PLAY BASED STIMULATION PROGRAMME FOR INFANTS WITH CEREBRAL PALSY AND MENTAL RETARDATION

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ABSTRACT

Formulating, implementing and documenting play based stimulation programmes for children with Cerebral Palsy (CP) and/or Mental Retardation (MR) was the main objective of the study. The study also focused on the mothers and equipped them with knowledge about the conditions. Six infants and their mothers enrolled in the Infant Stimulation Centre, Faculty of Home Science Baroda, India, formed the sample.

The study was conducted in 3 phases, consisting of 4 assessments on Developmental Assessment Scale for Indian Infants (DASII). Based on assessment results, individual need-based programmes were formulated and implemented at the centre and their homes. Additionally, the mothers were interviewed and the areas of concern were identified, around which intervention sessions were planned. Results showed that 66.6% of children showed increase in the motor score and 100% of children showed increase in mental score. Improvement was more in the areas of mental development. Time was a major constraint for giving inputs to the child at home. Increase in scores was more due to home intervention than the mother intervention programme.

INTRODUCTION

Early intervention is planned for children who are at risk, or have established developmental delays of various degrees and associated conditions from birth to 3 years. Research shows that the early years of life are crucial for establishing a foundation of learning and emotional development. If children miss the opportunity to develop intellectually and emotionally during these important years, precious time is lost forever (1).
The major purpose of early intervention is prevention of disability and developmental delays. The ultimate goal of intervention is to enhance normal development and independent functioning of the child. Since the child's development is dependent on genetic qualities and interaction with the environment, it becomes imperative to focus on the child and on the environment in early intervention (2). Similarly, a study by Bronfenbrenner (3), stated that the most effective agent of intervention in fostering and sustaining development, is the family. Research by Trivette and Dunst (4), shows that when intervention is done in a family centred manner, it strengthens the family and gives them the feeling of control and competence.

Intervention can be provided at the home or at a centre or as a combination of both. The home visits provide a perfect opportunity for the service providers and the parents (typically the mother), to establish and maintain rapport, as well as to discuss the effectiveness of the previously planned and implemented activities. In the centre-based intervention, team members can work closely with the child and have an easy access to him/her.

However, the difficulties in involving parents in centre based programmes are that, such programmes are potentially expensive and time consuming. Thus, a combination of both home based and centre based intervention can prove to be advantageous. It has the combined benefit of being able to provide individualised attention, as well as group attention and social interaction. It also provides a natural home environment to the child, to learn things and then generalise them easily. In addition, accessing appropriate toys becomes easier, and the child also gets a new environment to play in, besides giving respite to the parents. (5).

METHOD

The study was quasi-experimental, as the sample was well defined and naturally occurring, comprising of six infants with Cerebral Palsy or Mental Retardation and associated problems, who were enrolled in the Infant Stimulation Centre of the Department of Human Development and Family Studies, Faculty of Home Science, Maharaja Sayajirao University, Baroda, India. The total sample (N=12) consisted of six infants and their mothers. The sampling was purposive as the study was based on the ongoing work of the Infant Stimulation Centre. The children belonged to the age group of 2.5 years to 5 years. The mental ages of the children ranged approximately from 8 months to 2 years while their motor ages were between 5.7 months and 23 months. All children had varied degrees of cerebral palsy and/or mental retardation.
with associated visual or auditory and speech deficits. The mothers were housewives with their ages ranging from 26-44 years and their educational levels from 12 class to Master’s Degree. All mothers except one, were from nuclear families with an average household size of four.

The tools used were as follows:

1. **Developmental Assessment Scale for Indian Infants (DASII)**

   This is an Indian adaptation of Bayley’s Scale of Infant Development. DASII is used for infants in the age range of birth to 30 months and measures their motor and mental ages. In addition to providing the overall motor and mental developmental scores, DASII also indicates the specific clusters of delay under the broad areas of motor and mental functions. This information can be utilised in planning the individual programmes.

2. **Interview schedule for the mothers**

   The schedule consisted of three domains namely:
   a) Understanding of mothers about their child’s condition; b) the mother’s queries and the constraints faced; c) the mother’s coping.

   The tool was formulated by the investigator and validated by experts. Part of the tool related to coping was taken from the tool developed by Bhargava and Soudagar (6).

   The entire research consisted of five major components namely :
   a) Individualised programme formulation; b) programme implementation at the centre and the home; c) interviewing mothers; d) parental intervention and e) testing at different stages.

