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Activity limitations and participation in activities among children with disabilities in western Uganda

- A qualitative interview study

MAIN FIELD: *Occupational therapy*
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Summary

Background: Children with disabilities in Africa do not receive the help that they need and therefore face many challenges. Access to the most basic healthcare is often be poor in many parts of Africa, and therefore it can be hard for children with disabilities to even get recognised. The *purpose* of the study was to identify activity limitations and participation in activities among children with disabilities in western Uganda. The *method* used was qualitative with inductive approaches. 14 participants, who lived in western Uganda and in different ways were connected to children with disabilities, were recruited through purposive sampling. Data was collected through semi-structured interviews. The interviews were analysed according to qualitative content analysis. The *result* was split into three main categories: Knowledge, Exclusion and Poverty. These main categories are further split into 12 subcategories. The participants' experiences showed that knowledge shortage and poverty are factors that affect activity limitation and participation in activity. The *conclusion* made by the authors, was that knowledge should be spread about occupational therapy and what could reduce activity limitations and increase the participation in activities for children with disabilities in western Uganda.

Keywords: knowledge, poverty, exclusion, occupational therapy

Sammanfattning

Alternativ titel: Aktivitetsbegränsningar och delaktighet i aktivitet, bland barn med funktionsnedsättningar i västra Uganda - en kvalitativ intervjustudie. (Swedish)

Bakgrund: Barn med funktionsnedsättningar i Afrika får inte den hjälp som de behöver och de konfronterar många utmaningar. Tillgång till grundläggande sjukvård saknas ofta, i vissa delar av Afrika, och därför kan det vara svårt för barn med funktionsnedsättningar att bli igenkända. *Syftet* med studien var att identifiera aktivitetsbegränsningar och delaktighet i aktivitet bland barn med funktionsnedsättningar i västra Uganda. *Metoden* som användes var kvalitativ med induktiv ansats. 14 deltagare, från västra Uganda och som på olika sätt hade anknytning till barn med funktionsnedsättningar, rekryterades genom avsiktligt urval i västra Uganda. Data samlades in genom semistrukturerade intervjuer. Intervjuerna analyserades enligt kvalitativ innehållsanalys. *Resultatet* kom fram till tre huvudkategorier: Kunskap, uteslutning och fattigdom. Dessa huvudkategorier omfattades av 12 underkategorier. Deltagarnas upplevelser visade på att kunskapsbrist och fattigdom är delar som påverkar aktivitetsbegränsningar och delaktighet i aktivitet. *Slutsatsen* författarna kom fram till var att kunskap bör spridas om arbetsterapi och vad som kan minska aktivitetsbegränsningar och öka delaktigheten i aktiviteter för barn med funktionsnedsättningar i västra Uganda.

Nyckelord: kunskap, fattigdom, uteslutning, arbetsterapi

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1. Introduction

Children with disabilities in Africa do not receive the help they need and face many challenges. They are often denied the basics of healthcare and are excluded from society because of stigmatisation (Donald, Samia, Kakooza-Mwesige & Bearden, 2014). There is a lack of social and financial support as well as opportunities for children with disabilities to participate in activities (Nelson, Masulani-Mwale, Richards, Theobald & Gladstone, 2017; Ambikile & Outwater, 2012). Through this study activity limitations and participation in activities among children with disabilities can be identified. This could lead to help for the disabled children to participate more in activities. Through this study missing resources can be identified which could increase participation among children with disabilities. Suggestions for occupational therapy practice in western Uganda will be presented, with the aim to enhance occupational health treatment in the country. Continuing research can be encouraged through this study.

2. Background

2.1 Uganda

The official language in Uganda is English but not everyone speaks it. There are about 40 different local and regional languages in the country and these languages have affected the use of English. Most of the people in Uganda live in the countryside and the most common way to earn money is through farming. In rural areas, access to healthcare is poor, as healthcare facilities are mainly found in larger cities. Voluntary organisations account for a large part of public healthcare in the country and the social safety net is weak. As in many developing countries, the close family provide help for the sick and the old (Utrikespolitiska institutet, n.d.).

2.2 Children with disabilities in Africa

In a systematic review by Donald, Samia, Kakooza-Mwesige and Bearden (2014), problems regarding the situation for children with disabilities in Africa are discussed. It is difficult for the children to receive the help that they need. There is a lack of strategy and interventions regarding how to help children with disabilities. Access to the most basic healthcare can often be poor in parts of Africa, and it can therefore be harder for children with disabilities to even be recognised. For example, knowledge of how to care for and manage a child with cerebral palsy is missing and there is a shortage of trained health workers. Most of the children with disabilities face a lot of challenges because they are often denied the basics of healthcare, education, socialisation and recognition. Exclusion from the society is also a fact for children with disabilities and their families following stigmatisation..

