Experience in Counselling Down’s Syndrome

I read with great interest the recent communication titled “Issues in Counseling for Down syndrome”(1). The communication is very interesting and highlights the lacunae and deficiency in the knowledge of pediatricians in handling parents of this common syndrome. I recorded 17 children of recognizable malformations, 9 of whom were phenotypic Downs syndrome (chromosomal analysis not done in any child) while working at a community level charitable trust organization in Agra (UP) between January to November 2004(2).

These nine children were seen prior by pediatricians and were more than 5 years of age. All came from families of lower socioeconomic class (rural and urban slums). Only 3 parents were aware of the diagnosis, all knew about the incurability of the condition and presence of mental retardation. Few were fed up with the recurrent chest infections in their children and demanded an explanation for this. None were aware of the likely medical problems, schooling issues, recurrence in future children and what to about it. All were depressed about the mental retardation but some were happy that their child is very friendly and cheerful.

In the absence of a qualified medical geneticist in the town at the time, unwillingness of parents to go to other towns for specialized medical genetics services and available counseling services being unaffordable to most families, the best I could do for them was to screen for medical problems and do the counseling myself. I tailored the issues specific to individual families, high lightened the need for vocational training in long term and discussed and motivated all parents regarding future pregnancies. I used established strategy of motivational interviewing to increase family’s adherence to specific issues(3). I was disappointed to be only partially successful and felt a need for further training. The bulk load of children requiring counseling services comes to practicing Pediatricians first. It may not be feasible for every practicing pediatrician to undergo training courses in counseling after post-graduation due to different preoccupations. The best possible way seems to include a short-structured training module in genetic counseling during postgraduate training program in Pediatrics.

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REFERENCES

Kawasaki Syndrome in Coastal India

In response to your editorial(1) we present our observations on 26 children diagnosed with typical Kawasaki Syndrome (KS) conforming to American Heart Association criteria in a coastal district of South India between 1999 and 2006. All were referred, 30% (3/10) with probable diagnosis of KS before 2004 and 62.5% (10/16) thereafter. Mean age in years at presentation was 5 till 2004 and 3.5 thereafter with equal sex ratio contrary to male predominance reported worldwide. Though all children presented with fever, mean duration of