Nurse’s experiences of working with empowerment for children with disability in Sri Lanka

Caroline Carlsson
SUMMARY

**Background:** In Sri Lanka, children with disability are being met with discrimination and stigma based on cultural and religious beliefs. Sri Lanka has ratified the Convention on the Rights of the Child that states that children with disability should enjoy full and decent lives with active participation in the community. Empowerment is the process that makes it possible for these children to experience equality in society. Nurses have a vital role working with health promotion for these children. **Aim:** to describe how nurses work with empowerment for children with disability in a low-income country. **Method:** A qualitative and empiric interview study with Sri Lankan nurses from two different rehabilitation teams. **Result:** The nurse’s experiences in the subject are explained like; *nursing with focus on the child, nursing with focus on the mother, nursing with focus on the interdisciplinary team.* **Conclusion:** By nursing with these focuses, the nursing interventions for children with disability had a holistic approach that covered all aspects of life.

Keywords: children with disability, empowerment, low-income country, nursing, qualitative interviews.
SAMMANFATTNING

**Bakgrund:** I Sri Lanka blir barn med funktionsnedsättning mötta med diskriminering och stigma baserat på kulturella och religiösa övertygelser. Sri Lanka har skrivit under barnkonventionen som säger att barn med funktionsnedsättning har rätt till ett fullkomligt och värdigt liv med aktiv delaktighet i samhället. Empowerment syftar till processen som möjliggör jämlikhet i samhället för dessa barn. Sjuksköterskor har en viktig roll i denna hälsofrämjande process. **Syfte:** Att beskriva hur sjuksköterskor arbetar med empowerment för barn med funktionsnedsättning ett låginkomstland.  

**Metod:** En kvalitativ och empirisk intervjustudie med Sri Lankesiska sjuksköterskor från två rehabiliteringsteam. **Resultat:** Sjuksköterskorna beskrev sina erfarenheter så här: *omvårdnad med fokus på barnet, omvårdnad med fokus på modern och omvårdnad med fokus på tvärprofessionellt team.* **Slutsats:** Genom att ge omvårdnad för barn med funktionsnedsättning med dessa tre fokusområden är sjuksköterskans interventioner holistiska och täcker alla aspekter i livet.

Nyckelord: barn med funktionsnedsättning, empowerment, kvalitativ intervju, låginkomstland, sjuksköterskans interventioner.
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1. INTRODUCTION

Childhood disability affects millions of children around the world and most of them are living in low- and middle-income countries (Maulik & Darmstadt, 2007). In Sri Lanka, superstitious and general beliefs stigmatize children with disability and their families by perceiving them as omens of bad luck. They are often seen as objects of helplessness, which manifests the conviction that children with disability are not capable to function in the society. Poverty in Sri Lanka is a cause and an effect of having a disability and consequently it tends to expel families withholding a member with disability from the villages and of possibilities to achieve care, education and other rights for the child. The effect of this deprives children with disability to get empowered to achieve rehabilitation; they have few opportunities to develop their self-reliance and potential and also to achieve integration in the society (Ministry of Social Welfare [MSW], 2003). Nurses have an important role working with health care and empowerment for children with disability to give them opportunities to independence (Frain, Bishop & Tschopp, 2009). It is also essential to describe how the nurses work with everyday activities in order to promote the rehabilitation process. Seeing with own eyes the stigmatization and discrimination, affecting children with disability in Sri Lanka, woke interest of studying how my own profession, nurses, can empower these children through health interventions.
2. BACKGROUND

2.1 Definition of disability

Disability is an umbrella term covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Disability is a complex phenomenon, reflecting an interaction between features of a person’s body and features of the society in which he or she lives (World Health Organization [WHO] 2011). The definitions are encompassing both medical and socio-economic aspects of disability, which takes into account environmental factors. Environmental factors are those that “make up the physical, social and attitudinal environment in which people live and conduct their lives” (Ministry of Social Wellfare [MSW], p. 1, 2003).

2.2 Sri Lanka

Sri Lanka is an island located in Asia and more specific, southeast of India. Sri Lanka has a population of more than 20 million inhabitants, consisting of different ethnic groups where Sinhalese is the largest group among Sri Lankan Moors and Indian Tamils. The low-income country has been suffering from civil war for almost 30 years, between 1983 and 2009 and 23% of the population is living under poverty line. The most common languages are Sinhala, Tamil and English and the major part of the inhabitants is Buddhists. Life expectancy of life at birth is 75 years for the total population and the infant mortality rate is 9.7 deaths/1000 live births for the total population (Central Intelligence Agency, 2011). In Sri Lanka, the governmental nursing education is run by the Ministry of Health and takes place at ten different places and universities in Sri Lanka. The bachelor nurse science training to become a general nurse lasts for 36 months and contains clinical practice and theoretical education. The content of the different courses are for example: anatomy and physiology, sociology and anthropology, psychology, grounds in nursing practice, English for nursing, teaching and learning, nutrition, communication skills, primary health care and research in Nursing (Department of Health Science, 2011).

