1 INTRODUCTION

1.1 People with disabilities in the world

Hundreds of millions of people in the world today have permanent disabilities resulting from hearing, seeing, movement or mental impairments[1]. The precise number is not known, but several estimations suggest that seven to ten percent of the world's population suffer from some kind of disability[1, 2, 3]. Because of an increase in the proportion of elderly, as well as more people with disabilities live longer the rate of disability prevalence is expected to increase[4]. As explained by Einar Helander[3]: "close to ten million severely or moderately disabled people are added each year to the global figure – or about 25 000 per day". About seventy percent of the world's population of people with disabilities live in developing countries[3]. Poverty, malnutrition, poor sanitation, infectious diseases, wars and accidents are some of the reasons to this[5]. Also, most of the world's population live in developing countries[6].

Equipment and basic services are often lacking in developing countries, making it difficult to meet the needs of people with disabilities. Another problem is lack of possibilities for these people to participate in social life and work activities[1]. The social attitudes towards people with disabilities are a dominating disabling factor[7]. According to David Pfeiffer: "In some countries there is a need for the courts to recognize that disability rights are civil rights. In other countries there is a need to recognize that people with disabilities are humans"[8].

1.2 Why "Community-Based Rehabilitation"?

The inability to meet the needs of people with disabilities around the world is well recognized[1, 5]. Only one to two percent of the disabled population is estimated to get rehabilitative care[2, 3]. To improve this situation the World Health Organization (WHO) in the seventies suggested the application of "Community-Based Rehabilitation" (CBR)[3,9]. To understand why CBR was developed as a strategy for rehabilitation in developing countries it is essential to first gain some knowledge about how the rehabilitation activities were structured earlier.

1.2.1 *The term "rehabilitation"*

The term "rehabilitation" carries many meanings and several definitions have been suggested over the past forty years[3]. It has often been the case that rehabilitation focuses on the restoration of the physical aspects of the individual, giving little or no attention to the life quality of this person or the opportunities he or she has in life[10].

A variety of "rehabilitation models" has been applied, based on attitudes and believes in the society. The following four examples of such models are structured by Peat [11] :

- *The Charity Model* [of rehabilitation]
  Created and applied in Europe during the 19th and beginning of the 20th Century. In this model people with disabilities get dependent upon pity of rich people.
- *The Institutional Model*
  This model developed when the industrial era begun. Technology had been improved for people with disabilities, antibiotics had been discovered and some epidemics had been cleared. The institutions targeted specific disabilities, offered specialized medical

services, education and vocational training. In the institutions people with disabilities remained isolated and had great difficulties to fit in the mainstream of life.

- *The Medical Model*
  Here the disability is looked upon as a medical issue, lying in the individual and not in the society. The focus is on the impairment that a person suffers from rather than on the person him-/herself. People with disabilities are seen as patients not able to contribute to society. The aim is to "reconstruct" the individual through medication, surgery and other kinds of therapies until the person is as near "normal" as possible.
- *The Social Model*
  This model recognizes that the cause of disability is not the impairment that a disabled person has, but the environment and attitude of people towards people with impairments. Here the aim is to make the environment accessible and change negative attitudes towards people with disabilities. The social model, with influences of the medical model and the importance of efficient training, is a corner stone in CBR.

In 1981 the WHO gave a definition of rehabilitation as being "*all measures aimed at reducing the impact of disabling and handicapping conditions, and at enabling the disabled and handicapped to achieve social integration*"[12].
The United Nations (UN) has in several conventions and declarations stated that people with disabilities have the same rights to "freedom, equality, opportunities and development" as others. One such declaration is the "United Nations Declaration on Human Rights" [13]. The most recent document is the "Standard Rules for the Equalization of Opportunities for Persons with Disabilities" that was adopted by the General Assembly in December 1993 [14]. These declarations and conventions are the foundations of CBR. One of the most frequently used definitions of CBR is:

"(…) *a strategy within community development for the rehabilitation, equalization of opportunities and social integration of all people with disabilities*" [15]

1.2.2 *The term "community"*
One definition to the term "community" is that it consists of people who live together in a social organization. The members of the community share political, social, economical and cultural aspects in varying degree. Communities can vary in size from a little group of isolated homesteads to a city district[16].
For CBR to be a functional strategy it has to be "open" and possible to adapt to different settings, since no two communities are exactly the same. Differences in for example cultures, environments and social programs between different societies also mean that the term CBR gets different meanings[11].

1.2.3 *The term "empowerment"*
Rehabilitation of people with disabilities and CBR in specific should attempt to change community attitudes and behaviours towards disability, as well as *empower* people with disabilities. Empowerment and participation are main aims not only in CBR programs but also in many other developmental programs[7].

Prejudice against people with disabilities has long been a common problem all over the world[17]. They have been regarded as lesser beings to reject or to become objects of charity. Coleridge talks about "social Darwinism"; "(…) the (usually unspoken) assumption that only the fit and the fully functional have right to real life"[18].

To be "empowered" means to have the right to participate in decision-making regarding things that affect ones life, to have control over life[7, 19]. It can be described as a process by which individuals gain the ability to critically understand their environment and gain mastery over their own lives[20]. Empowerment is considered as a 'mind-set'. This means that even if someone is considered being empowered technically he or she is not, unless also considering him-/herself being or feeling so. People must believe that they are entitled to take control over their own lives to be able to do so[21].
CBR is a process of "democratising" rehabilitation – to make it accessible to everyone in need and give people with disabilities influence[11].

1.3 The structure of a Community-Based Rehabilitation program

1.3.1 *The CBR manual*

CBR originated from the observation of rehabilitative activities performed by people with disabilities and their families in several developing countries[3,6]. It is estimated that family and friends provide about 90 percent of the care of people with disabilities who live at home[22]. The observations were systematised and put together in what is now the main tool in CBR: "Training in the Community for People with Disabilities"[23]. This manual consists of 32 different packages (almost 900 pages) for different problems encountered in the rehabilitation process for different types of disabilities. Each of these packages are written in a way easy to understand and illustrated with simple drawings. Rehabilitation training is in most cases repetitive and simple. The thought is that family members can easily learn to do it if explained well. Today exist about 50 translations into local languages of the manual[24]. In the end of each package there is an evaluation sheet, meant to summarize problems that have been overcome and problems that still remain with suggestions of how to continue further[23].

