



University of Eastern Africa Baraton, Kenya



Master's Degree in Global Health Care

**Immigrant families' perceptions of rehabilitation in
children's neurological unit**

Master's Thesis

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| Student: | Kristiina Aalto c34546 |
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Abstract

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The purpose of this thesis is to present some of the perceptions that immigrant families have of rehabilitation in the children's neurological unit. The target group of the research were immigrant families with a disabled child, who come for a rehabilitation assessment to the unit. The research will help nurses' to understand the immigrant families' perceptions of rehabilitation and to develop nursing and the working policies in the unit. The results of the research and thesis will be presented to the multiprofessional staff of the neurological unit. The staff can then evaluate how the results benefit the development of nursing and working policies in the unit. Based on the results of the research, parents' perceptions can be taken better into consideration when assessing and planning the need for rehabilitation, since parents have a big impact on it. The research will also help to develop the culturally sensitive rehabilitation on the children of immigrant families.

The theoretical background used for this thesis was Leininger's transcultural care theory, Giger & Davidhizar's transcultural assessment model and the international ethical instructions developed by ICN – the International Council of Nurses. These theories and guidelines were the frame of the research, and the need for this thesis topic can be justified with the help of these guidelines.

The data was collected through five semi-structured interviews with immigrant parents, whose children were being assessed at the time in the neurological unit in a university hospital. The interviews took place in February-March 2017 in the children's neurological unit. Content analysis was used as a data analysis method.

The results were formed in four categories that are included in an environment of disabled children and their families: 1) importance of rehabilitation, 2) the role of the neurological unit, 3) the meaning of family and parents and 4) hopes and fears of the future. These categories represent the perceptions that the immigrant families have of rehabilitation. According to the results, the families wanted more information about their child's condition, development and disability. The child's independence and future as a disabled person were subjects that the families were reflecting considerably.

Keywords : disabled child, immigrant families, children's neurology, perceptions, rehabilitation, transcultural nursing

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List of Abbreviations and Symbols

| | |
|-------|--|
| Hilma | The Support Centre for Immigrant Persons with Disabilities |
| ICF | International Classification of Functioning, Disability and Health |
| ICN | International Council of Nurses |
| KELA | The Social Insurance Institution |
| UN | United Nations |
| WHO | World Health Organization |

1 INTRODUCTION

The World Health Organization (2017) defines disability as a wide term that includes impairments, which are problems in body function or structure; activity limitations, which are difficulties individual experiences in executing a task or action; and participation restrictions, which are problems individual experiences in involvement in life situations. Despite this definition, disability is not just a health problem. It is a complex, diverse phenomenon that reflects the interaction between features of a person's body and features of the society in which the individual lives in. According to Finnish law, a disabled person is someone who has long-term challenges in managing everyday life due to a disability or illness. The law also states that a disabled person must not be discriminated against due to their disability. Like everyone else, a disabled person has the right to live a normal life: to study, work and start a family. (L 417/2015.)

The World Health Organization has estimated that more than one billion people live with some form of disability, which is around 15% of the world's population (based on global population estimations from the year 2010). The Global Burden of Disease institute measured childhood disabilities between the ages of 0–14 years, which is estimated to be 95 million (5,1%) children in the world, 13 million (0,7%) of which have "severe disability". (WHO 2011, 7–8.) The number of intellectually disabled children in Finland is estimated to be around 10 000. Based on a 2000–2007 survey, around 0,22% of the Finnish population (116 000 people) were physically disabled in the age group of 15–64 (European Parliament, 2013; Statistics Finland, 2008).

Rehabilitation can be seen historically as measures that range from interventions to improve body function into more comprehensive measures to promote inclusion. Being able to participate in education, the labour market and civic life are essential for some of the people with disabilities and rehabilitation enables that. Rehabilitation always needs to be voluntary and the main goal for rehabilitation is to empower a person with a disability and his or her family. UN's Convention on the Rights of Persons with Disabilities demands for appropriate measures to enable disabled persons to reach

and maintain their maximum independence, full physical, mental, social and vocational abilities and maximum inclusion and participation in every aspect of life. Meanwhile, the Convention also describes the goals of rehabilitation very profoundly. (WHO, 2011.)

Madeleine Leininger (2006) developed The Cultural Care Theory in the 1960s, since the nurses needed to provide care for people from worldwide cultures but were unable to do so without a base of culture care research knowledge. Leininger predicted the future of a globalizing world; she saw culture and care knowledge as crucial needs for the society, and worldwide for sustaining and maintaining nursing as a profession.

The purpose of the thesis is to present some of the perceptions that immigrant families have of rehabilitation in the children's neurological unit. The target group of the research is immigrant families with a disabled child who come to the unit for a rehabilitation assessment. The research will help nurses' to understand the immigrant families' perceptions of rehabilitation, and to develop nursing and the working policies in the unit. Based on the results of the research, parents' perceptions can be taken better into consideration when assessing and planning the need for rehabilitation, since parents have a big impact on it. The research will also help to develop the culturally sensitive rehabilitation on the children of the immigrant families. In the unit, there are several encounters with immigrant families every week and the multiprofessional team is dealing with the issues related to the perceptions constantly.

2 TRANSCULTURAL NURSING

2.1 The meaning of transcultural nursing

Madeleine Leininger wanted to explain cultural competency, which is why she created the concept of transcultural nursing and eventually developed the Cultural Care Theory. Leininger's theory is an enormous leap to support transcultural nursing as a discipline and an essential part of the daily nursing practices. According to Leininger, nurses must acquire an in-depth knowledge of different cultures to provide care to people with various ethnicities. Cultural care theory is also the only theory that specifically is focused on the relationship between culture and care on health and wellness. Leininger addresses that the purpose and goal of the theory is for the nurses to understand diverse and universal, culturally based care factors, that influence the health and well-being of others. (Maier-Lorentz, 2008.) Due to the globalization and economic situation of the world, implementing transcultural care effectively is a challenge for health care.

The transcultural assessment model by Giger and Davidhizar (2002) is also an essential theoretical background for the subject. This transcultural assessment model was created based on the nursing students' need to assess and give treatment to multicultural patients. The model by Giger and Davidhizar includes six cultural phenomena altogether: communication, time, space, social organization, environmental control and biological variations. Based on these themes, nurses can create a framework for patient assessment and start the planning of culturally sensitive care. Since there are a lot of variations even within the cultures, the assessment model is a perfect starting point in providing culturally competent care for everyone. For instance, as for communication, a patient might need an interpreter for a specific dialect of a certain language. The tool can be applied also in the matter of end-of-life care, when certain rituals, traditions and values need to be respected within different cultures. (Sagar, 2012.)

ICN – the International Council of Nurses (2012) has composed international ethical instructions for nurses, the first of which were composed in 1953. Nurses naturally

need to respect these instructions that include the respect for cultural rights. In the instructions, there is a mentioning about not letting the following qualities have any impact on treatment: age, skin color, religion, culture, disability or illness, race, gender, sexual orientation, nationality, political opinions, or social status. ICN also points out that the care needs to be addressed in a culturally appropriate manner.

Høye and Severinsson (2008) encountered the impact on work patterns, communication challenges, responses to crises, professional status and gender issues to be primary themes regarding intensive care nurses' encounters with multicultural families in Norway. The nurses felt that overcrowding, the extended nature and diversity of demands from families, and the cultural characteristics such as pain and grief made them feel stressed in the workplace. In spite of this, the recognition and flexibility of using appropriate resources helped them to deal with these problems. The study gave evidence that awareness of cultural diversity among the nurses can be reached by increased knowledge of different cultures and religions in education in the hospital. In addition, it is necessary to explore the multicultural families' own perceptions of the cultural care when they are entering a hospital.

2.2 Transcultural nursing in Finland

According to Mulder, Koivula and Kaunola (2015) cultural awareness among the nursing staff in Finnish university hospitals is good, but one out of three nurses have stereotypes about foreign patients. Around one out of ten nurses acknowledges racism and avoids foreign patients. Nevertheless, work colleagues who have a foreign origin or who have lived abroad, have a positive connection with transcultural knowledge and skills. The less stereotypes and racism the nursing staff have, the better their use of interpreters, co-operation and transcultural skills are.

