

To ascertain the co-morbidities which can lead either to mortality or hospitalization in children with downs syndrome and its effect on the quality of life of their parents

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Introduction

In India the DS births occur with a frequency of 1 in 800. Because of medical advances and improvements in overall medical care; the median survival of individuals with DS has increased considerably. This longer life expectancy requires giving the necessary care to the individual with DS over their total longer lifespan and determining factors that aim at better quality of life both for the children and for their parents. As concerns about mortality diminish, causes and consequences of morbidity for these children gain importance (Horwitz et al 2000). This study was tailored to look at the reasons for hospitalization and mortality which may contribute to increased costs and loss of daily wages to their parents and have significant impact on the quality of life of the care givers.

Materials and methods

The information database was prepared in a span of 2 months. The DS patients with confirmed karyotype were recruited from Genetic Clinic. The sample size of the study was 70. A structured performa was filled by the caregivers for 54 cases and 16 DS deaths were analysed from their hospital records. Based on all these methods, each patients profile was prepared for identification of

the co-morbidities associated with DS and assessment of the quality of life of the caregivers.

Results

We found a high prevalence of CVS abnormalities such as septal defects, cyanotic and acyanotic heart disease as a major factor contributing both to morbidity as well as mortality in patients with Down's syndrome. Our study revealed mother's education, the socio economic status of the family and the social assistance to be positive and strongly correlating. We found that education status of the caregivers playing an important role in seeking medical attention as well as grappling and understanding the dilemmas in rearing an intellectually suboptimal child with Down syndrome.

Conclusion

1. The most common co-morbidity associated with Down's syndrome is found to be cardiac anomalies (64.81%)
2. The most common cause of mortality studied is found to be septal defects (62.5%)
3. A major number of care givers agreed that the disease has had a negative influence on their quality of life. 57.5% quoted the changes to be easily adaptable while 22.5% reported it to cost them heavily. 3% announced it to cause a detrimental influence on the various strata including job maintenance, social life maintenance etc.