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**LETTER TO EDITOR**

Investing in Community-based Physiotherapy: the Non-economic Benefits
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Editorial

Community based rehabilitation (CBR) was initially promoted to address needs of persons with disabilities living in developing countries. Today it is the accepted strategy to promote inclusive development for all persons with disabilities, based on the rationale that none should be excluded from the development process for any reason. Over the years, as CBR evolved, there has been some debate about how it can be applied in a developed society, with the premise that while the principles of CBR could be considered as universal, practice may differ according to the context.

There are vast differences between developing and developed countries in terms of the contexts or backdrop against which CBR practice can be viewed. In most developing countries, the major challenges include poverty, large populations, poor health care leading to high incidence of preventable causes of impairment, and low levels of education and awareness, especially in remote rural areas. Addressing basic needs remains a priority in these countries. Many of these countries have laws, policies and regulations for inclusion and protection of rights of persons with disabilities, and to prevent discrimination; but implementation of these laws leaves much to be desired, mainly because of lack of sufficient financial resources to ensure implementation. For example, laws to promote physical accessibility may be present, but in practice, most public places and transport systems remain inaccessible to persons with disabilities. Likewise, most rural areas where a majority of persons with disabilities live, have limited infrastructure, services and facilities that can be of benefit to them. Where present, welfare measures promoted by governments for persons with disabilities are generally viewed as inadequate in terms of both quantity and quality.

On the plus side is the family and community support that is still prevalent in developing countries that place a higher value on the ‘collective’ compared to the ‘individual’. This is not to say that such values do not exist in the developed world. In Japan for example, there are rural communities that are very close-knit and mutually supportive, where people do not lock their house doors, illustrating their inclusive and welcoming spirit.

Another positive factor in developing countries is the presence of an active and vibrant voluntary sector in disability and development issues; these came up
mainly as an alternative to address needs in development areas, in the absence of sufficient government involvement in the early years.

CBR and inclusive development thus clearly have different baselines on which to work towards inclusion in developing and developed countries. Developing countries have a lower baseline to work with in terms of limited services and facilities, poor accessibility, limited resources and support from government. In many instances, services have to be developed from scratch, especially in rural areas. These countries have to work with larger populations as well.

In contrast, developed countries have better developed services, systems and resources for implementation of laws and policies to promote inclusion, including accessibility provisions for different categories of impairment. Populations of persons with disabilities that need to be covered are generally less than what is found in developing countries. Against such a backdrop, CBR and inclusive development experiences from countries like Japan highlight some good practices of a twin track approach in promoting inclusive communities: identifying needs and opportunities in the community for marginalised groups on the one hand; and mobilising community resources and support to change attitudes and promote inclusion on the other. Persons with disabilities with high support needs are ensured access to high quality services. Other marginalised groups such as the elderly and the homeless also reap the benefits of inclusive development.

As and when the economic situations improve in developing countries, they can learn from the experiences of inclusive development from the developed world, especially inclusion of persons with high support needs and of other marginalised groups in the community.

Season’s greetings and good wishes for the new year to all our readers from the DCID team.

**Maya Thomas**
Editor-in-Chief
Disability, CBR and Inclusive Development
Knowlegde Management-based Classification Method for Disability-Inclusive Business

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ABSTRACT

Purpose: This study provides evidence to clarify disability inclusiveness in activities of rural business. As an alternative to the analysis method that deals with disability-inclusiveness as a vague concept, knowledge management principles were applied to propose a classification method for disability-inclusive business as an emerging concept at the community level.

Methods: The analysis focuses on: 1) productivity of entrepreneurs with disabilities; 2) knowledge of entrepreneurs with disabilities; and 3) understanding of customers. A total of 50 entrepreneurs with disabilities in micro and small businesses in Southeast Asia were identified in this context. Data were collected and analysed according to a story-based knowledge management approach and value chain analysis. Fuzzy logic analysis which exploited domain ontology was utilised to convert knowledge from tacit to explicit, in line with knowledge management principles. A numeric weight based on linguistic variables became available to describe each disability-inclusive business case, as well as the arrangements of fuzzy sets.

Results: Out of 50 cases, 7 were classified as fully disability-inclusive while 14 were classified as not disability-inclusive. Productivity of entrepreneurs with disabilities in 3 elements of the value chain, namely procurement, product/service development and distribution, was observed to be significant. The Study showed that disability-related knowledge of entrepreneurs with disabilities could contribute to business performance according to the key success factors to enhance added value. Two elements of the value chain, namely sales/marketing and customer service, are not the decisive factors to define and clarify disability-inclusiveness.

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Conclusion: Settings in Southeast Asia are diverse and at varying stages of economic and social development; hence the environment which promotes the disability-inclusive business concept may be inconsistent. Micro and small-scale rural businesses were tackled as a first step to evaluate comparative efforts of each case of disability-inclusive business from the viewpoint of entrepreneurs with disabilities. Therefore, in highlighting the differences, it is recommended that further research should seek to apply weighting factors depending on the individual size, contents and scale of major business areas.

Key words: Disability-inclusive business, fuzzy logic, knowledge management.

INTRODUCTION

According to the livelihood component of the Community-Based Rehabilitation (CBR) Guidelines, “self-employment” is a term applied to economic activities in both the formal and informal economies which are owned, operated and managed by an individual or a group (WHO, UNESCO, ILO, & IDDC, 2010). The CBR Guidelines noted three broad categories as i) income-generating activities; ii) small and medium enterprises; and iii) self-help groups and group enterprises (WHO, UNESCO, ILO, & IDDC, 2010). Indeed, the major local and international NGOs working for disability and academic institutes have referred to a variety of livelihood activities by persons with disabilities in developing countries. On one hand, there are many research papers that have addressed significant contributions of the business sector, such as the initiatives of Corporate Social Responsibility (CSR) for persons with disabilities and their organisations in rural areas. However, there was no specific strategy on disability and business, unlike the “green business” strategy in the environment field.

Against this background, the term “disability-inclusive business” was initially raised through the Senior Officials’ Meeting on South-to-South Cooperation on Disability organised by the Asia-Pacific Development Centre on Disability (APCD) and the United Nations Economic and Social Commission for Asia and the Pacific (ESCAP) at the United Nations Convention Centre in Bangkok, Thailand, in August 2010 (APCD, 2010). Through a series of discussions to elaborate the concept, the definition of disability-inclusive business was adopted as “an enterprise that has a positive impact on disability-friendly environment, communication, attitude, policy and regulation, taking into consideration the business model where its activities comply with the following criteria: 1) It incorporates the principles of accessibility into each of its business aspects; 2)
It offers disability-friendly products, communication and services that replace those which are not disability-friendly; and, 3) It has made a commitment to disability principles according to the United Nations Convention on the Rights of Persons with Disabilities in its business policies” (APCD, 2012).

Following this progress, the United Nations ESCAP recognised the concept of disability-inclusive business through a regional policy paper on disability and development called “Incheon Strategy to Make the Right Real, 2013-2022” (ESCAP, 2012). In collaboration with the United Nations ESCAP, APCD is requested to encourage private sector engagement in disability-inclusive business that promotes disability-friendly products, services, employment opportunities and entrepreneurship development (ESCAP, 2012). In terms of both the value-addition inherent to ensure enabling environments for persons with disabilities in the business context, and the increased market share for business in the delivery of disability-friendly products and services, the concept of disability-inclusive business is expected to extend beyond an advocacy-based approach to an enhanced business model. Therefore, disability-inclusive businesses could be viewed as those that incorporate and extend opportunities and services to persons with disabilities, and positively overcome the conventional barriers they face.

At the same time, it is necessary to clarify disability-inclusiveness in the promotion of the disability-inclusive business concept, assuming that a disability-friendly environment can prove beneficial to a company’s bottom line. While most business cases perceive disability as the topic of Corporate Social Responsibility (CSR), there is no clear method to understand, analyse and promote disability-inclusive business. Available disability-related information materials have not addressed knowledge that persons with disabilities could apply to tackle obstacles and promote businesses in an inclusive way. Moreover, there is no model that can demonstrate disability-inclusiveness, though an analysis is needed for persons with disabilities to apply knowledge into business. In collaboration with knowledge workers, the clarification of disability-inclusiveness is needed to elaborate the viewpoints of productivity, understanding and knowledge in the context of disability and business.

In line with this, the current study sought to apply the principles of knowledge management to explore the topic of disability-inclusive business pertaining to rural community settings in Southeast Asia. It also aimed to propose a classification method for further discussion and consideration.
Objective
The study aims to answer two questions:

1) What knowledge and other key elements are available from the identified disability-inclusive business cases by entrepreneurs with disabilities at the community level in Southeast Asia?

2) How can fuzzy logic be applied to clarify disability-inclusiveness in the business context in rural settings in Southeast Asia?

METHOD

Story-based Knowledge Management
Case study is one technique of qualitative research. While case study methods involve an in-depth examination of a single instance rather than of many samples, the distinction between tacit and explicit knowledge suggests four basic patterns: socialisation, externalisation, combination and internalisation: SECI model (Nonaka, 1994). For creating and managing knowledge in any community practice, Story-based Knowledge Management is one approach which indicates that the process of knowledge management can be documented as a story (APCD, 2010), and illustrate into knowledge creation, validation, production and distribution according to SECI model (Nonaka & Konno, 1998). It provides a systematic way of observing the case, collecting data, analysing information, and reporting.

Study Population and Sampling Method
In-depth interviews were conducted for data collection and analysis. Through field visits, 66 persons with disabilities were contacted, who were engaged in small businesses in communities in rural areas of Southeast Asia. A total of 50 cases were selected for further study and 16 were omitted as they did not comply with the entrepreneurship criteria.

Entrepreneurship Criteria:
- Business Role: Entrepreneurs who play the roles of employers, own-account workers, members of producers’ cooperatives or contributing family workers as defined by the ICSE-93.
• Sustainability: Entrepreneurs who run their business on a regular basis.
• Income Source: Entrepreneurs who get remuneration that is directly dependent upon the profit derived from their own business.

All interviews were conducted on a voluntary basis. The face-to-face interviews started with basic information about business and were followed by the semi-structured interviews to analyse the disability-inclusive business elements.

Disability-Inclusive Fuzzy Logic Analysis Tool

Recently, the fuzzy logic technique has been applied to a variety of topics in modelling of uncertainties, vagueness, impreciseness and the human thought process (Dahal et al, 2005).

In this study, fuzzy logic was utilised to classify disability-inclusive business by clarifying what disability-inclusiveness is. With the aim of dealing with “disability-inclusiveness” as a fuzzy, imprecise or vague concept, the “Disability-Inclusive Fuzzy Logic Analysis Tool” has been proposed, to ensure a perspective from all the target cases and to demonstrate the breadth of the study. A computer application software called “Matlab” was utilised for fuzzy logic analysis to respond to a linguistic and interactive environment for numerical computation and visualisation.

The unique point of this study is to classify disability-inclusiveness in business, and to establish that productivity of entrepreneurs with disabilities is significant to business, given the condition that either knowledge of entrepreneurs with disabilities or understanding of customers can also be observed based on 5 components of the value chain which includes 1) procurement; 2) product/service development; 3) distribution; 4) sales/marketing; and, 5) customer service. Mamdani’s (1977) method was chosen for fuzzy interference with direct method. Fuzzy Linear transformation function applied a linear function was set in the 0 to 100 range.

In line with the SECI model (Nonaka, 1994), the method to classify disability inclusiveness is presented in Figure 1.
1) **Socialisation**

50 cases were randomly divided into 2 groups. Group 1 comprised 25 cases of entrepreneurs who were selected to classify productivity, knowledge and understanding by classification of elements of the value chain: 1) procurement; 2) product/service development; 3) distribution; 4) sales/marketing; and, 5) customer service as fuzzy set 1.

The classification of productivity could be represented with the following 243 input fuzzy sets:

- “Productivity-high” if availability of productivity of entrepreneurs with
disabilities in at least 3 out 5 elements of value chain could be observed (51 fuzzy sets).

- “Productivity-medium” if availability of productivity of entrepreneurs with disabilities in 1 or 2 out of 5 elements of value chain could be observed (160 fuzzy sets).
- “Productivity-low” if availability of productivity of entrepreneurs with disabilities in value chain could be observed at the level of “somewhat” or “not at all” (32 fuzzy sets).

The classification of knowledge could be represented with the following 243 input fuzzy sets:

- “Knowledge-profound” if availability of knowledge of entrepreneurs with disabilities in at least 3 out 5 elements of value chain could be observed (51 fuzzy sets).
- “Knowledge-medium” if availability of knowledge of entrepreneurs with disabilities in 1 or 2 out of 5 elements of value chain could be observed (160 fuzzy sets).
- “Knowledge-superficial” if availability of knowledge of entrepreneurs with disabilities in value chain could be observed at the level of “somewhat” or “not at all” (32 fuzzy sets).

2) Externalisation

The sales/marketing element and customer service element could not be observed significantly in productivity, knowledge and understanding, so the above-mentioned elements were removed from the classification. For Group 1 of entrepreneurs with disabilities, the 3 classification elements included 1) procurement; 2) product/service development; and, 3) distribution as fuzzy set 2.

The classification of productivity could be represented with the following 27 input fuzzy sets:

- “Productivity-high” if availability of productivity of entrepreneurs with disabilities in at least 2 out of 3 elements can be observed (7 fuzzy sets).
- “Productivity-medium” if availability of productivity of entrepreneurs with disabilities in 1 out of 3 elements of value chain can be observed (11 fuzzy sets).
“Productivity-low” if availability of productivity of entrepreneurs with disabilities in value chain can be observed at the level of “somewhat” or “not at all” (9 fuzzy sets).

The classification of knowledge could be represented with the following 27 input fuzzy sets:

- “Knowledge-profound” if availability of knowledge of entrepreneurs with disabilities in at least 2 out of 3 elements of value chain can be observed (7 fuzzy sets).
- “Knowledge-medium” if availability of knowledge of entrepreneurs with disabilities in 1 out of 3 elements of value chain can be observed (11 fuzzy sets).
- “Knowledge-superficial” if availability of knowledge of entrepreneurs with disabilities in value chain can be observed at the level of “somewhat” or “not at all” (9 fuzzy sets).

The classification of understanding could be represented with the following 27 input fuzzy sets:

- “Understanding-deep” if availability of disability-related understanding of customers in at least 2 out 3 elements of value chain can be observed (9 fuzzy sets).
- “Understanding-medium” if availability of disability-related understanding of customers in 1 out of 3 elements of value chain can be observed (11 fuzzy sets).
- “Understanding-shallow” if availability of disability-related understanding of customers in value chain can be observed at the level of “somewhat” or “not at all” (9 fuzzy sets).

Priority was given to productivity. The classification of disability-inclusive business could be represented with the same 27 output fuzzy sets: as in ‘socialisation’

- “Fully disability-inclusive” if “productivity-high”, “knowledge-profound” and “understanding-deep” (1 fuzzy set).
- “Intensive disability-inclusive” if “productivity-high” and either “knowledge-profound” or “understanding-deep” (4 fuzzy sets).
- “Somewhat disability-inclusive” if “productivity-high” and either...
“knowledge-medium/superficial”; or, “understanding-medium/shallow” “productivity-medium” and either “knowledge-profound/medium/superficial” or “understanding-deep/medium/shallow” (13 fuzzy sets).

- “Slightly disability-inclusive” if “productivity-low” and either productivity-low” and “knowledge-profound/medium/superficial” or “understanding-deep/medium/shallow” (8 fuzzy sets).

- If “productivity-low” and “knowledge-superficial” and “understanding-shallow” then “not disability-inclusive” (1 fuzzy set).

3) Combination
Group 2 consisted of the other 25 entrepreneurs with disabilities, to check feasibility of the disability-inclusive business classification. The 3 classification elements still included 1) procurement; 2) product/service development; and, 3) distribution as fuzzy set 2. The classification of productivity, knowledge, understanding and disability-inclusiveness remained the same as for the externalisation stage.

4) Internalisation
The 50 entrepreneurs with disabilities were the 25 entrepreneurs from Group 1 and the 25 entrepreneurs from Group 2, so as to compare the 2 groups of samples and the total samples. The 3 classification elements still included 1) procurement; 2) product/service development; and, 3) distribution. The classification of productivity, knowledge, understanding and disability-inclusiveness remained the same as for the externalisation stage.

Ethical Approval
The study protocol was approved by the Research Committee, College of Arts, Media and Technology, Chiang Mai University, Thailand.

RESULTS and DISCUSSION
50 sets of documentation which complied with the entrepreneurship criteria, namely 1) business role; 2) sustainability; and, 3) income source, covered 8 entrepreneurs from Cambodia (16%), 6 entrepreneurs from Indonesia (12%), 7 entrepreneurs from Lao PDR, 6 entrepreneurs from Myanmar (12%), 6 entrepreneurs from the Philippines (12%), 8 entrepreneurs from Thailand (16%) and 9 entrepreneurs from Vietnam (18%).
The productivity, knowledge and understanding scores for fuzzy set 1 included all 5 components: 1) procurement; 2) product/service development; 3) distribution; 4) sales/marketing; and, 5) customer service. The procurement, product/service development, distribution of productivity, knowledge and understanding could be observed significantly in both Group 1 and Group 2 of entrepreneurs with disabilities.

The averages of availability of procurement, product/service development, distribution, sales/marketing and customer service of productivity of entrepreneurs with disabilities in Group 1 were used to set parameters of membership function for fuzzy set 1 as presented in Table 1.

**Table 1: Average of Availability of Productivity, Knowledge and Understanding**

<table>
<thead>
<tr>
<th></th>
<th>Procurement</th>
<th>Product/Service Development</th>
<th>Distribution</th>
<th>Sales/Marketing</th>
<th>Customer Service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Productivity</td>
<td>40.2</td>
<td>68.0</td>
<td>29.6</td>
<td>17.8</td>
<td>10.1</td>
</tr>
<tr>
<td>Knowledge</td>
<td>40.2</td>
<td>62.6</td>
<td>28.2</td>
<td>14.4</td>
<td>12.8</td>
</tr>
<tr>
<td>Understanding</td>
<td>21.6</td>
<td>29.2</td>
<td>20.8</td>
<td>3.2</td>
<td>7.6</td>
</tr>
</tbody>
</table>

It showed that entrepreneurs with disabilities were active or it was feasible for them to work in these functions. As a result, the fuzzy set 2 included only 3 significant components: i) procurement, ii) product/service development, and, iii) distribution.