1.3.2 *Stakeholders*

People with disabilities themselves are active partners in the rehabilitation effort in CBR. This also regards the family caregivers of people with disabilities[11]. Other people in the community involved in CBR are: village leaders, rehabilitation personnel, teachers, elders and others. Community health workers, sometimes also called "volunteers" or "CBR-workers", many times have disabilities themselves[25]. Rehabilitation professionals are needed to transfer basic skills and knowledge[11].

1.3.3 *Levels of the program*

There are different levels included in a CBR program [1, 3, 9]:

- *Community level*: This is the community where the person with a disability lives. The disabled people and their families receive support and gain knowledge and skills from the CBR workers in the rehabilitation process. Local schoolteachers receive information about children with disabilities and how to include them in their classes. Community members also contribute to the rehabilitation process[1]. A community committee is set up to provide local management[26].
- *District level*: Refers to the area covered by the first referral level hospital. The district centre is accessible (geographically) to most people in the area including people with disabilities. Personnel at this level can if needed travel out to the communities in order to supervise community workers and do home visits of their patients[1].
- *Central level*: Service staffed by specialists (e.g. medical, educational and vocational) [1] Personnel based at this level is responsible to give direct rehabilitative services to people with disabilities. Also they are meant to supervise at district- and community level.

1.4 The challenges with Community-Based Rehabilitation

To make changes in the environment around a person is time-consuming. It is often the case that developing countries has a need for larger coverage of services. To add to this the resources are most limited, which affects the quality of the services provided[27]. The mothers are many times some of the most involved in the community level of the CBR program. They often lack time to take on an even greater responsibility than they already carry. In many parts of the world there is still a strong reliance on traditional remedies[25].

1.5 Criticism towards Community-Based Rehabilitation

Criticism towards the CBR strategy has been raised in prior studies. Robert J Gregory questions the implementation of a strategy like CBR in a society like the one we live in today. "The talk of power, empowerment and inclusion, when people are powerless and excluded, is a masterpiece of disinformation". Our society, he means, could be seen to have gone from collective involvement in varied local communities to individualism with even wider divisions between rich and poor[28].
Another issue is whose the responsibility is for the CBR project to succeed. Would it push the responsibility and burden of health and health care over to the communities and the people with disabilities themselves and lift it off the shoulders of the politicians in power? Is it a way of drawing attention away from the up stream of health care[29]?

1.6 The Republic of Uganda

The target area chosen for this study in the field of CBR is the urban poor community Bwaise in Uganda, East Africa.

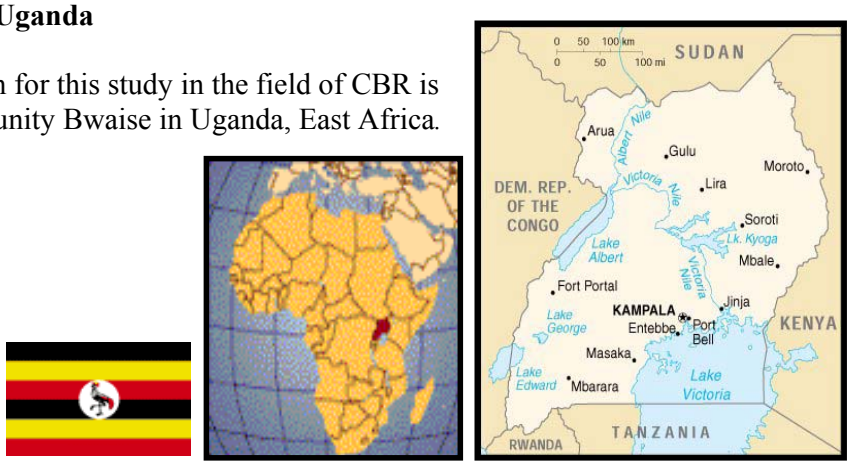

Figure 1-3* ***The flag and the maps of the Republic of Uganda***

Borders to[30]:	Kenya, Tanzania, Rwanda, Democratic Republic of the Congo, Sudan
Capital[30]:	Kampala
Population[31]:	24 748 977 inhabitants (of which 1 200 000 in the capital)
Age distribution[32]:	*0-14 years:* 51% *15-64 years:* 47% *65 years and over:* 2.1% (2002 est.)
Life expectancy at birth[32]:	*female:* 45 years (2002 est.) *male:* 43 years
Infant mortality[32]:	89 deaths/1 000 live births (2002 est.)
People living with HIV/AIDS[32]:	1.1 million – prevalence 6.1 % (2001 est.)

1.7 People with disabilities in Uganda

The exact number of people with disabilities in Uganda is unknown. The result of the 1991 National Housing and Population Census was that 1.2% of the total population in the country could be regarded as people with disabilities[33], while other estimations suggests that the number is 1.7 million people with disabilities[34, 3]. Approximately 500 000 people in Uganda are estimated to have movement disabilities. About 200 000 of these are in the so-called moderate or "severe" category, requiring assistive devices to overcome the disability[35].

Uganda's constitution today has five seats reserved for people with disabilities. The "National Union of Disabled Persons of Uganda" (NUDIPU) and other organizations of people with disabilities help spread information and through that raise awareness of disability and empower people with disabilities. According to Teresa May-Teerink[5] there is an "interesting social attitude" towards people with disabilities in Uganda. More people with disabilities consider themselves being seen in a positive light rather than in a negative[5].

There is an acute shortage of rehabilitation professionals in Uganda today. The Uganda Bureau of Statistics has in the year 2000 calculated the total number of physicians in Uganda to be 1 125 – in other words 18 600 persons on each doctor. The same year there were 1 331 registered nurses and 71 dentists in the country in total[31]. In discussions with "The Uganda Association of Physiotherapy" and the "Uganda Association of Occupational Therapy" (January 2003) the numbers presented were: 80 physiotherapists and 24 occupational therapists.

