

Feasibility Study of a Community-Based Intervention for Mental Retardation in Rural Pakistan

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Pak Paed J 2008; **32(4)**: 200-07

ABSTRACT

Background: After extensive formative research, we developed a parent-based community intervention for individuals with mental retardation, designed to be delivered by Lady Health Workers (LHWs). We conducted a feasibility study of the intervention in one rural area. Our objective was to assess the opinion of the Lady Health Workers and carers of individuals with mental retardation about the intervention.

Methods: We designed structured questionnaires to obtain anonymous feedback from carers and LHWs after they had been exposed to the intervention. We surveyed 25 LHWs in 2 Union Councils of Gujar Khan, Rawalpindi, and an equal number of carers randomly selected from the Basic Health Unit case registers.

Results: All the LHWs surveyed agreed there was a need for such an intervention, that the carers would find it useful, and that they would be able to integrate it into their day-to-day work. Over 80% of LHWs agreed that the total duration of the intervention (one year) and the length of the intervention (45 minutes) were appropriate. Similarly, over 80% of carers agreed that the intervention would be useful both for them and their child, they would find time to attend the sessions, and their families would support such an interventions. As with LHWs, over 80% of the carers agreed that the total duration of the intervention and length of the session were appropriate, and only 16% felt that the sessions should be fortnightly rather than monthly.

Conclusions: The study shows that a parent-based community intervention for children with mental retardation was strongly perceived to be feasible and useful by both carers and health workers in a poor rural area of Pakistan.

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INTRODUCTION

Epidemiological surveys carried out in Pakistan have revealed one of the highest rates of mental retardation in the world¹. With an estimated population size of 160 million and approximately 40% of Pakistan's population between the ages

of 0-14, the estimated rates of mental retardation of 1.9% for serious and 6.5% for mild retardation pose a considerable challenge^{2,3}. The increased prevalence rates of developmental disabilities in Pakistan are an impediment to its future social and economic development¹. Disability, be it physical, mental or both, has a strong correlation

with poverty, a correlation which operates in both directions; poverty leads to disability and disability in turn increases poverty⁴.

WHO's community-based rehabilitation (CBR) scheme was introduced in Pakistan in the early 1980's. This is a set of approaches to provide rehabilitation services for people with disabilities in developing countries¹. The scheme focused on volunteer "Local Supervisors" advising families on home rehabilitation of disabled persons. Efforts were also made to influence attitudes in the community. Evaluation reports gave conflicting views about the usefulness of the programme with an emphasis on the need for a more participatory approach involving an analysis of local conditions prior to project design and involvement of the community in planning^{5,6}. CBR was not scaled-up and remained confined to small non-governmental organizations, charities and pilot schemes.

Interventions are unlikely to be adopted by professionals and policy makers unless they are shown to be efficacious, cost-effective, integrated in existing community health services, and linked to other high priority health problems such as acute illnesses. The major impact of mental retardation is borne by individuals and their families. In addition to the difficulty of coping on a daily basis as a result of impairments in adaptive functioning, these care givers experience increased stress and the effects of associated stigma. A community-based intervention for children with mental retardation that includes individual as well as family intervention delivered by health workers in collaboration with existing community resources could result in relatively low delivery costs, less duplication of services, and appropriate identification of those who are most likely to benefit.

In 2005-2007, we carried out a mixed-methods study with the objective to develop a feasible, cost-effective community level intervention for mental retardation that can be integrated into primary care in Pakistan and delivered by village-based community health workers. Here, we describe the components of the intervention developed and a pilot study that was conducted

to evaluate its feasibility in a rural area of Pakistan.

Components of a community-based multimodal intervention for mental retardation

The data from our mixed-methods study and our literature survey has enabled us to formulate a community-based multimodal intervention that would be effective in the community. We were able to identify areas that are a priority for families and feasible for integration into the existing health care system. We consulted experts with experience in community based rehabilitation projects locally, to obtain knowledge about barriers in conducting such programs. Additionally, we reviewed existing literature and available manuals of interventions developed for community based programs.

The following principles of intervention were identified:

- 1) To be acceptable to the carers, there is a need for tangible outcomes so that the carers feel that their investment in seeking care is justified.
- 2) It needs to address health outcomes that are a priority in the literature⁷.
- 3) It needs to be tailored to the requirements of the family and community. This has been described by a number of authors including Nganwa & Khasnabis (2006) who describe the contradiction in priorities of parents and rehabilitation personnel in Uganda⁸. Similarly, House et al (1990) described their experience in Zimbabwe of trying to implement a program of teaching of disabled children, while the first priority of parents was to address the prevailing negative social attitudes and stigma⁹.