2.2.1 A organization working with rehabilitation

A Non Governmental Organization [NGO] withholding two rehabilitation teams is situated in the town Kandy in the center of Sri Lanka. It has been operating since 1972, when a Swedish woman and her Sri Lankan husband established it. Within the organization there are
children’s home, medical help, disaster help and a Community Based Rehabilitation [CBR] program. (G. Galekotuwa, head of the CBR, personal communication, 20111001). CBR is a rehabilitation program that focus on needs of people with disability, ensuring participation and inclusion in society and enhancing their quality of life (WHO, 2010). CBR is a model of rehabilitation developed by WHO in 1978 and the program is currently implemented in over 90 low- and middle- income countries, Sri Lanka, among others. CBR is a multi-sectional strategy that facilitates persons with disability to access and benefit from education, employment, health and social services and has as a goal to make people with disability and their family members be a part of decision making and take responsibility for changing their lives, improving their communities together with the government, NGOs and private sector (ibid). The organization co-operates with Digani Rehabilitation Clinic [DRC], situated in Kandy (G. Galekotuwa, head of the CBR, personal communication, 20111001).

2.2.2 The situation for children with disability in a low-income country

In the south east Asia region, where Sri Lanka is included, has a disproportionately high burden of injuries that account for more than a quarter of global injury amount where road traffic injuries, burns, drowning, falls and violence are the most common cause of all injuries (WHO South East Asia Regional Office, 2011). The civil conflict in Sri Lanka left a large numbers of military and civilians with injuries and disability (MSW, 2003). A majority of children with disability suffer the double burden; disability is associated with stigmatization, leading to a marginalized life (Maulik & Darmstadt, 2007). Article 23 in the Convention on the Rights of the Child [CRC], 1989 (United Nations) states that a child with mentally or physically disability should enjoy a full and decent life, which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community. Moreover all children have a right to special care and effective access to education, training, rehabilitation, social integration, individual development and preparation for employment (ibid). Despite this, early childhood care and preschools in Sri Lanka do not promote inclusion of children with disability. If the health system may detect disability in early childhood, there are seldom any programs that follow up interventions and this deprive children with disability from care, and simulation they need to develop. As a result, the effects of the disability can multiply as the children grow up (MSW, 2003).

2.2.3 Poverty as a cause and effect of disability

Together, poverty and disability create a vicious circle: poverty causes disability due to poor living conditions, health endangering employment, malnutrition, deprived access to health
care and education opportunities, among many. Families supporting a child with disability were significantly more likely to be living in poverty due to lack of employment opportunities, education and skills development (Emerson, Shahtahmasebi, Lancaster and Berridge, 2010). MSW (2003) says that the families are systematically excluded from the mainstream, and the poorer they are, the greater that exclusion is likely to be. Families with a child with disability have extra costs based on the disability and they are not possible to earn income that is necessary because one of the parents have to be home with the child. Emerson et al (2010) also say that people with disability risk to become dependent on other people for the duration of their whole life based on the poverty.

2.3 Working with empowerment in rehabilitation

Empowerment is both a process and an outcome and refers broadly to the expansion of freedom of choice and actions. A description of the word empowerment in both nursing care and other forums, includes having a say and being listened to, own decision-making and self-power, having control or gaining further control, being free, independent and able to fight for one's rights and being recognized and respected as equal citizens and human beings with possibilities to participation and a contribution to make (Crane-Ross, Lutz, Roth, 2006; Frain et al, 2009; Gibson, 1991; Narayan, 2002, WHO; 2010). According to Frain et al (2009), empowerment in rehabilitation is explained in terms of control, assertiveness, competence and self-esteem. Assertiveness is described as the ability to understand and ask for what is wanted. Empowerment through competence means the ability to self-manage disability and to have an understanding for what needs to be learned to carry on an active and emotionally satisfying life. Individuals, who feel positive about them, are able to self-advocate, not feel their condition is stigmatizing, are able to work towards their own goals, and are considering to be empowered through self-esteem. Working with these areas through interventions will lead to improved outcomes in rehabilitation (ibid). Empowerment in rehabilitation happens when persons with disability recognize they can change their situation to become more independent in society. This is to prefer in comparison to the medical rehabilitation model that provides rehabilitation to persons with disability without asking for anything in return which in turn creates dependency and mindset of giver and receiver (WHO, 2010). People with disability can experience dis-empowerment in the family and society; they are being rejected from society because of stigma and discrimination, without opportunities and choices in life. Furthermore, they may be over-protected by their families and the family members do everything for them. Absence of empowerment can be explained as power-, help- and
hopelessness, a sense of being abandoned, a sense of being a victim, subordinated, oppressed, less of a sense of control over one's life and dependency. This experience of disempowerment starts the process of empowerment and nurses have a major role in strengthening self-awareness and growth (Gibson, 1991).

2.3.1 The nurse role as working with empowerment in education, shared decision-making and motivation - a theoretical frame.

