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Submitting author: Mr Yee Ting IP

Post title: Clinical Psychologist, The Duchess of Kent Children Hospital

Understanding the Stress and Family Impact of Parents of Children with Neuromuscular Disorders (NMD) – A Study in Hong Kong West Cluster (HKWC)

Ip YT(1), Liang R(2), Chan HS(2)

(1) Clinical Psychology Department, The Duchess of Kent Children's Hospital at Sandy Bay, (2) Department of Paediatrics and Adolescent Medicine, The University of Hong Kong

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Introduction

Neuromuscular disorders (NMD) are diseases of the muscles, nerves and junctions when they meet. These are very rare conditions caused by genetic mutation that lead to muscle weakness and movement difficulties, which would chronically affect the child. A child's diagnosis with NMD would drastically impact the entire family, especially their parents in most cases. This is the first report to examine parental stress and family impact in a group of parents of children with NMD in Hong Kong.

Objectives

To examine parental stress and family impact in a group of parents of children with NMD

Methodology

Twenty-nine parents of children with diagnosis of NMD were recruited. Diagnoses of NMD in the sample include Duchenne Muscular Dystrophy (DMD), Spinal Muscular Atrophy (SMA) and others (e.g. Congenital myopathy and Congenital muscular dystrophy etc.). The PedsQM™ Family Impact Module and Parental Stress Scale (PSS) were administered to them.

Result

Parental Stress was found to have moderate negative correlations with overall parental functioning, Parent Health-related Quality of Life (HRQOL) and Family Functioning (all $p < .01$). All domains of parental functioning (Physical, Emotional, Social, Cognitive, Communication and Worry), Daily Activities and Family Relationships also showed significant low-to-moderate negative correlations with parental stress (all $p < .05$).

Participants' profiles of parental stress and functioning level were reviewed, no

significant difference was found among parents of children with different diagnoses of NMD. However, most participants reported high parental stress with fourteen of them (48%) experiencing stress overload that required clinical attention. This group of parents showed significantly worse overall functioning ($p < .01$), Parent HRQOL ($p < .05$) and Family Function ($p < .01$). Specifically, they demonstrated worse functions in Physical, Emotional and Social domains (all $p < .05$), as well as Daily Activities ($p < .05$) and Family relationships ($p < .01$). On the other hand, twelve participants in the sample had received or had been receiving Clinical Psychology service. Their reported parental functioning was relatively better as in expected directions, with improvement in Worry scale close to being statistically significant ($p = .06$).

In conclusion, parents of children with NMD experience high parental stress, which correlates with worse parental functioning across the board. Results also suggested Clinical Psychology service having promising effect in enhancing parental functioning, especially in relieving parents' worries in facing such rare and chronic health condition of their child. A comprehensive service model with timely intervention is proposed for this group of family.