.2.2 The occupational therapist´s cultural awareness and sensitivity

Two of the participants said that their occupational therapists had had an open mind when working with them. They argued that they had been asked if they wanted to change anything during their interventions due to the fact that the participants did not belong to the same culture as the therapists and there were also differences in their religions. The participants meant that their therapies were formed after them individually and that the occupational therapist had shown cultural awareness when working with them.
For example one participant said in regard to cultural differences that:

> *"No, the occupational therapist asked me what I wanted and if it was ok with me, or if I agreed with this decision or if I wanted this help. They did ask me."* (Behnaz)

The third participant described how a lack of understanding and disrespect to her cultural values shown by the occupational therapist created a lack of trust. She expressed she disliked her occupational therapist's way of working. This was, according to her, because she had felt disrespected from her therapist and she felt that her therapist had judged her cultural values and way of doing things. The participant stressed that her therapist had not shown understanding of other individuals' cultural values and that the therapist had completely disregarded her culture and told her that she lived in Sweden and thus she could not perform activities her way.
She expressed that her therapist told her that:

> *"… You live in Sweden and this is Sweden, you do not wash the carpets with your hands here. And this country is modern and there are machines that can wash them, and you cannot do this, you live in Sweden"* (Amina)

4.2.3 The occupational therapist´s interventions and practice

The participants pointed out that going to an occupational therapist when they were referred to them by the doctor meant that they had a hope for getting another type of treatment or solution

to their problems. All of them had some kind of expectations as to the result of their visits to their occupational therapists.
Behnaz said that:

> *"They sent me to an orthopedic clinic and told me I will get special shoes for my pain in the knees"* (Behnaz)

Having hope of getting better motivated the participants to engage and participate in the prescribed occupational therapy intervention. Moreover Behnaz stated that feeling hope from her therapist helped her improve in managing her daily activities. She could now walk or work without having pain. Before that she did not have anything that helped her in managing her pain during the day except for medicine which she did not want to take.
This participant said that:

> *"After that I could work outside my home. I started working in a school for children because I love working with children"* (Behnaz)

The women pointed out that going to their occupational therapists meant that they got another chance of doing the things they liked such as being able to do home chores, to work with what they loved such as taking care of their families, working with children in kindergarten and so on. One participant expressed that:

> *"It has helped me a lot."… "Now I can walk more and have less pain."* (Sara)

During the interviews, the participants expressed some views regarding the technical aid that they had gotten from their occupational therapists. One of the participants argued that she felt dissatisfied with the technical aid. She meant that it was annoying to use in daily life because she had to take it off and on all the time but she also pointed out that it was helping her in managing her pain and being able to be active during the day.

The participants also expressed their views regarding their training and if that helped them or not. One of the participants argued that her training, which consisted of doing hand and arm exercises, had not helped her in getting better but another said that training her legs had helped. One of the participants expressed that:

> *"I used the sticks outside but not inside, then the occupational therapist told me to let the sticks be and gave me the elastic band to use in an exercise .... That helped me, after that I could walk outside."* (Sara)

The participants had different views regarding what they thought was useful occupational therapy compared to therapy that did not work for them. Two of the participants regarded their occupational therapy sessions and interventions as having a calming effect on their minds and thoughts. They stated that it made them feel better and calmed their fears. They got time during the sessions to talk with their occupational therapists and it allowed them to speak about their fears. According to them this in turn made it easier to accept their situation.

5. Discussion

5.1 Method discussion

A qualitative study was chosen in order to capture the essence of the participant's experiences of occupational therapy. Alternatively the author had thought to use a quantitative study with questionnaires but that would not have been the best way to gather the aspects of their experiences. The aim was to take part of their experiences and this would not have been achieved by them answering a questionnaire. Semi-structured interviews were used in gathering the data because this data collection method was the most suitable for the aim and the type of study. The author thought that it would enable her to ask subsequent questions in relation to themes in the interview guide when there was a need to get more information in a particular area. This also enabled the participants to talk freely about different issues and made it easier for them to get their opinions forward. In order to analyze the data to its fullest, manifest content analysis was chosen as a data processing method. The author chose this method to allow a presentation of findings at a descriptive level.

In this study there were three participants due to the fact that the author was doing the study alone and the timeframe did not allow for more interviews. These participants came from the Middle East, more specifically Afghanistan and Iraq. Specific countries were not part of the selection criteria, and these countries were a result of these women being available and willing to participate in the study. As a consequence it meant that the author got participants who had different cultural backgrounds and views. They were between ages 40 to 65 and had been adults

when they came to Sweden; this meant that the data reflected deeply rooted cultural values and thoughts.

