

Impact of COVID-19 pandemic on the psychosocial well-being of children with neuromuscular disorders

Michael Kwan Leung Yu

University of Hong Kong

Winnie Wan Yee Tso

University of Hong Kong

Ka Man Yip

University of Hong Kong

Yu Liang Wang

University of Hong Kong

Wilfred Hing Sang Wong

University of Hong Kong

Oscar Kuen Fong Yiu

University of Hong Kong

Lok Kan Leung

University of Hong Kong

Godfrey Chi Fung Chan

University of Hong Kong

Patrick Ip

University of Hong Kong

Sophelia Hoi Shan Chan (✉ sophehs@hku.hk)

University of Hong Kong

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Abstract

To examine the impact of COVID-19 on the psychosocial wellbeing in children with neuromuscular disorders (NMD), the parents of 41 children with NMD aged 3-12 years completed a survey during COVID-19 pandemic. The findings were compared to those of the parents of 164 matched typically-developed (TD) children. Health-related quality of life and lifestyle habits of the NMD group were compared with the TD group using independent two-sample t-test. Children with NMD with uninterrupted disease-modifying treatments showed higher PedsQL total scores during the pandemic compared to the pre-pandemic state ($p=0.012$). PedsQL total score in the NMD group was significantly lower than the TD group ($p<0.001$). Those with disrupted rehabilitation training (73.8% of NMD group) had significant lower PedsQL scores compared to those with continuous training ($p = 0.012$). Parental guidance on the usage of electronic devices was significantly associated with the total score of PedsQL, particularly in the NMD group ($p=0.007$). In conclusion, children with NMD have had a poorer quality of life than TD children during the COVID-19 pandemic. Our study highlights the importance of parental guidance on electronic device usage, the continuation of drug treatment, and rehabilitation training for the psychosocial wellbeing of children with NMD during the pandemic.

Introduction

The outbreak of coronavirus disease 2019 (COVID-19) has significantly affected the physical and mental health of children worldwide. Due to the implementation of social distancing measures, such as the suspension of face-to-face teaching and closure of recreational facilities, children's learning and routine activities have been heavily disrupted. There are increasing concerns over children's psychosocial wellbeing as a result of their more sedentary lifestyles, disrupted sleep patterns, and poorer mental wellbeing and family functioning¹⁻⁴. This issues is especially relevant to children with special educational needs, who often require regular rehabilitation training and have been significantly impacted by the implementation of social distancing measures. Studies in Hong Kong also revealed that children with special needs are more vulnerable to psychosocial problems with poorer quality of life, and their parents have been found to have greater parental stress and increased child maltreatment risk^{5,6}.

Patients with neuromuscular disorders (NMDs), especially those with respiratory compromises, are at risk of severe disease and complications if they contract the SARS-CoV-2 virus^{7,8}. Therefore, adherence to social distancing measures is often high among families with patients of NMDs. On the other hand, decreased social contact and isolation from work/school has also been found to contribute to anxiety and depression reported in parents of children with NMDs⁹. Nonetheless, the number of studies that explore the parental stress and quality of life (QoL) of children with NMDs during the COVID-19 pandemic remains limited.

In this study, we aimed to compare the QoL of children with NMDs to that of children with typical development during the COVID-19 pandemic and to identify the factors that might influence their psychosocial wellbeing. We also studied the healthcare utilisation of children with NMD and whether the

continuation of essential disease-modifying treatments led to improved psychosocial functioning and quality of life during the COVID-19 pandemic.

By identifying the factors that have impacted the psychosocial wellbeing and QoL of children with NMDs during the pandemic, we hope to provide more information to guide the development of strategies that will better support this group of children beyond the pandemic and to think of the lessons that could be applied if there is a similar pandemic in the future.

