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Contents

EDITORIAL
Maya Thomas ........................................................................................................ 3

ORIGINAL RESEARCH
Narratives Around Concealment and Agency for Stigma-reduction: A Study of Women Affected by Leprosy in Cirebon District, Indonesia
Ruth M H Peters, Miranda E Hofker, Wim H van Brakel, Marjolein B M Zweekhorst, Francisia S S E Seda, Irwanto, Joske F G Bunders ................................................................................................................................. 5

Exploring a Model of Effectual Learning for a Student Speech Pathology Placement at a Community-Based Rehabilitation (CBR) Centre in Malaysia
Sandra Van Dort, Linda Wilson, Julia Coyle .................................................................. 22

Community Mobilisation in a CBR Programme in a Rural Area of Sri Lanka
Masateru Higashida ........................................................................................................ 43

Barriers to Early Diagnosis, Intervention and Social Integration of Children with Developmental Disabilities: A Qualitative Study from Rural Villages and a Poor Urban Settlement of Bangalore, South India
Carolin Elizabeth George, Gift Norman, Tanya Elizabeth Benjamin, Devashri Mukherjee ............................................................................................................................ 61

Assessing Parental Role as Resource Persons in Achieving Goals of Early Detection and Intervention for Children with Hearing Impairment
Mohammad Shamim Ansari ............................................................................................. 84

Disability Inclusion in Primary Health Care in Nepal: An Explorative Study of Perceived Barriers to Access Governmental Health Services
Suzanne Van Hees, Huib Cornielje, Prakash Wagle, Evert Veldman ................................ 99

Knowledge and Beliefs about Ear and Hearing Health Among Mothers of Young Children in a Rural Community in South India
Meivizhi Narayansamy, Vidya Ramkumar, Roopa Nagarajan ........................................ 119

LETTER TO EDITOR
The Application of Focus Group Discussions and Interviews in Community Physiotherapy
Pavithra Rajan .................................................................................................................. 136
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Sandra Van Dort, Linda Wilson, Julia Coyle ........................................................................ 22

Community Mobilisation in a CBR Programme in a Rural Area of Sri Lanka
Masateru Higashida ............................................................................................................ 43
<table>
<thead>
<tr>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barriers to Early Diagnosis, Intervention and Social Integration of Children with Developmental Disabilities: A Qualitative Study from Rural Villages and a Poor Urban Settlement of Bangalore, South India</td>
<td>61</td>
</tr>
<tr>
<td>Carolin Elizabeth George, Gift Norman, Tanya Elizabeth Benjamin, Devashri Mukherjee</td>
<td></td>
</tr>
<tr>
<td>Assessing Parental Role as Resource Persons in Achieving Goals of Early Detection and Intervention for Children with Hearing Impairment</td>
<td>84</td>
</tr>
<tr>
<td>Mohammad Shamim Ansari</td>
<td></td>
</tr>
<tr>
<td>Disability Inclusion in Primary Health Care in Nepal: An Explorative Study of Perceived Barriers to Access Governmental Health Services</td>
<td>99</td>
</tr>
<tr>
<td>Suzanne Van Hees, Huib Cornielje, Prakash Wagle, Evert Veldman</td>
<td></td>
</tr>
<tr>
<td>Knowledge and Beliefs about Ear and Hearing Health Among Mothers of Young Children in a Rural Community in South India</td>
<td>119</td>
</tr>
<tr>
<td>Meivizhi Narayansamy, Vidya Ramkumar, Roopa Nagarajan</td>
<td></td>
</tr>
<tr>
<td>LETTER TO EDITOR</td>
<td>136</td>
</tr>
<tr>
<td>The Application of Focus Group Discussions and Interviews in Community Physiotherapy</td>
<td></td>
</tr>
<tr>
<td>Pavithra Rajan</td>
<td></td>
</tr>
</tbody>
</table>
Editorial

An earlier editorial commented on the differences between developing and developed countries in terms of the context and baseline for development of community-based rehabilitation (CBR) policy and practice. Continuing on the same theme, it is interesting to note that despite differences in services, systems and resources to promote inclusion, there are some commonalities between these countries, along with some lessons from CBR practice from developing countries.

With recent economic downturns and recession, many developed countries are facing cuts in welfare spending, including for programmes for persons with disabilities. Because of this, the philosophy of CBR – “from welfare and charity to inclusive development and self-reliance” - assumes significance for these countries. However, what is debatable is that after raising expectations with the previously higher welfare spending, it may become more difficult to promote self-reliance. Conversely one can argue that in developing countries with low resources and limited allocations for welfare, expectations are low and hence it could be relatively easier to promote self-reliance, as CBR programmes have been doing over these past two decades.

Although developed countries have better services, systems and resources for implementation of laws and policies to promote inclusion, the recent decreases in welfare budgets have brought to the fore many planning and management issues that CBR programmes in developing countries have already been grappling with, and that have lessons for developed countries. These include, for example, how to manage with limited financial and skilled human resources; how to define what is the “optimum quality” of services to aim for, based on the needs and available resources in a given context; how to plan for multi-sectoral collaboration, especially between health, education and welfare sectors (which remains a continuing challenge in developing countries); how to promote government-civil society partnerships; and how to ensure on-going awareness programmes for key stakeholders, especially government at different levels.

Working with persons with disabilities and their associations, to build capacity towards self-reliance is a major focus of CBR. In addition, the lessons from CBR experiences underscore the importance of working with family groups to raise
awareness, combat negative attitudes and to provide mutual emotional and psychological support between members.

The ‘community’ and its participation are an important pillar for any CBR programme. A key lesson from CBR practice in developing countries is the necessity to be realistic about community participation, instead of harbouring romanticised, idealistic beliefs about ‘the community’. Even in rural areas in developing countries where communities are usually viewed as open and welcoming, there are places where communities are ‘closed’ and not helpful. CBR experiences have shown that in some places, the community was primarily mothers of children with disabilities. It has sometimes been commented that promoting community participation is a way for governments to justify lower spending on welfare. Developed countries may also face similar challenges in addressing community participation.

Whatever the context in any country, CBR implementers have understood the importance of defining ‘the community’ in their programmes, for example, is it persons with disabilities, or families, or volunteers, or other stakeholders. Equally important is the use of community development principles, where communities identify their common issues of concern and try to find solutions in a collective manner, to promote self-reliance. Another lesson is that working with other marginalised groups in the community can help to develop a more effective and collective voice towards community based inclusive development.

To conclude, although CBR was started as a strategy that was applicable to developing countries, there are increasing indications of how lessons from CBR experiences can be of significance to developed countries as well, especially in the light of economic problems faced by some of these countries.

Maya Thomas
Editor-in-Chief
Disability, CBR and Inclusive Development
Narratives Around Concealment and Agency for Stigma-reduction: A Study of Women Affected by Leprosy in Cirebon District, Indonesia

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ABSTRACT

Purpose: This study analyses the experiences of women affected by leprosy, taking into consideration whether they concealed or disclosed their status, and looks specifically at their ‘agency’. The aim is to provide recommendations for stigma-reduction interventions.

Methods: The study population consisted of women affected by leprosy who live in Cirebon District, Indonesia. Study subjects were purposively selected on the basis of characteristics such as age and role in the community. After informed consent was obtained, they were interviewed in their homes. Data was collected through semi-structured in-depth interviews. Analysis was done with six points of focus: who knows, care, social stigma, feelings, self-isolation and agency.

Results: In total, 53 women were interviewed. Eight were omitted due to ambiguity over who knew about their leprosy status. Five different categories of ‘disclosure’ were identified, ranging from 1 woman who concealed completely to 19 (42%) who disclosed fully. Disclosure created possibilities for care and support, which 84% mentioned they received. In contrast, disclosure was also found to be linked to negative feelings, isolation and social stigma, which 18 women experienced. The women coped with this through acceptance, comforting themselves, trusting in God, focussing on recovery, friendship or finding inspiration in others.

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**Conclusions:** An analysis of these experiences helps to understand how women affected by leprosy are coping, and what they are already doing for and by themselves. This could be a starting point for more appropriate and effective stigma-reduction interventions. It is recommended to consider the following: i) assisting people with their choice, if any, of either concealment or disclosure, ii) the appropriateness of any intervention for people who (want to) conceal their illness, iii) the existing sources of care and support, and iv) the inner strength demonstrated and its three sources (spirituality, relationships and the desire to be cured).

**Keywords:** disclosure, stigma, support, relationships, interventions

**INTRODUCTION**

The effects of stigma can be brutal; the discrimination it may engender can be a major affront to the dignity of affected people. The effects of stigma can also be subtle; the labelling, stereotyping and separation that characterise it can cause affected individuals to lose their identity, self-esteem and sense of purpose (Cross et al, 2011a).

Brutal and subtle; these are two distinct but prominent characteristics of the consequences of stigma. Unmistakably, stigma is something that should be addressed, for instance, with interventions such as self-care groups, counselling, education, contact, advocacy and protest (Brown et al, 2003; Heijnders and van der Meij, 2006). Reviews of studies on the effectiveness of these approaches have helped build an understanding of the factors that explain success and failure (Brown et al, 2003; Heijnders and van der Meij, 2006). This has led to some general principles: interventions should primarily aim at empowering affected persons, affect stigma at more than one level and require fine-tuning for greater specificity between conditions (Heijnders and van der Meij, 2006; Cross et al, 2011b).

In this paper, the focus is on how to adapt interventions to the specific experiences and needs of the target group. It is generally accepted that taking people’s own social history, cultural meanings, understandings and concerns into account is essential for successful stigma-reduction interventions (Gussow and Tracy, 1970; Secker et al, 1999; Smith, 2002). The target group in this study are people affected by leprosy, the archetype of a stigmatised health condition (Frist, 2003; Rafferty, 2005; van Brakel and Miranda-Galarza, 2013). The authors argue that, even within this specific target group, interventions will benefit from being tailored to the
experiences and needs of sub-groups because social histories, cultural meanings, understandings and concerns differ between individuals, especially between men and women. It is the authors’ belief that an in-depth look at the experiences and needs of these two sub-groups can provide new insights for stigma reduction. This study will focus on women only, though it is stressed that a focus on men is equally relevant.

Much research in the field of stigma reduction focuses on the negative effects of leprosy, justifying the need for interventions. This is important as such, but can also neglect what people affected by leprosy are doing for and by themselves, to bring about change in their own lives. The authors of this study set out to look for these ‘hidden’ actions and thoughts and their sources, or to put it differently, to look for the HUMAN CAPACITY TO ACT, also known as ‘agency’.

**Objective**

The aim of this study was to analyse the experiences of women affected by leprosy in Cirebon District, Indonesia, in order to determine what needs to be taken into account when designing stigma-reduction interventions, and whether more effective use can be made of people’s agency.

**Theoretical Concepts**

**Concealment and Disclosure** – The authors believe that concealment and, its antonym, disclosure are important and sometimes forgotten factors to consider while analysing the experiences of people affected by leprosy. The relevance is not only illustrated by Heijnders (2004b) while analysing the dynamics of stigma in Nepal, but also emphasised by Bos et al (2013). In this study, experiences with concealment and disclosure are connected with the potential positive and negative consequences of disclosure.

**Stigma** - Stigma is a complex social construct. Three interacting levels of stigma can be identified (Livingston & Boyd, 2010). The first level is the micro level which includes the three types of stigma exhibited by those who are stigmatised: ‘anticipated’ (or perceived), ‘internalised’ (or self-stigma) and ‘enacted’ (or experienced) stigma (Weiss, 2008, based on Scambler, 1998). The second level is the meso level, also known as social or public stigma. The third level is the macro level, also known as structural or institutional stigma.

**Agency** - Agency plays a role in both concealing and disclosing, as well as in the
potential positive and negative consequences of disclosure. There has been a long-standing debate by scholars on how to define the abstract concept of ‘agency’, beyond the human capacity to act. The work of Ortner (2006) was the basis for the analyses in the current study; she wrote that ‘agency’ in an abstract sense might seem a property of social subjects: “Some people get to ‘have’ it and others not; some people get to have more and others less”. According to her, ‘agency’ is not a thing in itself, nor is it equivalent to the capacity of individuals to act independently or the exercise of free choices. On the contrary, Ortner underlines that ‘agency’ is part of a process, and social subjects are embedded “in the webs of relations that make up their social world” and in that sense, the acts of social subjects are never fully free or independent.

Ortner adds that it is useful to distinguish between ‘agency of power’ and ‘agency of projects’. She wrote: “In one field of meaning ‘agency’ is about intentionality and the pursuit of (culturally defined) projects. In the other field of meaning, agency is about power, about acting within relations of social inequality, asymmetry, and force.”

Introducing the SARI Project

This study is part of the Stigma and Assessment and Reduction of Impact (SARI) project that was initiated in 2010 in Cirebon District, Indonesia. The SARI project aims to assess the impact of three stigma-reduction strategies: counselling, contact and socio-economic development. In 2011, the SARI project executed an exploratory study to identify and analyse the problem perceptions, opinions and ideas of the different stakeholders, in order to design appropriate stigma-reduction interventions. The project also organised a large mixed-methods study to establish a baseline regarding the situation of persons affected by leprosy in Cirebon District.

METHODS

The analysis of the women’s experiences is based on the qualitative semi-structured in-depth interviews that have been conducted during the exploratory and baseline studies. The puskesmas (community healthcare centres) provided the contact details of the persons affected by leprosy in their sub-district. The women were purposively selected based on characteristics such as age and role in the community. They were approached carefully - as some conceal their illness - and asked to participate in the study. Those who agreed were interviewed in their
homes. The interviews started in an exploratory manner and progressed towards more in-depth questions, and lasted for an average of one hour. During the interviews a guide was used. In the exploratory study the following topics were addressed: general information, life history, economic situation, social situation, health situation and leprosy. In the baseline study the topics were: leprosy history, feelings, family and friends, community, economic condition and future.

The interviews were recorded, transcribed and translated into English. Data management and analysis were performed using MAXQDA 2011 and NVivo. Analysis was done with six points of focus: who knows about the diagnosis, care, social stigma, feelings, self-isolation and agency. Occasionally there was ambiguity about who exactly knew about the leprosy status, and these interviews were left out of the analyses.

The study was approved by the relevant government offices and the Ethics Committee of Atma Jaya University. Written consent was obtained from individual study subjects. A small present (t-shirt, mug) was given to the participants as a token of appreciation.

RESULTS

Demographic Information about Participants
The 53 women who were interviewed were between 16 - 80 years old (average age 38 years). Of these, 33 (62%) were married, though some said that their current marriage was not their first, 9 were single, 1 was engaged, and 10 were widows. Most of the women were housewives and/or caregivers, 36 (68%) had children, and some were employed, for instance as shopkeepers, farmers, tailors, teachers or domestic workers. Most women had finished the 6 or 12 months of multi-drug therapy for leprosy. At the time of the interview, only 14 were still in treatment. Eight had a leprosy-related impairment to hands, feet and/or eyes.

Concealment versus Disclosure: “This is my own problem and I can make it through”

The women were asked who knew about their leprosy history or status. A clear picture emerged from the 45 interviews. The fact that others ‘know’ might be because the women intentionally informed them (disclosure), someone who knew informed others (disclosure of status by someone else), or because the
symptoms or side-effects of the medication were recognised as being leprosy. In the following instance, a doctor had informed others:

Interviewee: “Yes, everyone [in the community] knows about it [her leprosy].”
Interviewer: “How can they know about your disease?”
Interviewee: “Because the doctor told them about my disease.”
(Interview 29: age 20years)

Five different categories of ‘disclosure’ were identified, as shown in Table 1. The category ‘very few (1-3)’ most often consisted of a husband and/or mother, and sometimes included the father or a sibling. Three women with a leprosy-related impairment managed to conceal their disease to some extent from others.

Table 1: Five categories of Disclosure of the Leprosy History or Status (N=45)

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<th>Category: who knows?</th>
<th>Number (percentage)</th>
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<tr>
<td>1. Nobody</td>
<td>1 (2%)</td>
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<tr>
<td>2. Very few (1-3 people)</td>
<td>9 (20%)</td>
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<tr>
<td>3. People in the household</td>
<td>3 (7%)</td>
</tr>
<tr>
<td>4. Some extended family members, friends and neighbours, but not all</td>
<td>13 (29%)</td>
</tr>
<tr>
<td>5. Everybody</td>
<td>19 (42%)</td>
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</table>

Table 1 also demonstrates that several women intentionally conceal their status from others. This is not perceived as an easy choice and has negative consequences, as illustrated by the following quote:

“It would be nice if someone could understand my feelings. It can also help me to talk freely with the person. However, many people who know that this person or that person is affected by the disease, might avoid us. I did not want that to happen to me. It troubled me.” (Interview 9: age 35 years)

Apparently this woman conceals because she fears avoidance. This reason was mentioned most often by the women in this study, who feared avoidance by friends or customers. The women who intentionally concealed, managed to do so because the symptoms were not visible, appeared to belong to a different disease (e.g. rheumatism, measles, allergy), or because they deliberately covered spots and impairments (e.g. with veil, long sleeves, make-up) and asked people who
knew not to talk about the disease. This is demonstrated by the two quotes:

“The infection was not obviously seen in my case, so only few people asked me about it. On the other hand, my sister’s skin blackened. That was why everybody knew about her disease.” (Interview 13: age 30 years)

“I expect people around me, especially my family, not to talk about my disease to other people. This is my own problem and I can make it through.” (Interview 35: age 20 years)

**Care and Support: “Stay strong”**

When people around an affected woman knew about her condition, there was the possibility of what the women described as ‘care’, ‘support’, ‘love’, ‘compassion’, ‘closeness’ and ‘encouragement’. In total, 38 of the 45 women (84%) mentioned that they received some sort of care and support, frequently related to adherence to medication and getting cured. A total of 10 women specifically mentioned the care and support received from their husbands, and 6 mentioned their mothers. Some of the young women also mentioned the supportive role of their fathers. The responses of the husbands regarding the dark skin, and about not feeling ashamed, were important for the women:

“I suggested to my husband that he might want to leave me since I became black. ... Thanks to God that even though I suffered from leprosy and became black and dark, he [my husband] did not seem to have any evil-wish to leave his blackened wife. Not at all. He gave me his full support to get medication. He urged me to go and get the medicine when he saw me running out. ... He never felt ashamed of his wife who was suffering from such disease. He never tried to stay away from me. On the contrary, we became much closer to each other.” (Interview 18: age 35 years)

The same was relevant for people outside the household. One woman talked about the support she received from the head of the village, one about support from her extended family, and as illustrated by the following quote, one mentioned the motivation and support given by friends:

“Well, many of my friends who knew about it. They asked me about what happened with my feet and they told me to stay strong.” (Interview 15: age 50 years)
Social Stigma: “Well, let them be”

At the same time, disclosure can also create a mix of negative attitudes and behaviour. Words used by the participants that were categorised as social stigma included: avoiding, mocking, insulting, looking, gossiping, spreading rumours, feeling disgusted, separating utensils, asking them to stay away, and not buying their food or products. In total, 18 women mentioned that they had experienced some form of social stigma or still did; this is 62% of the women in categories 4 and 5 (see Table 1).

In one case this social stigma came from the husband, but more frequently the sources were friends, family, neighbours, vendors and children in the neighbourhood. For most of the 18 women, the social stigma was experienced during the time of treatment and faded away afterwards. However, for 7 (24% of categories 4 and 5) the social stigma persisted (sometimes for a long time) after being cured.

While coping with these negative attitudes and behaviour of others, some women showed strong inner, perhaps spiritual, strength and signs of inner acceptance. In other women, the “agency of projects” and the “agency of power” came to the front by respectively focussing firmly on getting cured and by standing strong against the ‘stigmatisers’.

“God meant this disease for me. Neighbour might not like me. Well, let them be. If they do not like me, then just continue not liking me.” (Interview 44: age 74 years)

“Well, I do not know. What I did was just taking the medicine. I resigned myself to God. That was all. Therefore, I did not feel shy or afraid. I did not feel such feelings at all. If people befriended me, I welcomed them, but if none wanted to do so, that was fine by me.” (Interview 18: age 35 years)

Interviewee: “Often my friends and my neighbour made fun of me. They said that I looked like a scarecrow.”

Interviewer: “How did you feel?”

Interviewee: “I felt fine. I told them that I would restore my fair skin.”

(Interview 32: age 18 years)
Internalised Stigma and Self-isolation: “She [my kid] inspires me to move on and live my life”

The mixture of negative feelings and emotions that may be evoked was also influenced by concealment and disclosure. These feelings could last for a long time – even after being cured – and were caused by a variety of factors. The main ones were: medical concerns (e.g. worry about contagiousness through breastfeeding or touching children), altered appearance (e.g. embarrassed by black skin), and the responses of other people (e.g. fear of being excluded). Mothers of young children were, in particular, afraid to infect others, as shown here:

“This disease is dangerous, contagious and pretty deadly. I felt pretty afraid that my children and other people that are close to me will be affected too.”

(Interview 8: age 31 years)

Other feelings related to perceived stigma (first quote) or were so intense that they could lead to self-mutilation (second quote) and suicidal thoughts:

“I act as a normal person who does not have any disease. Well, sometimes my colleagues did talk about one of our colleagues. ... His face is reddening and thickened, but it was not caused by leprosy. It is just a burn. ... People are avoiding him and avoid using the same gloves. ... I do wonder what if they know about my real condition. I started to worry after that. They must do the same to me or even worse [laugh].” (Interview 8: age 31 years)

Interviewer: “When you feel desperate, what do you do?”
Interviewee: “I have hurt my hand by myself, but my mother caught me.”
(Interview 10: age 20 years)

The women who had concealed their illness the most, reported feeling more emotions such as sadness, shame, low self-esteem and depression, compared to the other categories. Similar negative feelings were expressed more often by those who had experienced social stigma. These negative feelings, whether coming from within or being triggered by others, can result in self-isolation. It is important to note that a certain degree of self-isolation can exist, irrespective of having concealed or not.

“I sometimes felt a low self-esteem, meaning I know my position. So I kind of avoid gathering with them [neighbours] every so often. ... I used to be active in an organisation in Cirebon and now I pull myself away. ... It is because a voice comes to
my ear: Oh my, it might be contagious and I do not want that.” (Interview 44, age 74 years)

“After being affected by leprosy, I do not go anywhere. I do not go to the field either. I just stay at home like this. I just clean the house or wash the dishes.” (Interview 43: age 50 years)

An inner, sometimes spiritual, strength and the “agency of projects” could be found in at least 10 women who coped with these negative feelings and the self-isolation. The women who showed signs of acceptance tried to comfort themselves, trusted in God, focussed on recovering, reframed the meaning of a darker skin, and found inspiration in others:

Interviewer: “You never felt like giving up?”
Interviewee: “No. Being affected by the disease was my destiny.”
(Interview 4: age 30 years)

“Whether I feel comfortable or not with my life, I still need to live. So, what I should do is only enjoy what I can enjoy and be gracious about it.” (Interview 8: age 31 years)

“I cried a lot and kept thinking why God did not simply end my life. I once had an intention to hang myself, but then I remembered God and my religion, so I did not do it.” (Interview 20, age 34 years)

“I was sad, but I tried to comfort myself that I was being treated and will heal. I prayed to God to heal me soon. I did not want to think of my illness, I worried it will cause the other disease to attack me. So I tried to be indifferent.” (Interview 1: age 35 years)

“If I really had to suffer from the disease, then so be it. There is a cure for every illness. ... The most important thing was that I should not feel discouraged. ... I kept cool. What I needed to do was go to the Health Centre for a check-up every month.” (Interview 39: age 40 years)

“I remember when I had my first medicine. My skin turned so black, and that was when I knew the medication worked well.” (Interview 31: age 20 years)

“I used to be alone at home, while in the hospital, there were many people. ... I felt good. ... It is nice to have friends ... it feels rich. ... The doctor also advised: Mrs, you cannot be alone. There must be a friend for sharing things.” (Interview 44: age 74 years)
“I was going to end my life but then I knew that my kid was the reason I live. Sometimes I give up but then she inspires me to move on and live my life.” (Interview 37: age 27 years)

DISCUSSION

The analyses of the experiences of women affected by leprosy in Cirebon District, both those in treatment and those cured, with and without impairments, revealed dynamics around concealment and disclosure. In this paper, these were connected to potentially positive consequences (e.g. care, support) and negative consequences (e.g. social stigma, internalised stigma and self-isolation) and, most importantly to what women were doing for and by themselves, to bring about change in their own lives.