People with disabilities in Uganda can be disadvantaged in their workplace and in other public places. In Uganda, 19% of persons aged 5 and over have some kind of disability

(Uganda Bureau of Statistics (UBOS) & ICF International Inc, 2012). Many children in Uganda leave school because their parents do not have enough money. It is also common that children in the countryside work outside of school (Utrikespolitiska institutet, n.d.).

A study made in Malawi explored how children with and without disabilities participate in different kinds of activities. The most common activities for the children were the activities contributing to family life and in their homes, although children with disabilities were not able to take part in many activities contributing to family life because of their disability. Most of the children with disabilities spend most of their time at home. Children with disabilities want to participate more in activities but there is the lack of opportunities where these children can have the chance to participate. There is also a lack of culturally appropriate tools for African contexts to increase the participation for children with disabilities. It is important to integrate children with disabilities into the community, provide more practical support and have governmental input to ensure a higher level of participation in activities among disabled children (Nelson, Masulani-Mwale, Richards, Theobald & Gladstone, 2017).

When working with families of children with disabilities, it is important to have interventions that provide social support and create an environment for training and empowering families. This can for example be support groups where families meet and share emotional issues, relevant information or practical resources (Modesta et al., 2013). Families in Africa that have a child with disabilities lack things such as social support, money and professional assistance (Ambikile & Outwater, 2012).

People with a disability are also discriminated against, both in the labor market and in terms of education (Utrikespolitiska institutet, n.d.).

2.3 Activity limitations

According to the World Health Organization (2019) the word disability includes impairments, activity limitations and participation restrictions. An activity limitation is a difficulty encountered by an individual in executing a task or action. Öhrvall, Vroland Norstrand and Peny-Dahlstrand (2016) says that different types of functional impairments affect children's performance. Children with disabilities confront obstacles in their life for example in school, during leisure time or in other environments.

2.4 Participation

In the theory Model of Human Occupation, participation in activity is to feel engagement in occupations. Engaging in an occupation helps a person to feel pleasure, challenge and enjoyment. The person also feels a commitment to the occupation and feel a connection to other people who share the same interest in the occupation. Participation is influenced by a person's volition, habituation, performance capacity and environment. Some people can fully participate in activities while others cannot, because they need support to do so. A person can have failure performance or less volition that affects the participation in occupation. A

disability can change the participation in an activity, but it does not have to prevent the participation if there is adequate support in the environment. Different aspects of the environment influence the person. The Model of Human Occupation describes three dimensions of the environment: the physical environment means the space and objects, the social environment includes the relationships and interactions and the occupational environment means the occupations, activities and overarching context. The environment provides opportunities, challenges, demands or negative consequences. Other levels of environmental aspects influence the individual and their participation in society, such as the community, economic aspects, social attitudes, geography and systems of care. By evaluating the components and qualities of the environment, interventions can be implemented to enable participation in occupations (Taylor & Kielhofner, 2017).

If there is the possibility for adolescents with intellectual disabilities to participate in physical activity which they enjoy, they may want to engage more often in those activities. Efforts may be needed by service providers to include adolescents with intellectual disabilities in school and community programs. Parents also have an important role in identifying opportunities for their children (Stanish, Caroli, Must, Aviva, & Philips, 2016).

2.5 Global goals

This study relates to three of the 17 global goals that exist to make a sustainable development in all countries for all human beings. Goal number 1 "No Poverty", refers to the lack of financial means, knowledge, freedom or healthcare. To reach this goal every human should have the right to economic resources, basic service and appropriate new technology. By 2030 there should be a social protection system for the vulnerable. Goal number 3 "Health and well-being", concerns people having the opportunity to reach their full potential and contribute to the development of society and receive information about healthcare. Goal number 4 "Quality education" should lead to completely free and equitable primary and secondary education for all girls and boys. The environment where the education is taking part should also be adapted for children with disabilities (The Global Goals, n.d.).

2.6 Occupational therapy

In occupational therapy, the focus is on the treatment of what the person does, thinks and knows. The change in a person's life should be something that the person wishes to change. Therefore, it is important that the occupational therapist builds a relationship with the client. The occupational therapist should understand, respect and support the client's choices, actions and experience. How a person achieve a change depends on the multiple and complex interactions between; volition, habituation, performance capacity and environmental conditions (Taylor & Kielhofner, 2017).

Occupational therapists can help children with disabilities so that they can receive the support they need to be able to function in their everyday life and achieve higher levels of participation in society. The occupational therapist has a holistic view of the person's

everyday life and works to solve or alleviate the problems that a disability creates in a person's daily activities. The goal of occupational therapy is to promote the person's possibility to live a valuable life by developing the person's activity capacity or preventing impairment (Förbundet Sveriges Arbetsterapeuter & Riksförbundet FUB, 2012). The task of occupational therapy can be described as giving the opportunity for people to do the things that they want to do and the things they need to do in a way that they wish. Occupational therapy is therefore connected to every human's everyday life (Erlandsson & Persson, 2014).

