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A description of the occupational therapists' experiences of
stroke rehabilitation in Uganda.

Beskrivning av arbetsterapeuters erfarenheter av stroke rehabilitering i
Uganda.

Authors: Kristin Karlsson & Petra Källgren
Supervisor: Susanne Guidetti
Coordinator: Julius Kamwesiga

ABSTRACT

The aim of this descriptive qualitative study was to describe the occupational therapists' experiences of stroke rehabilitation in Uganda. Eight occupational therapists that had different backgrounds from working with clients with stroke participated in the study, and they were asked to share their experiences from stroke rehabilitation. The collected data was analysed and transcribed using a qualitative method that aimed to describe the studied phenomenon (that is, experiences of stroke rehabilitation). There was also a cultural perspective implemented in the analyses. Findings showed that the occupational therapists sought their own clients, the main reason due to a non-functioning referral system. They also described how the multidisciplinary teams did not function as well as the common ward rounds. The main role for the occupational therapists in the stroke rehabilitation was to train the client with stroke to be independent or as independent as possible. When assessing and performing the intervention, many of the occupational therapists used a mix of theoretical models. One of the difficulties the occupational therapists described was the clients' too early discharge from the hospital due to the clients' financial situation. The clients were described as often being very poor. As a part in the stroke rehabilitation, the occupational therapists educated and trained the caretakers in how to continue with the rehabilitation in the home after the client had been discharged. One conclusion from this study was that the occupational therapist worked a great deal with educating the caretakers. It would be of great interest, for example, to investigate the outcome of the stroke rehabilitation in the home carried out by the caretakers.

Keywords: Occupational therapy, stroke, Africa.

SAMMANFATTNING

Syftet med denna deskriptiva kvalitativa studie var att beskriva arbetsterapeuters erfarenheter av stroke rehabilitering i Uganda. Åtta arbetsterapeuter med olika erfarenheter av att arbeta med klienter med stroke blev intervjuade för att beskriva sina erfarenheter av stroke rehabilitering. Den insamlade datan blev analyserad och transkriberad enligt en kvalitativ analysmodell som syftar till att beskriva det studerade fenomenet (i detta fall erfarenheter av stroke rehabilitering). Datan analyserades även utifrån ett kulturellt perspektiv. Resultatet visade att arbetsterapeuterna ofta sökte upp sina klienter själva eftersom att remissystemet fungerade dåligt. Terapeuterna beskrev också hur multidisciplinära team saknades likaså gemensamma ronder. Terapeuterna beskrev att deras roll i stroke rehabilitering var att träna klienten med stroke till att bli så självständig som möjligt. Under bedömningen och under interventionen använde sig arbetsterapeuterna av en mix av olika teoretiska modeller. Svårigheter som arbetsterapeuten möttes av var den för tidiga utskrivningen av klienter som berodde på klientens ekonomiska situation. De flesta klienterna beskrevs som väldigt fattiga. En del i interventionen var för terapeuterna att utbilda och träna de anhöriga i hur de skulle fortsätta rehabiliteringen i hemmet efter att klienten blivit utskriven. En av konklusionerna i denna studie var hur ofta och mycket arbetsterapeuten arbetade med de anhöriga till klienten under rehabiliteringen. Det skulle därför vara intressant att till exempel studera utgången av den rehabilitering som utförs i hemmet av de anhöriga.

Sökord: Occupational therapy, stroke, Africa.

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INTRODUCTION

Uganda, on the north shores of lake Victoria in east Africa, has a large population where the number of children compared to adults is low as described in the figure below by the World Health Organization and where the life expectancy at birth for male and female, respectively, is 49/51 (World Health Organization [WHO], 2008).

Total population: 29,899,000
Gross national income per capita (PPP International) \$880
Population living below the poverty line (% with <\$1 per day) 1999, 84.9*
Life expectancy at birth m/f: 49/51
Probability of dying under five years of age (per 1,000 live births): 134
Probability of dying between 15-60 years m/f (per 1,000 population): 518/474

Figure 1. Country fact. (WHO, *2006a, 2008.)

The national health system in Uganda is structured in different levels: national referral hospitals, regional referral hospitals, district referral hospitals clinics and community services (Ministry of Health [MoH], 2005). In Uganda the healthcare in several hospitals is divided into a general wing and a private wing. In the general wing the healthcare and the drugs are free of charge with the exception of X-rays and ultrasound. In the private wing, the patients finance everything themselves (personal communication, 7 December, 2008).

In the National Health Policy from the MoH (2005), the Ugandan healthcare was founded. The Ugandan healthcare system was described to include all institutions, structures and actors whose actions have the primary purpose of achieving and sustaining good health. The actors are the private not-for-profit organisations, the private health practitioners, the traditional and complementary medicine practitioners and the communities (MoH, 2005). In the health policy it was understood that the healthcare in Uganda focused to a great extent on newborns, HIV/AIDS, tuberculosis, malaria and leprosy. WHO statistics shows how cerebrovascular diseases was in the top 10 causes of death in Uganda (WHO, 2006b), even though the treatment of these conditions in Uganda seems

to be neglected. For example, Uganda receives a lot of funding for the healthcare system from outside actors, meaning private organisations or aid from other countries. The funding is often targeted for a specific condition or prevention, where HIV/AIDS, malaria and tuberculosis get the most support in Uganda. According to rehabilitation professionals in Uganda the incidence of stroke is increasing among the population in Uganda (personal communication, 4 December 2008). The meaning of stroke is illnesses in the brain vessels. The most common form of stroke is cerebral haemorrhage. Stroke is caused by a clot of blood that stops transport of blood to an area in the brain or by a burst in a blood vessel so that a lack of oxygen occurs in the effected part of the brain, which can lead to different impairments. For example, paralyses in different levels, loss of mobility in the limbs, which is sometimes complete, and also perceptual/visual disorders, difficulties in speech or reduced conceptual awareness. Stroke as a condition often leads to multiple disabilities, which often require a lot of rehabilitation for the patient to be independent (or as independent as possible) in one's activities (Socialstyrelsen, 2005). De Wit et al. (2006) described in a study that stroke rehabilitation including treatment of the impairments that the patients had improved the outcome. It was described that the rehabilitation involved multidisciplinary teams, in which the occupational therapy was a key component.

