

KAP STUDY ON MOTHERS OF CHILDREN WITH DOWN SYNDROME

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ABSTRACT

We evaluated 50 mothers of children with Down syndrome attending Genetic Clinic of the Institute of Child Health and Hospital for Children, Madras, with special reference to their knowledge, belief and attitudes in the care of these children. After evaluation, they were educated individually and in groups with demonstration, picture cards and pamphlets, on the causation, expected health problems, developmental potential of Down syndrome and the ways and means to help the child to attain the maximum developmental potential. They were taught on preventive aspects of Down syndrome as well. Re-evaluation was done after three months, and considerable improvement was noted in the mother's knowledge, and attitude towards bringing up such a child. The mothers also showed an improvement in the skills in providing developmental enrichment to these children. Thus this study has formulated a programme in the management of such children, which can be practised in any population, anywhere, especially, in rural areas, and by less affluent folk, with poor educational background.

Key words: Down syndrome, Health education, Training of mothers.

Down syndrome (DS), with physical and mental handicap and multisystem involvement, requires a concerted effort in management. Besides the medical team, a co-operative parent, with knowledge of the problems and their management, is indispensable to achieve any success towards attaining maximum developmental potential(1). Most of the patients attending the hospitals are from poorer socio-economic strata and are poorly educated. To make such mothers develop proper attitudes in bringing up the child, besides educating them on various aspects of DS, including stimulation and prevention, a special programme has to be designed, keeping in mind their prior attitudes, belief and practices(2,3).

The present study was aimed at evaluating the knowledge, attitude and practices of mothers of children with DS. This was followed by a training programme, with demonstration by picture cards and pamphlets, in local language (Tamil). After three months, re-evaluation was done to assess the efficacy and the impact of the programme(4).

Material and Methods

Mothers of 50 children with DS attending the Genetic Clinic at Institute of Child Health and Hospital for Children were selected from May, 1989 till October, 1989. Children with DS, of different age groups,

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attending the hospital for the first time were included in the study. The study was conducted in 3 sittings: (a) preliminary evaluation, (b) education and counselling and (c) re-evaluation. Mothers were interviewed directly and genetic counselling and parental education were given side by side.

Printed Proforma were used for preliminary evaluation. It contained general particulars, various aspects on knowledge, attitude and practices.

Illustrations containing various postures to be adopted by an infant to improve their motor development were shown to the mother(5). Printed leaflets in Tamil were used for health education. It contained simple facts about DS (name, probable cause, persons at risk, improvement to be expected, chances of recurrence and

prevention), physical appearance of a DS child, their expected developmental achievement (motor/mental), behaviour, adolescent life and life span, common complications and illnesses that occur, general advice on nutrition, immunization and cleanliness and the facilities available at hospitals. Various aspects of early stimulation in sensory and motor/adaptive fields during various stages of development were also taught to the mothers individually and in groups.

Results

Fifty children with Down syndrome were selected for the study of which 29 were boys and 21 girls. Children below 3 years of age constituted 80%. The birth order was first or second in 60%(Table I).

TABLE I—Data on Mothers Selected for the Study

Maternal age (yrs)		20	20-30	30-40	40	Total
		6 (12)	27 (54)	12 (24)	5 (10)	50
Birth order	1	5	5	8	—	18 (36)
	2	1	10	—	4	15 (30)
	3	—	8	1	1	10 (20)
	4+	—	4	3	—	7 (14)
Number of siblings						
Only child						
		1	6	4	—	11 (22)
1		3	2	3	1	9 (18)
2		2	12	2	4	20 (40)
3+		—	7	3	—	10 (20)
Karyo type						
21 Trisomy		4	25	10	5	44 (88)
21 Trisomy/Normal mosaic		1	2	2	—	5 (10)
Translocation 14/21		1	—	—	—	1 (2)

Figures in parantheses indicate percentages.

The reasons for bringing the children with Down syndrome to hospital were developmental delay (62%); referral by an attending doctor (18%); recurrent respiratory infection (12%); cardiac ailments (4%) and cleft lip and palate (2%). Except for 9 children (18%) who were diagnosed at birth, 20 mothers (40%) were unaware of the disease and 21 (42%) felt that the child was weak with inadequate brain growth. None of the mothers found the facial features strikingly different from normal. Thirty two mothers (64%) did not possess any knowledge about the possible etiological factor, whereas 36% attributed it to some form of antenatal events such as poor diet, general weakness, injury, abortifacients, abdominal pain, hyperemesis gravidarum and long intervals between child birth. Ageing was not considered an important cause by the mothers. Often the mothers were solely blamed for giving birth to a defective child and this had created social and emotional problems in the family. Twenty eight (56%) mothers felt that their children would develop normally with advancement of age, 11 (22%) were unsure, 8% felt that it was curable and 3 (6%) anticipated delay in growth and development. Most of the parents (80%) were not aware of the significance of special care essential for their child's growth and development while 20% wanted to give some form of care with physician's advice.

