Perceived Needs Related to Social Participation of People with Leprosy-related Disabilities and other People with Disabilities in Cambodia: A Qualitative Study

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ABSTRACT

Purpose: *The objective of this study was to describe the similarities and differences in perceived needs related to social participation of persons with leprosy-related disabilities and other persons with disabilities in Cambodia, and to suggest key interventions to promote participation in the community.*

Methods: *A cross-sectional study was conducted. People with leprosy-related disabilities were selected at home during field visits or at the rehabilitation centre for people with leprosy in Phnom Penh. People with locomotor disabilities were selected at the rehabilitation centre for persons with disabilities in Phnom Penh and Prey Veng. A pilot-tested, face-to-face semi-structured interview, with open and closed questions, and focus group discussions were used to investigate the perceived needs related to social and economic participation in the community. The interview was based on the International Classification of Functioning, Disability and Health (ICF) model of the WHO.*

Results: *Both groups of people with disabilities struggle with social exclusion in society. People with leprosy-related disabilities, in particular, live below the poverty line of US$ 0.5 per day. Most of the participants lived in rural areas. Participants raised the need for enhanced self-esteem and help in finding jobs. To overcome the difficulty in finding employment, they felt vocational training and microcredit to start businesses, were required.*

Conclusions: *The study found that both groups of people with disabilities have similar needs to improve participation in social and economic life. Rehabilitation centres provide vocational training and microcredit. Self-help groups have also proven effective in reaching poor people with disabilities in rural areas*

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and improving social participation. The authors suggest that it is best to form multi-disability self-help groups to empower all the affected people and help fight poverty.

Key words: *Self-help groups, social exclusion, socio-economic rehabilitation*

INTRODUCTION

The Kingdom of Cambodia has a turbulent history, marked by almost 30 years of civil war and genocide. It is hard to get firm numbers on the percentage of the population living with disabilities in the country. One of the reasons is that surveys often measure disability exclusively on a narrow selection of impairments, as for instance the Cambodia Socio-Economic Survey conducted by the National Institute of Statistics in which4.5% of the population was found to have a disability (UN ESCAP 2009).The highest percentages of types of impairments were seeing (33%), moving (29%) and hearing difficulties (12%) (National Institute of Statistics, 2009).

The group of people with disabilities in Cambodia includes persons with leprosy-related disabilities. In 1998, leprosy was eliminated as a public health problem (prevalence less than 1 case per 10,000 population) (WHO, 2001a). According to the National Leprosy Elimination Programme (NLEP), 283 active cases of leprosy were on treatment at the end of 2009, with a prevalence rate of 0.19 per 10,000 (The National Leprosy Control Program, 2010). They estimated a new case detection rate of 2.4 per 100,000.Leprosy is a chronic infectious disease caused by a mycobacterium and is also called “Hansen’s disease” or “Khlung” in Khmer (Reichart et al, 2007). It principally affects the skin and peripheral nervous system. When detected early, only the manifestation of a mild insensitive red or pale (loss of pigment) spot on the skin is observed. However, when left untreated, progressive and permanent damage may occur that can lead to, for example, disfigurements of the extremities. Leprosy-related disabilities are classified into 2 categories: Grade I - insensitivity of the skin of hands and/or feet, and Grade II- visible impairments of the body (Brandsma & van Brakel, 2003; Nicholls et al, 2005).

Disability is frequently associated with social participation restrictions in the community because of stigmatisation (Bainson KA & Van den Borne, 1998; van Brakel et al, 2012). Community members often have their own opinions about people with disabilities. Social problems in the community are usually a consequence of having a visual impairment (Hiramani, 1992) or other visible disabilities (Yeo, 2005). This is the case for many people with leprosy-related disabilities and may lead to income-generating difficulties (Deepak et al, 2000). If community members do not see the talents and abilities of people with disabilities, then finding a job may be difficult or even impossible (Thomas, 2005). A consequence may be serious restrictions in functioning in society (Resnik & Plow, 2009).Income generation is an important facilitator for people with disabilities to become equal members of the society (Yeo, 2005). Socio-economic rehabilitation can help people to improve their self-esteem and to live self-supporting lives, which will bring them back into society (Ebenso et al, 2007).