Occupational therapy in Uganda is a very young profession. Occupational therapy started as late as 1994 by British occupational therapists headed by Jenny Smyth, an occupational therapist from the United Kingdom. The diploma programme in occupational therapy is under the Ministry of Education and Sports and collaboration with Makerere University, Kampala. The diploma programme has similar courses as the Swedish Occupational Therapy education because of the western perspective that has been implied on the diploma programme. In the curriculum both in Sweden and in Uganda, there are courses aimed at teaching the students about technical devices. The differences between these courses are that in Uganda the courses focus much more on teaching the students how to make the devices using locally available materials. For example they could use

paper, wood and bark cloth to make those simpler devices. Those materials are also used in the fieldwork when making devices. The Occupational Therapy programme has up to now provided approximately 80 therapists who have graduated with a diploma degree.

To understand the study, some key terms are presented. Activities of daily living (ADL) according to Kielhofner (2002) are typical life tasks required for self-care and self-maintenance, such as eating, grooming, and cleaning the house. Kielhofner (2002) presents the term patient centred as the therapist needs to have a focus and understanding of the patients' own values, interests, roles, habits and the patients' beliefs, perspectives, experiences and contexts in order to provide a therapy process. Therapeutic strategy or therapeutic interventions are according to Kielhofner (2002) a therapist's action that influences a patient's doing, feeling and/or thinking to facilitate desired change. Kielhofner (2008) describes interdependence meaning that all persons are dependent on one another; the concept is a part of a more complex one. For instance, interdependence includes a notion of relationship between people that is fluid and is based on changing context. A patient with stroke can further be named in the text as the patient and the occupational therapist can be named as the therapist. In Uganda, caregivers are commonly named as caretakers.

In the Swedish stroke rehabilitation units, the occupational therapists along with the other professionals in the multidisciplinary team are working after the National Guidelines for Stroke Care (Socialstyrelsen, 2005). In the guidelines the occupational therapy rehabilitation includes assessing ADL-ability, cognitive and perceptual ability usually performed in a structured assessment. In the Swedish stroke rehabilitation the therapist rehabilitates from both a biomechanical and holistic perspective training the patients' abilities in activities (Socialstyrelsen, 2005). In Sweden the patient often is trained individually where hospital rehabilitation is combined with home-based rehabilitation (Socialstyrelsen, 2005). Internationally and in Sweden there is a great deal of research about occupational therapy rehabilitation after stroke. For example, a literature study in

England showed that stroke rehabilitation increases the ability to do one's everyday life activities (Steultjens et al., 2003). The study showed evidence for improvement in primary activities of daily living (ADL) although there was limited evidence for the training of skills intervention and the writers referred further that more studies must be made to enable evidence-based occupational therapy for patients with stroke. Even the Legg et al. (2007) study showed that focused occupational therapy improves one's performance in activities in daily living and implied that focused stroke rehabilitation should be available to everyone who has stroke. In Sweden several studies have been made about rehabilitation at home after stroke (Ekstam, Uppgrad, Von Koch & Tham, 2007; Von Koch, Widén Holmqvist, Wohlin Wottich, de Pedro-Cuesta & Tham, 2000) and rehabilitation at home versus hospital (Von Koch, Widén Holmqvist & Wohlin Wottich, 1998). Other studies that have been made are for example a study made by Guidetti and Tham (2002) describing therapeutic strategies used by occupational therapists in self-care training. Even there, the writers say that there was a lack of studies focusing on therapeutic strategies used during self-care training. Nevertheless, studies about stroke made in Africa and Uganda were hard to find. A study made comparing stroke rehabilitation in general between Finland, Australia and South Africa (Green et al., 2005) showed that the biggest differences were found when comparing South Africa with Finland and Australia. The stroke rehabilitation in South Africa was described by Fritz (2006) to be under development where only 10-20% of the whole population had access to the rehabilitation. The study by Green et al. also implied that the stroke rehabilitation provided in South Africa was still poor compared to Finland and Australia. National stroke guidelines do exist in South Africa and were published in The South African Medical Journal. Fritz described that the guidelines included protocols specifically for rural and outlying areas and were based on international guidelines from Europe, the US, Canada, Australia and the United Kingdom. Furthermore, Fritz described that there had been a research programme in an outlying rural area in South Africa that views all the aspects of stroke prevention and stroke treatment in a non-urban area. Just recently a stroke unit started at

Mulago Hospital in Kampala; however, very little is studied about occupational therapy in Uganda.

In Uganda there are many different ethnic tribes, approximately up to 50 tribes. And in every tribe there are different traditions and usage that the people even today accept, because they see themselves belonging to their tribe (Briggs, 2007). Therefore also the way people see disabilities can differ from each ethnic tribe. Heartly (2002) describes disabilities in cultural, social and traditional perspectives where both men and women with disabilities have difficulties in the African society. Women especially confront unique disadvantages, such as performing traditional gender roles or the ability to participate in community life. In Uganda there is a widespread tradition for the relatives of the person with a disability to take the role as caretakers, whereas the person with a disability thereby becomes interdependent.