The universal aim for nurses is to promote health, prevent illness, restore health and alleviate suffering (Henderson, 2004, National Board of Health and Welfare [NBHW], 2005). The process of empowerment is a fundamental element in health promotion and nurses should facilitate development and opportunities to master one's life situation. Nurse’s empowerment interventions working with children with disability include psychological, socio, cultural, physiological, developmental and spiritual variables (Stepans, Thompson & Buchanan, 2002). Henderson (2004) claims that nurses working with children with disability and their families should protect the equal rights including education, employment and the right to integration and involvements in matters that affect their lives in everyday activities. Pelchat and Lefebvre (2004) says that nurses working with children with disability should promote the process where the children feel confident about having skills and recourses and families to children with disability together with nurses can recognize new competencies, which can lead to self-determination and an individuality that can change life (ibid). Empowerment in rehabilitation focus on a shift in mindset from being a passive receiver of rehabilitation to be an active contributor and participator by understanding the possibility of changing their situation and begin to do so (WHO, 2010).

According to the Sri Lankan MSW (2003) a part of the empowerment nursing care interventions, is educating the child and the parents. These concerns; making knowledge, skills, advice, counseling and information available to children with disability and their families to facilitate maximum possible individual empowerment, development and independent living as well as participation in community groups and organizations. Individuals have the ability in making own decisions on their own behalf although they may need information and help to do so. Nurses have a key role in empowering patients to make decisions in their life with the outcome that patients feel independent, more competent, self-determined, self-controlled and more socially integrated. Nursing through empowerment means to inform patients about shared decision-making and to support patients in their
decision-making process (ibid). According to NBHW (2008) working with empowerment in rehabilitation means to pedagogically motivate so that persons with disability understands that they have to and want to, take responsibility in the individual process of rehabilitation (ibid). Motivating children with disability as well as their parents, is important to give opportunities for individuals to develop personality, potential, physical talents as well as social participation in community (MSW, 2003).

2.3.2 Rehabilitation teams

A rehabilitation team can consist of nurses, doctors, physiotherapists, occupational therapists, psychologists, social workers, vocational therapists, volunteers and teachers. The children and caregivers are a part of the team in the aspect that the professionals do not work for the child but with the child (Preston, 1990). According to NBHW (2008) rehabilitation teams shall include the client in the matters of rehabilitation work but it can only proceed if the child and family participate by free will. The team works with the aim to create the utmost possible ability to function, development of an independent life and participation in society. According to MSW (2003) Sri Lankan rehabilitation care should ensure inclusion of the child, families and caregivers in the team to promote shared decision-making, their own participation and empowerment in their situation. The teamwork in rehabilitation is, according to Preston (1990), about goal setting, assessment, planning, implementation, evaluation and modification of plans. Each professional team member has focus on their own discipline but has to consider the whole patient and all the positive outcome of interdisciplinary work, which create a holistic care for the client. The overlap facilitates an understanding for the other professional’s activities, it provides consistency and convergence of opinions; it reinforces the validity of plans, goals and actions. All professionals together with the child, parents or caregivers create a holistic environment with good possibilities for independent function (Preston, 1990).

3. PROBLEM

The Convention on the Rights of the Child underlines the importance of equal participation for every child. Children with disability in Sri Lanka are being stigmatized and excluded, in society, due to environmental, communicational and cultural factors. To be able to participate in society, the process of empowerment is of utmost importance. Nurses work with
empowerment in the rehabilitation process, as a health-promoting element and this have not widely been described.

4. AIM

This study aims to describe how nurses work with empowerment for children with disability in a low-income country.

5. METHODS

5.1 Design and context of the study

A qualitative, empirical interview study was performed in Kandy, Sri Lanka. The study took place in a Sri Lankan NGO where nurses in rehabilitation teams were working with rehabilitation for children for disability, both in homecare and at clinic. In the CBR team working with home care, there were 15 personnel, of which three were nurses. In the hospitalized rehabilitation team at Digani Rehabilitation Clinic [DRC] there were ten nurses of totally 30 personnel.

5.2 Selection

The inclusion criteria’s were: being employed as registered nurse (RN), working daily with children with disability in rehabilitation teams within the organization and an ability to speak and understand English. To make contact with the respondents, one contact person was helpful by contacting one nurse at DRC and one nurse in the CBR program. After interviewing the first nurse at DRC/CBR program, the respondent became a gatekeeper by providing the names of two nurses in the team (Kvale & Brinkmann, 2009). The median value for the number of years that the nurses in the study had experience from nursing was 16 years. All of them were general nurses, three respondents also had further education in public health nursing and one of the general nurses were a diploma nurse with special competence in rehabilitation.

5.3 Interviews

Before going to Sri Lanka a pilot study involving a Swedish rehabilitation nurse working with children with disability, was conducted in Sweden. The goal was to evaluate the topic
guide, which was planned to be used in Sri Lanka (see attachments 10.2). The main focus of performing a pilot study is to explore if the aim of the study is clear as well as the topics and questions (Kvale & Brinkmann, 2009). The nurses received the interview guide with a variation of one to 24 hours before the occasion, to be able to read about the subject and to reflect upon their own experiences in the subject. The six interviews took place at the CBR office in Kandy, in a quiet room where the respondents could speak without being overheard or interrupted. The interviews lasted between 30 and 45 minutes each, and were recorded with the permission from each respondent. Initially, the respondents received an orientation and some background information about the purpose of the bachelor study, the importance of using a recorder and also asked if they had any questions. An understanding between the respondents and the interviewer was developed, which is important, while doing qualitative studies in order to gain and maintain a high level of trust with participants (Polit & Beck, 2010). This is to gain and maintain a high level of trust with participants. To concretize the word, the respondents were guided on the subject empowerment in three areas: education, shared decision-making and motivation. The respondents described his/her experience of working with empowerment in these areas and this is called semi-structured interviewing. The respondents were informed about the use of the example questions on the interview guide (see attachment 10.2). During the interview, an open and supportive environment in the room encouraged the respondents. For example, they spoke without being interrupted. After the interview, the respondent had an opportunity to ask questions.