This study indicates that due to anticipated stigma, some women affected by leprosy in Cirebon tended to conceal their disease and hence reduced the risk of enacted stigma. However, at the same time, this coping strategy seemed to increase negative feelings and emotions (sadness, shame, fear) and internalised stigma. Concealment among affected persons has been described by others (Kaur and Ramesh, 1994; Vlassoff et al, 1996), as has the relationship with enacted stigma (Heijnders, 2004b). Considering concealment and disclosure in the analyses of stigmatised conditions, enabled the authors of this study to give a more precise picture of the consequences of leprosy. The value of considering concealment and disclosure is also shown in the work of Heijnders (2004a, 2004b).

This study confirmed that the consequences of stigma can be indeed brutal and subtle. They are brutal, in particular, when self-isolation, self-mutilation or suicidal thoughts are encountered; subtle, when things are less visible, as for instance responses like, “I act as a normal person”, or being given separate eating utensils. Social stigma, negative feelings and self-isolation are common themes in this, as well as in other studies (Oliveira, 1997; Shale, 2000; Zodpey et al, 2000; Varkevisser et al, 2009). Positive responses from others are mentioned a few times, but these are often not explored in depth (Kaur and Ramesh, 1994; Vlassoff et al, 1996; Heijnders, 2004b). Only Try (2006) explored this theme further in a study in Nepal, and showed that relatives provide support to women affected by leprosy more frequently than their husbands. This differs from the current study in which husbands often play a role in providing support.
Agency came to the front in this study, not only in the narratives around disclosure and concealment but also in the ways in which women coped with social stigma, negative feelings and isolation. Women who decided to conceal could show agency, for instance by going to work every day despite the attitudes of others that provoked the anticipation of stigma. Equally, women who decided to disclose could show agency by portraying a ‘this is me’ attitude. Openly acting against others who bully or make fun of people affected by leprosy (existing power relations) can be seen as Ortner’s ‘agency of power’. The focus on goals that the women want to achieve, such as getting cured, fits with Ortner’s ‘agency of projects’.

Three main sources for ‘agency’ related to coping with social stigma, negative feelings and isolation for women, were found in this study. First, religion or spirituality was seen, for example, among the women in this study who engaged in faith-based activities to get cured or among the women who found acceptance in their situation because it was created by God. Second, relationships with significant others for care, support and inspiration, for example the woman who considered suicide but found inspiration to live in her child. Third, the goal and hope of getting cured, for example the women who realised that feeling ashamed or discouraged would not help them get cured. The first source was also found in the study on leprosy of Oliveira (1997) who wrote that “religious beliefs appeared as a powerful panacea in helping individuals face physical and emotional afflictions”. Similar results were found in a study of women with lymphatic filariasis by Person et al, 2009 who wrote “women, who positively reframed their situation, often drew upon their faith and engaged [in] faith-based activities to cope with their condition and manage stigma experiences”. The third source is also addressed in the study of Heijnders (2004a), in which she describes the ‘meaning of medication’ and how this motivated people affected by leprosy.

**Recommendation Arising from the Study**

Several of the following recommendations seem to also be of value to men affected by leprosy. This raises the interesting question whether the gender of persons affected by leprosy in Cirebon or elsewhere really matters for stigma-reduction activities. Several studies have described the experiences of women affected by leprosy in India, Africa, Nepal, Nigeria, Indonesia and Brazil, and many indicate that women are worse off than men (Rao et al, 1996; Vlassoff et al, 1996; Oliveira, 1997; Morrison, 2000; Shale, 2000; Zodpey et al, 2000; Try, 2006; van Brakel et al, 2012). For instance, more women in India than men seem to
discuss the diagnosis more frequently with their family, and seem to get negative
reactions rather than sympathy and support, more often than men (Vlassoff et
al, 1996). Also, compared to men, women affected by leprosy in Indonesia are
disproportionately affected by separation and divorce (van Brakel et al, 2012)
and, in Nepal, women have poorer chances of remarriage after divorce than men
(Try, 2006). Women are worse off than men, implying that they should be given
priority for stigma-reduction interventions and interventions should ensure that
women are not left out. More research using gendered analyses seems beneficial,
and it is hoped that this study can contribute to a better understanding in the
long term. In the recommendations that follow it has been decided to refer to
people affected by leprosy.

Discuss the Implications of Concealment and Disclosure
The authors recommend that after sharing the diagnosis of ‘leprosy’ with a person,
health professionals should discuss the positive and negative consequences of
concealment and disclosure. If there is a choice, this might help them to make
the choice more deliberately. They can then consider, by themselves or together
with others, how to conceal or disclose and the coping strategies to deal with, for
instance, increased sadness, shame (in case of concealment) or how to respond
in an effective and appropriate way to negative community responses (in case of
disclosure). The additional workload might be a concern for the health professional.
If this is the case, lay or peer counsellors could take up this role as well.

Deal with Concealment while Designing and Executing Services or Interventions
The authors propose that those who design leprosy services and stigma-reduction
interventions provide appropriate strategies or alternatives for affected people
who have concealed their illness and do not want to disclose it. They could consider
avoiding public announcements of their target group and instead focus on skin
diseases, neglected tropical diseases, or take another inclusive approach. This is
particularly challenging, but nevertheless very important, in the context of early
case detection work and studies that focus on prevention of leprosy by giving
contacts post-exposure prophylaxis. Also, the location for the activities should be
considered carefully; family houses, health centres, government offices, public
areas, all have advantages and disadvantages. Implementers should be careful
when approaching people affected by leprosy as they might not have informed
anybody, even their respective spouses, about their illness. Their consent should
be taken before home visits are made.
Tap into the Support and Focus on Relationships

Another recommendation is to make effective use of the existing support. The majority of women in this study told the authors that they received care, support, love and compassion. For adult women, their husbands and mothers seemed to be the most important persons; for young girls, both parents played a key role. Hence, it is recommended that the sources of support be targeted with leprosy services and interventions, such as education and family counselling, as early as possible.

Strengths-based Approach

Several women in this study have shown great inner strength that lies in the sphere of personal self-esteem/confidence ("this is me") and in close relations with others, including their faith and relationship with God ("God intended me to have this disease"). Focussing on these strengths and considering strength-based approaches instead of, or as a strategy for, stigma reduction, seems promising.

Limitations and Reflections

This study was executed in Cirebon District, West Java, and the findings cannot necessarily be generalised to other areas. The in-depth interviews covered many topics (inductive approach) and did not focus on concealment and disclosure, its impact or on agency specifically. This might have provided an even richer picture. This study is based on the interviewees' perspectives. An interviewee might think that, for instance, neighbours are not aware of her leprosy status, but they might in fact know. The numbers presented are thus based on the perceptions of the women and not necessarily on the actual situation.

CONCLUSION

The main recommendation of this study is that anyone who designs or plans leprosy services and stigma-reduction interventions needs to understand what affected people are already doing for and by themselves, and should think about how they can support and engage with these processes. In the authors' opinion, this could have great potential for reducing stigma in the long run.
ACKNOWLEDGEMENT

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Exploring a Model of Effectual Learning for a Student Speech Pathology Placement at a Community-Based Rehabilitation (CBR) Centre in Malaysia

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ABSTRACT

\textbf{Purpose:} Speech-language pathologists in Malaysia typically do not work within CBR. Therefore, exploring the use of services through a non-traditional student placement was a crucial first step in understanding how to develop capacity for such services. It was also important to develop an understanding of the ways in which the implementation of this student placement influenced learning in the context of a Malaysian CBR programme.

\textbf{Method:} An action research study was designed to implement and evaluate student speech-language pathology (SLP) placement within a Malaysian community-based rehabilitation (CBR) centre for children with communication disabilities. Data collection involved the learning experiences of key adult stakeholders (students, workers, parents, and the principal research investigator (PI) or lead author).

\textbf{Results:} Study findings indicated that all adult learners became better empowered by working together. Workers involved in impairment-focused rehabilitation activities grew in understanding and skills when supported by relevant professionals. The importance of mentoring as a learning-teaching relationship was demonstrated.

\textbf{Conclusion:} While the study has indicated that the setting is beneficial as a student placement, the development of a specialisation in CBR for allied health professionals would be a relevant way forward in the Malaysian context.

\textbf{Key words:} CBR, speech-language pathology, student placement, learning

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INTRODUCTION

The CBR approach is a strategy that seeks to promote “the rehabilitation, equalisation of opportunities and social inclusion of all people with disabilities” (WHO, ILO, UNESCO, 2004). Furthermore, CBR is multi-sectoral and ideally involves the collaboration of different stakeholders including people with disabilities, local stakeholders and relevant professionals. In Malaysia, CBR has been recognised as an augmentative approach to disability management that fills a large gap between rehabilitation needs and actual services (Rashid, 2004). Services typically focus on health, education and social (sports and recreation) sectors. These services are mainly provided by CBR workers who, while being expected to engage in health rehabilitation, presently receive limited training and are largely unsupervised (Kuno, 2007).

Studies have documented how parents and families of children with disabilities actively desire to learn, and that such learning contributes positively to child development (O’Toole, 1988; Kaiser & Hancock, 2003). At the same time, studies exploring parent experiences note that parent learning cannot be viewed from a “one-way or deficit” perspective (Todd & Higgins, 1998), where educators set learning goals and assume that parent knowledge and skills are inferior. Instead, a social constructionist model of learning should be utilised. This is especially necessary in health interventions where human behaviour change is targeted. Indeed, in such situations many researchers have commented on the importance of a dialogic or interactive relationship between parents and professionals. For instance, Ching and Wai (2012) noted that adopting such a perspective on parent learning reduced the risk of overemphasising professional knowledge. It also helped in the development of shared and new understandings and led to the empowerment of learners.

Literature Review

Most of the literature on CBR worker learning is made up of expert opinion papers. Recommendations include that curriculum content be relevant to a particular centre’s needs; that knowledge and skills must be re-contextualised to learners’ personal experiences; and that reflective reasoning skills and resourceful practice among workers need to be inculcated as they already work in a complex environment (Wirz & Chalker, 2002; Mannan et al, 2012; Kuipers & Cornielje, 2013). Empirical research on describing worker training needs suggest many need areas, ranging from health and rehabilitation to empowerment and...
advocacy (Como & Batdulam, 2012). Social learning environments in the field of sustainable natural resource management may be relevant as they describe the nature of collaborative learning in a group involving non-specialists. Some studies indicate evidence of a developmental pattern of learning among all stakeholders and the importance of specific interpersonal strategies to facilitate learning (Leeuwis, 2000; Rist et al, 2006).

Literature on the nature of learning and its development is much more extensive in the clinical education field. One much-researched aspect has been the description of the internal learning process. For instance, Argyris and Schön (1974) explored professional practice in terms of espoused theories of practice which, for professionals, may be related to theories in their respective disciplines, and theories-in-use, which are derived from practice and shaped by the individual’s experiences, values, attitudes and beliefs. Indeed, the ways in which individuals are made aware of these differences and critically reflect and act on them is critical to learning.

Another important aspect described in clinical education has been interpersonal dimensions. For instance, in their study of nursing student motivation, Levett-Jones and Lathlean (2009) discovered that belongingness (i.e., feeling accepted, valued and connected with a defined group) was a crucial precursor to students’ learning and success. Finally, many of these studies and clinical education models (Anderson, 1988; Raidal & Volet, 2009) have focussed on particular, distinct and qualitative differences in modes of thinking and knowledge construction as learners move from being novices to expert practitioners. These points echo findings described earlier about the importance of critical reflection, how interpersonal strategies facilitate the process and how learning has a developmental aspect.

Studies on adult learning have typically looked at specific groups of learners within a learning situation. This is important in order to explore and describe learners within a particular group. At the same time, in many learning situations, there are usually different groups of learners involved, and this article explored findings about a particular learning situation from a multi-group perspective. These perspectives were necessary in order to encompass the learning that occurred as it involved all stakeholders. In addition, the longitudinal and qualitative approach to inquiry adopted here aided a more in-depth investigation. Thus, this research explored how the implementation of student services at the
CBR centre influenced learning among significant adult stakeholders over the course of the study.

**METHOD**

This research was conducted in an urban Malaysian CBR centre where there were 19 children below 6 years of age, and 9 school-age children (including adolescents) with a range of developmental disabilities. The majority of these children had moderate to severe levels of disability and many had complex needs. The centre was staffed by 5 workers. The principal research investigator’s (PI’s) involvement with the centre commenced with the project.

**Design**

The research reported here was part of a larger action research study on the design, implementation and evaluation of a student SLP service. Action research is a research approach which addresses practical problems in a systematic manner using a cyclical process in order to achieve positive change. Participation with local stakeholders was ensured by adopting a “co-operative” model (Herr & Anderson, 2005) which aimed to facilitate the overall learning and development of all stakeholders. However, while active collaboration of all stakeholders was sought, the PI assumed responsibility for the selection of the evaluation tools, data collection, and analysis. This facilitated engagement by all the other research participants, since it lessened demands on their time and resources.

**Participants**

The participants who were directly involved in the research process comprised the PI, 5 mother-child dyads (selected using maximum variation purposive sampling), all 5 workers, 2 final-year SLP students, the secretary of the central stakeholder committee, and 3 parent participants.
**Brief Audit Trail**

**Table 1: The Action Cycles**

<table>
<thead>
<tr>
<th>Cycle 1</th>
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<tr>
<td>Initial planning (3 months)</td>
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<tr>
<td>Data collection – II, GI, FN</td>
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<tr>
<td>First stakeholder meeting</td>
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<tr>
<td>Action (3 months)</td>
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<tr>
<td>Speech pathology sessions – 3 days/week</td>
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<tr>
<td>Data collection – FN</td>
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<tr>
<td>Three CBR worker workshops</td>
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<tr>
<td>Observe and Reflect (1 month)</td>
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<tr>
<td>Data collection – II, GI, FN</td>
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<tr>
<th>Cycle 2</th>
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<tr>
<td>Revised plan</td>
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<tr>
<td>Second stakeholder meeting</td>
</tr>
<tr>
<td>Action (3 months)</td>
</tr>
<tr>
<td>Speech pathology sessions – 3 days/week</td>
</tr>
<tr>
<td>Data collection – FN, R</td>
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<tr>
<td>Two parent workshops</td>
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<tr>
<td>Parent day</td>
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<tr>
<td>Observe &amp; reflect (2 months)</td>
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<tr>
<td>Data collection – II, GI, FN</td>
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<tr>
<td>Third stakeholder meeting</td>
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**Key**

II = individual interviews
GI = group interviews
FN = field notes by principal investigator
R = reflection journals
Table 1 provides an overview of the study. The preparatory phase of this action research project found that activities were mainly centre-based, conducted in a noisy room, with little resources and no specific schedule of rehabilitation planned. This demonstrated the limited training, knowledge and skills of the workers for health rehabilitation. Indeed, at times they appeared to provide respite care only. That is, workers’ key focus seemed to be temporarily relieving families from caregiving duties for a few hours each day.

Two action cycles, spanning a year, were planned and conducted. In cycle 1, the stakeholder committee elected that the PI would provide impairment-focussed SLP services which actively involved workers and parents. This included the decision that workers would perform the role of assistants to build their understanding and skills. Students were only involved in the second action cycle, as the preparatory phase highlighted that the first cycle required the establishment of better relationships between the PI and participants before students entered the cycle. This was critical as this research involved the introduction of not only students, but also a new service, SLP, to the centre.

Activities conducted during these two cycles included individual and group therapy, parent counselling, planning and review sessions with workers, home and community visits, and finally, four formal worker and parent training workshops. At the end of the study, a greater number of rehabilitation resources had been obtained and the physical setting had been modified to include 2 smaller rooms for individual and small group sessions.

Notwithstanding the generally positive outcomes, difficulties were encountered. In the first cycle, there were issues with worker attendance and engagement with the SLP sessions, while in the second cycle there was an unscheduled major disruption of the student placement to accommodate three week-long centre renovations. A complete description of all research findings connected with this project is reported in an unpublished thesis by van Dort (2013).

Data Collection

Data collection involved interviews, reflection journals and field notes. The PI conducted semi-structured individual interviews with mothers and semi-structured group interviews with workers at the beginning and end of the cycles. Questions about parent and worker learning experiences were included in these interviews. Interviews for mothers and workers were conducted in Bahasa
Malaysia. The transcribed data was independently translated into English by a research assistant fluent in both languages. During their placement, students kept a weekly reflection journal about their learning experiences, and participated in a group interview at end of the placement. The PI kept field notes throughout the project. Data from interviews were transcribed verbatim, while field and reflection journal notes were compiled.

Data Analysis
Data analysis was conducted by the PI. The focus of the analysis was on learning issues common to all adult stakeholders. Data analysed included participants’ descriptions of their learning experiences and the actions and events arising from these experiences that were recorded in the PI’s field notes. Thematic analysis informed, by hermeneutic cycles of interpretive readings throughout the project, primary coding phrases of the texts which were then, through recurrent readings, categorised and re-categorised into sub-themes and themes. Finally, congruent with qualitative approaches where writing and analysis are combined, these were written and rewritten in collaboration with 2 allied-health research supervisors in order to synthesise and provide a credible account of the data. The fact that the PI was an active participant in the research process, allowed her closeness to the phenomena studied and an awareness of the contexts of the texts, two important principles in hermeneutic analysis.

Trustworthiness
Data triangulation, i.e., the use of different sources of data to gain a variety of perspectives on phenomena, was one measure to ensure trustworthiness. In addition, the PI’s closeness to the data increased credibility, as did the collaboration with 2 other researchers in writing up the findings.

Ethical Considerations
All participants were aware of data collection and had consented to such data gathering. Approval for this study was given by the Ethics in Human Research Committee of Charles Sturt University. Pseudonyms were given to all participants and research sites were de-identified to protect participant identity. For interview and journal transcripts, the PI handed out typed transcripts to involved participants. She instructed them to read and comment, amend or retract anything they were uncomfortable with. No one chose to make any changes.
RESULTS

Two broad themes conceptualised the learning that occurred among centre participants and these, and their sub-themes, will now be described.

(a) Learning at the Centre was Contextually Bound

The three sub-themes to be described indicate how learning was situated within the context in which it occurred.

Individual Attributes

Individual attributes were broadly categorised into personal history, role, status (level of mastery), and competency. Personal history referred to an individual’s family and educational background, and previous and current experiences. Workers adopted a range of roles including: service provider, learner, co-researcher and parent, especially for those who were also parents of children with disabilities. Status related to the level of mastery the individual learner possessed or was recognised by others as having. Competency referred to the knowledge, understandings, skills, personal traits and values an individual learner possessed that enhanced capacity to support children with disabilities.

Each learner possessed a unique set of attributes that will be discussed in the following sections.

A Focus on the Child

One theme that was evident throughout the study was that learning was focussed around the common aim of supporting the children at the centre. All adult stakeholders, at some point, expressed this desire. For instance, all the workers had stated that their primary motivation for becoming workers was their desire to help children with disabilities. Three of these workers were themselves mothers of children with disabilities. Similarly, the parents who were interviewed, even when asked to describe their own needs and difficulties, focussed upon their children’s difficulties. The impairment-focussed model of service delivery further intensified this focus on the child. As well, positive outcomes were often described in terms of the children’s behaviour. This focus on the child helped knit this community together. It facilitated learning, in that learners were more willing to reshape perceptions and adopt common values once they realised how this would support the children.
The Political Context of Disadvantage

The adjective ‘political’ is used here in its broad sense to refer to a particular segment in society. In this study, it referred to the centre community which was embedded within a larger disadvantaged community which consisted of individuals from low to mid socio-economic backgrounds. In this context, material and human resources were limited. Families of children with disabilities struggled to support their children with these resources. Furthermore, the workers had received little training and rehabilitation materials were scarce and often non-existent. In fact, this was the first time workers were being provided with consistent grassroots-level support from professionals. Adding to this was the issue of the spontaneous and unstructured approach to centre activities, many of which were decided upon at the last minute. The major disruption of the students’ placement schedule during the second cycle to accommodate three week-long centre renovations was an example of this. The head worker had stated that “she had been forced to comply with the schedule of the company donating the flooring” (Field Notes); that is, the need to accept generous offers as they occurred.

Undeniably, the disadvantaged context made this setting less conducive to learning. Paradoxically though, there was a positive aspect. The informal and unstructured setting allowed the SLP providers an opportunity to get to know the children, families and workers better. One of the students had lamented somewhat comically that parents often treated her as if she was “a worker” (Group Interview). That is, the environment created more democratic and closer relationships among learners. Such relationships aided learning since the workers and parents were more willing to open up about the difficulties they faced with their children, as well as in providing feedback to the PI and students about the therapy conducted.

(b) Facilitating Processes

In this section, the six processes that facilitated learning in the CBR will be described.

Prolonged Engagement: Developing trust and mutuality through the passage of time and reflecting together

As one of the students noted, “we got friendly as time went by” (Group Interview). This study found that time was a critical influence on the development of cooperation and trust among the stakeholders, which was a key facilitator of
learning. The centre had welcomed the plan for establishing SLP services there and the PI first initiated this service. Subsequently, the students (in cycle 2) provided the service. Thus, ownership and engagement among local stakeholders grew over time. Indeed, because the project spanned two cycles across a year, it helped create the context of engagement and trust necessary for the development of shared understandings and common goals. The first few months helped establish informal relationships that allowed deeper exchanges of information to occur subsequently between SLP providers and recipients.

Another consequence of prolonged engagement was the development of mutuality. This is a condition of mutual respect, understanding, and support that is equally rewarding for all parties in the relationship. One example of this was when the PI aided the head worker in addressing her own children’s communication needs. Her children were experiencing difficulties in integrating into a special school nearby. Working together thus had “deepened the relationship” (Field Notes). Subsequently, greater engagement and attendance at SLP sessions by the head worker could perhaps be attributed to a desire to reciprocate the PI’s actions. There were many such mutual relationships between stakeholders which facilitated learning. At the same time, as will be elaborated further, mutuality coexisted with other less trusting relationships between learners.

Reflecting together was a key element in learning. Deliberate efforts were made to provide such opportunities for all adult stakeholders. Sessions with workers were targeted after group SLP sessions to discuss the children’s progress, and future activities and plans. In addition, individual parent counselling sessions were held after therapy.

One example of the importance of reflecting together was when one mother adapted a student-recommended strategy to suit her particular situation. She had understood the principles of behaviour management explained to her but had chosen to modify the strategy to a practice she was comfortable with. Furthermore, the introduction of augmentative and alternative communication strategies for particular children at the centre, in collaboration with workers and parents, helped knit this community together as common advocates for such measures. Thus, reflecting together may seem to have strengthened the bonds between participants and contributed towards the reshaping of perceptions and the emergence of shared and new understandings.
Compromise and Negotiation

Other interpersonal processes that facilitated learning were compromise and negotiation. Here the terms are used as Leeuwis (2000) does, to refer to approaches that consider the strategic interests of the participants. Such strategies were already an integral part of centre practice. For instance, one of the mothers, whose child was not regularly involved in sponsored outings because of his tantrum-prone behaviour, had gathered together a group of mothers whose children were similarly excluded. They were then in discussion with the head worker to reach a satisfactory compromise. The mother had rationalised her organised use of dissent by commenting, “It is not that we want to insistently trouble (the workers) but our children need to participate in outside events too” (Interview). In a similar manner, compromise and negotiation were essential processes that facilitated learning.

The findings revealed instances where initial unsatisfactory compromises were changed into better actions after individual participants developed shared understandings. The initial compromises were starting points to reach consensus, and thus promoted learning. For example, there were initial differences of opinion about where the therapy sessions should be located. The PI’s suggestion to use an adjacent room which was less noisy, met with resistance from some workers. They were concerned that if some children were taken across the parking lot to the room suggested, there would be fewer workers left to manage the remaining children. Instead, they suggested the use of the makeshift partitions at the centre to section off space for SLP sessions. By agreeing to this compromise, the workers gained their own learning experience. After they tried out the partitioned area, one worker initiated the shift to the adjacent room.

There were, however, problems with this approach of accepting unsatisfactory compromises as a means to eventually achieve better actions. For instance, it failed to establish a consistent rehabilitation schedule outside of SLP placement activities. Here, the open conflict between two novice workers and the head worker complicated the issue. These novices had joined the centre two months before the project commenced and were openly critical about rehabilitation practices. They correctly perceived the centre functioning merely as “a child-care facility” (Interview). So as to not add to this conflict, and given centre capacity and worker skills, the PI elected to avoid the issue of consistent schedules. Thus, the daily centre rehabilitation schedule remained sporadic until the end of the
project. All this diminished the learning that could have been achieved. This point will be further considered in the discussion section.