Studying the literature in occupational therapy, stroke rehabilitation was a key component for the patient to come back to an independent life after stroke in activities of daily living. Even though there was a great deal of research found about stroke rehabilitation, none was found in Uganda, and the few studies found in Africa implied that the stroke rehabilitation differed a lot, for example, from Europe. Stroke rehabilitation in Uganda also seemed to be neglected but implied to be under construction with a new stroke unit at Mulago Hospital in Kampala. The cultural setting in Africa differs from the cultural setting where previous studies were made. With this as a background, it would be both interesting and relevant to study the occupational therapists' experiences from stroke rehabilitation in Uganda in a descriptive study.

AIM

To describe the occupational therapists' experience of stroke rehabilitation in Uganda.

METHOD

Participants

There were eight occupational therapists that participated in this study. The selection was made with “available group” as a selection method (Patel, 2003). “Available group” means that the therapists who participated were selected according to availability. The “available group” was restricted to a city in Uganda and its nearby area, where the participants would be English speaking and have experience of stroke rehabilitation in Uganda. A person who had good experience of occupational therapy and knowledge about appropriate participants suggested and contacted the available therapists in the area according to the criteria above. The occupational therapists participating in the study had different working backgrounds and different experiences of stroke rehabilitation and the number of patients with stroke varied among the therapists. All the occupational therapists had a diploma level in occupational therapy and were educated in Uganda. Overviews of the participants are presented in Table 1. The participants agreed to their participation in the study by the informed letter (Appendix 1), which they read and signed before starting the interview.

Participants	Years in the profession	Working in regional referral hospital	Working in national referral hospital	Working in general hospital	Working in Community based rehabilitation centre	Number of patients with stroke after occupational therapy education
1	3		X			8
2	11		X			40-50
3	2	X				2
4	7			X		Many*
5	10				X	4
6	12	X				15
7	6	X				40
8	4	X				60-80

Table 1. View of the participants' general background as occupational therapists. *The participant couldn't express the total number of treated patients with stroke and answered “many” on the question.

Data collection

The data as suggested above was collected through eight semi-structured qualitative interviews (Kvale, 2007). The interviews were carried out mainly following an interview guide (Appendix 2) with open questions and then follow-up questions were used to deepen the understanding of the occupational therapists' experiences. The interviews took between 26 to 38 minutes each. Both the students were present when the interviews took place. One author interviewed and the other author only asked questions when the first one considered herself to be finished with the interview. The interviews were recorded with a digital voice recorder. Each student, making a four interviews each, did every second other interview. The interviews took place in the participants' workplace with only one exception. The interviews were transcribed verbatim and included expressions like sighs and pauses, in direct connection with the interview.

Data analyses

A qualitative analysis according to Lantz (2007) was applied in data processing. The analysis model was made in seven steps where the data was analysed and interpreted. Steps one and two were made separately for each participant in the analysis.

In the first stage of the analysis, both of the students read through the interviews to get an understanding and comprehensive picture of the data. Further, one the students tried to get an overview on the participant's experience of stroke rehabilitation.

In step two of the analysis, the collected interviews were divided between the students and they searched after aspects in the interviews that responded to the purpose of the study, which were then coded. The students valued the names carefully so that the codes would keep their substance and not lose their meanings.

In step three the codes of the same or similar meaning were put into a table where each category of codes started to form groups that further on created a comprehensive view in the analysis.

Furthermore, in the fourth step the students made stories describing each group. After processing the stories furthermore in step five, the main outcome, the core of each story was summarised for each group and became the introduction to each story starting to form themes of the findings. In the sixth stage, the final heading themes of the stories were made. In the final step seven, the students made a definitive conclusion of the summaries for all themes and highlighted the greatest common experience of the occupational therapists in stroke rehabilitation. Finally, findings were revised according to discussions with experienced occupational therapist researchers with cultural competence (i.e., long experience of working in Africa) and according to field observations the students had made.

Ethical aspects

The participant received an informed letter, a so-called informed consent (Appendix 1) before the interview began where the written approval of respective participants allowed voluntary participation in the interview. The informed consent contained information that participating in the study was voluntary and participants could withdraw without explanation about the participation. The data provided from the interviews have been treated confidentially. The participant was given before the interview information about the purpose of the study, and what the participation and the interview implied (Kvale, 2007). Furthermore, the participant was informed that this study can be used in education both in Sweden and Uganda. The students tried to have a professional approach in each interview and with each participant on the basis of a so-called patient-centred perspective that is to take into account the whole person in the context he/she is in and his/her cultural background (Townsend, 2002). This study will not reveal which cities or neighbouring areas the study has been conducted in since there are only approximately 80 occupational therapists in the whole country.

FINDINGS

The occupational therapists participating were working at different workplaces at different levels in the health system. The experience from working with patients with stroke also differed between the therapists where some had more experience than others. But all the therapists described similar working conditions where they implied that they often did not have the opportunity to work with the patient as much and long as they would have wanted to. The rehabilitation was effected in a great extent by problems connected to the organization, such as structure and resources. Some of the therapists described the stroke rehabilitation to be directly unstructured both in the way the occupational therapists received the patients and the non-existing multidisciplinary teams. A small number of the therapists mentioned problems like people in the community not knowing about their services and the non-existing teamwork. Several of the therapists expressed the lack of resources because they were too busy. They were undermanned and the workloads were too heavy for one therapist at the hospital. Some described a lack of facilities. All the therapists described the patients as often being very poor. Thus, the patients wanted to leave the hospital as soon as possible after the medical treatment was finished. The patients who were described as poor often could not afford to come back to continue the rehabilitation as an outpatient or be able to pay for assistive devices.

