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Original Article

The Impact of Paediatric Neuromuscular Disorders on Parents' Health-Related Quality of Life and Family Functioning

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Abstract ***Aims:*** This study aimed to evaluate the impact of hereditary neuromuscular disorders on parent's health-related quality of life and family functioning, and to study the correlation of parental stress on family impact. ***Methods:*** This retrospective cross-sectional study analysed responses from 80 parents of 80 children with different neuromuscular disorders on two self-reported questionnaires: the Chinese version of PedsQL™ Family Impact Module and the Parental Stress Scale. ***Results:*** We found the Parental Stress Score exhibited a moderate negative correlation with the PedsQL™ Family Impact Module total score (Pearson correlation coefficient: -0.55). Among different neuromuscular disorders, spinal muscular atrophy had the worst negative family impact. Additionally, a non-walking status had moderate negative effects on family impact (T-test effect size: 0.71). ***Conclusion:*** Neuromuscular disorders cause a significant negative family impact. Evaluation of parental stress, parental health-related quality of life and family functioning should be part of the standard of care for affected families.

Key words Neuromuscular disorders; Quality of life research

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Introduction

Hereditary neuromuscular disorders (NMDs) are a heterogeneous group of conditions cause by underlying genetic mutation(s) leading to diseases arising from different parts of the lower motor neuron units. These diseases differ regarding age of onset, disease progression and life expectancy and commonly cause orthopaedic, respiratory, cardiovascular, nutritional and gastrointestinal complications. A child with an NMD presents a complex challenge to the whole family. Parents of chronically ill children frequently report physical, emotional and cognitive problems.[1] Conversely, the family's wellbeing affects the care received by the ill child.[2] Therefore, the importance of assessing the impact of chronic illness on parents or families has become evident. Parents with children having chronic illnesses often have significant stress affecting multiple aspects of their life.[3]

The family impact of an NMD can be evaluated by considering the effects of the disease on individual

members (e.g., the parental HRQOL) and the overall family (e.g., family functioning). The parental HRQOL is a multi-dimensional construct used to evaluate parents' perceptions of the effects of their children's disease on the different life domains related to physical, mental and social wellbeing.[4] Family functioning refers to a family's ability to accomplish tasks important to wellbeing, adapt to changing circumstances or balance the needs of individuals with those of the entire family.[5] Up to date, very few reports have documented the family impacts of NMDs, or compared the family impacts of different paediatric NMDs.

The Family Impact Module (FIM) of the Paediatric Quality of Life Inventory (PedsQL™ 4.0) (PedsQL™ © 1998 JW Varni, Ph.D. All rights reserved) is a validated parent-report questionnaire developed by Varni et al[6] and cross-culturally adapted into Chinese by Chen et al.[7] The Chinese version comprises nine domains-Physical functioning, Emotional functioning, Social functioning, Cognitive functioning, Communication, Worry, Daily activities, Family relationships and Finance. The first 4 subscales measures parent self-reported HRQOL functioning, and the Daily activities and Family relationships subscales measure parent-reported family functioning and is commonly used to assess family impact. By contrast, other available instruments are generally brief and one-dimensional.[8]

The Chinese version of the Parental Stress Scale (PSS), a validated self-report scale developed by Cheung,[9] was adapted from the Parental Stress Scale developed by Berry and Jones.[10] This scale measures the level of stress experienced by parents and considers both positive (e.g., emotional benefits, self-enrichment, personal development) and negative components of parenthood (e.g., demands on resources, opportunity costs, restrictions). This one-page questionnaire is half the length of the PedsQL™ FIM and is commonly used in Hong Kong to screen and identify parents experiencing stress and to facilitate early referrals to clinical psychology services. However, it remains uncertain whether the PSS score correlates with a poor parental HRQOL or poor family functioning. Therefore, this study aimed to systemically evaluate the parental HRQOL and family functioning in the families of paediatric patients with NMD and to examine the correlations of these measures with parental stress.

Methods

Study Design

At our hospital, all families of children with hereditary NMDs attend paediatric neuromuscular disorder clinics and complete the Chinese versions of the PSS and PedsQL™ FIM upon diagnostic confirmation. This retrospective study evaluated the parents' responses to both questionnaires during follow-up visits at our neuromuscular disorder clinics during the period of 4th July 2016 to 15th March 2018. Data on the age, sex, diagnosis, comorbidities, ambulation status (walker/non-walker), ventilation support (does/does not require) and feeding status (requires/does not require assistance) of each paediatric NMD patient were systematically collected from the electronic patient health record system at the same time as the questionnaire completion.