Mentoring Processes: The teaching–learning relationship

Mentoring, another interpersonal process, was also critically important in facilitating learning by providing necessary insights to learners to assist them in their efforts. The most common type of mentoring occurred when more-experienced participants guided and provided feedback to less-experienced participants. For instance, the SLP providers mentored the others regarding the facilitation of communication. Similarly, the PI who was an experienced SLP, played the role of mentor to the students.

An added feature was that participants less experienced in SLP often provided feedback to SLP providers. Both students were open to this feedback and perceived themselves as being in a reciprocal relationship with the workers and parents, in which a learning exchange occurred and empathy developed. Indeed, the students were quick to acknowledge how the workers and parents had helped them learn and had deepened their understanding. For instance, a student commented, “Previously, I perceived only the disability… but when I observed the workers’ attitudes, i.e., seeing children as being able to learn and being happy over the slightest changes…. So, I now see the children differently” (Group Interview).

Similarly, one worker commented on the reciprocal relationship thus:

“The two students are definitely good. They both possess ability and they definitely know how to make use of what they have learned for the children. I can learn from (them), but at times they don’t seem to know much about children with disabilities, probably because they have little experience with such children…We have the experience of the children, while they have the knowledge. We get to exchange this information, so this helps the children to develop further” (Group Interview).

At the same time, ineffective mentoring could limit learning. For instance, one of the students had a stronger need and desire for direction in learning, especially in managing children with behaviour difficulties in the complex and under-resourced setting. Unfortunately, the initial mentoring approach used by the PI was focussed on providing her with choices and letting her learn through trial and error. It was only towards the end of placement that the PI changed the approach and began providing more direction. Not enough attention had been paid to how the unfamiliar and unstructured setting and the rescheduling of
sessions with different clients had affected this student’s anxieties and influenced her ability to learn.

Self-reflection Processes
There was also self-reflection by learners as they viewed actions, both their own and by others, in the light of prior experiences and knowledge. Those who had innate capacity for reflection, or those who developed the capacity in this study, learned more effectively. For instance, one student displayed a better capacity for critical reflection. In one of her journal entries, she initially documented her annoyance with the workers for “doing the talking instead of (the child)” during the initial group therapy sessions. However, she reflected further to conclude that this was probably motivated by “their (workers’) instinct to help the child immediately” (Student Journal). The capacity to reflect deeply on worker motivation allowed her the opportunity to clarify these issues with the workers and improve overall learning. In contrast, the other student struggled with self-reflection as her cognitive attention was focussed on coping with the unstructured setting. Thus, it appeared that the cognitive competence of reflection could be diminished when there were other pressing cognitive and affective demands.

Being in Control
This theme of being in control arose out of the individual learner’s sense of being able to balance her needs with the demands and expectations of the learning situation. Indeed, learners in this research were often engaged in a balancing act because of personal needs and situational constraints. Achieving some measure of control appeared to be critical to optimising learning; otherwise the learner risked being overwhelmed by centre complexity.

Both students expressed anxieties about many of the features of the setting. However, one of them, higher up on the novice-expert continuum, retained a sense of control and even blossomed in the complex environment. The other student experienced more incidents of not being in control in this unfamiliar setting. The workers and mothers faced their own sets of needs, learning opportunities and demands. For many of them, the complex learning environment of the centre was a microcosm of the disadvantaged community with limited resources in which they lived. Their perceptions of an inability to balance their own and their children’s learning needs with other family and societal demands and expectations often created this sense of not being in control. For instance, in
cycle 2, one of the children’s self-injurious behaviour had suddenly intensified. Although there was ongoing work to manage this, the new worry dampened his mother’s enthusiasm for the small improvements in his communication skills. This underlined the continuum aspect of being in control since experiences of not being in control mingled with experiences of control and success.

Undeniably, the learners recognised that it was the individual’s determination to keep engaged - “have to have the words ‘have to’ in our vocabulary” (from Group Interview) - that would make the difference. This revealed how engagement could itself influence being in control, whereby an individual learner’s self-regulation towards learning remained strong despite challenges.

At the same time, this model of learning underlined the inappropriateness of sweeping generalisations because of the different attributes of individual learners. Being in control did not guarantee positive learning orientation. The head worker, a mother of two children with disabilities, had her own instances of feeling overwhelmed that affected her engagement and sense of control. On the other hand, she also used her position, in an authoritarian manner, to resist changes to rehabilitation activities which would have entailed higher work commitments from her. In this respect, she sought to maintain control in a manner that limited her own learning.

Confidence

A key finding was the close association between being in control and the development of confidence. It appeared that confidence diminished whenever the demands of the situation or the complexity of the task exceeded the abilities of the learners and resulted in failed actions. This was congruent with previous literature, in which confidence among adult learners is often perceived in terms of performance (Norman & Hyland, 2003). This, more often than not, created a negative spiral with experiences that further diminished confidence affecting the performance of the learner. This was especially true among the novice workers and one of the students, where demands were frequently greater than abilities.

On the other hand, confidence greatly contributed towards engagement and learning. Individual attributes such as being more experienced, knowledgeable and having higher status, equipped some learners initially with more confidence. A positive spiral ensued, as having such confidence helped them adapt to situations quickly, take on more responsibility and independence, and interact
more easily with others. This in turn led some mothers, the experienced workers and one of the students to engage more fully in the learning process and learn more comfortably. In addition, mothers who grew in confidence were quick to share their knowledge and understanding with other parents. For example, one mother willingly shared her experiences with other parents during a hospital-based Makaton workshop. Similarly, one of the students commented, at the end of the placement, that she had grown in confidence as a result of working with parents and workers with dissenting viewpoints (from Group Interview).

**DISCUSSION**

This study explored and described the learning experiences of adult stakeholders during an action research project to establish a student placement at a CBR centre. A model of effectual CBR learning was synthesised from the findings (see Figure 1). This will now be described, after which individual themes will be further discussed.

**Figure 1: Model of Effectual CBR Learning**

The results point to the situational nature of this learning which was strongly influenced by the disadvantaged centre setting, the individual attributes of learners and their focus on the children. The outermost triangle indicates how these factors contextualised learning and, in some respects, set boundaries and

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limited learning. The second set of themes (the rectangle within the triangle) is related to how specific processes provided a scaffolding effect and facilitated learning. For instance, the learning was sparked and sustained through the social encounters and interactions between all learners within this context. The interpersonal processes of prolonged engagement, negotiation and compromise, and mentoring worked through such encounters. When these encounters were positive, learning was strengthened; conversely, negative encounters engendered learning difficulties. In addition, a capacity for self-reflection facilitated learning. Finally, a sense of control and confidence interplayed with each other and other themes to critically influence engagement and learning. Control and confidence are denoted using double-headed arrows to emphasise how, in the complex centre setting, they fluctuated on a continuum. Finally, engagement with learning, denoted as a series of steps, indicated how this took time to develop.

Student placements are a small, but perhaps important, step in mediating the current knowledge divide between professionals and grassroot CBR communities in Malaysia since they build up capacity for such measures. Study findings indicated that all adult learners became better empowered by working together. Shared understandings and even new understandings evolved from such partnerships. While CBR participants acquired knowledge and skills in managing children with communication disabilities, the PI and students grew in empathy and ability to provide effective rehabilitation. Thus, the CBR framework, despite its limitations, provided a natural community framework in which services could be developed. Furthermore, this study indicated how workers involved in impairment-focussed rehabilitation activities grow in understanding and skills when supported by relevant professionals. This calls for greater collaborations between allied health professionals and CBR in Malaysia to provide workers with better training. Some form of supervisory support for any workers who engage in impairment-focussed rehabilitation is crucial.

A finding of this study, similar to that of Rist et al (2006), was the developmental nature of interactions, which moved from an initial focus of establishing trust among participants to later foci of deepening communication, changing attitudes, reshaping perceptions, and developing shared and new understandings about communication rehabilitation. Prolonged engagement allowed the context for these developments to take place. In addition, particular cognitive (e.g. reflecting together), social (e.g. consensus building) and personal (e.g. the development of
empathy) competencies described in the findings became outcomes of this social learning approach.

At the same time, given the real problems that often arise when different groups of people seek to learn and reflect together, this study found that negotiation and compromise were critical. The PI’s lack of ability to successfully negotiate for a more consistent centre rehabilitation schedule is a case in point. She unwittingly focussed too much on waiting for consensus from all participants. On the other hand, Leeuwis (2000) noted that a facilitator in a negotiation setting requires a more active strategy, resources and a power base to successfully forge agreements. This finding, about negotiation difficulties, is similar to other findings in the literature where problems arise in projects with multiple stakeholders with different needs (Jones & Stanley, 2010). Indeed, an important finding of this study was the necessity for facilitators of social learning projects to be properly equipped to pursue the complex negotiations necessary to facilitate learning. In fact, the development of a specialisation in CBR for allied health professionals would be a relevant way forward in the Malaysian context.

This study found that learners required a sense of security so that the demands of the placement would not overwhelm them. Mentoring is a strategy that recognises this need for the scaffolding of real-life experience during learning. This is in order to minimise negative performances among learners, which can diminish confidence. The unfamiliar and unstructured study setting appeared to be significantly difficult for one student. This resonates with other literature which indicates learners’ positions on the novice-expert continuum are not static but dependent on knowledge and skills relative to the specific context (Anderson, 1988). It alerted the university programme to the importance of sensitive mentoring in such cases. Additionally, students who are involved in initially establishing non-traditional placements should be selected carefully and include only those who are on the higher end of the novice-mastery continuum of student development. Such students would cope better with the spontaneous events typically found there. This may also facilitate better student ownership of the service and provide opportunities for developing leadership and innovative practice.

The findings demonstrated that mentoring can be perceived as a learning-teaching relationship in which clients and caregivers can furnish SLP providers with important feedback to help them develop as clinicians. This finding is also consistent with studies in professional practice literature, in which learners
often describe how important their clients are to their own learning (Black et al, 2010). As has been described, this mentoring relationship was an outcome of the better and deeper interactions that the SLP service providers experienced in this community setting. It pointed to the value of such settings in SLP education. The learning-teaching relationship also empowered CBR participants and led them to value their own contributions to the service developed. This was evidence of a “re-valuation of their own resources” as workers and parents became more aware of their own understandings and stores of knowledge (Rist et al, 2006). This gave them the confidence to provide practical insights to the PI and students, which aided the creation of new understandings. Another facilitating process described was the cognitive competency of self-reflection which has long been recognised as critical to learning (Argyris & Schon, 1974). All adult stakeholders exhibited this capacity for reflection, although some learners were more proficient. The fact that learners had opportunities to reflect together and become aware of multiple viewpoints aided self-reflection. Conversely, the complex demands of the setting increased anxieties for many of the learners and affected their sense of control. This study found that diminishing control could limit the capacity for self-reflection. Educators need to take these factors into account.

Finally, this study found that an individual learner’s levels of control and confidence had a significant influence on learning. These findings resonate with many previous studies (Norman & Hyland, 2003; Raidal & Volet, 2009). At the same time, this study was able to demonstrate how both control and confidence are related to other themes, such as the facilitating processes of mentoring and self-reflection, individual attributes and the context in which learning occurs. Indeed, all these themes are interrelated and in any learning situation they are important factors to consider.

**Limitations**

One limitation of the placement was that the community was only addressed by the focus on worker training and did not extend, in the main, to training and raising awareness among other members of the community. This may have further added to the burden of responsibility mothers faced, since the focus was on changing child, mother, and worker practices rather than working directly on community inclusiveness and attitude change. However, both parent and worker stakeholder groups had wanted this initial focus on impairment-focussed rehabilitation, identifying it as their greatest need.
Another limitation was that CBR participants played minimal roles in data gathering and analysis. This has already been justified, although the personal initiation of the project by the PI, who commenced the project as an outsider, surely contributed to the challenges described in the findings. For instance, the need to build up trustful relationships and better engagement with CBR centre participants may have been associated with the lack of ownership they initially felt towards the project. It is recommended that future researchers use more participatory approaches (i.e., critical action research) to increase a sense of ownership. Utilising better criteria in initial CBR centre selection would help delineate centres that are clearly open to such approaches.

**CONCLUSION**

This study has explored several themes common to all adult learners in a social learning situation involving a student SLP placement at a Malaysian CBR centre. The study has indicated that the setting is beneficial as a student placement. Indeed, the university has continued CBR sites to the present time. However, it has been critical for these experiences to be implemented in ways that support positive learning experiences for all involved, using the recommendations discussed above. While the findings cannot be generalised, they would be of importance to contexts that are similar to the context described in this article. Furthermore, it would be interesting to continue to investigate the common experiences of different groups of learners within a particular learning situation in order to further develop the understandings about these events.

**REFERENCES**


Community Mobilisation in a CBR Programme in a Rural Area of Sri Lanka

Masateru Higashida*

ABSTRACT

Purpose: This article examines community mobilisation in a model administrative division of the national community-based rehabilitation (CBR) programme in Sri Lanka.

Method: After comprehensively analysing local human resources related to the CBR programme at the study site, the focus of the study was on volunteers (n = 17), youth club members (n = 7), and local government officers from multiple sectors (n = 33). A semi-structured interview, focus group discussion and case information provided data, which was collected through social work practice in line with a previously developed one-year action plan. Narrative data was analysed using a qualitative procedure.

Results: The findings suggest that the local supporters, including people with disability, made a positive contribution to the CBR programme, and felt satisfied with the activities. Although the local resources and opportunities for people with disability are limited, the analysis points to the importance of coordination, attitudes, and mutual support rituals by villagers, in promoting community mobilisation.

Conclusions: Although it is an exploratory study with a limited sample of stakeholders at one study site in Sri Lanka, the study contributes to a growing body of literature that suggests the significance of community mobilisation in CBR. Future studies could explore some of the issues identified here, such as promotion of community-based inclusive development (CBID). However, since a limited sample of stakeholders was involved, findings can be generalised only to a similar context and setting.

Key words: community-based rehabilitation, community mobilisation, social work, qualitative research

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INTRODUCTION

Community-based rehabilitation (CBR) has been adopted in more than 90 countries, including many in South Asia. In the guidelines presented by the World Health Organisation (WHO, 2010), the CBR Matrix shows 5 main components: health, education, livelihood, social, and empowerment. Community mobilisation is placed in one of the five elements of empowerment on the Matrix.

The World Health Organisation (2010) defines community mobilisation as ‘the process of bringing together as many stakeholders as possible to raise people’s awareness of, and demand for, a particular programme to assist in the delivery of resources and services, and to strengthen community participation for sustainability and self-reliance’. The WHO shows the four steps of community mobilisation: (1) bringing people together, (2) raising people’s awareness, (3) assisting in the delivery of resources and services, and (4) facilitating and strengthening community participation.

According to a literature review of CBR, only a few papers are available on community mobilisation and participation of stakeholders that have been researched comprehensively (Finkenflügel et al, 2005). The actual number of papers whose titles include ‘mobilisation’ and ‘community-based rehabilitation (or CBR)’ could not be found on the electronic database PubMed (accessed on 1st October, 2014), although some research studies, such as the evaluation of CBR (for example, by Biggeri et al, 2013), examine community mobilisation and participation.

In Sri Lanka, CBR was launched as a national programme in 1994. As of 2012, the programme had covered all of the administrative divisions in Sri Lanka (Ministry of Social Services, 2013). The Ministry made a draft of the five-year plan on the national CBR programme in line with the CBR guidelines. The Ministry (2012a) mentions the goal of community mobilisation as ‘local communities (that) are empowered to remove barriers for people with disabilities and their families, and play an active role in facilitating the inclusion of people with disabilities and their families’. In particular, indicators such as a situation analysis of divisional secretariat (DS) divisions, different stakeholders within the community who participated in awareness-raising programmes, key stakeholders who participated in different aspects of CBR activities and other community work, are shown in the action plan.
Although Peiris-John et al (2013) reviewed published literature relating to disability issues in Sri Lanka and pointed to gaps in existing studies on the living conditions of people with disabilities, the practice and effectiveness of CBR in Sri Lanka has rarely been studied.

The aim of this study is to examine community mobilisation in a model administrative division in Sri Lanka, while focussing on the impact made by key stakeholders on the CBR programme.

**METHOD**

For this study a triangulation method, using mostly qualitative and some quantitative research, was applied. The reason is that qualitative data allows for clear and in-depth insights into contexts, which enables one to extract more comprehensive and holistic data in CBR (Sharma, 2004).

After commencing work in a local government office as a social worker in February 2013, the author applied action research to social work practice (Higashida, 2014). The duration of the research period was from 1st September, 2013 to 15th October, 2014.

This study attempted to answer two research questions:

1) Which factors promote stakeholders’ mobilisation? (Entry and promotional factors)

2) What is the impact of stakeholders’ mobilisation on the programme? (Impact)

**Study Site**

The target study site was the R-division (name changed), the model administrative division of the national CBR programme, located in Anuradhapura district. Consisting of 21 villages, the population of the R-division was estimated at 32,684, as of December 2013. The Sinhalese people, who are mostly Theravada Buddhists, constitute more than 99% of the population. The proportion of people with disability registered at the divisional secretariat office was around 1.1% of the total population in 2013. The CBR programme began here in 1998, and long-term overseas volunteers commenced support activities in 2007.

In Table 1, information on human resources in the R-division, as summarised by the author and the social services officer (SSO) is shown. Although the situation
analysis reveals a wide range of stakeholders in the community, the focus is on 3 human resources who actively participate in the CBR programme: CBR volunteers, youth club members, and local government officers.

Some of the core CBR personnel in the R-division are the group of community volunteers (CBR volunteers). Under the national CBR programme, 9,321 volunteers were officially registered within the country as of 2012 (Ministry of Social Services, 2013). The main role of a CBR volunteer is to connect people with disability to local resources, in order to improve their quality of life (Ministry of Social Services and Social Welfare, 2008), and to provide personal assistance and guidance to people with disabilities and their families (Ministry of Social Services, 2012b). In the R-division, 17 CBR volunteers are registered by the SSO. Their allowance is Rs. 250 for three months. The average duration of their work in the division is a period of approximately 6.7 years (SD=6.6).

Youth club members are also active supporters in the community. As of September 2014, around 100 youth, including 25 with disability, have registered as youth club members in the R-division.

Local government officers such as Grama officers (village officers), development officers, zonal education officers, the Medical Officer of Health (MOH), Samrudhi officers (poverty reduction sector), and the officer of the Technology and Science sector, have been important stakeholders who collaboratively conduct inclusive activities in the R-division.

Table 1: List of Human Resources related to the CBR Programme in the R-division

<table>
<thead>
<tr>
<th>Human Resources</th>
<th>Element of CBR Matrixa</th>
<th>Placement</th>
<th>Public/ Private</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with disability</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>Family</td>
<td>-</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>CBR volunteer</td>
<td>Social Empowerment</td>
<td>Social services sector</td>
<td>Public</td>
</tr>
<tr>
<td>Doctor</td>
<td>Health</td>
<td>Medical institution</td>
<td>Public/Private</td>
</tr>
<tr>
<td>Midwife</td>
<td>Health</td>
<td>Medical Officer of Health (MOH)</td>
<td>Public</td>
</tr>
<tr>
<td>Nursery teacher</td>
<td>Education</td>
<td>Montessori (Pre-school)</td>
<td>Private</td>
</tr>
</tbody>
</table>
Logical Framework of Action Plan

In September 2013, the SSO and the author wrote a one-year action plan, which included indicators aimed at challenging the issues that were found out in the previous research (Higashida, 2014). The logical framework focuses on community mobilisation of the main stakeholders: CBR volunteers, youth club members, local government officers and local institution staff (Appendix). Activities with the youth services sector were commenced prior to the action plan.

Data Collection

Table 2 shows the methods of data collection for 3 key stakeholders, in line with the research questions of this study.

Semi-structured interviews were held with CBR volunteers (n=10) and youth club members (n=7; Table 3). Two interviewers conducted all the interviews in Sinhalese, which is the native language of the study site. Interviews were guided by semi-structured questions to stimulate dialogue. Free-flowing narrative was encouraged to gain unrestricted opinions on the topic of interest. Participants were briefed about the ground rules to ensure confidentiality and the objectives of the study.

<table>
<thead>
<tr>
<th>Teacher</th>
<th>Education</th>
<th>School (including special needs class)</th>
<th>Public</th>
</tr>
</thead>
<tbody>
<tr>
<td>Local government officer</td>
<td>Livelihood</td>
<td>Samrudhi (poverty reduction)</td>
<td>Public</td>
</tr>
<tr>
<td>Livelihood</td>
<td>Sector of Technology and Science</td>
<td></td>
<td>Public</td>
</tr>
<tr>
<td>Livelihood/Social/Empowerment</td>
<td>DS sector of Social Services</td>
<td></td>
<td>Public</td>
</tr>
<tr>
<td>Livelihood/Social</td>
<td>Other sectors</td>
<td></td>
<td>Public</td>
</tr>
<tr>
<td>Buddhist priest</td>
<td>Social</td>
<td>Temples</td>
<td>Religion</td>
</tr>
<tr>
<td>Youth club member</td>
<td>Social/Empowerment</td>
<td>Residents/Local government</td>
<td>Public</td>
</tr>
</tbody>
</table>

*aThe applicable elements of the CBR Matrix: health, education, livelihood, social, and empowerment*
Focus group discussions were carried out with CBR volunteers (n=13; groups of 6 and 7). Two facilitators promoted discussions in line with questions, and probes for discussions were developed based on the aim of the study. Multi-sector meetings, usually organised by the divisional secretary, were held at the divisional secretariat in the R-division.

Data from field notes in social work practice was also used to analyse the realities in the study. In particular, the case information and narrative data from interviews with local government officers (n=33) was utilised in the process of interpretation and analysis. Statistical data was collected from documented sources such as local government documents.

Table 2: Data Collection Methods

<table>
<thead>
<tr>
<th>Key Stakeholders</th>
<th>Interview</th>
<th>Focus Group Discussion/Meaning</th>
<th>Field Work/Field Notes</th>
<th>Statistical Data/Questionnaire</th>
</tr>
</thead>
<tbody>
<tr>
<td>CBR volunteer</td>
<td>Q.1</td>
<td>Q.1, Q.2</td>
<td>Q.1, Q.2</td>
<td>Q.2</td>
</tr>
<tr>
<td>Youth club member</td>
<td>Q.1, Q.2</td>
<td>-</td>
<td>Q.1, Q.2</td>
<td>-</td>
</tr>
<tr>
<td>Local government officer</td>
<td>-</td>
<td>Q.1, Q.2</td>
<td>Q.1, Q.2</td>
<td>Q.2</td>
</tr>
</tbody>
</table>

Notes: The ‘Q’ numbers correspond to those of the research question

Table 3: Characteristics of Interviewees (youth club members)

<table>
<thead>
<tr>
<th>No.</th>
<th>Sex</th>
<th>Age</th>
<th>Enrolment year in Youth Club</th>
<th>Period of Participation in CBR (years)</th>
<th>Remarks</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>M</td>
<td>32</td>
<td>1995</td>
<td>5</td>
<td>Former member. Assistant in the National Youth Services Council.</td>
</tr>
<tr>
<td>2</td>
<td>M</td>
<td>22</td>
<td>2005</td>
<td>5</td>
<td>Current member</td>
</tr>
<tr>
<td>3</td>
<td>M</td>
<td>19</td>
<td>2006</td>
<td>5</td>
<td>Current member</td>
</tr>
<tr>
<td>4</td>
<td>M</td>
<td>24</td>
<td>2007</td>
<td>5</td>
<td>Current member</td>
</tr>
<tr>
<td>5</td>
<td>M</td>
<td>35</td>
<td>2012</td>
<td>2</td>
<td>Current member. Person with disability</td>
</tr>
<tr>
<td>6</td>
<td>F</td>
<td>21</td>
<td>2013</td>
<td>1</td>
<td>Current member</td>
</tr>
<tr>
<td>7</td>
<td>F</td>
<td>18</td>
<td>2013</td>
<td>1</td>
<td>Current member</td>
</tr>
</tbody>
</table>
Data Analysis
Quantitative data was analysed by descriptive statistics.

The data from the interview and focus group discussion was analysed with reference to the KJ method (Kawakita, 1967). This approach emphasises the significance of context in analysing and understanding data. Two raters analysed the narrative data in 6 steps: carefully transcribing and reading interviews; putting transcribed data onto sticky notes; putting sticky notes on a white board; positioning and grouping similar sticky notes; naming each group; and, drawing lines between groups in accordance with relevance.

Data from the other methods was chronologically and descriptively summarised with the assistance of study participants.

Ethical Consideration
This research was conducted on the basis of the ethical guidelines of the Japanese Society for the Study of Social Welfare. The study was approved by the Department of Social Services, the local government office, and the Japan International Cooperation Agency (JICA) office in Sri Lanka.