Currently, persons with leprosy-related disabilities in Cambodia receive separate rehabilitation services at one centre within the context of the NLEP, instead of being helped by mainstream programmes for other people with disabilities that are available at several locations. More efficient strategies may be possible. Not much research has been conducted on perceived needs in the area of social participation of people with leprosy-related or other disabilities in Cambodia. Hence, the purpose of this study was to investigate the similarities and differences in perceived needs related to participation of people with leprosy-related disabilities and people with locomotor disabilities in Cambodia. The underlying aim was to suggest key interventions to promote participation of both groups of persons with disabilities in their communities and in social life, and to facilitate access to rehabilitation services through the integration of leprosy-specific rehabilitation into general programmes. The definition of 'participation' used is the one given in the WHO International Classification of Functioning, Disability and Health(ICF), namely, "participation is involvement in a life situation" (WHO, 2001b).

METHOD

Study Design

The study used a comparative cross-sectional design.

Study Population and Sampling

The study population consisted of persons with leprosy-related disabilities and other persons with disabilities living in several urban and rural areas of Cambodia. To increase the validity of the comparison between the perceived needs related to social participation of these 2 groups, people with locomotor disabilities were included. The latter have activity limitations that correspond to those found in people with leprosy-related disabilities. Both groups were selected through convenience sampling. People with leprosy-related disabilities (n=37) were selected either during field visits to their homes, as part of the NLEP's follow-up of newly diagnosed, relapsed or former leprosy clients (to provide them with multi-drug therapy, inform them about medication use and how to recognise the disease in other family members), or when they attended or were admitted to Kien Khleang National Leprosy Rehabilitation Centre at the National Centre for Disabled Persons in Phnom Penh. People with Grade I or Grade II disability were selected. Among people with disabilities, those included were the ones with locomotor disability (n=28) who lived at home or were admitted at the rehabilitation centre of Veterans International Cambodia (VIC) in Phnom Penh or Prey Veng.

Participants between 15- 61years of age were selected. People with intellectual disabilities were excluded. As far as possible, the researchers tried to include as many newly-diagnosed leprosy clients as they could, as well as persons yet to be referred. Furthermore, this study used a selection grid for the study sample to ensure that subjects were equally distributed in each group.

Data collection

Qualitative data was collected through in-depth interviews and focus groups, between March and July 2011. Perceived needs related to social participation of people with leprosy-related or locomotor disabilities were determined through a semi-structured interview that contained questions related to the components of the ICF model (WHO, 2001b).

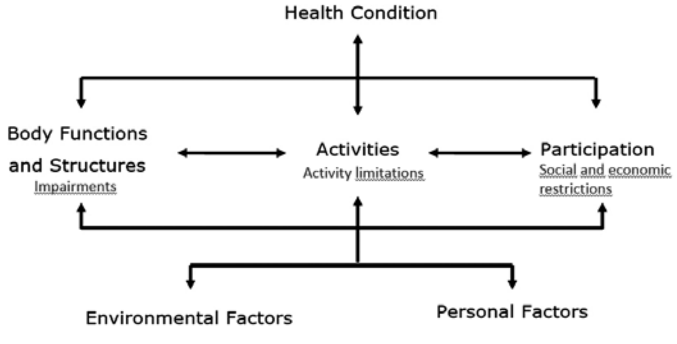

Figure 1: International Classification of Functioning, Disability and Health model
(Topics of the semi-structured interview are underlined)

The interviewer used a generic assessment form, that contained open and closed questions, which comprised personal information, part 1 of the ICF Checklist (WHO, 2003), parts of a leprosy needs assessment developed in Indonesia (Rural Development Academy, n.d.), socio-economic information of a needs assessment developed in Nepal (International Nepal Fellowship, 2005), and 8 mental health questions of the WHO Self-Reporting Questionnaire(SRQ) (Beusenberg & Orley, 1994) (Table1). Mental distress was considered to be present when participants gave more than 5 positive responses to mental health questions or suicide was mentioned. Interviews lasted for an average of 30-45 minutes.