The number of immigrants is rising all the time in Finland, which means that health services also receive more patients with a native language other than Finnish. The use of interpreters is growing at the same time. According to Eklöf, Hupli and Leino-

Kilpi (2015) a relevant part of the public health nurses' process is to plan the appointments in primary health care with immigrant families and interpreters well. The ethical issues must be acknowledged as well. The cost of interpreters, the interpreter's ability to be neutral, professionalism and language skills are some of the biggest challenges when using interpreters. Nurses also recognize the need for their own education when there is the need to use interpreters.

Koponen et al. (2016) summarized results from the Migrant Health and Wellbeing study called Maamu, which was the most comprehensive survey done so far with this topic. It gathered information on how immigrants are using health services in Finland and targeted three different migrant groups: those of Russian, Somali and Kurdish origin. The results were compared with the general population health survey from 2011 and it showed that migrants from Somali and Kurdish origin use more specialist and emergency care when compared to the general population. However, all three migrant groups utilize screening and health examinations, rehabilitation and mental health care services less than the general population. Even though only a few other relevant Finnish studies have been made concerning migrants' health service utilization, the results from the survey are in line with register-based information about the use of health services and with a few other studies on screening and rehabilitation. The research proved the need for information on how the health service needs of migrants are met in the Finnish health care system.

2.3 Transcultural nursing with families

The need for transcultural nursing and the nurses' ability to give culturally competent care are essential nowadays when working with families. According to Berlin, Johansson & Törnkvist (2006), the primary child health nurses working conditions have a connection to the nurses' ability to give culturally competent care to children and families from other origins. Many primary child health nurses reported inadequate working conditions. They were unsatisfied with the quality of the health care they had given for the families from other origins. They were also lacking support in the form of written guidelines, support and help. The more families the nurse had from other origins, the

more the nurse was facing difficulties concerning the quality of given health care. Many of the nurses felt that they had clear lack of formal training concerning cultural competence or the formal and clinical cultural competence was not enough.

In the United States, the number of first and second-generation Chinese immigrants is rising all the time, which requires the health care to develop their care to be more culturally sensitive. According to Cheung, Nelson, Advincula, Cureton & Canham (2005) school nurses play an important part in allowing Chinese immigrants to maintain their cultural values and beliefs and at the same time provide appropriate care for the student. The challenge is for the nurses to familiarize themselves with Chinese culture, which holds values and beliefs that may contrast with those in the Western culture. Despite this, the values, beliefs and practices may vary even in families from the same country of origin. An assessment of the family's culture and family system at the beginning of a nurse-family interaction is a significant, initial step of the nursing process and of providing culturally sensitive health care in the school settings.

Regarding the relationship between the nursing environment and delivering culturally sensitive perinatal palliative care, education and technology are suggested to be the most significant factors, according to Mixer, Lindley, Wallace, Fornehed & Wool (2015). Recommendations concerning culturally sensitive care in palliative care by National Consensus Project include: communication in a language that the parents understand, use of interpreter services, availability of written materials, identification of and referral to community services, and implementation of a culturally relevant plan of care. The study by Mixer et al. (2015), was mainly focused on language while providing culturally sensitive care: the availability of interpreter services, written materials in the parents' language and multilingual staff. It seems that an environment that promotes and stimulates education is more likely to offer culturally sensitive care for perinatal families. Demonstrating respect and addressing the health values, beliefs and practices of different families along with cultural assessment of the families' needs are essential to build a trusting relationship with the families dealing with perinatal loss.

Maintaining integrity, moral responsibility, role division and presence were recognized as important topics concerning family support as a care resource in an African context among the Bena in the Tanzanian village of Ilembula (Juntunen & Nikkonen, 2008).

The family played a fundamental role in caring for and supervising ill relatives in the hospital, and being the mediator between the health care professionals, the patient and the rest of the family. The wellbeing of the patient was very much dependent on the family since the nurses mainly just implemented doctor's orders and administered medication. At the same time, however, families were given very little encouragement from the nurses, since traditionally it was not acceptable to become too involved in another family's situation within their culture. Accepting the family as a part of care resource would have been interpreted as a lack of respect for their profession and status. These similar types of problems arose when the patient didn't have any family taking care of them, which emphasized the social security system and its change in Tanzania.

3 DISABLED CHILDREN WITH AN IMMIGRANT BACKGROUND

3.1 Literature search

From a broader way of thinking, the aim of this thesis is to develop transcultural nursing and especially culturally sensitive rehabilitation, as well as to increase the understanding between the immigrants and nursing staff, since the number of immigrants will only increase in the future. The transcultural aspect needs to be included more in the development in health care, so that multicultural patients will as well receive the support and individual care that they need. Based on the results of the interviews, the purpose is to present the perceptions that the immigrant families have of rehabilitation. The research will help nurses to understand the immigrant families' perceptions of rehabilitation, and to develop nursing and the working policies in the unit. Based on the results of the research, parents' perceptions can be taken better into consideration when assessing and planning the need for rehabilitation, since parents have a big impact on it. I decided to choose this topic for my thesis due to my own interest as

well. During my thesis process I am hoping to gain more knowledge on the topic itself and the perceptions of the parents, but also about the Master’s thesis process: information search, critical approach to sources and qualitative study process.

The literature search took place mostly in spring 2017 but continued until August 2017. The literature search for the topic and thesis began by looking into different databases including EBSCO Academic Search Premier, CINAHL Fulltext, EBSCO Ebook Collection and Pubmed, all of which provided materials online, in different forms. For finding literature of qualitative research, the University of Applied Sciences’ library’s search service DIAK Finna was used. In the beginning, it was hard to pre-plan the literature search, since I didn’t know how much literature that was available for this topic. The pre-planning started by framing different word and search combinations as seen in Table 1. Considering the topic and the definitions used in the topic, the literature research was challenging, and the help of an information search specialist from the University of Applied Sciences was used. The search was restricted mostly to peer reviewed articles in English language and between the years of 2007 – 2017 with the advanced search of EBSCO Academic Search Premier and CINAHL Fulltext. However, also the basic search was utilized. During the literature search it become obvious that there isn’t a lot of literature available in this topic so the literature search criteria was not possible to be narrowed down too much.

Table 1. Literature search – search words used with databases

| | |
|-----------------|---|
| Advanced search | Immigrant* famil*, multicultural* AND disab* child* AND rehabilitation* |
| | Perception*, meaning*, attitude* AND Immigrant famil* AND rehabilitation* |
| | Transcultural nursing* AND disab* AND rehabilitation* |
| Basic search | Immigrant families’ perceptions about rehabilitation |

Besides the information search, the coordinator Eeva Airikkala and customer counselor Elisa Montonen from Hilma – The Support Center for Immigrant Persons with Disabilities were interviewed about the same topics as the thesis interview questions and

type of experiences they had with their customers concerning the perceptions of rehabilitation. The Hilma employees' answers are reflected in the results of this thesis in discussion. Regarding the theoretical framework and background info, WHO and UN webpages were very helpful to find info about disabilities and rehabilitation in a world-wide perspective.

3.2 Disabled children

A UK-based research aims at describing the practices of Pakistani parents taking care of their disabled child and how they explain and understand the child's disability. The results contain specified details on how the parents understand the reason's leading to the child's disabilities. (Croot, Grant, Cooper & Mathers, 2008.)

Providing culturally sensitive care is an important element of family-oriented rehabilitation, but very little is known about it, especially in pediatric settings. Lindsay, King, Klassen, Esses & Stachel (2007) described the experiences of service providers who are working with immigrant families raising a child with a physical disability. The health service providers face several challenges when providing services to the immigrant families raising a child with a disability. These challenges include the following: lack of training in providing culturally sensitive care, language and communication issues, disparities in conceptualizations of disability between health care providers and clients/parents, building a relationship, and helping clients/parents to defend for themselves. In the study, the results showed that disability is often understood differently based on cultural beliefs that can influence health behaviors, health outcomes and impact how health care services are approached.

When a newborn child with several disabilities is born in the family, the health care professionals have a huge challenge in communicating with the parents since the situation is very fragile. Graungaard and Skov (2007) described the parents' experiences, coping and needs when the newborn child is severely disabled. The certainty of the diagnosis of the child was connected clearly to the experiences of the parents. The research recognized three major causes of the importance of diagnostic certainty.

The first one was that the emotional reaction of the parents was highly connected to the diagnostic process and how it was proceeding. The second one was the necessity of a possibility of doing something practical for the child. The third one was the difficulty of coping with an uncertain future. The communication with the health professionals and parents during the diagnostic process was very important and it did have an influence on the way the parents coped with their new life with a disabled child. In addition to communication, information received from the health care professionals was discovered to increase parental satisfaction and coping abilities, and thereby improve their quality of life.