The findings are presented by seven themes (see Figure 2) where the findings under the first theme are applied under the following five steps (themes 2-6), which describe the rehabilitation process as the occupational therapists had experienced the stroke rehabilitation. The last theme describes how the therapists experienced the caretakers under the whole rehabilitation intervention. The roles of caretakers are also integrated under some of the previous steps as well.

1. The therapist's role when mixing models in rehabilitation for independence
2. Seeking their patients in different ways
3. Interviewing and assessing the patient at the first meeting
4. Setting goals and facing the patient's cultural context
 - Working towards a goal in the rehabilitation
 - To present meaningful activities in a patient-approached way
5. Trying to implement ADL-training despite too early discharge
 - Focusing on ADL-training in the intervention
 - Interrupted training due to lack of money
 - Being both a occupational therapist and a physiotherapist
 - Creating simple solutions to ADL-problems
6. Different follow-up policies between occupational therapists
7. Cooperation with the caretakers an important part in the rehabilitation process

Figure 2. Occupational therapists' experiences of rehabilitating a patient with stroke.

1. The therapist's role when mixing models in the rehabilitating for independence

The occupational therapists described their overall role in the stroke rehabilitation was to train the patients with stroke to be as independent as possible in activities of daily living. In their work the therapists often used a mix of different models when rehabilitating the patients.

The occupational therapists described their role in the rehabilitation; they would like to train the patients in their occupational issues in activities of daily living, in areas like self-care, work and leisure in order for the patient to be as independent as possible.

"Whatever we do we focus at helping them to being independent, as independent as possible in performance of their activities of daily living."

The therapists continued describing that their role in the stroke rehabilitation was to train the patients in activities that the patients wanted to improve in. The

activities they described were mostly considering self-care and activities of daily living where the therapists' role was to involve the patients and help them to achieve their goals of independence.

Some were using only one model like the Canadian model, the problem-solving model or the Model Of Human Occupation. However, most of the therapists were using a mix of models.

“Sometimes you have to mix up quite a number of models, and you won't stick to one.”

“I didn't use models to follow those strict.”

For example, one therapist described making an intervention without knowing which model the therapist was borrowing from. A few also described that they went back to models if needed when challenging problems occurred or were reading new information about stroke and putting that new knowledge into practice.

A few also described their role as an occupational therapist in stroke rehabilitation as educating.

“...people don't have a proper information, they lack all that to go and seek our services. That's a big challenge, people don't have the information.”

The therapists educated the patient and people in the community about stroke. A few therapists described how people in the community didn't have the knowledge that occupational therapy existed.

2. Seeking their patients in different ways

The occupational therapists described the referral to occupational therapists to be thin because they rarely had patients referred to them and most occupational therapists sought patients by themselves. The majority of the occupational

therapists received only a few referrals of patients with stroke from other professions or other professionals within the same workplace.

The therapists said that it was almost exclusively the doctors who contributed with these referrals. Other professionals who referred to the occupational therapist were the physiotherapist, social worker and speech therapist but even to a lesser extent. The occupational therapist could receive stroke patients through previously treated patients but also to a lesser extent. Some therapists made referrals to the larger hospitals in cases where they could not continue to rehabilitate the patient themselves. The therapists thought that there was a problem with the current referral system. An occupational therapist said that which a common experience among the occupational therapists was.

"Rarely do they refer us patients here."

Another occupational therapist commented that:

"I think there is a problem with referrals here."

Some of the occupational therapists experienced that it was difficult to take part in the ward rounds and receive patients that way. The difficulties mentioned with the ward rounds was that, for example, the doctor who conducted the ward rounds conducted them at different times and didn't have the time to discuss the patients with other professions. And since the ward rounds were at different times, the different professions could not know at which time the ward round would be.

"Somehow they just don't refer, because different disciplines are in a different time, so the doctor does his round."

"Because they don't have time to, to discuss with different disciplines in how we can collectively help the patient."

The majority of the occupational therapists described how they had to take the initiative by themselves, to go on their own ward rounds to see if there were patients who were in need of their services.

“We do not do ward rounds together there's no such a system here. You have to do your own rounds. If we see any patient that will benefit from our service, then we start working on that patient.”

3. Interviewing and assessing the patient at the first meeting

When first meeting the patient, the therapist started the stroke rehabilitation by collecting information about the patient by carrying out an initial interview and assessing the patient's abilities.

Some of the therapists described that they were reading through the patient's background information from medical forms about how the dysfunction started and what had been done before the patient came. Then all the therapists started by carrying out an initial interview in their first meeting or in one of the first meetings with the patient. In the initial interview the therapists asked questions in order to get a small biography of the patient. Some of the therapists also mentioned establishing a relationship with the patient during the first meeting. The initial interview or initial assessment, like some of the therapists named it, was described as asking questions and filling in a form with information like name, age, date, hospital number, the therapist, the caretaker, where the patient lived and the patient's education. After that followed questions about the condition, how the condition started, what happened and how long the patient had the condition. Then the therapist asked the patient to describe what the patient found difficult doing and assessed the patient using different assessments to find out the weak and the strong areas of the patient.

“The first appointment when I went home I did ADL assessment, I did an environmental assessment, I did an initial interview.”