An occupational therapist works to ensure that children with disabilities are as well-functioning as possible. The occupational therapist also has a pedagogical role by spreading knowledge about what should be done to increase a child's everyday functioning (Jacobsson, 2016).

3. Aim

The purpose of this study is to identify activity limitations and participation in activities among children with disabilities in western Uganda.

4. Material and method

Pre-understanding is inevitable and an important part of identifying the essence in research (Kristensson, 2014). The pre-understanding is that Uganda is a poor country and with a lack of adequate healthcare. The country is missing both a positive image of children with disabilities and a lack of effort in order to ensure disabled children participate more. This pre-understanding and the knowledge that it can affect the study has been considered throughout the process.

4.1 Design

A qualitative study with an inductive approach was undertaken, using semi-structured interviews. The focus was on the participants' own perspectives and their experiences of activity limitations and participation in activities among children with disabilities in western Uganda (Kristensson, 2014).

4.2 Participants

The participants were individuals that work with or are somehow involved with children with different disabilities. To increase the credibility of the results, people with different involvement with the phenomena were interviewed (Kristensson, 2014). The participants represented various professions such as teachers, physiotherapists and social workers and where based in both educational and healthcare settings. They lived in different areas and had various access to supplies and help. Both women and men participated in the study. The participants were collected by purposive sampling to get a variety of the phenomenon (Kristensson, 2014).

4.3 Data Collection

Information was gathered through 14 semi-structured interviews. Each interview took between 15 and 40 minutes. The interviews were held by the authors; one carried out the interview, while the other one took notes. The interviews were made in a semi-structured way, where the participants were asked the same open questions and space was made for supplementary questions. An interview guide, to strengthen the trustworthiness (Kristensson, 2014), was prepared in advance (appendix 3) and worked as support during the interviews. The interviews were recorded which allowed the researchers to listen to them several times and ensure all data was transcribed. The interviews was conducted in an environment which the participant chose, where they felt comfortable and relaxed (Kristensson, 2014).

4.4 Data processing

The interviews were transcribed and anonymised. The transcribed interviews became around 90 pages of text. To analyse the text, a qualitative content analysis was undertaken. To show credibility the transcription from the recorded interviews were analysed and construed by two people, so called triangulation (Kristensson, 2014). The interviews and the meaning units

were read and thoughts written down. The parts of the interviews that related to the aim of the study were identified and the rest was deleted. A summary of the meaningful units were condensed and then coded. This process made the text shorter. The various codes were reviewed to identify similarities and differences. The codes that fit well together were summarised in categories and subcategories (Lundman & Hällgren Graneheim, 2017).

A combination of latent and manifest content analysis was used for this study. Manifest analysis was used to identify similarities and differences that are more obvious and visible in the text. Latent analysis was used to find importance, meaning or underlying surface attributes (Lundman & Hällgren Graneheim 2017). The aim of the study was always in focus.

Table 1: Example of meaning unit, condensed meaning unit, code, subcategory and category

Meaning unit	Condensed meaning unit	Code	Subcategory	Category
He can't prepare meals. He can't go to the garden. He can't wash clothes properly.	Can't prepare meals, go to garden, can't wash clothes properly	Lots of activities he can't do	Activity limitations	Exclusion
Another challenge is that they fear that the disability will transfer to another child or another person.	Fear that the disability will transfer to another person	Fear that the disability is contagious	Fear	Knowledge
And in their homes it is even worse. Cause you make them sleep the whole day and the whole night. So they are never taken out.	Sleep the whole day and the whole night and never taken out	At home the whole day, never taken out	Isolated	Exclusion
Sometimes the children are supposed to learn how to feed and dress themselves, but	Learn to feed and dress themselves, don't have people to train them.	No one that can teach the child with a disability to eat or to dress.	Lack of health care / rehabilitation	Poverty

they don't have people to train them to do that by themselves.				
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4.5 Ethical considerations

The four central principles: autonomy, non-maleficence, beneficence and justice were considered (Kristensson, 2014). The participants were informed of the purpose of the study and the method that was going to be used. Participation was voluntary and the participants could withdraw at any time and without giving any reason. The participants gave their consent to the interview being recorded and they signed a consent form (appendix 1). Before and after the interview the participant could ask questions. Information was given that the material was kept in a secure way. All information was processed confidentially and no identifying factors were given. After six months the material from the interviews will be destroyed to ensure that no unauthorised person can access the data. The benefit of this study is that continuing research can be done to help children with disabilities to be more participating in activities (Kristensson, 2014).

An ethical self-examination form the School of Health and Welfare, Jönköping University, was made and approved before the study started.

5. Results

The 14 interviews resulted in material that was analysed using similar methods to Lundman and Hällgren Graneheim (2017). The result is presented in categories and subcategories with quotations from the participants.

The number inside the parentheses after the quotations means the number of the interview/the participant.

Table 2. Reporting of subcategories and categories.