The availability of product/service development component was ranked highest in productivity, knowledge and understanding in all countries in both Groups 1 and 2 of entrepreneurs with disabilities. The productivity in procurement component could be observed more significantly than in the distribution component, except in Indonesia.

**Classification of Productivity of Entrepreneurs with Disabilities**

The averages of availability of procurement (40 scores), product/service development (68 scores), distribution (30 scores), sales/marketing (18 scores) and customer service (10 scores) of entrepreneurs with disabilities in Group 1 were used to set the parameter of membership function of productivity for fuzzy set 1. The fuzzy set 1 classified 7 cases (28%) as medium productivity, 7 cases (28%) as high productivity and 11 cases (44%) as low productivity among entrepreneurs with disabilities of Group 1.
The parameter of membership function of fuzzy set 2 was set by the averages of major value chain components including procurement (40 scores), product/service development (68 scores), and distribution (30 scores). The fuzzy set 2 classified 3 cases (12%) as medium productivity, 10 cases (40%) as high productivity and 12 cases (48%) as low productivity among entrepreneurs with disabilities of Group 1.

For Group 2 of entrepreneurs with disabilities, the fuzzy set 1 classified 8 cases as medium productivity, 8 cases as high productivity and 9 cases as low productivity. With the fuzzy set 2, the number of medium productivity cases decreased to 3 (12%) and the number of high productivity and low productivity cases increased to 12 (48%) and 10 cases (40%), respectively.

For all entrepreneurs with disabilities with the fuzzy set 2, the number of medium productivity decreased from 15 cases (30%) to 6 (24%); while, high and low productivity increased to 22 cases (44%).

The components of fuzzy set 2 illustrated clearer classification of productivity between high and low as shown in Table 2.

**Table 2: Classification of Productivity of Entrepreneurs with Disabilities**

<table>
<thead>
<tr>
<th>Productivity Classification</th>
<th>Group 1</th>
<th>Cambodia</th>
<th>Indonesia</th>
<th>Lao PDR</th>
<th>Myanmar</th>
<th>Philippines</th>
<th>Thailand</th>
<th>Vietnam</th>
<th>Group 2</th>
<th>Cambodia</th>
<th>Indonesia</th>
<th>Lao PDR</th>
<th>Myanmar</th>
<th>Philippines</th>
<th>Thailand</th>
<th>Vietnam</th>
<th>Groups 1 &amp; 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>High</td>
<td>7</td>
<td></td>
<td>11</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>12</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
<td>10</td>
<td></td>
<td>22</td>
</tr>
<tr>
<td>Medium</td>
<td>7</td>
<td></td>
<td></td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low</td>
<td></td>
<td>4</td>
<td></td>
<td></td>
<td>2</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Classification of Knowledge of Entrepreneurs with Disabilities

The parameters of membership function of productivity for fuzzy set 1 comprised the averages of availability of procurement (40 scores), product/service development (63 scores), distribution (28 scores), sales/marketing (14 scores) and customer service (13 scores) of entrepreneurs with disabilities of Group 1. The fuzzy set 1 classified 11 cases (22%) as medium knowledge, 22 cases (44%) as superficial knowledge and 17 cases (34%) as profound knowledge.

The parameter of membership function of fuzzy set 2 was set by the averages of major value chain components including procurement (40 scores), product/service development (63 scores), and distribution (28 scores). The fuzzy set 2 classified 1 case (4%) as medium knowledge, 11 cases (44%) as profound knowledge and 13 cases (52%) as superficial knowledge among entrepreneurs with disabilities of Group 1.

For entrepreneurs with disabilities of Group 2, the fuzzy set 2 did not affect classification of knowledge, which included 4 medium knowledge cases, 10 profound knowledge cases and 11 superficial knowledge cases. For all entrepreneurs with disabilities with the fuzzy set 2, the number of medium knowledge cases decreased from 11 (22%) to 5 cases (10%); while, profound knowledge increased to 21 cases (42%) and superficial knowledge increased to 24 cases (48%).

The components of fuzzy set 2 demonstrated clearer classification of knowledge between profound and superficial as shown in Table 3.
Table 3: Classification of Knowledge of Entrepreneurs with Disabilities

<table>
<thead>
<tr>
<th></th>
<th>Knowledge Classification by Fuzzy Set 1</th>
<th>Knowledge Classification by Fuzzy Set 2</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Profound</td>
<td>Medium</td>
</tr>
<tr>
<td><strong>Group 1</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cambodia</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Indonesia</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Lao PDR</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Myanmar</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Philippines</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Thailand</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Vietnam</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td><strong>Group 2</strong></td>
<td>10</td>
<td>4</td>
</tr>
<tr>
<td>Cambodia</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Indonesia</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Lao PDR</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Myanmar</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Philippines</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Thailand</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Vietnam</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td><strong>Groups 1 &amp; 2</strong></td>
<td>17</td>
<td>11</td>
</tr>
</tbody>
</table>

Classification of Understanding of Customers

The averages of availability of procurement (22 scores), product/service development (29 scores), distribution (21 scores), sales/marketing (3 scores) and customer service (8 scores) of entrepreneurs with disabilities in Group 1 were used to set parameters of membership function of productivity for fuzzy set 1. The fuzzy set 1 classified 7 cases (28%) as medium understanding, 6 cases (24%) as deep understanding and 12 cases (48%) as shallow understanding among entrepreneurs with disabilities of Group 1.

The parameter of membership function of fuzzy set 2 was set by the averages of major value chain components including procurement (22 scores), product/service development (29 scores) and distribution (21 scores). The fuzzy set 2 classified 4 cases (16%) as medium knowledge, 7 cases (28%) as profound knowledge and 14 cases (56%) as superficial knowledge among entrepreneurs with disabilities of Group 1.
For Group 2 of entrepreneurs with disabilities, the fuzzy set 2 also associated the clearer classification of understanding. The knowledge cases decreased to 4 (16%), with 10 profound knowledge cases and 11 superficial knowledge cases. For all entrepreneurs with disabilities with the fuzzy set 2, the number of medium understanding decreased from 14 cases (28%) to 8 (16%); while, deep understanding increased to 13 cases (26%) and shallow understanding increased to 29 cases (58%).

The components of fuzzy set 2 associated clearer classification of understanding between high and low as shown in Table 4.

Table 4: Classification of Understanding of Customers

<table>
<thead>
<tr>
<th>Understanding Classification by Fuzzy Set 1</th>
<th>Understanding Classification by Fuzzy Set 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Deep Medium Shallow</td>
<td>Deep Medium Shallow</td>
</tr>
<tr>
<td>Group 1</td>
<td>Group 1</td>
</tr>
<tr>
<td>6 7 12</td>
<td>7 4 14</td>
</tr>
<tr>
<td>Cambodia</td>
<td>Cambodia</td>
</tr>
<tr>
<td>0 2 2</td>
<td>1 0 3</td>
</tr>
<tr>
<td>Indonesia</td>
<td>Indonesia</td>
</tr>
<tr>
<td>1 2 0</td>
<td>1 2 0</td>
</tr>
<tr>
<td>Lao PDR</td>
<td>Lao PDR</td>
</tr>
<tr>
<td>1 0 3</td>
<td>1 0 3</td>
</tr>
<tr>
<td>Myanmar</td>
<td>Myanmar</td>
</tr>
<tr>
<td>1 0 2</td>
<td>1 0 2</td>
</tr>
<tr>
<td>Philippines</td>
<td>Philippines</td>
</tr>
<tr>
<td>0 1 2</td>
<td>1 0 2</td>
</tr>
<tr>
<td>Thailand</td>
<td>Thailand</td>
</tr>
<tr>
<td>2 1 1</td>
<td>2 1 1</td>
</tr>
<tr>
<td>Vietnam</td>
<td>Vietnam</td>
</tr>
<tr>
<td>1 1 2</td>
<td>0 1 3</td>
</tr>
<tr>
<td>Group 2</td>
<td>Group 2</td>
</tr>
<tr>
<td>5 7 13</td>
<td>6 4 15</td>
</tr>
<tr>
<td>Cambodia</td>
<td>Cambodia</td>
</tr>
<tr>
<td>0 3 1</td>
<td>1 1 2</td>
</tr>
<tr>
<td>Indonesia</td>
<td>Indonesia</td>
</tr>
<tr>
<td>0 3 0</td>
<td>1 2 0</td>
</tr>
<tr>
<td>Lao PDR</td>
<td>Lao PDR</td>
</tr>
<tr>
<td>0 1 2</td>
<td>0 1 2</td>
</tr>
<tr>
<td>Myanmar</td>
<td>Myanmar</td>
</tr>
<tr>
<td>1 0 2</td>
<td>0 0 3</td>
</tr>
<tr>
<td>Philippines</td>
<td>Philippines</td>
</tr>
<tr>
<td>1 0 2</td>
<td>1 0 2</td>
</tr>
<tr>
<td>Thailand</td>
<td>Thailand</td>
</tr>
<tr>
<td>2 0 2</td>
<td>2 0 2</td>
</tr>
<tr>
<td>Vietnam</td>
<td>Vietnam</td>
</tr>
<tr>
<td>1 0 4</td>
<td>1 0 4</td>
</tr>
<tr>
<td>Groups 1 &amp; 2</td>
<td>Groups 1 &amp; 2</td>
</tr>
<tr>
<td>11 14 25</td>
<td>13 8 29</td>
</tr>
</tbody>
</table>

Classification of Disability-Inclusiveness

The parameters of input membership function were set at 50 scores for productivity, knowledge and understanding. The output membership function was set in bell shape as shown in Figure 2.
The pattern of disability-inclusiveness per country is shown in Figure 3. The input membership function with fuzzy set 1 also showed the clearer classification of disability-inclusiveness. The numbers of somewhat cases changed as below:

- from 7 cases (28%) to 3 cases (12%) in Group 1 of entrepreneurs with disabilities
- from 8 cases (32%) to 6 cases (18%) in Group 2 of entrepreneurs with disabilities
- from 15 cases (30%) to 9 cases (18%) among all entrepreneurs with disabilities

Figure 3: Pattern of Disability-Inclusiveness
Table 5: Classification of Disability-Inclusiveness

<table>
<thead>
<tr>
<th></th>
<th>Disability-Inclusiveness Classification by Fuzzy Set 1</th>
<th></th>
<th>Disability-Inclusiveness Classification by Fuzzy Set 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Group 1</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cambodia</td>
<td>9</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Indonesia</td>
<td>2</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Lao PDR</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Myanmar</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Philippines</td>
<td>1</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Thailand</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Vietnam</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Group 2</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cambodia</td>
<td>5</td>
<td>2</td>
<td>8</td>
</tr>
<tr>
<td>Indonesia</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Lao PDR</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Myanmar</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Philippines</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Thailand</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Vietnam</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Groups 1 &amp; 2</td>
<td>14</td>
<td>4</td>
<td>15</td>
</tr>
</tbody>
</table>
As shown in Table 5, full disability-inclusive business was observed in Myanmar, the Philippines, Thailand and Vietnam. The disability-inclusiveness by fuzzy set 2 demonstrated clearer classification. The portion of somewhat cases reduced significantly in almost all countries except Vietnam.

- Cambodia: Disability inclusiveness was observed less in Cambodia. Most entrepreneurs with disabilities in Cambodia were not disability-inclusive with degree of “less than somewhat” and “not at all”.
- Indonesia: Both “full” and “not at all” disability-inclusiveness was observed in Indonesia. The fuzzy set 2 enhanced clearer classification of disability inclusiveness in Indonesia than in other countries.
- Lao PDR: Disability inclusiveness was observed less in Lao PDR. The fuzzy set 2 turned “somewhat” cases into “less than somewhat” disability-inclusive cases.
- Myanmar: The portion of “not at all” disability-inclusive business in Myanmar was higher than other countries. The fuzzy set 2 turned all “somewhat” cases into “not at all” disability-inclusive cases.
- Philippines: With fuzzy set 2, the portion of “full” disability-inclusiveness was ranked top 2 while “not at all” disability inclusiveness was ranked top 3.
- Thailand: The portion of entrepreneurs with disabilities in Thailand demonstrated outstanding disability-inclusive business.
- Vietnam: Disability inclusiveness was observed clearly in Vietnam. Fuzzy set 2 did not affect the classification of disability-inclusiveness.

**CONCLUSION**

By using fuzzy logic, disability-inclusiveness was made more tangible. In this sense, the classification method of disability-inclusive business consisted of three components: 1) productivity of entrepreneurs with disabilities; 2) knowledge of entrepreneurs with disabilities; and, 3) understanding of customers. Moreover, the study showed that fuzzy logic techniques could be applied to clarify disability-inclusiveness, so as to give an overview of inclusion of persons with disabilities in different parts of Southeast Asia. Furthermore, the study data found that entrepreneurs with disabilities were active in procurement, product/service development and distribution significantly. It is feasible for persons
with disabilities to start rural businesses by focussing on either one of three elements.

**Limitations**

This study has several limitations. The selected cases are all entrepreneurs with disabilities in rural areas, so the proposed method cannot be generalised for application in all types of businesses. The reason for the focus on entrepreneurs with disabilities was to clearly demonstrate the involvement of persons with disabilities in this study; however, the selected cases included 32 entrepreneurs with physical disabilities (64%), 5 entrepreneurs who are blind and with visual impairment (10%), and 3 entrepreneurs who are deaf, hard of hearing and deafened (6%). It was challenging to use fuzzy logic which has never been used in the context of disability, particularly when addressing persons with diverse disabilities.

**ACKNOWLEDGEMENT**

The author would like to thank entrepreneurs with disabilities in Southeast Asia for their permission and support in data retrieval; Mr. Akiie Ninomiya, Executive Director, Asia-Pacific Development Centre on Disability for his guidance to work on disability and development; and Dr. Nopasit Chakpitak/Dr. Tiraotp Chandarasupsang, Professors, College of Arts, Media and Technology, Chiang Mai University, for their review and valuable suggestions.

**REFERENCES**


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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2. Officer in Charge, National Leprosy Elimination Programme, Ministry of Health, Cambodia
3. Senior Technical Consultant, Netherlands Leprosy Relief, Amsterdam, Netherlands

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 which 4.5% 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 “Klung” 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 15-61 years 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](image)

(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) (Table 1). 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

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

*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
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

<table>
<thead>
<tr>
<th>People with leprosy-related disabilities (n=37)</th>
<th>People with locomotor disabilities (n=28)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interviews n=20</td>
<td>Focus group</td>
</tr>
<tr>
<td>Field visit</td>
<td>17</td>
</tr>
<tr>
<td>Rehabilitation centre^</td>
<td>3 Khleang^ (8/9 participants)</td>
</tr>
</tbody>
</table>

^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

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

^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

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

**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

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

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

^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

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

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 in 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 re-integrate 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

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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.

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A Transect Walk to Establish Opportunities and Challenges for Youth with Disabilities in Winterveldt, South Africa

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2. Odi District, Department of Health, Gauteng, South Africa

ABSTRACT

Winterveldt was one of the 9 sites included in a national study to determine the livelihood strategies of youth with disabilities, undertaken by the Occupational Therapy Departments of 6 Universities in South Africa. Community-based rehabilitation (CBR) programmes were initiated in Winterveldt in the 1990s by non-governmental organisations and the Occupational Therapy Department at the University of Limpopo - Medical University of South Africa (MEDUNSA).

Purpose: This paper describes the use of a Transect Walk to identify aspects of context that contribute to the vulnerability of youth with disabilities with regard to their livelihood strategies.

Method: Transect Walk was employed as a participatory rapid-appraisal tool to gather data. Convenience sampling was used to identify 11 participants, including three youth with disabilities. Field notes and observations were analysed deductively for themes related to the 5 categories of livelihood assets.

Results: The findings describe the natural and built environment, the access to health, educational and financial services, and the social attitudes of people in this community towards youth with disabilities. The discussion uses the 5 CBR components as a framework to explore strategies for enhancing the assets of youth with disabilities, namely, empowerment, social, health, education, and livelihood.

Conclusions: There is significant development that could be maximised if youth with disabilities were aware of their rights and were able to access services and resources. The implication for local government is to create an inclusive environment in which youth with disabilities are able to participate in mainstream youth development opportunities.

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Key words: Community-based rehabilitation; livelihood strategies, youth with disabilities, development practice, human rights

INTRODUCTION

The African Youth Charter provides policy structures for youth development and seeks to lift youth out of poverty (African Union, n.d.). Yet, the voice of youth with disabilities is absent. The National Youth Policy outlines a youth development strategy for South Africa, but again the voice of youth with disabilities is not represented (The Presidency, 2009). In 2009, the government established the Ministry for Rural Development and Land Reform, which provides an opportunity for youth with disabilities to lobby for inclusion in development opportunities. Community-based rehabilitation (CBR) has shifted from service delivery to community development, in recognition of the link between poverty and disability (WHO, 2010). It has promoted the use of local resources in improving quality of life and development opportunities for people with disabilities, through a multi-sectoral strategy to facilitate their participation in community-based inclusive development and in reducing poverty (WHO, 2010). The reality is that in the context of poverty and underserviced areas, youth with disabilities have to construct livelihoods in many ways. The livelihood strategies used by youth with disabilities in Winterveldt are not known. CBR is a practical strategy to implement the UN Convention on the Rights of Persons with Disabilities by developing and monitoring local action plans. This paper reports on the findings of a Transect Walk done in Winterveldt, to establish the contextual vulnerabilities of and the existing opportunities and challenges for youth with disabilities in relation to their ability to sustain their livelihoods. The Transect Walk is a participatory tool that local government can use to facilitate community participation in the development of action plans and in monitoring their implementation.

Context of Winterveldt

Winterveldt is a large area in Odi District of the North West Province, one of the 9 provinces in South Africa. In many ways, the community is typical of informal settlements on the periphery of a major ‘core’ metropolitan area. During the 1960s and 1970s, refugees from neighbouring countries such as Mozambique, Botswana and Zimbabwe moved to the area, hoping to find work in Pretoria. Since the change of government in 1994, significant changes have taken place; so much so...
that Winterveldt is no longer considered ‘rural’, but has become an urban area, with government structures in place for service delivery and development.

In 1996, Nelson Mandela who was the then President, donated a substantial amount of money to Winterveldt for development. The community has changed spectacularly since then. Tarred roads are being constructed and 11 public schools were built, including one for children with intellectual disabilities. Fresh water was supplied for the first time; previously, people had to buy water for 20 cents per litre. Now, common water points are available for everybody to access water (Vivian, 1997). Gardens and parks were developed, businesses started up, and people began to see purpose in their daily lives – even crime and violence began to decrease (these are personal experiences of both the authors who have worked in Winterveldt since 1992, and one of whom also lives here).