RESULTS

CBR Volunteers

1) Entry and promotional factors
Table 4 shows the proportion and main activities of the CBR volunteers, who consisted of 4 people with disabilities, 5 family members and 8 other stakeholders. The CBR volunteers, comprising people with disabilities and their families, were appointed by SSOs after consulting them. Others were found at the village meetings, such as elderly associations which the SSOs supported as part of their duties, and were appointed as CBR volunteers. The meetings of CBR volunteers were held bi-monthly to report the progress of supports and share necessary information in the R-division. Training for CBR volunteers was held once, in 2013, by the SSO and chief SSO in Anuradhapura district.

Reporting on the method of introduction and guidance, the SSO stated, “The new CBR volunteers go to the field with me to find non-registered disabled people because they have more information on disabled people in their living area. Additionally, I recommend
holding the CBR village committees to gather disabled people in order to share the community situation and discuss disabled people’s needs”. The SSO also recognised the importance of management and capacity building of CBR volunteers “because they don’t tend to work actively alone by themselves”.

All the CBR volunteers reported positive feelings about working with disability issues. The main contents are categorised into 3 areas: ‘As a peer volunteer’, ‘Happy to make contributions’, and ‘Religious well-being’. ‘As a peer volunteer’, interviewee no. 1 stated, “Because I have spent a long time with them, I enjoy working with them. At the beginning, I felt resistance to support them. But, after being familiar with it, I felt a sense of fulfilment”. He continued, “I needed somebody’s assistance and help in the past, but … now it is possible for me to help someone, because I have participated in CBR for many years”. Under the second category, all interviewees said that they were satisfied with their activities because they could make a positive contribution. Interviewee no. 5 said, “I’m very happy to support other disabled people. Because they can develop their capability through various activities, although I think more disabled people should take part in such activities”.

Finally, regarding ‘Religious well-being’, interviewee no. 9 stated, “One of the reasons for working as a volunteer is the action of accumulating many virtuous deeds”.

However, the interviewees revealed barriers which restrict their commitment to grassroots activities. Among the personal reasons given, interviewee no.10 said that she was required to take care of her mother whose health condition was severe, and interviewee no. 6 stated that she needed to take care of her cows every day. In addition, during the focus group discussion, interviewee no.12 mentioned, “Some community people don’t show respect to us, so that it is difficult for us to do assertive home visits”.

Table 4: Activities of CBR Volunteers in 2013–2014

<table>
<thead>
<tr>
<th>No.</th>
<th>Age</th>
<th>Sex</th>
<th>Years</th>
<th>Position before CBR Volunteer</th>
<th>Village Committee</th>
<th>Community Workshop</th>
<th>Events</th>
<th>Home Visits</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>25</td>
<td>M</td>
<td>5</td>
<td>DP</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>19</td>
<td>F</td>
<td>2</td>
<td>DP</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>36</td>
<td>M</td>
<td>1</td>
<td>DP</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>61</td>
<td>F</td>
<td>5</td>
<td>DP</td>
<td>✔</td>
<td>✔</td>
<td>✔</td>
<td></td>
</tr>
</tbody>
</table>
Note: ✔ = continually conducted; T = temporarily conducted; A = visited all households in the area; DP = people with disability; SA = Samrudhi association; EA = elderly association; Montessori = teachers in Montessori.

Though not an official CBR volunteer, No. 3 is included in the list due to his activities as a ‘building relationship officer’.

2) Impact
Case data registered by CBR volunteers and the SSO are compared by the presence or absence of placement of CBR volunteers. The number of children with disability under 18 years of age, registered in the presence areas (3.22 per 1,000 population), is significantly higher than in the absence areas (1.39 per 1,000 population) in the R-division (p=.04).

Nevertheless, at the focus group discussion the CBR volunteers placed more importance on other activities. Only one participant (interviewee no.10) mentioned personal assistance and the home visit programme in the target area to find hidden people with disability. Other volunteers pointed to a higher impact from group and community activities, such as religious events for people with disability, community workshops, and CBR village committees. Interviewee no.6 said, “I believe that it is important for us to involve disabled people in many opportunities. Thanks to CBR and our community workshops, our ‘families’ (people with disability) have chances to go outside, to interact with their friends, and to develop their skills”.

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Youth Club Members

1) Entry and promotional factors
According to the youth services officer (YSO) who was interviewed, she did not have a substantial relationship with social services, including disability issues, prior to 2008. The YSO said, “The previous SSO didn’t recognise disabled people in this division due to the lack of home visits, and I didn’t have a chance to collaboratively conduct any activities with them”.

Youth club members commenced participation in disability issues after the present SSO was assigned to the local government office in 2008. About 10 members regularly take part in the inclusive events mainly considered by the SSO and the YSO. The first event held by people with disability and youth club members was the New Year (on lunar calendar) Festival of people with disability in April 2009. Youth club members participated in the event to support and liven it up.

All interviewees mentioned the change in their attitudes regarding disability issues, while being satisfied with inclusive activities. Interviewee no.1 said, “I knew some disabled people, but …I used to consider them as they are just innocent poor people who were born according to ‘karma’. (After participation in the CBR programme) I realised that disabled people are also human beings same as us ... So, they should have rights same as ordinary people”. Interviewee no. 6 found people with disability were accomplished, “Now, I realise they are very talented people because they have many talents; some people can sing very well”.

2) Impact
The members regularly take part in the events for people with disability, such as cultural events and Disabled People’s Day Festival (3rd of December), while inviting people with disability to the events held by youth clubs, such as sports festivals, leisure camps, and leadership camps. In 2014, for example, 83 youth with disabilities from 3 divisions participated in a 3-day camp that the youth club members coordinated in the R-division. In addition, 7 youth with disabilities took part in a Youth Sports Festival in 2013. Moreover, since 2013 one of the persons with disability (interviewee no. 5) has become an officer of the club through the recommendation of the YSO. Interviewee no. 5 said, “I am very happy to participate in youth club activities, because I can invite my peers (other people with disabilities) to great opportunities”.

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Apart from change in personal attitudes, the impact of participation by youth club members was also demonstrated. Stating the need for change in the attitudes of other community people, interviewee no. 3 said, “They have the ability to do something, they have their own skills, we have to identify what their skills are, and they need somebody’s help to sharpen their abilities, like CBR volunteer services. And, it is worth it if people like us also give our support too”.

Interviewee no. 1 mentioned the desire to take action in the community in the future by stating, “I want to be a YSO and to support disabled people as well as people without disability in the area, in order to empower them. I consider it as a meritorious act”. Interviewee no. 3 stated, “I want to be a divisional secretary who can develop the community. For example, if accessibility in the community is improved, many disabled people would be able to participate in local activities”.

**Local Government Officers and Local Institution Staff**

1) Entry and promotional factors

While multi-sector collaborative activities and programmes were limited, some officers had contact with the SSO in the field of coordinating services such as poverty reduction and support for livelihood of people with disability. The interview with the SSO and other officers revealed that absolutely no collaborative project was implemented before 2008.

The turning point came when the SSO and overseas volunteers began to organise these collaborative projects. Holding meetings to share ideas and giving reasons for the activities were significant developments, although official letters were sometimes required to invite other sectors. Table 5 gives examples of the meetings held to involve stakeholders.

For example, in 2014, when a new project was begun for dropout pupils including children with disability, the conference on child development and CBR played an important role in building a working network with development officers, child-related officers, zonal education officers and school teachers, among others.

At the same time, the involvement of stakeholders to build networks between the social services sector and other sectors was fundamental. Involving community stakeholders - such as the midwives at the Medical Office of Health (MOH), the Grama officers (village officers), and co-medical staff at the community psychiatric
unit - was necessary for sharing information, for liaison, and for reference in order to provide accurate support for people with disability and their families.

Table 5: Multi-Sector Meetings (examples)

<table>
<thead>
<tr>
<th>Meeting</th>
<th>Purpose</th>
<th>Stakeholders</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Child development and CBR</td>
<td>To discuss child issues such as dropout pupils, including children with disability</td>
<td>Child-related officers, SSO, officers of the educational sector, Medical Officer of Health, police, overseas volunteers, etc.</td>
<td>Twice a year</td>
</tr>
<tr>
<td>CBR progress meeting</td>
<td>To manage progress of the CBR programme based on the action plan</td>
<td>Divisional secretariat, SSO, Samrudhi officers, youth services officer, officers of the educational sector, overseas volunteers</td>
<td>Monthly or bimonthly</td>
</tr>
</tbody>
</table>

2) Impact

In the process of building networks between multi-sectors, a wide range of programmes have been implemented in the R-division.

Firstly, as shown in Table 6, referrals to appropriate sectors were carried out by multi-sectors. The interview with the SSO did not reveal any cases referred between the social services sector and health and educational sectors, as of 2012. When action was taken on the basis of the one-year plan, the number of referring cases increased in each area. For instance, a person with psychiatric disability, isolated in the community, was referred to a training opportunity which the local government implemented.

Secondly, the project on dropouts and non-attending children under 18 (including children with disability) was started. After making plans to collect and integrate information on all villages with the development officers and Grama officers, the survey identified dropout children, including children with disability and one borderline child. The overseas volunteers have collaboratively implemented home visits to refer the children to appropriate existing resources and to develop alternative local resources.
Thirdly, awareness-raising events were conducted. For instance, people with disability, their families, local government officers and other stakeholders implemented an awareness-raising demonstration. The aim was to advocate for women’s rights, including women with disability in society. The event was publicised in the national newspaper in September 2014.

**Table 6: Referring to Other Stakeholders**

<table>
<thead>
<tr>
<th>Case Information</th>
<th>Human Resources</th>
<th>Before Intervention</th>
<th>After Intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infants with disability and children under 5</td>
<td>Medical Officer of Health (MOH)</td>
<td>0 cases</td>
<td>11 cases</td>
</tr>
<tr>
<td>Dropout pupils including people with disability</td>
<td>Teachers (two schools)</td>
<td>0 cases</td>
<td>9 cases</td>
</tr>
<tr>
<td></td>
<td>Development officers/ Grama officers</td>
<td>0 cases</td>
<td>13 cases</td>
</tr>
<tr>
<td>People with a psychiatric disability</td>
<td>Officers at a community psychiatric unit (Anuradhapura)</td>
<td>0 cases</td>
<td>6 cases</td>
</tr>
</tbody>
</table>

**DISCUSSION**

To sum up, this study found strong support for community mobilisation in the CBR programme. The promotional factors and the impacts of community mobilisation, which are the research questions, are discussed in the following sections.

**Entry and Promotional Factors of Community Mobilisation**

The opportunities for participation in the CBR programme vary for stakeholders. The analysis reveals, however, the importance of coordination, attitudes, and community inclusive development for the promotion of community mobilisation.

Coordinators to connect stakeholders with the programme, and meetings with stakeholders are essential to effectively promote community mobilisation. In this study, the SSO took the main responsibility of managing CBR volunteers and activating a multi-sector approach. However, there are limitations to be considered. The number of CBR-related officers, such as SSOs, is limited to only 2 - 3 in each division in Anuradhapura district.
Attitudes are also a fundamental factor in promoting continual participation. All CBR volunteers had positive feelings about their work in the programme; however, the type of attitude depended on individual volunteers. Although the youth club members initially felt confused, through mutual participation they had gradually become accustomed to collaborating with people with disability. Interviews with youth club members revealed a change in their attitudes towards disability issues, which led to further participation.

Finally, multi-sector practices were implemented, such as the programme for school dropouts and non-attending children (including children with disability). This is one of the examples of community-inclusive development. Multi-sector meetings are very necessary to make decisions and take action related to community-inclusive development. In addition to promoting dialogue at meetings and with the coordinators, sharing positive achievements and rewards would foster a win-win relationship between all the sectors.

The results of the study support the 4 steps that the WHO (2010) describes in the CBR guidelines, while showing the promotional factors with the micro project at the grassroots level.

**Impact of Community Mobilisation**

The analysis reveals that local supporters, including people with disability, make positive contributions to the CBR programme. Using the concept of the ‘Twin-Track Approach’ (Kuno, 2003), which emphasises a simultaneous process of empowerment and inclusion in CBR, the impact is divided into 2 aspects: empowerment and community development.

Firstly, community mobilisation influenced the practice of empowerment. For example, CBR volunteers took on the responsibility of identifying people with disability in the community and of promoting social participation in local activities. In addition, multi-sectors undertook a supportive role to identify children with disability less than 18 years of age and people with psychiatric disability, and to refer them to appropriate sectors.

Secondly, mutual support rituals by villagers in the community have developed through the CBR programme. For instance, by collaborating with the youth services sector, mutual participation in youth activities has been developed since 2009. Youth club members have participated in disability issues, and youth with
disability have taken part in youth club events on a regular basis. Furthermore, programmes related to inclusive development have been conducted at the grassroots level. One such example is the women’s rights awareness-raising event organised by various stakeholders, which included women with disability.

**Limitations**

There are several limitations to this study. As the sample consisted of key stakeholders in only 1 division, the study findings can be generalised only to a similar context and setting. Another limitation is the use of imprecise measures for the impact of community mobilisation. The findings therefore need to be carefully interpreted with these limitations in mind.

In future, community mobilisation should be evaluated more comprehensively and an accurate tool for assessment and evaluation should be developed.

However, despite the preliminary nature of this study, it will contribute to a better understanding of the impact of community mobilisation on the lives of people with disability and on community development, as well as the promotional factors.

**CONCLUSION and RECOMMENDATIONS**

Although it is an exploratory study with a limited sample of stakeholders at one study site in Sri Lanka, the study contributes to a growing body of literature that suggests the significance of community mobilisation in CBR.

Future research related to other CBR practices is recommended because the progress and condition of the programmes would vary according to the different communities in the country. Furthermore, it is important for practitioners and policy makers to assess, plan, act, and evaluate community mobilisation. Future studies could also explore some of the issues identified in this research, such as promoting community-based inclusive development (CBID), while using a larger and more representative sample of all stakeholders in the CBR programme.

**ACKNOWLEDGEMENT**

The author would like to express sincere gratitude to the Department of Social Services, and his counterpart, Ms Saroja Priyani, for providing this valuable research opportunity.
# APPENDIX
One-Year Action Plan

<table>
<thead>
<tr>
<th>Project Summary</th>
<th>Indicators</th>
<th>Verification Sources</th>
<th>Assumptions</th>
</tr>
</thead>
</table>
| **GOALS**  
Inclusive development and empowerment in Anuradhapura district. | Empowerment and inclusion of people with disability in the prefecture is promoted by 2017. | -Department of Social Services  
-Divisional Secretariat | Positive political environment will develop further. |
| **PURPOSE**  
Multi-sector practices are promoted in the R-division and accessibility to local resources is improved in target divisions in Anuradhapura district. | By December 2014:  
-Performance of multi-sector practices increases by 20% or more.  
-Number of participants in local resources increases by 10% or more. | -Divisional Secretariat  
-Self research including participatory evaluation | Government will allocate the same level or higher budget to national CBR programme. |
| **OUTPUTS**  
1. Networking between multi-sectors is strengthened.  
2. Quality of support by stakeholders is improved. | By September 2014:  
1-1. The number of cases within the health sectors and psychiatric clinics increases.  
1-2. The number of cases within the education sectors increases (dropout pupils including children with disability).  
1-3. The number of inclusive events held with multi-sectors increases.  
2-1. The number of registered children with disability, less than 18 years old, significantly increases.  
2-2. Quality of support methods is improved. | Baseline as of April 2013:  
1-1. 0 cases  
1-2. 0 cases  
1-3. Unclear  
2-1. No official data  
2-2. None | Anuradhapura district will conduct CBR programme. |
ACTIVITIES
1. To share information with multi-sectors and hold inclusive events.
2. To hold workshops for CBR volunteers and SSOs, conduct outreach activities (home visits).

INPUTS
1. Overseas volunteers

Cooperation with the Department of Social Services and Divisional Secretariats will be maintained

REFERENCES


Barriers to Early Diagnosis, Intervention and Social Integration of Children with Developmental Disabilities: A Qualitative Study from Rural Villages and a Poor Urban Settlement of Bangalore, South India

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2. Colorado State University, Fort Collins, Colorado, USA

ABSTRACT

Purpose: Children with developmental disabilities, if given skilled early intervention, have the potential to lead productive lives and can contribute to the social and economic development of their communities. This study explores the barriers to early diagnosis and intervention for children with developmental disabilities who live in rural and urban areas of Bangalore city, India.

Methods: The study was conducted in selected villages of Devanahalli Taluk in Bangalore Rural District, and in Devara Jeevanahalli (DJ Halli), a shanty town in Bangalore city. The qualitative study design consisted of in-depth interviews and focus group discussions (FGDs). Parents of children with developmental disabilities, doctors practising in the area and school teachers were interviewed using a purposive sampling framework. An inductive, data-driven thematic analysis was carried out.

Results: The physician-related barriers were identified as lack of skills and understanding of children with developmental disabilities, lack of knowledge and resources, lack of specialist back-up services, and communication difficulties with regard to conveying bad news to clients. Parent-related barriers were financial constraints, delay in accepting the diagnosis, and prevalent myths, beliefs and stigma pertaining to disability. The teachers viewed children with special needs as an additional responsibility, and were also apprehensive about the attitudes and interaction of other children at school with children with disabilities.
**Limitations:** Although the conditions are more or less similar in the different shanty towns and villages in South India, inclusion of more such settlements and villages using probability sampling would have increased the external validity of the study.

**Implications:** Better understanding on the part of parents, doctors and teachers can influence rehabilitation policy and practice, thereby facilitating early diagnosis and rehabilitation of children with developmental disabilities.

**Key words:** children with developmental disabilities, childhood disability barriers, inclusive development, CBR, accessing disability care, inclusive education

**INTRODUCTION**

Developmental disabilities are disorders of the developing nervous system that manifest during infancy or childhood as developmental delay or as limitations of function in one or multiple domains, including cognition, motor performance, vision, hearing and speech, and behaviour (Solarsh & Hofman, 2006).

In India, 35.29% of all the people with disabilities are children. There are other estimates that India has 12 million children living with disabilities and that only 1% of them have access to school (Childline India Foundation, no date). Studies have reported a prevalence of 1.5% to 2.5% of developmental disability among children under five in India (Nair & Radhakrishnan, 2004; Nair et al, 2009).

Children with developmental disability face a number of barriers and challenges. They need to be identified early, assessed and stimulated in order to achieve their full potential. The people who can play a crucial role are parents, doctors and teachers.

For several years, the Bangalore Baptist Hospital has been delivering preventive, promotive and curative health and community development services to 50 villages of Devanahalli Taluk and to DJ Halli, one of the shanty towns in Bangalore. In the course of their work, the health team came across children with developmental disabilities who had different problems: some were diagnosed late, others had developed contractures, some were left neglected in their households, a few had died due to neglect and associated malnutrition, and many had dropped out of school. These observations were a cause for concern and became the basis of this action-oriented research.
Objectives
1. To identify barriers to early identification, appropriate treatment and rehabilitation of children with developmental disabilities, as perceived by parents
2. To determine barriers to diagnosis and provision of appropriate care to children with developmental disabilities, as perceived by doctors.
3. To identify barriers in providing inclusive education to these children, as perceived by teachers.

METHOD

Definition of terms
Taluk: A subdivision of a district, consisting of a group of several villages organised for revenue purposes.
Community: A group of people living in the same place or having a particular characteristic in common.

Study Setting
This study was undertaken in DJ Halli, one of the shanty towns in Bangalore city, and in 5 villages of Devanahalli Taluk, a sub-district. DJ Halli is a densely populated and overcrowded area, where the majority of the people are engaged in construction work or small-scale industries like making garments and beedis. Other features are the high pollution levels, high crime and infant mortality rates, prevalence of infectious diseases, non-communicable diseases and deaths due to malnutrition. Devanahalli, which is part of Bangalore Rural District, is a predominantly rural area with a small semi-urban population. It is sparsely populated, and majority of the people are engaged in agriculture and animal husbandry.

Study Design
A qualitative study design was chosen to elaborate on the multi-dimensional aspects of the stated problem and to better understand the experiences of the critical ‘influencers’, namely, parents, doctors and teachers, in dealing with children with developmental disabilities. The research questions were broad,
so as to accommodate inductive, data-driven thematic analysis. The strategies of Corbin and Strauss (2007) for qualitative research were used to guide data collection and analysis.

**Study Population and Sampling**
The Community-Based Rehabilitation (CBR) field team had conducted household surveys in the selected villages in the rural area and in the shanty town. As a part of this CBR programme, children with developmental disability were identified and community-based rehabilitation services were initiated. Information about parents of children with developmental disabilities was taken from the CBR programme register and they were contacted by the research team. The team, which consisted of a doctor, an occupational therapist and social workers, visited these households to establish rapport, explain the purpose of the study and to conduct the interviews. The parents were interviewed at a time convenient to them, using a semi-structured questionnaire which was largely a list of open-ended questions. With permission from the parents, the research team also looked into the medical records available.

The semi-structured interview guide contained the following prompts:

- Can you describe your child’s condition?
- Can you describe the events leading to the diagnosis of your child’s condition?
- Who told you about the child’s condition? How did you feel?
- Can you tell me about the treatment suggested?
- What were the challenges faced regarding the treatment of your child?
- How did you respond to these challenges?

Parents of 32 children were interviewed; of them in 18 children, both parents were present during the interview, and in the other 14 children, only the mother was present. In cases where both the parents were interviewed, it was noticed that mothers were able to remember and share the experiences more clearly than fathers. Therefore the interview was conducted if both parents were present or if the mother was available. The questionnaire referred to demographic details, age, educational qualifications, occupation of the parents and family income. Parents were encouraged to share their experiences in getting to know about their child’s condition, their interactions with the doctors, and the social pressures and stigma
that they experienced. All the interviews took place at their homes, for a duration of 35 to 90 minutes (average 46 minutes). In accordance with the conventions of thematic analysis, recruitment ceased when no new information emerged from the interviews (Corbin and Strauss, 2007). Thematic saturation was attained after conducting 30 interviews; however, an additional two interviews were conducted to confirm saturation.

All the doctors, including indigenous practitioners in the proximity of the selected areas, were identified and contacted for interviews. Though all the 41 doctors were willing to be interviewed, due to unavoidable circumstances 3 of them were not available on the date of the interview (one was out of town, one had a family emergency and the other did not give any reason). In-depth interviews were conducted using a semi-structured questionnaire. Apart from their qualifications and number of years of experience, the doctors were asked about the challenges they faced in dealing with diagnosis and management of children with developmental disabilities.

The interview guide contained the following prompts:

- In your practice, do you see children with developmental delay?
- Can you describe the challenges you face in diagnosing developmental delay?
- Once you get a clue that the child has developmental delay, what do you do?
- In your experience, what are the challenges in treating a child with developmental delay?

Doctors were encouraged to speak about their competence in identifying children with developmental delay, as well as their ability to provide appropriate management and referral. They were assured that their identities and the information they provided would be kept confidential and used for academic purposes only.

All the schools in the selected geographical area were mapped on the basis of information provided by the education department at the sub-district office. Using the lottery method, 8 schools from the list, 4 each (2 private and 2 government) from rural and urban areas, were chosen at random for the study. After obtaining permission from the school officials, the research team conducted focus group discussions with teachers and school children. The teachers who were available
and were willing to participate were selected. Focus Group Discussions (FGDs) were held with 31 school teachers and 39 children without disabilities; four FGDs with teachers and four FGDs with students. Each FGD had 6 – 9 participants and the duration varied from 90 to 130 minutes.

As part of the school visit, the research team also conducted an environmental analysis. Environmental analysis consisted of an audit of the school infrastructure, to assess whether the school conformed to a minimum set of barrier-free provisions which are essential for facilitating children’s accessibility and independence. These barrier-free provisions are a necessary part of Sarva Shiksha Abhiyan (SSA), a government initiative for achievement of Universalisation of Elementary Education (UEE).

All the interviews and FGDs were conducted in the respondents’ first language (either Kannada or Hindi). The research team built rapport with the respondents to promote open and honest communication. It is claimed that most researchers have organisation and institutional power compared to the participants (Henry, 2003; Karnieli-Miller et al, 2009). However, in this instance, the power effect was nullified by the fact that the researcher had been working in the area for more than 2 years and had developed a certain level of rapport and trust with these communities and the participants. Also, the research team had experience in dealing with children with disability, and sharing these experiences became a unifying factor.

The study was approved by the Institutional Review Board.