The patients' diagnoses were classified into one of four groups. Group 1 comprised patients with deteriorating muscle diseases, mainly Duchenne muscular dystrophy and congenital muscular dystrophy. Group 2 comprised patients with types 1 to type 3 5q spinal muscular atrophy (SMA), representing deteriorating motor neuron diseases. Group 3 comprised patients with stable neuromuscular diseases including congenital myopathy and congenital myasthenic syndrome. All patients with congenital myasthenic syndrome received oral medical therapy that resulted in clinical motor improvement. Group 4 comprised patients with hereditary stable peripheral nerve diseases with minimal or mainly distal weakness.

The parent who served as the main caregiver was invited to complete the questionnaires. If the questionnaires were completed during multiple visits, only the results from the first set were collected and documented. The total score, parental HRQOL summary score, family functioning summary score and each dimensional score in the PedsQL™ Family Impact Module were computed according to the guideline provided by the developer. The total PSS score was also computed.

Measures

The primary study outcomes were the parental HRQOL and level of family functioning, measured by the PedsQL™ FIM. The secondary outcome was the correlation between PedsQL™ FIM and PSS.

The PedsQL™ FIM comprised 37 items across 9 domains. The Finance domain was not included in the analysis since this domain was only introduced in the Chinese version of the questionnaire and was not part of the validated original questionnaire developed by Varni et al. The parental HRQOL summary score was calculated as the average of the physical, emotional, social and cognitive functioning scores. The family functioning summary score

was calculated as the average of the daily activities and family relationships scores.[8] All scores ranged from 0 to 100, with higher scores indicative of better functioning. The total PedsQL™ FIM scores were compared with those of children with other neurological conditions. These were obtained from published studies that used the PedsQL™ FIM to assess paediatric neurological diseases in comparable sample sizes. The selected data for comparison were extracted from a study of acquired brain injury by de Kloet et al.[11]

The PSS comprised 17 items scored on a 6-point scale; higher scores indicate greater stress. Previous data indicated that a cut-off point of 52/53 could be used to demarcate parent groups exhibiting satisfactory adjustment vs maladjustment. This scale had demonstrated satisfactory levels of internal reliability and test-retest reliability.[9,10]

Statistical Analysis

Descriptive statistics were calculated for the demographic features. Means and standard deviations (SD) of the PedsQL™ FIM and PSS scores were calculated for the total study sample and subgroups stratified by diagnosis and ambulation status. A t-test was used to compare data sets.

To compare the PedsQL™ FIM scale and total scores of patients with different diagnoses, the data was log10 transformed before analysis since the distribution of the data was not normal. A one-way analysis of variance (ANOVA) and post-hoc Tukey Kramer analysis were conducted.

A Pearson product-moment correlation analysis was used to determine the linear correlation between the PSS score and PedsQL™ FIM scale and summary scores. All statistical analyses were conducted using SPSS Statistics 20 (IBM, Armonk, NY, USA). Statistical significance was defined as p-value of <0.05.

Ethics

This study was approved by the relevant Institutional Review Board.

Results

Eighty parent reported PedsQL™ FIM and PSS questionnaires were collected from 21 fathers and 59 mothers. Most of the affected NMD children were medically stable and ambulatory (81% walkers, 94% not requiring ventilation support, 99% on full oral feeding). The distribution of the patient demographics and age ranges of patients in the four disease groups are shown in Table 1.

The means and standard deviations of the PedsQL™ FIM scores of the four NMD groups are presented in Table 2. Among the eight inventory domains, the domain on 'Worry' received the worst scale score. The Cronbach's alpha coefficients for the total and all scale scores ranged from 0.86 to 0.98. No floor or ceiling effect was observed (floor/ceiling percentages: 0.0-18.7%). Furthermore, when the PedsQL™ FIM scores were compared among the 4 different groups of NMDs, parents in Group 2 (deteriorating motor neuron diseases) reported the lowest total and scale scores across all items. Parents in Group 4 (hereditary peripheral neuropathies) yielded the highest total and scale scores. A one-way ANOVA revealed significant differences among the mean PedsQL™ FIM total, parental HRQOL and family functioning scores of different disease groups (all $p<0.01$). A post-hoc analysis revealed that Group 2 accounted for the greatest differences in the mean scores when compared with the other groups. The results of the ANOVA and post-hoc analysis are shown in Table 3. Additionally, the PedsQL™ FIM scores were compared according to ambulation status. A non-walking status was found to have moderate negative effects on the overall family impact, parent HRQOL and family functioning scores (T-test effect size: 0.71-0.83) (Table 4). Moreover, the PedsQL™ FIM total score in our NMD cohort was worse than that of the patients with acquired brain injuries,[11] as demonstrated in Table 5.