Subcategory	Category
Parents do not know what to do	Knowledge
Lack of knowledge	
Fear	
Stigmatisation	Exclusion
Left alone	
Activity limitations	
Isolated	
Poor environment	
Involving makes them happy	
Lack of money	Poverty
Lack of assistive devices	
Lack of healthcare/rehabilitation	

5.1 Knowledge

Parents do not know what to do

Parents do not know what to do if they have a disabled child. The child cannot for example wash clothes or do house work because the parents do not know how to train or help them. Some children do not know how to turn themselves in bed or cannot move in their

wheelchair, and that can cause pressure ulcers. Children with disabilities are staying at home because they fear that other children will laugh at them because of their disability. The mother is often blamed for giving birth to a child with a disability. It is said to be because she cheated on her husband whilst pregnant or because she had been disrespected her mother in law.

"Most children have stigma. And their parents do not want to expose them to the community so most of them are locked inside their house. They don't access the outside environment because of the disability. And sometimes the parents are tired of them and don't show up so they keep those indoors ." (7)

Lack of knowledge

Lack of knowledge leads to activity limitations as people do not think the children can participate, and they might need some extra support to participate.

"So if more knowledge will be spread these children could be able to be more participating in activities."(1)

There is a school for disabled children where the teachers know how to use sign language. But when the children come home, they fail to communicate because the parents and the people in the community do not know how to use the language. In hospital the social worker tries to play with the children and they sometimes improve but when they go back to the community the conditions are not the same. For example, if a child is deaf their communication is limited and their friends do not understand them.

"Then when you observe the child, he cannot do anything here in class. It's a child who can escape from anytime from school. Cause of that kind of disability" (9)

Fear

Some of the children with disabilities are afraid that others will laugh at them because of their disability. This results in the children not participating in activities and it limits them to a great extent. They stay at home and do not interact with others, they do not go to school and they might stay indoors all the time. People also have a fear of disabilities. They are afraid that the disability will affect other persons, that it is contagious. Sometimes, if the disabled child has a sister or brother they can play together.

5.2 Exclusion

Stigmatisation

Most of the children with disabilities do not go to school, because they are both neglected and stigmatised. People do not think that these children are able to learn and therefore feel that it is a waste of money to put them in school. The lack of the participation in activities among children with disabilities is because they are not included and they are further isolated because of stigmatisation. The children with disabilities are not engaged in activities.

"So they are excluded. And if there is an epilepsy related it consider it to be possessed by demons so will often not be included" (13)

Left alone

The children with disabilities cannot play because they have nothing to play with. Some of them go to a school for disabled children where the children have helpers but if the helper is not there the child will suffer. They never participate independently, and when they do it is always with assistance. There are not many things in place to get the child more participating more in activities. Most of the children are not able to walk and they are then left behind. Some of the children cannot even go out in the garden because of the stiffness in their bodies.

Children with disabilities are being locked in their homes with no one at home to can take care of them. They are just laid on a mat for the whole day. The parents let them sleep the whole day so they will never be able to go outside. If a child is sitting in a wheelchair, he can play with other children who also sits in a wheelchair or are in a similar situation. However, it is difficult for the child to play with other children because the child cannot go to other areas and play with them. Sometimes the children in wheelchairs are left behind because they cannot physically come along.

"And there are still barriers with the inclusion.. in the societies. So that one is also a limiting factor" (10)

Activity limitations

Some disabled children have activity limitations such as preparing meals, washing themselves, playing around and moving. In fact, most children with disabilities are limited in range of movements and so will experience activity limitations. The children want to play football, netball and skip using a rope but they cannot because of the physical impairment; they cannot run, jump or carry heavy things. Some cannot even walk and are therefore left behind - they do not go to sing or go to church where they can attend different activities. The disabled child cannot prepare meals, go out in the garden or wash clothes properly. A blind child is blind the child is not able to see what kind of things there are to play with and this will affect the child's enjoyment in the activity.

"The child is disabled so he cannot do something" (3)

Isolated

Most children with disabilities are left isolated at home laying on a mat the whole day. The parents lock the child inside and go out in the garden or to work. When the mother comes back home, she is busy with cooking, going to the market or washing clothes. If the child is urinating, on the mat, in the morning, it will be there the whole day. Maybe in the evening when the mother has finished everything will she attend to the child's personal hygiene.

Poor environment

The environment affects the child's participation in activities and it also excludes the child from doing some activities. If a child in a wheelchair lives up in the mountains it can be hard to move around and especially during the rainy season - the wheelchair then becomes useless. If the wheelchair breaks it might be very far to the nearest place where it can be repaired, and it can be very expensive. The toilets in school are not adapted for children in a wheelchair so they cannot access the toilet. There is also a problem for the children with disabilities to get to school. The environment poses a challenge to moving the children from their homes to the school and then picking them up. Even if the disabled child has a wheelchair it is hard to use it because of the mountainous area; the roads are muddy which makes it hard to get the wheels to work.