Table 2. Literature results on disabled children

| The topic of the study | Study type | Study objective | Principle results | Conclusion |
|---|--|--|---|--|
| Morgan, F., & Tan, B. (2011) Rehabilitation for children with cerebral palsy in rural Cambodia: parental perceptions of family-centred practices | Qualitative study; semi-structured individual and small group interviews | The study examined the perceptions of parents living in rural Cambodia regarding family-centred rehabilitation practices. | Three themes from family-centred rehabilitation practice raised as results: collaborative partnerships with staff, information exchange and respectful and supportive care offered by the rehabilitation team. Many of the needs and preferences of parents living in rural Cambodia were similar with parents in Western contexts. | Family-centred approaches to paediatric rehabilitation were found to be valued in and appropriate for a rural Cambodian context. Social and cultural mechanisms need to be considered when adapting a Western, family-centred model of rehabilitation to the rural Cambodian context. It includes the hierarchical nature of Cambodian culture, the emphasis on group relational patterns rather than individual needs and the context of chronic poverty. |
| Øien, I., Fallang, B., & Østensj, S. (2010) Goal-setting in paediatric rehabilitation: perceptions of parents and professionals. | Qualitative study; two-step focus group interviews | The study's aim was to explore parents' and professionals' perceptions of setting and implementing goals in family centred rehabilitation programme for children with cerebral palsy (CP). | The results were summarized in three categories: (1) 'Goals enhance competence', (2) 'Goals direct attention' and (3) 'Goals enter everyday life'. A fourth theme 'child perspective' was both an exclusive theme and integrated into the other three main themes. | It seems that when parents are actively involved in the goal setting and implementation, it does increase the feeling of competency and partnership with professionals. Practical goals based on the families' needs, participatory observations and discussions with professionals came out as meaningful results from the study. |
| Barlindhaug, G., Umar, E., Wazakili, M., & Emaus, N. (2016) Living with disabled children in Malawi: Challenges and rewards | Qualitative study; anthropological field study including interviews and observations | The aim of the study was to describe how families experience parenting of disabled children and how they experience the support provided by the rehabilitation system in Malawi | The findings were combined with themes such as the struggle to create a life worth living and hopes and dreams for the future. Especially the heavy everyday life of the mothers would require more support from the rehabilitation system and professionals. | The support given to mothers and families by the rehabilitation professionals should be strong and together with the professionals. Families' realistic goals should be set in-sight with the objective to maintain hope and construct meaning. |

| | | | | |
|--|--|--|---|--|
| <p>Kruijsen-Terpstra, A. A. et al. (2014).</p> <p>Parents' experiences with physical and occupational therapy for their young child with cerebral palsy: a mixed studies review.</p> | <p>Mixed studies review: both qualitative and quantitative methods were included in the literature review.</p> | <p>The aim of the review was to give an overview of the experiences and related factors of parents of young children (0–5 years of age) with cerebral palsy in relation to the physical and/or occupational therapy of their child in a rehabilitation setting.</p> | <p>Parents expressed various aspects in context, process and outcomes when asked about their experiences with their child's intervention and rehabilitation. They had different needs over time and needed time to build a collaborative relationship with their child's therapists.</p> | <p>The proposed framework acknowledges the various aspects in context, process and outcomes that parents reported when asked about their experiences. Knowing this, the importance of the broader context of the child in a family should be acknowledged; realizing the impact that the demands of daily life, supports and resources provided to parents, attitudes in the community and culture have on parental experiences.</p> |
| <p>Skyrme, S. (2016).</p> <p>Living with Duchenne Muscular Dystrophy: Relational Autonomy and Decision-Making.</p> | <p>Qualitative study: interview based method</p> | <p>The study examined how boys and young men with Duchenne muscular dystrophy (DMD) make decisions to take part in medical research. This question is raised at a significant point in the development of clinical research, which is exploring several potentially therapeutic treatments to modify and possibly cure DMD, which is a progressive muscular disease.</p> | <p>Parental support continues to be significant as the participants move into adulthood. Healthcare professionals, among others, should recognise and respect disabled children and young people's agency, which is exercised within a network of relational autonomy. Disabled children are often denied the right to communicate their views, and considering the participants' thoughts and experiences contributes vital understandings on the role of independence, agency, autonomy and shared decision-making.</p> | <p>Support provided by the parents stays to be important as the participants mature, a point that may be specific to this group who have a severe, degenerative condition that is currently untreatable. The independence these disabled children and young people exercise emerges from a supportive network of relational autonomy, demonstrating how this can be an effective means of coping with the challenges of living with DMD, and how these relationships can work and be productive.</p> |

3.3 Rehabilitation of disabled children

The World Health Organization (2011) defines rehabilitation as actions that help individuals who experience (or are likely to experience) disability to achieve and maintain certain amounts of functioning in interaction with their environments. However, not everything related to disabilities can be part of rehabilitation, even though the definition and meaning of rehabilitation is broad. Rehabilitation aims to improve the daily functioning of an individual, for example a person's ability to drink and eat independently. The following Table 3 describes the overall rehabilitation of a child with cerebral palsy. The figure also describes the environment and activities that the child needs for the rehabilitation. Information included in the figure also presents what the role of the professionals is in the child's rehabilitation process.

Table 3. WHO's (2011) description of a child with cerebral palsy and rehabilitation

Table 4.1. Child with cerebral palsy and rehabilitation

| Difficulties faced by the child | Rehabilitation measures | Possible outcomes | Potential barriers | People involved in the measures |
|---------------------------------|--|---|--|---|
| Unable to care for self | <ul style="list-style-type: none"> ➤ Therapy <ul style="list-style-type: none"> – Training for the child on different ways to complete the task. – Assessment and provision of equipment, training parents to lift, carry, move, feed and otherwise care for the child with cerebral palsy. – Teaching parents and family members to use and maintain equipment. – Provision of information and support for parents and family. – Counselling the family. ➤ Assistive technology <ul style="list-style-type: none"> – Provision of equipment for maintaining postures and self-care, playing and interaction, such as sitting or standing (when age-appropriate) | <ul style="list-style-type: none"> – Parents better able to care for their child and be proactive. – Reduced likelihood of compromised development, deformities, and contractures. – Reduced likelihood of respiratory infections. – Access to support groups or peer support. – Coping with stress and other psychological demands. – Better posture, respiration, feeding, speech, and physical activity performance. | <ul style="list-style-type: none"> – Timeliness of interventions. – Availability of family and support. – Financial capacity to pay for services and equipment. – Availability of well trained staff. – Attitudes and understanding of others involved in the rehabilitation measure. – Physical access to home environment, community, equipment, assistive devices and services. | <ul style="list-style-type: none"> – The child, parents, siblings, and extended family. – Depending on the setting and resources available: physiotherapists, occupational therapists, speech and language therapists, orthotists and technicians, doctors, psychologists, social workers, community-based rehabilitation workers, schoolteachers, teaching assistants. |
| Difficulty walking | <ul style="list-style-type: none"> ➤ Rehabilitation medicine <ul style="list-style-type: none"> – <i>Botulinum</i> toxin injections. – Surgical treatment of contractures and deformities (therapy interventions usually complement these medical interventions). ➤ Therapy <ul style="list-style-type: none"> – Therapy, exercises and targeted play activities to train effective movements. ➤ Assistive technology <ul style="list-style-type: none"> – Orthotics, wheelchair or other equipment. | <ul style="list-style-type: none"> – Decreased muscle tone, better biomechanics of walking. – Decrease in self-reported limitations. – Increased participation in education and social life. | <ul style="list-style-type: none"> – Access to post-acute rehabilitation. | <ul style="list-style-type: none"> – Doctor, parents, therapist, orthotist. |
| Communication difficulties | <ul style="list-style-type: none"> ➤ Therapy <ul style="list-style-type: none"> – Audiology. – Activities for language development. – Conversation skills. – Training conversation partners. ➤ Assistive technology <ul style="list-style-type: none"> – Training to use and maintain aids and equipment, which may include hearing aids and augmentative and alternative communication devices. | <ul style="list-style-type: none"> – Better communication skills. – Participation in social, educational and occupational life opportunities. – Improved relationships with family, friends, and the wider community. – Reduced risk of distress, educational failure, and antisocial behaviour. | <ul style="list-style-type: none"> – Availability of speech language therapists. – Social and economic status of the family. – Costs of purchasing and maintaining devices. | <ul style="list-style-type: none"> – Parents, speech and language pathologist/therapist, communication disorders assistant, community-based rehabilitation worker, teachers, and assistants. |

The International Classification of Functioning, Disability and Health (ICF) is a part of WHO's International Classifications. The purpose of ICF is to describe the effects an illness or a disability can have on the life of an individual. From ICF's point of view, functioning and disability are understood as a complex, interactive and dynamic status consisting of interaction between an individual's health and features of the person and the comprehensive situation in which the person lives in. (THL, 2016.)