Based upon these principles, this proposed intervention consists of the following components designed to be delivered at the individual and family level.

1. Individual Level Intervention

Early detection: Our ongoing work has informed us that there is a significant delay in the detection of mental retardation

especially in the rural setting where majority of the population of Pakistan resides. One available intervention to remedy this is the use of *Ten Question Screen*. This screen has been used successfully in the past in Pakistan¹⁰ as well as a number of other Asian and African countries¹¹.

Addressing poor adaptive behaviour/ Self injurious behaviour: Children with intellectual disabilities are more likely to engage in challenging behaviours than other children¹². This not only results in poor adaptive behaviour but also can result in harm to the child through self injurious and destructive behaviour. These behaviours impact significantly on the family. Parents of children with intellectual disabilities report higher parenting stress and mental health problems than parents of normally developing children¹³. Current research supports a bidirectional effect, where the child's behaviour problems predict parental stress over time and parental well being predicts child behaviour problems over time^{14,15}. Improved social behaviour was the outcome most desired by parents.

Nutrition: Poor nutrition may exacerbate the impact of disability¹⁶. One component of the intervention is to monitor growth, educate carers about healthy diet, use of de-worming medication and micro-nutrient supplementation. This aspect of intervention would be delivered by the lady health workers under the supervision and guidance of local physicians.

Stimulation of the child: This will be based on the principles of early intervention, occurring in the child's natural environment. Everyday family routines and community settings provide a wide variety of experiences that can assist children in gaining developmental competencies. Lady health workers, (through their training and ongoing supervision) will work towards enhancing parental capacity and confidence. They will impart practical skills on how to stimulate the child early on, in home settings, working together with the carers through psycho-education, learning with hands on practice, mutual support and problem solving. The Urdu translation and

pictorial versions of the Portage Guide to Early Education will be used as a guide.

2. Family Level Intervention

Stress reduction: High parental stress predicts fewer gains in early intervention programs¹⁷. Similarly, interventions to enhance parenting skills show small gains in the presence of high parental stress (Baker et al 1991). Behavioural intervention for problem behaviour is most effective when family issues including stress have been addressed prior to the intervention¹⁸. LHW's will support the parents in stress reduction strategies.

Support groups: Lady Health Workers, as part of their official duties with the Maternal and Child Health program, are required to convene self-help support groups of mothers with infants. A similar support group will be organized for parents with MR children.

Education: Many health messages related to primary prevention of MR are already part of the LHWs routine practice and these will be reinforced in this study. These messages include measures for family planning (information and provision of contraceptives); prenatal care (adequate nutrition in pregnancy, avoiding smoking, appropriate birth attendants, screening for phenylketonuria and congenital hypothyroidism); immunization; optimal nutrition (growth monitoring, iron, Vitamin A, iodine supplementation, and correction of iron deficiency anaemia).

These components were incorporated into a training manual for health workers with clear instructions for how information was to be communicated to carers. The intervention was to be delivered in 12 monthly sessions over one year. This was in line with the current workload of community health workers, which requires them to visit each family in their local area approximately once a month.

We undertook a pilot study of the above intervention in one rural area of Rawalpindi with the objective of obtaining feedback from carers and Lady Health Workers about the usefulness and feasibility of the intervention.

METHODS

Setting and participants: The study was conducted in the district of Rawalpindi, Pakistan. The district has an area of 5285 square kilometers and population of about 3.5 million of which 57% is rural¹⁹. The average household consists of 6.2 members. The study area consisted of two out of seven rural sub-districts of Rawalpindi, conveniently selected for ease of access from Rawalpindi City. Most families in the area depend on subsistence farming, supported by earnings of one or more of the adult male members serving in the armed forces or working as government employees, semi-skilled, or un-skilled labourers in the cities. Agriculture depends almost entirely on rainfall, and wheat, maize and millet are the main cash crops. Farmers usually have small land holdings. Male and female literacy rates are 79.6% and 48.6% respectively. Infant mortality rates are 84 per 1000 live births. There is one Basic Health Unit (BHU) providing primary care to about 20,000 people. Each BHU is staffed by a doctor, midwife, vaccinator and 15-20 female primary health workers called Lady Health Workers or LHWs. LHWs are members of the local community, have completed secondary school, and are trained to provide mainly preventive mother and child health care and education. Each LHW is responsible for about 1000 women in her catchment area.

As this was a descriptive study, we did not calculate sample sizes. All Lady Health Workers from two BHUs, Mohra Fatima and Mandra willing to take part in the study (n=25) were included. Only 5 were unwilling or unavailable to take part, giving us a response rate of 75%. Sixty-eight children with mental retardation were identified from the case register. They were listed, and 25 were randomly selected using a random numbers list. All the families approached agreed to take part in the study.