The choice of where the interviews would be carried out was left up to the participants and the author thought that this would ensure that the participants were feeling safe during the interview. To some degree this ensured that the data collected had a good quality, and that the participants were able to talk freely, since they had more control over the situation than the author. Before the data was collected the author had thoughts regarding the fact that a group of three participants was small and would not be enough to get the information the author needed for the study, but according to Malterud (2014) the number of participants in a study is not as important as having information of good quality collected from these participants. Though this group was small, the collected data gave rich information on their views regarding occupational therapy.

Before the inclusion criteria were set, the author had thoughts regarding where the women would come from since the target group was immigrant women. After searching in the databases, the author found that there were many research papers regarding women from Asia, America, and other western countries. Thus the author chose to focus on the Middle East and West Asia. The author chose not to set any criteria regarding the participant's religions since the people in these areas have the same basic cultural views. According to Awaad (2003), though different minority groups may have different religions, they still have the same basic cultural views if they are from the same places. The fact that no religious issues came up during the interviews indicated that religion did not matter in relation to occupational therapy.

All of the interviews were carried out by the author herself and subsequently transcribed verbatim by the same author. According to Dalen (2011) it is important that the interviews are transcribed immediately or as soon as possible after the session in order to get closer to the text itself which is a help later in the analysis. In accordance with this, the author transcribed all the interviews as soon as they were carried out. This most likely had a positive effect on the validity and reliability of the collected data. During transcribing, the author noticed that some last questions in the interview guide were being answered in connection with other previous questions.

Before the real interviews, a trial interview was carried out by the author who found that the answers to the interview guide questions could lead the way to prompting questions. The reason for the trial interview was to check the adequacy of the interview guide questions, test the author`s skills at interviewing and test the dictaphone.

In order to strengthen the trustworthiness of this study, the author has described the analysis in details. In the result, citations are given in order to back up the claims. In order to make the analysis and result credible, the author took an effort in putting her thoughts and personal views aside and went through the analysis twice.

5.2 Result discussion

The aim of this study was to find out how first generation immigrant women experienced occupational therapy. The result showed variations in how these women experienced occupational therapy and their therapist. The major differences were their opinions regarding the occupational therapist's interaction with them and how they were received. They pointed out that cultural differences were very clear during their sessions with their therapists. The findings showed how their experiences regarding occupational therapy and the therapist depended on how the participants were encountered by their occupational therapists.

The findings are consistent with Aboul-Enein and Aboul-Enein, (2010) showing how health care professionals should ease into their meetings with their patients who have different cultural backgrounds and this due to the fact that Middle Easterners value politeness and friendliness. The results of the present study showed that there were complaints in that not all participants had been received respectfully or been shown understanding and sensitivity to their life situation and cultural values. On the other hand, according to Aboul-Enein and Aboul-Enein (2010), because health care professionals are unfamiliar with Middle Easterners´ cultures and their characteristics, they perceive them to be tough to work with. As a reflection in relation to this claim, the findings showed that one participant experienced negativity from her occupational therapists. One reason behind this could be for example that the occupational therapist had limited knowledge of other cultures and had a lack of cultural sensitivity.

In contrast, the other participants had a very positive attitude towards their occupational therapists. They meant that they had been met respectfully and their occupational therapists had been positive towards them and their problems. According to the Ethical code for occupational

therapists (FSA, 2012), the therapists should have a client-centered approach and work in accordance with what the code says. Keeping this in mind one participant´s experiences reflected that to some extent, her occupational therapist may have not acted in accordance with the code.

The findings also revealed how issues related to language and communication generated further challenges for the participants and their occupational therapists which is also consistent with studies by Pooremamali et al. (2012). The findings also showed differences in how the participants perceived the interventions they received and if the interventions worked for them or not.

In accordance with Yosef (2008), whose findings showed that language problems and cultural misconceptions were one of many problems that prevented immigrants from seeking help, this study's result showed that the participants who had difficulties with language and communication did indeed have more difficulties with getting the help they needed.

The study found that both professionals and family members were used as interpreters. In accordance with Meyer, Pawlack and Kliche (2010) the findings showed how family interpreters might be strongly affected emotionally which may lead to subtle prejudice in patients, additional misunderstanding in knowledge transfer and inadequate formulation. As this study's findings showed, a participant who used her daughter as an interpreter was affected by the daughter´s prejudice and what she perceived was the occupational therapist´s tone in conveying information. In this case, if a professional interpreter had been there, things might have been explained in different words, in a more professional way, which may have had affected the participant´s opinions of what the therapist said. This study thus illustrated the issue of family interpreters and whether that is an appropriate method to overcome language barriers in occupational therapy interventions.