5.4 Manifest content analysis

The interviews were transcribed verbatim and the analysis of the texts was conducted in several stages. First, each interview was read repeatedly to become immersed in the data and to receive a deeper understanding for the nurse’s experiences (Polit & Beck, 2010). Inspired by Graneheim and Lundman (2003), the text was systematically coded and categorized. The data was divided into meaning bearing units; the constellation of words or sentences with the same central meaning. The process included shortening the text while preserving the core and the meaning bearing units were made into condensed meaning units where the text is reduced to its extent, while the core and the quality of the data remains (see example in Table 1, p. 9).
Table 1. Example from the content analysis

<table>
<thead>
<tr>
<th>Meaning bearing unit</th>
<th>Condensed unit</th>
<th>Code</th>
<th>Sub Category</th>
<th>Category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Our goal is to make sure that the child can manage to live in their home and have good possibilities in life. Therefore we educate about things that can lead to this goal; about activities of daily living.</td>
<td>Nurses educate about every day activities to make the child empowered to take care of him/herself.</td>
<td>2.2 Educating the child.</td>
<td>Covering children’s need in activities in daily living.</td>
<td>Nursing with focus on the child.</td>
</tr>
</tbody>
</table>

The text was divided into codes, sub-categories, categories and theme. When coding the text the condensed meanings were given numbers that labeled the unit in relation to a new context that later created categories. The condensed meaning units and codes were sorted in groups of content that have commonality and are called sub-categories. The sub-categories were read through, both separately and together with the meaning bearing units and the condensed units to find relationship with the text (Graneheim & Lundman, 2003).

6. ETHICAL ASPECTS

Information about the aim with the study was given to the respondents verbally as well as in a letter (see attachments 10.1). An approval signature from the head of the organization as well as from the respondents was received to confirm consent of the study. Also the respondents were informed that they had the decision making power about their participation in the study; if, how long, and on what conditions they participated in the study. The participants have the right to expect that any data they provide will be kept anonymously and in confidence and this was explained to the nurses in the way that information from the study subjects will not be identifiable and all results will be presented so that single persons or wards will not be identified. The respondents were also informed about the possibility for them to receive the results of the study (Polit & Beck, 2010).
7. FINDINGS

The main finding in this study explained the aim and outcome of the work the nurses together with the rehabilitation teams preformed with focus on empowerment. The focus was to achieve independence for the children with disability. To reach this aim, holistic interventions were used, and that was explained through the three categories (see table 2, p. 10). The result is presented through the three categories as headlines with belonging sub categories beneath every headline.

Table 2. Presentation of sub-categories and categories

<table>
<thead>
<tr>
<th>Sub-categories</th>
<th>Categories</th>
</tr>
</thead>
<tbody>
<tr>
<td>Covering children’s need in activities in daily living.</td>
<td>Nursing with focus on the children.</td>
</tr>
<tr>
<td>Centralizing the child in the family.</td>
<td></td>
</tr>
<tr>
<td>Focusing on the healthy part of the body.</td>
<td></td>
</tr>
<tr>
<td>Motivating to improvements.</td>
<td></td>
</tr>
<tr>
<td>Creating entrances to the society.</td>
<td></td>
</tr>
<tr>
<td>Seeing the importance of the mother.</td>
<td>Nursing with focus on the mothers.</td>
</tr>
<tr>
<td>Educating non-educated mothers.</td>
<td></td>
</tr>
<tr>
<td>Meeting the need for mothers to get-together with other mothers.</td>
<td></td>
</tr>
<tr>
<td>Seeing gender aspects.</td>
<td></td>
</tr>
<tr>
<td>Cooperating in the team.</td>
<td>Nursing with focus on</td>
</tr>
<tr>
<td>Working towards a common goal. interdisciplinary co-operation</td>
<td></td>
</tr>
<tr>
<td>Promoting integration in society.</td>
<td></td>
</tr>
<tr>
<td>Searching for the rejected families.</td>
<td></td>
</tr>
</tbody>
</table>

7.1 Nursing with focus on the children

The nurses covered the children’s needs in life. In all cases they educated children with disability about daily activities. They educated about nutrition, elimination, skin care, sanitation and medicine, immunization and vitamins: “We give children resources to manage their situation and give them tools to create a future. We provide more specialized information about health in different areas” (respondent 4). The possibility to develop skills in daily activities differed among the children and therefore nurses adjusted the education to each individual to achieve independence for them. Teaching children with disability, especially children with mental disability, a daily activity could be difficult and took long
time compared to educating a child with physical disability. The nurses focused on the children and gave opportunities for them to make decisions. The nurses assessed the individual needs for each child; if the children could not talk, they recognized in which way they need to be stimulated and how they would like to form their daily activities. The major hindrance for getting children with disability to become a part of the shared decision-making process was that they were treated as persons with less value by their mothers: “Sometimes mothers are angry with their children; they see the disability as a curse from Buddha and the child as a reason to destroy their normal life” (respondent 2). Children were being hidden and neglected without anybody seeing or hearing them and were recognized as the children in the corner of the room. The nurse’s were working to create bonds between the children and the parents. If the parents saw their child as a central part of the family, the children were being given natural decision-making power. The nurses integrated children in the families with the aim to promote decision-making power: “We try to remove the corners from the room and make the child centralized” (respondent 6).