The therapists used different informal assessments according to the condition of the patients. The assessments they mentioned were head injury assessment, ADL assessment, environmental assessment, mobility assessment, assessing muscle strength, hand injury assessment, visual assessment, sensation test, and one therapist mentioned assessing the patient's cognitive ability.

“...the assessment having the range, that 0 means nothing, 5 does is that strength maximum, normal strength that's the ..the testing I would do on voluntary muscle testing. Just grading and then I see what areas, what strength someone has...”

“The sensation test, use just textures, things with different textures. And there most of the things which I could be using were pins, cotton all those things, simple, simple things and then I would get the result of lost sensation, what sensation is on...there I would see, how I would do improve of that full use of sand, breakfast cereals yes and then water.”

The therapists described that they observed how the patient was managing with washing and with feeding. Some also assessed the home environment and the patient's workplace. Some of the therapists who didn't have the opportunity to see the home environment for themselves interviewed the patient and the caretakers about the home instead.

“Questions of asking person his home, the environment, if he is living in a relatives house... the type of home, the terrain, the compound.”

4. Setting goals and facing the patient's cultural context

After assessing the patient and finding out the patient's difficulties and abilities, the therapists used goal setting as a strategy for the upcoming rehabilitation. In order to train meaningful activities with the patients, the therapists discussed the goals with the patients using a patient-approached strategy. This was a way to meet up with the patients' own goals, interests and needs, as well as to involve the patients in their own rehabilitation.

Working towards a goal in the rehabilitation

All of the occupational therapists worked with goal setting as a therapeutic strategy in the rehabilitation to accomplish a good outcome. Some of the therapists described their own goals within the rehabilitation with their patients, such as completing the entire rehabilitation programme with the patients or to try to gain maximum independence in activities of daily living. In order to achieve the therapeutic goals with the patients, the next step in the rehabilitation process was to create a relationship with the patients and see to the patients' interests. A small number of the occupational therapists could face the reactions from caretakers on the patient's condition from a traditional approach. Some therapists experienced how caretakers thought the condition was due to witchcraft or that the patient had been charmed. Another problem that therapists could encounter was that the patient's independence could be dismantled because the relatives were doing everything for the patient during the illness and rehabilitation period, making the patient interdependent instead of independent.

“There are caretakers attended to assisted most of them. 99% its being done by the the caretakers. We look at the patient as just someone who just there, helpless. It is us to fill in that gap.”

An occupational therapist described that the independent approach was sometimes hard to integrate with the beliefs of the caretakers in the community. Therapists in these cases had to start by implementing the occupational therapeutic ideas by trying to explain to the caretakers that the patient's disease had nothing to do with witchcraft and how it was important and possible for the patient to be independent or as independent as possible.

Further on in the goal setting, some of the occupational therapists described how they guided the patients to set their goals on a reasonable level along with their abilities. A couple of the occupational therapists explained how they divided the goals into sequences "A, B, C, D" for the patient to finally be able to achieve the final goal. For example one

therapist described that the patient sometimes had too high goals in comparison to the patient's own ability. The therapist then explained to the patient to work towards the goal by small steps, which the therapist called A, B, C, D. The steps were different for every patient and made after each patient's own ability. For example, when practicing feeding, start by letting the patient practice gripping by holding a spoon and after that continuing by maybe positioning the arm.

"This is what you want to do, but do you think that if you first do A, B, C, D, E to help you to be able to do this later."

To present meaningful activities in a patient-approached way

In order to have success in the emerging rehabilitation, the occupational therapists described how they were using a patient-centred approach. The therapists considered the patient's own goals and wishes. To offer meaningful activities to patients is a part of the patient-centred approach, where the patients' opinion was considered to a high extent. Occupational therapists expressed that it was of great importance for the patients to become active participants in setting their own goals for the rehabilitation where the patients can express their own wishes about which areas they want to improve in. An occupational therapist said:

"I wouldn't really want to just impose some kind of treatment on somebody, something that they don't believe in, something that they're not comfortable with. So we usually sit down with the patient. I discuss details with the patient, see which options we have, and maybe ask for their contribution of what they think about what we can do. So somehow it's integrated, I integrate his ideas into mine."

A small number of the therapists described how they communicated with the patient's family about the patient's interests and abilities to maintain a patient-

approached focus if the stroke patients were not able to express themselves due to speech difficulties. Some of the therapists sometimes suggested training the patients' abilities using leisure activities, which the patient found appealing. One therapist described considering the patients' interests, gender, roles and the patients' occupation when suggesting an activity. Activities prescribed could be tabletop games, making doormats or knitting.

5. Trying to implement ADL-training despite too early hospital discharge

After the patient's ability was identified by the assessment/assessments and the goals were made, the occupational therapists described the next stage in the rehabilitation was to train the patients in activities that the patient wished to do again according to the goals. The occupational therapists almost exclusively trained the patients in activities of daily living during the rehabilitation, using different therapeutic techniques and strategies.

Focusing on ADL-training in the intervention

During rehabilitation with the patient, the therapists usually initiated the intervention with training the patient in self-care activities while the patient was still in the hospital. Therapists usually started by training the patient in personal ADL, which initially could mean holding a tooth brush, brushing one's teeth, combing one's hair or starting to take food with the defective hand from the plate and putting the hand with food to the mouth. The activities were intended to improve and/or maintain the patients' abilities but, above all, raise the prospect of being more independent for the patient according to the rehabilitation goals. One occupational therapist exemplified it as:

"Self-care, grooming, dressing, train them in occupation, writing, brushing her teeth and how to wash her face, to demonstrate how they carry out activities."