Analysis
Inductive thematic analysis, whereby themes are generated from the data as opposed to a pre-existing thematic framework, was performed concurrently with interviews until thematic saturation was reached, in accordance with the methods described by Corbin and Strauss (2007). Journal entries and memos were included in the analysis. Thematic analysis took an iterative approach, whereby as new themes were identified and added to the thematic framework, earlier transcripts were recoded (Corbin and Strauss, 2007).

In-depth interviews and focus group discussion tape-recordings were transcribed and translated verbatim. A preliminary analysis was conducted to get a general sense of the data and reflect on its meaning. The data was then open-coded in a systematic fashion, on the basis of repeating words and concepts. Each data item
was given equal importance in the coding process. Constant comparative analysis was performed repeatedly; data was compared to the categories to determine consistency in coding. Each code had to have a supporting sentence, extracted from the one-to-one interview or FGD transcript, and a relevant comment added by the evaluator. The coding was done until no new categories emerged from the data. In the next stage, the codes were collated into potential themes, by gathering all data relevant to each theme. Themes were repeatedly checked against each other and against the original data set, to ascertain that they were internally coherent, consistent and distinctive. The themes were then analysed to explain the core phenomenon, causal conditions, strategies and consequences through axial coding by connecting themes. Rigour was addressed by repeated coding of transcripts by different team members to ensure a comprehensive themes list and framework; an iterative process of constant comparison between the existing framework and new data; detailed documentation of the analysis process; and, discussion of emerging and final themes with all authors. Guided by the triangulation protocol of Farmer et al (2006), the data was triangulated further to validate the findings. A summary of the triangulated results was sent for review to a senior researcher who concurred with the results.

RESULTS

Demographic Details and Diagnosis of the Children in the study
The oldest child was 15 years old and the youngest was 2, the mean age being 7.6 years. 62.5% of the children in the study were males. Their medical conditions were cerebral palsy (43.8%), mental retardation (28%), cerebral palsy and mental retardation (12.5%), spinal muscular atrophy (6.3%), blindness (3.1%), seizure disorder (3.1%) and Treacher Collin syndrome (3.1%).

Parents
Among the parents interviewed, 40.5% belonged to the rural areas while 59.5% were from the shanty town. Almost three-quarters (75%) of the households had an average monthly income of Rs. 4000. Majority of the mothers (90.6%) were housewives; around 28% of them were illiterate and 28% had completed high school.
The dominant themes that emerged from the interviews are described below.

1. Delay in diagnosing the problem by the doctors

Even though the health-seeking behaviour of the selected population was relatively good, the most important barrier that parents reported was that the doctors failed to spot the problem early. One parent said, “I had taken my child to the doctor 10 - 12 times for loose stools, breathlessness, allergies, etc., but no doctor told me my child has a problem at that time. After three years, one doctor told me my child is different.” Similar experiences were shared by majority of the parents. 75% of them agreed that the doctors did not do everything in their capacity to help them.

In their first year of life, most children (87.5%) had been taken to a physician at least once in three months and the others once a month. Despite frequent visits, the doctors treated these children for infections only. They seemed to ignore the disabilities the children presented. Lack of competency of the health professionals emerged as a major barrier in these communities.

2. Confusion regarding where to seek help for their child’s condition

The parents faced many challenges in deciding what was best for their child. The doctors failed to give them proper directions. All that was communicated was that the child had to be taken to another hospital, but no information was provided regarding where to go and whom to meet.

“Doctors don’t seem to know about my child’s condition. The first 6 doctors gave us a vague explanation and told us to go somewhere else,” one parent stated. “Even after telling our child’s problem, the doctors failed to inform us where to go, what to do and what will happen to our child in future. All of them left us confused.”

Almost all the parents had made multiple visits to different hospitals and wasted a lot of time, energy and money.

“We have asked many, but no one seems to know; we tried different places and wasted a lot of money. We lost hope and the child is at home.”

Most parents were frustrated because they had no idea where to go for help and no one helped them.

“We are poor, where can we go and find out? There is no one to help”, a parent stated angrily.

Lack of education, financial constraints and large family size made matters worse.
3. Treatment options are expensive and require dedicated time with the child
When poverty and disability intersect, the expenses associated with children’s care have important implications for their families. Childhood disabilities impose very high costs on poor families. The analysis of parents’ expenditure revealed that they had spent an average of Rs. 1,80,000 on their child’s treatment. Parents may be forced to make trade-offs between the needs of their child with developmental disability and the basic needs of their family. Majority (90.6%) of the interviewed parents used the words “too expensive” and narrated how they could not provide optimal treatment to their child.

“There are no services provided by the Government and private treatment is expensive. There are no facilities available nearby and we have to travel at least 40 km to go to the town. The treatment is very expensive, 350 rupees for half an hour. We can’t afford it.”

“If we have to sit with him every day, there won’t be food on the table”, said the father of one child.

4. Myths and beliefs
Many myths and beliefs prevalent in society pose a threat to children with developmental disabilities and their parents.

“This is due to our family’s past sins, nobody can do anything about it and we have to go through this suffering,” one parent said.

“We have to pay the price for the bad karma which we might have done in the previous birth,” added another mother.

There is a strong conviction that only sinners in a previous birth are born with disabilities in this life.

These beliefs also caused distrust of medical and rehabilitation services.

“Even if doctors provided treatment, the child is unlikely to improve. This is God’s curse,” a young mother remarked.

A few of them revealed that they had taken their child to traditional healers and faith healers.

The frustration of social exclusion was evident. One mother said, “We have suffered enough because of this child. Many of the relatives do not call us for any functions. Even if someone calls us, they talk behind our back that we had this child because God wanted to teach us a lesson.”
5. Delay by the parents in accepting the diagnosis
Some parents (18.8%) were in denial regarding the diagnosis for a long time, and had multiple physician consultations hoping to hear that their child was normal.

“Our child was normal, just like her sister when she was born,” said one parent.

“There was nothing unusual about my child. It’s just that he is not as smart as other children,” another parent said.

These respondents were younger (mean age was 23.1 years) than the rest of the mothers. 66.6% of them belonged to rural areas. Even when faced with severe developmental delay, these mothers were in denial.

There is a widespread dislike of the doctor who first diagnosed the child. One parent even blamed the doctor for causing the child’s disability.

“Our child was okay, but the doctor gave some medicines for cold. After that only he started getting all the problems. He must have the given wrong medicines. We no longer go to that doctor,” a mother said.

6. Caregiver burnout
A child with special needs requires constant care and support, which results in excessive stress and strain for the parents.

“He needs a lot of attention. Someone has to sit with him all the time, the roads outside are busy, he will run out if we don’t prevent him,” said one.

“No matter how much I explain, she likes to play with water. All the water which is kept for drinking is wasted. I get very angry. I am tired of telling her,” another mother said.

“We tried everything; we spent more than Rs. 4,00,000 on our child. We are tired of taking him to different places. We have no hope,” a parent lamented.

Though many parents expressed their frustrations in dealing with their children, the researchers did not probe to explore the possibility of abuse.
Table 1: Barriers to Early Diagnosis, Intervention and Social Integration of Children with Developmental Disabilities: Parents’ perspectives

<table>
<thead>
<tr>
<th>Concepts basic (Open codes)</th>
<th>Organising theme</th>
<th>Global theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illustrative quotes</td>
<td></td>
<td></td>
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</tbody>
</table>

**Lack of knowledge and skills**

“"It’s not that we did not go to show our child...S had diarrhoea when she was 3 months, many times fever...but no doctor told me that S has other problem.”

(G, mother, 11th Oct 2013)

**Lack of information**

“S has a problem, Doctor told us, but did not tell where to go and what to do. He did not tell what to do next.”

(N, mother, 11th Oct 2013)

**Expensive**

“350 per treatment session, that too for many days... expensive.”

(G, 44 years old)

**Non-availability**

“N has to be taken to town, in this village...uh... doctors said they can do nothing... it is difficult...town is unfamiliar...costly...”

(U, 24 years old, 25th Sep 2013)

**Chronicity**

“G will not become okay...I do not think it is like cough or fever... He has to be taken to the doctor for treatment.. how many times I can...um... you know...it is difficult...”

(N, 32 years old, 11th Sep 2013)
<table>
<thead>
<tr>
<th>Dedicated time</th>
<th>Energy drain</th>
<th>Caregiver related</th>
</tr>
</thead>
<tbody>
<tr>
<td>“I cannot work, have to sit with A every day... I am not able to provide for my other children...”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(G, 30 years old, 12th Oct 2013)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Burnout</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“With other three children, it’s tough to take care ... treatment is difficult... I am so tired... lose temper too...”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Z 26 years old, 15th Oct 2013)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hopelessness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“We are tired of taking the child to different places... when we ask whether N improves, always they give a blank look... We have no hope.”</td>
<td></td>
<td></td>
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<tr>
<td>(M, 22 years old, 13th Aug 2013)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stigma</td>
<td></td>
<td>Social avoidance</td>
</tr>
<tr>
<td>“We do not want to go...they will talk...you know... behind our back... that why we are cursed...”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(S, 24 years old, 24th Oct 2013 )</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of faith in therapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“It is due to our family’s past sins, nobody can do anything about it...it is beyond medicine...next birth... maybe we will all be healthy...”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(M, 23 years old, 15th Sep 2013)</td>
<td></td>
<td></td>
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<tr>
<td>Need for suffering</td>
<td></td>
<td></td>
</tr>
<tr>
<td>“It is God’s curse upon us...what treatment can make a difference...we have to go through pain...uh...umm... suffering...to cleanse...”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(L, 22 years old, 10th Sep 2013)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Denial</td>
<td></td>
<td>Lack of adaptation</td>
</tr>
<tr>
<td>“I do not believe that something is wrong... I do not want others to know... it’s a false thing... why should others spread a rumour... my child is ok...”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(P, 25 years old, 12th Sep 2013)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Doctors**

Thirty-eight doctors were interviewed, of whom 13.2% were from the rural area and the rest were from the urban area. With a mean age of 38 years, their experience varied from 1 - 25 years. While 70% of them held a post-graduate degree, one doctor was an *Ayush* (indigenous medicine) practitioner.

Three major themes emerged.

**1. Breaking bad news is difficult**

Many physicians, both GPs as well as specialists, reported feeling considerable anxiety while conveying “bad news” to parents, due to factors such as fear of a negative reaction and a sense of powerlessness from not being able to provide a cure. This was more pronounced among doctors with less than 5 years of experience.

The doctors demonstrated a lack of confidence in handling emotional issues.

“It is a very sensitive issue, what if they overreact? I don’t know how to handle such situations.”

The doctors also showed hesitation in conveying the diagnosis of a child’s developmental disability, though it was not such a problem to break bad news to an adult.

“I don’t have a difficulty in telling a 40-year-old patient that we are suspecting cancer; they take it better when compared to a parent of a child with developmental disability. Parents are very emotional regarding their children.”

“If the parents are uneducated, the matter becomes worse. They overreact and blame us.”

Uneducated parents and time constraints are the major barriers in explaining a child’s condition to the parents.

“I see hundred patients a day, all kinds of patients; I can’t afford to spend so much time with the parents.”

Many doctors felt there was no need to explain the diagnosis to the parents because they believed that since most parents were uneducated, they would not be able to understand.
Another interesting concern that was pointed out was the stigma towards the doctors who diagnosed these conditions.

“One child’s mother did not speak to me for five years because I was the first to break the news. The whole family stopped coming to me. I have become a bad omen for them. I learned my lesson. Now I refer all such children to another centre, let them deliver the bad news.”

“They won’t take it in the right sense. Parents don’t want to hear anything bad about their child.”

Though this experience was not common to all, the doctors who were involved had taken it too personally and had vowed never to take the risk again.

2. Lack of competency

Majority of the doctors (76.3%) expressed difficulty in diagnosing children with developmental disabilities. Only 9 doctors rated their competence in dealing with this issue as satisfactory.

“I am not very confident that I can identify children with special needs. We were not taught about all this in detail. I can pick up these disabilities at a later age, if it is moderate to severe. Only a specialist can pick up subtle signs.”

“Though not a specialist, I do come across these types of children. I am confused most of the times.”

The paediatricians, psychiatrists and the neurologist showed confidence in diagnosing children with special needs. All of them expressed their desire to attend training programmes to build capacity.

3. Referral

Even though many general practitioners often dealt with children with developmental disabilities, they had no information and showed no interest in finding out about referral hospitals and institutions that provided specialised services for diagnosis and rehabilitation. They referred such children to medical college hospitals, assuming that all the facilities were available, and did not follow up.

“I usually tell them to go to a medical college or a big hospital” one doctor stated.

“I know it will be difficult for parents to find the right doctor and right place but I don’t know either” exclaimed another doctor.
Table 2: Barriers to Early Diagnosis and Management of Children with Developmental Disabilities: Physicians’ perspectives

<table>
<thead>
<tr>
<th>Concepts basic (Open codes)</th>
<th>Organising theme</th>
<th>Global theme</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illustrative quotes</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Difficulty in breaking bad news**

“Any problem regarding child...parents do not take in the right sense... Too much for me to handle... No time to sit and talk and manage their feelings...”

(Dr. V, 7th Dec 2013)

**Lack of time**

“Crying...sadness...takes a lot of time to console the parents... Deal with them...I can’t afford to spend so much time with the parents...there are other patients waiting...”

(Dr. G, 12th Dec 2013)

**Fear of blame**

“I have become a bad omen for them because I first broke the news of their child...the whole family stopped visiting me... Its too much of risk to take...easy to refer...let others say it...” (Dr. G, 22nd Dec 2013)

**Lack of knowledge and skill**

“I am confused most of the times... With the current level of understanding, hard to identify early...”

(Dr. R, 22nd Dec 2013)

“Not very confident... The child can be normal, but slow compared to others... But it may be pathological too...”

(Dr. M, 14th Jan 2014)

**Specialist domain**

“Only a specialist can pick up subtle signs... Is there any screening test...I mean,other than looking at the milestones...it’s difficult ...we are not specialists..”

**Lack of information regarding referral**

“I usually tell them to go to medical college or a big hospital. The specifics I do not know, I assume that in medical colleges the treatment will be available.”

(Dr. M, 8th Dec 2013)
<table>
<thead>
<tr>
<th>Expensive</th>
<th>Financial drain</th>
<th>Environment</th>
</tr>
</thead>
<tbody>
<tr>
<td>“It is expensive... They have to go to the advanced centres... Travel, treatment...most of the parents cannot afford... Initially there is hope and they will shell out money... Then the enthusiasm slowly diminishes.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Dr. M, 8th Dec 2013)</td>
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</table>

<table>
<thead>
<tr>
<th>Caregiver burnout</th>
<th>Energy drain</th>
<th>Caregiver related</th>
</tr>
</thead>
<tbody>
<tr>
<td>“The condition is not curable... The parents also get tired carrying the child to different places... Difficult to manage at home also. parents give up, it’s difficult to motivate them...the situation is different from western countries...We can’t totally blame the parents...”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Dr. N, 14th Dec 2013)</td>
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<td></td>
</tr>
</tbody>
</table>

**Teachers**

While more than half (54.8%) of the interviewed teachers belonged to the shanty town, the rest belonged to the rural area. 87% of the teachers were females. About 75% of them were in the age group of 20-43 years. 51% of the teachers were from government schools and the rest from private schools. An important observation was that 71% of the teachers did not have any training in managing children with disabilities.

Most schools lacked trained personnel, special materials and resources to aid children with developmental disabilities in their basic learning and daily activities. Consequently, children with developmental disabilities were not getting appropriate, specialised attention and care, and the education of regular students was frequently disrupted.

Four themes emerged.

**1. Extra burden**

Teachers showed reluctance to include and manage children with developmental disabilities in the same class alongside normal children. They looked on it as an extra burden.

“With normal children alone, we are finding it difficult to cope; children with developmental disabilities, unthinkable!” one teacher exclaimed.
2. Pressure to perform and obtain good school results
Most schools were understaffed. Teachers felt that a lot of time had to be dedicated if there were children with developmental disabilities in the school.

“We are being evaluated by our students’ performance. To maintain a reasonably high pass rate, we need to put in a lot of effort.”

“We do not have enough staff and there is pressure to produce good results. Having a child with disability in the class is a distraction.”

3. Lack of trained manpower
There was considerable anxiety among all the teachers with regard to managing children with developmental disabilities.

“What if they get fits or something like that?”

“What if they fall and injure themselves?”

“Who will accompany them always?”

4. Concerns about the interaction between normal children and children with developmental disabilities
The other concern which the teachers raised was the interaction and relationship between other school children and the children with special needs.

“I don’t know how the other children will accept them. It’s complicated. We are not ready for such things.”

Children without disabilities
Focus Group Discussions were conducted among school children. All of them used the words ‘deaf’, ‘dumb’, ‘blind’, ‘handicapped’ to describe children with disabilities. The school children were ready to accept them and voluntarily promised their wholehearted cooperation to help in any way they could. They were eager to make friends with them. The responses from these children were: “I will teach him”, “I will help him with the homework”, “I will carry her”, “I will teach her to walk”, and “we can sing together”.

www.dcidj.org Vol. 25, No.4, 2014; doi 10.5463/DCID.v25i4.333
Environmental analysis of the schools showed that the facilities were not designed to accommodate children with disabilities. None of the schools had accessible toilets. There were a lot of steps and no ramp access to many classes.

“We can’t construct ramps for these five children. These are only on paper for government to show, it’s a waste to do all these things,” one school principal stated.

**DISCUSSION**

The value of early identification of children with developmental delays has been well documented (Ramey et al, 1992; Shonkoff et al, 1992; Brooks-Gunn et al, 1994; McCarton et al, 1997; Hollomon & Scott, 1998; McCormick et al, 1998; Campbell et al, 2002). Not many studies in India have explored the barriers in providing early intervention services so as to facilitate inclusive development of children with disability. The delay from the doctors’ side has been reported in a few studies which concluded that there is lack of knowledge and skills in this area, which requires emphasis and training (Campbell et al, 2002; Rydz et al, 2006). Other physician factors include attitudes, awareness, or interest (Esposito, 1978); insufficient training (Thorburn et al, 1993); doubt about the value of early detection or non-acceptance of early treatment (Mousmanis & Watson, 2008); uncertainty about how or where to refer (Desai & Nohite, 2011); time limitations of the clinic visit and inadequate reimbursement (Ertem et al, 2009); and cost factors (Dobrez et al, 2001). In some cases, practitioners might be legitimately concerned about unnecessarily alerting a family and would prefer to wait until the problem is too obvious to ignore (Shevell et al, 2001). The appropriate education and training, and issues affecting professional interest, motivation and health-provider acceptance, need extensive study in the context of local geographic and cultural conditions.

Some studies have explored the myths and beliefs related to disability that prevail in different parts of the world. A World Health Organisation report (Promoting the rights of children with developmental disabilities, 2007) states that in cultures where guilt, shame and fear are associated with the birth of a child with disability, the children are frequently hidden from view, ill-treated and excluded from activities that are crucial for their development. As a result of discrimination, children with disabilities may have poor health and education outcomes; they may have low self-esteem and limited interaction with others; and they may be at higher risk for violence, abuse, neglect and exploitation (UNICEF, 2007; WHO, 2011).
The National Sample Survey (NSS) 58th round (Ashappa, 2013) reported that nearly a third of Indian children with mild disability were out of school, despite the fact that they needed no assistive device to be able to attend school. Yet, irrespective of the levels of disability - mild, moderate or severe - they rarely progress beyond the primary school level. Lack of knowledge and negative attitudes of the teachers and school authorities play a major role in this outcome.

Delay in early diagnosis, and failure to provide timely interventions, inclusive education, rehabilitation and social integration among children with developmental disabilities, are almost universal in India. A better understanding of the critical barriers in early intervention and inclusion of children with developmental disabilities as perceived by parents, doctors and teachers has been accomplished through this study. The recommendations made here can influence rehabilitation policy and practice, thereby facilitating early diagnosis, appropriate interventions and rehabilitation for these children.

Table 3: Barriers for Early Diagnosis, Rehabilitation and Social Integration for Children with Developmental Disabilities: A conceptual framework

<table>
<thead>
<tr>
<th>Contextual conditions</th>
<th>Causal conditions</th>
<th>Phenomenon</th>
<th>Action/interaction strategy</th>
<th>Consequences</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resource constrained settings</td>
<td>Lack of competency</td>
<td>Diagnostic, therapeutic and rehabilitative delay</td>
<td>Multiple doctor consultations</td>
<td>Irreversible progression of disease</td>
</tr>
<tr>
<td>Inappropriate referral</td>
<td>Inappropriate referral</td>
<td></td>
<td>Depletion of resources</td>
<td>Poor Quality of Life</td>
</tr>
<tr>
<td>Cost of treatment</td>
<td>Cost of treatment</td>
<td></td>
<td>Energy drain</td>
<td>Neglect/Abuse</td>
</tr>
<tr>
<td>Caregiver burn-out</td>
<td>Caregiver burn-out</td>
<td></td>
<td>Social withdrawal</td>
<td>Poverty</td>
</tr>
<tr>
<td>Myths and stigma in the community</td>
<td>Myths and stigma in the community</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>

| Intervening conditions | Attitude / education of parents | | |

Vol. 25, No.4, 2014; doi 10.5463/DCID.v25i4.333
Table 4: Recommendations put forward by the Stakeholders to overcome the Identified Barriers

<table>
<thead>
<tr>
<th>Key Stakeholders</th>
<th>Key Recommendations</th>
</tr>
</thead>
</table>
| Parents          | 1. Provision of a help desk or hotline for information  
                  | 2. Facilities for counselling and support for the families  
                  | 3. Services to facilitate financial as well as treatment entitlements to children with developmental disabilities |
| Doctors          | 1. Demystification of diagnosis and simplified algorithms for doctors and healthcare workers  
                  | 2. Increasing the technical pool, and short orientation courses for health personnel  
                  | 3. Publicising referral centres and establishing a systematic and organised referral system  
                  | 4. Establishing centres in all district hospitals with government providing incentives to specialists who are willing to visit and help in early diagnosis and intervention.  
                  | 5. CME programmes for doctors including communication and counselling skills |
| Teachers         | 1. Reorientation of teachers in simplified ways to manage a differently abled child at school  
                  | 2. Organising sensitisation workshops before implementation of the policy  
                  | 3. Providing support with trained manpower and disability-friendly facilities |

Limitation of the study

Though the conditions of different shanty towns and villages in South India are more or less similar, inclusion of more poor urban settlements and Taluks through the use of probability sampling methods would have increased the external validity of the study.
CONCLUSION and RECOMMENDATIONS

The study throws light on the various challenges faced by parents, doctors and teachers in dealing with children with developmental disabilities in India. It reveals that parents felt there was a delay in diagnosis, and lack of access to correct information about where to go for help. Treatment options, when available, were inaccessible and unaffordable. Myths and misconceptions about disability, added to their woes. The doctors felt their competency levels were not optimal to diagnose and manage disabilities among children. They also felt that there was insufficient information on where to refer such children. In addition, they lacked communication skills to deliver ‘bad news’ to the parents. The teachers, in general, had a negative attitude towards children with special needs. They viewed them as an additional burden and responsibility. They lacked the knowledge and skills to care for such children. They were also apprehensive about the attitudes and interactions of normal children at school with children with disability.

Primary care doctors and general practitioners need training to increase their skills and confidence. Simple algorithms to facilitate this should be made available. There is also a need for specialist services to assess and treat children with developmental disabilities. Referral centres within a district should be widely publicised and a systematic chain of referral needs to be established. All Taluk / district government hospitals should be supported by visiting specialists. Doctors need to be given special inputs on communication skills. Reorientation for teachers, enabling them to address the needs of children with disabilities, and provision of barrier-free environments at schools would help in promoting inclusive education.

ACKNOWLEDGEMENT

Baptist Global Response was the funding source for this study.

REFERENCES


Assessing Parental Role as Resource Persons in Achieving Goals of Early Detection and Intervention for Children with Hearing Impairment

Mohammad Shamim Ansari*

ABSTRACT

Early detection and intervention for any degree of hearing loss is critical to the linguistic, social and educational development of children with auditory deficit. Since parents and family members are in a position to identify hearing loss at an early stage, they can play a vital role in achieving the goals of early identification and intervention for their children.

Purpose: This study was conducted to determine the age at which parents and significant others begin to suspect hearing impairment in their children, and to advocate for using them as resource persons in the early detection of hearing loss.

Method: Parents of children with hearing impairment were retrospectively surveyed and interviewed to determine the age at which suspicion, diagnosis, fitting of amplification and initiation of interventions occurred.