“Challenge of environment, of environment. Even that if a person can be given a certain, a certain device, for example a child is having wheelchair. So that they, the environment that he lives in, does not allow him to use the wheelchair.” (1)

Involvement makes them happy

When someone talks to the disabled child the child starts smiling. The child becomes happy when they are playing with something, for example a balloon. Disabled children need to be engaged and do things together with others to feel happy. A child that never gets involved in different activities will not develop the same way as the other children and might instead develop a second disability.

5.3 Poverty

Lack of money

Assistive devices are too expensive for the family to afford, as is making the home adapted for the disabled child. The school does not have the money either to make the environment adapted for children with disabilities.

“Because you don't have money to buy that” (4)

Many families do not even have enough money to let the children go to school. Instead the children have to stay at home, take care of the home or work to help the family. If the child is disabled neither the school nor the family have the funds required to help the child to satisfy their needs.

Lack of assistive devices

Adapting equipment, such as wheelchairs, is lacking to enable children with severe disabilities to participate. There is also lack of assistive devices to transfer the children to school and to other areas. Even if the family does receive assistive devices they do not use them. The reason for this is that they do not consider themselves the owner of the assistive devices and therefore wait for the hospital staff to use them with the child. The mountainous area also poses a problem for using a wheelchair, for example, as the wheels get stuck in the

muddy roads. If the wheelchair breaks it is difficult for the family to get it repaired because of the distance to the hospital.

Lack of healthcare/rehabilitation

With no one teaching them how to do activities, it is difficult for children with disabilities to learn skills. This in turn will cause secondary disabilities for the child. If the parents are educated about how they can work with the child, to see an increase in functioning, they would work really hard to try. If the disability is severe it may be hard to see any improvement, but it is possible to see better engagement and a better relationship between the parent and the child.

6. Discussion

6.1 Method discussion

The language may have been a barrier for the participants when it comes to the ability to explain their experiences and thoughts, as most of them are more used to their local language over English (Utrikespolitiska institutet, n.d.).

The World Health Organization (2019) includes both activity limitations and participation restrictions in the word disability. The purpose of this study has therefore been to identify the two phenomena activity limitations and participation restrictions. According to Kristensson (2014) the transferability is one of the aspects of reliability which needs to be described in a qualitative study. Since the sample size of this study is small, it is hard to transfer the results to a bigger population.

There was a pre-understanding that many countries in Africa are poor and that access to healthcare is limited. The pre-understanding affected the formulation of the purpose to identify activity limitations among children with disabilities. The purpose has been discussed and in order to create a purpose where the pre-understanding would not have any influence, a different formulation of the purpose could have been applied. Instead of identifying activity limitations, identification of activity could have been considered. The purpose would then have been “Identify activity and participation in activities among children with disabilities in western Uganda”.

The selection process and the survey group

A qualitative study was chosen to ascertain experiences and thoughts from different people. Interviews were conducted to get a deep and detailed picture and understanding of the phenomena interviews were carried out. People from different professions were interviewed to achieve a variegated sample which also leads to a higher credibility.

The initial thought was to limit the study to children with Down syndrome, but not enough information could not be collected, so the concept of disability was used instead. The concept of disability is wide and it could be a variety of activity limitations between children with different kinds of disabilities.

To strengthen the transferability a careful description of the participants has been made (Lundman & Hällgren Graneheim, 2017). To show the results dependability, the time of material collection is presented under the headline Data Collection. In the result, are quotes from the interviews to show how they relate to the result and to show confirmability (Lundman & Hällgren Graneheim, U., 2017).

The interview guide and the quality of interviews

The interviews were conducted in an environment where the participants felt comfortable. A good atmosphere provides the conditions for the interview to be rich in content and depth in

relation to the purpose of the study. In an interview study the researcher will be seen as a co-creator of the text, meaning that the result cannot be seen as independent of the researcher (Henricson, 2017).

The questions were created to ensure that they were in line with the aim. Question number one “What kind of activities is common for children with disabilities in western Uganda” and question number two “What kind of disabilities have you experienced” (appendix 3) did not answer the aim but they were used to get an understanding of children's activities and what kind of disabilities are present in western Uganda. At the start of the interviews the concept "activities" and "participation" were defined, to avoid misunderstandings (appendix 3).

Due to cultural differences there was a chance of the participants misunderstanding the questions. Some of the questions could have been clearer because they had to be rephrased for some of the participants to understand. For example “What kind of consequences can you see that this disability/disabilities has on children’s activity participation?” The interview guide made it easier to focus on the purpose of the interview and increased dependability in the study (Kristensson, 2014).

Analysis process

The qualitative content analysis was considered appropriate to this study. It focuses on review and interpretation of different texts from mixed interviews (Lundman & Hällgren Graneheim, 2017). The interviews were transcribed, and read through separately to later discuss the overall impression. A triangulation was made, which means that two people read and analyse the material (Kristensson, 2014). By doing this it strengthened the credibility and confirmability of the study and the risk decreased that the material would be affected by individual opinions (Lundman & Hällgren Graneheim, 2017). To strengthen the reliability, the analysis process is documented in the title method (Kristensson, 2014). Some struggle with constructing the subcategories, when processing of the material, occurred. Many parts in the result overlap. For example, that lack of money leads to lack of assistive devices, that leads to less participation in activities and that in turn leads to exclusion.