Recommendations created for children's good rehabilitation practices in Finland can also be based on the ICF and its framework. The goal of these recommendations is to have similar principles in implementing rehabilitation for children in the entire country. Supporting child's development, development path, self-image and also the participation from a child's point of view in different life situations, are highlighted and they are also the general goals of a child's rehabilitation. Learning based on the goals that have been set, has a key role in rehabilitation, which means that the child's

opinion is respected, he/she will be heard and will get more confirmation to their self-confidence and trust. There needs to be set realistic, concrete and measurable goals for both short and long periods. As in rehabilitation in general, there is a problem considering enough evidence on the effectiveness in children's rehabilitation as well. Rehabilitation needs to be based on scientific evidence and/or national policies regarding good rehabilitation. (Kiviranta, Sätilä, Suhonen-Polvi, Kilpinen-Loisa & Mäenpää, 2016.)

In a Japanese research, researchers have tried to describe the beliefs that the mothers of disabled children have about disabilities. The mothers reflected the common feelings of the family members and mutual relationships when it has involved taking care of the child in a day-to-day life. The aim of the research has been to develop knowledge in the Japanese families to confront diseases in different ways. (Sato, Araki, Ito & Ishigaki, 2015.)

According to Starck (2016), Somali families have a relatively positive image about the health care services concerning rehabilitation as well. They still found it important to gain more information about the health care system, children's developmental delays, potential care and rehabilitation methods. It became evident that in the Somali culture, disability is a shameful and sensitive topic. The researcher pointed out that the sample size for the study included only four parents. One interpreter and a Somali culture specialist were also interviewed.

LOOK-project (Sipari, Vänskä & Pollari, 2017) was established in the co-operation of all the stakeholders concerning children's rehabilitation: universities, healthcare professionals, therapists, families and especially the children themselves. The project set new mutual guidelines for the stakeholders to use and in these guidelines the participation and activation of the child was especially highlighted. Furthermore, the surroundings and the role of the child should not be forgotten. The child should be active for the rehabilitation to succeed, everything should be in the child's terms. This also includes the decision-making, especially when the child grows, and decisions need to be made about the child's future and rehabilitation. This will develop the autonomy of the child from an early age concerning their own health.

3.4 Perception about disabilities globally

Disabilities have been tried to be standardized to a classification globally. One of these attempts was the WHO's International Classification of Impairments, Disabilities and Handicaps that was established in 1980. Whether there are classifications or definitions for it, in many societies people with different physical shapes, sizes and bodily functions are often the target for considerable stigma, prejudice and discrimination. Even though the disabled body is not necessarily a sick body, the disabled might confront a lot of different social disadvantages. The degree of stigma and the economic effect of physical impairment can depend on several factors. They include the type of impairment, socio-economic position of the person, the types of rehabilitation or treatment available, and the level of technology and social organization of the community. In the age of computers, information technology and Internet, physical impairment does not exclude from working life, which might also decrease the amount of stigma from the disabled people. (Helman, 2007.)

Physical impairments are often blamed on a variety of causes – it can be originated in individual behavior or in natural, social or supernatural worlds. Supernatural theories are quite common; a good example is a study conducted in Ethiopia, where 33 percent of the blind people interviewed blamed supernatural forces, such as curses or divine punishments for their blindness. The Songye people from Democratic Republic of Congo divide the physically unusual or “abnormal” children into three categories: “bad” children include albino, dwarf and hydrocephalic children; “faulty” children include deformed upper or lower limbs, such as polio or birth defects; and “ceremonial” children include twins, children born with the feet or hands first or with the cord around their neck. The children mentioned in the last category are given special attention, a higher social status and are believed to have special powers of healing. On the other hand, the children with disabilities are seen as inferior beings, not fully human. In industrial societies in particular, there is a strong will to shift the definition of disability, with all the disadvantages it implies, towards a more neutral definition of physical impairment. (Helman, 2007.)

Community knowledge, beliefs, attitudes, and practices towards children with spina bifida and hydrocephalus in Uganda was a topic covered by Bannink, Stroeken, Idro & van Hove (2015). The results of the research describe how negative knowledge, beliefs, attitudes and practices create barriers to treatment and inclusion of children with spina bifida and hydrocephalus and their parents in Uganda in four regions. The results also show that knowledge, beliefs, attitudes and practices develop over time and become more promotive to access treatment and inclusion. One of the reasons is the peer support from other families, giving support and courage to spread knowledge and be involved in the community activities along with the disabled child. Early intervention is one of the recommendations to be able to facilitate more positive attitudes and beliefs.

3.5 Alternative and complementary treatment

Sanders et al. (2003) did a research about the complementary and alternative medical therapies used for children with special needs in Southern Arizona. The children with special needs included children with the following diagnoses as an example: cerebral palsy, spina bifida, cleft lip and circulatory, heart problems. The complementary and alternative medical therapies used that families listed were oral and topical herbs, megavitamins, massage, acupuncture, osteopathic manipulation, chiropractic manipulation, prayers/blessing/spiritual healing, self-hypnosis, special diets, homeopathy, and hippotherapy (physical therapy that uses the movement of the horse as a treatment tool). The research shows the broad use of complementary and alternative medical therapies by children with special health care needs. Of the 363 children who participated in the research, 64% were recipients of a least 1 of the listed therapies. The use of these alternative methods was much more frequent with children having non-correctable conditions. As the researchers mention, the data of the research wasn't that big but the value of the research is important. There aren't many previous studies about children with cerebral palsy or spina bifida, for example, and the use of alternative methods in their cases.

Wray et al. (2014) described parents' attitudes towards the use of complementary therapy by their children with moderate or severe cerebral palsy. Limitations were evident in the study since children with mild CP were not included in the study due to its small sample size, but essentially the study was qualitative. The study indicates that parents of children with CP are motivated to try complementary treatments that will help their children, but that they need information, guidance and practical support to facilitate the use of complementary treatments. According to the results, it also suggests that when parents are confident that a treatment is supported or provided by medical or professional staff is safe and is funded, they want to take the opportunity for their child to receive complementary treatments.

3.6 Challenges in the care of disabled children

Based on all this information search done, it brings up several studies about the perceptions of disabled children's families and how it impacts nursing. These studies, however, are constrained to a specific immigrant minority and generally on health perceptions. Based on the information search results, the need for a topic on immigrants' perceptions about rehabilitation is needed. The rehabilitation of physically disabled children needs more visibility, also from the perspective of transcultural nursing, which is why I feel that the topic of this thesis is important. The most important factor in cooperating with immigrant families is accepting different cultures and customs related to them and the respect for them (Invalidiliitto, 2012). Just as Etene (2001) says in their publication, the right for appropriate care and treatment worthy of a human being can't be dependent on a patient's age, residence, social status, mother tongue, sex, ethnic background, culture, sexual orientation or religion. The rights of children, elderly and anyhow handicapped patients' to receive good care should be specifically addressed. Hilma – The Support Centre for Immigrant Persons with Disabilities (2017) also argues for the disabled people to have the same rights as anyone else and for them to have the possibility to receive many kinds of help for an independent life.

4 THE PURPOSE, AIMS AND RESEARCH QUESTIONS

The aim of the research is to present some of the immigrant families' perceptions of rehabilitation in the children's neurological unit. The target group of the research were immigrant families that have a disabled child, who come for a rehabilitation assessment to the unit. The research will help nurses to understand the immigrant families' perceptions of rehabilitation and to develop nursing and the working policies in the unit. Based on the results of the research, parents' perceptions can be taken better in to consideration when assessing and planning the need for rehabilitation, since parents have a big impact on it. The research will also help to develop the culturally sensitive rehabilitation on the children of the immigrant families.

The objective of the research:

What kind of perceptions immigrant families have of rehabilitation of disabled children?