Nurses rehabilitated the whole person by focusing on using healthy parts of the body and tried to promote empowerment by using that part. Motivation was a circular model; when nurses were motivating and educating children, they managed to improve in the disability and life situation, which lead to a new motivation to exercise and improvement in more areas in life. The best way to obtain children with disability motivated in rehabilitation was to focus on their own improvements. If children managed to do one small activity that they had not been able to do before, they got motivated to continue with another activity: “With motivation children are improving and by improving they get more motivated to continue rehabilitation” (respondent 6). Another method of motivating was to cooperate with a Buddhist monk who talked with the children, tried to make them understand why the disability happened to them and how they could manage their life. The monk told them that they were not mistakes and through that they became empowered to continue rehabilitation. The motivation process continued after the children had been discharged from the clinic, by follow-ups; the nurses motivated then about coping in the home environment.

To promote empowerment and integration in the society for children with disability, nurses were trying to create entrances to the society. A hinder to do this was people that were lacking education about disability; they created a resistance against the children’s existence. A society
educated about disability opened up for the otherwise embarrassed parents to bring their children to school and other social activities in the village without being uncomfortable. A good outcome of educating the society was that people that have done progress in rehabilitation and empowered in their life, could manage to live by themselves in the village, have a job and can go into town by themselves without being harassed by people in the village. The aim of education was to rehabilitate the children up to a social status to a point where they could be self-empowered, which means that the children understood what they could do for themselves and for others in society and do so.

7.2 Nursing with focus on the mother

Parents, and primarily mothers alone, were the most important person for the child’s empowerment process: “She knows the child best and is responsible for the child’s health, rehabilitation and development in the future” (respondent 5). The mothers were at home, taking care of their children and they were also the ones living with their child at the rehabilitation clinic both day and night while the fathers were working to earn money for the family. The nurses gave opportunities for the mothers to internalize the nurse’s knowledge in health and daily activities. This was, with the purpose that they could take care of their child in the right way, both at the clinic and in their homes. The nurses educated the mothers about health habits, hygiene, vitamins and medicine as well as preventing malnutrition, pressure ulcers, and constipation. The mothers were not able to work alone; they needed the nurse’s competence in health science.

Poor and uneducated mothers made the empowerment process harder. These mothers lacked knowledge and time to spend with the child because they had to work all hours of the day. The children were then not being given enough attention to, and often hid which lead to a constant neglect. Also poverty caused mothers unable to supply for the necessary things for the children such as going to town to see a doctor or getting medicine and vitamins: “Money is the key to start the rehabilitation process” (respondent 6). Uneducated mothers tended, more often compared to other mothers, to lack ability to provide rehabilitation to the children and they ignored the knowledge the nurses tried to give to them. At the initial phase, nurses, both at the clinic and within the homes, were trying to make the mothers willing to attend the rehabilitation program and approve that their child is getting rehabilitation and help. This was a possible obstacle because they might be convinced that the disability was from Buddha and they did not want to interfere on Buddha’s will. Based on this it was important that nurses
brought trust to the mothers so they let their child participate in the rehabilitation. This developed by giving information about the program; how to work with disability and also by giving examples of good outcomes with other children with disability that have been rehabilitated and empowered. When starting a rehabilitation program for children with disability, continuity, trust and communication were of importance in the relation between the mother and the nurses. The responsibility of the children was both the mothers and the nurses:

If we teach the mother how to take care about the child’s medicine or nutrition and then never come back, we put all the responsibility to her. Then she has a lot more to take care about, with our advices and guidelines that means that they have to learn many new things. This is why it’s so important with follow-ups, to show that we care (respondent 5).

Both at the clinic and in the home care, nurses arranged meetings where mothers and children could meet and enjoy each other’s company, sharing and learning from experiences and give each other support. Happy children gave the mothers motivation to continue the rehabilitation process because they understood then that they could live as normal families. The nurses had to motivate the mothers and the child simultaneously but in different ways: “Motivate mothers at the left and motivate the child to the right” (respondent 4). During the rehabilitation program, mothers, the child and professionals in the team meet to exchange problems and solutions. They did future planning, talked about behavior in the home and how to increase compliance in the rehabilitation process. This was a good opportunity for mothers to tell their point of view and the nurses could respond to that and give advices about health.