Table 1: Mental Health questions of the Self-Reporting Questionnaire of the WHO

Mental Health questions*	Answers
I1 Do you feel unhappy?	Yes / No
I2 Is your appetite poor?	Yes / No
I3 Do you sleep badly?	Yes / No
I4 Are you easily frightened?	Yes / No
I5 Do you feel nervous, tense or worried?	Yes / No
I6 Do you have trouble thinking clearly?	Yes / No
I7 Did you also have these feelings before you had this impairment/ condition?	Yes / No
I8 Do you have a positive feeling about the future? Explain.	Yes / No

*Mental health questions of the Self-Reporting Questionnaire of the World Health Organisation (Beusenberg & Orley, 1994)

Prior to the interviews, the needs assessment form was pilot-tested in accordance with the guidelines of the ESCAP project (EscapStatistics, 2010).Questions were adapted to the Cambodian culture and lifestyle. The validity of the translation was tested by back-translating the questions into English. Where necessary, adaptations were made in the Khmer translation. Subsequently, 5 former leprosy clients were interviewed to study how well these questions would be understood by the study groups.

Focus group discussions collected information about the most important perceived needs related to social participation of people with disabilities among the study groups, and about interventions they considered useful to improve their quality of life. These focus group discussions included 8-9 persons of both sexes and lasted for approximately 2 hours. Discussion topics were determined based on interview results (social status, economic status, self-help group).

To ensure that participants did not give socially desirable answers, the researchers avoided asking questions to which the 'right' answer could be guessed. However, it is not clear whether this was achieved. Voice-recordings and notes were made during interviews and focus group discussions which were conducted in the Khmer language. Two Cambodian English students, who were almost graduates, were trained to conduct the interviews and focus group sessions following the qualitative field guideline (Mack et al, 2005). In addition, two staff members of the NLEP were involved in the study, to conduct the pilot-test and several interviews in the field.

Data Analysis

Data collection consisted of notes and voice-recordings of interviews and focus group discussions. Voice-recordings were immediately transcribed and translated into English using Microsoft Word. The researcher made categories of participants' responses per question. These categories were then used to thematically code each line and paragraph of the text. Subsequently, codes of each participant per question were entered on an Excel spreadsheet, the codes were checked twice and, where relevant, used for descriptive statistics using SPSS software. A comparison in outcomes between the 2 study groups provided information on frequently encountered problems, perceived needs related to social participation and possible interventions.

Ethical Considerations

This study was approved by the Ethics Committee of the Cambodian Ministry of Health. Support and approval papers were obtained before field research was conducted in the province. Individuals were included in the study only after informed written consent was given. Participants received small incentives such as food, soap and/or vitamins.

RESULTS

Personal Information

People with leprosy-related disabilities were interviewed during follow-up field visits (17/20) and at the rehabilitation centre (3/20). The mean age was 47 years (range 22-61years). All interviews with people with locomotor disabilities were carried out at VIC. The mean age was 34 years (range 19-61years) (Table 2).

Table 2: Interviews and Focus Group Locations of people with leprosy-related disabilities and people with locomotor disabilities in Cambodia

	People with leprosy-related disabilities (n=37)		**People with locomotor disabilities (n=28)**	
	Interviews n=20	**Focus group**	**Interviews n=20**	**Focus group**
Field visit	17	0	0	0
Rehabilitation centre^	3 Khleang^	2 Khleang^ (8/9 participants)	12 VIC (Phnom Penh) 8 VIC (Prey Veng)	1 VIC (Prey Veng)

^Khleang is the National Leprosy Rehabilitation Centre ‘Kien Khleang’ for people with leprosy-related disabilities in Phnom Penh, and VIC is the Veterans International Centre for people with locomotor disabilities in Phnom Penh or Prey Veng.