The author also found that the participants showed respect to their occupational therapists and listened to them as they were educated professional staff. Aboul-Enein and Aboul-Enein, (2010) argue that Middle Easterners looks at professional medical staff as being authoritative and show respect for the work they do and the knowledge they carry. The participants argued that since the occupational therapists knew best what would help them, they listened to them and trusted them.

Additionally there was a basic lack of knowledge regarding occupational therapy and this gave positive results. The positive aspect was that the participants did not have any prejudice against the occupational therapists and no earlier negativity to base the meetings on since they did not have any previous knowledge about occupational therapy.

The author found that the women more often than not connected their physical issues to emotional ones. For example they argued that the interventions and their meetings with their occupational therapists had a calming effect on their minds. Their anxiety and fears were laid to rest because they were in some cases able to discuss with their occupational therapists what they feared and were anxious about. This is akin to a study showing that immigrants need more than the physical help they get from their therapists in order to get better (Aboul-Enein & Aboul-Enein, 2010).

It is important as a healthcare professional to take into account the whole individual and not focus on the disability itself. This in accordance with the Health and Medical Services Act (2013) recommending, ”vården ska ges med respekt för alla människors lika värde och med respekt för den enskilda människans värdighet. Den som har det största behovet av hälso- och sjukvård skall ges företräde till vården” (p. 10).
Despite what the law says, there are flaws in the health care system and according to Echeverri (2010) there are shortcomings in the health care educations in Sweden regarding the care of individuals who have a foreign cultural background. According to Hanssen (2007) it is important that one shows respect to the client’s cultural and religious difference as this makes the healthcare meaningful for the individual. As an occupational therapist it is important that one works client centered and that means that one shows respect for the client´s own wishes, experiences and how the client thinks about his/her own situation (Fisher & Nyman, 2007).

6. Conclusion

To summarize, this study showed that two out of three interviewed first generation immigrant women had mainly positive experiences of occupational therapy. They had been shown respect and been met professionally by their occupational therapists. Their cultural backgrounds and personal views had been taken into account by their therapists when working with them. Yet there were also issues that did not work well for one participant. The result of this study showed

to a degree that these therapists were culturally competent and knew how to work with these women.

6.1 The importance of more studies

The aim was to find out how first generation immigrant women experienced occupational therapy. This study showed that though there were positive aspects in these women's experiences there were also negative aspects. There were problems in communication and the study showed signs of lack of cultural knowledge in particularly one of the occupational therapists. At this point, there are not many studies in this specific area and more studies are needed due to the fact that Sweden is getting increasingly multi-cultural. It is important that occupational therapists understand what immigrant women think and experience as immigration rises steadily in Sweden.

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Appendix

1. Interview guide
2. Information letter
3. Information letter Participant
4. Consent form

Appendix 1

Interview Guide

Specific background questions

What is your age?
Where are you from?
How long have you been in Sweden?
What is your main language(s)?
What type of disability do you have?

Interview themes

Tell me how your disability has hindered you from having a normal life?
How long have you had this problem?
How and when did you first hear about occupational therapy?
How long ago did you first meet your occupational therapist?
Tell me what occupational therapy is according to you?
Have you encountered occupational therapy before in your home country?
Tell me what's important for you in terms of occupation? Based on a cultural perspective as many activities are based on a cultural value. (Including Religious beliefs)
Tell me what you think about the interventions in terms of what is important for you?
According to you, has the occupational therapist thought about your preference/cultural difference before the intervention?
And during the whole process of meeting the occupational therapist and getting interventions?
What kind of changes have the interventions brought in your life in terms of cultural perspective? Negative or positive

Appendix 2

INFORMATIONSBREV

LUNDS UNIVERSITET
Medicinska fakulteten

Arbetsterapi program

Till: Arbetsterapeut

"Experiences of occupational therapy among first generation immigrant women with physical dysfunctions"

"Upplevelser av arbetsterapi av första generation invandrarkvinnor med fysiska funktionsnedsättningar"

Syftet med denna studie är att utforska hur första generations invandrar kvinnor med fysiska funktionsnedsättningar upplever arbetsterapi, dess interventioner och om detta har ändrat deras livssituation från ett kulturellt perspektiv. Jag har valt detta syfte eftersom studier kring kvinnor med fysiska funktionsnedsättningar/hinder med en kulturell bakgrund är väldig få. Detta tillsammans med att alla har olika bakgrunder samt värderingar gör det intressant att veta hur dessa kvinnor tänker kring arbetsterapi.