Having a child with disability was often very hard for both the parents. It could lead to divorce because of all the things in life that had to change when having children with a disability. A divorce had the consequences that mothers, who often had no job, were left alone with their child with disability to provide for and the child was left without safety. This was also a major problem that could retreat the children's rehabilitation development. The nurses saw the gender aspect of this and listened to the mother’s will and their solutions to this problem in an attempt to create safety for the mother and children:

We try to build up their relationship to last whole life because a disabled child needs safety in the home. We arrange the time for the mother and child to go home from the hospital once a week so the parents can do their sexual activities and then the father doesn't leave the mother (respondent 3)
7.3 Nursing with focus on the interdisciplinary co-operation

The overall aim with the rehabilitation teams was to cover children’s need in every aspect of life: “By working together in the team we cover all the patients’ needs in life and they will be empowered to develop in life” (respondent 4). When doing so, the child had the possibility to develop skills about activities of daily living: “I do not know the exact physical therapy exercises because I am a nurse, but I can motivate the child to use the skills they have already got” (respondent 1).

It was important that the team was working towards a common goal to create opportunities for the child. The physiotherapists taught them how to use their body, the occupation therapists taught them how to cope with the environment around them, and the doctors were responsible for medicine. Also there were teachers who created a good educational environment for the child and volunteers that were contact persons between families and team, and they helped the families with every day activities. Nurses in the team were responsible for health advises and they were working with preventive education in the society with the aim to reduce the amount of disability. The nurses educated volunteers in the team about preventive health and the volunteers give the information to the society. It was about road traffic safety, safe home environment, how to avoid blood relations and they gave general health advices to prevent disability. All these professionals worked together to achieve the individually adjusted goal for each child.

By giving opportunity to social adjustment in the environment and let children with disability be a part of the activities in the village, they increased empowerment in their life. This demanded an open, trustful and tolerant society that encouraged the sense of well-being and autonomy of the child. Discriminating attitudes based on stigma in the communities made parents unwilling to draw attention to their child with disability: “The team thinks different; if you confirm and see the child it will create an accepting atmosphere in the community” (respondent 4). The stigma in the society was a barrier to inclusion and had the consequence that the parents were embarrassed and unwilling to send their child to the community school and they hid the child at home. The team was aware of the depriving circle of poverty and disability, and they promoted giving education to children with disability to earn money in
order to be able to integrate in society. Poverty was leading to regress in children’s process in shared decision-making: “The families are often very poor and uneducated and that makes the whole process much harder” (respondent 6). The team was searching in villages outside the society for children with disability because often they have been rejected and pushed away from the society. Then they lived without any social support or possibilities to be integrated in society. This was the reason the rehabilitation team conduct these programs mostly in rural areas; it was where the families were the poorest and least educated and needed the help most.
8. DISCUSSION

8.1 Method discussion

Qualitative interviews were chosen as a method to collect data, and can be motivated by Kvale and Brinkmann (2009) as a preferable method when striving to understand the lived every day from the respondent’s perspective. In the planning phase, observation interviews seemed to be a preferable method to collect data; the nurses would be observed within their own environment and their methods would be visible to observe. Based on the research aim, interviews were found to be a preferable method. This was because the nurse’s experiences would be more concrete if they talked about it from their own perspective. Another method to elucidate the phenomenon empowerment for these children would have been to interview the children themselves about their experiences. The result would probably then be reflecting only upon the one person's experiences in their own life world. Using nurses as respondents strengthened the study and opened up to receive experiences of working with empowerment with a broader field, they had experience of working with several patients with different disability.

Based on the outcome of the pilot study, supportive questions were made. The respondent seemed to give more exhaustive answers and explanations of experiences when an example question was given. This strengthened the interviews. The pilot respondent was a Swedish rehabilitation nurse who preferred to be interviewed in Swedish. Therefore, the interview guide was being translated into Swedish and the interview was being held and analyzed in Swedish. After that, the result of the pilot study was interpreted and used in an English version; the interview guide. Could the use of two languages in the study be a bias that creates an incorrect result and a weakness in the study? Nevertheless, according to Kvale and Brinkmann (2009) the aim with doing a pilot study was to improve upon the interview guide and that were fulfilled. The example questions were added to the interview guide to support the respondents in the interview situation.

The researcher was new in the context and did not know the respondents or the environment around them, so to receive an understanding for the respondent's lived every day, one week was dedicated field work at DRC and CBR. Also, knowledge about the subject was received through literature at international, national (both Sri Lankan and Swedish) and local level and
this strengthened the study. Using and centralizing the word “empowerment” as a term in the study could have been a possible obstacle because people could have different opinions and experiences about the meaning of the word depending on context and situation and it has got many definitions (Frain, Bishop & Tschopp, 2009). This could have caused the researcher and respondents to reflect upon the phenomenon with different basis. To reduce the risk of confusion and to strengthen the study, an information text (see attachment 10.1) on paper was handed out. Time was spent talking about the word in the beginning of the interviews to create consensus, receive an understanding of each other’s definitions of the phenomenon and make clear what should be focused on in this study. To broaden the view of the empowerment phenomenon and to reduce the risk of bias by only using nurses from either the DRC or public health nurses in the CBR program, nurses from two workplaces participated in the study. Five of the six respondents were women; this corresponds to the real gender distribution in the two workplaces. All six of them fulfilled the inclusion criteria; they had experience of working with rehabilitation for children with disability and they spoke English. Doing research in another cultural context where English is neither the researcher’s nor the respondent’s first language, it was of utmost importance to make sure that both parts understood each other and that the communication was impeccable.