Most of the participants were male and all of them were Buddhist. Data shows that people with locomotor disabilities have a higher mean education level than people with leprosy-related disabilities. While the majority of the former have had primary (8/20) or high school (9/20) education, most of the latter have only had primary education (11/20) or have never had any education (6/20) (Table 3). Of the people with leprosy-related disabilities who had primary school education, 50% reportedly cannot read or write anymore; the figure for the other group is 25%. Furthermore, most participants lived in rural areas.

A similar number of people with leprosy-related disabilities (5/20) and people with locomotor disabilities (4/20) were considered to have mental distress (Table 3). More persons in the latter group gave negative answers (category 0) to all mental health questions compared to persons affected by leprosy (6/20 vs. 2/20).

Table 3: Personal information of people with leprosy-related disabilities and people with locomotor disabilities who participated in interviews

Personal Information (number (%))	People with leprosy-related disabilities n=20	People with locomotor disabilities n=20	Total n=40
Age (M (range))	47(22-61)	34 (19-61)	41 (19-61)
Male	14 (70)	16 (80)	30 (75.0)
Education level			
Never	6 (30)	1 (5)	7 (17.5)
Primary school	11 (55)	8 (40)	19 (47.5)
Secondary school	2 (10)	1 (5)	3 (7.5)
High school	1 (5)	9 (45)	10 (25.0)
Advanced	0 (0)	1 (5)	1 (2.5)
Living area			
Rural	19 (95)	16 (80)	35 (87.5)
Urban	1 (5)	4 (20)	5 (12.5)
Mental health situation^			
0	2 (10)	6 (30)	8 (20.0)
1-5	13 (65)	10 (50)	23 (57.5)
>5/suicide	5 (25)	4 (20)	9 (22.5)

^Mental health situation is estimated by the number of positive responses on mental health questions (Self-Reporting Questionnaire)

Body Functions, Structures and Activity

Almost all the people with leprosy-related disabilities had Grade II impairment (19/20) and only one had Grade I impairment. People with locomotor disabilities had impairments that were mainly caused by accidents (10/20) or diseases (6/20), as well as high blood pressure (2/20), complications during birth (1/20) or unknown causes (1/20). Participants defined accidents as traffic, work or conflict accidents, and diseases were mainly polio or cancer. The ICF checklist indicated that most people with leprosy-related disabilities have deformities of limb or impairment of sensation, while most people with locomotor disabilities have weakness/paralysis of limbs or a missing limb (Table 4). Questions of the checklist indicate that both groups experience similar activity limitations, such as difficulty in walking.

Table 4: Results on Impairment and Activity of people with leprosy-related disabilities and people with locomotor disabilities who participated in interviews

Impairment and Activity (number (%))	People with leprosy-related disabilities n=20	People with locomotor disabilities n=20	Total n=40
Body Functions & Structure			
Disfigurement of limb	19 (95)	4 (20)	23 (57.5)
Impairment of sensation	16 (80)	2 (10)	18 (45.0)
Weakness/paralysis of limb	6 (30)	10 (50)	16 (40.0)
Seeing disorder	2 (10)	1 (5)	3 (7.5)
Missing limb	0 (0)	9 (45)	9 (22.5)
Activity Walking			
Difficult	16 (80)	20 (100)	36 (90.0)
Easy	4 (20)	0 (0)	4 (10.0)
Using tools (e.g. materials, spoon, pen)			
Difficult	11 (55)	6 (30)	17 (42.5)
Easy	9 (45)	14 (70)	23 (57.5)

Social Participation

Most people with leprosy-related disabilities (16/20) and people with locomotor disabilities (17/20) visit other people and are visited by others (Table 5). However, some participants would rather not visit other people because they do not feel welcome, are afraid of discrimination or are not visited by others.