5 DATA COLLECTION AND ANALYZING

5.1 Description of the environment

The interviews were conducted in the children's neurological unit in a university hospital. In the unit are children between the ages of 0-16. The children coming into the unit have different physical disabilities, such as cerebral palsy, meningomyelocele and different kinds of muscle diseases. The unit is divided into two parts: the ward and policlinic. The staff in the unit is very multiprofessional, it consists from medical doctors, nurses, physiotherapists, speech therapists, occupational therapists etc. Children come to the unit for rehabilitation and ancillary assessments, and for long-term rehabilitation after an operation, accident or, for example, after a cerebral hemorrhage. Rehabilitation assessments last approximately from one to five days. Ancillary assessments usually take one to two days. Long-term rehabilitation might last from few weeks to several months. Since the work is done in a multiprofessional team, the number of therapists involved in the process is based on the needs of the child and family. Families are very strongly involved during the time a child is in the unit. Guidance and support given to the families during this time is a very essential part of the work in the unit.

5.2 The target group of the research

The reason for choosing the immigrant families as a target group is because their perceptions have a big effect on how the rehabilitation of the child is implemented. Immigrant families have very different backgrounds that also have effects on their perceptions. When the families and nursing staff have different perceptions of rehabilitation, it is very challenging to support and give guidance for the family. On a weekly basis, the multiprofessional team meets immigrant families in the unit, so transcultural nursing is conducted often and understanding between nursing staff and immigrant families is needed.

For the interview, parents that cope well communicating in Finnish or English language were chosen, so that the interview can be done without an interpreter. Two information leaflets about the research were given to the families; the information about the research (Appendix 1) and the consent of participating in the research (Appendix 2), which were also in English. The families had been clients to the unit for more than one time, so they knew the unit and the rehabilitation, such as physiotherapy or occupational therapy supported by Kela – The Social Insurance Institution, for the child had begun. In the interviews participated five parents, both mothers and fathers. Seven parents were asked to participate in the research, but two declined to participate. One declined due to a lack of interest and one because they didn't feel they were a member of the target group. Interviews were conducted both in English and Finnish. The interviewees were immigrants whose country of origin was other than Finland. There were parents from the following countries: Turkey, Kosovo, Somalia and South Africa. The parents had lived in Finland for 8–25 years. The interviewees were chosen together with the head nurse of the unit and other members of the nursing staff, so that the interviewees had all the above-mentioned inclusion criteria and that the interviews were conducted successfully. The information about the thesis were given to the staff of the unit in a weekly meeting.

5.3 The methods used in the research

The method used in the research was chosen to be qualitative. The perceptions of immigrant families would be difficult to interpret in a quantitative method since there should be more research done on the topic to form the interview questions for a questionnaire. However, when you are working with stories, tales and meanings, it's not possible to gain a lot of information that can be generalized, as it is possible with a quantitative method. If the research is done thoroughly, following ethical principles and methodological guidelines, qualitative research is just as valuable an area of research. Despite the differences between the qualitative and quantitative method, the goal for both is to find out the truth about a phenomenon that is the object of the research and to form it to be more controllable. (Kylmä & Juvakka, 2007.)

The data collection method was qualitative semi-structured interviews. The interviews were conducted individually. The reason to choose this method was because there isn't a whole lot of research made from this topic. A typical feature for qualitative research is that its goal is to describe a phenomenon and understand the target group in the research. That is the reason for this research also to not have so many participants and to be able to produce new data and findings. (Kylmä & Juvakka, 2007.)

Semi-structured interviews are a useful method in qualitative research since the technique ensures that the researcher will obtain all information required and at the same time permitting the participant freedom to respond and to describe and illustrate concepts. The freedom to reply to the given questions provide the rich descriptive context that makes qualitative research so valuable and the analysis very interesting and significant in the research process. Preparing the interview questions is one of the most important phases of the research, since the quality of the questions has a big impact on the quality of the research overall. (Morse & Field, 1996.)

In a qualitative research, the main criteria for reliability is the researcher herself and the criteria of the reliability concerns the whole research process. Usually in qualitative research, the present ability and generalization of the results are the most doubted issues. That is the reason for the researcher to be openly subject and admitting that the researcher herself is a crucial tool of the research itself. (Eskola & Suoranta, 1998.)

5.4 Data collection

The goal was to have 5–10 parents for interviews. The number of the interviews was also based on the received material: the evaluation made after five interviews showed that the data collected is large, so the number of interviews was enough. After five interviews the data gathered started to saturate and resemble itself, which was also a sign of the enough amount of data collected. In advance, it was challenging to know how many parents would agree to participate in the research. There was also a structure prepared for theme interviews with its questions and supportive words, in case the person being interviewed found it hard to understand the question, or if the theme

of the question wanted to be explained (Appendix 3). The interviews progressed well, supportive words were used and questions asked during the interviews were based on the answers of the interviewees. The very first interview was a pilot. It was possible to see the effect of the questions and evaluate if any replies were received for the research question. After the pilot, it was not needed to modify the questions, since the answers were being received for the research questions. The interviews were organized in a quiet space with no interruptions. The interviewees were explained the meaning of the research and interviews, highlighting the fact that participating is voluntary and identities will stay anonymous. They were also entitled to stop the interview at any point (Leino-Kilpi, 2003). The interviews were recorded, but after the report is published, the recordings will be destroyed by deleting them from the recorder. The transcripts will also be torn apart and destroyed after the publishing. One of the interviewees got scared due to the fear of being filmed; in their religion, it was prohibited. The interviewee agreed to start the interview after the explanation of them being voice recorded, not filmed. It was emphasized for the interviewees that nothing told in the interview will have any impact in the treatment, availability of the treatment they or their child will receive now or in the future (Appendix 1).

5.5 The analysis method of the data

For the analysis of the data, content analysis was used which allowed dividing the results into certain topics. From these topics, I was capable to make conclusions and discuss how the results answered the research questions.

The first step in analysing the data by content analysis is to transcript after the interviews are recorded. Even though it is thought to be only as a mechanic process, it is one of the most important points of the data analysis. When the data of the interviews were all written down electronically to a Word file, it ultimately became 12 A4 sized pages. The font was size 12, the font type was Arial, and the space between rows was 1,5. The interviews lasted for 8–18 minutes. Already at this point it is possible to make assumptions, conclusions and overall understanding of the data that was gathered.

The goal for content analysis is to produce information about, in this case, the perceptions of rehabilitation, based on the data gathered. With the help of content analysis, we can analyse documents systematically, and organize and describe the data. Even though it would be possible for someone else to transcribe the interviews from the recordings, I personally felt it to be an important part of the research since it enabled me at some level to already analyse and go through the data. It is possible to get a bigger picture from the data which will help in the evaluation and analysing phase. Writing the data does consume time from the author of the thesis, but at the same time it is a factor of reliability since he/she has written it him/herself. (Kylmä & Juvakka, 2007.)

After writing down all the interviews, I started to reduce the data into words and phrases said by the parents. I used colours and was writing the words and phrases down that the parents had said and which ones I felt to be relevant and important. I used small post-it markers and it led to combining similar words, phrases or things that were somehow connected to each other. Eventually these groups formed into sub-categories and categories which helped to process the results of the research. In this stage of the analysing process, my experience from the work and interacting with the parents helped to form the categories and subcategories.

6 RESULTS

The purpose of this thesis is to present what kind of perceptions the immigrant families have of rehabilitation. "Perception" is defined as the act, power, process or product of perceiving. "To perceive" is defined as to come to understand or apprehend with the mind. (Landau, 1996.)

Based on the results received from the interviews, the analysing of the results was continued. Individual words and phrases were used as analysing units that originated from the interviews. These words and phrases were analysed and divided into four different categories: importance of rehabilitation, the meaning of families and parents, the neurological unit's role and hopes, and fears of the future. Since nothing involving children, disabilities and rehabilitation is simple, in the following Table 4 is visualized some of the things that the parents were telling in the interviews and how these expressions were divided in these categories. As an example, the category of the role of the neurological unit was presented more widely based on the answers of the interviews.