1.8 Community-Based Rehabilitation in Uganda

To increase the access of rehabilitation services and improve the situation for people with disabilities in Uganda the Government in 1986 adopted the CBR-strategy. The "Uganda Society for Disabled Children" (USDC) and the "Norwegian Association of the Disabled" (NAD) have been the two major contributors to the national budget for CBR[33, 36].
Today the Government, in association with a variety of nongovernmental organizations, cover's twenty districts of Uganda with CBR[35]. Also the CBR training has spread widely and includes formal training at the 'Uganda National Institute of Special Education' (UNISE), 'Makerere University' (with support from London University) and the 'Community Based Rehabilitation Alliance' (COMBRA)[37].

1.8.1 *The Community Based Rehabilitation Alliance, COMBRA*

The Community Based Rehabilitation Alliance (COMBRA) is an indigenous, nongovernmental organization that has operated in Uganda since December 1990. The reason for the founding of the organization was the urgent need to increase the rehabilitation services in the country as well as reduce society attitude barriers towards people with disabilities and enhance the participation of these people. This was to happen through the CBR approach[38].

Mrs. Maria Kangere, one of the founders of COMBRA, has proclaimed that:
"*COMBRA advances that each person can contribute towards nation building and hence should not be segregated against on the basis of sex, race, disability or any other factor*" [38].

Vision of COMBRA:
"A world where all people with disabilities have access to equal opportunities in society"
Mission of COMBRA:
"To empower and advocate for and with persons with disabilities for their sustainable development through community based rehabilitation" [38].

1.8.2 *The Bwaise Community-Based Rehabilitation Project*
Bwaise is an urban poor area located five kilometres north of Kampala city centre in the Kawempe division. The area is swampy with high water table and flooding during rain season. Rubbish heaps, poor sanitation, stagnant water and poorly constructed houses are building blocks for diseases such as malaria and cholera, which are common problems in Bwaise. The area is densely populated. The majority of people are poor and live from 'hand to mouth' for their daily survival.

COMBRA initiated a CBR project for people with disabilities and elderly persons in Bwaise in 1990, with financial support from the African Developmental Foundation (ADF). One of the reasons for the choice of target area for this project was that the number of children with disabilities was remarkably high in Bwaise. Further Mulago Hospital was close by for referral cases and personnel at the hospital had noted that many of its patients came from Bwaise. In 1997 COMBRA started an "extension project" in Bwaise in order to phase out and let the inhabitants of Bwaise, the "Bwaise Disabled and Elderly Association" (BDEA), take over and finally independently run the CBR project[39, 40]. The goal of the extension project was to:
"(...) establish, within the entire Bwaise slum, a permanent and autonomous, self-sustaining community based rehabilitation program that will improve the quality of life of the elderly and disabled persons and incorporate them into the community as respected and productive members of society" [39, 40].
In the end of 2001 the project was officially handed over to the care of BDEA and ADF withdrew as financier of the project [39, 40]. For the BDEA aims and objectives please, see appendix I.

1.9 Research considering Community-Based Rehabilitation

The interest in CBR is increasing, but few studies within the area have been published [41]. Even though the number of publications has increased during the nineties few deal with scientific literature and are rarely to be found in conventional scientific journals. The researches done are many times more of "experiential descriptions" of CBR projects[42, 43].

If there is no evidence on the impact of CBR it will be difficult to persuade governments to spend large amounts of money on the strategy. Without this kind of research the risk increases that this field will not be able to sustain and fades away[27].
Also in Uganda it is challenging to find scientific literature on the CBR strategy, even though it is adopted by the government and applied in many parts of the country[36]. This also regards the Bwaise CBR project. In order to facilitate adequate planning of the project the different stakeholders' perceptions of the effects of the project is needed[42]. No evaluation of the extension project in Bwaise has been done since its inception in 1997. The only materials to be found are the quarterly reports compiled by COMBRA.

2 AIM OF STUDY

To analyse and describe clients and personnel experiences of the Bwaise CBR project in Uganda.

3 METHOD

3.1 Theoretical background

The method for data analysis used in this study was *phenomenography*.
The two Greek words "phainomenon" and "graphein" (i. e. "appearance" and "description") together make up the word "phenomenography". In other words the translation for the word phenomenography is: "*a description of appearances*" [44]. Phenomenographic research aims at identifying, analysing, describing and understanding the various ways in which people experience certain phenomena or certain aspects of the world[45, 46, 47]. These ways of understanding are revealed in the form of categories that capture the differences of understandings from a certain interest or viewpoint. Instead of studying the process of thinking and learning, on an abstract level, the focus is on the *explanations* people have to the reality they encounter[48]. The assumption is that there only exists a relatively limited number of qualitatively different ways a phenomenon can be conceptualised[46].

3.2 Informants and ethical aspects

The informants were strategically selected. Circumstances made the author reliant on BDEA personnel to move around in the community to find them. Informed consent was obtained prior to inclusion in the study.

The sample of the 21 informants consisted of: ten clients, four CBR workers and seven people of the administrative personnel of the CBR program. In order to get diversity in experiences, clients representing all categories of members in BDEA were selected: people with disabilities, care givers of children with disabilities and elderly. All personnel in BDEA (CBR workers and administrative personnel) took part in the study. The inclusion criteria were ability to understand and express oneself in English or Luganda and involvement in the project for a minimum of one year.

An ethical application was handed in to and was approved upon by the local ethical committee SYD, at Huddinge Hospital in Sweden. Dnr 339/02, date of approval 9 September 2002. The right of the participants in the study to withdraw at any time was made clear and they were given an assurance that all data would be handled confidentially (appendix II).

3.3 Collection of data

Data was collected by semi-structured interviews. The interviews were recorded on tape and lasted 40 – 60 minutes regardless of whether an interpreter was used or not. To reduce possible bias introduced by the interpreter instructions were given to emphasize the importance of providing the answers word-by-word and avoid subjective interpretation. The interpreter who assisted the interviews was not known in Bwaise, but was a physiotherapist well informed about CBR and work within the field of rehabilitation in Uganda. He was fluent in both English and Luganda.