> *"Sometimes I visit other people, but not often, because it feels like my friends are not happy to see me" (Male with leprosy-related disabilities, age 22 years).*

Table 5: Social Participation of people with leprosy-related disabilities and people with locomotor disabilities who participated in interviews

Social Participation (number (%))	People with leprosy-related disabilities n=20	People with locomotor disabilities n=20
Visit How often do you visit other people and other people visit you?		
(rather) No	1 (5)	2 (10)
Sometimes	3 (15)	1 (5)
Often	16 (80)	17 (85)
Negative attitude How often have other people's attitudes towards your condition been a problem at home, at school or at work?		
Never	12 (60)	14 (70)
Sometimes	6 (30)	3 (15)
Often	2 (10)	3 (15)
Stigma Are you discriminated against because of your condition? Or do you feel like you are discriminated against? Please explain		
No	12 (60)	13 (65)
Felt stigma:	2 (10)	5 (25)
• Afraid of stigma	2	5
• Shy of others	2	3
• Stay inside the house	0	2
Discrimination	6 (30)	2 (10)
• Other people do not talk to me (when I talk to them)	6	2
• Afraid of stigma	3	0
• Gossip about me	2	1
• Look down on me	3	1
• Cannot sell (or buy)	2	0
• Family/friends do not like to see me	2	0
• Other people fear me	2	0
• Family does not want to eat together	1	0

Participants were asked their own views on perceived negative attitudes of other people. Some people with leprosy-related disabilities (8/20) and other people with locomotor disabilities (6/20) 'sometimes' or 'often' experience negative attitudes from other people. Most participants experience no discrimination. However, a few people with leprosy-related disabilities and also people with locomotor disabilities responded that they were afraid to be discriminated against or felt like they were discriminated against.

> *"I am afraid to go outside (in public). Therefore, I stay often inside the house. I am afraid that people at the market will discriminate me, because I am poor and have crutches. I have seen other people with crutches who were seen as beggars… They just ignore them and not sell anything to them"* (Male with locomotor disabilities, age 55 years).
>
> *"I hide the disease for other people, because I am afraid of what will happen when everyone of the village knows that I had leprosy"* (Female with leprosy-related disabilities, age 49 years).

People with leprosy-related disabilities, in particular, reported that they experienced actual discrimination (6/20). This was also reported by a few people with locomotor disabilities (2/20). Indicators mentioned for felt stigma or discrimination of participants are listed in Table 5. Half of those considered to have mental distress said they experienced stigma or felt discrimination; the other half said they did not experience this.

> *"My family and friends are not happy to see me and do not like to talk with me…I was first discriminated by my family and neighbour and therefore I live with my grandma now… because she does not discriminate me as much as the others… my grandma is not happy to help me out… I do all the work in the house, like cooking, earning the money, wash the clothes… I have to earn money to live and also give some to my mom and grandma"* (Male with leprosy-related disabilities, age 22 years).
>
> *"The children at school never talk to me and wherever I go, I am always alone. First I had a friend at school, but then another girl told her that she may not talk to me because I have the impairment… She stopped talking to me"* (Female with locomotor disabilities, age 19 years).

Participants who are discriminated against were asked how they think discrimination against people with disabilities can be prevented. Responses were: *"I do not know"*, *"I need to be cured of leprosy"*, *"I need to move normal again"*, *"People need more education"* and *"I need to earn more money"*.

> *"I think that now that I am poor and have the impairment people discriminate me. But if I had a better job and would earn more money, then the number of people who discriminate me will be lower"* (Male with locomotor disabilities, age 48 years).

Economic Participation

Factors of people with disabilities related to economic participation are described in Table 6. Most people with leprosy-related disabilities were farmers/fishermen (11/20), and some were unemployed (5/20). Relatively more people with locomotor disabilities were unemployed (10/20). About a third of unemployed persons also said they experienced stigma or discrimination. The income of participants was divided by the number of people in the household who had to live off this money per day. The World Bank (2006) measured the poverty line of Cambodia to be approximately 2000 Riel per capita per day (about US$0.5). This income guideline was adopted by the researchers to calculate the number of participants living in poverty. Results indicated that fewer people with locomotor disabilities (2/20) live in poverty than people with leprosy-related disabilities (11/20). Responses to questions about earnings indicated that most people in both groups believed they were earning less at the time of being interviewed, compared to earlier when they did not have an impairment.