Today, Winterveldt is divided into a rural northern half and an urban southern half (called Klippan). The population is approximately 800,000 people (Stats SA Census, 2006), though local sources estimate it to be closer to 1 million. Population densities are much higher in the southern (urban) portion of Winterveldt. In 2007, it was made part of Gauteng Province.

**Disability and Community-based Rehabilitation in Winterveldt**

Two government health clinics (Kgabo Health Centre and Dube Clinic) were provided with facilities for outpatient and maternity care, including ambulance service. Both facilities offer a fully comprehensive 24-hour service. Mercy Clinic is run by the Catholic Church, and receives a subsidy and medication from the government. Mercy Clinic offers medical services to people with disabilities, but no rehabilitation services. St Peter’s Church initiated community-based rehabilitation (CBR) services in Winterveldt in 1990, and sent community members to training courses run by the Institute of Urban Primary Health Care (IUPHC) in Alexander, Johannesburg. The community-based rehabilitation facilitators (CRFs) worked alone until the coordinator at IUPHC approached the Occupational Therapy (OT) Department at the University of Limpopo – MEDUNSA campus. They established CBR services together with the final-year students (Shipham and Meyer, 2002). The lecturing staff assisted with the supervision of three CRFs during their training. The CBR programme addressed the need (of mothers of children with disabilities) for day-care centres, and the establishment of a self-help organisation for adults with disabilities (Shipham and Meyer, 2002). The vision of the programme was to improve the quality of
life of people with disabilities by improving service delivery as well as access to equitable opportunities that would promote and protect the rights of people with disabilities and their family members. Access to education and lifelong learning enhances the fulfilment of potential, promotes a sense of dignity and self-worth, and facilitates participation in society (WHO, 2010). The present CBR programme resources include an audiologist, an occupational therapist, a physiotherapist and three CRFs.

Meyer and Moagi (2000) identified the need for a study to determine the priority needs of mothers of children with disabilities. There seemed to be reluctance on the part of some mothers to participate in the management and running of the day-care centre programmes. The 3 priority needs identified (through use of Venn diagrams) were: education on handling children with disabilities, training in skills to generate an income, and day-care centres and employment. Support groups, sponsors and transport were also identified as ‘real’ and ‘felt’ needs. These needs reflect the extent of poverty and unemployment in the area. Meyer and Moagi (2000) found that the need for making money, though hidden, was present in all these needs, as the community had been neglected and deprived for years.

Barriers to participation usually lead to the social isolation or exclusion of those with disabilities. Maart et al (2007) did a study in rural and urban areas in the Eastern and Western Cape in South Africa, on how people with different impairments perceived environmental factors as a major cause of disability. The barriers identified in the urban areas were related to the ‘products and technology’ category, and the ‘natural environment and human-made changes’ category. Inadequate provision of mobility and communication devices, and seasonal changes in climate were identified as the most frequent barriers to accessing education and labour. Access to public buildings and housing were other specific barriers. Participants in the rural area experienced barriers in the attitude category with regard to friends, assistance, society and practices, and ideologies. There were an equivalent number of people in the two areas who identified barriers related to the services category. Access to transport was influenced by the nature of the environment: urban areas had roads, and rural areas were hilly and sometimes had rough terrain (Maart et al, 2007). A comparative study of communities in South Africa and India by Coulson et al (2006) identified the key challenge to be improving mobility in home and settlement environments. Affordability of public transport and empowerment of people with impairments who live in
poverty were identified as critical factors that influenced participation. The sustainability of community-based programmes has been influenced by partnerships between communities and higher education institutions in the development of services and related research (Shipham and Meyer, 2002; Lorenzo and Joubert, 2010).

**METHOD**

Participatory rural appraisal has been used for research on monitoring policy implementation and disability advocacy (Lorenzo, 2004; Lorenzo and Cloete, 2004). The use of participatory approaches involving community rehabilitation facilitators as research fieldworkers has been found to be valuable (Shipham and Meyer, 2002; Lorenzo, 2005; Lorenzo, 2010). Maart et al (2007) trained people with disabilities as enumerators for a study on environmental barriers to participation in rural and urban contexts. The sustainable livelihoods approach or SLA (DFID, 1999) is a way to understand the main factors that affect people’s livelihoods, including the complexities of their environment and how this determines their ability to create livelihoods for their households. Livelihood factors include human assets of education, employment and health, natural assets, physical assets related to the built environment, social assets, and financial assets.

A Transect Walk is a participatory approach that enables the gathering of data, and is normally conducted by a group of local people and visiting professionals (Van Staden et al, 2006). It is a systemic walk along a predetermined route through areas, to gather information about things such as land use, social and economic resources or state of the environment. Chappel and Johannismeier (2009) used a Transect Walk in both rural and urban settings as one participatory method to evaluate the impact of CBR programmes on people with disabilities, their families and their communities in South Africa. They advocate for a participatory approach on the grounds that the needs of people with disabilities are often ignored.

In this study, the purpose of the Transect Walk was firstly to describe the prevailing social environment in Winterveldt and the public’s awareness of disability and attitude towards youth with disabilities; and secondly, to identify the challenges and opportunities in the environment that would support the livelihoods of youth with disabilities in terms of natural resources, the built environment, access to services, and access to finances.
Sample
Convenience sampling was used to select participants who were readily available along the main road, and who were willing to share their understanding of disability and explore the creation of jobs for youth with disabilities. Eleven people, including 3 youth with disabilities who had ‘stalletjies’ (stalls selling goods) on the road, were approached by the researchers and agreed to be interviewed.

One limitation of the Transect Walk was that it was carried out in the rain, leaving little time to interview the participants in depth. Also, the sample of participants was limited to people who were on the street, excluding business owners or workers in businesses. ‘Invisible’ impairments such as youth with cognitive, communication or mental health impairments were not easily identified. Snowballing could be used as researchers could ask participants if they were aware of youth with such impairments. Their selection would be dependent on awareness in the community, as well as the accessibility of information and attitudes towards persons with these impairments.

Data-gathering Tool
Data gathering took place during the day. The process of data gathering stimulates awareness of disabling societal structures that require social change. The Transect Walk covered a distance of 2½ kilometres along the main road in Winterveldt, known as Bushveldt Road. This is a tarred road that leads to the R80 highway. The distance took the interviewers 2½ hours to walk. They were accompanied by 4 people with disabilities or their family members, who identified how communities had changed since the CRF had commenced working in the area.

The researchers were a senior lecturer and supervisor from the Occupational Therapy Department at the University of Limpopo - MEDUNSA, and the senior community rehabilitation facilitator from the Department of Health, who is a resident of Winterveldt. One researcher made field notes of responses given. Four pre-planned questions were identified, namely:

1. Are you aware of any youth with disabilities in Winterveldt, and of their disabilities?
2. Who cares for youth with disabilities? Where?
3. What does the government do for youth with disabilities?
4. What jobs do youth with disabilities do? Do they have the same opportunities as people without disabilities?
The researchers interviewed participants along the main road, which is well structured, with ‘stop’ signs, information signs and speed humps where necessary (See Figure 1). Along this road, there is an accessible cement side path for passengers and people using wheelchairs. Though this cement path is incomplete, there is ongoing construction work. This particular area of the main road was chosen because it is where most business takes place. It is also the most densely populated area. As it is the oldest section, many of the houses are still built of mud, though some rebuilding in brick has been started. Other information on natural resources, the built environment, access to services, and access to finances was gathered mainly through direct observation of accessibility via roads and entrances to buildings, environmental health risks, development initiatives, and the availability of services in the area where the walk took place.

**Data Analysis**

Field notes and observations were analysed deductively for themes related to the 5 categories of livelihood assets. They were categorised into those that afford opportunities to youth with disability, and those that present barriers or challenges in terms of ability of the youth to sustain their livelihoods.

Ethical approval for the study was obtained from the Research and Ethics Committees of the Faculty of Health Sciences, University of Cape Town.
ensure confidentiality, no particulars of the participants were disclosed. Verbal informed consent was obtained from them.

RESULTS

There was general openness and a sympathetic attitude towards people with disabilities; no one expressed any aggression or intolerance towards them. Youth with disabilities seem to be known in Winterveldt despite the relative ambiguity of the term ‘disabled’. Nearly everybody had seen someone in a wheelchair, walking on crutches, or those “that are not right in their head” (people with psychosocial disabilities), and some had seen blind people. Everyone knew of children with disabilities, but there seemed to be extensive ignorance about youth with disabilities. The 3 participants interviewed were youth with disabilities: 2 of them were clients from the CBR programme and knew about services of CBR; the third youth did not know about the available services, but had seen people go in and out of some homes, to take care of people with disabilities. Participants indicated that there is care for people with disabilities at Kgabo Health Centre. The other sources of care they knew about were the HIV/AIDS counselling clinic and NGO, and a special school behind Kgabo Health Centre.

The findings to the 4 questions that are elaborated on relate to the 5 livelihood assets of the sustainable livelihoods approach: natural assets; physical assets; human assets which cover education, health and employment; financial assets; and social assets.

1. Natural Assets

‘Natural assets’ are defined as resources available in the environment, such as land, vegetation, water, and natural energy sources (DFID, 1999). Land in Winterveldt still belongs to the plot owners. Roads become more difficult to use in rainy weather due to gravel and potholes in the few tarred roads. There is significant amount of waste in the environment and one person with mental health impairment was seen filtering through the waste. The water table is high, which provides a valuable resource for garden projects.

2. Physical Assets

‘Physical capital’ refers to infrastructure needed to support a person’s livelihood (DFID, 1999).
Brick houses with lovely gardens and patches of lawn are in the majority. At the same time, there are some mud houses with outside toilets. In rainy weather, many of mud houses fall down. Water on tap is still a problem in Winterveldt. Water taps were noticed outside some houses, as well as old, unused water tanks. Water still needs to be carried to the house in containers, and people with disabilities need assistance to do this. In previous years, plot owners owned water tanks and would sell water to their tenants; some dug deep pits in their yards, to draw water. A number of illegal water connections were observed. Electricity is still a problem - there are some areas without this service. Access to services such as public phones was noted. It was evident that one public phone booth was not accessible to people with disabilities.

Access to police services was noted as there is one police station along the main road. Participants indicated that people with disabilities access their social grants at Winterveldt multi-purpose hall which is a pay point for South African Social Services Agency.

The section of road along which the researchers walked had a very good cement path, about 1½ metres wide, on which persons with wheelchairs or walking aids could travel without hindrance. This path is a few kilometres long and is in the process of being extended. The main road is tarred, but roads branching off from it are mainly uneven gravel roads, with a lot of potholes and sand in some areas, making it difficult for people with disabilities, including those with mobility problems who use wheelchairs and crutches. One person who was interviewed mentioned that the side streets are also not in good condition. Some streets are so narrow that vehicles cannot pass through them, and people with wheelchairs cannot move about freely.

Transport is still a major problem for people with disability. Accessibility of public transport presents a major barrier, specifically for those who need to go to clinics and hospitals.

Taxis were observed to be the most common means of transport but are difficult to access. Two participants who were taxi drivers said that they do stop to pick up persons with disability if required to; however, they charge a double fee for those with wheelchairs.

There is awareness of the need for accessibility among those working in or owning shops. On investigation it was found that a mobile ramp is available when needed, to negotiate the very high step at the entrance to the telephone
booth. At one of the plots where the shopkeeper was interviewed, there was even a ramp built at the entrance to the shop. A popular supermarket along the main road is also accessible to people with disabilities. It has made life easier for them as it means they can go shopping without using public transport. Public buildings along the road include a library and a public hall, both of which are accessible to people with disabilities.

Streets lights are installed along the main road; while some function well, there are others that do not. Legal, safe electricity installations for individual households have been available since 2007. Each household can apply for the installation from ESKOM, the national electricity supplier, at a cost of R500 (equivalent to approximately US$60). This service has reduced the incidence of illegal connections. There appeared to be electrical connections to most houses seen on the walk.

Waste and refuse removal is a problem, even though the municipality delivers containers for storing waste. Garbage patches lie open along the main road; there are no communal containers for garbage. Goats, chickens, dogs and pigs feed on the garbage and wander freely across the busy road. Children also play in the open garbage; this could contribute to infection and disease. A well-known local man with a psychosocial disability has been known to feed himself from the garbage. Clearly, hygiene is still a concern.

There seems to be limited sewerage service. Public toilets have been built by the local government but have no steps, making them inaccessible to people with disabilities. Pit toilets were seen but most of them were also inaccessible. One youth with a disability reported that he could not use the toilet at his house. Only public facilities and registered crèches have flush toilets.

### 3. Human Assets

‘Human capital’ refers to skills, knowledge, the ability to work, and good health. These are important for a person’s access to income. Education and health are seen as important components of human capital (DFID, 1999). Along the main road, Manamelong primary and Lesolang high schools were noted. The researchers passed through Ratanang crèche and learned that they do accept children with disability. Outside the crèche good play equipment was noticed. Just behind Kgabo Health Clinic there is a special school for children with intellectual disabilities, and there is also a community library. Those who were
interviewed appeared to know about the special school. One of the researchers, a community rehabilitation facilitator, met a community person who knew her and who reported that her sister’s child with cerebral palsy was not coping at school. An appointment was made to see the CRF at the clinic.

Regarding health assets, the presence of 5 herbalists were noted. The researchers visited one of them on the main road. He was chatting with his friend who was on crutches after a car accident. The herbalist reported that some people with disabilities consult him. The herbalist’s friend reported that he had seen people visiting the homes of people with disabilities, and was aware of the physiotherapy and occupational therapy undergraduate students from MEDUNSA who do practice learning in the community, involving home visits and caring for people with disabilities. Good referral systems are in place, which enhances the wellbeing, trust and security that people with disabilities feel in accessing health services.

The other sources of help that people were aware of were the two HIV/ AIDS counselling non-governmental organisations, also located along the main road. Both offer the service of home-based care, give counselling and run support groups. One NGO is run by professional nurses and has a visiting doctor. The other clinic refers clients to the Kgabo Health Centre. Both dispense ARVs.

The Kgabo Health Centre is the government clinic on the main road. All those interviewed were aware of health and rehabilitation services available at this clinic. Two of the participants were young people with disabilities who knew about the CBR services. One of them was on his way back from the CBR programme, after attending a support group for clients with mental health impairments. Another respondent did not know of any service in Winterveldt for persons with disabilities, but he had seen “people go in and out of the homes to take care of disabled people in the houses. They were talking also to the families”. Nearly all those interviewed were aware that rehabilitation services were available at the clinic “down there” (indicating the location of Kgabo Health Centre). People knew they could get medicine there. It is accessible to people with disabilities and to the broader community.

There is also a medical doctor in the same area, with a very busy surgery. This facility benefits those people who can afford to pay for a doctor.

A variety of active informal small businesses exist along the main road: public phones, TV and radio repairs, hair salons, panel beaters, brick-makers, a car wash, second-hand clothing sellers, a bakery, a butcher’s shop, carpenters, and
several *spaza* shops (small grocer shops usually in a room or garage within a home). These businesses are accessible, but it is not known what opportunities exist for the employment of youth with disabilities. There are also many small ‘*stalletjies*’. These makeshift shops consist of wooden tables and corrugated iron or shade-cloth, set up on the pavement. Most of them sell fruit, vegetables and sweets. Some stall owners lay out their produce on plastic sheets on the ground.

The researchers also met 2 youth with disabilities. One was visiting his friend at a *stalletjie*, and suggested that *stalletjies* could be a source of job creation for youth with disabilities. The other has a *stalletjie* on the other side of Winterveldt. Both appeared very motivated to use this opportunity to provide finance for themselves. However, there were many young people loitering around the main road, apparently doing nothing. This indicates that in general, there are few job opportunities for the young population of Winterveldt. The data revealed that the participants did not really understand the question related to job opportunities for youth with disabilities. The researchers had to explain what was meant. Almost everybody answered that youth with disabilities could work if they acquired skills, though they were unsure about their participation in any high-level jobs.

### 4. Financial Assets

‘Financial capital’ refers to access to cash or its equivalent for the purpose of engaging in livelihoods (DFID, 1999). Financial services are limited as there are no bank services, banks or ATMs in Winterveldt. However ATMS are available in certain shops such as U-Save Shoprite and there is one at the petrol station. For other transactions, people travel to Mabopane shopping complex, about 10 kilometres away. Taxi drivers said they would transport people with disabilities, but financial expense is sometimes a barrier. Participants are aware of the government social services (SASSA). They mentioned that people with disabilities access their money at the multi-purpose hall. All those interviewed said that the government gives money to those with disabilities: “*They go every month to the big [Winterveldt multi-purpose] hall behind the clinic to get their money*”, and, “*That is a good thing*”.

Government social services administer the provision of child care grants and disability grants, which helps enormously in changing the lives of individuals. It was evident that many teenagers live alone and carry adult responsibilities, as their parents have died. The public hall is used as a pay point for social grants and for running other multi-purpose tasks. The awareness events run in the
community include disability-awareness campaigns. Participants did not come up with any other suggestions regarding what the government should do for them, or what else is required by people with disabilities.

5. Social Assets

‘Social assets’ are support systems on which people draw in pursuit of their livelihood objectives or what a person relies on to survive, as well as how people make use of free time (DFID, 1999). People socialise in the streets and at the stalletjies, some of which are even run by people who have disabilities themselves. Several Pentecostal churches and a Catholic church were to be seen along the main road. Like other people, youth with disabilities also go to churches for support and to worship. The inaccessibility of the recreational facilities used by other people was a barrier for youth with disabilities. These facilities are minimal, which further limits their opportunities to socialise.

DISCUSSION

The discussion reflects on the findings that emerged from the data gathered during the Transect Walk. The 4 questions proposed for the Transect Walk are explored in greater depth, using the 5 components of the CBR guidelines as a framework for interpretation to address implementation of programmes for community-based inclusive development. CBR is an intersectoral approach that involves health, education, social, livelihoods and empowerment (WHO, 2010). Focussing on these components will also contribute to the achievement of the millennium development goals for youth with disabilities, related to reducing poverty by improving access to health services, education and skills development for employability (Lorenzo et al, 2014).