Results: Interviews revealed the average age to be 16.5, 24.3, 31.7 and 33.4 months, for suspicion, diagnosis, fitting of amplification and initiation of early intervention for hearing loss respectively. The obtained age of suspicion is lower than the age of identification of hearing loss reported in Indian literature. The current study found delays in diagnosis and fitting of amplification, both of which are essential to initiate early remedial programmes which facilitate development of speech and language skills in children with hearing impairment. Surprisingly, it was found that these delays were caused by professional failures.

Conclusion: It is emphasised that parents are in the best position to detect hearing problems in their children, and can be effectively utilised as manpower/equal partners in achieving the goal of early identification of hearing loss. The study outlines appropriate ways and means to facilitate early identification and

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provide effective intervention for children with hearing impairment.

Implications: In the absence of a universal hearing screening programme for newborn infants, parents can be used as manpower/resource persons to identify children with hearing impairment.

Key words: hearing loss, early detection and intervention, diagnosis, amplification, language remedial programme.

INTRODUCTION

Hearing loss in children has a serious impact if left undetected and untreated. It leads to delayed development of speech and language skills, social and emotional problems, academic under-achievement, and interferes with quality development of the child (Markowitz & Larson, 1989; Northern & Downs, 1991; Arehart et al, 1998; Marschark, 1998; Dalzell et al, 2000; Wake et al, 2005; JCIH, 2007). With the recent advancement in rehabilitation technology, it is unnecessary for the child to suffer these consequences (Marttila & Karikoski, 2006). By detecting hearing loss as early as at the newborn stage, effective treatment which significantly reduces the disabling condition can be employed (Northern & Hayes, 1994; Carney & Moeller, 1998; Nicholas & Geers, 2006). Many research studies have demonstrated that early identification and intervention for hearing-impaired children results in improved speech and language development, communication skills, better social adaptation, enhanced academic success and increased lifetime earnings (Yoshinaga-Itano et al, 1998; Yoshinaga-Itano et al, 2000; U.S. Bureau of Census, 2000).

Unfortunately, despite the benefits of early identification and intervention, the average age at which identification of hearing loss takes place in India is rather late. A report by the Rehabilitation Council of India (2000) titled “Status of Disability in India – 2000” indicates that the average age of identification of children with severe to profound hearing loss is 5 years. Basavaraj et al (1984) reported a similar age of identification of hearing loss in Bangalore, India. This is much later than it should be for the development of communication required for linguistic, social and cognitive development in a child (Schlesinger & Acnee, 1984; Northern & Hayes, 1994; Harrison & Roush, 1996; Kittrell & Arjmand, 1997; Yoshinaga-Itano et al, 1998; Yoshinaga-Itano et al, 2000; U.S. Bureau of Census, 2000; Nicholas & Geers, 2006).
The Persons with Disabilities Act of India (Ministry of Law Justice and Company Affairs, 1996) guarantees early identification and intervention of disabilities. Inspite of this provision in the Act, it is surprising that only few sporadic programs have been implemented on this aspect. At the same time, there is insufficient manpower to support such a programme. Although professionals are essential to design and implement early identification and intervention programmes (Arehart & Yoshinaga-Itano, 1999), parental involvement in the programme is an important determinant of its success in promoting the communicative abilities of the child (Reamy & Brackett, 1999). Thus, the objective of the present study is to explore and focus on the effectiveness of parents in detecting hearing loss and providing early intervention services to facilitate better development of communication skills in young children. The hypothesis is that parents, especially the ones who are well-informed and spend quality time with their children, are in the best position to detect hearing loss and could be used as a resource to achieve the goals of early detection and intervention for infants and young children.

METHOD

Participants
The study was conducted at Ali Yavar Jung National Institute for the Hearing Handicapped (AYJNIHH) based in Mumbai, India. The parents of 110 boys and 98 girls with confirmed severe to profound hearing loss, ranging in age from 8 months to 96 months (mean age 36.1 months), participated in the study. Participants who had attended the 1-day monthly training programme during the years 2010-11 and 2011-12, were interviewed retrospectively. The programme was specially designed to educate parents of hearing-impaired children about hearing loss, assessment, prevention and management. 103 mothers and 84 fathers responded to the questionnaire.

9 parents could not answer the questionnaire because of certain constraints. Another 12 were excluded because of limited data. The majority of the participants (70%) were from the municipal limits of Mumbai city, 21% were from adjoining districts and 9% from other parts of Maharashtra state. 21% of the participants had at least primary education and 79% had education up to secondary level and above (Table 1).
Table 1: Educational Background of Respondents

<table>
<thead>
<tr>
<th></th>
<th>Average Age</th>
<th>&lt;Primary</th>
<th>Primary</th>
<th>High school</th>
<th>Pre-university</th>
<th>Under Graduate</th>
<th>Post Graduate</th>
<th>Doctorate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Father</td>
<td>39.04 yrs</td>
<td>18</td>
<td>16</td>
<td>13</td>
<td>18</td>
<td>12</td>
<td>06</td>
<td>01</td>
</tr>
<tr>
<td>Mother</td>
<td>33.16 yrs</td>
<td>20</td>
<td>23</td>
<td>33</td>
<td>21</td>
<td>05</td>
<td>01</td>
<td>00</td>
</tr>
</tbody>
</table>

Materials
A questionnaire was developed (Appendix I) to obtain information from parents and families regarding early identification and intervention for hearing loss in their children. The aim was to elicit information about the ages of suspicion, diagnosis and intervention for hearing loss, reasons for delay in diagnosis such as parental and professional failures to identify hearing loss, and reasons for delay in fitting amplification and facilitating speech and language programmes. Those who suspected hearing loss had got it diagnosed and provided intervention. The survey also contained questions about the parents’ level of education, socio-economic status, and about the professionals they had consulted for early identification and from whom they were receiving the early intervention programme. At the interview, the participants were also asked about the duration of early intervention services provided and the present status of their children.

Data Collection and Analysis
The interview survey was conducted with the help of trained volunteers, under the supervision of the author. One or both parents responded to the questionnaire. Two sittings were required as all the participants did not respond to every question at the first sitting. The obtained data was analysed using Statistical Package for Social Sciences.

RESULTS
A total of 177 questionnaires were descriptively analysed because many participants did not respond to every survey question. The results from 135 participants indicated that hearing impairment was suspected at an average age of 16.5 months (Table 2). The ones who first had doubts about the child’s hearing ability were the parents in 95 cases (70.37%), the grandparents in 20 cases (14.82%), General Physicians in 2 cases (1.48%), ENT Specialists in 8 cases (5.92%), Audiologists in 6 cases (4.44%) and Paediatricians in 4 cases (2.96%).
these 135 participants, 7(5.18%) reported that friends and others had questioned the hearing status of their children.

Table 2: Mean Ages (in months) of Suspicion of Hearing Loss by Family Members, Relatives, Professionals and Others

<table>
<thead>
<tr>
<th>Suspicion of Hearing Loss</th>
<th>Obtained Responses</th>
<th>Mean</th>
<th>Median</th>
<th>Range</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Father</td>
<td>32</td>
<td>11.1</td>
<td>10.2</td>
<td>00 - 30</td>
<td>08.79</td>
</tr>
<tr>
<td>Mother</td>
<td>63</td>
<td>12.5</td>
<td>10.0</td>
<td>00 - 18</td>
<td>09.17</td>
</tr>
<tr>
<td>Grandparents/Relatives</td>
<td>13</td>
<td>11.2</td>
<td>10.5</td>
<td>00 - 21</td>
<td>10.22</td>
</tr>
<tr>
<td>General Physician</td>
<td>02</td>
<td>28.0</td>
<td>28.0</td>
<td>00 - 25</td>
<td>17.33</td>
</tr>
<tr>
<td>ENT Specialist</td>
<td>08</td>
<td>20.3</td>
<td>19.5</td>
<td>00 - 29</td>
<td>07.43</td>
</tr>
<tr>
<td>Audiologist</td>
<td>06</td>
<td>8.7</td>
<td>7.0</td>
<td>00 - 16</td>
<td>09.19</td>
</tr>
<tr>
<td>Paediatrician</td>
<td>04</td>
<td>18.4</td>
<td>21.5</td>
<td>00 - 24</td>
<td>14.24</td>
</tr>
<tr>
<td>Friends/Others</td>
<td>07</td>
<td>22.5</td>
<td>24.2</td>
<td>00 - 39</td>
<td>11.67</td>
</tr>
<tr>
<td>Total</td>
<td>135</td>
<td>16.5</td>
<td>18.6</td>
<td>00 - 39</td>
<td>17.71</td>
</tr>
</tbody>
</table>

While 68 parents revealed that non-responsiveness to name call and environmental sounds were the primary reasons that led to suspicion, 27 parents stated that doubts had arisen due to noticing delay in speech and language as compared to the peer group, and finding their children staring at the face of the speaker. Professionals suspected hearing loss due to the presence of risk factors such as meningitis and congenital factors among 6% of the children for whom data was available. The age of suspicion (detection) in the joint family was found to be lower than in the nuclear family. Socio-economic status had no impact on the early detection of hearing loss. However, the educational background of parents and family members had a positive impact on early detection. The average age of confirmation of hearing loss was found to be 24.8 months, the age at which these children were fitted with hearing aid was 31.7 months, and initiation of language intervention programme was 33.4 months (Table 3).
Table 3: Mean Ages (in months) of Suspicion of Hearing Difficulty, Diagnosis, Fitting of Amplification and Initiation of Early Intervention Programme

<table>
<thead>
<tr>
<th>Events</th>
<th>Obtained Responses</th>
<th>Mean</th>
<th>Median</th>
<th>Range</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suspicion of Hearing Loss</td>
<td>135</td>
<td>16.5</td>
<td>13.2</td>
<td>00 - 21.2</td>
<td>9.2</td>
</tr>
<tr>
<td>Diagnosis of Hearing Loss</td>
<td>139</td>
<td>24.3</td>
<td>21.0</td>
<td>1.5 - 23.0</td>
<td>8.70</td>
</tr>
<tr>
<td>Fitting of Amplification</td>
<td>165</td>
<td>31.7</td>
<td>26.5</td>
<td>2.5 - 26.6</td>
<td>11.5</td>
</tr>
<tr>
<td>Initiation of Early Intervention</td>
<td>67</td>
<td>33.4</td>
<td>24.2</td>
<td>1.0 - 37.7</td>
<td>14.1</td>
</tr>
</tbody>
</table>

It was found that the average delay between suspicion of hearing loss and diagnosis was 7.8 months, between diagnosis and fitting of hearing aid was 4.9 months, and between diagnosis and intervention was 1.97 months (Table 4). The participants reported that 97 children (54.80%) were diagnosed with hearing impairment by an Audiologist, with 17.4 months and 26.3 months being the average age of identification and fitting of hearing aids respectively. 61 children (34.46%) were diagnosed by an ENT specialist, with 18.6 months and 22.6 months being the average age of identification and fitting of amplification respectively. The remaining 19 children (10.73%) were fitted with hearing aids by hearing aid dealers and dispensers at an average age of 33.40 months.

Table 4: Average Ages (in months) of Delay in Suspicion of Hearing Difficulty, Diagnosis, Fitting of Amplification and Initiation of early Intervention Programme

<table>
<thead>
<tr>
<th>Delay between Events</th>
<th>Obtained Responses</th>
<th>Mean</th>
<th>Median</th>
<th>Range</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Suspicion - Diagnosis</td>
<td>78</td>
<td>7.8</td>
<td>4.25</td>
<td>00 - 35</td>
<td>7.79</td>
</tr>
<tr>
<td>Suspicion - Amplification</td>
<td>102</td>
<td>10.2</td>
<td>8.75</td>
<td>00 - 31</td>
<td>8.15</td>
</tr>
<tr>
<td>Diagnosis - Amplification</td>
<td>97</td>
<td>6.3</td>
<td>5.25</td>
<td>00 - 09</td>
<td>8.21</td>
</tr>
<tr>
<td>Amplification - Intervention</td>
<td>59</td>
<td>5.7</td>
<td>3.50</td>
<td>00 - 21</td>
<td>7.13</td>
</tr>
</tbody>
</table>

95 parents reported both the ages of suspicion and confirmation of hearing loss. Of these, 67 reported a delay of about 7 months between suspicion and confirmation of hearing loss, while 28 indicated a delay of more than 7 months, with 51 months
being the longest period of delay. Among the latter group, 21 explained that professionals had advised them not to worry, to wait till the child started going to school and/or that a few children start speaking late; 5 children were categorised as hyperactive and 2 were labelled as mentally/developmentally slow. Majority of the participants were of the opinion that professionals were responsible for the delay in diagnosis and in providing and guiding them towards early intervention services. The delay between diagnosis and intervention was unreasonably long, with 5.7 months as the average.

105 parents waited for approximately 6 months to obtain hearing aids, while 17 months was the longest waiting period for those who wanted to avail of the Government of India’s subsidised scheme for aids and appliances. Those who bought the device from a hearing aid dispenser did not receive any training, as neither the Audiologist nor the hearing aid dealer had any facility for very young children and provided no information to the parents. Children from urban areas were fitted with hearing aids at a younger age as compared to children from rural areas.

At the time of the survey, 67 children were undergoing the language remedial programme. Though these children were diagnosed at the age of 17.5 months, intervention services were initiated at an average age of 28.2 months. While 23 children, a sizeable number, were attending preschool programmes at the age of 28.4 months, 17 were enrolled in Parent-Infant Programmes at an average age of 19.87 months. Speech and language pathologists at the AYJINHH centre were giving therapy to 13 children, and special educators were helping 5 children at home, at an average age of 37.2 months. 65 parents reported that their children could speak using two-word phrases, with a maximum vocabulary of 25-35 words. Majority of the children undergoing the language remedial programme came from joint families or nuclear families and had no other siblings. Those who attended the speech and language remedial programme were from better socio-economic backgrounds than the others.

DISCUSSION and CONCLUSIONS
There were encouraging results related to the ages of suspicion, diagnosis, fitting of amplification and initiation of language remedial programmes for children with severe to profound hearing loss. The current study found lower average ages of suspicion and identification of hearing loss than the figures reported in the Status of Disability in India -2000 (Rehabilitation Council of India, 2000).
The study results are consistent with the findings of Kittrell and Arjmand (1997) who reported 20.2 months as the average age of diagnosis. Arehart et al (1998) observed a similar age of identification. However, the study differs from the findings of Harrison & Roush (1996) which reported that children with a similar degree of hearing loss with risk indicators were identified at an average age of 12 months, and children with no risk indicators were diagnosed at 13 months of age. Nevertheless, with respect to delay in early intervention services, the findings of the present study are consistent with the findings of Harrison & Roush (1996) and Arehart et al (1998) which have reported delays of more than 1 year.

Early Detection, Diagnosis and Intervention for Hearing Loss

The study aimed to explore and emphasise parental contribution in the detection of hearing loss. The analysis has indicated that 68% of parents suspected hearing loss at the mean age of 12.46 months and had approached professionals for confirmation and intervention; unfortunately, the diagnosis and intervention were made available at an average age of 24.36 months and 28.36 months respectively. Reportedly, the primary reason for parents and family members to suspect hearing loss was their child’s failure to respond behaviourally to environmental sounds and name call, as well as delayed speech and language development. The parents cited several reasons for delay, the most common one being the professional’s failure to corroborate their suspicion and to give proper advice. Most of the parents were unaware that hearing loss could be identified in young children and intervention provided to them. Further, parents had visited the professionals at least 3 - 5 times before hearing loss was confirmed. This indicated that although parents were certain about their child’s problem, they had waited patiently for the professional to conduct the necessary tests to confirm and categorise the hearing loss. Thus, it can be concluded that parents are in the best position to identify hearing loss in their children, and professionals need to be more responsive to parental concerns. Also, professionals must hasten the diagnostic and intervention processes so that the gap between diagnosis and intervention is reduced. This will be of more benefit to the children.

Initiation of Language Remedial Programmes

67 children in the survey were attending language remedial programmes. The parents reported 28.36 months as the average age for initiation of intervention. The observed delay between diagnosis and intervention was unreasonably long.
(5.7 months. The shortest period that elapsed between fitting the hearing aid and the intervention programme was 2.1 months. 45% of these children were referred to early intervention programmes when they were aged between 3 to 5 months. Hence, it is reasonable to suppose that these children could be diagnosed and fitted with amplification at an earlier age if only parents and professionals had information and knowledge about developmental schedules of speech and hearing skills, the presence of risk indicators and the availability of resources and services. It has also been observed that the level of family education, socio-economic background, family size and other factors have an impact on early detection of hearing loss and provision of early interventions for young children.

Those whose children were not attending any remedial programme cited reasons such as finance, family size (having more than one child in a nuclear family) and non-availability of services near their residence.

Though the present study found that the age for early suspicion and identification of children with severe to profound hearing loss was lower than the reported ages in Indian literature, it remained very far from the optimal age essential for speech and language development, which is under 6 months, as recommended by Yoshinaga-Itano et al (1998) and Position Statement 2007: Joint Committee on Infant Hearing (JCIH, 2007). Thus, early identification and intervention for children with hearing impairment is of critical importance, and in this regard a Head Start Programme must be started, employing all available means and methods.

Considering the scarcity of professionals, the author recommends that the family, especially the parents, are in the best position to identify hearing impairment in their children and can be used as a resource.

Limitations
The study sample may not represent the overall population as the participants were educated people and the majority belonged to the metropolitan city of Mumbai. Moreover, the survey was conducted for children with severe to profound hearing loss, and listening deficiencies for this group are easily identifiable. The results may also be limited because they are based on parents’ reports of events that had occurred months and even years prior to the investigation. Furthermore, despite
being careful, the responses could have been influenced by the opinion of other parents who participated in the survey.

RECOMMENDATIONS
These suggestions are made in the absence of any dedicated national programme for identification of hearing loss. The present study reveals that about 70% of parents suspected hearing loss in young children by observing their auditory and delayed speech and language behaviour. These findings support the idea that parents are efficient and effective in observing the developmental behaviour of their children. Therefore parents, in particular those who spend quality time with children, can be utilised for the early identification and intervention programmes. Educating parents to identify the cardinal signs of hearing loss and training them in aspects of rehabilitation may help in lowering the ages of identification and can make intervention programmes more effective.

Clearly, if the goal of identifying hearing loss is to be on par with other developing countries, a nationwide awareness and educational programme for parents, caregivers and professionals must be initiated in a committed manner. To achieve this goal, the following recommendations are made:

• On discharge from the maternity home, every parent and family member should be given the developmental schedules of speech, language and hearing, along with the addresses of rehabilitation centres.

• Pamphlets describing the behaviour that signals the presence of hearing problems and the consequences of late identification should be distributed to local clinics, primary health centres and district hospitals.

• Parents, caregivers and medical professionals should be educated to spot behaviour that identifies hearing loss. Parental education and participation may help in lowering the early ages of identification and can facilitate intervention programmes.

• Representations about the need and procedures for early identification of hearing loss should be made at professional meetings of family doctors, Paediatricians, and ENT specialists.
• Orientation programmes should be organised to update the high-risk register for hearing disability and to expose primary and child healthcare professionals to use developmental screening tools to detect the disability.

• Most importantly, in the absence of trained professionals and appropriate laws, many people who lack essential knowledge and skill and are involved in providing services to hearing-impaired children, should be given the necessary training to meet the needs of the population under discussion.

In view of the study findings, the author believes that at present it is best to involve parents in the rehabilitation processes for children with hearing impairment.

ACKNOWLEDGEMENT
The author would like to thank Professor R Rangasayee, Director of AYJNIHH, Mumbai, for his constant support and encouragement, as well as Chandrakas Chandanshieve for his suggestions and feedback regarding this article. The author is also very grateful to all those who participated in the study.

REFERENCES


APPENDIX

Assessing Parental Roles as Resource Persons in achieving Goals of Early Detection and Intervention for Children with Hearing Impairment

QUESTIONNAIRE FOR PARENTS

NAME: ____________________________________ AGE/SEX: ____________________
ADDRESS: ________________________________CONTACT NO: _______________

1. Could you please provide the following information?

<table>
<thead>
<tr>
<th></th>
<th>FATHER</th>
<th>MOTHER</th>
</tr>
</thead>
<tbody>
<tr>
<td>NAME</td>
<td></td>
<td></td>
</tr>
<tr>
<td>AGE/SEX</td>
<td></td>
<td></td>
</tr>
<tr>
<td>EDUCATION</td>
<td></td>
<td></td>
</tr>
<tr>
<td>OCCUPATION</td>
<td></td>
<td></td>
</tr>
<tr>
<td>INCOME</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. What is the age and sex of your child?

   Male/Female
   Age_____years ____months

3. Who suspected the hearing difficulty in your child?

   Father/ Mother/ Grandparents/ Relatives/ Others

4. How many hearing-impaired children have you?

5. What is the hierarchy of your hearing-impaired child among your children?

6. How old was the child when you suspected the hearing loss?

   1st child_________
2nd child__________ (Please mention the age of the child).

7. Who identified hearing loss in your child?
   Father/ Mother/ Grandparents/ Relatives/ Friends/Others/
   General Physician/ ENT/ Paediatrician/ Audiologist

8. What made you suspect the hearing difficulty in your child?
   - Child was not responding whenever called
   - Child was not developing speech and language
   - Any other

9. Whom did you consult about the hearing difficulty of your child?
   - GENERAL PHYSICIAN
   - ENT
   - PAEDIATRICIAN
   - AUDIOLOGIST
   - ANY OTHER

10. What did your consultant say about your child’s hearing and about your suspicion?

11. At what age and who confirmed the hearing loss of your child?

12. Do you think that the consultant delayed in confirming the hearing loss in your child? Yes/No

13. What is the degree of hearing loss in each ear of your child?
   Right Ear _______dBHL  Left Ear _______dBHL

14. At what age was the child fitted with hearing aid?

15. Is your child attending any language remedial programme? Yes/No

16. What type of language remedial programme is your child receiving and where?
   - Parent – Infant Programme
- Preschool Programme
- Speech and Language Therapy

17. Since how long has your child been receiving a language remedial programme?
   Please mention in months.

18. Who is providing the Speech and Language Therapy Programme to the child?
   - Speech and Language Pathologist.
   - Special educator
   - Any other

19. What is his/her present status?
   - Does not speak at all
   - Speaks a few words
   - Speaks in phrases/sentences

20. Do you think that your child could have made more progress if he could have been identified with hearing loss earlier and have been fitted with hearing aid along with speech and language training?
Disability Inclusion in Primary Health Care in Nepal: An Explorative Study of Perceived Barriers to Access Governmental Health Services

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1. Radboud University, the Netherlands
2. Enablement, the Netherlands
3. Bikash, Nepal

ABSTRACT

Purpose: Persons with disabilities face additional barriers in accessing primary healthcare services, especially in developing countries. Consequently, the prevalence of secondary health conditions is higher among this population. This study aims to explore the perceived barriers to access primary healthcare services by persons with disabilities in the Western region of Nepal.

Methods: 10 primary healthcare providers and 11 persons with disabilities (physically or visually impaired) were selected by non-governmental organisations from the hilly and lower areas. Based on the International Classification of Functioning and the health accessibility model of Institute of Medicine, semi-structured interviews were conducted and analysed using analytical induction.

Results: In general, healthcare providers and persons with disabilities reported similar barriers. Transportation and the attitude of family members and the community were the main environmental barriers. Even with assistive devices, people still depend on their families. Financial barriers were lack of funds for health expenses, problems in generating an income by persons with disabilities themselves, and the low socio-economic status of their families. Personal barriers, which affect help-seeking behaviour in a major way, were most often mentioned in relation to financial and socio-environmental barriers. Low self-esteem of the person with disability determines the family’s attitude and the motivation to seek out healthcare. Lastly, poor public awareness about the needs of persons with disabilities was reported.

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Conclusions: Besides the known physical environmental barriers, this study found several environmental, financial and personal barriers that also affect access to primary healthcare. In particular, the attitudes of families and poor financial conditions seem to be interrelated and greatly influence help-seeking behaviour.

Implications: There is a definite need to educate primary healthcare providers who work at the community level about disability-related health conditions, and train them to diminish barriers to access health services. In addition, the government support system for persons with disabilities should be revised and implemented accordingly. Lastly, further research is needed to understand the interaction between the reported barriers that influence the inclusion of persons with disabilities in healthcare.

Key words: persons with disabilities, accessibility, barriers, primary healthcare

INTRODUCTION

Compared to persons without disabilities, persons with disabilities face additional barriers in accessing primary healthcare services and health promotion activities (Beatty & Dhont, 2001; Beatty et al, 2003; World Health Organisation, 2011). Research shows that persons with disabilities have greater medical vulnerability and a higher prevalence of secondary health conditions than the general population (Kinne et al, 2004; Drainoniet al, 2006; Trani et al, 2011). Therefore, access to primary healthcare services is even more important to persons with disabilities.