Instruments and data collection: Structured questionnaires to evaluate the feasibility and usefulness of the intervention were developed for both groups of participants. These were based on questionnaires we used in previous studies to evaluate the feasibility a community-based psychosocial intervention for perinatal depression. The questionnaires used a Likert scale from 1 = strongly disagree to 5 = strongly agree to

obtain feedback about various aspects of the intervention. A score above 3 indicated a positive response; a score of 3 was neutral; and a score below 3 indicated a negative response. Additionally, participants were required to give open-ended comments about the intervention.

The LHWs were administered the questionnaires after they had undergone a one-day workshop in which they were introduced to the intervention and taught to conduct a typical session. In the workshop they practiced the session using role play, with each LHW alternating between carer and health worker role. This allowed them to get a feel of the intervention from both carer and worker's perspective.

Carers were invited to the BHU and were administered a session according to their child's age and developmental concerns by one of the research team. At the end of the session, they were administered the questionnaire by a field worker not part of the research team. The survey instruments were administered anonymously to all the participants. Descriptive analysis was carried out of the feedbacks.

RESULTS

The results from the carers and health-workers' survey are shown in Table 1 and 2 respectively. 20/25 (80%) of carers thought the total duration of the intervention, i.e., 12 monthly sessions over two years was appropriate. Only 2 (8%) thought it was too short while the rest were unsure. 22/25 (86%) agreed that the duration of each session, about 45 minutes, was appropriate, 1 respondent thought it was too short and 3 were unsure. 19/25 (76%) carers agreed that the interval between two sessions, i.e., one month, was appropriate. 4/25 (16%) felt it was too long. 23/25 (96%) of the carers agreed that the intervention would help reduce their worry and stress, while 22/25 (88%) agreed it would lead to an improvement in their child's condition and about the same number agreed they would be able to carry out the activities suggested by the LHW for their child and meeting the LHW would be helpful. 23/25 (96%) of the carers agreed they would have the time to attend the sessions and almost all (97%) agreed that their families would support this work by the LHWs.

TABLE 1: Carers Feedback on Intervention (n=25)

Statement	Response (N/%)				
	Strongly disagree	Disagree	Don't know	Agree	Strongly agree
1. The total duration of the intervention, i.e., 12 monthly sessions over one year is appropriate.	-	2(8%)	3(12%)	9(36%)	11(44%)
2. If you disagree with the above statement, do you think the duration is too long?	-	-	-	-	-
3. Or too short?	2(8%)	-	-	-	-
4. The duration of each session, i.e., about 45 minutes, is appropriate.	-	1(4%)	2(8%)	8(32%)	14(56%)
5. If you disagree with the above statement, do you think the duration is too long?	-	-	-	-	-
6. Or too short?	-	1(4%)	-	-	-
7. The interval in between two sessions, i.e., one month, appropriate.	-	4(16%)	2(8%)	11(44%)	8(32%)
8. If you disagree with the above statement, do you think the monthly interval is too long.	-	4(16%)	-	-	-
9. Or too short?	-	-	-	-	-
10. The intervention will help reduce my worry/stress?	-	1(1%)	1(4%)	15(60%)	8(32%)
11. The intervention will lead to an improvement in my child's condition.	-	1(4%)	2(8%)	18(72%)	4(16%)
12. I will be able to do the activities suggested by the LHW with my child?	-	-	1(4%)	8(32%)	16(64%)
13. Overall, I think such meetings with my LHW will be useful.	-	1(4%)	1(4%)	16(64%)	7(28%)
14. I don't think I will find time to attend these sessions.	-	1(4%)	1(4%)	11(44%)	12(48%)
15. My family will support such an intervention.	-	-	1(4%)	13(52%)	11(44%)

TABLE 2: Health Workers' Feedback on Intervention (N=25)