Empowerment component – Public awareness of Disability

The empowerment component of the CBR matrix comprises 5 elements: advocacy and communication, community mobilisation, political participation, self-help groups, and DPOs (WHO, 2010). Although the community is aware that people with disabilities exist, they seem to take very little notice of youth with disabilities, appearing to be uninformed about their needs and challenges, and about the opportunities that could be provided for them to live in Winterveldt in a more sustainable manner. Using narrative action-reflection workshops in participatory research with women with disabilities in informal settlements in
Western Cape, Lorenzo et al (2002; Lorenzo, 2010) found that there is potential for raising awareness and networking to overcome a sense of isolation. Rule et al (2006) identified new challenges in implementing CBR, namely, intersectoral collaboration, the need for partnerships, the link between rehabilitation and community development, the nature of grassroots workers, and the need for monitoring and evaluation, and the dissemination of information. The findings of the Transect Walk revealed that these strategies are still relevant for this community.

It is encouraging that schools are integrating disability into their life-orientation curricula, through voluntary work with disabled people’s organisations (DPOs) and with CRFs. The notion of citizenship and equal rights for youth with disabilities must be fostered. It is evident that there is a need to test the notion of reciprocal empowerment of stakeholders, rather than just assuming that youth with disabilities need to be empowered. In addition, CBR programmes need to facilitate the political development of youth with disabilities so that they may participate in the democratic processes of elections and advocacy for service delivery.

Health and Education components – Access to Clinics and Public Schools

The health component of the CBR matrix consists of 5 elements: promotion, prevention, medical care, rehabilitation, and assistive devices (WHO, 2010). The findings showed that people are aware of health services available at Kgabo Health Centre. The CBR services seem to be known only to those clients who received or continue to receive rehabilitation. Several non-governmental clinics no longer operate in Winterveldt, including St Peter’s, St Joseph’s, and Thusong (a preventative clinic focusing mainly on persons with disabilities) which played a major role in rehabilitation of persons with disabilities. They were the first clinics to implement the CBR programme in Winterveld by identifying persons with disabilities in the community and the need to send people to train as CRFs. Intersectoral collaboration with other units within the clinic should be facilitated. Although not recognised as formal service providers in the district health system, traditional herbalists play a significant role in the health and social support of people with disabilities; therefore it is important to build partnerships with them. The researchers identified the need to educate the medical and nursing fraternity about the needs of youth with disabilities and the importance of referral, as most youth with disabilities attend the clinic for consultations. This need for
continuing professional development was also identified across other sites in the study (Lorenzo and Cramm, 2012).

The 5 elements of the education components of the CBR matrix are: early childhood; primary schooling; secondary and higher schooling; non-formal education; and lifelong learning. The number of schools and crèches in Winterveldt and the facilities they offer have improved enormously. The researchers’ findings were that children with disabilities are being integrated into crèches and schools. Provision of meals would also enhance the nutrition and wellbeing of the children, which demonstrates the close link between health promotion and disability prevention. Outdoor equipment adds to the development of children through play, but more needs to be provided in terms of toys for fine motor coordination, and the education of caregivers about the importance of play for development (Ramugondo, 2011). However, the uncertain electricity supply means greater challenges for further education and training of youth, which would generate more awareness and communication with other communities.

Livelihoods component – Employment Opportunities and Financial Services

The 5 elements of the livelihoods cluster of the CBR matrix are: skills development, self-employment, wage employment, financial services and social protection (WHO, 2010). ‘Stalletjies’ along the main road indicate that people have initiative and potential, as shown by the development of entrepreneurial opportunities. While youth with disabilities also operate stalletjies, most of them were run by adults from Mozambique and Zimbabwe, and only a few by local South Africans. The U-SAVE Shoprite is accessed by both persons with and without disabilities. Food is readily available, as well as hairdressers, shoe repairers, second-hand clothing sellers, car battery chargers, and radio repairers. Given the high rate of unemployment, youth with disabilities could be motivated to start their own small businesses. Different skills they have acquired could also provide other opportunities for employment, and the role of occupational therapists working together with the CRWs would be of great value in this regard (Lorenzo et al, 2014). These experiences confirm the findings of Meyer and Moagi (2000) concerning money being vital to all priority needs that were identified. They found that some families are supported by disability grants “to have food to eat”. The community seems to have little idea of how they can use natural assets, such as energy sources and land, to benefit the economic empowerment and development of youth with disabilities through agriculture projects.
Yet another major problem facing youth with disabilities in Winterveldt is the inadequacy of financial resources, which is compounded by the inability to gain employment. For a long time, poor people in this community have depended on handouts, creating a culture of dependency.

There is recognition that the government plays a major role by issuing social grants, because the findings showed that people are aware of a pay point behind Kgabo Health Centre for those who receive these grants. Lorenzo et al (2014) found that youth with disabilities have more sources of income compared to youth without disabilities. Issuing of social grants contributes to the alleviation of hunger, which was confirmed through the personal experiences of the researchers who had worked in the community. They found that families with social grants were better off than those without, especially if there was no source of income in the family. In addition, the disability grant is difficult to access, and is inadequate to facilitate economic development (Sierlis and Swartz, 2006; Swartz and Schneider, 2006; Watson et al, 2006).

While it is encouraging that there is an awareness of disability among taxi drivers, who indicated their willingness to accommodate youth with disabilities, the high cost of public transport makes it inaccessible. Lorenzo (2008) reported on how women with disabilities in informal settlements had mobilised to achieve a public transport system that would increase their participation in social and economic development.

Social component – Family Life and Community Living

The 5 elements of the social component of the CBR guidelines are: personal assistance; relationships, marriage and family; culture and arts; recreation, leisure and sport; and justice (WHO, 2010). It is surprising that the Transect Walk revealed so little about the social assets that are accessed by youth with disability. Faith-based organisations and churches provide opportunities for socialisation, especially to find comfort while so many people are dying from HIV/AIDS. The researchers did not sense the nature of the support of family, neighbours and friends. Maybe other participatory methods such as Venn Diagrams and the Wheel of Opportunities would be better to elicit information regarding these assets.

The provision of housing is essential for youth with disabilities to feel part of the community. It is a natural transition for youth to aspire to moving out of the
family home and to start up on their own. Local and provincial governments are providing resources, but they need to be aware of the housing needs of youth with disabilities and their vulnerability in poorly-constructed houses. While Coulson et al (2006) found that water supply is more accessible, sewerage is largely by means of pit latrines which are inaccessible to some youth with disabilities, while others manage somehow.

CONCLUSION

There is scope in Winterveldt to achieve significant development by maximising whatever assets are already there. Public awareness campaigns, especially about CBR as a strategy for community-based inclusive development, must be organised to facilitate access to schools and health services. Youth with disabilities should be empowered to understand and know their rights, so that they will be able to influence local government to utilise natural resources such as land and accessible water for their development. Inaccessibility of toilets, housing and transport as physical assets must be addressed through infrastructure developments. There is little information about how to engage youth with disabilities in social activities. Recreational facilities need to be made accessible, to accommodate their needs. Attention must be paid to the role of occupational therapy students as part of the CBR team. The findings of this study show that the community has little knowledge about the financial needs of youth with disabilities.

Implications

A strategy of communication – between the community, key role-players, local government services and development programmes – should be put in place in order for youth with disabilities to be heard and given opportunities to participate in decision-making processes. While the community is aware of youth with disabilities, campaigns should be organised to achieve the continued participation and involvement of all stakeholders in disability issues. The CRFs need to take a lead in this effort. The CRFs need to take a lead in this effort by participating in community stakeholder forums involving the departments from local government together with DPOs and families. They need to organise and take leadership in capacity building to understand disability inclusion as part of community development, with a specific focus on youth with disabilities. More job opportunities should be created and made equally available to youth with disabilities. Accessible public transport needs to be provided to increase participation in all facets of family and community living.
REFERENCES


Characteristics and Quality of Life Among People Living with HIV at Drop-in Centres and Shelter Homes in Malaysia

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ABSTRACT

**Purpose:** The aim of the study was to examine whether there are any significant differences in demographic characteristics and health-related Quality of Life (QoL) among people living with HIV (PLWH) at shelter homes and drop-in centres in Malaysia.

**Method:** 117 PLWH were recruited by using the purposive sampling method. Data were collected through a questionnaire survey.

**Results:** Significant differences were found between PLWH at shelter homes and drop-in centres, in their demographic characteristics and in the 3 factors in the HIV/AIDS-Targeted Quality of Life Instruments (HAT-QoL) – namely, overall function, health worries, and provider trust.

**Conclusion:** Due to the differences in characteristics and QoL among PLWH in these two settings, different approaches are suggested to assist PLWH from shelter homes and drop-in centres.

**Key words:** HIV, HAT-QoL, shelter homes, drop-in centres, Malaysia

INTRODUCTION

In 2012, the estimated number of people living with HIV globally was approximately 32.2-38.8 million. The new infection rate has declined from 3.4 million cases in 2001 to about 2.3 million cases in 2012. Due to the antiretroviral treatment, AIDS-related deaths have also declined from approximately 2.3 million cases in 2005 to about 1.7 million cases in 2011 (Joint United Nations Programme on HIV/AIDS, 2013).

The first case of HIV in Malaysia was reported in 1986. It was estimated that there were a total of 94,841 HIV infections, 17,686 AIDS cases, and 14,986 AIDS-related

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deaths in Malaysia (Ministry of Health Malaysia, 2012). In 2011, the incidence rate of HIV infection among adults between 15-49 years of age has been decreasing. It is now 26% - 49% less than in 2001. Nonetheless, the mortality rate among PLWH in 2011 has remained unchanged or decreased less than 25% than in 2005. This could be related to the fact that only 20% -39% of eligible people receive antiretroviral therapy (Joint United Nations Programme on HIV/AIDS, 2013). The most-at-risk populations were drug users, commercial sex workers and the transgender population (Ministry of Health Malaysia, 2012).

The patterns of HIV transmission were relevant to the geographic regions in Malaysia. Most PLWH in the eastern regions were infected by sharing drug needles, while most PLWH in the central, northern and southern regions were infected by unsafe sex. About 90% of PLWH were males. However, the trend of female to male ratio has increased from 1: 99 in 1990 to 1: 4 in 2011. Also, the trend of sexual transmission of HIV among injecting drug users has increased from 1: 9 in 1990 to 1: 1 in 2010. Nonetheless, it is acknowledged that there is an overlap between drug addiction and those involved in sex trade, as drug users may be involved in commercial sex to get money to buy drugs (Ministry of Health Malaysia, 2012). The prevalence of HIV infection among people who inject drugs versus the general population in Malaysia was found to be higher than among sex workers or homosexuals versus the general population. Therefore, Malaysia has 75%-100% coverage for an HIV prevention programme for drug users (Joint United Nations Programme on HIV/AIDS, 2013).

Shelter homes and drop-in centres have been set up in Malaysia to provide care and support services for PLWH and other affected persons. There are 16 shelter homes for women and children that were funded by the Ministry of Women, Family and Community Development in 2011 (Ministry of Health Malaysia, 2012). The shelter homes serve the function of half-way homes that provide proper care to the homeless and abandoned PLWH. They provide follow-up support and service that hospitals may not able to offer, such as psychosocial support and treatment education. PLWH will be sent back to the community after they have recovered.

In contrast, the drop-in centres function as an extension of outreach activities. Different drop-in centres provide services to a certain targeted population, such as commercial sex workers and some injecting drug users. The drop-in centres offer basic healthcare, warm meals, peer education, and support groups as well as referrals for voluntary HIV counselling, testing, and legal aid (Malaysia AIDS
Council, n.d.). Due to the different functions of the drop-in centres and shelter homes, the QoL of PLWH in these two service providers can be quite different.

Cella and Bonomi (1995) defined health-related quality of life (HRQL) as the extent to which one’s usual or expected physical, emotional, and social health are affected by a medical condition or its treatment. With the success of the HAART treatment in reducing the mortality rate of PLWH, researchers and clinicians pay attention to improving the quality of life of this population (Miners et al, 2001; Westburg and Guindon, 2004). Some QoL measurements have been developed, such as Sickness Impact Profile (SIP), Quality of Well Being Scale (QWBS), Medical Outcomes HIV Health Survey (MOS-HIV), HIV-QOL Questionnaire (HIV-QL31), HIV/AIDS Targeted Quality of Life (HAT-QoL) and Multidimensional Quality of Life Questionnaire for HIV/AIDS (MQOL-HIV) (Clayson et al, 2006). In this study, the HAT-QoL was chosen since it is a QoL measurement that has been developed and targeted at PLWH (Holmes and Shea, 1999).

Studies have found good correlations between similar dimensions in HAT-QoL and MOSHIV (Taylor et al, 2009) and in HAT-QoL and SF-36(Holmes et al, 2007). Some studies have figured out the relationship between poor HAT-QoL and depression, personality disorder, and physical symptoms (Gore-Felton et al, 2006; Lorenz et al, 2006; Hansen et al, 2009).

The authors of this article are not aware of any study that compares the key characteristics and the QoL of PLWH at drop-in centres and shelter homes in Malaysia. The comparisons are important, as the identification of key characteristics and QoL differences among PLWH at drop-in centres and shelter homes may enable programme developers to better tailor services to improve the QoL of PLWH at their drop-in centres or shelter homes.

Objectives
The aims of this study were:

1. To attempt a socio-demographic profile of PLWH in shelter homes and those visiting drop-in centres;
2. To discover differences (if any) in the patterns of QoL between PLWH in shelter homes and those visiting drop-in centres; and,
3. To establish if there is any significant association between the socio-demographic profile and QoL of PLWH in shelter homes and those visiting drop-in centres.
METHOD

Participants
117 PLWH from 5 non-governmental organisations (NGOs) in Malaysia were invited to participate in this study. Through the purposive sampling method, only those PLWH who stayed at HIV shelter homes or visited the drop-in centres were included. About 42% were from HIV shelter homes and about 58% were from drop-in centres. The age range was 17-70 years (M = 40.25, SD = 11.57). Most of the participants (78.6%) were under medication adherence, 74.8% were males, 69% were already married or in a relationship, 64% had not had a sexual partner in the past 3 months, 63.3% were unemployed or housewives, 60.9% were living with friends, and 54% were Malay (see Table 1).

Table 1: Demographic Characteristics of Participants

<table>
<thead>
<tr>
<th>Centres</th>
<th>Drop-in 42.7% (50)</th>
<th>Ethnicity</th>
<th>Malay 54.3% (63)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shelter home</td>
<td>57.3% (67)</td>
<td>Chinese</td>
<td>29.3% (34)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Others</td>
<td>16.4% (19)</td>
</tr>
<tr>
<td>Gender</td>
<td>Male 74.8% (86)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Female 25.2% (29)</td>
<td>Religion</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Muslim</td>
<td>59.8% (67)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Others</td>
<td>40.2% (45)</td>
</tr>
<tr>
<td>Age</td>
<td>40 or below 50.4% (59)</td>
<td>HIV duration 60 months or below 47.9% (56)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>above 40 49.6% (58)</td>
<td>above 60 months</td>
<td>52.1% (61)</td>
</tr>
<tr>
<td>Employment</td>
<td>Employed 37.7% (43)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Housewife or Unemployed 63.3% (71)</td>
<td>Relationship</td>
<td>Single, divorced or widowed 31% (36)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Married or in a relationship 69% (80)</td>
</tr>
<tr>
<td>Living</td>
<td>Alone 11.3% (13)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arrangement</td>
<td>With family 27% (31)</td>
<td>Drug-addict</td>
<td>Yes 24.1% (31)</td>
</tr>
<tr>
<td></td>
<td>With friends 60.9% (70)</td>
<td>No</td>
<td>75.9% (84)</td>
</tr>
<tr>
<td>Sexual Orientation</td>
<td>Heterosexual</td>
<td>48.4% (44)</td>
<td>Commercial sex workers</td>
</tr>
<tr>
<td>--------------------</td>
<td>--------------</td>
<td>------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Sexual Orientation</td>
<td>Homosexual</td>
<td>40.7% (37)</td>
<td></td>
</tr>
<tr>
<td>Sexual Orientation</td>
<td>Bisexual</td>
<td>11.0% (10)</td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td>Yes</td>
<td>78.6% (92)</td>
<td>Sexual</td>
</tr>
<tr>
<td>Adherence</td>
<td>No</td>
<td>21.4% (25)</td>
<td>partners in the past 3 months</td>
</tr>
<tr>
<td>Adherence</td>
<td>No</td>
<td></td>
<td>more than one</td>
</tr>
</tbody>
</table>

Note: Number in bracket indicates the number of respondents

**Questionnaire**

**Demographic Information**

In this section, participants were asked to fill in some information that was relevant to their backgrounds, such as gender, education, and employment status.

**HAT-QoL**

The HAT-QoL scale includes 34 items and measures 9 dimensions, which are overall function (6 items), life satisfaction (4 items), health worries (4 items), financial worries (3 items), medication worries (5 items), HIV mastery (2 items), disclosure worries (5 items), feelings about doctors or provider’s trust (3 items), and sexual functions (2 items). Participants needed to circle a number from 1 to 5 to indicate how often they have had such feelings in the past 4 weeks. Scores on each subscale were recorded on a scale from 0 to 100. A higher score indicated a better QoL (Holmes and Shea, 1997, 1998, 1999; Holmes et al, 2007; Holmes and Ruocco, 2008). The Cronbach Alpha reliabilities of the 9 dimensions were found to be higher than 0.8 (Holmes and Ruocco, 2008).

**Procedure**

Through the internet and introductions to workers at NGOs, the authors contacted some NGOs that provide services to PLWH for permission to conduct this study. The NGOs were provided with the study proposal, a sample of the informed consent form for PLWH and a sample of the questionnaire. Permission was obtained from 5 NGOs that are located at two different states in Malaysia: 1 in Penang and 4 in Selangor. Thereafter, the authors employed the purposive sampling method to recruit PLWH participants who were clients of drop-
in centres or shelter homes. Purposive sampling is a type of non-probability sampling method where sample selection is based on the fit of the sample with the purpose of the study, with special inclusion and exclusion criteria (Daniel, 2011). In this study, only those PLWH who either stayed at shelter homes or visited the drop-in centres were recruited.

The exploratory cross-sectional survey-based research design was adopted in this study. All PLWH at the NGOs were briefed about the aims of this study and their right not to participate. Only those who agreed to participate and signed the informed consent form were recruited. Questionnaires were then distributed to participants. Researchers or the contact persons of the NGOs stayed to assist the participants with any problems which might occur while they were answering the questionnaires. A token was given to participants after they completed the questionnaires.

RESULTS

Differences between Demographic Characteristics of Participants from the HIV shelter homes and drop-in centres

The demographic backgrounds of participants from the HIV shelter homes and drop-in centres were different. The results of Chi-square test for independence showed that most participants from the HIV shelter homes were drug users, heterosexual, under medication, older, non-Malays, non-Muslim, unemployed, had been diagnosed as a PLWH for a longer period and were not staying with family (see Table 2).