The therapists described other activities that they were training with the patient such as was dressing or like fastening buttons on the shirt. One therapist

described how the patient was taught to begin with dressing the weaker side of the body first as a technique to enhance dressing. Therapists also gave out techniques, demonstrated and guided the patient in the transfer technique, where the patient learned to go from one side of the bed to the other using the patient's own power. Therapists described how they divided the activities into sequences to see what the patient could handle.

"I grade it, I go and break down the sequence and see, how much he is achieving in this level ... then go for another level."

They trained the patients in one part of the sequence at a time until the therapist saw progress in the patient's ability and then went on to the next part of the sequence of the activity that the patient was training in.

However, many of the occupational therapists described how the patients were often poor, and they were discharged from the hospital too early from an occupational therapy perspective due to the patients' financial situation.

Interrupted OT training due to lack of money

The therapists met the patient approximately two times per week while the patient was still admitted at the hospital, but there could be occasions where the therapist didn't see the patient at all because of an early discharge. Many of the patients were described as being poor, and the patients were discharged from the hospital too early from an occupational therapy perspective in the rehabilitation process. This affected the rehabilitation process because the therapy was ended too early.

"Now the moment you are starting a programme on the patient, they are being discharged."

The reason for the early discharge often was described because it had to do with the patients' financial situation. Many of the patients didn't have the financial

resources to stay for a longer period at the hospital and get all the required treatment since the patients had to pay for the medical treatment as well as the occupational therapy. Most often the patients themselves chose to leave the hospital after a short period when they didn't have enough money for the rehabilitation.

"Cause usually here its the financial piece of it that comes up. The financial implication is usually big. So they will not wait to recover all the areas."

Even after discharge many of the therapists described how patients who barely could afford a meal a day could not be able to afford the transport to the hospital. Many of the patients could not even afford to buy the technical devices that the therapist provided.

Being both an occupational therapist and a physiotherapist

Some of the occupational therapists described that they also carried out some functional training with the patient. The functional training meant passive exercises and to inform the patient of reactionary techniques of the defective part of their body. One therapist described how the therapist sometimes took a physiotherapist's role. For example, how the therapist carried out mobility training on parallel bars or teaching the patients how they could position themselves to avoid oedema. Half of the hospitals had physiotherapy services, in the workplaces where there was a physiotherapist, some occupational therapists described that they tried to work with the same patient and communicate on a patient's rehabilitation.

Creating simple solutions to ADL-problems

The therapists described that the patients were also training and managing their activities by the use of aids, i.e., getting out of bed to a wheelchair and back again with the help of a sliding board. Another tool used during training in ADL was a rope ladder that was tied at the bottom of the bed where the patient grabbed and pulled himself up on when the patient wanted to be seated in bed.

Cooking was another important activity for some patients, where a few occupational therapists described that they had the opportunity to train with the patient in the patient's own home. Some occupational therapists also focused on activities like writing with a pen on paper where the pen was adapted to have a thicker grip for better grip ability and the same sort of adjustment could be carried out to improve the grip ability, for example, on a toothbrush.

Many of the aids were described being made from locally available materials both in the hospital and from the patients' private homes. The aids that were made of local available materials in some hospitals were the rope ladder sliding board and many hospitals also produced splints to patients, for example, to reduce the spasms in their hand. Some of the therapists described that patients who could not afford to buy these technical devices had the splints drawn on a paper by the therapist to bring to their local artist who produced it to a lower cost than what the hospital could offer. In the manufacture of the splints, the therapist could sometimes work with orthopaedic technologists to make an adjustable splint to fit the patient.

A couple of the occupational therapists described how they were using local available materials when making adaptations in the patients' home and with the help of the patients' caretakers. One therapist gave an example of a simpler adaptation where the patient wanted to cook or participate in cooking, but the cooking place was too low.

“You can sit and we put the stove on a higher level where you can reach.”

The therapist described asking the patient to sit down at a cooking site while the therapist raised it.

6. Different follow-up policies between occupational therapists

After and during the interventions, the follow-up policies differed among the therapists. Some of the therapists had a policy of making regular follow-ups while others made follow-ups occasionally or not at all.

Half of the therapists have a policy of making follow-ups. The therapists who made follow-ups on a regular basis could do it by visiting the patient in their home or do the follow-up when the patient came in to the hospital, and one therapist telephoned the patient to see how the patient was managing.

"After three months I went back, to review, and after three months she came here..., and now she was walking, before she was not able to walk ... After nine months I made another home visit to her, now she give me back my standing .. my walker cause she was able to walk. "

Some therapists described making follow-ups and reviewing the patient as difficult both during and after the rehabilitation and some made follow-ups occasionally.

"No facilities for follow-ups. We don't follow up patients."

The reasons the therapists described for not making follow-ups was because of the insufficient facilities at the hospital and the distance to travel to the patient. One therapist mentioned that the patient did not want to do a follow-up because the patient didn't believe that he/she would benefit from the occupational therapy.

7. Cooperation with the caretakers is an important part in the rehabilitation process

To work around the financial issues where the patient wanted a early discharge and maybe not coming back to the hospital, the occupational therapist focused a lot of the rehabilitation to educate the caretakers.

The caretakers often stayed at the hospitals during the time the patient was admitted on the ward. There are no rooms or beds for the caretakers to stay in, so they slept in the corridors and took care of the patient at the same time (field observation). All the occupational therapists described that they transferred

responsibility to the patient's caretakers for them to continue the rehabilitation when the patient had been discharged home from the hospital.

