

Abstract

Introduction:

The numbers of children with neurodisability, especially children with cerebral palsy (CP) are increasing mainly due to the increased survival of premature babies. There are problems of parental awareness of the disease condition, follow up and related social problems in these children. Understanding the gaps of knowledge in those areas would help to provide better care for the children with CP.

Objectives:

To describe the parental knowledge on the disease, counselling, alternative practices, and the social impact on families of children with cerebral palsy treated at Lady Ridgeway Children's Hospital, Sri Lanka.

Method:

This descriptive cross-sectional study included 300 children with CP under the age of 12 years treated at medical clinics or in medical wards of the Lady Ridgeway Children's Hospital, Colombo, Sri Lanka. The sampling method used was Systematic Sampling of every other eligible patient with the first patient being selected randomly. Data was collected using interviewer administered questionnaire after taking informed written consent. The knowledge on the disease and adequacy of counselling was assessed using a questionnaire which was scored in a way that higher scores reflect better outcomes. The social impact was assessed using a questionnaire which was scored in a way that lower scores reflect better outcomes.

Results:

The sample consisted of 56% males. 47% of the children had to travel more than 100km to reach the Lady Ridgeway Children's Hospital. 86% of children were spastic and were in Gross Motor Function Classification Scale (GMFCS) stage 4 or 5. 74% of care givers scored $\geq 50\%$ marks in the knowledge score on the child's disease status whereas 61% had scored $\geq 50\%$ in the counselling score. Only 8.3% of the families had scored $\geq 50\%$ of social impact score. Almost all (97%) attended rehabilitation clinic while 66% attended the neurology clinics. Overall, 43% of patients had tried alternative medical streams.

Mothers' education up to A/L and above was significantly associated with the high level of knowledge on their child's disease ($p < 0.05$). There is no statistically significant difference in the level of counselling received with the child's diagnosis ($p = 0.463$), sex of the child ($p = 0.146$), or with the province of residence ($p = 0.469$).

Conclusions:

Majority of care givers had $\geq 50\%$ of knowledge score on child's disease status and received $\geq 50\%$ for counseling score. Less than 10% of families had $\geq 50\%$ social impact score due to the child's disease.