All interviews apart from one were conducted in the Bwaise community. The clients were all interviewed in their homes and the personnel mainly at the BDEA centre in the third parish of Bwaise. An interview guide, developed in Sweden and edited in Uganda, was used (appendix III). Three test-interviews were conducted in Uganda, of which one together with the interpreter, before the start of the data collection.

All the interviews started with the same request: *"As have been explained to you in this sheet of information I am here in Uganda to learn more about Community-Based Rehabilitation, CBR. Therefore I would like you to please tell me what the Bwaise CBR project means to you / to your clients"*

3.4 Analysis

The interviews were transcribed and stored in a computer after they had been cleared of all personal data in order to ensure confidentiality.
Prior studies describe a number of steps that may be discerned in the analysis and that was also applied in this specific case[49, 50, 51]:

- Familiarization. The author read through the transcripts in order to get introduced to the material. Errors in the transcripts were corrected.
- Condensation and comparison. Identification of the most significant elements in answers given by each informant was made. Compilation of answers from all respondents to a certain question.
- Grouping and articulating. Answers that were related to each other were grouped into categories. The informants could only be placed in one category each. Borders between categories were established. The essence of similarities within each group of answers was described. This step was revised several times before considered satisfactory.
- Naming. The categories were labelled with an expression that captured the essence of the articulation.
- Contrastive comparison: The categories obtained were compared at a meta level.

During the cause of the analysis the author came to the understanding that a special focus on the weaknesses in the CBR project was also needed. This was done by a thematic analysis in order to find themes for description.

3.5 Validity

The data analysis in phenomenography is a "discovery procedure" rather than a measurement. The discovery should be communicated in such a way that other researchers could recognise instances of the different ways of experiencing the phenomenon in question[50].
To control for validity in analysing in this study two supervisors identified significant elements in two of the interviews and was a support through discussions when applying categories to the material.
Two people not involved in the study, with Luganda as first language and fluent English, evaluated the translations (from English to Luganda and from Luganda to English) in two of the interviews.

4 FINDINGS

Six different categories for description of experiences of the Bwaise CBR project were found. These cannot be placed in a hierarchical system. There is however a clear division between the categories to which the different groups of informants belong. The categories have been specified by themes, as described in 'Figure 4'. At a meta level three main categories were found and presented in a model inspired by Peat[11].

The quotations that follow the descriptions of each category exemplify the individual answers. As the transcripts were made from spoken language the text has in some cases been revised in order to facilitate reading. In some instances the term "personnel" is used for description of a group consisting of both CBR workers and administrative personnel in the project.
Three themes describing weaknesses in the Bwaise CBR project is presented separately in the end of this chapter.