Results

NMD children and matched control cohort

Forty-one families with children with NMD aged 3-12 years joined the study and completed the questionnaires (response rate: 97.6%). The mean age of children with NMD and TD controls was 7.46 years (SD: 2.96 years) and 58.5 % of them were male (n=24/41 in NMD,88/164 in TD controls). There were no significant differences in the socioeconomic status index (SES) between the NMD group and TD controls (-0.25 vs 0.05, $p=0.294$). Half of the NMD group (48.8% ;n=20/41) had SMA (Type I: 13; Type II: 5; Type III: 2). Dystrophinopathy (7 patients, 17.1%) and congenital myopathy (7 patients, 17.1%), each accounted for one-sixth of the group. The remaining patients had congenital muscular dystrophy (7.3%), myotonic disorders (7.3%), or ocular myasthenia gravis (2.4%) (Table 1). Among the NMD group, more than half of the children were non-ambulatory (n=22/41, 53.7%), and 41.5% (n=17/41) required feeding assistance on Ryle's tube/gastrostomy feeding. Similarly, 41.5% (n=17/41) of the NMD group had scoliosis. Among the children (26.8%; n=11/41) who required non-invasive ventilation (NIV), seven were on nocturnal NIV, one was on NIV at night and part of the day, and three were on whole-day NIV. The mean daily duration of sleep and physical activity during the school closure period was 10.53 hours (SD: 2.46 hours) and 1.11 hours (SD: 1.16 hours), respectively (Table 1).

Disruption of medical appointments and rehabilitation training

Due to the COVID-19 pandemic, 73.8% (31/41) of children with NMD experienced disruptions to their rehabilitation training. Those who experienced disrupted training had significantly lower PedsQL scores compared to those who continued rehabilitation, $t(37) = 2.63$, $p = 0.012$ (Table 2).

Lower HRQOL in NMD children compared to the matched TD control group

Children with NMD were found to have significantly lower PedsQL total scores when compared to the matched TD control children (55.66 vs 81.6, $p<0.001$). The largest difference identified in the PedsQL subscale was in the physical functioning (41.48 vs 83.55, $p<0.001$), psychosocial functioning (80.23 vs 67.30, $p<0.001$) and social functioning (59.65. vs 81.49, $p<0.001$) domains. For SDQ scores, we did not observe a statistically significant difference between the NMD group and matched TD children (Table 3). The emotional domain of SDQ was found to be negatively correlated with the PedsQL social and psychosocial domain scores, and PedsQL total score ($r = -0.41$, $p < 0.05$).

In addition, children with NMD had significantly less physical activity per day compared to TD controls (1.16 hours vs 2.04 hours, $p = 0.009$). Parents of children with NMD also showed significantly less guidance and limitation on their children's e-device usage (2.15 vs 5.80, $p < 0.001$). With regards to the other variables, although we observed higher parental stress levels, more electronic device usage, and less sleep among children with NMD when compared to the matched control group, those differences did not reach a significant difference.

HRQOL in patients with SMA and DMD during Covid-19 pandemic compared to pre-pandemic

Table 4 compares the PedsQL total score of 3-12 year old children with SMA receiving nusinersen. The pre-COVID-19 data of 11 children with SMA (Type I: 3; Type II: 8) were collected between 2018-2019. The same 11 patients with SMA were found to have significantly higher PedsQL psychosocial functioning subscale scores (70.85 vs 58.18, $p=0.016$) and total scores (50.98 vs 41.67, $p=0.012$) during the COVID-19 pandemic compared to their pre-COVID-19 scores. Table 4 also compares the PedsQL total score of 3-12 year old children with DMD receiving regular steroid. The pre-COVID-19 data of the children with DMD ($n=11$) was collected between 2014 & 2015 and retrieved from our earlier study [10]. Patients with DMD with no interruption of the steroid therapy were found to have comparable PedsQL total scores pre-pandemic and during COVID-19 pandemic (68.41 vs 67.13, $p=0.874$)

HRQOL associated factors and interaction analysis

To explore HRQOL associated factors in the multiple linear regression model, PedsQL total score was inputted as a criterion, with age and SES as covariates, and physical activity, parental guidance on e-device usage, e-device usage time for social and gaming, parental stress and parental-child interaction put as predictors respectively. We found that only parental guidance on e-device usage ($\beta = 0.34$, $p < 0.001$) and parental stress ($\beta = 0.151$, $p < 0.001$), were significant predictors of the PedsQL total score.