Table 2: Differences between Characteristics of PLWH in HIV shelter homes and drop-in centres

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Drop-in Centre (n) (%)</th>
<th>Shelter Home (n) (%)</th>
<th>Chi-square</th>
<th>df</th>
<th>Total n</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Drug User</td>
<td>Yes</td>
<td>3 (6.1)</td>
<td>28 (41.8)</td>
<td>19.61</td>
<td>115</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>46 (93.9)</td>
<td>38 (56.7)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexual</td>
<td>Heterosexual</td>
<td>6 (16.7)</td>
<td>38 (69.1)</td>
<td>23.95</td>
<td>91</td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Orientation</td>
<td>Homosexual or Bisexual</td>
<td>30 (83.3)</td>
<td>17 (30.9)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medical</td>
<td>Yes</td>
<td>33 (66)</td>
<td>59 (88.1)</td>
<td>8.29</td>
<td>1</td>
<td>117</td>
</tr>
<tr>
<td>---------</td>
<td>-----</td>
<td>---------</td>
<td>-----------</td>
<td>------</td>
<td>---</td>
<td>-----</td>
</tr>
<tr>
<td>Adherence</td>
<td>No</td>
<td>17 (34)</td>
<td>8 (11.9)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>40 or below</td>
<td>37 (74)</td>
<td>22 (32.8)</td>
<td>19.41</td>
<td>1</td>
<td>117</td>
</tr>
<tr>
<td></td>
<td>Above 40</td>
<td>13 (26)</td>
<td>45 (67.2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Malay</td>
<td>37 (75.5)</td>
<td>26 (38.8)</td>
<td>15.37</td>
<td>1</td>
<td>116</td>
</tr>
<tr>
<td></td>
<td>Non-Malay</td>
<td>12 (24.5)</td>
<td>41 (61.2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Religion</td>
<td>Muslim</td>
<td>38 (80.9)</td>
<td>29 (44.6)</td>
<td>14.91</td>
<td>1</td>
<td>112</td>
</tr>
<tr>
<td></td>
<td>Non-Muslim</td>
<td>9 (19.1)</td>
<td>36 (55.4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employment</td>
<td>Employed (Full/Part time)</td>
<td>31 (66)</td>
<td>12 (17.9)</td>
<td>27.15</td>
<td>1</td>
<td>114</td>
</tr>
<tr>
<td>Status</td>
<td>Unemployed</td>
<td>16 (34)</td>
<td>55 (82.1)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diagnosis</td>
<td>60 months or below</td>
<td>34 (68)</td>
<td>22 (32.8)</td>
<td>14.19</td>
<td>1</td>
<td>117</td>
</tr>
<tr>
<td></td>
<td>Above 60 months</td>
<td>16 (32)</td>
<td>45 (67.2)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Residence</td>
<td>With family</td>
<td>18 (37.5)</td>
<td>13 (19.7)</td>
<td>4.45</td>
<td>1</td>
<td>114</td>
</tr>
<tr>
<td></td>
<td>Single or with friends</td>
<td>30 (62.5)</td>
<td>53 (80.3)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**HAT-QoL**

There were significant differences between HAT-QoL of participants from drop-in centres and those from shelter homes. The results of **t-test for independent sample means** found that participants from the drop-in centres have lower provider trust and health worries, but have higher overall function than those from shelter homes (see Table 3).
Table 3: Comparisons of HAT-QoL of PLWH at drop-in centres and shelter homes

<table>
<thead>
<tr>
<th>HRQL</th>
<th>Location</th>
<th>M</th>
<th>SD</th>
<th>t</th>
<th>df</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Overall function</td>
<td>Drop-in centre</td>
<td>63.59</td>
<td>19.61</td>
<td>2.53</td>
<td>115</td>
<td>0.013</td>
</tr>
<tr>
<td></td>
<td>Shelter home</td>
<td>52.96</td>
<td>24.41</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Life satisfaction</td>
<td>Drop-in centre</td>
<td>64.38</td>
<td>19.41</td>
<td>1.29</td>
<td>114</td>
<td>0.201</td>
</tr>
<tr>
<td></td>
<td>Shelter home</td>
<td>58.81</td>
<td>25.52</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Health worries</td>
<td>Drop-in centre</td>
<td>60.88</td>
<td>29.09</td>
<td>2.13</td>
<td>114</td>
<td>0.035</td>
</tr>
<tr>
<td></td>
<td>Shelter home</td>
<td>49.53</td>
<td>27.83</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Financial worries</td>
<td>Drop-in centre</td>
<td>52.04</td>
<td>28.84</td>
<td>-1.58</td>
<td>113</td>
<td>0.117</td>
</tr>
<tr>
<td></td>
<td>Shelter home</td>
<td>60.61</td>
<td>28.74</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication worries</td>
<td>Drop-in centre</td>
<td>74.58</td>
<td>24.98</td>
<td>0.91</td>
<td>91</td>
<td>0.364</td>
</tr>
<tr>
<td></td>
<td>Shelter home</td>
<td>69.32</td>
<td>27.44</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>HIV mastery</td>
<td>Drop-in centre</td>
<td>57.38</td>
<td>31.48</td>
<td>-0.18</td>
<td>112.61</td>
<td>0.858</td>
</tr>
<tr>
<td></td>
<td>Shelter home</td>
<td>58.52</td>
<td>37.29</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disclosure worries</td>
<td>Drop-in centre</td>
<td>45.04</td>
<td>38.21</td>
<td>-1.94</td>
<td>114</td>
<td>0.055</td>
</tr>
<tr>
<td></td>
<td>Shelter home</td>
<td>57.08</td>
<td>28.76</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Provider trust</td>
<td>Drop-in centre</td>
<td>59.72</td>
<td>24.93</td>
<td>-4.54</td>
<td>114</td>
<td>0.001</td>
</tr>
<tr>
<td></td>
<td>Shelter home</td>
<td>78.79</td>
<td>19.89</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sexual function</td>
<td>Drop-in centre</td>
<td>79.51</td>
<td>23.39</td>
<td>1.69</td>
<td>109.95</td>
<td>0.094</td>
</tr>
<tr>
<td></td>
<td>Shelter home</td>
<td>70.31</td>
<td>34.54</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Associations between HAT-QoL and Demographic backgrounds
The authors examined whether or not the 3 factors of HAT-QoL (overall function, health worries, and provider trust) were significantly associated with the demographic variables that have been found to differ between the two settings. The 3 HAT-QoL factors were categorised into two groups each by using their median score, and then the Chi-square test for independence was used to find the associations. Firstly, the overall functions of participants who were 40 years old or below, were better than those who were above 40 years (64.2% vs. 38.8%), X² (1, n = 102) = 6.57, p = 0.011. Secondly, participants who were homosexual or bisexual and were employed, had more health worries than those who were heterosexual (65.2% vs. 43.2%), X² (1, n = 90) = 4.41, p = 0.036, and were unemployed (64.3% vs. 39.4%), X² (1, n = 113) = 6.52, p = 0.011. Lastly, the participants who were drug users, aged above 40, unemployed, and diagnosed as PLWH for more than 60...
months, had higher provider trust than those who were non-drug users (56.7% vs. 20.7%), \(X^2(1, n = 112) = 15.52, p = 0.001\); aged 40 or below (41.4% vs. 21.4%), \(X^2(1, n = 114) = 5.25, p = 0.022\); employed (38% vs. 15%), \(X^2(1, n = 111) = 6.49, p = 0.011\); and diagnosed as PLWH for less than 60 months (42.6% vs. 18.9%), \(X^2(1, n = 114) = 7.41, p = 0.006\) (see Table 4).

### Table 4: The associations between Demographic Characteristics and the 3 HAT-QoL factors

<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>Overall Function (n) (%)</th>
<th>Health Worries (n) (%)</th>
<th>Provider Trust (n) (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Below median</td>
<td>Above median</td>
<td>Below median</td>
</tr>
<tr>
<td>Drug User</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>14 (56)</td>
<td>34 (45.3)</td>
<td>16 (53.3)</td>
</tr>
<tr>
<td></td>
<td>11 (44.1)</td>
<td>41 (54.7)</td>
<td>14 (46.7)</td>
</tr>
<tr>
<td>Sexual Orientation</td>
<td>Heterosexual</td>
<td>Homosexual or Bisexual</td>
<td></td>
</tr>
<tr>
<td></td>
<td>18 (47.3)</td>
<td>15 (36.6)</td>
<td>20 (52.6)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>16 (34.8)</td>
<td>30 (65.2)</td>
</tr>
<tr>
<td>Medical</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>40 (51.3)</td>
<td>9 (37.5)</td>
<td>38 (48.7)</td>
</tr>
<tr>
<td></td>
<td>38 (45.3)</td>
<td>26 (64.2)*</td>
<td>43 (46.7)</td>
</tr>
<tr>
<td>Adherence</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td></td>
<td></td>
<td>19 (35.8)</td>
<td>26 (44.8)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>34 (62.5)</td>
<td>24 (41.4)</td>
</tr>
<tr>
<td>Age</td>
<td>40 or below</td>
<td>Above 40</td>
<td>15 (37.5)</td>
</tr>
<tr>
<td></td>
<td>32 (54.2)</td>
<td>32 (54.2)</td>
<td>30 (60.6)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>27 (45.8)</td>
<td>43 (60.6)</td>
</tr>
<tr>
<td>Ethnicity</td>
<td>Malay</td>
<td>Non-Malay</td>
<td>Malay</td>
</tr>
<tr>
<td></td>
<td>27 (48.2)</td>
<td>21 (46.7)</td>
<td>29 (51.8)</td>
</tr>
<tr>
<td></td>
<td>29 (51.8)</td>
<td>24 (53.3)</td>
<td>30 (48.4)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>25 (48.9)</td>
<td>29 (54.7)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>15 (35.7)</td>
<td>27 (45.3)</td>
</tr>
<tr>
<td>Religion</td>
<td>Muslim</td>
<td>Non-Muslim</td>
<td>Muslim</td>
</tr>
<tr>
<td></td>
<td>29 (49.2)</td>
<td>16 (42.1)</td>
<td>30 (50.8)</td>
</tr>
<tr>
<td></td>
<td>30 (50.8)</td>
<td>22 (57.9)</td>
<td>34 (51.5)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>15 (35.7)</td>
<td>27 (45.3)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>25 (62.5)</td>
<td>43 (60.6)</td>
</tr>
<tr>
<td>Employment Status</td>
<td>Employed (Full/Part time)</td>
<td>Unemployed or Housewives</td>
<td></td>
</tr>
<tr>
<td></td>
<td>15 (37.5)</td>
<td>32 (54.2)</td>
<td>25 (62.5)</td>
</tr>
<tr>
<td></td>
<td>25 (62.5)</td>
<td>27 (45.8)</td>
<td>43 (60.6)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>32 (54.2)</td>
<td>43 (60.6)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>27 (45.8)</td>
<td>27 (49.1)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>60 months or below</td>
<td>Above 60 months</td>
<td></td>
</tr>
<tr>
<td></td>
<td>22 (44.9)</td>
<td>27 (50.9)</td>
<td>27 (49.1)</td>
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<td></td>
<td>27 (55.1)</td>
<td>26 (49.1)</td>
<td>28 (50.9)</td>
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<td>27 (50.9)</td>
<td>33 (54.1)</td>
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<td>17 (54.8)</td>
<td>14 (45.2)</td>
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<td></td>
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<td>41 (50)</td>
<td>41 (50)</td>
</tr>
<tr>
<td>Residence</td>
<td>With family</td>
<td>Single or with friends</td>
<td></td>
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<tr>
<td></td>
<td>14 (51.9)</td>
<td>34 (47.2)</td>
<td>13 (48.1)</td>
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<tr>
<td></td>
<td>17 (54.8)</td>
<td>41 (50)</td>
<td>53 (66.3)</td>
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<td>14 (45.2)</td>
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</tr>
<tr>
<td></td>
<td></td>
<td>41 (50)</td>
<td>53 (66.3)</td>
</tr>
</tbody>
</table>
| Notes: * p < 0.05 ** p < 0.01 *** p < 0.001
DISCUSSION

Some drop-in centres and shelter homes have been set up by the Malaysian government to serve the PLWH. Since there has been no study on the demographic characteristics and QoL among PLWH at these two different settings in Malaysia, the authors aimed to examine these issues by building a profile of the targeted population at these settings and by comparing their QoL. The results of this study may provide information to the programmers and policy makers to design effective strategies to improve the QoL of PLWH at these two different settings.

Firstly, the results confirmed differences in the targeted population that were served by drop-in centres and shelter homes. Compared to PLWH at the drop-in centres, most PLWH at the HIV shelter homes were drug users, heterosexual, under medication, older, non-Malays, non-Muslim, unemployed, had been diagnosed as PLWH for a longer period and were not staying with their families. The higher percentage of Malays at drop-in centres and the higher percentage of Chinese at shelter homes can be of relevance to the NGOs that granted permission to conduct this survey. In Malaysia, all Malays are Muslims and therefore Malay PLWH were always served by Muslim-based NGOs. In contrast, most non-Muslims, such as Chinese and Indians, were always served by non-Muslim-based NGOs. Due to the difference in religion, most Muslims and non-Muslims are allocated to different faith-based organisations on the basis of their religious beliefs (Ministry of Health Malaysia, 2012).

Besides the religious and ethnic differences, the results supported the characteristic differences between the two settings. PLWH at shelter homes were mostly those who could not take care of themselves and were abandoned by their families, older, unemployed, with a longer history of HIV, and under medication. These background differences reflect the differing target population of the drop-in centres and of the shelter homes. In other words, the results confirmed the importance of setting up these two different service providers as they cater to the needs of PLWH with different backgrounds.

Importantly, the study results showed that PLWH from the drop-in centres have lower provider trust but higher health worries and overall function than those from the shelter homes. These differences were found to be associated with some background factors. Firstly, closer examination of the associations between demographic factors and QoL suggested that drug users, unemployment, older age and long-term diagnosis are associated with better provider trust. In Malaysia,
the policy on illicit drug use is very strict (Kamarulzaman, 2009), and most PLWH faced discrimination in society since their HIV infections were usually regarded as a punishment for their sinful activities, such as drug misuse and prostitution (Hasanah et al, 2011). As most of these PLWH stayed at shelter homes, needed others to take care of them and were usually neglected or discriminated against by society for their drug use, the unconditional assistance and care given by service providers could be the reason for higher provider trust reported by PLWH at shelter homes rather than by those at drop-in centres. In other words, PLWH who stayed at shelter homes received more social support than PLWH at drop-in centres. The social support has been found to be significantly associated with QoL of PLWH (Chou et al, 2013; Kipke et al, 2013).

Secondly, health worries are associated with sexual orientation and employment status; most of the PLWH who were employed, homosexual or bisexual, had higher health worries than those who were unemployed or heterosexual. In other words, most of these PLWH are served by drop-in centres. This could be because most PLWH who were employed needed to take the initiative to care for themselves, such as how to face conflicts between healthcare and the demands of their job. In contrast, PLWH who were unemployed, generally stayed at shelter homes and did not have to handle these worries as they were cared for by workers at the shelter homes. Some studies have pointed out the significant association between employment status and QoL (Blalock et al, 2002; Rueda et al, 2011). Apart from this, the higher health worries among homosexual PLWH could be related to the higher number of their sexual partners in the past 3 months. Further analysis by the authors showed that these homosexual PLWH had more sexual partners in the past 3 months (M = 1.93, SD = 2.29) than these heterosexual PLWH (M = 0.14, SD = 0.41), t (45.87) = 5.12, p = 0.001.

Lastly, the overall function is associated with age; thus, the younger PLWH have better overall function than older PLWH. Again, most of these PLWH are served by drop-in centres. While comparing the younger and the older PLWH, the analyses of Chi-square test for independence suggested that more of the younger PLWH had a shorter period of diagnosis (57.6% vs. 37.9%, p = 0.033), were employed (60.3% vs. 14.3%, p = 0.001), were not drug-addicted (11.9% vs. 42.9%, p = 0.001), and were not under medical adherence (64.4% vs. 93.1%, p = 0.001). In other words, the overall physical and psychological condition of PLWH from drop-in centres (most of them are younger) are better than those from shelter homes, and therefore, the PLWH from drop-in centres have higher
overall function than those from shelter homes. These findings are quite similar to the findings that examine the QoL of PLWH attending HIV clinics in Malaysia (Hasanah et al, 2011).

CONCLUSION

Since the results have shown that there are significant differences between demographic backgrounds and HAT-QoL among the PLWH from drop-in centres and those from shelter homes, the findings of this study will be able to assist NGOs in designing better services to meet the needs of PLWH at the two different settings. The continuing services from both drop-in centres and shelter homes are therefore necessary, as services are provided to a different targeted population. Moreover, the authors also found differences in QoL among PLWH from drop-in centres and those from shelter homes. These differences were associated with some demographic factors. Based on the findings, it appears that different strategies are required to assist PLWH from the drop-in centres and those from shelter homes. Programmers at drop-in centres may consider implementing more strategies to improve provider trust and reduce health worries among their clients, and programmers at shelter homes may consider implementing more strategies to increase overall function among their clients.

Since most PLWH in Malaysia are allocated to different settings based on their religious beliefs, future studies could include more drop-in centres and shelter homes catering to people from different religious backgrounds. Besides, as suggested by Mprah (2013) and Shanbhag and Krishanmurthy (2012), future studies could further examine the QoL among PLWH with different disabilities at shelter homes and the QoL of caregivers or helpers at the two different settings.

ACKNOWLEDGEMENT

This study is sponsored by Universiti Tunku Abdul Rahman Research Fund (6200/S17). The authors would like to thank Mr Nazarius Celsus Dorus, Ms Elizabeth Thomas, Ms Rina, Mr Tony Gomez, Mr Matron Fadzilah Abd. Hamid, Ms. Zabedah and Ms. Wan Roraini for allowing them access to the group of PLWH and to recruit them as participants. Thanks also to Mr Sivan for assisting in data collection. The authors declare no potential conflict of interests.
REFERENCES


Fatigue and Functional Capacity in Persons with Post-Polio Syndrome: Short-term Effects of Exercise and Lifestyle Modification Compared to Lifestyle Modification Alone

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1. SBB College of Physiotherapy, VS Hospital, Ahmedabad, Gujarat, India

ABSTRACT

Purpose: Post-polio Syndrome (PPS) affects polio survivors many years after the initial attack, and causes new musculoskeletal symptoms and decline in physical function. This study aims to compare the effect of exercise and lifestyle modification versus lifestyle modification alone, on fatigue and functional capacity in persons with PPS.

