Do the paediatricians perceive the impact of disability of children same as their parents?

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Background

It is important to understand the complex interrelationships between a disabled child and the child’s family. While assessing the impact of the disability of the child on the family, the parents or the carers of these children are one of the best proxies to report it. Parental reports may not substitute the child self-reports, but could play the role as complementary and important information. It is important for the health professionals who are designing the management plans for such children to understand the impact of the children’s disability on their family as it could well reflect their quality of life.

However, do the healthcare professionals perceive the impact of the disability as the parents do?

Method

We selected a cohort of children diagnosed with cerebral palsy registered on the ‘Norfolk Disability Register’ which is a parental and self-assessment based register. All local authorities in the UK have a duty under the 1989 Children Act to hold a register of disabled children in their area.

Out of total 94 children on the register with the diagnosis of cerebral palsy, 44 parents consented to participate in the study. Reviewing the clinical records of these 44 children, 3 were classified as GMFCS 1; 5 as GMFCS 2; 13 as GMFCS 3, 10 as GMFCS 4 and 13 as GMFCS 5.

The blank registration forms used by the parents to register their children’s disability or special need, were sent to the children’s respective community paediatricians or general paediatricians who knew the child best through regular and long term follow up visits. For each child, they were asked to fill in section ‘E’ which lists 18 areas of impairment and functioning and section ‘F’ which enlists child’s diagnosis and a ‘scale of impact of their impairment on their daily life’ between 1 to 5, where the scale 1 means ‘no difficulty’ and scale 5 is ‘impact felt on almost all activities every day’.

Result

24 were male (60%) and 20 were females. Weighted Kappa statistics was used for comparing the number of impairments and the impact of the disability reported by the parents and the healthcare professionals.

For section ‘E’, the patient’s and doctor's scores agreed on 76.01% of the observations, or 31.34% (k=0.3134, SE 0.0738) of the way between random agreement and perfect agreement. This translated to the agreement being classed as “Fair”. A p-value of <0.0001 indicated that the patients and doctor were not scoring randomly.

While there was a fair agreement between both the groups for number of impairments reported, poor agreement was found for the impact of disability perceived by both the groups (p 0.07).

Conclusion

With this study, we have shown that there seems to be a difference in the perception of the impact of a child’s disability by their carer and the healthcare professionals. It is important for the clinicians to understand the impact of disability of the child as perceived by their carer so as to facilitate and deliver the services more effectively. The authors are aware that the questionnaire used in our study is not a validated one and hence further research on this topic would be beneficial.