

Developmental disabilities in children- Findings from focus group discussion in Southern India

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Abstract

Background: This study was done in order to understand common perceptions of developmental disabilities which would be important to prioritise educational, financial and infrastructural facilities to the community. **Methods:** This focus group discussion, conducted in southern part of India involving four distinct categories of people in the community, identified speech delay and speech disarticulation as the major developmental disabilities in children. **Results:** Interestingly, the groups themselves struggled with lack of understanding of common developmental disabilities, their causes, management and various preventive strategies available for disabled children among the groups. **Conclusion:** Further education of health care professionals in identifying and accessing support network to manage these children with special needs a proactive approach including incorporation of training in the medical and nursing curriculum.

Keywords: Childhood disabilities, developmental delay, Speech delay, Cerebral palsy

INTRODUCTION

Developmental delay in a child refers to significant deviation in the acquisition of skills, in one or more developmental domains (i.e. gross motor, fine motor, speech/language, cognitive, personal/social or activities of daily living.^[1] Although, perception of childhood disabilities differs in various sections of the community related to the socioeconomic and educational status, understanding specific patterns is important in prioritising health infrastructure needs, especially in view of paucity of data related to this. This study, undertaken in the state of Kerala situated in southern part of India, attempts to explore these issues

MATERIAL AND METHODS

Focus groups are a form of group interview that capitalises on communication between participants in order to generate data.^[2] Here, the groups are encouraged to talk to one another, ask questions, exchange anecdotes and comment on each others' experience and points of view.^[3]

For this study, Focus group discussion was conducted among mothers attending outpatient department of Vimala Hospital, Kanjoor, a rural hospital, MBBS interns of Amrita Institute of Medical Sciences, nursing interns of Vimala Hospital and Amrita Institute of medical sciences and primary school teachers of Kanjoor government primary school, each group consisting of eight participants selected randomly. The study was conducted over a period of 6 months with two hours spent on each session. The factors taken into consideration during the focus group discussion are given in table 1. The topic was first

introduced at the time of initiation of discussion, and the topic guide was adhered to in order to streamline the group interaction. The discussion was written down in real time, and audio recorded for recall and analysis. The study received ethical approval from the Child Development Centre, Thiruvananthapuram, Kerala.

RESULTS AND DISCUSSION

The groups believed that there was 20-30% incidence of developmental delay in the community, mostly subtle and minor. The most common disability encountered by all the participating categories was speech delay followed by difficulty in speech articulation. They believed that major causes of developmental delay like cerebral palsy constituted only about 1 to 2 % of the total cases. In a previous study conducted in northern India, it was demonstrated that parents perceive speech delay as an important problem, and there is lack of awareness of other forms of disabilities in children.^[4]

Regarding the common causes identified for developmental disabilities, adverse antenatal factors were identified as the major cause. An adverse emotional event during pregnancy was recognised as an important factor contributing to developmental problems in children; although, the mechanism for it could not be identified by any of the groups. Speech delay was considered most often to be secondary to lack of stimulation. In case of speech, "ka" and "tha" tends to be confused by children and they appeared to interchange these words. They believed that this could be a normal developmental deviation. The group was unsure how much importance could be given to such problems.

The groups were divided on the question of inclusive education. There was concern regarding the possibility of inability of these children to adjust with the rest of normally performing children, while others felt that incorporation of these disabled children in normal education system could in fact foster development. Aggressiveness and inattentiveness in children were thought to be not well perceived by parents, and were often accounted as normal childhood behaviour. This lack of understanding could contribute to delay in seeking help and

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treatment of the same.

Parental education and awareness was considered the major strategy in management of developmental problems in children. As far as interventions were concerned, the groups agreed upon speech therapy as the most important, probably reflecting their perception of speech difficulty as the most common developmental abnormality. Health care professional education and awareness was a major preventive measure indicated by medical residents. However, the groups in general including the medical residents appeared to be unaware of the concept of early stimulation, which has been well demonstrated to significantly improve the quality of life of disabled children.^[5]

Early identification and management and improvement in nutrition were considered by majority as the major preventive measures against developmental disabilities. Kerala being the most literate state in India, it is widely believed that the employment status is better and hence the earning potential. However, earning potential appeared not to translate into provision of better nutrition for children. Hence, there is still a knowledge gap in nutritional requirements in spite of the high educational status. However, it appeared that the groups were not sure of the mechanism of interaction between nutrition and developmental delay. Earlier reports in literature have indicated that about 60% of disabilities could be accounted for by environmental factors, and micronutrient deficiencies like iron and folic acid.^[6]

Kerala is also considered a state with high suicidal rate. The groups felt that the psychological effect of presence of having a disabled child resulting in depression which increased the incidence of suicide. The groups felt that the financial constraint was not a factor in caring for these children given the economic stability of the people of the state.

On the matter of awareness of support systems, there is gross lack of awareness among the groups of support systems available for disabled children. Among the various support systems available for disabled people, the participants were aware only of governmental financial aid. Medical students appeared to be better aware of the facilities available, but still lacked understanding of administration of these facilities. This reflects a lack of information regarding the various governmental programmes and the different facilities available for disabled children, resulting in underutilization of these specialised facilities by doctors and other health professionals. A previous study conducted in Kerala indicated that 52% of disabled preschool children did not utilise the rehabilitation services, especially with regards to speech and hearing disability.^[7]

There was increasing concern regarding lack of parental awareness of developmental disabilities resulting in long term health implications. Many minor abnormalities were considered

variants of normal state and neglected. This needs to be addressed by adequate education to medical staff, teachers and to the parents by appropriate government initiatives. The medical curriculum could be improved upon to impart education with regard to early identification and management of disabled children. There is a dearth of speech pathologists and allied health professionals employed in the community. These specialists tend to be concentrated in major public or corporate hospitals making public access to these facilities limited. There should be a proactive government initiative to address this deficiency in order to improve the general health of the community.

The study being qualitative, objective assessment of the impact of developmental disabilities couldn't be made. Moreover, the focus group discussion had focussed on the disability perception of specific sections of the community which may not be representative. However, the study provides important insights into the various perceptions on childhood disabilities, and educational lacunae in the medical and nursing curriculum with regard to developmental issues in children which could be topics for future research, discussion and appropriate remediation.

ACKNOWLEDGEMENT

We thank all the Nursing residents (Karuna Hospital , Kanjoor) , MBBS residents (Amrita Institute of Medical Sciences , Kochi) , Teachers (Primary school , Kanjoor) and mothers who wholeheartedly participated in the discussion . We thank the guidance of Child Development Centre, Thiruvananthapuram, Kerala in Conducting the study , with special gratitude to Dr.MKC Nair and Babu George .

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Table 1 – Topic guide for focus group discussion

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| <ol style="list-style-type: none"> 1) Common developmental disabilities among children 2) Prevalence / magnitude of developmental disabilities among children 3) Risk factors for developmental disabilities among children 4) Socio cultural beliefs and practises in community regarding developmental disabilities 5) Importance of early diagnosis and referral of children with developmental disabilities 6) Difficulties faced by parents of developmentally delayed children 7) Intervention strategies for developmental disabilities 8) Prevention of developmental disabilities |
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