Persons with disabilities develop similar health problems as the general population (World Health Organisation, 2011). However, misconceptions about the health of persons with disabilities exist, and lead to the assumption that they do not require equal access to health promotion and disease prevention (World Health Organisation, 2011). Even in countries where resources and knowledge about inclusion and accessibility are available, persons with disabilities encounter barriers to use primary healthcare services. A study by Stillman et al (2014) found that persons with physical impairments receive fewer preventive interventions and health assessments in primary healthcare centres than able-bodied persons. As a result, persons with disabilities tend to underutilise preventive healthcare services (Drainoni et al, 2006; Trani et al, 2011). This leads to neglect of preventable diseases (Ormond et al, 2003; Drainoni et al, 2006; Tomlinson et al, 2009).
Situation in Nepal
The health status in Nepal is poor due to the high prevalence of preventable infectious diseases, caused by poor sanitation, malnutrition, illiteracy, poor access to clean water and poor quality of healthcare (Zaidi et al, 2004). Low utilisation of healthcare services by the general population could be due to distance, lack of medicines, unavailability of staff, lack of finances and opening hours of the facility (Yadav, 2010; Paudel et al, 2012).

Inclusion of Persons with Disabilities
Disability inclusion is a construct that was initially developed in the educational sector. Inclusion is based on the social model of disability (Shakespeare, 2002), which uses human rights as a starting point to explain disability. Persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability (United Nations, 2012). Possible perceived barriers that might hinder this right to inclusion in primary healthcare include environmental, financial and personal challenges. On all levels, those barriers might lead to social exclusion and prevent the process of inclusion (Nuwagaba et al, 2012).

Objective
The aim of this study is to gain a better understanding of the perceived barriers faced by persons with disabilities in accessing primary healthcare services in Nepal. The study also explores environmental, financial and personal barriers from the perspectives of primary healthcare providers and persons with disabilities.

METHOD

Setting and Study Design
This qualitative study was conducted in both the lower (Terai) and the hilly areas of Nepal, namely Rupandehi district and Tanahun district respectively.

Sampling
Participants were recruited with the help of non-governmental organisations working in these geographical areas. The method of purposive sampling (Boeije,
2006) was used to select primary healthcare providers from several health posts within the district, and persons with a physical or visual disability living in the same area.

Participants
Twenty-one (21) participants were recruited from the two target groups - 9 healthcare providers working in primary healthcare and 11 persons with disabilities, all living or working in Rupandehi district (lower area) and Tanahun district (hilly area). One president of a Disabled People’s Organisation (DPO) was also included.

Inclusion criteria were as follows:

- For the healthcare providers - either the manager of the sub-health post (SHP) or health post (HP) - also referred to as health facility- or one of the staff members. These participants would have had at least 1 year of experience in this health post and a minimal education level of CMA (Community Medical Auxiliary: a diploma in primary healthcare).

- For the persons with disabilities –those with either a visual impairment or a physical impairment, who were consequently faced with mobility challenges due to their inability to see or who had walking difficulties or were using an assistive device (wheelchair, prosthesis, crutches or walker). The participants would have to be at least 18 years old and living at home.

Data Collection
Semi-structured interviews were used. Interviews were conducted by the researcher (not a native Nepali-speaker) and a local Nepali interpreter. The interpreter had a public health background and was trained extensively. Interviews were conducted at the work stations of healthcare providers and at the homes of persons with disabilities.

Instrument
A topic list was developed based on a healthcare model to identify barriers and the International Classification of Functioning, Disability and Health (ICF), a classification of health and health-related domains (World Health Organisation, 2001). As functioning and disability are related to the person in a context, ICF also includes a list of personal and environmental factors. Those factors are used
as categories to classify possible barriers. The Institute of Medicine or IOM (1993) sets forth a conceptual framework for classifying perceived barriers to access healthcare services, that is useful for thinking about functional limitations and their relationship to such barriers. The IOM framework identified three broad categories of barriers: structural, financial, and personal/cultural, of which financial barriers are separately mentioned, unlike the ICF model. Since this framework provides items for financial barriers and the study takes place in a developing context where financial resources are often limited, it was decided to use this category as an addition to the framework of the ICF. Thereafter, a meeting between the researcher and disability experts took place to examine the topic list on its feasibility for the Nepalese setting. The topic list was adapted during data collection and analysis, while comparing the answers of participants with the original theoretical framework.

Environmental barriers are defined as impediments to healthcare services, which directly relate to availability, concentration, location, or organisational configuration of healthcare services and the physical environment. The social environment around the person with a disability is also incorporated. As described in other studies, attitudes, local stigmatisation and misconceptions of persons with disabilities (Noseket al, 1995; Nakabuye et al, 2006) influence help-seeking behaviour.

Financial barriers may restrict access by inhibiting the ability of persons to pay for needed healthcare services or transportation. There is a bi-directional link between poverty and disability (Ghai, 2009; Sen, 2009). According to Peters et al (2008) and Yeo (2001) poverty may increase the likelihood of disability for a person with an existing health condition. Once a person has a disability, he/she faces increased barriers to accessing healthcare services, education, employment, and other public services.

Lastly, personal barriers may inhibit persons with disabilities from seeking medical attention (IOM, 1993). The Health Belief Model and Hidden Distress of Stigma Model were used to elaborate health beliefs and stigmatisation (Scambler, 1998; Abraham & Sheeren, 2005).

Data Analysis
The procedure of analytical induction was used during data analysis (Boeije, 2006). The code tree with codes, categories and themes is presented in the Appendix.
Ethical Considerations
Approval for the study was given by NHRC before the start of data collection. Every participant was asked to give informed consent, with a letter written in Nepali. Participants were not given any incentive to take part in the research.

RESULTS
The perceived barriers of both groups will be presented separately, to show reports from two different perspectives. Differences in reports are presented in Table 1.

Table 1: Major differences in the reports of Healthcare Providers and Persons with Disabilities

<table>
<thead>
<tr>
<th><strong>Transportation</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare providers think that giving out wheelchairs helps persons with disabilities to visit the health post. Persons with disabilities report that even with a wheelchair they still depend upon others to visit the governmental health facility.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Quality of care</strong></th>
</tr>
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<tbody>
<tr>
<td>Healthcare providers mention they need more specialised knowledge about disabilities.</td>
</tr>
<tr>
<td>Persons with disabilities do not mention this as a reason not to visit the centre; they mention more basic needs that are lacking in the health centre; lack of staff, lack of variance in medicine, getting low doses of medicine compared to the private services, and no positive experiences in the past.</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th><strong>Stigma by family and community</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Healthcare providers report a high level of stigmatising behaviour of both family members and community members.</td>
</tr>
<tr>
<td>Persons with disabilities, who are interviewed in their homes, report positive attitude of their close neighbours and family members in helping them with practical tasks around the house.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>Public awareness on disability</strong></th>
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<tbody>
<tr>
<td>All healthcare providers opt for more public awareness on disability issues.</td>
</tr>
<tr>
<td>The participants with disabilities who were higher educated also mentioned the need for more public awareness activities; the participants with lower education levels did not report this.</td>
</tr>
</tbody>
</table>
Financial situation

Both groups agree this barrier is one of the major ones. They all agree on the dependence of persons with disability on their family and their financial situation. There were different reports about the governmental support system which implies a lack of transparency of this system.

Self-stigma by persons with disabilities

Healthcare providers all report hesitation and shame on the part of the person with disability to move outside. Responses of the society are reported as the reason. Persons with disabilities report that their hesitation is based on the responses of healthcare providers and inconvenient situations (for example, incontinence).

Barriers perceived by Healthcare Providers

1. Environmental barriers

   a) Transportation

   Bus transportation was only used when the health facility was near the main road. Healthcare providers reported both discriminatory and helpful behaviour of bus personnel. For example, some bus drivers do not stop for persons with disability; however, they sometimes offer a seat or help to carry these people into the bus. Distance is a great barrier; hence persons with disabilities and caregivers prefer to visit the medical shop which is closer. All healthcare providers stated that family members prefer to visit the health facility on behalf of the person with disability, since it is a burden for them to carry the person. Even when they are given a wheelchair, persons with disabilities totally depend on their family members to visit the health facility.

   b) Physical environment

   The road condition was cited as a barrier in the hilly area, especially during the rainy season. All healthcare providers, from both the lower and the hilly areas, mentioned that the health facilities are not disability-friendly, in terms of the path leading to the building, ramps, and accessible treatment room and mobility devices. They are willing to treat the persons with disabilities outside; however, privacy is a problem.
c) Quality of care

Healthcare providers reported that persons with disabilities prefer other health facilities like medical shops and the hospitals in the cities. The reasons they mentioned were the unavailability of the health worker and their own limited knowledge about disability-specific conditions. They also reported that other healthcare providers used the health facility for private business and that people in the community believed that the variety and dosage of medicines given were better in the medical shop (privately owned by a healthcare provider).

d) Community-based health services

In the hilly area, community health workers conducted home visits, which seemed more urgent due to the topographic condition. These community health workers live closer to the community and assist the health worker at the health facility.

e) Social environment (family and community)

Most healthcare providers reported that stigmatising behaviour of the family and community was a barrier for persons with disabilities who seek health care. The families’ busy schedules, money problems and poor awareness of the needs of persons with disabilities were responsible for the delay or denied them the opportunity to seek out health care. Although this barrier was mentioned, healthcare providers also reported a general improvement in the stigmatising behaviour of the family and the community.

2. Financial barriers

All healthcare providers clearly cited the poor financial condition of persons with disabilities as the major barrier to their use of healthcare facilities, both for primary and secondary/tertiary care.

“The first reason for not coming to the health post is the lack of money. And for using secondary health care facilities, money is already finished. So they don’t go for further treatment due to the financial barrier” - Healthcare provider.

Healthcare providers reported that because persons with disabilities were unemployed, they lacked financial resources to take care of their own health. They also mentioned there was a poor grading system to determine levels of disability that would entitle one to receive a disability card and subsequent
benefits. It was pointed out that the money did not always reach the beneficiaries, but might remain with the village development committee or with the family.

3. Personal barriers

a) Knowledge

Most healthcare providers reported that they wanted more training on disability-related issues. The majority of them mentioned the importance of health education to increase knowledge about general public health issues among persons with disabilities.

“Being a health worker, I give health education and refer them for tertiary treatment. I used to provide public awareness and also suggest family members not to hate the disabled persons”- Healthcare provider.

b) Communication

Healthcare providers reported difficulties in communicating with persons with disabilities, especially with those who were not able to hear and speak. They also indicated that persons with disabilities who were able to speak hesitated to tell the health worker their problems, and preferred to ask their caregivers to report their health complaints.

d) Health beliefs

All healthcare providers perceived that people with disabilities were more susceptible to infectious diseases, diarrhoea, hits/bruises, malnutrition, skin diseases and other conditions.

e) Self-stigma by persons with disabilities

The behaviour of persons with disabilities themselves was also reported as a barrier to seeking healthcare services. According to healthcare providers, persons with disabilities hesitate to go outside and face the community. It was reported that these people had low self-esteem and would not speak out and explain their problems to the health worker at the health facility.

4. Additional theme

a) Public awareness of disability

In both topographic areas, healthcare providers reported the lack of general public awareness of disability as a barrier to the use of health services by persons with disabilities.
Barriers perceived by Persons with Disabilities

1. Environmental barriers

a) Transportation

By and large, persons with disabilities reported about their dependence on others when visiting the health facility. The main reasons for the visually impaired were the unfamiliar environment, and for physically impaired wheelchair users the long distances and bad roads. A wheelchair would make them independent only if their houses and the health facility were near a paved road; otherwise, the wheelchair made it easier for family members to transport them. Distance was another barrier; therefore, persons with disabilities preferred the medical shop or asked family members to collect their medicine. Public transportation was perceived as a barrier because bus personnel would not stop for them, as persons with disabilities do not have to pay bus fare and consequently, privately owned bus companies cannot make a profit.

b) Physical environment of health facility

Only a few persons with disabilities reported that the health facilities were not built in a disability-friendly way. Instead, the indoor facilities to transfer themselves and positioning for physical examination were mentioned as a barrier. In general, this was not perceived as a major barrier.

c) Quality of care

Persons with disabilities reported the unavailability of the medicines they specifically needed at the governmental health facility. Also, in the private medical shop they received a higher dosage of medicine, which cured their illness faster. Furthermore, they felt they were treated better by the health worker in the private facility, because they paid for the service.

d) Social environment (family and community)

Persons with disabilities did not report bad attitudes of the family and community. On the other hand, when people understood their position and condition, there was love and affection. Family members hesitated to take the person with disability to the health facility only due to their busy time schedules.
2. Financial barriers
Most persons with disabilities reported that a major barrier in seeking health care was their limited financial resources. Participants who did not generate income indicated that they had to rely on assistance provided by the community, on receiving gifts of money, or had to offer to pay in instalments. Moreover, minimal financial support from the government and the non-transparency of policies about the disability fund were a major concern.

“My husband refused to take me to the Village development committee to take the disability fund. He used to tell me, your fund is being eaten by some of the persons”- Person with disability.

Few participants utilise the discounts provided for use of public transport services. This was largely attributed to lack of awareness of the discounts and lack of policy implementation.

3. Personal barriers
a) Health beliefs
Persons with disabilities reported their traditional health beliefs which were related to bad spirits, God’s protection and the role of faith healers. The tendency was to first visit the traditional healer, and thereafter visit the health facility when they were not cured. In general, knowledge about hygiene, healthy food and general check-ups appeared to be connected with the educational level of the person. Also, bad experiences at a particular health facility would make a person hesitate to go there again.

b) Self-stigma by persons with disabilities
Persons with disabilities mentioned that anticipating possible negative reactions of others created fear of moving about outside, though they did not hesitate to move around in their own familiar neighbourhood. They reported self-blame and guilt about being a burden to their family.

“I don’t want them to carry me. I don’t want to give them more burden, this is the same for moving me to the health facility”- Person with disability.

Barriers perceived by the Disabled Persons’ Organisation (DPO)
The chairperson of one DPO was interviewed, and reported about their public awareness activities which were also focussed on the local government. According
to this chairperson, the three major barriers are transportation, financial resources and attitude of family members. In general, awareness of disability-related issues is improving in the community. However, the behaviour of the community and family members towards persons with disabilities continues to be discriminative.

Persons with disabilities are invited to meetings of the DPO. However, those who are not able to reach the place where the meeting is held do lack knowledge and empowerment skills.

The chairperson underlined the importance of the governmental support system (disability card) and advocated for free services up to secondary healthcare level.

**Severity and Relationship between Perceived Barriers**

Most participants mentioned barriers according to the order of severity and how those barriers were interrelated. A schematic overview of all barriers, in terms of importance and their relationships, is presented in Figure 1.

**Figure 1: Overview of Barriers and their Relationships**

Pwds = persons with disabilities
DISCUSSION

Among the environmental barriers, transportation and social environment are the most prominent ones. Many persons with disabilities do not reach the health facility. Transportation in Nepal is generally challenging due to bad road conditions, long distances to main roads and the rainy season. In line with other studies in Nepal and other developing countries, distance was found to be a barrier to access public services, for both persons with and without disabilities (Yadav, 2010; Nuwagaba et al, 2012; Paudel et al, 2012). Healthcare providers believe that wheelchairs would diminish the transportation barrier, while persons with disabilities report that having a wheelchair does not mean there is no transportation barrier (Scovil et al, 2012).

The other major environmental barrier was the stigmatising behaviour of the family and community (enacted stigma) (Scambler, 1998). This barrier seemed strongly related to transportation and, even more, to financial barriers. Since persons with disabilities travel with their family members, these family members are also exposed to the community. They try to hide the disability from the community due to enacted (social) stigma (Weiss et al, 2006). Concerning the financial barrier, persons with disabilities generally are highly dependent on their relatives for transport and money (Gautam, 2009; Wasti et al, 2012).

When further treatment is required (secondary health services which are not free of cost), the chief barrier is limited financial resources. Money needed to pay health services directly is defined as out-of-pocket payment and does not provide any financial protection, as for example with a health insurance, which increases the risk of poverty (Peters et al, 2008). In addition, persons without disability often do not recognise that persons with disabilities can make positive and meaningful contributions to the economy and the society (Mosharaff, 2004), resulting in a low rate of income generation among persons with disabilities (Nuwagaba et al, 2012). Participants reported varied information about the government support system.

Healthcare providers reported that more specific knowledge about prevention and treatment of secondary conditions, communication with persons with disability, and knowledge of rehabilitation treatment and referral systems were needed, as found in another study (Berry et al, 2009). The need to provide optimum healthcare for persons with disabilities was confirmed in other studies (Lightfoot, 2003; Drainoni et al, 2006; Francis & Adams, 2010). Also, considering
that persons with disabilities have a higher susceptibility to infectious diseases and secondary conditions, health promotion activities should be inclusive of them (Kinne et al, 2004; Parish & Huh, 2006).

With regard to personal barriers, persons with disabilities hesitate to seek healthcare and to ask their relatives for support. They have negative perceptions about themselves (felt stigma). As reported by Steward et al (2008), enacted stigma (by family or community) highly influences felt stigma. Moreover, felt stigma seems to provoke a negative attitude towards help-seeking behaviour (Wrigley et al, 2005), which implies that persons who are stigmatised and who also feel stigmatised will be less likely to seek healthcare.

**CONCLUSION**

This study gives a comprehensive picture of perceived barriers that affect the access to primary healthcare services for persons with disabilities in Nepal. Healthcare providers and persons with disabilities showed similar perceptions about most barriers, which implies that the problem is understood well. In addition to well-known environmental barriers like lack of transportation, long distances and the poor quality of care, this study found the following barriers which largely affect the access to care:

- Social environment and the dependence upon others to visit the health facility;
- Stigma by the family and the community – refusal to take the person to the health facility and not providing support for transportation or health expenses;
- Out-of-pocket payment;
- Lack of income;
- A poor disability grading system to obtain government support;
- Lack of awareness or incorrect information about government support systems;
- Self-stigma which has an effect on help-seeking behaviour;
- Lack of public awareness about disability, which influences social participation.
The financial barriers and attitude of the family seem interrelated. The impact of one barrier on other barriers and help-seeking behaviour seems far-reaching and complex.

**IMPLICATIONS**

The lack of knowledge about the prevention and treatment of secondary conditions and general health problems faced by persons with disabilities shows that there is a great need for training government primary healthcare providers. Training should also be provided to general healthcare organisations, especially in government facilities. Findings of this study can be used to create awareness about barriers faced by persons with disabilities. Beneficiaries of training should be primary healthcare providers who work at the community health facility and community health workers who come across many people within the community. With well-trained health personnel, the Nepalese government could work on the right to the enjoyment of the highest attainable standard of health (Article 25) and providing training for stakeholders on accessibility issues (Article 9), as stated in the UN Convention on Rights of Persons with Disabilities, signed by Nepal in 2008 (United Nations, 2012).

In the light of the poor social security system for persons with disabilities in Nepal, the first recommendation is to revise the disability grading system and train the medical officers who allocate grades to individuals with disability. The system should also ensure that the funds reach the beneficiaries. Second, reorganising healthcare facilities to be inclusive will require inputs from those who are familiar with, and affected by, current barriers. If healthcare providers and persons with disabilities are involved in the planning and decision-making process, then the system will be more responsive. As a result, persons with disabilities will be more likely to access and utilise health services, leading to better health outcomes.

Social initiatives such as income generation and health education activities should be inclusive for persons with disabilities and their families, so as to reduce stigmatisation and increase help-seeking behaviour. This could be done by disabled persons’ organisations, healthcare providers and non-governmental organisations, by including persons with disabilities in their mainstream programmes. Current initiatives to improve societal attitudes should be encouraged to enhance social participation.
Limitations

Though this study was carefully designed and conducted, there were some limitations. Interviews with persons with disabilities were conducted in their home environment. It was culturally and practically not possible to create an environment with total privacy and separate from family members. Therefore, a response bias may have influenced the reports by persons with disabilities, especially regarding the attitude of their family members. This could explain the differences in reports, presented in Table 1. Due to limitations in time and availability of interpreters, the data was translated and coded by one researcher and one interpreter. The analysis of the interviews was not double-checked. Lastly, the conclusions are based on a small group of participants, especially the group of persons with disabilities among whom a wide variety of disabilities is not represented.

This study explored a broad range of barriers to access healthcare. The relationship between barriers was greatly emphasised by the participants. Further research on those relationships and their in-depth systems is needed to enhance effective access to primary healthcare.

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The authors declare that they have no competing interests.

REFERENCES


Appendix

**Code tree barriers to use Primary Health Care**

<table>
<thead>
<tr>
<th>Barriers General</th>
<th>Category</th>
<th>Public awareness of disability and health</th>
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<tbody>
<tr>
<td>Environmental</td>
<td>Transportation</td>
<td>Using devices</td>
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<td>Using bus (getting inside- seat- ask bus to stop)</td>
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<td>Family member gets medicine</td>
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<td>Physical environment</td>
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<td>Distance</td>
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<td>Quality of care</td>
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<td>Geography of area</td>
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<td>Disability-friendly environment</td>
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<td>Community- based services</td>
<td>Better treatment non-government</td>
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<td>Continuity and monitoring of health post</td>
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<td>Care capacity of health facility</td>
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<td>Financial</td>
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<td>Benefits, costs. social involvement</td>
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<td>Money generation and management</td>
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<td>Paying for services by loan</td>
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<td>Personal/ Cultural</td>
<td>Knowledge</td>
<td>Awareness of health facility</td>
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<td>Receiving/giving health education</td>
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<td>Health beliefs</td>
<td>Spiritual beliefs and treatment</td>
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<td>Severity of illness</td>
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<td>Busy schedule family</td>
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<td>Expression of the problem by person with disability</td>
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<td>Raising voice and self-confidence</td>
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<td>Demographic</td>
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<td>Educational level</td>
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<td>Living situation</td>
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<td>Time constraint health care provider</td>
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<td>Priority order and attention</td>
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<td>Behaviour of hcp</td>
<td>Knowledge of health care provider</td>
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Knowledge and Beliefs about Ear and Hearing Health Among Mothers of Young Children in a Rural Community in South India

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ABSTRACT

**Purpose:** To study the knowledge and beliefs about ear and hearing healthcare among mothers from a rural community.

**Method:** In 1 week, 6 focus group discussions were conducted across 6 villages of a district in Tamil Nadu in southern India. The participants were 60 mothers who had children below 5 years of age.

**Results:** Mothers in this rural community had information about some aspects of ear and hearing healthcare. They were aware that use of hairpins and safety-pins to clean ears was harmful; they were knowledgeable about ways to identify hearing ability (child responds to name call, verbal instructions, and startles at loud sounds); and, conditions like consanguinity and malnutrition of expectant mothers were recognised as risk factors for hearing loss. However, misconceptions also existed. The practice of pouring herbal juices to remove insects in the ear continued; there was the perception that all children with a hearing problem were “deaf”, and a lack of awareness about the possibility of partial/unilateral hearing loss. Regarding the age of identification, mothers believed that a child’s ability to speak and the ability to hear was pertinent to assess hearing. None of the mothers related normal speech development to normal hearing.

**Conclusion:** For the success of a community-based hearing screening programme, it is important to utilise the existing knowledge of the mothers, and simultaneously attempt to fill in gaps in knowledge and clarify misconceptions. These measures will facilitate greater compliance from the community in

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achieving the goals of early identification and early intervention for problems of hearing loss.

**Key words:** rural community, knowledge and belief, ear and hearing

**INTRODUCTION**

Poverty, ignorance, poor hygiene, inadequate medical guidance, and customs and beliefs based on tradition and culture are reported to be reasons for poor health awareness (Kumar, 1997). Having appropriate health-related information ensures that people are better equipped to access services (WHO, 2010). Hence, lack of health awareness results in poor primary and secondary prevention of diseases or health conditions. This lack of awareness also extends to the area of ear and hearing healthcare. Attempts have been made to create awareness about hearing loss and ear care through information, education and communication strategies using health personnel and grassroot workers using local, culture-specific innovative strategies (Garg et al, 2009).

With the aim of preventing avoidable hearing loss (primary prevention), early identification and treatment of ear problems, and rehabilitation of persons with hearing impairment, the Government of India initiated the National Programme for Prevention and Control of Deafness (NPPCD) and integrated it with National Rural Health Mission (NRHM) at the state and district levels. In line with such efforts, the Department of Speech, Language and Hearing Sciences at Sri Ramachandra University proposed a rural community-based hearing screening programme for infants and young children, with the focus on newborns, in Thirukazhukunram and Madhurantagam blocks of Kancheepuram district in Tamil Nadu in southern India. During this programme, trained Village Health Workers (VHWs) conducted hearing screening using Oto Acoustic Emission equipment on a door-to-door basis in the villages. For those children advised to be ‘referred’ after screening, telehealth technology with Auditory Brainstem Responses was used to conduct diagnostic testing.