Table 4. Example of analysing and categorizing the results

| Interview | Phrase | Subcategory | Category |
|--|---|---------------------------------|------------------------------|
| "Rehabilitation is to be independent" | Being independent as a result of rehabilitation | Independence | Importance of rehabilitation |
| "My child learnt to move from the wheelchair to a normal chair" | Learning to move from one place to another | Developing new skills | |
| "I always hope to get more information from the doctor" | Hope to gain more information | Information from a professional | |
| "I expect to receive guidance from the physiotherapist" | Expectation of receiving instructions from a professional physiotherapist | Guidance from a professional | |

| | | | |
|---|---|---|-----------------------------------|
| “You can get all the rehabilitation services at once in the ward” | The services families’ need is available in the same place easily | Support from the neurological unit | The role of the neurological unit |
| “By time I have understood why we need to come here” | Understanding the need to visit the rehabilitation unit | Importance of the neurological unit | |
| “It’s different when a professional is evaluating your child compared to a parent” | Evaluation of the child by a professional is different compared to a parent | Appreciation of a professional’s opinion | |
| “The parents of a disabled child need support” | The need for support of the parents that have a disabled child | Support for parents | |
| “The special needs of my child are being taken in consideration” | Special needs of a child are taken in consideration | Children’s individual needs | |
| “I am waiting to hear how my child’s development is progressing – information on that” | Information about how the child is developing | Information concerning development | |
| “Before making decisions, the doctors should discuss with the parents” | Discussing with the parents regarding decisions made about their child | Parents are the guardians of the child | The meaning of family and parents |
| “I am trying to do the same things as therapists” | Parents trying to copy what therapists are doing | The importance of parents as a part of rehabilitation | |
| “We wouldn’t have received so much help in our own country” | Wouldn’t get so much help in their own country | Appreciation for living in Finland | Hopes and fears of the future |
| “When I die, he will be rootless” | Insecurity about the future without parents and his own culture | Future in Finland with as a second-generation immigrant | |
| “I hope for her to have a job and a family in the future” | Hoping for the child to have a normal life with a job and own family | Future as a disabled person in Finland | |
| “I am afraid of the future” | Insecurity of the future | Insecurity about the future of the child | |

6.1 Importance of rehabilitation

Independence was a definition several parents used when they were asked about what rehabilitation means to them. The parents described rehabilitation as the child learning to do things by themselves. Learning to walk and learning how to move from the wheelchair to a normal chair by themselves were examples that the parents mentioned of a successful rehabilitation. The reason for rehabilitation (illness, disability) was important to know. When the diagnosis is clear, the rehabilitation will be easier to conduct for everyone involved in the process. The right kind of exercises would also gain better results in rehabilitation.

The parents felt that the holistic point of view needs to be taken in consideration in rehabilitation since all the aspects of a person's wellbeing have an influence on each other. The psychological wellbeing was still considered as the most important. Self-esteem and willpower were also qualities required in rehabilitation and would help a disabled child to manage in life in general as well. Giving time for rehabilitation, for the child to do things by themselves and to practice and learn, was mentioned as something important, but not always possible in everyday life. Setting goals for rehabilitation was essential, something for the child to reach out for and for the family as well. Ancillaries and different kind of individual needs for the child were said to be important. In general, the parents acknowledged that their perception about rehabilitation has changed after having a disabled child. They see how the child has developed with the help of rehabilitation, and that without rehabilitation it wouldn't have been possible.

6.2 The role of the neurological unit

Mostly parents wanted to gain a lot of knowledge from the visit to the neurological unit. They have a lot of expectations and hope to get a lot of information from the doctor, especially about how the development of the child is proceeding. Depending on the visit, the parents were always expecting something from certain professionals. However, it was emphasized that all of them respect the professional's opinion and expect to hear it during their time in the unit. They felt that it is still a different thing when a

professional is evaluating their child compared to themselves. Nurses' presence was appreciated during the time the families were in the unit; a familiar nurse was something the parents were expecting to see.

The possibility to receive all the rehabilitation services from the same place was seen as convenient and easy. The parents were expecting to receive guidance on what exercises to do with the child and general instructions from a physiotherapist. The role of a speech therapist was also understood by a parent during a rehabilitation assessment visit and how important it is when the child is learning how to eat due to motoric difficulties in the mouth area. It was confessed that they didn't necessarily understand when the child was a small baby, why they needed to come to the unit. In time that has changed, and the parents have created positive impressions about the neurological unit.

The parents weren't however always happy about the decisions made in the unit. The parents felt that the doctors should listen more to the parents, the families need to see some specific therapists wasn't always filled, and the constant change of staff participating in the rehabilitation planning was negative. The parents felt like the doctors would be able to do a better job if they would also know the child from before. Also, the amount of physiotherapy that had been decided in the neurological unit by the therapist was mentioned as something a parent was not satisfied with.

6.3 The meaning of family and parents

The parents' and families' role in rehabilitation became evident during the interviews. Parents recognized the necessity that a disabled child's parents need support. Especially after the child has received a diagnosis to an illness or a disability. Peer support from other parents was hoped for and a request for an open environment in the neurological unit where the parents could interact with each other was even made.

Parents do have the will to do things by themselves for the sake of rehabilitation and are eager to receive instructions from professionals. They also try to do the same

things that they have seen professional therapists doing with their child. The motivation given and positivity by the parents is vital for the children to proceed with rehabilitation. When the parents have seen the progress of the child, it has also helped them to continue to motivate the child.

The parents' feel that their wishes have been taken in consideration during their visit to the neurological unit, but still hope more for the doctors to discuss with the parents before making big decisions. Parents are the ears and voice of the child. Flexibility and individuality with each family was appreciated during the visit. It was appreciated also that parents were told what benefits they are entitled to from the social security system to support their well-being this way.

6.4 Hopes and fears of the future

6.4.1 Life in Finland as an immigrant

All the parents felt that they were being respected and treated well in the neurological unit based on their culture and religion. Not eating pork due to religion was taken into consideration as an example. Some of the parents felt that their own culture was taken well into consideration and that the way one's culture is considered depends a lot on the individual themselves as well.

Future as a foreigner in Finland and especially with a disability, and how the society will treat the child in the future, is something the parents were worried about. Bullying in schools is something that was mentioned, for the child feeling sorry for himself. Even though the children might have been born in Finland, the parents did express that the child is still in a foreign country, with foreign language and foreign people. The child has a different skin colour and one parent described the child as rootless once the parents die. Some of these feelings might occur due to the parents' own experiences, since they feel that a minority of Finnish people will always consider them as a foreigner, no matter what they do. Despite these worries and difficulties in Finland, the

parents felt that Finland has given them a lot and don't regret being here. They wouldn't have necessarily received so much help in their own country and they feel that Finland is the best country to be with a disabled child.

6.4.2 Future in Finland as a second-generation immigrant with a disability

The parents biggest hope for their children for the future was to be able to live life by themselves. Normal life was how the parents described it. Moving away from home, getting an education, job and family were listed for the future of the child. One parent had even thought that the child would have an education and job in the IT-field, since it doesn't require anything physically. After seeing how the child has developed in time with the help of rehabilitation, it has helped the parents to see the future brighter and the child as more independent. The parents were also thinking about what happens to the child when they die, especially if the child would be dependent on other people's help.

Even though the parents were able to think about the future of their child with a disability, they admitted at the same time that the future does concern them and the future holds a lot of insecurity. The parents were thinking about all the special needs of the children, about the long way the child has to become independent, and about what happens when the parent themselves die. One parent was thinking if the child needs to go to a facility to live after the death of the parent. As a parent of a disabled child, all the big changes in the child's life seem to be something that worries the parents already beforehand.

One parent did say in the interview that one thing what the child will always have is the problems in the muscles. However, the parent said that they hope to hear something good from the doctors, that there would be something that would cure the child's disability. Another parent said that hopefully in the future or anytime there would be a medicine that would slow down the progressive illness of the child.

7 DISCUSSION

7.1 Discussion of the results

One thing was very clear, what the parents wanted from the neurological unit: more information about their child's development and disability. It is something that other studies have discovered as well to be important for parents (Graundgaard & Skov, 2007; Morgan & Tan, 2011). As Graundgaard & Skov (2007) describe, the information received from health care professionals increases parental satisfaction and coping abilities, which all in all improve parents' quality of life. Even though this study was based on the early stages of being a parent of a disabled child, that feeling hardly changes once the child grows and the challenges of a disabled child change their form. According to Kruijsen–Terpstra et al. (2014) it is just as well essential for the families and parents to develop a trusting relationship with the professionals involved in the child's rehabilitation process. Lindsay et. al. (2007) also brought up the building of a relationship with the professionals as important. The parents in the neurological unit felt that too often the therapists and doctors are changing when the family comes for a rehabilitation assessment, which makes the creation of a trust-worthy relationship very challenging.