Method: An experimental study was conducted at the physiotherapy department of VS Hospital in Ahmedabad. As per the criteria of Halstead (1985), 21 PPS subjects who were between 18 and 65 years of age, and able to walk indoors and outdoors, with or without assistive aids, were included. They were randomly allocated into 3 groups using the envelope method. Those with physician-diagnosed respiratory or cardiac insufficiency, disabling co-morbidity which interfered with the intervention programme or influenced the outcome, and those unable to cooperate due to cognitive impairment or use of any psychotropic drugs, were excluded. Fatigue and functional capacity were measured using Fatigue Severity Scale (FSS) and 2-minute walk distance, respectively. Physical and psychological functions were assessed using Patient Reported Outcome Measurement Information System (PROMIS) questionnaire and Patient Health Questionnaire (PHQ-9) respectively. Intervention was given for 5 days a week, over 4 weeks. Group A received exercise and lifestyle modification, group B received lifestyle modification alone and group C continued their usual routine for 1 month.

Results: There was a significant difference in fatigue and functional capacity within groups A and B, with group A showing better reduction in fatigue.

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than groups B or C. Physical function improved only within group A, and a significant difference was seen compared to groups B and C. Psychological function showed no difference within or between the groups.

**Conclusion:** There was improvement in fatigue, functional capacity and physical function in PPS subjects after 4 weeks of exercise and lifestyle modification. Lifestyle modifications alone for 4 weeks improved fatigue and functional capacity in PPS subjects. There is significant reduction in fatigue and improvement in functional capacity when lifestyle modification advice is given along with exercise.

**Limitation:** Long-term follow-up of the subjects was not undertaken, blinding was not possible, and confounders such as the number of body sites with residual paresis, duration and number of new neuro-musculoskeletal symptoms, and level of physical activity were not considered.

**Key words:** physical function, psychological function, aerobic exercise, strengthening, activity pacing, energy conservation

**INTRODUCTION**

Post-polio Syndrome (PPS) is a condition that can affect survivors many years after the initial paralytic attack caused by the polio virus. It is characterised by progressive or new muscle weakness, or decreased muscle endurance in muscles that were previously affected by the polio infection and in muscles that seemingly were unaffected, as well as generalised fatigue and pain (Halstead, 1991). These symptoms often lead to a decline in physical functioning. Prevalence of PPS ranges between 20-85% among polio survivors (Nollet et al, 1999). It usually begins very slowly, although it can appear suddenly with events like fall, surgery or immobility seeming to be trigger factors. PPS occurs irrespective of age and in people who had paralytic or non-paralytic polio (Halstead and Rossi, 1985). Exclusion diagnosis is followed as there is no diagnostic test for PPS. Hence, diagnosis is based on a proper clinical work-up where all other possible explanations for the new symptoms are ruled out.

Rehabilitation is considered the mainstay of management in PPS, with an emphasis on physical therapy (Dalakas, 1995). This rehabilitation differs from the approach employed to provide relief during the recovery phase of poliomyelitis. The aim is to reach a functional balance by increasing capacities and reducing demands. Several different approaches can be followed, as there
is no specific treatment for PPS. Frequent periods of rest, energy conservation, and work simplification skills are also useful, and general lifestyle modifications including weight control, physical activity, adaptation to assistive devices, and modification of daily activities are advocated to diminish fatigue (Howard, 2005). Properly fitted orthoses can improve the biomechanical movement pattern and be energy-saving (Farbu, 2005). Aerobic exercise using the treadmill improves fatigue, functional capacity and quality of life in persons with PPS (Onçu et al, 2009). Cup et al (2007) reviewed studies dealing with exercise therapy for clients with PPS and found evidence for the effectiveness of strengthening or aerobic exercise to be insufficient. Grimby and Stalberg (1994) suggested endurance and resistive training to be effective in increasing muscle strength and endurance in subjects with PPS. Lygren et al (2007) noted that clients with PPS who had regular physical activity had fewer symptoms and a higher level of functioning than those who were not often physically active.

Acute polio is no longer a constant threat to people in the polio-free areas of the world, but there are still thousands of polio survivors who are at risk of developing late manifestations of the disease. India is a country with a large number of polio survivors (Polio India fact sheet, 2012). There is no published evidence on the epidemiology of PPS in India so far; however a study by Sheth et al (in-press) identifies the prevalence of PPS to be around 80% among polio survivors in Gujarat, India. So far there have been very few research studies that address the problems of PPS and the possible treatment options. It is important to highlight the need to carefully screen all clients with PPS, to study the effect of various treatment options and to evaluate the benefits of each, so that a set of appropriate and effective interventional strategies are implemented promptly. Therefore, this study aims to evaluate and compare the outcome of exercise and lifestyle modifications versus lifestyle modification alone, on the fatigue, functional capacity, physical and psychological function of PPS subjects.

Objectives

The study aimed to determine the effect of exercise and lifestyle modification on fatigue, functional capacity, physical and psychological function in subjects with PPS, using Fatigue Severity Scale, 2-minute walk distance, and PROMIS and PHQ-9 questionnaires, respectively. With the same tools, the study also aimed to determine the effect of lifestyle modification alone on fatigue, functional capacity, physical and psychological function in subjects with PPS, and tried to compare
the effect of exercise and lifestyle modification versus lifestyle modification alone on all the variables under study.

METHODS

An experimental study was conducted from December 2012 to October 2013 at the out-patient physiotherapy department of Vadilal Sarabhai General Hospital in Ahmedabad, India. Ethics approval was obtained from the Institutional Review Board of the college (PTC/IEC/52/2012-2013).

Participants

Subjects with PPS were recruited from various parts of Gujarat, the OPDs of general hospitals of Ahmedabad, and from camps conducted for persons with disabilities. They were also contacted with the help of previous hospital records. As per the Halstead criteria (1985), 21 persons were included in the study. They were between 18 and 65 years of age, diagnosed with PPS, and able to walk indoors and outdoors, with or without assistive aids. They were randomly allocated into one of the 3 groups by the envelope method. The nature and purpose of the study was explained to them in the language they could understand, and informed written consent was obtained. Individuals were excluded if they had any physician-diagnosed respiratory or cardiac insufficiency, were unable to cooperate due to cognitive impairment, had disabling co-morbidity that interfered with the intervention programmes or influenced the outcome, or if they were using any psychotropic drugs. A complete neuromuscular examination was done and demographics along with baseline assessment of outcome measures were taken. Intervention was given on 5 days a week, for 4 weeks.

Tools

Fatigue was measured using Fatigue Severity Scale (FSS) which is a self-administered questionnaire, developed to measure fatigue in medical and neurological diseases. It has also been used to measure general fatigue in PPS. It has a good internal consistency (Cronbach’s alpha=0.81 to 0.95). FSS consists of 9 statements that are scored on a 7-point Likert scale, ranging from 1 (strongly disagree) to 7 (strongly agree), to explore severity of fatigue symptoms. A low value indicates that the statement is not very appropriate whereas a high value indicates agreement (Horemans et al, 2004a). Subjects were asked to encircle a
number from 1 to 7, depending on how they felt the statement applied during the preceding week.

2-minute walk distance (2MWD) was used to measure functional capacity. It is a recommended measure of functional capacity in PPS (Horemans et al, 2004b) and has good validity (r=0.69) and reliability (ICC=0.92 to 0.94). Participants were asked to walk as far as they could at a comfortable speed for 2 minutes. The distance was recorded in metres. The test was terminated if subjects reported any discomfort, fatigue or increase in pain.

Physical function was assessed using Patient Reported Outcome Measurement Information System (PROMIS). It assesses an individual’s ability to perform a range of physical activities. There are 12 questions and the average ability to engage in various tasks over the past week is measured on 5-point scales that range from “without any difficulty” to “unable to do”. The higher the raw score of PROMIS, the better the physical function.

Psychological function was assessed using Patient Health Questionnaire (PHQ-9). This is a 9-item measure in which respondent’s rate how frequently they experienced 9 symptoms of depression during the past 2 weeks, by using a 4-point scale where 0 is “not at all” and 3 is “nearly every day.” The total score can range from 0 - 27 and a higher score represents higher levels of depressive symptoms. It has been widely used to assess depression severity and has a great deal of support for its validity in populations with physical disabilities (Jenson et al, 2011).

**Intervention**

Subjects in group A received exercise and lifestyle modification. Exercises were divided into 4 phases. Phase 1 consisted of warm up, in the form of gentle, active range-of-motion exercises in the pain-free range of any 8 possible joints of 4 limbs. The subject performed 5 repetitions. Phase 2 consisted of strengthening exercises (Feldman and Soskolne, 1987) of any 8 possible muscle groups of 4 limbs, out of the 12 muscle groups mentioned in Table 1 on the right and left extremities. These were performed by means of dumbbells, weight cuffs or limb weight. Gravity-minimised positions were used for large muscles having power <3 on MMT (manual muscle testing), and anti-gravity body positions were used for large muscles >3 on MMT. Subjects actively performed 2 sets of 5 repetitions each. A 30-second rest period was given between each set and also between the exercises.
of each muscle group. If subjects reported any symptoms of pain aggravation or fatigue, exercises were discontinued immediately during the session. Phase 3 was the aerobic exercise phase during which subjects performed 10 minutes static cycling on a regular lower extremity cycle ergometer. They were asked to maintain their exertion at moderate intensity (i.e. RPE of 13-15 on modified Borg’s scale). Phase 4 was the cool down phase consisting of gentle, passive range of motion exercises of all the muscles actively exercised in the warm up phase. The therapist performed 5 repetitions.

Table 1: Muscles Exercised

<table>
<thead>
<tr>
<th></th>
<th>Muscles Exercised</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Shoulder flexors</td>
</tr>
<tr>
<td>2.</td>
<td>Shoulder extensors</td>
</tr>
<tr>
<td>3.</td>
<td>Shoulder abductors</td>
</tr>
<tr>
<td>4.</td>
<td>Elbow flexors</td>
</tr>
<tr>
<td>5.</td>
<td>Elbow extensors</td>
</tr>
<tr>
<td>6.</td>
<td>Hip flexors</td>
</tr>
<tr>
<td>7.</td>
<td>Hip extensors</td>
</tr>
<tr>
<td>8.</td>
<td>Hip abductors</td>
</tr>
<tr>
<td>9.</td>
<td>Knee flexors</td>
</tr>
<tr>
<td>10.</td>
<td>Knee extensors</td>
</tr>
<tr>
<td>11.</td>
<td>Ankle dorsi-flexors</td>
</tr>
<tr>
<td>12.</td>
<td>Ankle plantar-flexors</td>
</tr>
</tbody>
</table>

Group B subjects received lifestyle modification alone. Lifestyle modification remained common for groups A and B and consisted of:

1) Activity pacing - Balancing of activity with rest periods interspersed throughout the day.

2) Energy conservation technique - Adoption of strategies that reduce overall requirements of the task and overall level of fatigue. It also included modifying the task or the environment for successful completion of daily activities.

3) Advice on use of assistive devices - Crutches, canes, sticks, calipers, footwear modification based on their needs.

4) Advice on maintaining health body weight - Eating less fat and high fibre diet.

5) Advice on adequate rest – Getting 7 - 8 hours of uninterrupted sleep.

6) Management of pain - Application of hot/cold packs to the painful area for 10 minutes, once a day.
The subjects were also given a handout listing the instructions to be followed; in a language they could understand (Appendix 1).

Group C subjects continued their usual routine. None of their activities were restricted. They were asked to continue their routine schedule and activities of daily living, and to wait until called for the exercise intervention, at 4 weeks. Compliance to intervention was monitored and was categorised as ‘Daily’ (20 sessions), ‘Mostly’ (15-20 sessions), ‘Partly’ (10-15 sessions), and ‘Never’ (<10 days).

**Data analysis**

Level of significance was set at 5% and data were analysed using Graph-Pad Prism version 5 and SPSS version 20. Variables were checked for normal distribution using Histogram and Kolmogorov Smirnov test, and appropriate test of analysis was applied. Changes in the outcome measures were examined within and between the groups. Mean difference in FSS score was analysed using Wilcoxon signed-rank test within each group, and Kruskal-Wallis test between the groups. Mean difference in 2MWD was analysed within each group using paired t-test, and Kruskal-Wallis test between the groups. Mean difference in PROMIS and PHQ-9 was analysed within the groups using Wilcoxon signed-rank test and Kruskal-Wallis test was used for analysis between the groups.

**RESULTS**

There were 8 males and 13 females, with a mean age of 41.71 ± 5.12 years. Age and body mass index (BMI) were normally distributed and one-way ANOVA was applied for comparison between the groups. There was no difference in between the groups with respect to age (F2,18 = 1.035; p= 0.376) or BMI (F2,18 = 0.458; p= 0.640).

Compliance to programme was assessed for subjects in group A and group B. 20 subjects completed the study. One subject in group A who participated for <10 days was considered as a dropout (for social reasons), and 1 subject in group B participated for 15-20 sessions.

Tables 2 and 3 show within-group and between-group analysis of outcome measures respectively. There was a statistically significant difference in FSS within group A (Z= -2.375; p <0.018) and group B (Z= -2.207; p=0.027) but not within group C (Z= -0.577; p=0.577). Between the groups, there was a statistically significant difference in FSS score (p<0.003).
Table 2: Mean Difference in Outcomes within the Group

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Statistics</th>
<th>Group A</th>
<th>Group B</th>
<th>Group C</th>
</tr>
</thead>
<tbody>
<tr>
<td>FSS</td>
<td>Pre- FSS</td>
<td>5.5 ± 0.34</td>
<td>5.1 ± 0.37</td>
<td>5.3 ± 0.19</td>
</tr>
<tr>
<td></td>
<td>Post-FSS</td>
<td>4.9 ± 0.40</td>
<td>5.1 ± 0.35</td>
<td>5.3 ± 0.15</td>
</tr>
<tr>
<td></td>
<td>P value</td>
<td>0.018*</td>
<td>0.027*</td>
<td>0.577</td>
</tr>
<tr>
<td></td>
<td>Z value</td>
<td>-2.375</td>
<td>-2.207</td>
<td>-0.577</td>
</tr>
<tr>
<td>2 MWD</td>
<td>Pre-2MWD</td>
<td>93.91 ± 9.68</td>
<td>100.14 ± 10.59</td>
<td>107.26 ± 2.14</td>
</tr>
<tr>
<td></td>
<td>Post-2MWD</td>
<td>94.60 ± 9.67</td>
<td>100.57 ± 10.71</td>
<td>106.60 ± 3.28</td>
</tr>
<tr>
<td></td>
<td>P value</td>
<td>&lt; 0.001*</td>
<td>0.003*</td>
<td>0.276</td>
</tr>
<tr>
<td></td>
<td>t value</td>
<td>-6.00</td>
<td>-4.804</td>
<td>0.197</td>
</tr>
<tr>
<td>PROMIS</td>
<td>Pre-PROMIS</td>
<td>39.60 ± 5.31</td>
<td>43.50 ± 5.88</td>
<td>43.50 ± 4.65</td>
</tr>
<tr>
<td></td>
<td>Post-PROMIS</td>
<td>42.00 ± 4.92</td>
<td>42.00 ± 6.13</td>
<td>43.50 ± 5.45</td>
</tr>
<tr>
<td></td>
<td>P value</td>
<td>&lt; 0.014*</td>
<td>1.00</td>
<td>0.18</td>
</tr>
<tr>
<td></td>
<td>Z value</td>
<td>-2.456</td>
<td>0.00</td>
<td>-1.342</td>
</tr>
<tr>
<td>PHQ-9</td>
<td>Pre-PHQ9</td>
<td>3.85 ± 1.06</td>
<td>5.29 ± 1.97</td>
<td>5.42 ± 1.61</td>
</tr>
<tr>
<td></td>
<td>Post-PHQ9</td>
<td>3.83 ± 1.06</td>
<td>5.59 ± 2.07</td>
<td>5.57 ± 1.51</td>
</tr>
<tr>
<td></td>
<td>P value</td>
<td>0.317</td>
<td>0.157</td>
<td>0.317</td>
</tr>
<tr>
<td></td>
<td>Z value</td>
<td>-1.00</td>
<td>-1.42</td>
<td>-1.00</td>
</tr>
</tbody>
</table>

*Significant

Table 3: Mean Difference in Outcomes between the Groups

<table>
<thead>
<tr>
<th>Group</th>
<th>FSS (Median + SD)</th>
<th>2 MWD (Mean + SD)</th>
<th>PROMIS (Median + SD)</th>
<th>PHQ-9 (Median + SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>0.50 ± 0.12</td>
<td>0.63 ± 0.17</td>
<td>2.40 ± 0.61</td>
<td>0.02 ± 0.06</td>
</tr>
<tr>
<td>B</td>
<td>0.17 ± 0.15</td>
<td>0.41 ± 0.32</td>
<td>0.00 ± 0.68</td>
<td>1.00 ± 0.00</td>
</tr>
<tr>
<td>C</td>
<td>0.05 ± 0.11</td>
<td>1.1 + 1.13</td>
<td>0.00 ± 0.94</td>
<td>-0.29 ± 0.4880</td>
</tr>
<tr>
<td>P value</td>
<td>0.003*</td>
<td>0.206</td>
<td>0.008*</td>
<td>0.810</td>
</tr>
<tr>
<td>F/ \chi^2 value</td>
<td>12.734</td>
<td>3.156</td>
<td>9.945</td>
<td>0.444</td>
</tr>
</tbody>
</table>

*Significant

Table 4 shows that Dunn’s multiple comparison test was applied for multiple comparisons between the groups. Group A had a statistically significant difference over group B (p<0.05) and group C (p<0.05). Group B had no significant difference over group C (p>0.05).
For 2MWD, there was a statistically significant difference within group A (t=−6.00; p=0.001) and group B (t=−4.804; p=0.003) but no difference in group C (t=0.197; p=0.276). There was no significant difference between the groups.