According to Kristensson (2014) the transferability is one of the aspects of trustworthiness which needs to be described in a qualitative study. Since the sample size of the study is small, it is hard to transfer the results to a bigger population.

6.2 Result discussion

The most important results in this study is the lack of knowledge, that people do not know what to do and how to help the children.

According to Taylor and Kielhofner (2017) is it important for every human to feel participation in an activity. This is something that creates enjoyment and commitment. Based on information that has been collected, it is evident that children with disabilities in western

Uganda experience a lack of participation in activities. The problem for most disabled children in western Uganda is that there is no support in the environment for them to be able to participate in activities. A disability can change the participation in an activity, but it does not have to prevent the participation if there is support in the environment. The community, social attitudes and economic aspects, geography and systems of care are all factors that affect an individual and their participation in society (Taylor & Kielhofner, 2017). The categories that have been presented in the results, namely lack of knowledge, exclusion and poverty are factors that influence the everyday participation in a negative way (Hammel et al., 2015).

Knowledge

There is lack of knowledge about how to enable the disabled children to participate in activities. Knowledge is missing in Africa around how to care for a child with cerebral palsy (Donald, Samia, Kakooza-Mwesige & Bearden, 2014). The parents do not know how to get the child participating in activities and the child will get secondary disabilities because the child never develop any skills. According to UNICEF (n.d), all children are equally valuable and have the same rights. In western Uganda, some people believe that a child with a disability is less valuable than a child without a disability. If a child is born with a disability, some people believe this is because the mother has been unfaithful or that she has not shown respect to her mother. Therefore, knowledge needs to be spread that every child has the same rights whether the child has a disability or not. Knowledge also needs to be spread about why a child is born with a disability.

Exclusion

Cultural aspects have an influence on the physical and social environment. Culture includes norms, values and behaviour shared by a group or society. Social norms can affect a person's activities and activity patterns (Taylor and Kielhofner, 2017). One norms which exists in the society in western Uganda is that children with disabilities do not have the same rights as other children. The parents do not give them access to school because it is considered a waste of money to educate them.

Because of the exclusion of children with disabilities, obstacles are created in the social environment preventing the children from participating in activities. There is stigmatisation of children with disabilities, leading to them being perceived as less valuable and to a fear that the disability can affect other people. Therefore, other children will not play with children with disabilities and mothers blame themselves for having a disabled child. Some disabled children are isolated at home which makes them unable to participate in any activities.

Fear causes people to avoid socialising with the disabled children. Many children are at home all day so they do not come out and meet other people. Society does not provide opportunities for children with disabilities to participate. According to previous studies done in Africa, stigmatisation is a major problem (Donald, Samia, Kakooza-Mwesige & Bearden, 2014). It emerged from the interviews that the situation for children with cerebral palsy is very serious

since many children are left at home.

Poverty

Economic aspects are one environmental construct which influences individuals in their participation in society (Taylor & Kielhofner, 2017). Poverty creates barriers in the physical environment where the lack of access to assistive technology is a major limitation. It is something that is expensive, and accessibility does therefore not exist in the country. The parents cannot afford assistive devices and the school does not have the money to adapt the environment for children with disabilities. Also, the environment, in which the child lives affects the participation of disabled children. Where the children live it is mountainous, with roads that become muddy after it has rained, making it difficult to use aids such as wheelchairs. The children do not get help from the society and according to previous studies there is also a lack of social support and professional help in many African countries (Ambikile & Outwater, 2012).

One goal in Uganda is that every child shall go to school (Utrikespolitiska institutet, n.d.). This study shows that there are many children that do not go to school because the parents do not have enough money or they do not get the help that they need.

Global goals

Three global goals have been in focus during this study: goal number one "No Poverty", goal number three "Health and well-being" and goal number four "Quality education". The goals are that all people should have the opportunity to reach their full potential and receive information about healthcare by 2030. Societies should have social protection systems for the vulnerable and everyone should have equal rights to economic resources and appropriate new technology. All girls and boys should have a completely free primary and secondary education and the education environment where the education is taking part should also be adapted for children with disabilities (The Global Goals, n.d.). As confirmed by the results presented in this study, there is a lot to be done to reach these global goals in western Uganda. The situation for disabled children in western Uganda today is that they are not given the opportunity to reach their full potential and they do not have access to quality essential health care services. There is no social security system in the society for these people and economic resources and new technology are missing. The schools are not adapted for the disabled children and according to Utrikespolitiska institutet (n.d.) children in Uganda leave school because their parents do not have enough money.