**RESULTS**

a) **Data related to children**

Table 1 shows the clusters that needed interventions under the motor and mental scales, separately for children with CP and for those with MR.
Irrespective of the condition of the children, it was found that all of them needed inputs in the cluster of Manipulation, and Locomotion 2, under the motor scale. Intervention was not provided for all the children in the cluster of Locomotion 2, as the required inputs were either taken care of by the physiotherapist or the child had yet to achieve the rudimentary milestones. However, Manipulation was focused upon for all. The scores showed lesser increase for children with Cerebral Palsy, as compared to children with Down Syndrome or Mental retardation in this cluster.

For children with Cerebral Palsy, though the child understands the concept of the activity, the limitations placed by the condition on the movement of his/her body makes it difficult to perform them. However, this was not the case with the activities/tasks which needed understanding, like concept of one, pointing or naming pictures, understanding prepositions etc. which they successfully completed.

In case of the children with Mental Retardation, it was observed that the results were different. There were 2 children with mild mental retardation and one with severe mental retardation. For all the 3 children, the performance was found to increase maximally in the cluster of Reaching and manipulation. Improvement was seen to some extent in the clusters of Manual dexterity and Understanding relationships for children with mild Mental Retardation. However, the effect of intervention in these two clusters was found to be less for the child with severe
The comprehensive results for all the infants consist of their initial and final scores i.e. scores obtained in Testing-1 and Testing-4, under the motor scale as well as the mental scale, as indicated in Figure 1.

**Figure 1. Initial and final scores of all the infants (n=6).**

The figure clearly depicts that there was improvement in the mental scores for all the infants, whereas in case of the motor score only 4 out of the 6 infants showed improvement from the first to the last testing.

Among the children with Cerebral Palsy (n=2), child 2 shows less increase in motor score. For child 1 however, there was increase only in the mental score. For the children with Mental Retardation there was more increase in the mental score as was found for child 5. This shows that for the study, there has been more increase in the mental score across all the children, irrespective of their condition.

**Data related to mothers**

The data obtained from the interview schedule, showed that the mothers were aware about the terms that were used to describe the condition of their child. However, all the mothers were not realistically equipped with knowledge about the limitations of the conditions and thus their expectations from the infants did not match the child’s present or future performance. In the words of the mother with a severe MR child, “He will be able to do everything and stand on his feet”. Additionally, the mothers needed information on more effective methods
of implementing activities with their children and activities to foster independence in the child. The method of coping that the mothers used was generally approaching the doctors, while a few believed in destiny. All the mothers reported that time was a major constraint and that attending the centre helped them in maintaining a fixed schedule for the child. Based on the information obtained from the mothers through the interview schedule, six sessions were planned.

Session 1: Stimulation and its importance in Cerebral Palsy
Session 2: Mental Retardation
Session 3: Down Syndrome
Session 4-5: Milestones for normative development
Session 6: Activities of Daily Living (ADL)

Some activities of daily living were also included as the mothers ignored it, believing that the academic part was more important for the child. Besides this, appropriate methods of conducting an activity were also discussed.

For all the infants, the home intervention contributed more in the improvement of the test scores as compared to the mother intervention programme. Greater increase in the scores of Testing 3 (after home intervention) was found as compared to Testing 4 (after mother intervention).

DISCUSSION

The issues of concern that emerge from the study are:

Limitations of uses of a standardised scale - In the research DASII was used to assess the children on their motor and mental abilities. The tool is standardised for the children of Baroda and so is culturally relevant. Additionally, it is used for children in the age range of birth to 30 months and was therefore appropriate to be used in the study. However, the results of the research indicated that certain achievements of the child were not being tapped by DASII and so had to be reported descriptively. These gains in the child’s performance could neither get reflected in terms of percentage nor in the graphs that depicted the movement in the scores. Thus, in order to assess a wider range of abilities of the child and to keep an
account of the child’s other capabilities, use of a battery of tests can be made. The tests like Binet Kamat Test and Vineland’s Social Maturity Test can be included for the assessment so as to tap the child’s abilities across the various areas of development, and make available comprehensive information for the parents/interventionists.

Understanding between the parents and the professionals - The mothers’ data revealed that though they approach the doctors and other professionals for help, these professionals share information in a manner which is not understood by the parents. Use of technical language by the doctors and the inability of the parents to understand, make them all the more apprehensive about the condition of their child. The parents need to be informed about the tests that there child is undergoing and the findings of those tests need to be explained to the parents. The doctors should be made aware about the importance of sharing information with the parents in the way that is easily understood by them. According to the parents, the report of their children highlights the child’s incapabilities, making the parents feel more guilty. Thus training should be provided to the professionals, so as to equip them with the ability to deal with the parents, making them feel more comfortable and less apprehensive about the child’s condition, about the tests that the child undergoes, his/her future and the best solution that should be suggested for the child.

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