Table 4: Dunn’s Multiple Comparison Test for FSS between the Groups

<table>
<thead>
<tr>
<th>COMPARISON</th>
<th>Difference in rank sum</th>
<th>p &lt;0.05</th>
</tr>
</thead>
<tbody>
<tr>
<td>GROUP A vs B</td>
<td>7.7</td>
<td>Yes *</td>
</tr>
<tr>
<td>GROUP B vs C</td>
<td>2.2</td>
<td>No</td>
</tr>
<tr>
<td>GROUP C vs A</td>
<td>9.8</td>
<td>Yes *</td>
</tr>
</tbody>
</table>

*Significant

Physical function as measured by PROMIS, showed a statistically significant difference in group A (Z= -2.456; p=0.014) and no difference in group B (Z= 0.00; p= 1.00) and group C (Z=-1.342; p=0.18). Also, there was a statistically significant difference between the groups (p=0.007) and Dunn’s multiple comparison test was applied between the groups as shown in Table 5. Group A had a statistically significant difference over groups B and C. Group B had no significant difference over group C (p=1.000). Psychological function as assessed by PHQ-9 revealed no difference within or between the groups.

Table 5: Dunn’s Multiple Comparison Test for PROMIS between the Groups

<table>
<thead>
<tr>
<th>COMPARISON</th>
<th>Difference in rank sum</th>
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<tr>
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</tr>
<tr>
<td>GROUP C vs A</td>
<td>8.500</td>
<td>Yes *</td>
</tr>
</tbody>
</table>

*Significant

DISCUSSION

The results of this study showed positive findings, with significant improvement in fatigue, functional capacity and physical function in group A. In group B also, fatigue and functional capacity showed significant improvement. Improvement in fatigue and functional capacity was significantly better in group A as compared to group B.
Subjects in groups A and B showed a significant difference in fatigue from the baseline. This reduction in fatigue can be attributed to lifestyle modification, which balances the physical demands and energy utilisation. Lifestyle modification in the form of pacing has been shown to be effective in minimising muscle aching and cramping (Jones et al, 1989). Group A subjects showed significant improvement in comparison to group B subjects, which can be explained by changes in response to exercise causing increase in maximal oxygen consumption at tissue level with capillary organisation, one of the peripheral mechanisms of fatigue. An aerobic exercise programme can break the circle of inactivity, impaired performance and increased fatigability (Kilmer, 2002). In a randomised control trial, Klein et al (2002) observed a significant decrease in the mean number and mean severity of the shoulder symptoms following a 16-week non-fatiguing strengthening exercise and lifestyle modification programme for PPS subjects. Oncu et al (2009) also noted improvement in fatigue after an exercise programme consisting of flexibility exercises and aerobic exercises. Jones et al (1989) found improvement in fatigue, work capacity and aerobic power following a 16-week thrice-weekly aerobic programme for 16 subjects with PPS.

Various studies have concluded that non-fatiguing strengthening exercise at sub-maximal levels can be beneficial for polio survivors to improve their aerobic capacity (Agre and Rodriguez, 1997). In keeping with this, group A subjects in the present study showed significant improvement in functional capacity. Improvement in functional capacity in group B can be explained by reduction of fatigue-causing increased aerobic performance and hence, the functional capacity. Central and peripheral mechanisms are responsible for exercise adaptations leading to greater functional capacity. Increased myocardial contractility, improved venous return, increased maximum minute volume; increased tidal volume and increased stroke volume facilitate increase in the cardiopulmonary performance. Greater pulmonary diffusion is another favourable change that may be expected (Wilmore and Costill, 2004).

Group A subjects showed a significant difference in physical function, which could be because of increased motivation and empowerment of the clients after exercise. Fatigue and decrease in functional capacity, the most important features of PPS, cause restrictions in daily activities such as walking and climbing stairs, and this affects quality of life. Willen et al (2001) reported significantly lower pain and increased wellbeing with non-swimming dynamic exercise. Group B subjects
showed reduction in fatigue and increase in functional capacity; however there was no improvement in physical function.

Psychological function showed no difference from baseline in all the 3 groups. This is in contrast to various studies in the literature (Rekand et al, 2004; Bertelson et al, 2009), which suggest improvement in various domains of quality of life and mental health following exercises and lifestyle modification advice. One possible reason could be that the short 4-week duration of the study may have been insufficient to benefit psychological health. Another reason could be because of fewer disturbances in psychological function in all the 3 groups at baseline.

Group C showed decline in fatigue, functional capacity, physical and psychological function, but this was not statistically significant. This suggests that PPS subjects may experience a gradual deterioration in their overall functional status if given no exercise or lifestyle modification. Consistent with these findings, various long term observational studies (Ghahari et al, 2010) have shown that there was a significant decrease in physical functioning and walking capacity and a significant increase in co-morbidity and extent of paresis, whereas continuous rehabilitation seems to maintain physical independence in polio clients, improves their ability to earn their own income, and lessens the need for disability pensions (Trojan et al, 2009).

CONCLUSION

After 4 weeks of exercise and lifestyle modification, there was improvement in fatigue, functional capacity and physical function in PPS subjects. Lifestyle modification advice followed over a period of 4 weeks led to improvement in fatigue and functional capacity among them. Reduction in fatigue and improvement in functional capacity was significantly more when lifestyle modification advice is given along with exercise. Both exercise and lifestyle modification and lifestyle modification alone had no effect on psychological function.

Implications

Administration of a regular exercise programme can be beneficial to clients with post-polio syndrome. It would be appropriate to give those with distinct impairment in functional capacity an exercise programme along with lifestyle modification. Those who cannot follow an exercise programme can be advised lifestyle modification only.
Limitation

Long-term follow-up of the subjects was not undertaken, blinding was not possible, and confounders such as the number of body sites with residual paresis, duration and number of new neuro-musculoskeletal symptoms and level of physical activity were not considered. Future studies could bear these in mind.

ACKNOWLEDGEMENT

The authors are grateful to Dr Hemant Tiwari for his guidance on statistics and to Dr. Sagun Desai for providing valuable insight into the research topic. They thank all the study participants for their enthusiasm and cooperation.

REFERENCES


APPENDIX 1: INSTRUCTIONS

ACTIVITY PACING:
1. You can set your baseline by timing how long you can do a task before you begin to tire.
   For example, the next time you climb the stairs count the number of steps it takes you to get tired. If you get tired after 10 steps you can work out your activity baseline – half of 10 steps = 5 steps.
2. While doing any activity, stop and rest before you begin to feel tired. After rest, continue your activity. When you feel tired, you stop and rest again.

ENERGY CONSERVATION:
1. Prioritise a task:
   • Does it all need to be done today?
   • Can I get someone to help me?
   • Does it need to be done at all?
2. Planning:
   • Can I break the job down into different stages?
   • What do I need to carry out the job?
   • What basic activities does each stage involve, e.g. walking/sitting/standing?
   • Is there too much to do on any one day?
   • Could easier/lighter tasks be alternated with more difficult/heavier tasks?
   • Have I scheduled enough rest periods?
3. Work areas should be arranged in the most effective way:
   For example, in the kitchen have the most frequently used items in the most easy to reach places. Sit down when preparing a meal as this uses 25% less energy.
4. For heavy tasks, plan the whole schedule on a daily/weekly basis.
Profile of Childhood Health Conditions referred to Physiotherapy and Attributing Factors to Disablement

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1. JSS College of Physiotherapy, Mysore, Karnataka, India

**ABSTRACT**

**Purpose:** This study attempted to profile the prevalence of childhood health conditions and the factors that contribute to the disablement process leading to disability among children who visit a tertiary referral hospital in Mysore, India.

**Method:** A mixed methods approach was adopted. Phase 1 of the study delineated the profile of cases being referred for physiotherapy treatment. Cases of Cerebral Palsy were reported to be the highest (46%). Phase 2 of the study identified 4 major themes based on the mothers’ experiences with their children.

**Result:** The findings revealed the need to create awareness among paediatricians about the importance of early intervention in childhood disorders and optimal referral to physiotherapy. The other themes which emerged included various attitudes of family and society, lack of cooperation from school as well as the presence physical barriers in school and community and frustration experienced by caregivers due to lack of help and facilities.

**Conclusion:** There is a need to educate parents and society at large that disability should not be associated with “abnormal”. It is rather an interrelated phenomenon where the health issues of an individual and the outlook of society both play an important part.

**Keywords:** Disability among children, prevalence

**INTRODUCTION**

Childhood disorders which lead to lifelong disability are a significant cause of disease burden, especially in resource-poor countries like India. Statistics on the
prevalence and incidence of any health condition, including childhood disorders, help people who work in medical, research and government fields. Prevalence refers to the number of individuals in a specified population who have the condition being studied at a specified time, such as a particular day, regardless of when it began (My Child, 2013). Developed countries like the United States, Australia, Canada and UK, have a lower prevalence rate of childhood disorders compared to developing countries like China, Saudi Arabia, and India (Boyle et al, 2011).

The reason for developing countries showing a significant increase in disabilities compared to developed countries may be attributed to low economic income, low education background and poor nutrition of the mother and child (Gladstone, 2010). Impairment is a problem in body function or structure such as significant deviation or loss; activity limitations are difficulties encountered by an individual in executing a task or action; while participation restrictions are problems experienced by an individual in involvement in life situations (WHO, 2002). Therefore, disability is not just a health problem. It is a complex phenomenon, reflecting the interaction between features of a person’s body and features of the society in which he or she lives.

The term disablement, according to Nagi, refers to the “various impact(s) of chronic and acute conditions on the functioning of specific body systems, on basic human performance, and on people’s functioning in necessary, usual, expected, and personally desired roles in society” (Jette, 1994). Therefore, disablement is a process which results in disability. Halfon et al (2012) and Fougeyrollas et al (1999) offer a new and forward-looking definition of childhood disability that reflects emerging and developmentally responsive notions of childhood health and disability. They highlight the relationship between health, functioning, and the environment; the gap in function between a child’s abilities and the norm; and how that gap limits the child’s ability to engage successfully with his or her world. Their definition also recognises the dynamic nature of disability and how the experience of disability can be modified by the child’s environment.

Disability workers and policy in India continue to focus on impairment as the chief cause for disability. However, there is adequate evidence that the health condition is only one factor in the disablement process (Danesco, 1997; Conners & Stalker, 2007; Seligman & Darling, 2007).

We tried to explore factors other than health conditions that contribute to a parent’s experience of disablement. It is imperative to understand that in addition
to impairments in functioning; both environment and personal factors, such as attitudes of society, physical barriers, etc. play a key role in disablement and should be brought to the attention of human rights commission.

Objective
This study attempted to profile the prevalence of childhood health conditions and factors that contribute to the disablement process leading to disability among children who visit a tertiary referral hospital in Mysore city of Karnataka state, India.

METHOD

Study Design
A mixed methods approach was adopted.
Phase 1: Prevalence
Phase 2: Qualitative – phenomenological
Permission to conduct the study was taken from the Institutional Review Board.

Sampling and Strategy: Convenience
In Phase 1, all children with special needs who received physiotherapy between the years 2009 and 2013 were included from the intake register.
In Phase 2, children from 2 - 9 years of age who received physiotherapy regularly were included.

Sample Size
Phase 1: Complete enumeration
Phase 2: Five children
Inclusion criteria: Children between 2 and 9 years of age, of both genders, with any diagnosis pertaining to developmental anomalies and neuro-developmental disorders.
Exclusion criteria: Children presenting with traumatic disorders. In Phase 2, the primary care-giving parents of identified children were included till data saturation was reached.
Procedure

Phase 1: The in-patient register for the years 2009 - 2013 was scrutinised, and participants who fulfilled the inclusion and exclusion criteria were identified. The children were referred from JSS Hospital and/or various nearby hospitals to the JSS Physiotherapy Department (by Paediatricians, Neurologists and other departments like Occupational and Speech & Hearing). Information was taken from medical records under the following headings: (a) Diagnosis, (b) Pre-natal, Peri-natal and Post-natal history, (c) Milestones, (d) Primitive Reflexes and Deep Tendon Reflexes, (e) Sensory Evaluation-Visual, Auditory, Tactile, (f) Protective Reflexes and Reactions, (g) Range of motion and Muscle tone evaluation, (h) Balance and Gait evaluation, (i) Gross Motor Functions, (j) Cognitive and Social Functions. In cases where there was a mismatch between the clinical diagnosis and findings, the grouping was done on the basis of the physiotherapy assessment. Although diagnoses are different, the disability is comparable as these children were unable to play with their peers and participate in other life situations as efficiently as typical children of their age.

Phase 2: The purpose of this study was to identify causes of disability, not diagnosis. No attempt was made to recruit clients on the basis of diagnoses noted in Phase 1. After the initial profiling, those children were identified who attended physiotherapy sessions regularly, for more than 5 consecutive times, and who had a significant functional limitation or developmental delay. Primary care-giving parents of the children were approached for informed consent. Those who consented were recruited till data saturation was reached. To study the maternal causative factors that could lead to childhood disability, assessment was done of the mothers’ health and emotional and social status before, during and after pregnancy. A questionnaire based on Pregnancy Risk Assessment Monitoring System (PRAMS) was administered, and open-ended in-depth personal interviews were conducted to explore the mother’s experiences with their child (CDC, 2013). The items in the PRAMS questionnaire, which was originally designed to be administered in USA, were scored for relevancy in the Indian context by 10 Indian mothers with typically developing children. After the irrelevant items were excluded, the questionnaire was administered and followed by in-depth personal interviews. These interviews took place in a secluded room where the mothers were requested to describe their mothering experiences in the language of their choice. In case mothers were not able to elaborate or would go out of context, probing questions like, “How is your family’s attitude towards the
child?” and “Are they sensitive or indifferent?” etc. were asked. Data was tape-recorded by the interviewer to get accurate accounts. The average duration of each interview was 20-30 minutes. No incentives were offered to the participants.

Data Analysis
Phase 1: Descriptive analysis - frequency
Phase 2: Observational analysis

To maintain the data quality and credibility of the analysis, the questionnaires as well as the recordings were analysed manually by 2 of the authors. Emergent themes were identified. Descriptions provided by the preconceived themes and the emergent themes were noted down.

RESULTS
Phase 1: The results showed that the children referred for physiotherapy treatment between the years 2009 and 2013 were largely children with a diagnosis of Cerebral Palsy (n=43), followed by those with Developmental delay (n=30), Erb’s palsy (n=12), Mental retardation (n=11), Hydrocephalus (n=2) and Autism (n=2).

Figure 1: Graph depicting percentage of Childhood Disorders referred for Physiotherapy treatment between the years 2009 and 2013
Phase 2: The PRAMS questionnaire suggested that the social life of the mothers had changed immensely since the birth of their child. Four major themes that were identified while exploring the causative factors of disablement from mothers’ experiences with their children.

**THEME 1: Inadequate Information from Healthcare Providers**

“We went to many doctors in hope of a cure and one doctor gave us false hopes and turned his back after seeing the scan reports which frustrated me a lot.”

“My child’s file was thrown in the dustbin by the doctor.”

“Doctor wrongly diagnosed my child with polio without any investigation and asked us to accept it.”

“They couldn’t diagnose my child’s condition and it took visits to four different doctors to get a correct diagnosis and by then, I think, the recovery period was already lost.”

“I was told that my child will never walk by the doctor, but no information as to what should be done.”

“We were not involved or told about my son’s progress during therapy and were made to sit out.”

**THEME 2: Attitudes of Family and Society**

“People in the locality make fun of my child and call her names because of her bowel incontinence.”

“Neighbours pity him since he can’t speak.”

“Family members pity and pamper my son and I feel that has made him stubborn and lazy.”

“My in-laws want her to become alright but do not help in care-giving.”

“I was told that someone had done black magic on my son and to get him treated for it.”

“My husband and family blame me for the child’s deformities.”

**THEME 3: Lack of Cooperation from Schools**

“My son, though having a normal IQ, was denied admission in three schools and we were told that his presence would be a disturbance to other children.”

“First two schools did not take my son because they couldn’t give extra care to a disabled child.”
THEME 4: Physical Barriers in School and Community

“Class is on the third floor and there are no ramps.”

“Toilets are far from classroom.”

“The school is not disability friendly and I find it difficult to carry him around all the time.”

THEME 5: Caregiver’s Frustration due to Lack of Help and Facilities

“Being in a joint family, responsibilities are too much and I’m unable to give proper attention to my daughter and sometimes I tend to take out my frustration on her.”

“I’m unable to spend time with my other children.”

“No one to share the burden of household work and helping with the child.”

Table 1: The results of Phase 2 are represented below in the ICF Framework
Although most clients with GBS recover, some of them have residual impairments. This Table depicts the case of a child with GBS who has not recovered. The denial of admission for this child in a regular school was reported by the mother and audio-recorded during the interview.

DISCUSSION
In India, it has been found that the prevalence rate of developmental delay is 19.8% (Ali et al., 2011) and Cerebral palsy is 2-2.8 per 1000 live births (Gladstone, 2010). Every 2-3% of children in India have Mental retardation (Kabra & Gulati, 2003), while Autism is found among 1 in 250 (Barua & Daley, 2008). The results proved that more children with Cerebral Palsy are referred (43%), followed by cases of Developmental delay (30%), Mental retardation (12%), Erb’s palsy (11%), Autism (2%) and Hydrocephalus (2%). According to the National Census, more Developmental delay cases should have been referred to the physiotherapy department but referral seems to be delayed until gross signs appear. Referral to the paediatric physiotherapy department for other childhood health conditions such as Spina bifida, Osteogenesis imperfecta, multiple congenital contractures, etc., are also less frequent. This may be due to inadequate knowledge among paediatricians about the role of physiotherapy in treating all these conditions.

The participants in this study were chosen by convenience from the paediatric population that visits this hospital department. Five primary caregiving parents and their children with differing diagnoses, ranging in age from 2-9 years, were included. The primary caregivers in all these cases were the mothers. They came from different backgrounds in terms of religion, family structure, socio-economic status, geographical region, mother tongue and educational levels.

THEME 1: Inadequate Information from Healthcare Providers
The emergent theme that came to light here was that the parents were not given proper counselling by healthcare professionals. Four out of 5 mothers gave an account of the number of doctors and healthcare providers from various fields that they had visited. Their expectations of receiving counselling on how to handle a child with disability, what to do and what not to do, what to expect, etc., were not met. This resulted in visits to various healthcare providers in search of answers, and consequently delayed rehabilitation. In most cases, it was the parents’ failure to accept their child’s impairment which resulted in disablement. Thus, the focus shifts from what the child “can do” to everything the child “cannot do”.

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THEME 2: Attitudes of Family and Society
Mysore has a diverse population with varied cultures, languages and beliefs; the authors attempted to explore whether these differences could influence beliefs about causes of disability. A Hindu mother blamed “karma” and “fate” for her child’s state. A Muslim mother had been told that her child was a victim of black magic and the child was given treatment for it. A Christian mother showed more acceptance of her child’s impairments. These varying responses signify that personal beliefs and mind-sets caused by diverse cultural and social backgrounds can hinder parents’ acceptance of the child’s impairments and thus, cloud the abilities that are present and cause disability (Barnes et al, 2000).