Occupational therapy

The results showed that there are many activity limitations among children with disabilities. Some children are unable to do anything, depending on what kind of disability the child has. Occupational therapy is therefore something that is needed in western Uganda. The goal of occupational therapy is to increase the person's chance of living a valuable life by developing the person's activity ability or preventing impairment (Förbundet Sveriges Arbetsterapeuter & Riksförbundet FUB, 2012). An occupational therapist can work to prevent impairments that

the disabled child has and creates opportunities for the children in western Uganda to have a more valuable life. In order for a change to take place in the daily life of a child with disabilities, it is important that the occupational therapist considers all the aspects in the change process: the child's volition, habituation, performance capacity and environmental conditions. Focus in the treatment should always be what the child does, thinks and feels (Taylor & Kielhofner, 2017).

To feel independent in daily activities is important for the development of a child's identity and self-esteem. An occupational therapist can work to enable children with disabilities to participate and be independent in daily activities. This can be done by influencing the child's own conditions and skills or by changing the activity and the environment so that the child's activity performance can increase (Öhrvall, Vroland Norstrand, & Peny-Dahlstrand, 2016). It is a major problem that most children with disabilities in western Uganda do not go to school, as education is important for the child's learning, development and psychosocial well-being, and is crucial for the child's opportunity to continue to study and work. An occupational therapist can work to make children with disabilities more involved and increase participation in school. This can be about adapting the school environment for children with disabilities or to increasing social participation, as well as creating greater interaction among children (Hemmingsson, 2016). As mentioned earlier, lack of knowledge is a big problem in western Uganda. The occupational therapist can therefore work to spread knowledge about how to increase the child's everyday functioning (Eliasson, Lidström & Peny-Dahlstrand, 2016). Further research that can be undertaken to investigate how different professions meet the needs for children with disabilities in hospitals or how the schools are working to enable participation in activities for children with disabilities.

7. Conclusion

The children with disabilities in western Uganda have many activity limitations and there is a lack of participation in activities. The main reasons why children with disabilities do not participate in activities are lack of knowledge, exclusion and poverty. Knowledge needs to be spread about occupational therapy and what could be done to reduce activity limitations and increase the participation in activities for children with disabilities in western Uganda.

8. References

- Ambikile, J., & Outwater, A. (2012). Challenges of Caring for Children with Mental Disorders: Experiences and Views of Caregivers Attending the Outpatient Clinic at Muhimbili National Hospital, Dar Es Salaam - Tanzania. *Child and Adolescent Psychiatry and Mental Health* 6(1).
- Donald, K, A., Samia, P., Kakooza-Mwesige, A., & Bearden, D. (2014). Pediatric Cerebral Palsy in Africa: A Systematic Review. *Seminars in Pediatric Neurology*, 21(1), 30-35.
- Erlandsson, L. & Persson, D. (2014). *ValMo-modellen : Ett redskap för aktivitetsbaserad arbetsterapi* (1 ed.). Lund, Sweden: Studentlitteratur AB.
- Förbundet Sveriges Arbetsterapeuter & Riksförbundet FUB. (2012). *Arbetsterapeutiska insatser – en förutsättning för ett kvalificerat stöd till personer med utvecklingsstörning*. Förbundet Sveriges Arbetsterapeuter, Riksförbundet FUB.
- Hammel, J., Magasin, S., Heinemann, A., Gray, D. B., Stark, S., Kisala, P., et al. (2015). Environmental barriers and supports to everyday participation: A qualitative insider perspective from people with disabilities. *Archives of Physical Medicine and Rehabilitation*, 96(4), 578-588.
- Hemmingsson, H. (2016). Barns aktiviteter i dagligt liv. I A-C. Eliasson, H. Lindström & M. Peny-Dahlstrand (Red.), *Delaktighet i skolmiljön*. (1:3 ed., p. 179-192). Sweden, Lund: Studentlitteratur AB.
- Henricson, M. (2017). *Vetenskaplig teori och metod : Från idé till examination inom omvårdnad* (2. ed.). Lund, Sweden: Studentlitteratur
- Jacobsson, H. (2016). Arbetsterapeutens roller och metoder. I A-C. Eliasson, H. Lindström & M. Peny-Dahlstrand (Red.), *Arbetsterapi för barn och ungdom*. (1:3. ed., p. 145-164). Lund, Sweden: Studentlitteratur AB
- Kristensson, J. (2014). *Handbok i uppsatsskrivande och forskningsmetodik för studenter inom hälso- och vårdvetenskap* (1. ed.). Stockholm, Sweden: Natur & Kultur.
- Lundman, B., & Hällgren Graneheim, U. (2017). Kvalitativ innehållsanalys. I B. Höglund Nielsen & M. Granskär (Red.), *Tillämpad kvalitativ forskning inom hälso- och sjukvård*. (3. ed., p. 211-226). Lund, Sweden: Studentlitteratur AB.