Forty per cent of mothers (64%) did not know about the possibility of recurrence of DS in the family, 12% of study group were sterilised either due to large family or for fear of recurrence; 12% expected recurrence and 8% felt that this defect will not recur.

In all cases, DS was diagnosed only by medical officers unlike in developed countries and among affluent section in

our country, where parents possibly suspect DS with advanced maternal age and from the presence of typical facial features and delayed development.

On being informed that their children were suffering from a birth defect which was not curable, 52% were depressed. The other types of reactions noted were disappointment, shock and dejection. Six per cent were still unaware of the magnitude of the problems. One mother did not show any reaction and another accepted the situation after seeing children with other forms of serious physical and mental handicaps. In spite of these varied reactions, 88% of mothers wanted their children to be cared for. Only 6% of the mothers either showed no reaction or were not eager to give special care for these children.

Despite differences in knowledge and attitudes of the mothers towards their affected children, their practices in routine day to day care of their affected children were not different in any way from that of the normal ones. Forty eight children (96%) were breast fed and appropriately weaned. Ninety per cent were given essential immunization. Only 4% of the mothers failed to breast feed on account of inadequacy and 10% failed to immunise due to illiteracy or intercurrent infections.

The care for the children with Down syndrome during various illnesses like respiratory, gastro-intestinal, cardiac and surgical diseases were adequate as evidenced by their frequency of hospital visit monthly (40%), fortnightly (14%) and weekly (20%). Ninety eight per cent of the children were brought up by mothers despite initial and intermittent conflicts with their life partners (6 cases). But 94% of the mothers were not aware, prior to health education, of the special care to be practiced so as to improve the sensory motor

and speech development. Only 24% of parents were sterilised and 4% wanted to get sterilised, 66% were not sterilised and one mother was pregnant and was willing for prenatal diagnostic procedures.

Reassessment of the mothers after genetic counselling and health education were conducted after 3 months period. Eighty per cent were reviewed and 20% dropped out. All the mothers were able to understand the magnitude of problem. They became aware of the course and complication of the disease.

Three-fourths of the mothers were doing passive exercises at home and helped their children in developing their vocabulary. Only 25% were unable to give an adequate care due to lack of time, as they had to go for work due to economic constraints.

Discussion

Down syndrome is a condition where much improvement in the developmental field can be achieved by proper management. As for other handicaps, domiciliary management is ideal, and the family, especially the mother, has a crucial role to play in development of enrichment and early stimulation programmes.

Barbara *et al.*(6) after a longitudinal study of follow up of children with DS, report on the positive effect of EIP (early intervention programme) in providing a foundation for subsequent learning and developing. Hartley(7) states that the parents are a vital resource, as they are willing and able, particularly with guidance, to stimulate and encourage their children in all aspects of growth and development.

The present study endorses our view that parents are keen on improving their children's performance by their whole hearted participation.

Irrespective of age and sex of their affected children, the rearing practices were same as for the other normal children. But the knowledge about various facilities available were insufficient. Because of ignorance and illiteracy they were not aware of an existing disease and its magnitude. When proper education was given, they did accept the diagnosis and were eager to participate in intervention programmes for their child's physical and mental development(8). By emphasising the chance of recurrence to the mothers at risk, the importance of family planning could be stressed and where ever needed antenatal screening could be done to prevent the birth of a child with Downs syndrome. The study also revealed that simple health education regarding the disease through conversation, pictures and booklets did have an impact on mothers in creating awareness for a better life to their children.

Though there are papers on training aspects of DS children and their mothers, there is, to our knowledge, no published paper on KAP studies on such mothers.

The present study enabled us to evolve a successful educative and training programme for mothers of Down syndrome children, from low socio economic and poor educational background. This can be practised in rural areas also, where hospitals with rehabilitation facilities are not accessible. Further repeated evaluation and comparison with controls is necessary to ascertain its effect in development of these children.

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