THEME 3 & 4: Lack of Cooperation and Physical Barriers in School and Community
Three of the 5 participants who were of school-going age did not attend school due to lack of facilities and because the authorities were not sensitive to their needs. Two of the participants, despite having normal IQs, were denied admission in regular schools due to their inability to walk independently. This throws light on the ignorance of the school authorities whose prejudices are barriers to the social integration of these children.

THEME 5: Caregiver’s Frustration due to Lack of Help and Facilities
Analysis of the questionnaires and personal interviews with the mothers revealed that each one’s social life had changed drastically after her child was born. There were increased levels of stress in providing care and fulfilling the child’s needs, apart from responsibility towards the other children and the family.

Implications
Lack of information from healthcare providers proved to be the major cause of disability as it interfered with parents’ quality of life and the child’s integration into society.

The attitudes of family, society and school authorities was also responsible for jeopardising the opportunities for integration of children with disability into society.

This study reveals the need to create awareness among paediatricians about the importance of early intervention in childhood disorders and optimal reference to

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PT for the same. The parents and society at large need to be educated that disability should not be associated with “abnormal” as it is an interrelated phenomenon where the health issues of an individual and the outlook of society both play an important part. Healthcare practitioners may show callous indifference in dealing with a child with disability. Statements such as “Your child will never walk”, can be catastrophic to the parents, and such situations are to be handled with utmost care. The need for a team-based approach in dealing with children with special needs and their families is evident.

**Limitations**

The PRAMS questionnaire may not be sensitive to measure the maternal causative factors. Further research in this field is needed.

The results of this study have to be interpreted with caution as it is a hospital-based study and is in no way expected to be indicative of the profile of society in general.

**REFERENCES**


Comparative Effect of Massage Therapy versus Kangaroo Mother Care on Physiological Responses, Chest Expansion and Body Weight in Low Birthweight Preterm Infants

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ABSTRACT

Massage therapy (MT) and Kangaroo Mother Care (KMC) are both effective in increasing the weight of low birthweight preterm infants. However no comparisons have been made until now between the two.

Purpose: The aim of this study was to compare the effectiveness of MT and KMC on body weight, physiological responses and chest expansion of low birthweight preterm (LBWPT) infants.

Method: Using convenience sampling, 20 LBWPT infants from the Neonatal Intensive Care Unit of VS Hospital were randomly divided into 2 groups of 10 each. Group 1 received MT and Group 2 received KMC for 15 minutes, thrice daily for 5 days. Medically stable babies with gestational age <37 weeks and birth weight <2500g were included. Those on ventilators and with congenital, orthopaedic or genetic abnormality were excluded. Outcome measures including body weight, physiological responses (heart rate, respiratory rate and body temperature) and chest expansion were taken pre-intervention on day 1 and post-intervention on day 5. Level of significance was kept at 5%.

Results: Data were analysed using SPSS version 16. Both MT and KMC were found to be effective in improving body weight (p=0.005, p=0.007), decreasing heart rate (p=0.005, p=0.004), respiratory rate (p=0.018, p=0.004) and body temperature (p=0.005, p=0.007), and improving chest expansion (p=0.026, p=0.014). However, while both were found to be equally effective for body weight (p=0.341), heart rate (p=0.22), respiratory rate (p=0.969) and chest expansion (p=0.331), MT was found to be better than KMC in decreasing body temperature (p=0.003).

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**Conclusion:** MT and KMC were both found to be equally effective, though MT appeared better at decreasing body temperature.

**Limitations:** Factors that may affect the physiological responses and body weight were not monitored.

**Implications:** Massage Therapy and Kangaroo Mother Care can be used in the community for weight gain, improvement of chest expansion and regularisation of physiological responses among preterm infants.

**Key words:** Neonatal Intensive Care Unit, heart rate, respiratory rate, body temperature

**INTRODUCTION**

Preterm birth is defined as childbirth occurring at less than 37 completed weeks or 259 days of gestation (World Health Organisation, 1992).

Classification based on birth weight is as follows:

- Low birth weight (LBW) – birth weight <2500g
- Very low birth weight (VLBW) – birth weight<1500 g
- Extremely low birth weight (ELBW) – birth weight<1000g.

Children who are born prematurely have higher rates of cerebral palsy, sensory deficits, learning disabilities and respiratory illnesses compared to children born at term. The morbidity associated with preterm birth often extends to later life, resulting in enormous physical, psychological and economic costs (Petrou, 2005).

Researchers have provided hospitalised preterm infants with various forms of supplemental stimulation in an effort to enrich the environment of the neonatal intensive care unit (NICU) or to accelerate development (Dieter & Emory, 1997; Feldman & Eidelman, 1998). Two of the most widely studied interventions are Massage Therapy and Kangaroo Mother Care.

Massage is referred to as “a methodological touch intended to stimulate the baby”. A number of studies have shown the positive effects of Massage Therapy on preterm infants. These include weight gain, improved sleep/wake states, decreased stress, early discharge from the NICU, improved skin integrity, increased development of the sympathetic nervous system, and enhanced parent-infant bonding (Leonard, 2008).
Kangaroo Mother Care is defined as “early, prolonged and continuous skin-to-skin contact between the mother and low birthweight infant, both in the hospital and after discharge, with exclusive breastfeeding and proper follow-up” (Rey & Martinez, 1983). Kangaroo Mother Care regularises heart rate and respirations, deepens sleep and alert inactivity, reduces crying, prevents infections, shortens the neonatal hospital stay, enhances weight gain, improves physical growth and breastfeeding rates, decreases pain from heel prick procedure and lessens maternal depression (Anderson, 1991; Alencar et al, 2009; Lawn et al, 2010; Conde-Agudelo et al, 2011; Nimbalkar et al, 2013).

A systematic review by Conde-Agudelo and Belizan in 2003 concluded that KMC appears to reduce severe infant morbidity without any serious deleterious effect reported; however there is still insufficient evidence to recommend its routine use in LBW infants (Conde-Agudelo et al, 2011).

Literature is scarce regarding the effects that Massage Therapy and Kangaroo Mother Care have on chest expansion. This is a new area to be studied and researched.

Massage Therapy (MT) and Kangaroo Mother Care (KMC) are both effective in increasing the weight of low birthweight preterm infants, though their effectiveness on the physiological responses and chest expansion is still unclear.

Objectives

To compare the effectiveness of MT and KMC on physiological responses, chest expansion and body weight among low birthweight preterm infants.

The study was approved by the Institutional Ethics Committee of S.B.B College of Physiotherapy, V.S General Hospital, Ahmedabad, Gujarat.

METHOD

A quasi-experimental study was conducted with a convenience sample of 20 infants at the NICU of V.S. Hospital, in 2013. Infants born at a gestational age of <37 weeks, of low birth weight and medically stable were included, while those who were medically unstable, had any congenital, orthopaedic or genetic abnormality, or were on ventilators were excluded. Informed consent was taken from the parents.

The infants were randomly divided into 2 groups, with 10 in each group. Group 1 received 15 minutes of MT, thrice daily for 5 days. Group 2 received 15 minutes
of KMC, thrice daily for 5 days. Outcome measures including body weight, chest expansion and physiological responses (heart rate, respiratory rate and temperature) were taken pre-intervention on day 1 and post-intervention on day 5. Level of significance was kept at 5%.

MT was given according to the Field Massage therapy protocol. Infants were massaged for 15 minutes, 3 times a day, at least 1 hour after being fed. Each massage session consisted of 5 minutes of tactile stimulation, 5 minutes of kinesthetic stimulation, and another 5 minutes of tactile stimulation. During the tactile stimulation, the infant was placed in a prone (face down) position and given moderate pressure stroking with fingertips of both hands. During the kinesthetic massage, the infant was placed in a supine (on back) position and led through passive flexion/extension actions (Dieter & Emory, 1997).

During KMC the infant, wearing only a diaper, was placed between the mother’s uncovered breasts. The mother was seated on a standard rocking chair, tilted at an angle of approximately 60°.

RESULTS
Data were analysed using SPSS version 16. Wilcoxon test was applied to determine whether there was significant difference within the groups. Mann-Whitney U test was applied to determine whether there was any significant difference between both the groups. Both MT and KMC respectively were found to be effective in improving body weight (p=0.005, p=0.007), decreasing heart rate (p=0.005, p=0.004), respiratory rate (p=0.018, p=0.004) and body temperature (p=0.005, p=0.007), and improving chest expansion (p=0.026, p=0.014) as shown in Table 1. Both were found to be equally effective for body weight (p=0.341), heart rate (p=0.22), respiratory rate (p=0.969) and chest expansion (p=0.331) as shown in Table 2. However, MT was found to be better than KMC in decreasing body temperature (p=0.003).

DISCUSSION
The findings show that MT and KMC promote weight gain and regularise heart rate, respiratory rate and body temperature. Both MT and KMC also improve chest expansion.

There was an increase in body weight in the MT group, similar to the findings of Dieter et al (2003) who studied that massage therapy leads to weight gain (Petrou,
Table 1: Comparison of means of Body weight, Heart rate, Respiratory rate, Temperature and Chest expansion in Groups A and B

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Group</th>
<th>Pre</th>
<th>Post</th>
<th>Z value</th>
<th>p value</th>
<th>Significance</th>
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<tr>
<td>Body Weight (kgs)</td>
<td>A</td>
<td>1.5+0.26</td>
<td>1.54+0.26</td>
<td>-2.805</td>
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<td></td>
<td>B</td>
<td>1.47+0.23</td>
<td>1.51+0.21</td>
<td>-2.705</td>
<td>0.007</td>
<td>Yes</td>
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<tr>
<td>Heart Rate (beats/ min)</td>
<td>A</td>
<td>135.4+17.33</td>
<td>123.8+13.93</td>
<td>-2.814</td>
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<tr>
<td></td>
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<td>135.1+6.77</td>
<td>128.1+6.12</td>
<td>-2.844</td>
<td>0.004</td>
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<td>A</td>
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<td></td>
<td>B</td>
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</tr>
<tr>
<td></td>
<td>B</td>
<td>98.68+0.29</td>
<td>98.44+0.34</td>
<td>-2.687</td>
<td>0.007</td>
<td>Yes</td>
</tr>
<tr>
<td>Chest Expansion (cms)</td>
<td>A</td>
<td>0.45+0.08</td>
<td>0.56+0.05</td>
<td>-2.232</td>
<td>0.026</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>B</td>
<td>0.43+0.07</td>
<td>0.49+0.7</td>
<td>-2.449</td>
<td>0.014</td>
<td>Yes</td>
</tr>
</tbody>
</table>

Table 2: Comparison of difference of means of Groups A and B

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Group A</th>
<th>Group B</th>
<th>U value</th>
<th>p value</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Body Weight (kgs)</td>
<td>0.04+0.02</td>
<td>0.04+0.03</td>
<td>37.5</td>
<td>0.341</td>
<td>NO</td>
</tr>
<tr>
<td>Heart Rate (beats/ min)</td>
<td>11.6+7.17</td>
<td>7+1.33</td>
<td>34.00</td>
<td>0.22</td>
<td>NO</td>
</tr>
<tr>
<td>Respiratory Rate (breaths/ min)</td>
<td>7.4+10.29</td>
<td>6.8+7.67</td>
<td>49.5</td>
<td>0.969</td>
<td>NO</td>
</tr>
<tr>
<td>Body Temperature (˚F)</td>
<td>0.65+0.51</td>
<td>0.24+0.13</td>
<td>10.5</td>
<td>0.003</td>
<td>YES</td>
</tr>
<tr>
<td>Chest Expansion (cms)</td>
<td>0.11+0.11</td>
<td>0.06+0.05</td>
<td>38.00</td>
<td>0.331</td>
<td>NO</td>
</tr>
</tbody>
</table>

2005). Dieter et al in 2003 examined the effects of 5 days of Massage Therapy on the weight gain and sleep/wake behaviour of hospitalised stable preterm infants. They concluded that even 5 days of Massage Therapy was effective in improving weight and reducing sleep, instead of the earlier practice of 10 days (Dieter et al, 2003). Also, there was a decrease in heart rate and respiratory rate, as observed by Smith et al in 2013. They speculated that it could be due to improved autonomic nervous system function, as most preterm infants suffer from ANS dysfunction.
However there was a decrease in temperature, as opposed to the findings of Diego et al (2008) who concluded that Massage Therapy brings about an increase in infants’ temperature.

In the KMC group there was an increase in body weight and decrease in heart rate and respiratory rate similar to the findings of Moore et al (Smith et al, 2013). However, no studies were found that stated that MT or KMC had an effect on chest expansion. The present study shows that both MT and KMC are statistically significant in increasing chest expansion.

The weight gain seen in both the groups may be attributed to increase in release of digestive enzymes and gastric motility due to stimulation of vagal activity (Moore et al, 2012; Smith et al, 2013). Also, the decrease in heart rate and respiratory rate may be due to inhibition of heart and constriction of bronchi (Diego et al, 2008; Moore et al, 2012). The increase in chest expansion seen in the MT group might be due to the chest strokes applied during therapy, which could facilitate the respiratory muscles. However, the drop in temperature in both groups and the improvement in chest expansion in Kangaroo Mother Care group cannot be explained.

Limitations
Several factors could have had an effect on the outcome measures in this study. Factors such as the feeding amount and urine and stool output for body weight, and Basal Metabolic Rate measures were not monitored. Also, though required, measures like electroencephalography, electrogastrography, etc., to monitor vagal activity, were beyond the scope of physiotherapy.

CONCLUSION
Massage Therapy and Kangaroo Mother Care are both effective in improving weight and chest expansion, and decreasing heart rate, respiratory rate and temperature. MT is more effective in reducing body temperature compared to KMC. MT and KMC can be used interchangeably as both are equally effective. In settings where professionals are not available to apply MT, KMC can be used in its place. KMC is also more community-friendly as it does not require any special set-up or training. It can be given at any time, according to the mother’s wish. Moreover, in the mother’s absence, the procedure can be performed by any other family member.
ACKNOWLEDGEMENT

The authors are grateful to the neonates and their parents who participated in this study. They would also like to thank their colleagues, staff members and all those who supported the study. A special thanks to Dr. Shraddha Diwan and Dr. Neeta Vyas for their support, guidance and help.

REFERENCES


LETTER TO EDITOR

Dear Editor,

Investing in Community-based Physiotherapy: the Non-economic Benefits

In continuation of the theme of an article (Rajan, 2014) published in issue No.1, Volume 25 of Disability, CBR & Inclusive Development, this seeks to highlight the non-economic benefits of community-based physiotherapy, which are less tangible but more relevant to the health of underprivileged communities. Although published research on community physiotherapy in developing countries is sparse (Rajan, in press), the non-economic benefits of the same cannot be underestimated.

The beneficial effects of community-based physiotherapy are contingent upon the client population that is being treated (see Figure 1). In the study by Effing et al (2011) on 153 clients with COPD (Chronic Obstructive Pulmonary Disease) in the Netherlands, improved exercise capacity and improved exercise behaviour were reported after one year of community-based physiotherapeutic treatment. In another study by community physiotherapists in the United States (Sullivan et al, 2014), the use of pedometers for 6 weeks enhanced satisfaction and improved activity in chronic stroke clients. Physiotherapy intervention through workshops and postural training for the community of underprivileged school children in India proved beneficial in fostering better ergonomics and postures (Rajan and Koti, 2013a). Improved physical function, reduced pain, increased flexibility and range of motion at the hip and knee were reported by chronic osteoarthritic clients in the United Kingdom, following a 12-month community aquatic rehabilitation (Lin et al, 2004). One of the most beneficial aspects of incorporating community-based physiotherapy into a client’s treatment regimen is “intervention in the living environment” (Lord et al, 2008). This ensures faster return-to-function as the client receives the treatment in the same environment where she/he resides (Park et al, 2011). A similar community programme involving graded muscle-strengthening exercises for community-dwelling older adults in Bangladesh improved their quality of life, including strength, balance and gait (Nallathambi, 2012).

Community-based physiotherapy has been used with promising results among varied client populations across the globe. Innovative techniques have also been employed in resource-constrained countries like India (Rajan and Koti, 2013b) and Bangladesh (Ellangovin, 2009). This has not only ensured sustainability of
the new community model but also affordability for the target communities. Such models, that have been tailored and developed to suit the communities being treated, have demonstrated long-lasting effects. Due to this, better health outcomes have been achieved despite the chronicity of health conditions (see Figure 1).

However, despite the various beneficial effects and innovations to ensure sustainability, community-based physiotherapy has always been plagued by one persistent issue: lack of qualified staff (Ellangovin, 2009; Christian Medical College, 2010; Rajan, 2013). Attempts have been made to tackle this problem, by skill transference to the local staff/volunteers in the communities. This has ensured increased participation and continued treatment (Ellangovin, 2009; Christian Medical College, 2010).

Figure 1: The Non-economic Benefits of Community-based Physiotherapy
It can thus be concluded that community-based physiotherapy has many beneficial effects, such as improved function, higher levels of satisfaction with treatment and better quality of life, among others. Attempts have been made in a few countries to tailor the community programmes to ensure sustainability and feasibility. Such innovations could ensure longer-lasting effects.

REFERENCES


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Netherlands Leprosy Relief (NLR) is a Dutch non-profit organization committed to a world without leprosy and its consequences. It tries to achieve this by supporting health authorities in countries where leprosy is prevalent. NLR promotes the independent social and economic functioning of leprosy patients and their families. By supporting scientific research NLR wants to improve the effectiveness of leprosy control.

Netherlands Leprosy Relief is a member of the International Federation of Anti Leprosy Associations (ILEP). NLR supports national health authorities in over twenty countries with endemic leprosy problems, collaborates with international partners in leprosy control, and works professionally and efficiently.

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CBM is an international Christian disability and development organisation whose primary purpose is to improve the quality of life of the world’s poorest persons with disabilities and those at risk of disability.

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Light for the World stands up for equal rights of persons with disabilities in developing countries. Their support focuses on three domains:

1. Special services for people with a disability, such as eye care and rehabilitation services through financial support and capacity building of local NGOs and governments.

2. Promoting inclusive development by building the capacity of organisations and institutes to give better access to persons with a disability to their services (leading to increased access to health, education and the labour market).

3. Support to Disabled People's Organisations to help them advocate for their rights and to increase their self-sufficiency.