To specify and concretize the term empowerment, three focus areas were determined through literature and talked about during the interviews: education, shared decision-making and motivation. This is in accordance with the nursing literature handling the subject, important areas when working to increase empowerment for children with disability (Frain, et al 2009; Hendersen, 2004; MSW, 2003; NBHW, 2008; Stepans et al, 2002; WHO, 2010). In these semi-structured interviews the respondents described their experiences freely around these areas, as described by Polit and Beck (2010). The predetermined themes were a guide and a mutual help but did not obstruct the respondents to speak freely about their experiences in the subject.

When data collections were extensive and extends over time, there was, according to Graneheim and Lundman (2003), a risk of inconsistency during data collection. The interviews were collected for three weeks and during this time an evolving process created new insights and a deeper understanding for the phenomenon. This could have, according to the authors, caused subsequent influence on the follow up questions and changed the focus of the subject. This situation was recognizable in this study, but consciously avoided by having
an open dialogue with colleagues in the field, and this strengthened the study. Qualitative manifest content analysis was being used, as recommended by Graneheim and Lundman (2003). The collected material was processed to find what had been said from the respondents and then condensing the meanings. The codes, sub-categories and categories were also made with a manifest content withholding a deeper interpretation of what had been said by the respondents.

8.2 Result discussion

The findings in this study underlined the importance of nurses working with a holistic approach in the matter that it focused on the child with disability, the mother as well as the rehabilitation team.

When nursing with focus on the child, the nurses covered the children’s need in activities of daily living, centralized the child in the families, focused on the healthy part of the body, motivated to improvements and created entrances to the society. Nurses and the other team members saw the children as whole persons with needs in different areas in life; they did not only see the disability and hindrance. When nursing interventions were holistic, the process of empowerment could start; the children then felt confident about having skills and resources (Hendersen, 2004; Pelchat & Lefebvre, 2004; Stepans et. al, 2002). Nurses in the rehabilitation teams educated about health with the purpose to give tools to children with disability for them to manage daily activities. This was confirmed by Frain et al (2009) and NBHW (2008), that claimed that to be able to experience empowerment and independence, nurse’s health education was vital. The method of individually adjusted motivating to improvement, was confirmed by van der Ploeg et al (2008) that claimed that personalized, tailored counselling interventions improved behaviour for people with disability. The nurses claimed giving motivation was important in many aspects; it developed personality and individual responsibility, potential and social participation in family and society and this was in accordance with MSW (2003) and NBHW (2008).

Nursing with focus on the mother was explained by seeing the importance of the mother, educating non-educated parents, meeting the need for mothers to get-together with other mothers and seeing gender aspects. The importance of the mother was prioritized and stressed
in the matter of centralizing the child. According to Stacey et al (2007) nursing intervention should include decision coaching, decision-making aid and guidance to patients. The respondents stated that the best way of doing this was to encourage the mothers to give decision-making power to the child. The nurses supported the mothers with individually adjusted information, education and with emotional support, which was, according to Mok, Chan, F., Chan, V. and Yeung (2002) and MSW (2003) ideal for nurses to meet. They were aware of the negative consequences for the mother and children if the father left the mother. The nurses gave special support to these mothers and created forums for mothers and children to come together to discuss, change experiences and become encouraged, which nurses were in a ideal position to create (ibid).

Nursing with focus on the interdisciplinary team was explained by cooperating in the team, working towards a common goal, promoting integration in society, searching for rejected families. All professionals in the team needed to be motivated to be able to cooperate, set common goals, have good communication and support each other in decisions. This was in accordance with Preston (1990) and Stepans et al (2002) that described multidisciplinary team as, in accordance with interdisciplinary teaming assessments, a process where the different team members in their particular area of expertise evaluated the child independently (ibid). According to Velema, Flinkenflugel and Cornielie (2008), effectiveness in rehabilitation work was achieved when patients together with health care personnel set goals in the beginning of the rehabilitation and evaluated these aims in the end of the rehabilitation process. The teams worked with rehabilitation for the children in order to make them able to cope with the environment around them and they educated the society to make families withholding a child with disability less ostracized. This interdisciplinary method developed holistic imbrications, which covered the children's needs and promoted empowerment and independence. This was in accordance with Preston (1990) and NBHW (2008) that stressed the importance of the team working together with the client to achieve the maximum level of independent function. The team searched for the poorest and most vulnerable families that lived far away from the villages in the hard to get jungle. This agreed with the CRC article 2 and 23 and WHO (2010) that stressed the importance of all children being included in rehabilitation programs in society.
During the same time period as this study was conducted, a study was made by Edblom (2012) in the same context with the aim to investigate how the CBR team worked to help children with disability participate in their own situation and in the community. Interviews were conducted with 15 members of the CBR team with different professions. The results of this study were also a holistic work. The result in Edblom (2012), strengthen the degree of reliability in this study. The rehabilitation teams described in this study and in Edblom (2012), were similar to rehabilitation teams working in Sweden; they included the same categories of professionals as in Sri Lanka and were working with the aim to cover children's needs in every aspect of life. In the south part of Sweden, an interdisciplinary research platform called HAREC; Disability and Rehabilitation Research Centre in Sweden promoted knowledge development in the area of disability (Lunds Universitet; Faculty of Medicine, (2009). In the pilot study made before the study in Sri Lanka, a children's rehabilitation nurse from Stockholm, Sweden, stressed the importance of team work and holistic care;

Everything with the child has to be covered, for example toilet- and eating training, health, future of the child and parents, siblings, grandparents and class mates' involvement and understanding for the situation. As a nurse I am focusing on health and areas in my profession, but without the others in the team, the child could not be empowered to become independent (personal communication, Swedish Children Rehabilitation Nurse, 20110605).