"I was mostly training the caretakers, cause they are the people who are going to continue with the intervention."

The length of the stroke rehabilitation both as an inpatient and as an outpatient varied between the hospitals. After the patient had been discharged as an inpatient, the therapists described how they lost many of the patients if they didn't return as outpatients. A large part of the continuing rehabilitation process took place outside the hospital after the patient had been discharged. The therapist often gave further rehabilitation responsibility to caretakers usually within the patient's family. The therapists continued describing that the caretakers are the ones who have the closest contact with the patient. Therefore, it is important to educate the caretakers about the patient's problems and to train the patients in how they will be able to handle the problems that will arise when the patient has been discharged from the hospital.

"I was teaching even the people at home. The ones, that ones that are closed to the patient to continue with the therapy."

Most occupational therapists educated and trained the caretakers at the hospital by allowing them to observe how they worked with the patient and then let the caretakers try by themselves with the therapists' supervision.

"Teaching them transfers, or teaching them how to wheel patient around...."

The therapists sometimes educated the caretakers in the transfer technique in and out of bed and also larger transfers, for the caretakers to help and train the patient independently.

CONCLUSION

The challenge the therapists faced first of all was getting in contact with the patients. Most of the therapists described how there was a problem with the referral system. For example, the therapists sought their patients themselves by conducting their own ward rounds. When first meeting the patient, the therapists conducted an initial interview and different informal assessments to find out the patient's strengths and weaknesses. The therapists described their role in the stroke rehabilitation was training the patient in activities so that the patient would become independent or as independent as possible. After assessment, the therapist and the patient discussed the goals for the rehabilitation together. The patient had the opportunity to express needs and wishes, and the therapists tried to keep the goals at a reasonable level.

The therapists described how their main task in the rehabilitation was to train their patients in activities of daily living. The problem the therapists now were facing was being able to complete the whole rehabilitation programme. Since many of the patients were poor, they could not stay for very long in the hospital. The therapists could, for example, one day see the patient and the next day the patient could be discharged without the therapist's knowledge. To continue the programme with the patient, as an outpatient, was often difficult if the therapists didn't have the opportunity to go out in the community themselves since the patients had financial difficulties in returning to the hospital.

When rehabilitating a patient, the therapists often trained the activities that were important to the patient in that activity or breaking the activity down to pieces to eventually achieve the final goal. Some of the therapists described how they performed some of the physiotherapists' work. The therapist used the same training techniques as a physiotherapist, skills which they had picked up from previous experiences from observing the physiotherapist in action. For example, they trained walking with parallel bars or trained mobility when the physiotherapist was lacking at the workplace.

A way of dealing with the patient's financial issues was teaching the caretakers how to carry on with the rehabilitation programme, transfer the patient and to encourage the patient to participate in activities. Some of the therapists described how they sometimes had to work also on the caretaker's attitude towards the condition of the patient. The follow-up policies were another issue, which differed between hospitals; some therapists made regular follow-ups and some made them occasionally or not at all.

DISCUSSION

The purpose of this descriptive study was to describe the occupational therapists' experiences of stroke rehabilitation in Uganda. The experiences that have been presented show in general how the stroke rehabilitation presents in Uganda from an occupational therapist's perspective.

In the findings presented, many of the therapists used a mix of models. The models the therapists used were similar to the Swedish stroke rehabilitation, models applied from both biomechanical and holistic models. The models the therapists mentioned were models created in a different cultural context than the context they were working in. There is more research and written studies about stroke rehabilitation in the industrial countries. These models, interventions and policies created may not be applicable to stroke rehabilitation in Uganda.

Applying that knowledge into practice might not work due to the culture and also the economical perspective. Kielhofner (2002) uses this definition of culture: "beliefs and perception, values and norms, customs and behaviour that are shared by a group or society and are passed from one generation to the next through both formal and informal education"(p. 111). The cultural perspective could encourage the therapists to mix models and in this way create their own new models reflecting the cultural setting.

When assessing the patient, the therapists interviewed and observed the patient in an unstructured assessment. According to Kielhofner (2002), the unstructured assessments make a good complement to the structured assessments. The unstructured assessment had the advantage of collecting information about natural circumstances. Kielhofner continues by conducting some situations where therapists will make good use of the unstructured assessment. For example, when there is no appropriate structured assessment available and when structured assessments take more time than available. There is no structured assessment evaluated and the uses of structured assessments are low. However Kielhofner claims that many of the assessments connected to the

Model Of Human Occupation do not reflect cultural basis. Since all the therapists experienced being undermanned, the unstructured assessment seems an alternative under these circumstances in Uganda. However, from a patient safety and quality assurance perspective, it could be considered being a negative aspect that occupational therapists do not use structured assessments. Also any retrospective in follow-up studies based on data from the medical records is useless if the assessment is not performed in a structural way.

Another interesting finding was how the patients' financial situation affected the rehabilitation. The community ranks people with disabilities in Uganda lowly, and also by the Government and other organisations such as NGOs (Non-Governmental Organisation), which are supposed to work with the poorest (Hartley, 2002). However, if a person with disabilities now called a patient with stroke had a good financial situation, the rehabilitation could have been continued until the patient regained all abilities or learned how to compensate for the lost abilities. These patients often had the possibility to buy the medication in the private wing at the hospital. For patients without these financial abilities the medications were for free at the general wing, but most of the time the medications were out of stock. Another finding considering the financial situation of the patient was the costs during their stay at the hospitals. The majority of the patients are very poor and don't have the money to finance their stay at the hospital for treatment and training. Thus, the rehabilitation often came to an early end. However, there are studies that show that early supported discharge followed by home rehabilitation had a good outcome for the patient's recovery and rehabilitation outcomes (Widén Holmqvist et al, 1998). The Wade (1992) study showed that it was economical for both the hospital and the patient with rehabilitating the patients in their home. However, without resources as a multidisciplinary team, well-organised stroke rehabilitation, and home-based rehabilitation, it becomes a problem in Uganda where most of the above was not found.