> *"I earn nothing at this moment and before I had a normal job. So there is a big difference between* (what I earn) *now and before"* (Male with locomotor disabilities, age 32 years).

Table 6: Economic Status of people with leprosy-related disabilities and people with locomotor disabilities who participated in interviews

Economic Factors (number (%))	People with leprosy-related disabilities n=20	People with locomotor disabilities n=20	Total n=40
Occupation			
Unemployed	5 (25)	10 (50)	15 (37.5)
Student	0 (0)	2 (10)	2 (5.0)
Retired	1 (5)	0 (0)	1 (2.5)
Farmer/fisherman	11 (55)	3 (15)	14 (35.0)
Employed in business	2 (10)	2 (10)	4 (10.0)
Owner of business	1 (5)	1 (5)	2 (5.0)
Official	0 (0)	2 (10)	2 (5.0)
Income p.d.p.c^			
<0.5 USD	11 (55)	2 (10)	13 (32.5)
>0.5 USD	3 (15)	6 (30)	8 (20.0)
Unknown^^	6 (30)	12 (60)	18 (45.0)
Earning		*(n=15)*	*(n=35)*
Similar	8 (40)	3 (20)	11 (31.4)
Less than before	12 (60)	12 (80)	24 (68.6)

^The World Bank published the poverty line of Cambodia 2009= US$0.5 per day per capita (p.d.p.c); ^^People are unemployed or do not know their income.

Focus groups discussed the topic 'work'. Some people with leprosy-related disabilities and most people with locomotor disabilities were still able to carry out the jobs they had earlier. However, most people with leprosy-related disabilities had trouble finding a job or had to carry out another job because of their disability. Issues mentioned were: *"cannot do anything"*, *"cannot do the work I like to do"*, *"people do not want to buy from me anymore"*, and *"no money to start a business"*. Main needs to carry out the job they would like to do were: learning new skills, money to start a business, and assistive devices.

> *"If we only have skills, but no money, I cannot start working. Thus, then there is no use of learning new skills. This result will not improve my living standard"* (Male with locomotor disabilities, age unknown).

People in both groups responded that they have no job opportunities because of their impairment (Table 7). According to them, not having the right skills, in particular, as well as age and/or weakness were important factors responsible for this. Most people with leprosy-related disabilities explained that they were able to contribute to their family because they earned money. Those who did not earn any money explained that they could only do household work or look after the children.

Table 7: Opportunities and Contribution of people with leprosy-related disabilities and people with locomotor disabilities who participated in interviews

(Number (%))	**People with leprosy-related disabilities n=19**	**People with locomotor disabilities n=18**
Opportunity Do you have the same opportunity to find work as others?		
Yes	9 (47)	8 (44)
No	10 (53)	10 (56)
Contribution (n=19) Can you contribute to the family as others do?		
Yes	15 (79)	9 (47)
No	4 (21)	10 (53)

After explaining what a Self-Help Group (SHG) was, all people with leprosy-related disabilities and almost all people with locomotor disabilities responded that they had never been members. However, most participants were interested to become members if a SHG was present in their area.

> *"I think it is important to come together to discuss about subjects related to our disability and help each other out"* (Female with leprosy-related disabilities, age 44 years).

One of the participants with locomotor disabilities stated that he was a member of a SHG specifically for people with disabilities. The group consisted of 10 people and focussed mainly on agriculture. They only discussed work-related problems, and not about their impairments or where to find special services. He explained that the SHG had really improved his farming skills. Participants in the focus groups also said they were not members of a SHG. Most of them were interested in joining one. All of them believed it was important to share knowledge about skills and discuss experiences and problems they have had, related to their disability, with one another.

DISCUSSION

The perceived needs related to social participation of people with leprosy-related disabilities and persons with locomotor disabilities are described in this study, in order to investigate the similarities and differences and suggest possible interventions to address these needs.