The Cronbach's alpha coefficient for the PSS was 0.89, indicating high internal consistency. The PSS score exhibited a moderate negative correlation with the PedsQL™ FIM total score (Figure 1) (Pearson correlation coefficient: -0.55). Specifically, parents with a higher level of stress reported a significantly lower HRQOL and poorer family functioning. When a cut-off of 52/53 was used to categorise parents into low- and high-stress groups, 36.63% of parents were in the high stress group. The corresponding mean PedsQL™ FIM total scores were 75.92 (SD = 12.83) and 62.16 (SD = 15.38), respectively. This difference was significant and had a large effect size of 0.98.

Discussion

This study conducted a multi-dimensional investigation of the family impact of NMDs. In this cohort, the affected NMD patients were mostly medically stable and ambulatory. The parents reported a poor parental HRQOL

Table 1 Patient demographics

Demographic factors	Number	Percentage		
Age (years)				
0-4	18	22.5		
5-8	26	32.5		
9-12	15	18.9		
13-18	21	26.2		
Sex				
Male	60	75.0		
Female	20	25.0		
Ambulation status				
Walker	65	81.3		
Non-walker[†]	15	18.8		
Ventilation status				
No ventilation support needed	75	93.8		
Ventilation support needed[‡]	5	6.2		
Feeding status				
Oral feeding	79	98.8		
Tube feeding	1	1.2		
Diagnosis			**Mean age (years)**	**Age range (years)**
Deteriorating muscles diseases[§]	26	32.5	8.7	3.6-16.5
Deteriorating motor neuron diseases	12	15.0	6.0	1.2-17.6
Stable neuromuscular diseases	34	42.5	9.2	0.9-17.2
Stable peripheral nerve diseases	8	10	12.0	5.4-17.8

[†]Bedridden = 1, Wheelchair user = 14

[‡]Nocturnal non-invasive ventilation = 5

[§]Congenital muscular dystrophy (unclassified) = 3, Duchenne muscular dystrophy = 17, Emery-Dreifuss muscular dystrophy = 1, Infantile facioscapulohumeral muscular dystrophy = 1, Megaconial congenital muscular dystrophy = 1, Muscular dystrophy (unclassified) = 2, Ulrich congenital muscular dystrophy= 1

Table 2 PedsQL™ FIM scores

	NMD Group 1		NMD Group 2		NMD Group 3		NMD Group 4		Total	
	Mean	**S.D.**	**Mean**	**S.D.**	**Mean**	**S.D.**	**Mean**	**S.D.**	**Mean**	**S.D.**
Total score	71.9	13.42	58.19	16.8	68.57	15.76	81.44	6.31	69.55	15.58
Parent HRQOL summary score	69.66	16.02	49.79	23.62	63.81	19.77	76.59	12.32	64.80	20.27
Physical functioning	72.84	14.98	59.72	17.5	73.02	14.76	83.62	10.59	65.42	20.10
Emotional functioning	72.89	16.12	58.67	24.51	68.59	18.28	81.33	19.55	62.37	24.50
Social functioning	75.19	14.87	60.83	20.6	71.37	19.36	85.83	12.39	65.81	23.33
Cognitive functioning	77.78	16.49	60.33	17.77	70.82	18.52	80	12.65	65.77	23.02
Family functioning summary score	65.22	17.80	44.47	19.02	62.34	22.17	76.39	16.26	62.06	22.18
Daily activity	68.72	16.41	50	19.72	66.86	22.95	83.81	10.61	58.44	26.71
Family relation	74	16.24	59.67	21.19	71.41	17.33	80	19.94	65.00	24.10
Communication	73.46	18.56	58.89	20.52	66.67	21.08	89.52	14.19	62.23	26.24
Worry	57.38	17.04	54.67	16.52	57.88	19.55	72.57	16.76	48.27	23.56

PedsQL™: Paediatric Quality of Life Inventory, FIM: Family Impact Module, HRQOL: health-related quality of life, S.D.: standard deviation, NMD: neuromuscular disorder

and a low level of family functioning significantly worse than those reported in acquired brain injury. Our findings suggested that rare hereditary NMD diseases with complex medical needs, have significant negative family impacts and the family needs should not be neglected.