The most interesting findings were how the role of the caretakers was implemented into the rehabilitation process by the therapists. One cause could be the early discharge of the patient. The caretakers therefore needed education to proceed with the rehabilitation in the home where the therapists in most cases couldn't. One other important aspect during rehabilitation was that the caretakers did not understand the therapists' aim to rehabilitate the patient back to independence. In a cultural perspective, it's the closest family to the patient that had the major responsibility for the patient when the patient became sick and traditionally to do the entire patient's activities of daily living, making the patient interdependent. The rehabilitation should aim at maximizing the patient's independence (Wade, 1992). Having the caretakers intervening instead of encouraging the patient to do the patients' own activities could increase the risk of the patient becoming interdependent. However, this could leave the patient in a position of being left out from the family life if not being taken care of by the family members. Education of the family members probably is a crucial factor for the patient's participation in rehabilitation.

Method discussion

The findings of the study described the stroke rehabilitation in Uganda from these eight occupational therapists' experience. The study gives a good general description of the stroke rehabilitation since the eight therapists are from 80 occupational therapists in the whole country, even though it cannot give an exact picture of occupational therapeutic rehabilitation. As presented in Figure 2, the therapists had not met so many patients with stroke during their career. This meant that one could question their answers to be more based on theoretical knowledge than clinical experience. The students also expected the therapists to have more experience of stroke cases since they had completed a whole rehabilitation programme to a greater extent. The students therefore focused their questions in the interview on finding out about the whole rehabilitation process, for example, instead of giving the therapist the chance to speak even more extensively about how they experienced stroke rehabilitation in Uganda. For this reason, there was also a possibility that the students didn't have a large

enough variety in the answers where the cases described by the therapists only had positive outcomes. Another limitation the students had was knowledge about the cultural context the therapists worked in, where taking field notes as a part of the data collection could have been useful or using another type of model than Lantz (2007) for data analyses. Data analysing according to Lantz was based on being very close to one's original material, for example, where you don't interpret the material focusing on culture. The students instead made a deeper cultural analysis with guidance from experienced occupational therapist researchers with cultural competence. There was hard to find published literature as well as published statistics from Africa especially in Uganda, although there are a few studies found from South Africa. The students had to collect information through personal communication. There were also difficulties to access the Internet where the students had expected to find references even though they were prepared with material in advance.

Future studies

From the findings of the study some interesting unanswered questions have been highlighted. Considering the circumstances in Uganda such as economy, the patients financial situation, and the fact that there was still too few occupational therapists in Uganda, it would be very interesting to study the outcomes of rehabilitation in the home after discharge performed by the caretakers who were taught by the therapist. Also, depending on the outcome to create and evaluate an occupational therapy intervention, which is focused on how to educate the caretakers to achieve a good or better outcome for the home rehabilitation performed by the caretakers.

It could also be of interest to study how applicable models and assessments created in industrial countries work in Uganda and how the therapeutic aim of independence is affecting the patient and the family.

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A study describing occupational therapists experience of clinical stroke rehabilitation.

We are two Occupational therapists students from Karolinska institute, Stockholm, Sweden, who are going to do a student project according to Karolinska institute occupational therapy program.

During the autumn of 2008, a study in Uganda is made. The study aims to describe the occupational therapeutic interventions and the occupational therapists experience in the rehabilitation of stroke clients.

There is a lack of knowledge today about occupational therapists experiences of stroke rehabilitation in Uganda. This knowledge is of great importance to develop and improve rehabilitation efforts for this population.

You who are asked and have an interest to participate in this study will be interviewed by two occupational therapist students from the Karolinska Institute in Stockholm, Sweden. The interview will be about 60 minutes long, and will take place at your work. The interview is about your clinical experience in the rehabilitation of stroke clients. The interviews are recorded on tape. When the interviews are written down and processed the interview tape will be erased. The printed interviews and result will be anonymous, that is your name will not appear on the documents and we will avoid to disclose personal information that might reveal your identity. All documents are stored in a room.

Your participation is completely voluntary and you can at any time, without explanation discontinue your participation in the study.

You are welcome to contact us if you would like further information or if problems arise:

Supervisor:

Julius Kamwesiga

Phone: 071 28 08 747

Susanne Guidetti

Mail: susanne.guidetti@ki.se

Occupational therapist students:

Kristin Karlsson and Petra Källgren.

I have taken part of the information and want to participate in the research.

Signature

Interview guide

Appendix 2

Where do you work now?

How long have you been working as an Occupational therapist?

When did you finish your occupational therapy education?

Are you specialized in any area in occupational therapy?

Can you describe a day at your work?

- Can you describe your work with clients who had stroke?
- In what stage is the first time you meet the client?
- Can you describe what you do when you meet the client at the first time?
- Can you describe what goals there is with the client's rehabilitation?
- How do you continue your work?
- When do you finish your work with the client?

- Can you estimate how many stroke clients you have worked with?
- How many stroke clients do you work with now?
- What role do you have as an OT in stroke rehabilitation?

- Do you collaborate with other professions.
- Do you use any models in your work?