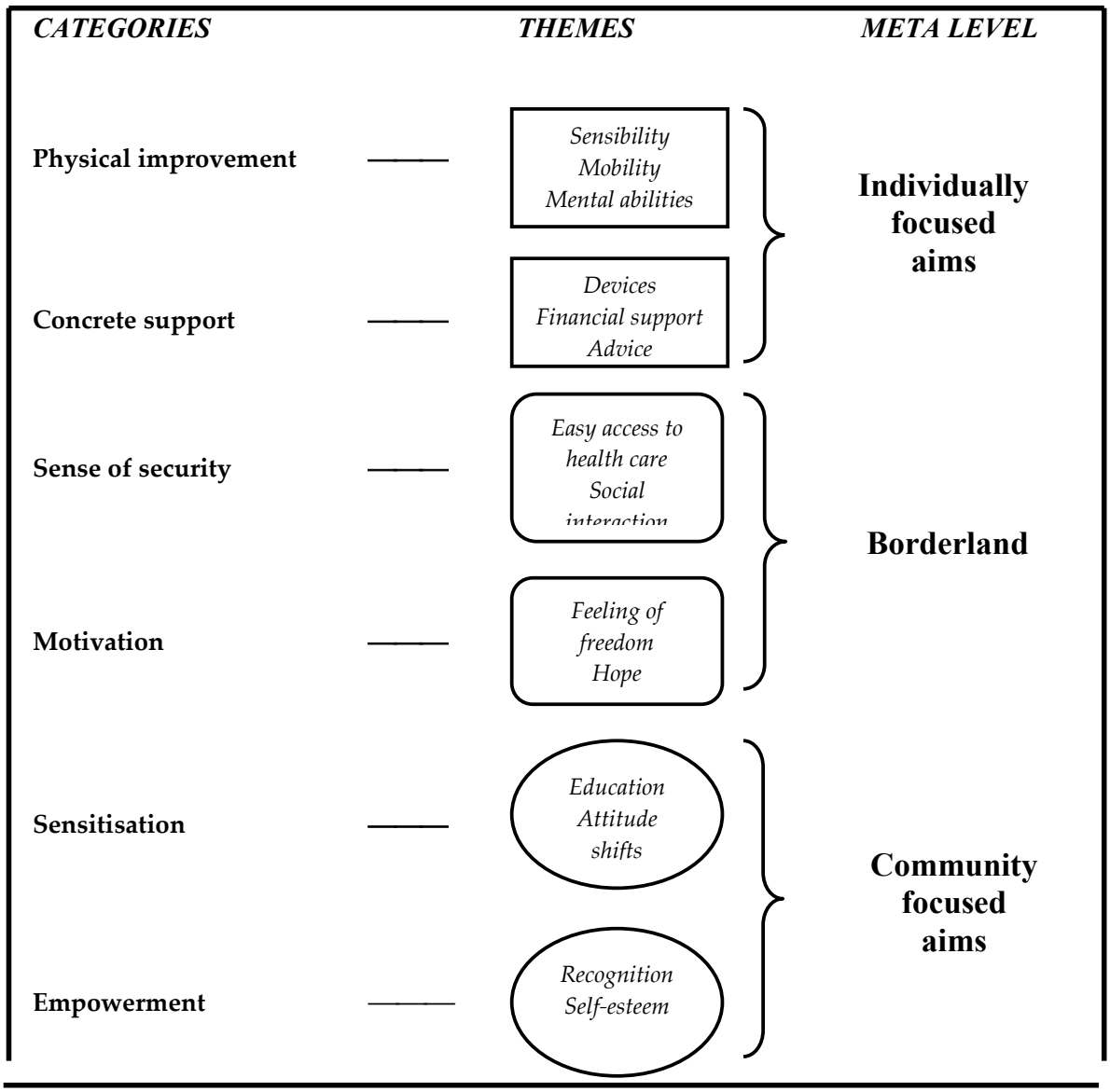

Figure 4: ***Experiences of the Bwaise CBR project***

4.1 Physical improvement

This category focused on the physical changes the clients had experienced since joining the program. It was exemplified as improvement in *sensibility, mobility and/or mental abilities*. The "mental abilities" were described mainly as the ability to respond to people in the surroundings. This category regarded either own physical progress that the persons with disabilities had noted themselves or progress in the children with disabilities noted by caregivers. The physical exercises instructed by CBR workers or a physiotherapist was the most frequently mentioned cause of this progress. A number of clients expressed interventions at this level as being the most important aspect of the program, while none of the CBR workers or the administrative personnel focused on it. This was also what many clients emphasized the program should focus its resources on.
In a model by Peat describing "aims of CBR programs" this category is placed under the individually focused aims, where direct service to the clients and their families is seen as most important [11].

> *"Then when they decided to do some exercises on me... Originally I could not feel at all – my legs could not feel, both legs, from the hip. But now I can feel – if you touched me or something, scratched, I would feel it. (...) I have seen a very big change since I joined BDEA. (...) I can tell you that now I can move, that is by crawling. I can move from one place to another, from the room here to the sitting room to the veranda"*
>
> Person with disability [C1]

4.2 Concrete support

The experience of "concrete support" was expressed as coming from *devices, financial support and advise*. The financial support was in form of loans and subsidized prices of medicines. It was the theme where the majority of the clients were to be found, mainly focusing on the loans they have received through the project. To provide clients with loans in order to start own businesses and in the long run become self-supportive is one of the objectives of the Bwaise CBR project (appendix I). Many of the clients saw the loans as resources to improve their living standard, provide their children with school fees or invest it in hospital-based health care. It was repeatedly stated a wish for increased provision of such services, also including provision of assistive devices and advises in the handling of children with disabilities, such as physiotherapy.
This was one of the two categories belonging under the heading "individually focused aims" at the meta level[11].

> *"Then these very ladies here taught me how to roll a mattress and make it like a roll... a CP-roll, so that when I put him on it he lifts his head. He's able to see his friends and he like's to see people around"*
>
> Care giver of child with disability [C3]

> *"This money they lend us usually helps us to do some small businesses. Then later on we pay it back. But, the businesses will help us to keep us going since we... our age and the disabled we can do nothing much"*
>
> Elderly [C10]

> *"(...) we get medicines at subsidized prices. You know the prices of the clinics are very expensive. To BDEA you take some little money and you're given the medicine"*

Person with disability [C6]

4.3 Sense of security

Easy access to health care in the community and *social interaction* were the two main reasons found to the sense of security the clients developed as members in BDEA. To know that health care was close by and available at an affordable price brought comfort - especially for the elderly for whom it is especially difficult to arrange with visits at the hospital at own initiative and funding. In case of illness the clients knew who to turn to and who could help them with referrals in case the problem could not be solved within the project. To have the help and support from friends living close by "in case something would happen" was another greatly appreciated factor that brought a sense of security**.** This category would in Peat's system of "individually focused" and "community focused" aims end up in a "borderland" between the two[11].

> *"But, in case someone gets such a problem [malaria or cholera] and you run to the Bwaise CBR project these people are always at hand to give us help – whether you are disabled, elderly or who ever. When it comes to emergency they don't discriminate, they always give the help necessary"*
>
> Elderly and caregiver of child with disability [C2]

> *"Well, I've been helped so much, especially when I go to meetings of our group the elderly. (...) For these meetings we always talk about very many things, but in particular how we should help each other. (...) we pay each other visits and talk about the way we should handle the money that we are lent"*
>
> Elderly [C9]

4.4 Motivation

Motivation was viewed as coming from the *feeling of freedom* and the *hope* that the clients had experienced through their participation in the project. The caregivers of children with disabilities, the mothers in specific, were greatly appreciative of having found other families and parents in the same situation as themselves. Instead of feeling shame they could now "get back to" their children and work with them. They saw a future in their children and got a goal to work towards.
As regarded the elderly and the adults with disabilities they claimed to have found a new perspective on life and had come to the realization that their lives were not at an end**.** The CBR project had provided them with hope for the future and stated that even if some of their goals were not yet reached their participation in the project kept their hopes and spirits up. This category is at meta level placed in a "borderland" since the motivation stems from interventions directed at the client in first hand, but is not realizable without the support from the community[11].

> *"It's good [to meet other parents with children that have disabilities]. In that... you can be so scared; 'So, now I've got this kid, he's disabled and what not...' But, at least when you find other kids you feel free and can say; 'Ah, it's not only the fault on me – there are many people who are disabled' and you have to appreciate it cause it's what God has planned for you"*
>
> Caregiver (mother) of child with disability [C5]

"What I've learnt most and I think that keeps me going is; if this person is really disabled you don't have to leave this person in this stage..."

Caregiver of child with disability [C8]

4.5 Sensitisation

In this context the word sensitisation stand's for "creation of a better understanding" [of people with disabilities and elderly]. It is suitable for the group of BDEA personnel that focused the importance of the CBR project as a catalyst of *education* and *attitude changes* in the community. The informants saw the interventions made in the project as something that profited the clients "indirectly" through changes in the community, therefore placed under "community focused" aims at meta level[11]. The word *"enlightenment of the community"* was a frequently used description of the result of the project. Children and adults with disabilities have long been disregarded and neglected in Bwaise. Since the CBR project started this negative outlook has started to change. The community members are learning the causes of disabilities and are slowly shifting their view upon the people with disabilities as cursed or as "lesser beings" to seeing them as people that can contribute to the community. They have slowly started to realize that *"disability is not inability"* and that people with disabilities can be talented people. It was claimed that the children with disabilities have been brought out and an attitudinal change on part of the professionals was also stated.