This study found that out of the eight domains of the PedsQL™ FIM, parents reported the worst scores in the 'Worry' domain, which included worries about others' reactions to their child's condition. Previous studies revealed that some parents of children with disabilities avoided their relatives and friends since their child's and family's needs were often not understood by others.[14] As NMDs are rare diseases, they are often poorly understood by the general public. Therefore, parents might be particularly worried about others' reactions to their affected child. The Worry domain also addressed worries on the efficacy and safety of the child's treatment, as well as the child's future. The current findings may correlate

Table 3 One-way ANOVA table of (log-transformed) total score, parental HRQOL summary score and functioning summary score

Score	NMD Group 1	NMD Group 2	NMD Group 3	NMD Group 4	Tukey Post Hoc Test - Multiple comparisons^#	*p*-value
Total score*	1.86 ±0.78 (n=26)	1.75±0.14 (n=12)	1.82±0.11 (n=34)	1.91±0.04 (n=7)	Group 1, Group 2: 0.11 (0.02-0.20)	0.012
					Group 2, Group 3: 0.08 (0.01-0.17)	0.101
					Group 2, Group 4: 0.17 (0.04-0.29)	0.005
Parental HRQOL Summary score*	1.83±0.11 (n=26)	1.64±0.259 (n=12)	1.78±0.15 (n=34)	1.88±0.08 (n=7)	Group 1, Group 2: 0.19 (0.05-0.34)	0.004
					Group 2, Group 3: 0.15 (0.006-0.28)	0.037
					Group 2, Group 4: 0.24 (0.05-0.44)	0.009
Family Functioning Summary score*	1.80±0.13 (n=25)	1.60±0.24 (n=12)	1.76±0.19 (n=34)	1.88±0.10 (n=7)	Group 1, Group 2: 0.20 (0.04-0.36)	0.010
					Group 2, Group 3: 0.16 (0.01-0.32)	0.036
					Group 2, Group 4: 0.28 (0.06-0.50)	0.007

*Score are expressed in Mean ± SD; # Statistically significant result (p<0.05) were shown

^ Multiple comparisons are expressed in Mean Difference (95% CI)

NMD: neuromuscular disorder, HRQOL: health-related quality of life

Table 4 Independent T test comparing ambulation status with scale scores and total scores for PedsQL™ FIM impact for NMD sample

	Walker		Non-walker			
	Mean	S.D.	Mean	S.D.	Difference	Effect Size
PedsQL™ FIM total score	71.57	14.79	60.93	15.92	10.64*	0.71
Parental HRQOL summary score	67.47	18.91	53.42	22.57	14.05*	0.72
Family functioning summary score	65.43	20.60	47.92	23.70	17.51*	0.83

*Statistically significant result (p<0.01) were shown

PedsQL™: Paediatric Quality of Life Inventory, FIM: Family Impact Module, NMD: neuromuscular disorder, S.D.: standard deviation, HRQOL: health-related quality of life

Table 5 Independent T test comparison of PedsQL™ FIM total scores of this NMD cohort and acquired brain injury cohort[11]

	NMD (N=80)		Acquired Brain Injury (N=108)			
	Mean	S.D.	Mean	S.D.	Difference	Hedges' g effect size
Total score	70.55	15.58	80.4	17.9	-9.85*	-0.58

*Statistically significant result (p<0.05) was shown

PedsQL™: Paediatric Quality of Life Inventory, FIM: Family Impact Module, NMD: neuromuscular disorder, S.D.: standard deviation

with the fact that treatments for some NMDs remain under research and there are still lack of cures or disease-modifying treatments for many NMDs at the current stage. Furthermore, NMDs have variable prognoses, and the uncertain treatment outcomes might increase parents' concerns about their child's future.

The lack of the availability of effective treatment that resulted in a negative family impact at the time of this study, was especially evident in the deteriorating motor neuron disease group 2 comprised of patients with 5q SMA. SMAs are mainly treated via supportive interventions during the study period from July 2016 to March 2018. The first US Food and Drug Administration (FDA)-approved drug treatment for SMA, named nusinersen, was available in the United States since December 2016. During the study period, Spinraza was not available to the patients with SMAs in Hong Kong. Parents were anxious about the deteriorating course of the disease without accessibility to the available treatment, and these concerns may have contributed to the poorer parental HRQOL and level of family functioning in this group. On the other hand, the PedsQL™ FIM scores from the deteriorating muscles diseases (the group with muscular dystrophies) and the stable neuromuscular diseases groups (the group with congenital myopathy and congenital myasthenic syndrome) were comparable. The PedsQL™ FIM scores of the peripheral neuropathy group were highest. This suggests the inaccessibility of available treatment might have a significant negative family impact in addition to the rate of disease progression. For DMD, the currently available steroid treatments help to maintain the motor function and delay motor deterioration; so, the negative family impact was not as significant as that for SMA. In Hong Kong, nusinersen was eventually made available to patients with SMA type I in May 2018 and to patients with later onset SMA in 2019. A follow-up study of the HRQOL and family functioning of those families with children receiving the treatment would be valuable to evaluate the proposed impact of treatment on parental HRQOL and family impact.