Jag vill genomföra halvstrukturerade narrativa intervjuer med 3-4 klienter/patienter. Dessa ska ha haft kontakt med arbetsterapeuter i minst 2 veckor och fått någon typ av intervention. Försökspersonerna ska också kunna prata något av dessa språk: Svenska, Engelska, Pashto, Dari, Persiska, Hindi, Kurdiska, Arabiska. Dessa deltagare ska även vara antingen från Mellan Östern eller/och Västra Asien. Intervjuerna kommer att vara ca 30-60 minuter och genomföras på plats önskad av klienterna/patienterna alternativt att jag ger förslag. Intervjuerna kommer att spelas in och därefter att transkriberas och analyseras enligt kvalitativ innehållsanalys.

Aktuella Klienter/Patienter kommer att kontaktas via telefon efter muntligt godkänt samtycke med dig som Arbetsterapeut alternativt att de kontaktar mig. Informationsbladet ges ut av dig som arbetsterapeut och samtyckesblankett ges när vi träffas. Information om att deltagandet är frivilligt kommer att framföras samt att de när som helst kan avbryta sin medverkan i studien med omedelbar verkan och ingen som helst konsekvens för deras del. All data kommer att behandlas anonymt. Efter att studien är färdig kommer det insamlade rådata att raderas på ett säkert sätt.

Studien ingår som ett examensarbete i Arbetsterapeutprogrammet i Lund Universitet.
Om Du/Ni har några frågor eller vill veta mer, ring eller skriv gärna till mig eller till min handledare.

Med vänlig hälsning

Namn: Fatima Sadat	Namn: Parvin Pooremamali
Titel: Student/författare	Titel: Handledare
Tfn: 0765803890	Tfn:0700850620
E-post: art12fsa@student.lu.se	E-post: parvin.pooremamali@liu.se

Appendix 3

LUNDS UNIVERSITET
Medicinska fakulteten

Arbetsterapi program

INFORMATIONSBREV 15-02-23

"Experiences of occupational therapy among first generation immigrant women with physical dysfunctions"
"Upplevelser av arbetsterapi av första generation invandrarkvinnor med fysiska funktionsnedsättningar"

Hej!

Vill Du hjälpa till att öka förståelsen för vilka erfarenheter kvinnor har med arbetsterapeuter inom arbetsterapi för personer med fysiska funktionsnedsättningar/hinder?

Jag är en student som läser Arbetsterapeutsprogrammet på Lund universitet och har påbörjat ett examensarbete med syfte att utforska hur Du upplever Arbetsterapi, dess interventioner och om detta har ändrat Din livssituation.

Jag har valt att utföra denna studie eftersom det inte finns så mycket forskning kring denna grupp och detta tillsammans med att alla personer har olika bakgrunder gör det intressant att veta hur Du tänker kring Arbetsterapi från ditt kulturella perspektiv.

Att delta i studien innebär följande:

Att intervjun beräknas ta cirka 30-60 min och genomförs av student/författare. Jag erbjuder plats för intervju alternativt att du själv föreslår plats.

Med Din tillåtelse vill jag gärna spela in intervjun på band. Inspelningen kommer att förvaras säkert så att ingen obehörig kan ta del av den. Efter att arbetet har slutförts så förstörs all råmaterial som har samlats in.

Deltagandet är helt frivilligt och Du kan avbryta när som helst utan att ange någon orsak eller med några konsekvenser för din del. Resultatet av studien kommer att redovisas så att all känslig data kommer att avidentifieras för att försäkra din identitet.
Om Du har några frågor eller vill veta mer, ring eller skriv gärna till mig eller min handledare.

Med vänlig hälsning

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Appendix 4

Samtyckesblankett

Jag har tagit del av informationen om *”Upplevelser av arbetsterapi av första generation invandrarkvinnor med fysiska funktionsnedsättningar”*.

Jag har också tagit del av informationen att deltagandet är frivilligt och att jag kan avbryta när som helst utan att ange någon orsak eller med några konsekvenser för min del.

Härmed ger jag mitt samtycke till att bli intervjuad och att intervjun spelas in på band/videoband.

Underskrift av undersökningsperson	*Underskrift av student*
_____	_____
Ort, datum	Ort, datum
_____	_____
Underskrift	Underskrift
_____	_____
Telefonnummer	Telefonnummer