Øien et. al. (2010) discovered that the parents also need to be involved in the goal-setting of rehabilitation for children with cerebral palsy. According to Barlindhaug, Umar, Wazakili & Emaus (2016) the goals have to be also realistic for rehabilitation with the children and families. In the interviews conducted in this thesis, the parents mentioned the importance of goals in rehabilitation and as a part of the child's development. The goals will inspire the child to develop themselves and to become more independent, and the parents action in the rehabilitation will motivate the child and help to keep the interest in the rehabilitation. Kiviranta et. al. (2016) also bring up the need for long-term and short goals and highlight the fact that goals need realistic, measurable and concrete.

Even though in the interviews parents recognized the need for rehabilitation, there was still a hope that maybe in the future there will be a medicine or a way to cure their child of the disability. Eeva Airikkala (personal communication, April 13, 2017) from Hilma (Support Centre for Immigrant Persons with Disabilities) says that her experience is that if the immigrant has a lower education level, it has an effect on the knowledge about disabilities compared to people in Finland, for example. She has the perception herself, based on her own experiences on the job, that often immigrants try to cure the disability, or they have the impression that once they came to Finland, the disability can be cured. Rehabilitation in the form of physiotherapy can be frustrating if there aren't big improvements on the condition of the child or a relative. Airikkala says, that naturally understanding the condition and permanency of the disability requires grieving time from the family and parents. The parents interviewed also mentioned the need for support from the professionals, especially after hearing the child's diagnosis.

Autonomy and independence were themes that came up in the interviews several times. According to Skyrme (2016) relative autonomy is important, even though the child would have a severe progressive disease. In this thesis, parents many times acknowledged the willingness for the children to be independent in the future, to be able to survive by themselves. Barlindhaug et. al. (2016) described how the families in Malawi struggle with everyday life and think about the future concerning their disabled children. They had also hopes and fears about the future, similar to the results of the thesis. Graungaard and Skov (2007) also described how diagnostic uncertainty concerning newborn disabled and their parents created the feeling of an uncertain future. Nevertheless, the disability of a child did not decrease the want for the parents to hope for a normal life for the child: developing normally from that point onwards, being independent, having an education, starting a family. The parent's also said that knowing the child's diagnosis also helped them all to plan and implement rehabilitation along with all the members being part of the rehabilitation process.

The purpose of this thesis was to find out kinds of perceptions immigrant families have of rehabilitation. Previously in this chapter I have discussed how the results based on this research connect with the literature and research done earlier. As WHO (2011) describes rehabilitation, it is not something that can be understood or explained in a very simple way. Rehabilitation can be implemented during physiotherapy sessions

and more importantly as a part of daily routines, such as brushing teeth or moving small distances without a wheelchair. That is why the results of this research needed to be visualized (Figure 1). The categories surrounding the child and family are subjects that have a big impact on how the rehabilitation and development of the child will progress. These categories have been completely built based on the data gathered from the immigrant families. The categories represent the perceptions of rehabilitation that the families have, so the focus of this thesis and results are completely on the parents' experiences.

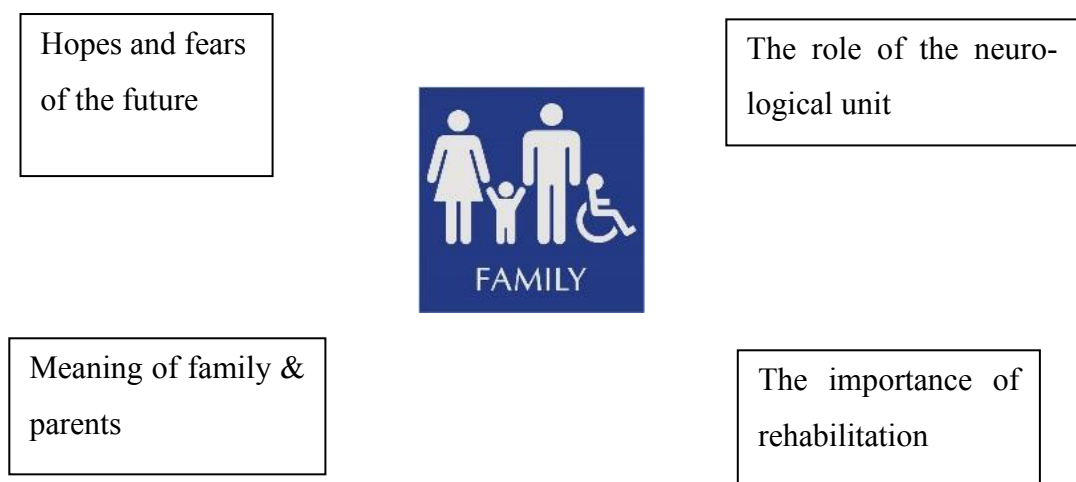


Figure 1. The environment of a disabled child and the family

The aim for this thesis was to describe the perceptions that the immigrant families have of rehabilitation, when they are in a rehabilitation assessment in the children's neurological unit with their disabled child. The aim was also to bring understanding to the nurses in the unit and in that way to be able to take in consideration the families' perceptions while planning the rehabilitation and give more culturally sensitive care. Based on the results of this thesis, the idea is not to give any recommendations for the nurses or the multiprofessional team working in the unit. The main point is to bring understanding and the multiprofessional team in the unit to see rehabilitation from the immigrant families' perspective (Figure 2). The immigrant families' voice need to be heard and their perceptions should be understood and respected By creating more understanding, it is possible for the nurses and multicultural team to develop their

working policies more culturally sensitive for the immigrant parents. This creates possibility to further develop nursing as well.

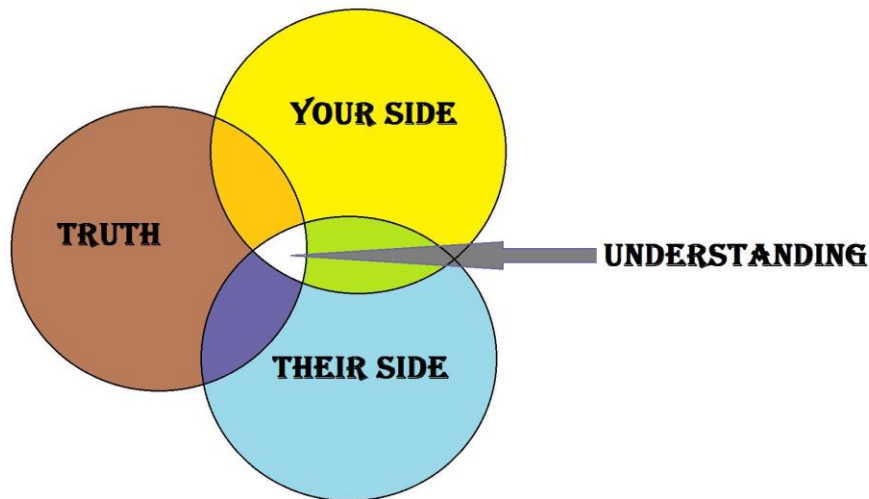


Figure 2. Visualizing what understanding is

7.2 Ethical and validation discussion

The topic is very sensitive when it concerns disabled children and their families. The disability of one's own child is already challenging itself, which was one of the reasons the ethical point of view had to be given a lot of thought considering the thesis topic. In the interviews, I didn't ask specifically about their child or youth but only the interviewees own perception of rehabilitation and what kind of effect it has on the child. In the headline of the thesis topic will not be mentioned a city or a specific neurological unit so that the answers can't in any way be linked. From the ethical perspective, it is also good that to the interviews are participating immigrants from different origins. It will be also difficult to connect the answers to anyone since the amount of the patients is huge in the unit.

When asking the consent for the interviews, I emphasized volunteering and confidentiality but also that in the unit we want the voices of the immigrant families to be heard and gain information of their perceptions. Burns & Grove (2001) also write about the right to self-determination as a part of human rights. While conducting a research it is

needed to treat the possible target group as autonomous individuals by informing them about a proposed research and allowing them to voluntarily choose whether to participate or not. Before conducting the interview, I gave the interviewees information about the research both in oral and written form (Appendix 1). The consent for the research was also requested in written (Appendix 2). The interviewees had the possibility to stop the interview at any point. This is also how the interviewees' privacy is protected, since the interviewees have been informed and have consented to participate in a study, and are voluntarily sharing private information with the researcher (Burns & Grove, 2001). The results were reported in a way that an individual can't be recognized from them and being anonymous as a part of the research was guaranteed. It was also explained how the recorded interviews and transcripts will be destroyed after the thesis is published.