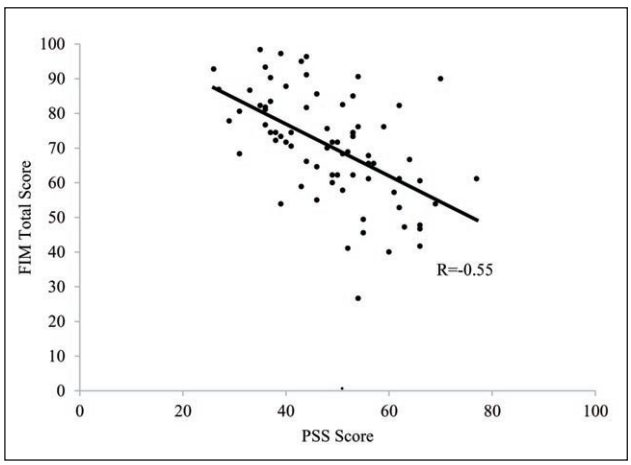

Figure 1 Scatter plot of the Paediatric Quality of Life Inventory (PedsQL™) Family Impact Module (FIM) total score against the Parental Stress Scale (PSS) score.

Our findings also revealed lower parental HRQOL and family functioning scores in the group of non-walkers when compared to those remained ambulant. This finding was consistent with previous reports of a negative correlation of parents' QOL with children's functional independence. In Bray P et al study, parents had greatest emotional disturbance of their child's DMD during the time of loss of ambulation.[12] In Liang R et al study, the overall family functioning in those with affected DMD boy was found to worsen as the child increased in age with advancing disease stage.[13] These results suggest the need for a reassessment of family impact as the child's ambulation deteriorates or develops additional medical complications. Our observation that the PedsQL™ FIM scores of the peripheral neuropathy group 4 were highest again added support to the above findings, as all the affected children in this group were ambulant with minimal or only distal weakness, and did not required other medical support having a stable disease course.

We further examined the correlations of the PedsQL™ FIM with PSS scores. Notably, we demonstrated that a PSS cut-off point of 52/53 could be used effectively to identify parents with poor HRQOL and low level of family functioning with significant difference in mean PedsQL™ FIM total scores between high stress and low stress groups being demonstrated. While the shorter PSS could be used as a brief screening tool to identify high-risk parents, it also helps to identify families with significant negative family impact and impair functioning that needs early support.

This study had several limitations. First, comparisons of our findings with other neurological diseases were performed using data extracted from previous report, given the lack of local PedsQL™ FIM score data for direct comparison. Future research should consider the inclusion of time-matched samples of other disease condition for direct comparison. Second, the collected parental demographic information was limited, and the effects of some factors on the family impact such has the family income, accommodation, parents' educational level and

health status, could not be assessed. Furthermore, families between NMD groups were not matched by demographic variables, as inter-group differences may not be solely explained by the difference in diagnosis. Future studies with larger number of NMD patients with data stratification by different demographic variables, could be helpful to identify underlying risk and protective factors for parental stress and family functioning. Finally, this study included only patients attending the outpatient NMD clinics with a stable general health and not those with frequent inpatient admissions with more severe disease complications. Therefore, the results may not be able to reflect the family impact of NMDs of the whole spectrum of severity but only those more stable with higher functional performance.

In conclusion, this is the first multi-dimensional study on the family impact using PedsQL™ FIM on paediatric NMDs. We found that paediatric onset NMDs can cause significant negative family impact and affect the family functioning. Evaluation of parental stress, parental health-related quality of life and family functioning should be part of the standard of care for families with affected children with NMDs. The significantly lower family impact in the group of 5q-SMA may be attributed to both the rapid deteriorating disease course and the inaccessibility of treatment available overseas, at the time of the study. While PSS could be used in the clinic setting to screen for high risk families with affected paediatric NMD children, the use of PedsQL™ FIM self- reported questionnaires help to understand the affected parental HRQOL and the family impact better, so to guide the necessary support for the family.

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Declaration of Interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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