8.3 Conclusion

The nursing interventions when working with empowerment in rehabilitation for children with disability had a holistic approach that covered all aspects of life. This was made with a focus on the child, the mother and the interdisciplinary co-operation in the team. Nurses saw the healthy parts in the child and focused on that in the individually adjusted health care. Nurses recognized the mothers as the most important person for the child and gave her health education that would benefit the child in the future. The mothers were also recognized as the person with possibility to centralize the child by removing the figurative corners from the room, where the child use to be hidden. The nurse in the interdisciplinary team prevented the marginalization based on stigma, by educating societies about disability and health. The rehabilitation team made active decisions, trying to reach the most poor and vulnerable children living outside societies in the hard to get jungle.
8.4 Clinical significance

The study could be a possible platform to underline and discuss the importance of the nurse’s role in rehabilitation care. It emphasised the importance of nurses working with empowerment in rehabilitation care by focusing on the child, the mother and on the interdisciplinary rehabilitation team. The study confirmed and encouraged the nursing interventions used in the two teams in Sri Lanka and could be a role model for other rehabilitation teams in low-income counties. The holistic approach that was explained and exemplified in this study was, according to the author in this study, universal and could be used in rehabilitation care and other settings, all over the world.

8.5 Suggestions on further research

The stigmatization, discrimination and ostracizing that children with disability in Sri Lanka was being met with, are occurring in other countries as well. To improve on the situation for these children world wide, as the Convention on the Right of the Child stresses, this kind of research has to continue in nursing research. Also, an interdisciplinary research in the same area would be interesting, to obtain different professionals point of view. This research can be preformed in other counties with the aim to learn from each other and to improve on the situation for children with disability.
9. REFERENCES


Lunds Universitet; Faculty of Medicine (2009). *HAREC: Disability and Rehabilitation Center*. Collected 20110928 from http://www.med.lu.se/english/hvs/harec


Inquiry regarding empowerment for children with disability and their caregivers; a minor field study

I, Caroline Carlsson, am a nursing student from the Red Cross University in Stockholm, Sweden. In my last year of education I am to perform a bachelor essay that consists of ten weeks of study nursing science. For me this is an opportunity to seek understanding for how nurses are working with rehabilitation for children with disability in Sri Lanka with the focus on empowerment.

“A study on how CBR nurses in Sri Lanka work to empower children with disability; an interview study with focus on education, shared decision-making and motivation” is the topic of the study. I will examine the methods of working concerning these three areas and also the nurse’s experiences of how their work leads to empowerment for the children with disability and their parents.

The main data gathering will be in form of interviews with some of the nurses working in the CBR team with children with disability. Also what I have observed during my weeks together with the nurses in the CBR-team will be material in the discussion of the essay. Therefore I ask if you are willing to let me interview you on this topic. The data gathered will be treated anonymously and confidentially and will be performed in the way that no single person is possible to identify.

I ask for permission to perform this study.

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Caroline Carlsson  Respondent’s signature
10.2 Interview guide

Empowerment is the process in which children with disability and their caregivers achieve a belief on their own capacities, self-reliance, and a will to be a part in their rehabilitation process.

According to nursing research, International Council of Nurses (ICN), WHO (2010) the three following areas are important to work with to achieve empowerment for children with disability; education, shared decision-making and motivation.

Based on this and on your situation in working with children with disability and their parents;

- What is your experience as a nurse working with education for children with disability and their caregivers; in which way, with what methods do you educate and how do you think it leads to empowerment?

Supporting topics:
- Can you tell me about a situation where you educated the child with a disability and the caregivers.
- Can you tell me about a situation where you can say that a child with a disability and the caregivers did receive empowerment after education.
- Do you remember your and other caregiver’s participation in those situations?

- Shared decision-making is said to be an important part in empowerment; persons are a part of their own care and they feel they have been listened to and they have a say when it comes to their own decision-making process. Can you tell me about an experience of working with shared decision-making?

Supporting topics:
- Can you tell me about any directions or strategies to promote children with disability and their caregivers to be a decision-making part?
- How do you reckon your role as a nurse in a shared decision-making situation?

- For children and the caregivers to understand that he or she has to take responsibility in the individual process of rehabilitation it is important to motivate the person. What is your experience of working to motivate children with disability and their caregivers; what methods do you use and how do you think it leads to empowerment?

Supporting topics:
- Can you tell me an example of this situation?
- Can you tell me what you are focusing on when motivating children with disability and their caregivers?