I needed to think about my role considering the interviews, since I am working in the unit and I might have been familiar to some of the parents. In these cases, I was emphasizing that in the interview I am as an interviewer, not a nurse. Part of my ethical thinking has also been to exclude the alternative and complementary treatments from the interviews. This topic is not so important in this thesis to include it to the interviews. I also felt that I wasn't able to find a strong enough ethical approach to the matter. I will include the topic of alternative and complementary treatments in the thesis as a part of the literature research.

Keituri (2005) writes in her own development work that good professional skills of the staff promote an atmosphere for well-being, and co-operation and mutual assistance are ethical principles that support the services of transcultural nursing. For these principles, I also base the ethical aspect of this thesis.

Before starting the thesis' research and writing process, a lot of information search needed to be done to gather enough information from the ethical point of view to justify the need for this thesis. By adding the ethical background for this thesis' research plan, an ethical approval was applied from the ethical board of the university hospital. The ethical board requested for minor details to be changed before giving the permission. After the final permission, the actual research approval was applied for from the university hospital.

7.3 The reliability of the research

The reliability aspects of a qualitative research are related to the author of the research, the quality of the data, the data analysis and to the presenting of the results. The quality of the data is being emphasized on how the data gathered answers for the set research questions. Personal skills of the author are being highlighted on this part of the process as well. Based on the content analysis as a data analysis method, which is used also in this research, it is important that the author can prove a link and connection between the results and data collected. (Latvala & Vanhanen-Nuutinen, 2001.)

The validity of a research where content analysis has been used can be assessed as face validity or by using agreement coefficients. The main problem of the research reliability concerning content analysis is the researcher's subjective role concerning the results and conclusions. The challenge of the process is the abstract nature of the data and the forming of categories so that they describe the phenomenon as reliably as possible. The most important thing is to be able to prove the link between the data and the results, as stated before. The results presented in a table, for example, might look good in theory, but if it is not possible to prove the connection between the data and results, the research cannot be seen as reliable. This is also an ethical issue, since the researcher is responsible for the results and data. (Kyngäs & Vanhanen, 1999.)

While analysing the quality of the research, it needs to be acknowledged that the sample size for this research is relatively small. One of the biggest reasons for the sample size to be small, as the fact that an interpreter was not available for the interviews, which made the criteria for the interviewees quite strict language-wise. Limited amount of time was available to conduct the interviews. The validity of the research is taken into consideration, since the research question is answered based on the results of the research and the results are being discussed related to the previous literature and research. There isn't research done directly from this viewpoint, which makes the thesis more valuable. All in all, even though the sample size of the research is small, the topic is important and valuable for the development of transcultural nursing.

7.4 The utilization of the research

The results of the thesis were presented to the employee's of the children's neurological unit and other employee's working in the same university hospital at a specified date in November 2017. After the presentation, there was time for discussion and comments. In general, there was good feedback given for the thesis and there was some discussion regarding the results of the research.

There was interest if the dissatisfaction of the immigrant families concerning decisions made in the unit was similar to that of the Finnish families and what the dissatisfaction was about. The questions included whether or not the disabilities of the children of these parents were visible and if that was part of the reason, why the parents had a hard time understanding the disability. Some development ideas came up. The participants talked about the fact that immigrant families do not always know why they are being asked to visit the unit regularly and it especially needs to be explained in the beginning when the rehabilitation is starting. It was also discussed how the rehabilitation goals made for every year need to be very concrete and practical, which helps the parents understand that everyday life is the best rehabilitation there is.

The employees discussed the need for developing more understanding of the immigrant families, just to see things from their perspective and taking into consideration their perceptions while planning the rehabilitation.

Finnish journals *Pro Terveys*, *Sairaanhoitaja* (The Finnish Nurses Association's members' journal) and *Kuntoutus* (The Rehabilitation Foundation's journal) have been contacted to offer an article about the thesis and the journals have been interested in publishing an article in their journal or webpage. Due to the low amount of research done on this topic before, the thesis will receive visibility and transcultural nursing will be promoted by publishing articles in different journals.

7.5 Further research possibilities

The UN (2017) approved The Convention on the Rights of Persons with Disabilities and its Optional Protocol in 2006. The convention obligates all the countries to guarantee all the same human rights for disabled persons as for all other citizens; the right for disabled persons to move around freely is highlighted, as is the right for a good life including work and education. Persons with disabilities are also called the world's largest minority group and their voices need to be heard, which is why I believe the next possible research topic would need to be concerning the disabled children and their opinions about their lives and disabilities. Especially the topic on the change from childhood to adulthood is interesting, since the adolescent time might be already challenging without having to deal with things such as a disability which shows to everyone else that you are different. Persons with disabilities are also more acknowledged due to the UN's Sustainable Development Goals, that aim to make the rights of disabled persons more visible and to promote equality (UN, 2015).

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APPENDICES

APPENDIX 1. Information for study participants´

Immigrant families´ perceptions of rehabilitation in children´s neurological unit

Dear parent,

I study in a Master´s Degree in Global Health Care–program and I am doing a thesis related to my studies in children´s rehabilitation unit in Lastenlinna. The topic of the thesis is Immigrant families´ perceptions of rehabilitation in children´s neurological unit. The goal is to develop the transcultural nursing and the working policies in the unit with the help of the thesis. As a part of my thesis I will interview 5-10 parents in the rehabilitation unit. The interviews will be conducted during your stay in the ward or polyclinic.

The questions of the interview are the following:

- 1) What does the word “rehabilitation” mean to You?
- 2) Which factors are the most important for you, while you are visiting the ward or polyclinic?
- 3) Please describe, what do you see your child´s future like?

You are free to tell about your experiences and I might ask some more detailed questions during the interview. I will record the interviews. Before taking part of the interviews, I will ask for a written consent for you to take part in the interview. The interviews are completely voluntary. You have the chance to refuse from the research in any part of it. Although, after the data has been analyzed, it will be impossible to delete any of the answer´s from a specific person. Everything that you will say in this interview, will not have any impact on your child´s treatment or the availability of the treatment now or in the future. Refusal to participate in the research, discontinuation of the participation in the research or the withdrawal of the consent will not have any effect on any of the treatment you will be receiving. The material of the interviews will be only used for

my thesis and after the analysis the information will be destroyed. Thank you for your co-operation in beforehand.

Best regards,

Kristiina Aalto

Registered Nurse

Contact information

The doctor in charge of the children's neurological unit

Contact information

APPENDIX 2. Consent of participating in the research

Immigrant families' perceptions of rehabilitation in children's neurological unit

I have been requested to participate in a thesis with the topic of Immigrant families' perceptions of rehabilitation in children's neurological unit. The thesis is a part of Master's Degree in Global Health Care-program in Diaconia University of Applied Sciences. I have received, read and understood the fact sheet given to me about the thesis. From the fact sheet I have gained enough information about the thesis and the data collection in the form of interviews and the process itself. The content of the fact sheet has also been given to me orally and I have received the answers of the questions related to the thesis. The information has been given to me by Kristiina Aalto. I have had enough time to consider my participation in the interviews related to the thesis.

All the information gathered from me during the interviews will be held confidential. I understand that my participation in this thesis and the interviews is completely voluntary. I have the right to refuse from the interview in any part of it and without explanation. Refusal to participate in the research, discontinuation of the participation in the research or the withdrawal of the consent will not have any effect on any of the treatment I will be receiving.

I confirm my participation in Immigrant families' perceptions of rehabilitation in children's neurological unit - research and an interview related to it with a signature

| | |
|-----------|------|
| Signature | Date |
|-----------|------|

| | |
|--------------------|------------------------|
| Name clarification | Social security number |
|--------------------|------------------------|

The consent has been received

| | |
|---------------------------------------|------|
| Signature of the author of the thesis | Date |
|---------------------------------------|------|

Name clarification

APPENDIX 3. Structure for a theme interview

A structure for a theme interview in a Master's Thesis of Immigrant families' perceptions of rehabilitation in children's neurological unit.

Background information: For how long have you lived in Finland? Where are you from originally?

1) What does the word "rehabilitation" mean to You?

(the themes related to this question are: understanding, therapies, daily rehabilitation, ancillaries, the importance of rehabilitation, healing)

2) Which factors are the most important for you, while you are visiting the ward or policlinic?

(the themes related to this question are: doctor, meeting the therapists, the role of the nurse, rehabilitation)

3) Please describe, what do you see your child's future like?

(the themes related to this question are: school, education, independence, growth, family)