Participation of a person with disabilities can be influenced by impairments of the hands affecting dexterity, or of the legs/feet affecting mobility, or by mental distress. On the basis of the responses to the questions of the SRQ, a similar number of persons of both groups were considered to have mental distress. This is similar to the findings in an unpublished study of Ramerman (unpublished), who investigated the association between activity limitation (Green Pastures Activity Scale) and mental health (SRQ) of persons with leprosy-related disabilities, persons with other disabilities, and controls in the Eastern Region of Nepal. Both groups of persons with disabilities showed similar results on mental distress scores, and both scored significantly higher than the controls. In addition, in the current study, only a few persons with leprosy-related disabilities responded with ‘no problem’ to all mental health questions (category 0), compared to about a third of persons with locomotor disabilities. This might suggest that, in general, the former group of persons experience more mental distress. The fact that persons affected by leprosy are more prone to ‘disturbance of mental health’ as measured with the SRQ was also shown convincingly by Tsutsumi et al, 2007.

Furthermore, participation of people with disabilities is often affected by stigma. Outcomes indicated that people with leprosy-related disabilities, in particular, as also people with locomotor disabilities, still suffer from felt stigma and/or discrimination. They raised the need for greater self-confidence and measures to reduce stigma and to improve their social participation in the community. Only if the personal and environmental barrier of social stigma is overcome through acceptance, will they consider participating socially and visiting public places again. According to participants, only reduction or compensation of their physical impairment and, where relevant, their disfigurement, can reduce discrimination. However, participants also described being ‘well off’ as an important factor to prevent discrimination. Living in poverty was described as a 'visible disability' that was a source of discrimination in itself. This fits with findings of Ebenso et al (2007) in Nigeria that socio-economic development was an effective means to reduce stigma against leprosy.

Participants expressed the wish to participate in economic life by earning money to support their households. Leprosy treatment and medical rehabilitation, though effective in overcoming the infection and improving their body function, was often not enough for the client to return to daily life like before. Results showed that at least half the participants who were employed earned wages below the poverty line (US$0.5 per day). Most participants who experienced disability later in life explained that they earned less at present, compared to the period when they did not have a disability. Similar results were described by other disability studies in Cambodia by Thomas (2005) and Cambodia Socio-Economic Survey (NIS, 2007).The mutual relationship between disability and poverty has been described in detail by Yeo and Moore (2003). They show how impairments and disabilities can lead to or aggravate poverty in multiple ways. Discrimination plays a major role is this process. They also show how poverty, in turn, may cause or aggravate disability, thus creating a vicious cycle. Most unemployed participants believed they have no opportunity to find a job due to loss of special skills and/ or slower body functioning. The focus groups also argued that there is a lack of job opportunities for people with disabilities. In order to participate in economic life, respondents emphasised the need to improve their employment opportunities through assistive devices, vocational training and microcredit to fund self-employment.

Research has demonstrated that economic rehabilitation will empower people with disabilities through activities that they are involved in and through the ability to support themselves (Ebenso et al, 2007;Velema, 2008). This results in improved self-esteem and brings the person back into the community as a contributing member of society. Fortunately, VIC and Kien Khleang both provide vocational training and/or microcredit to people who need help to start a job or business. However, when receiving microcredit, the loan has to be repaid within a limited time. Most businesses are successful, but this may be too challenging for some people. Consequently, part of the loan is often subsidised by the institution (Allen, 2006; De Klerk, 2008).In addition, access to microfinance may be difficult. Even though most of the very poor people with disabilities live in rural areas, microfinance institutions are reluctant to operate in these areas (Thomas &

Thomas, 2004; Thomas, 2005) because their services are often more successful in urban areas (Allen, 2006; De Klerk, 2008).