The key to the success of a community-based programme lies in the developmental spirit of ‘fact-finding’ and ‘learning lessons for improvement’ from the grass root (Garg & Laskar, 2010). Although measures have been initiated to improve ear and hearing care at the community level, the goals will be achieved only when programmes implemented at the grassroots level relate to the region, community, or even the family. For example, Scheppers et al (2006) who reviewed studies on
ethnic minorities conducted in different countries, reported low use of screening health services among them due to lack of awareness. Strong local beliefs and traditional health practices in the community, such as “health problems are caused by natural and supernatural causes” or “a result of the act of God”, deter people from availing healthcare services (Scheppers et al, 2006). Studies in South Africa by various researchers such as Olusanya (2000), de Andrade and Ross (2005) and Swanepoel and Almec (2008), note that poor public awareness regarding childhood disabilities is often aggravated by superstitious customs and beliefs. Lack of knowledge among programme planners about these local customs and beliefs can impact the use of healthcare services in the community.

The purpose of the present study was to gain insight into the knowledge and beliefs of the community regarding ear and hearing. Specifically, the researchers wanted to find out whether the community was aware that hearing could be tested/screened as early as at birth; when they first suspected hearing loss and whether they knew the consequences of unidentified and untreated hearing loss; also, whether there were any culture-based beliefs that deterred the community from availing screening services.

It was considered necessary to obtain this information prior to the initiation of the rural community-based hearing screening programme in order to incorporate appropriate messages for the VHWs to convey: a) during sensitisation programmes carried out before screening, and b) after screening, as a part of the counselling for parents /caregivers. Such measures are expected to improve compliance for availing of the hearing screening service in the village. The mothers were the target group to obtain this information, as they represent the specific population for whom the screening programme is designed. Compliance for hearing screening has been reported to increase when the mothers were educated on infant hearing loss and its consequences (Francozo et al, 2007).

This study was approved by the Institutional Ethics Committee. Participants were included after obtaining their informed consent.

**METHOD**

**Location**

The study was conducted in 6 randomly sampled villages from Thirukazhukunram and Madurantagam, 2 blocks of Kancheepuram district in Tamil
Nadu, India. Kancheepuram district is located on the northern East Coast of Tamil Nadu. The population of Thirukazhukunram and Madurantagam is approximately 39,000 and 41,000 respectively.

Participants
The 60 women participants included mothers of children between 0-5 years of age who were residents of the rural area under study. None of them had family members with congenital hearing loss. The average age of the mothers was 28.73 years (SD= 5.12) and 73% had children under 2 years of age. All the mothers were fluent in Tamil, the local language. All of them had some level of education, but only 4% had completed an undergraduate Degree. The annual income of 93% of these mothers was less than Rs. 20,000.

Developing Focus Group Guides
To facilitate the focus group sessions and lead the discussions, the investigator developed guides in Tamil. Literature reviews were conducted, using databases such as Medline, Pubmed, and EBSCO, employing the key words ‘parent and caregiver’, ‘knowledge and belief’, and ‘ear and hearing healthcare’. Literature search was conducted in the areas of: i) ear care, ii) assessment of hearing ability, iii) risk factors for hearing loss, iv) consequences of hearing loss, and v) professionals and services for persons with hearing loss. Expert opinions of people working in the area of hearing healthcare and the inputs of VHWs working in the area of community health were also included while developing the guides. Two pilot studies were conducted to assess appropriateness of the guides in promoting participation and discussion.

Based on the pilot studies, minor changes were incorporated and a final set of guides to lead the FGDs was developed. Guides used under each heading are provided in Appendix I. They have been translated from Tamil to English for the purpose of this publication.

Execution of Focus Group Sessions
FGDs were conducted with the assistance of the VHWs, who identified the venue for the sessions and communicated information about the time and place to the participants. FGDs were conducted at a residence accessible to all the participants. Each FGD included: 1) participants, 2) principal moderator (audiologist) to
initiate and guide the discussion, 3) facilitator (VHW) to assist the moderator in the discussion, and 4) observer (VHW) to take notes. Each session was audio-recorded using 2 digital voice recorders (Sony IC recorder ICD-UX70 and Cenix VR-P2340 voice recorder). The duration of each session ranged from 45 minutes to one hour.

Data Analysis
The recorded data was analysed and written transcriptions were developed. The observer’s notes were referred to for clarifications. The transcriptions were verified by another audiologist (co-investigator). The transcribed data was reviewed to identify 3 themes: correct knowledge, gaps in knowledge and misconceptions. Themes were analysed under the broad areas of: 1) ear care, 2) identification of hearing status in children, 3) age at which hearing can be assessed, 4) risk factors for hearing loss, 5) consequences of hearing loss, and 6) professionals and services available for children with hearing impairment. Both word coding and thematic analysis were done. Thematic analysis carried out by the principal investigator was verified by both co-investigators. The responses are reported using the descriptive summary method. To understand the responses better, verbatim transcripts of a few participants are quoted as examples.

RESULTS
Results are reported according to the broad areas under which FGDs were conducted. Quantifiers used to describe the results are: ‘All’ for 100%, ‘Majority’ for more than 50%, ‘Many’ for more than 20% but less than or equal to 50%, ‘Some’ for more than 10% but less than or equal to 20%, and ‘Few’ for less than or equal to 10%.

1. Ear Care
All the mothers believed that ears should be kept clean. Many used either ear buds or cloth to clean ears. They were aware that foreign objects (insects, sticks, grains) could enter the child’s ear and had approached medical professionals for help in such cases. Some reported that insects were removed using traditional home remedies such as pouring warm water, saline water, and herbal juice into the ear.
“If there is any dirt inside the ears, we don’t put anything else because it might damage the ears. So we take it out using ear buds” (FGD 5 - participant 8).

“Sometimes we pour salt water inside the ear. If there is any insect gone inside, that is how we take it. Otherwise we take the child to the doctor” (FGD 4 - participant 6).

2. Identification of Hearing Status of Children
The majority reported that they were certain that the child could hear when he/she responds to name call. A few mothers stated that if a child demonstrates comprehension when spoken to, or if the child is startled or responds to loud sounds, then it is certain that the child can hear. One mother reported that the child’s ability to localise sound is an indication that the child hears. On further probing regarding levels of hearing loss and its manifestation, the general consensus of the groups was that all children with hearing problems are “deaf” or have “no hearing”. The possibility of children having partial and/or unilateral hearing loss was not recognised.

“If the child turns towards us when we call, then we understand that the child can hear” (FGD1- participant 2).

“If any vessel is dropped, when we switch on the television or radio, or if there is a loud noise, then the child cries. With that we can understand that the child hears well” (FGD1- participant 7).

“The child comes to you on hearing your call. Likewise, if somebody else calls they will move towards them” (FGD 6- participant 3).

3. Age at which Hearing can be Assessed
Mothers had varying opinions regarding the age at which hearing could be assessed. The majority believed that since babies sleep a lot in the first 3 months of life, it is not possible to ascertain whether they can hear. Some believed that only at 1 year of age would it be possible to ascertain that the child could hear, since there would be response to commands and soft sounds. A few mothers reported that hearing ability could be identified at birth using informal methods, and they offered their observations with their own children as evidence.

“As soon as the child is born, the child is not able to see around. It takes about 1 to 1.5 months for the child to look at you and smile and to turn for even soft sounds. I
just wanted to say that we do not know anything about its hearing ability as soon as the child is born. In fact, the child is able to hear even when it is in the womb of the mother before birth. It cannot open its eyes to see whether we talk or not. It is difficult to even lift the child as soon as it is born. We do not know whether the child is hearing at that time or not. It takes a month or two, for the child to turn or cry on hearing even soft sounds” (FGD 4 - participant 3).

“We can perceive the child’s (hearing) ability only after he /she starts growing. At birth, the child has the ability (to hear) but we do not get to know it” (FGD4 - participant 6).

“I got to know (about child’s hearing) at birth itself. The child will stop crying on listening to voice. When the nurses come and go inside the room, the child starts crying on hearing the sound of the doors when shut. With that I could confirm the hearing ability” (FGD 5- participant 8).

4. Prenatal, Perinatal and Postnatal risk factors for Hearing Loss

To gain insight into the mothers’ knowledge about risk factors for hearing loss, “word coding” of the transcribed conversation was carried out. Most common risk factors reported were consanguinity (which was mentioned 7 times) followed by malnutrition of expectant mothers (which was mentioned 6 times).

“If we marry within blood relations, such things (hearing loss) occur” (FGD 2- participant 5).

A few mothers reported that they were not aware of the risk factors leading to hearing loss. Figure 1 shows the risk factors for hearing loss as reported. Knowledge about consanguinity and maternal malnutrition during pregnancy was high and it was thought that these could cause even other types of disability.

Beliefs such as expectant mothers doing work during the solar eclipse, leading to congenital malformation of the ear, lip or face, were reported. In order to prevent disability such as hearing loss in unborn children, participants reported that pregnant women were not allowed to strain boiled rice or go out of the house during the solar eclipse.

“If a child is born on an eclipse day, it might be born with its head and ear tilted. Even lips will be raised (referring to cleft lip and palate)” (FGD 6 - participant 1).
“When you filter the boiled water when cooking rice, (pregnant women) should not cover it with lid. If you do that, you will get children born with closed ears or mouth” (FGD 4- participant 10).

Other prenatal risk factors for hearing loss such as maternal infections and iodine deficiency were not reported. Perinatal risk factors such as low birthweight, hypoxia, jaundice, infections, and ototoxicity of hearing loss, and postnatal factors such as otitis media, measles and mumps, were not mentioned. A few mothers believed that ear discharge when treated with ear drops resolved the condition and therefore was not a risk factor for hearing loss.

Figure 1: Reported Causes of Hearing Loss by Mothers

5. Consequences of Hearing Loss

Majority of the mothers were aware of the consequences of hearing loss for a child. They reported that the child with hearing loss would have difficulty in learning, understanding verbal instructions, and leading an independent life. A few mothers reported problems with verbal expression, and psychological problems such as being aloof, low confidence levels and frustration.

“Even if you try to teach the child, the child is not going to hear” (FGD1- participant 8).
“It is a matter of great difficulty when you take the child out. The child is not going to hear when the bus conductor is asking for something while issuing the ticket. One must touch the child” (FGD 3- participant 8).

“The child’s mental health will be very much impaired. The child will find it very difficult to play with other children” (FGD 4 - participant 6).

“The child will feel inferior when compared with other children” (FGD 5 - participant 2).

6. Professionals and Services for Children with Hearing Impairment

The general opinion among mothers was that a paediatrician should be approached for any medical problem concerning children, including ailments related to hearing. However, few were aware that Ear, Nose and Throat (ENT) specialists were medical professionals for ear treatment. None were aware of audiologists and their role in ear and hearing healthcare.

It was evident that the majority of mothers were aware that hearing aids could be fitted for children with hearing impairment. Consensus of the group was that hearing aids were fitted only after 1 year of age. They believed that once a child was equipped with a hearing aid, he/she could hear normally and therefore could go to regular school. No mother reported the need for rehabilitation or intervention after fitting the hearing aid.

Only a few of the mothers were aware of the availability of special schools. One mother reported surgery or cochlear implantation as a treatment option for hearing impairment. However, another mother contradicted her and said that surgeries were meant for adults and not for children. A few mothers reported the availability of government allowances for children with hearing impairment. One mother reported that there are facilities and allowances for people with disabilities but none were available for individuals with hearing impairment.

“There are allowances for people with disability but none of them are bothered about people with hearing impairment” (FGD 3 - participant 8).

Table 1 summarises the participants’ correct knowledge, inferred gaps in knowledge and misconceptions about ear and hearing healthcare.
<table>
<thead>
<tr>
<th>Area</th>
<th>Correct knowledge</th>
<th>Inferred gaps in knowledge</th>
<th>Misconceptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ear care</td>
<td>Use of instruments (such as hairpin, safety pin, key, stick, etc) will harm the child’s ear.</td>
<td>Ear buds should be avoided for cleaning ears.</td>
<td>Practices like pouring herbal juices for removal of insects in ear.</td>
</tr>
<tr>
<td>Methods to identify normal hearing in children</td>
<td>Response to name call, understanding verbal instructions, startles at loud sounds.</td>
<td>Normal speech development in children is an indicator for normal hearing.</td>
<td>_</td>
</tr>
<tr>
<td>Age of identification of hearing ability</td>
<td>_</td>
<td>Hearing ability can be ascertained at birth.</td>
<td>_</td>
</tr>
<tr>
<td>Causes of hearing loss</td>
<td>Following conditions lead to hearing loss: Consanguinity, malnutrition of expectant mothers, ear wax, and ear trauma.</td>
<td>Causes of hearing loss such as <strong>Prenatal causes:</strong> Infections to expectant mothers.  <strong>Perinatal causes:</strong> Low birthweight, hypoxia, jaundice, infections, ototoxicity. <strong>Postnatal causes:</strong> Otitis externa, chronic otitis media, measles, mumps, ototoxicity, noise exposure</td>
<td>Ear discharge is a condition to be treated but not a cause of hearing loss. Pregnant women doing work at home or outside during pregnancy can cause malformations of the ear.</td>
</tr>
<tr>
<td>Consequences of hearing loss</td>
<td>Children with hearing loss have difficulty in understanding verbal instructions, in pursuing education and leading an independent life.</td>
<td>Hearing loss could affect speech development.</td>
<td>_</td>
</tr>
<tr>
<td>Area</td>
<td>Correct knowledge</td>
<td>Inferred gaps in knowledge</td>
<td>Misconceptions</td>
</tr>
<tr>
<td>-------------------------------------</td>
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<td>------------------------------------------------------------------------------------------</td>
<td>--------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Procedures for hearing testing</td>
<td>—</td>
<td>Hearing can be tested at birth.</td>
<td>Hearing can be tested only when the child starts speaking.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Test procedures are available for hearing testing.</td>
<td></td>
</tr>
<tr>
<td>Ear and hearing healthcare professionals</td>
<td>E.N.T specialists as professionals for ear and hearing healthcare.</td>
<td>There are professionals (Audiologists) who are involved in hearing evaluation and rehabilitation.</td>
<td>—</td>
</tr>
<tr>
<td>Services for persons with hearing loss</td>
<td>Appliances such as hearing aids can be used for hearing loss.</td>
<td>Allowances/concessions are available for children with hearing impairment.</td>
<td>—</td>
</tr>
<tr>
<td></td>
<td>Special schools are education options for children with hearing impairment.</td>
<td>Child with hearing loss needs training in hearing.</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hearing aids can be fitted at less than one year of age.</td>
<td></td>
</tr>
</tbody>
</table>

**DISCUSSION**

From the discussion on ear care, it is inferred that mothers were aware that cleaning a child’s ear with instruments (such as a safety pin, key or stick) would cause damage. However, the use of herbal juice and oil to remove insects from the ear seems to be a common practice. Practices like pouring mother’s milk, neem or garlic oil into the ear, and going to tantric and faith healers for ear diseases have been reported even in an urban community in North India (Gupta et al,
In a rural South Indian community, high prevalence of otitis media was attributed to earache being disregarded (26.4%) or treated with home remedies (67.2%) by most caregivers, while a doctor’s opinion was often sought for ear discharge (50%) (Srikanth et al, 2009). Such misconceptions seem to exist in both rural and urban areas, emphasising the need for health education regarding ear care in general.

Regarding identification of hearing status, majority of the mothers mentioned “response to name call” as an indication of normal hearing; however, none directly reported the achievement of normal speech milestones as being related to normal hearing. Similar findings were reported in a questionnaire-based study conducted in rural West Bengal. The authors reported that suspicion of hearing loss was aroused mostly by “no response to name call” (65.6%), followed by “no response to clap” (13.4%), and only 10% reported “lack of speech development” (Rout & Singh, 2010). This would suggest that since delay in a child’s speech development may not arouse suspicion, it could lead to delayed identification of hearing loss. Hearing loss in children was associated with “deafness” and it is possible that mothers therefore missed the subtle symptoms of partial or unilateral hearing loss in speech. This may have also influenced their beliefs regarding the consequences of hearing loss, as difficulty in leading independent lives, psychological problems and educational difficulties were reported. Studies have shown that parental concern was low regarding detection of minimal or mild hearing loss in their child (Cone et al, 2010). It is imperative that hearing screening programmes for infants and young children focus on identification of mild to moderate hearing loss. Information, education and communication to parents and caregivers should reinforce the possibility of partial and / or unilateral hearing loss in children, and highlight milestones of hearing and speech development.

In this study, the responses of mothers regarding age of hearing testing suggests that there is a misconception that normal hearing ability can be ascertained only when the child can voluntarily respond (e.g. localisation, saying “I can hear”, or by comprehending verbal instructions). The belief that hearing ability can be ascertained only when the child is older, could be detrimental to early identification and intervention. It is important to educate the community about objective hearing testing methods that can be carried out even at birth, so that there is a change in attitude. In a study done in rural West Bengal in India, Rout et al (2010) reported that though children’s caregivers first suspected hearing loss
at the mean age of 1.5 years, the first visit to the doctor was at a mean age of 2.4 years and consultation with an audiologist was at a mean age of 9.3 years. Hence, information about early diagnosis and early intervention should be provided to the community.

Majority of the mothers acknowledged consanguinity as a prenatal risk factor for hearing loss; however, awareness about peri- and postnatal factors was limited. A study in a tertiary care hospital in an urban city of South India, shows a similar high rate of awareness regarding consanguinity (64.1%) as a risk factor for hearing loss, followed by noise exposure (61.2%), ear discharge (57.3%), and family history (53.4%) (Revathy et al, 2014). Among Nigerian and South African mothers, poor awareness regarding medications, asphyxia, jaundice, measles and preterm/low birthweight as a risk factor for hearing loss has been reported (Olusanya et al, 2006). The findings of this study and review of literature suggests that this lack of knowledge exists in developing countries, and therefore should be addressed in all public awareness programmes on ear and hearing health.

In a study among residents of an urban locality in New Delhi, awareness about preventable causes of deafness such as ear infections, trauma and any infection during pregnancy has been reported (Gupta et al, 2010). However, they were unaware that being hit on the ears, excessive use of headphones to listen to loud music and indiscriminate use of ear buds could be harmful. In contrast, among mothers in this rural community there was a lack of awareness regarding preventable causes. The difference could be attributed to better health-related awareness in cities. Also, superstitious beliefs did exist about risk factors for hearing loss and other disabilities, such as the ill effect of solar eclipses and pregnant women carrying out certain household chores. Similar superstitious beliefs were also reported in South Africa (Swanepoel et al, 2008). Misconceptions regarding risk factors should be corrected through culture-specific strategies and the community should be sensitised to prenatal, perinatal and postnatal factors responsible for hearing loss.

While it is encouraging to note that some mothers were aware of ENT specialists, in general there was limited awareness about professionals and services available for individuals with hearing impairment. It is not surprising that mothers from rural areas were unaware of the ear and hearing healthcare professionals, as specialists are almost non-existent in rural areas. The majority believed that fitting a hearing aid solved the hearing loss. The need for intervention after identification should be emphasised in the community. As the paediatrician is
the first medical professional that a mother may interact with, it is important that this group of professionals be sensitised to early identification and intervention for hearing loss.

**CONCLUSION**

This study was carried out to gain insights into the knowledge and beliefs about ear and hearing health in a rural community where it was proposed to have a hearing screening programme for infants and young children. The objective was to use the information obtained to incorporate appropriate messages into the sensitisation and counselling of the community by village health workers.

The results of the study suggest that while mothers in this rural community were knowledgeable regarding some aspects of ear and hearing healthcare, lack of information and misconceptions were also prevalent. For greater compliance with the community-based programme aimed at identification of hearing loss in children, it is important to use the existing knowledge of these mothers. Simultaneously, attempts should be made to fill in the gaps in knowledge and work towards dispelling prevalent myths.

In the proposed hearing screening programme, screening in the villages will be conducted by VHWs who will be in close and constant contact with the community. They will be trained to provide the following information on ear and hearing healthcare:

1. Prior to hearing screening, meetings will be conducted in every village at the Balwadi (pre-school) to sensitise parents about:
   a. Risk factors for hearing loss, such as low birthweight, hypoxia, jaundice, maternal infections, and hearing loss due to untreated ear infections.
   b. Speech and language development as an indicator of hearing ability.
   c. Possibility of partial and unilateral hearing loss other than ‘Total’ deafness.
2. In order to dispel the misconception that hearing can be tested only when the child is old enough to respond verbally, the VHWs will inform the community about the availability of hearing testing methods that are objective and suitable for newborns. This is expected to improve participation in the screening.
3. Before the screening, in order to capitalise on the mothers’ knowledge about informal assessment of hearing, questions on behavioural response to sounds will be incorporated in the case history.

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REFERENCES


APPENDIX I
Focus Group questions (Translated from Tamil)

A. Ear care
1. How do you keep your child’s ears clean?
2. What do you all do when any object or insect goes inside the ear?

B. Causes & prevention of hearing loss, specific to early childhood hearing loss
3. What according to you are the reasons for a child to have hearing loss?
4. How do you think hearing loss can be prevented?

C. Hearing assessment
5. How will you ascertain that the child is able to hear?
6. At what age can hearing ability of a child be assessed?
7. People may have complete loss of sight or some can see partially; are you aware of any such thing for hearing loss? How will you come to know about it?
8. What will you do if your child has any problem in hearing?
   1) Do you know anything about hearing testing?
   2) At what age can a child’s hearing be tested?
   3) Are you aware of any specialist or professionals for ear and hearing?

D. Consequences/ Signs of hearing loss
9. What do you feel are the consequences of hearing loss?

E. Hearing rehabilitation (Hearing aid/ surgery/ education)
10. What can be done for children with hearing loss?
11. Are you aware of any schemes for persons with hearing loss?
LETTER TO EDITOR

Dear Editor,

The Application of Focus Group Discussions and Interviews in Community Physiotherapy

Focus group discussions and in-depth interviews with participants have been commonly used in community settings in remote or rural areas. In large-scale community projects, these tools of research help to understand health issues such as smoking, mental health conditions like depression and anxiety, dengue control, nutrition regulation, sexual health, Parkinson’s disease, childhood obesity, and cancer.

Though there is evidence that focus group discussions and in-depth interviews have been extensively used with much success in medical research, their application in the field of community physiotherapy is seldom studied (Sim and Snell, 1996). In a recent study on stroke survivors in Zambia (Mapulanga et al, 2014), 50 households in the Livingstone district were included in focus group discussions to understand the socio-economic burden of the disease at the individual, family and community levels. The analyses of the data collected from these discussions helped to highlight the burden created by the disease at different levels. A review paper by Smith et al (2009) suggested the novel method of using telephone-based group discussions in physiotherapy. The authors emphasised the benefits of this method in terms of greater coverage area, increased participation and handling of sensitive issues. In another study that used focus group discussions, in-depth interviews and participant observations in a semi-urban hospital in Kenya (Gona et al, 2013), the need for cost-effective community physiotherapy for management of chronic aches and pains in low-resource settings was realised. In India, a series of focus group discussions were conducted with slum women and children by Rajan and Koti (2013). These discussions helped to understand the prevalent musculoskeletal health issues in this cohort; thereafter, community physiotherapy was recommended for these problems. In an earlier study by Rajan (2012), focus group discussions were used to look into the lacunae in the community physiotherapy system in western India. While focus group discussions and interviews have proved to be effective in understanding community physiotherapy issues, studies on the subject are few.
Focus group discussions and in-depth interviews are cost-effective qualitative methods of research (Fok-Han and Ratnapalan, 2009). This is one of the major advantages of using these tools in community physiotherapy, which in itself can be considered a cost-effective tool of rehabilitation (Rajan, 2014a & 2014b). In addition, during discussions there is detailed sharing of information among/ between participants, which might be missing in other forms of data collection like surveys (Mansell et al, 2004). However, one of the important drawbacks is that the quality of the data collected depends tremendously on the skill of the leader. Appropriate and relevant data can only be collected if the leader is trained and is able to focus on the issue at hand (Fok-Han and Ratnapalan, 2009).

In conclusion, focus group discussions and in-depth interviews seem to show promise as tools for data collection in community physiotherapy. However, the number of studies is insufficient to substantiate this. Their efficacy could be assessed only if they are optimally used for research purposes.

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.