Modesta, P., Guillamón, N., Hernández-Encuentra E., Muñoz, E., Redolar, D., Boixadós, M., & Gómez-Zúñiga, B., (2013). Impact of Caring for a Child with Cerebral Palsy on the Quality of Life of Parents: A Systematic Review of the Literature. *Journal of Developmental and Physical Disabilities*, 25(5), 545-77.

Nelson, F., Masulani-Mwale, C., Richards, E., Theobald, S. & Gladstone, M. (2017). The meaning of participation for children in Malawi: Insights from children and caregivers. *Child Care Health and Development*, 43(1), 133–43.

Stanish, H I., Caroli, C., Must, Aviva, M., & Philips, S. (2016). Physical Activity Enjoyment, Perceived Barriers, and Beliefs Among Adolescents With and Without Intellectual Disabilities. *Physical Activity and Health*, 13(1), 102-110.

Taylor, R., & Kielhofner, G. (2017). *Kielhofner's model of human occupation : Theory and application*. (Fifth ed.). Philadelphia, USA: Wolters Kluwer.

The Global Goals. (n.d.). *The 17 goals*. Retrieved May 20, 2019, from <https://www.globalgoals.org/>

Uganda Bureau of Statistics (UBOS), & ICF International Inc. (2012). *Uganda Demographic and Health Survey 2011*. Retrieved from <https://dhsprogram.com/pubs/pdf/FR264/FR264.pdf>

UNICEF. (n.d.). *What we do*. Retrieved May 22, 2019, from <https://www.unicef.org/what-we-do>

Utrikespolitiska institutet. (n.d.). *Uganda*. Retrieved May 20, 2019, from <https://www.ui.se/landguiden/lander-och-omraden/afrika/uganda/>

World Health Organization. (2019). *Disabilities*. Retrieved May 20, 2019, from <https://www.who.int/topics/disabilities/en/>

Öhrvall, A-M., Vrolander Norstrand, K., & Peny-Dahlstrand, M. (2016) Barns aktiviteter i dagligt liv. I A-C. Eliasson, H. Lindström & M. Peny-Dahlstrand (Red.), *Arbetssterapi för barn och ungdom*. (1:3. ed., p. 145-164). Lund, Sweden: Studentlitteratur AB

Consent form

Inquiry about participation in study: A qualitative study about activity limitations and participation in activities among children with disabilities in western Uganda.

We study at Jönköping University to become Occupational Therapists.

The purpose of the study is to identify activity limitations and participation in activities for children with disabilities. We have not found any research about the aim and would like to know about your experience.

Through this information we ask you if you can participate in our interview study. We would like to talk to you because you have experience of children with disabilities.

Your participation in the study is voluntary and you can cancel the participation in the study at any time without giving a reason. We are not going to mention any names or other identifying factors of the participants. The interview will be recorded and notes will be made. All information will be processed confidentially. Only the research group has access to the material. Great importance will be attached to the fact that the notes cannot be deduced to any person. During the study all the information is going to be kept in a secure way and will be destroyed after 6 months.

The results of the study will be published at SIDAs website and at the website of Jönköping University, School of Health and Welfare.

If you want to take part of the result of the study let us know, and we will try our best to make that possible for you.

Responsible for the study
Jönköping University, School of Health and Welfare.

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Occupational Therapy student
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Nina Sundell
Occupational Therapy student
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Written consent

I have been informed orally of the study and have read the written information.

I agree to participate in the study.

I am aware that my participation is fully voluntary and that I may cancel participation at any time and without further explanation.

Date sign

Printed name

I have explained the study and today received the participants consent to participate in the study.

Date the student sign

Printed name

Interview guide

Introduction:

- Say hi in their language
- Introduce ourselves (name, where we come from, what we are studying)
- Introduce the study (aim, why we would like to talk to them, that we are going to record the interview, that they can cancel at any time and if they don't want to answer all the questions they don't have to, the interview will take about 30 minutes, if there is something that they don't understand they should not hesitate to ask, and we will try to explain)

Activities: All the things the child during the day, for example, cleaning, playing, moving to different places, school time

Participation: The engagement in the activity, if the child feel pleasure/enjoyment in the activity

The aim of the study is to identify activity limitations and participation in activities among children with disabilities in western Uganda

Questions

1. What kind of activities is common for children here in western Uganda?
 - In the home
 - in school
 - spare time
2. What kind of disabilities among children have you experienced?
3. What kind of activity limitations have you experienced among the children?
 - In the home
 - in school
 - Free time
4. What kind of consequences can you see that this disability/disabilities has on children's activity participation?
 - In the home
 - in school
 - spare time
 - Hur utgör hen istället aktiviteten?
5. Is it something you would like to add about the aim?

- Hjälp för intervjupersonen att utveckla sina svar: kan du beskriva.. hur ser det ut.. hur gör barnet när.. vad beror det på..

What kind of consequences can you see that this disability/disabilities has on children's activity performance?

- In the home
- in school
- spare time

Ending:

- Thank you so much for participating
- Give a small gift from Sweden