"Quite a number of parents resorted to native doctors (...) knowing that their offspring had bad spells on them or had been bewitched. (...) Our major objectives of the seminars and workshops were to help parents deal with their children in a proper way. Helping them understand that disability is not a curse or spell, but can be cured or helped - especially mental disabilities – if given proper medical attention from qualified personnel. (...) We also realized the resource that we put to waste in the past. In fact we came to conclusion that some of the disabled have great ideas that 'able' people may not have"

Administrative personnel [P1]

4.6 Empowerment

One of the main objectives of CBR is "empowerment" of people with disabilities[3, 7,17,18]. Based on the interviews only personnel in the program could be placed as representatives of this category as regards the Bwaise CBR project. This since they had a conviction that a result of the interventions of the project was *recognition* by the community members of people with disabilities and elderly. Further the clients were thought to have developed a greater *self-esteem* thanks to the changes in the community.
The emphasis was on letting people with disabilities and elderly take active part in decision-making and strengthen their ability to take control over their own lives. Therefore also this category belongs to the community focused aims of the project[11].

"The most important thing we need is to see that people with disabilities are also recognized a... by government and by the community. (...) So, now they [the community members] have started – they know how to do that. They are now friendly to those people"

Administrative personnel [P6]

"This organization has helped them [the clients] learn how to be self-supportive, active and even appreciate the need to work and develop a sense of self-esteem. The elderly have realized they can still be of use – above all learnt how to be social and developed healthy interpersonal skills, all which are a result of the seminars and workshops organized by BDEA"

Administrative personnel [P2]

4.7 Weaknesses in the project

The thematic analysis of the interviews revealed a number of *weaknesses* in the Bwaise CBR project, as experienced by clients and personnel. The three main themes in question are:

- *Lack of financial resources*
- *Personnel in the project are mistrusted by the community*
- *Few CBR workers*

4.7.1 Lack of financial resources

Clients, CBR workers and administrative personnel considered this category as the main weakness and a cause of a threat to the continuation of the CBR project. It was also seen as the greatest cause of eventual failures in the project today. Many of the respondents claimed, *"as regards finances we [BDEA] are the disabled also financially"* and that *"no changes can be made without money"*. The grant received by the start of the project was running out and no present incomes could replace it. A majority of respondents expressed a wish for charity from the author's home country (Sweden/Europe/Western World) and/or financial support from national Non-Governmental Organizations (NGOs) in order to sustain the project. As Bwaise is a swampy and waterlogged area changes in the physical environment needed to be made in order to facilitate access for people with moving restrictions. At the present this was not seen as possible without economical support from the government or other donor. Many of the clients advertised for adaptations in the community for people with disabilities. Administrative personnel, CBR workers and clients all wished for a vehicle for BDEA personnel. This was in order for the CBR workers to make more frequent home visits, make it possible to arrange with transport for the clients to hospitals and various events.

It was brought up that *"the children that got better in the beginning of the program are retarding again"*. This was seen as due to decreased frequency in attendance by CBR workers, caused by lack of funds. Assistive devices were being difficult to provide clients since money for material was lacking and sparse resources of locally available material were to be found. Many plans for the project were seen as not being able to realize without an increase in the budget.
The two remaining categories were also those related to funds.

4.7.2 Personnel mistrusted by community members

Some of the personnel, administrative as well as CBR workers, brought light upon the fact that they, at times, were mistrusted by community members. This made their work more straining and they had a hard time to get the message across that their resources were not enough to make all the changes needed. It was said that the accusations were possible to cope with, this by seeing pass them or trying to explain the true cause behind the lack of services provided the people with disabilities and elderly. Despite this fact it was experienced as straining to repeatedly be stated as a 'liar'. It was said to decrease the motivation of the CBR workers to approach the community to the extent that they do today. This especially since the

personnel did hard work with little refund and personally had a hard time to make "both ends meet".
In some cases personnel have taken from their personal funds in order to provide assistance to clients in the project. As expressed by one member of the administrative personnel in BDEA: *"The community don't know about our financial constraints. They say we have 'eaten their money'"*. Personnel were accused to *"steal money given the elderly and the disabled by the Wazungu [the white people]"*. Personnel claimed that when collecting the money lent to the clients it was frequently occurring that people refused to pay back or pretended they had never been given the loan in the first place. This was also suspected to be one of the causes for the constant reduction in BDEA's budget.

4.7.3 Few CBR workers
Four CBR workers together covered the three parishes of the Bwaise community. In 1997 there were 540 clients registered in the project[40]. The CBR workers earned 50 000 Ugandan Shillings per month, which equals 16 British Pounds or 200 Swedish Crowns. The CBR project were dependent upon the rehabilitation workers, to a great extent, in order to spread the message of the association, give the clients visits and treatment as well as run the sale of medicines. It was brought up that they find it straining to cover as many different diagnoses as they did and most of them expressed a need for more training in CBR. They also expressed that the decrease in frequence of attendance of their clients that they were forced to do, due to lack of personnel and resources, bothered them. Even if family members were seen as a big component in the rehabilitation process of a person with a disability they could not be left without support such as home visits[25].

> *"Sometimes we find we strain ourselves (…) My motivation is my disabled family member, plus the fact that these people are 'our own people' – we can't just leave them…"*
>
> CBR worker [P10]

> *"(…) we find it's hard to find motivation to work. By the time you get your allowances you're already in debt. I work because I'm 'in the system' and can't give up on my patients"*
>
> CBR worker [P11]

5 DISCUSSION

This study is one of a very small number of studies on CBR in Uganda. The findings indicate that there are qualitatively different experiences of the Bwaise CBR project. As it was not the intention to compare the different groups, but instead increase the range of views captured, further studies are needed to confirm this. Further research is also needed in order to examine the effects the project has had on its stakeholders.