To further explore the interaction between the group effect and the effect of other associated factors on HRQOL, exploratory moderated multiple regression was conducted. We used PedsQL total score as the criterion; the group (NMD vs control) as the focal predictor; parental guidance on e-device usage, parental stress, parent-child interaction, sleep and physical activities as potential moderators; and age and SES as control covariates. We found a significant interaction between the effect of parental guidance on e-device usage and group (parental guidance on e-device usage * group $p = 0.007$), which suggests that the impact of parental guidance on e-device usage on PedsQL total score is stronger in the NMD group compared to the control (figure 1a). There is also an interaction between the effect of parental stress and group (parental stress * group $p = 0.043$), which suggests that the association between PedsQL score and parental stress is stronger in NMD children compared to the control (figure 1b). In addition, in a model which does not adjust for age and SES, the effect of parental-child interaction was found to have interacted with the group effect (parent-child interaction* group $p = 0.030$), which suggested that parental-child interaction played a more important role in affecting the PedsQL score in children with NMD compared to the control (figure 1c). However, the interaction (parent-child interaction* group) will no longer be significant once controlled for age and SES. All other variables did not significantly interact with

the group effect on PedsQL total score, neither in an adjusted model (for age and SES) nor an unadjusted model.

Discussion

Our study showed that children with NMD had significantly poorer quality of life compared to children with typical development during the COVID-19 pandemic. Our findings are consistent with a previous study showing that children with special educational needs had poorer psychosocial wellbeing compared to those with typical development during the COVID-19 pandemic⁵. Our study also showed children with NMD had poorer physical-related quality of life than typically-developed children during the pandemic. Our NMD cohort had a spectrum of medical complexity and physical disabilities. Nonetheless, even those with mild disease manifestations may experience functional impairments and physical limitations that directly affect their activities of daily living and adaptive skills¹⁰, thus leading to poorer physical-related quality of life. In addition, we found that children with NMD having more emotional difficulties were associated with poorer social and psychosocial-related quality of life. Previous studies have shown that children with NMD are at an increased risk of mental health problems¹⁰⁻¹³. For example, children with myotonic dystrophy¹⁴ and DMD are more likely to have weaker social skills and internalise their symptoms e.g. anxiety and depression¹³. On the other hand, children with SMA were reported to have social and communication skills comparable to their healthy peers¹⁵. Hence, we wish to highlight the importance of emotional development in children with NMD, especially during the time of the pandemic. Due to their increased vulnerability to have co-morbid mental health problems, children with NMD might have difficulties coping with the sudden changes in routines during a disease pandemic.

To alleviate the detrimental effects on psychosocial wellbeing of children with NMD, our study aimed to identify potential factors that were associated with better quality of life in children with NMD during the pandemic. We demonstrated that higher level of parental guidance on electronic devices usage was associated with better overall quality of life among children with NMD, especially related to physical functioning of HRQOL. Prolonged use of electronic devices and habitual postures are known to be associated with musculoskeletal problems and increased musculoskeletal pain¹⁶. Interestingly, less parental guidance on electronic device usage in NMD group was more strongly associated with a poorer quality of life among children with NMD compared to the control group of children. This could be related to the higher level of dependency on electronic devices in children with NMD. Children with NMD, in fact, tends to rely on electronic devices as their major source of social interaction due to their physical disability. Therefore, parental guidance on usage of electronic devices is essential for children with NMD. For young preschool children, the American Academy of Pediatrics and World Health Organization recommend limiting the use of electronic device for recreational purposes to no more than one hour a day¹⁷. For parents with school-aged children or adolescents, they are encouraged to devise a Family Media Use Plan so that parents can negotiate the limits and boundaries around electronic device usage with their children and promote digital wellness^{18,19}.