An alternative and recommended approach to improve support and assist the socio-economic status of disadvantaged people is the establishment of Self-Help Groups (SHGs). Through the formation of a SHG, a shift occurs from the individual to a community-based rehabilitation approach. The operational model is often a "savings-first business" model(De Klerk, 2008). The savings of members will be used to finance loans, allowing members of the group to monitor the repayment, loan distribution and decision-making regarding the loan. Unlike commercial microcredit, this approach has the potential to reach the poorest people with disabilities in rural areas (Allen, 2006; De Klerk, 2008) and challenges them to be more involved in the rehabilitation process. In addition, SHGs also help to enhance confidence and self-esteem. For these purposes, SHGs were effectively established in many Asian countries, such as India(De Klerk, 2008) and Nepal(Cross & Choudhary, 2005), and in African countries (Allen, 2006; Ebenso et al, 2007).The Leprosy Mission Trust India facilitated access to mainstream resources and networking with NGOs(De Klerk, 2008). The groups receive support in the form of education, such as skills training, employment and social services. A microfinance system has been developed, with loans, savings and credit for the members. They showed this approach to be effective to empower people and fight poverty(De Klerk, 2008). A similar system ('community based savings and lending groups') was set up in Africa by international NGOs, such as CARE (Allen, 2006).

VIC already creates SHGs for their rehabilitation clients. However, at the time of the study, no SHGs for people with leprosy-related disabilities existed in Cambodia because, according to the rehabilitation centre, they live too far apart to create such groups. Therefore, the authors suggest that a suitable approach for socio-economic rehabilitation might be the formation of multi-disability SHGs that include persons with leprosy-related disabilities. Successful groups are already in operation in other countries, like in India (De Klerk, 2008),in the STEP programme in Nepal(Cross & Newcombe, 2001) and in Indonesia (Beise et al, unpublished). Creating multi-disability SHGs that include persons with leprosy-related disabilities could be the first step to integrate rehabilitation services for former leprosy clients into general rehabilitation programmes for people with disabilities in Cambodia. This would fit with the recommendation of WHO (2005) to integrate leprosy-related rehabilitation services, because rehabilitation programmes for (former) leprosy clients are costly and difficult to maintain in countries where there are few endemic pockets of leprosy, as is the case in Cambodia. Integration would result in a more efficient provision of general rehabilitation services.

CONCLUSION

A significant minority of people with leprosy-related disabilities and people with other disabilities still struggle with social and economic exclusion. There is a need for socio-economic rehabilitation to enhance their opportunities to reintegrate into society and subsequently improve their self-esteem and economic life.

Various rehabilitation centres provide vocational training and microcredit as economic rehabilitation, but these are not yet utilised by persons with leprosy-related disabilities. Based on evidence from the literature and experience elsewhere, the authors suggest a community-based rehabilitation approach through the introduction of multi-disability SHGs for people with leprosy-related disabilities and other people with disabilities. This would also have the potential to reach the poorest people with disabilities, especially in rural areas. Adoption of this approach could be the first step towards integration of rehabilitation services for former leprosy clients into the general rehabilitation programme of Cambodia.

Further research is required to confirm the findings of this study in a larger, representative sample, and to investigate the feasibility and effectiveness of multi-disability SHGs in Cambodia and the factors that have a bearing on their effectiveness.

Limitations

The biggest limitation was the non-random sampling of the respondents. The sampling method depended on the cooperation of the NLEP team, because former leprosy clients were interviewed at home during follow-up visits. As a result, NLEP staff chose the locations where interviews were conducted. Unlike most people with leprosy-related disabilities, people with locomotor disabilities were mainly interviewed at the rehabilitation centres. No matching for sex and age was possible. The sex distribution was similar in both groups, but the people with locomotor disabilities were significantly younger than those affected by leprosy. This may have introduced a bias in some responses, such as the lower percentage of persons with mental distress in the former group. Despite this limitation, the authors believe they were able to portray a useable picture of the participation-related needs of people with disabilities in Cambodia. However, the conclusions cannot be generalised because of the small number of participants in this study.

ACKNOWLEDGEMENT

The authors would first like to thank all the participants in this study. They express their gratitude to the staff of the National Leprosy Elimination Programme in Cambodia, the rehabilitation centre Kien Khleang and Veterans International. They are also grateful to the translators Mey Huong Kim, Marina Lay, Mr. Sambath and Mr. Hieng.

The study was supported by grants from the Netherlands Leprosy Relief (NLR) and the VU University Amsterdam.

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