Statement	Response (N/%)				
	Strongly disagree	Disagree	Don't know	Agree	Strongly agree
1. The total duration of the intervention, i.e., 12 monthly sessions over two years is appropriate.	-	2(8%)	2(8%)	14(56%)	7(28%)
2. If you disagree with the above statement, do you think the duration is too long?	-	-	-	-	-
3. Or too short?	-	-	-	2(8%)	-
4. The duration of each session, i.e., about 45 minutes, is appropriate.	-	3(12%)	4(16%)	12(48%)	6(24%)
5. If you disagree with the above statement, do you think the duration is too long?	-	-	-	-	-
6. Or too short?	-	-	-	2(8%)	1(4%)
7. The interval in between two sessions, i.e., one month, appropriate.	-	13(52%)	2(8%)	7(28%)	3(12%)
8. If you disagree with the above statement, do you think the monthly interval is too long?	-	-	-	7(28%)	6(24%)
9. Or too short?	-	-	-	-	-
10. The intervention will be relevant to my everyday work.	-	-	-	17(68%)	8(32%)
11. The intervention will be an extra burden in my everyday work.	14(56%)	11(44%)	-	-	-
12. I understand the concepts explained in the training?	-	-	-	18(72%)	7(28%)
13. I will be able to communicate these concepts to the carers I see.	-	-	-	19(76%)	6(24%)
14. I think the carers will find this intervention useful.	-	-	2(8%)	16(64%)	7(28%)
15. I think there is a need for such an intervention in the community.	-	-	-	3(12%)	22(88%)

The health workers' responses were similar. 21/25 (80%) of LHWs thought the total duration of the intervention, i.e., 12 monthly sessions over two years was appropriate. Only 2 (8%) thought it was too short while the rest were unsure. 18/25 (72%) agreed that the duration of each session, about 45 minutes, was appropriate, 3/25 (12%) thought it was too short and 3 were unsure. Only 10/25 (40%) LHWs agreed that the interval between two sessions, i.e., one month, was appropriate while 13/25 (52%) thought it was too long and fortnightly sessions would be more appropriate. All the LHWs surveyed agreed that the intervention was very relevant to their everyday work and none felt it would be an extra burden on them. All of them agreed they could understand the concepts outlined in the intervention and communicate the same with the carers and their families. Most of them (over 90%) agreed that the carers would find the intervention useful and that there was a need for such an intervention in their areas.

DISCUSSION

The study show that a parent-based community intervention for children with mental retardation, delivered by Lady Health Workers as part of their routine duties, is perceived to be feasible and useful by both carers and health workers in a poor rural area of Pakistan.

While the study was carried out on a small but representative sample of carers and health workers in one area, we are confident that the results will be generalisable to all areas of Pakistan covered by the Lady Health Worker program. This is because the intervention was developed after careful consultation with the community and health system personnel. The study was carried out in a typical rural area of Pakistan. The results validate the process of intervention development.

However, the study does not inform us about its impact on the child and parent outcomes such as behaviour, functioning, physical health or carer stress. It would not be possible to elucidate these outcomes in a small time-limited feasibility study. We envisage that the effects of the intervention will be cumulative and based on a 'process' of engagement of the health worker with the family, which will take time. It would be

important to measure outcomes over a longer period of time to assess if such an intervention is, indeed, effective in reducing the burden from mental retardation in the community. Future research using a randomised controlled design and a large and representative sample would be appropriate to test these outcomes over the long term. However, such studies are expensive and require technical expertise to be carried out.

Integration of such an intervention would require regular training and supervision for it to be successfully implemented²⁰. Working with severely disabled individuals and their families in very poor settings can be stressful for health workers. It is therefore essential to have strong supervisory mechanisms. This could be in the form of peer-groups where health workers from each locality meet on a regular basis to discuss the families under their care. In our experience, such meetings where health workers brainstorm for solutions, discuss their successes and failures, in a supportive environment can be a sustainable model for supervision where there are no resources to employ trained supervisors. Guidelines for such peer supervision need to be incorporated into training. Such an intervention can be sustainable if it built on partnership using recognised community participatory models²¹.

Integrating this intervention into work of village-based health workers will potentially result in early detection and management which would prevent chronic problems from developing. This opportunity for rehabilitation in early formative years could prevent significant distress for the caregivers who rarely receive valid information about course, prognosis and what remedial action to take. There is an educational component in the proposed intervention for the general population as well as primary care health practitioners. Being community based, the intervention would ensure maximum population coverage, with an emphasis on solving problems that are prioritized by the carers. The intervention should also ideally have a component of advocacy and local community mobilization which would be valuable in supporting the health workers in their work.

Our previous multi-method study that formed the basis for the intervention, and this study which demonstrates the feasibility of integrating it into the LHW programme, provide evidence that

mental retardation can be managed in the community. We strongly advocate the implementation of this intervention on a larger scale and testing its long-term effectiveness through well-planned trials.

ACKNOWLEDGEMENTS

We would like to thank Dr Tariq Mehmood, Prof Fareed Minhas, Prof. Khalida Tareen and Prof. Francis Creed and Prof Rachel Jenkins for their valuable support. The study was funded by the Fogarty International Center, National Institute of Health (USA) (R21 TW07754).

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