Individually focused: "Physical improvement" and "Concrete support"
As presented in 'Figure 5', exclusively clients in the project brought these two categories forward and the majority of them could be placed under "physical improvement" or "concrete support". The physical improvement was (naturally) greatly appreciated and a focus for both people with disabilities themselves and parents of children with disabilities. In the literature on CBR the emphasis lies on equalisation of opportunities and social integration of people with disabilities[3, 15, 23] placing physical improvement and concrete support in the background, even though it is a momentous part of the strategy. In Bwaise, few of the clients stated for

example attitude change and integration as necessary in their community. A sparse number even stated it as not necessary at all. Instead they found their lack of resources, lack of frequent assistance from professionals in the field of rehabilitation and lack of adequate medicines as most troublesome. Many of the clients tended to focus on the specific impairment and saw their own or their child's disability much as a medical issue.

The Borderland: "Sense of security" and "Motivation"
The categories "sense of security" and "motivation" had representatives from all groups included in the study; clients, CBR workers and administrative personnel. The sense of security the clients experienced, and that the personnel claimed they experienced, mainly originated from the improved access to health care related to the start of the project. Apart from that, it was a support for the clients to "have access to each other". The task to organize the people with disabilities and elderly in groups has had a positive outcome in Bwaise. Coleridge question's the logic in forming separated groups of "disabled". This since it runs counter the aim of integrating these people in society[18]. However, in this study the stakeholders saw such groups as facilitating integration, since the people involved had a constant support from each other and found friends in the same situation with whom to hold discussions on how to handle various issues on this and other topics. Most important they found a security and comfort in knowing there were always people there to assist them if needed. A support hard to find among "external" people, who may not always understand the trouble the elderly and people with disabilities may encounter.
The people who experienced "motivation" as the greatest effect of the CBR project were mainly clients, by a vast majority represented by mothers of children with disabilities. Their stories of how they had found a way back to their children and now saw a future in them revealed that the CBR-project had had a great influence on their lives and their well-being.

Community focused: "Sensitisation" and "Empowerment"
Administrative personnel and CBR workers represented the categories "sensitisation" and "empowerment". None of the clients were placed under these categories, even though some of them in short mentioned positive outcomes that can be related to sensitisation of community members. The answers given in the interviews corresponded well with literature on CBR[3, 7,11,17,18] and also with the aims and objectives of the Bwaise CBR project (appendix I). The majority of the respondents saw attitude changes (towards people with disabilities and elderly) and education of community members as the main task and the greatest outcome of the project. Many of them emphasized the fact brought up in a prior study on disabilities in Uganda, that more people with disabilities today consider themselves being seen in a positive light rather than in a negative[5]. In Bwaise this was stated as closely linked to the interventions of the CBR project.

The term "empowerment" has a wide range of definitions. Even though it means that 'the individual gain mastery over his or her own life'[20] it involves that other people in the community relate to these people positively. Recognition from the surrounding is needed in order to reach empowerment. An individual cannot take part in decision making in the community if the community is not open for it. Of this reason the category "empowerment" is, in contradiction to Peat's suggestion[11], placed in the group of community-focused aims.

Uganda as a country has been successful at this point and COMBRA that initiated the Bwaise CBR project is working hard in the direction of empowerment for all people with disabilities. The enthusiasm and fighting spirit of the founders were evident in the responses of the personnel in the project that to a great extent seemed to have adopted a related way of

thinking. The fact that people, and especially people with disabilities and elderly, may be powerless and excluded in society today was seen as yet another argument *for* implementing CBR instead of seeing it as more or less of an "impossible strategy", as argued by Gregory[28].

INDIVIDUALLY FOCUSED AIMS	BORDERLAND	COMMUNITY FOCUSED AIMS
clients	*clients&personnel*	*personnel*

Figure 5: ***Distribution of informants in the different categories at meta level***

The themes of weaknesses of the project, threatening the future of the CBR project, encountered during data collection do not respond to the aim of this study. Despite this fact the themes are considered essential to include to serve as basis for discussion and to state examples of further research needed in the area.

Sixteen of the twenty-one informants emphasized *lack of financial resources* as the main weakness of the project, both as regards the individually focused interventions and the community focused interventions. The reason for the overwhelming agreement to this specific theme needs to be explored further. Of course outspread poverty in the community and in the country in general is the most obvious background, this also the reason being why CBR has been initiated in Bwaise. One theory is also that the informants may have seen a chance to, through the interviewer, communicate their needs to a developed country with better economy and possibly willing to provide them with funds to improve the project and/or their personal financial state. A cause that is well understandable but that still need to be included in discussions on the topic. Revealed in the interviews was a wish for a resumed support from COMBRA, to secure that the project does not cease before co-operation with a national NGO or other external financier is initiated. A support in the search for such an organization was also wished for. The point is not yet reached where the local inhabitants of Bwaise are ready to carry the whole responsibility for the project themselves. It is not yet an "autonomous, self-sustaining community based rehabilitation program", as was stated being the goal of the extension project[40] . Listening to their reasoning you might want to assume that BDEA as an organization is not yet "empowered" itself, since its members do not believe in the ability nor the capacity of BDEA to be self-sufficient.

> *"We would request they [COMBRA] make frequent visits. It's like if you left something behind of course you want it to go on. Why wouldn't you pay it visits to see if there is any progress? (...) people are pushed when something is being done and if someone keeps saying 'you should do this' you feel it's a little push and things will keep going. So we need them to come back and pay us visits and keep us going."*
>
> Administrative personnel [P7]

The workload on the personnel in BDEA, the CBR workers in specific, is heavy. Few people are responsible for the running of an extensive project. A decrease in co-operation from people in the community that are not members in BDEA, as well as family members of people with disabilities and elderly, will make the running of such a project very troublesome. The fact that Uganda has suffered a recent history of lawlessness and corruption makes suspicion from the side of the community members easier to understand. These people are important stakeholders in the community level of CBR and should be encouraged to participate. They must be clearly educated about the background and the conditions of the project.

To keep up the motivation of the CBR workers in order to keep the project running has been a problem in many CBR projects around the world[9, 26, 29]**.** In Bwaise as in many other places the refund for the rehabilitation workers is sparse and each worker is responsible for many patients. An increase in number of CBR workers employed is needed and should be a priority at this stage, in order to cover all clients taking part in the project. This is also to make the work conditions for the present CBR workers more realistic. CBR courses need to be held continuously and a fairly high dropout rate of CBR workers must be taken into account in further planning of the project. All people getting educated in CBR and about people with disabilities and elderly will in some way contribute to the total awareness on the issue in the community. A high dropout rate does not necessarily mean the project has failed[9].

The great lack of resources within the field of rehabilitation of people with disabilities and elderly in Uganda today makes CBR a most appropriate strategy for reaching out with rehabilitation services to the people. The Bwaise CBR project has proved to be a positive implement in the community and the fact that its mother organization is Ugandan, and not a foreign aid organization, is encouraging. There are many parts of the country that are in need of projects like this one[33, 36] and the Bwaise CBR project has much of the capacity needed to be a role model in the work of starting up such projects elsewhere.
However, the project has some important weaknesses. The aim of establishing a permanent and self-sustaining CBR project[40] has had a kick start but the steam is fading. There need to be clear goals set up for the future of the project, to prevent realization of the threat that the project will not sustain. In order to make these goals feasible the clients views on important issues to include and prioritise should be voiced and taken under consideration. Without it co-operation from clients and community members will be hard to find. After all, a CBR project is established for the good of people with disabilities, elderly and the family members of these people so of course their opinions should be included in planning of the project. It is in a prior study stated that the needs of different groups who are affected by the interventions have to be identified in order to make further planning of the project successful[42]. Though social attitudes is a dominating disabling factor, shifts in attitudes is not the only solution to the problem.

5.1 SWOT-analysis

The findings in this study can be comprised in a "SWOT-analysis" in order to make a lucid picture of the S*trengths, Weaknesses, Opportunities* and *Threats* in the project. This might serve as a basis for discussions around how to improve and sustain the Bwaise CBR project. It also gives guidance to areas where further research is needed. The SWOT-analysis was developed as an instrument to "diagnose" a system. The system can be for example a municipality, an organization or a product[52]. In this case it is applied on the Bwaise CBR project, as presented in 'Figure 6'.

STRENGTHS	***WEAKNESSES***
- The project has showed positive outcomes that benefit the clients involved (e.g. physical improvement, motivation, empowerment). - The community where the CBR project is implemented is located close to the national referral hospital, which facilitates referrals of clients. - Dedicated personnel. - Motivated clients, who wish for a continuation and expansion of the project. - Government work for the rights of people with disabilities and encourage CBR.	- Lack of financial resources. - Personnel mistrusted by community members. - Few CBR workers. - The physical environment of Bwaise is challenging, especially as regards making adaptations for people with difficulties in moving. - BDEA, as an organization, is not yet empowered (?)
OPPORTUNITIES	***THREATS***
- Realize the goals set up for the extension project. - Be a role model and encourage the start of CBR projects in other parts of the country. - Stand up for the rights of people with disabilities and elderly people in Uganda.	- The project fails to be sustainable. - Rehabilitation services cannot reach the community. - Decreased awareness about disabilities. More difficult for people with disabilities to get integrated in society and become active community members.

Figure 6: ***A SWOT- analysis of the Bwaise CBR project***

5.2 Methodological considerations

After having been informed about the inclusion criteria of the study, the CBR workers and the co-ordinator of the project selected the clients that were to take part in the study. This can have meant they only chose clients that they had a good co-operation with and that they knew could give "appropriate" answers to the questions asked. In order to get a greater representation of answers from adults that have disabilities themselves more interviews with such clients would have been preferred. A fair variety of informants were still possible to include, considering that children with disabilities and elderly were the biggest group of clients in this specific CBR project. If more informants had been interviewed an even larger

range of categories would possibly have emerged. With more data the risk, however, is that the analysis would have become superficial.
Informed consent from the participants in the study was not possible to collect until right before conductance of the interview. Due to various circumstances the clients involved in the study had to be interviewed in their homes. It is possible that this may have tuned down the interview situation and made the respondents more comfortable. At the same time, a visit by a white person was the cause of much commotion. Curious neighbors and relatives in substantial numbers tended to surround most of the informants.

The people who volunteered to control the translations in two of the interviews, from Luganda to English and from English to Luganda, found the translations being satisfying. In a few cases the interpretations resulted in leading questions, which may have biased the answers of the respondents. Also, a few specific words were translated incorrectly. As for example there was a misrepresentation regarding the position of one informant. The translator addressed the informant as the "treasurer" of the project while the two people checking the translations both called the informant "secretary". One of the people that controlled and evaluated the interviews also transcribed all parts spoken in Luganda to English. This gave the author and the co-authors the opportunity to make own statements of the validity of the translations. The translations were found satisfying and well agreeing to the given answers of the informants.

Shades of meaning and certain expressions by the respondents may have been lost at an early stage in the interview process. This might have been due to the language barriers and the cultural differences between the people involved in the interview situation. In order to better understand the target area of the study and the culture of the country in general, the author did a clinical practice of two months at the national referral hospital located close to Bwaise. Interaction with people from diverse parts of the country was done to an extent as great as possible. A review of documents regarding the history of Uganda was done before departure to and during the stay in the country. The three months experience of Uganda formed a good platform for building a greater understanding of many aspects of the country, but it was only a grasp in the air as regards getting the full picture of life in Uganda, Africa and developing countries. Future research should preferable be conducted by inhabitants in Uganda alternatively foreign researchers living in the country for longer time periods.

The validity-check made showed a good agreement between the author's and the supervisors' apprehension of the material.

6 CONCLUSION

This study described qualitatively different ways of experiencing the Bwaise CBR project in Uganda. These experiences were presented in six different categories: *physical improvement, concrete support, sense of security, motivation, sensitisation and empowerment*. Encountered were also weaknesses that may be a threat to the future of the project. The Bwaise CBR project was experienced to have brought many positive changes to people with disabilities, the caregivers of children with disabilities and elderly people in the community, but was considered to be in need of various forms of support - for example funding - in order to sustain. To estimate the effects of the CBR project and the impact of the different views on the project more and other forms of research is needed.

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Figure 2
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