Apart from guidance on usage of electronic devices, parental care and interactions with children with NMD are crucial during disease pandemics. Our study also found that parent-child interaction had a greater association with the quality of life of children with NMD than in TD children, though given the small sample size, the differences between the two groups may become insignificant after adjustment for age and socioeconomic status. In fact it has been showed that children with good parent-child relationships have better quality of life and also are at lower risks of developing smart phone use problems such as addiction and pathological use²⁰ .

Our study showed that the stress of parents with children with NMD was comparable to the stress of parents with typically-developed children during the time of the pandemic, which is indicative of the dedication and resilience of the parents when caring for their children with NMD. However, we also found that the association between the quality of life of the children and parental stress was stronger in the NMD than the TD group. Hence, it is essential to provide adequate support for parents/ carers with children with NMD. Future studies should be conducted to evaluate the needs and burdens of the parents/carers with children with NMD so that they can receive the necessary support during pandemic times.

Notably, our study demonstrated that children with NMD suffered from disruptions in rehabilitation services, with high rates of training appointment cancellations. Moreover, children with disrupted services were found to have poorer quality of life. Our children with NMD had a higher rate of hospital appointment cancellations compared to that in the study in Denmark (73.8% vs 12.8%)²¹ . Similarly, we also observed a higher rate of cancellations in out-patient clinics than in Italy (73.8% vs 40%)²² . This may reflect the higher level of anxiety and concern of COVID-19 infection in Hong Kong, which is supported by another local study²³ . Other reasons for the higher disruption rate could be the restricted hospital visiting policy for the families²⁴ . Some families may have preferred to reschedule the routine checkup or therapy appointments to a later time when the pandemic situation was better controlled or when restrictions about whether family members were allowed to stay and visit their child were loosened. On the other hand, some of the elective admissions, such as those for lung function evaluation, were deferred by the hospital teams during the study period due to pandemic.

Despite the high rates of disruption to rehabilitation services, scheduled admissions for disease-modifying treatments for our patients with SMA, as well as the regular follow-up appointments for steroid therapy for our patients with DMD, were not disturbed. We demonstrated the importance of continuation of all treatment for children with NMD during the pandemic. Patients with SMA who continued nusinersen treatment during COVID-19 showed an improved health-related quality of life, especially with regards to their psychosocial functioning, when compared to pre-pandemic state. In addition, patients with DMD who continued the steroid therapy had similar pre-and-during Covid-19 pandemic health-related quality of life.

Our study should be interpreted with the several caveats. Firstly, children with NMD did not have data on their emotional difficulties or parental stress before the COVID-19 pandemic for comparison. . Secondly,

due to the small sample size of the study, it is possible that our study underestimates the impact of the pandemic on the psychosocial well-being of children with NMD. Thirdly, there may be sampling bias in the subject recruitment. Our study recruited patients from the out-patient clinics or in-patient admission, therefore patients who were absent from the clinics, for example due to concern of infectious risks of COVID-19, were excluded from our setting. This might thus underrepresent the impact of COVID-19 in terms of accessibility to healthcare and psychological issues. Lastly, although we identified factors that were associated with poorer quality of life in children with NMD, it did not imply causality due to the cross-sectional design of some of the study variables.

In conclusion, children with NMD have experienced a poorer quality of life than TD children during the COVID-19 pandemic in Hong Kong. Parental guidance on usage of electronic device is essential for children with NMD. Continuation of medical treatment and rehabilitation care are crucial for children with NMD. Children with NMD require integrative care and support from the healthcare, social welfare and educational sectors so that they can thrive better during and after the difficult times of the pandemic.

Methods

The parents of paediatric patients with NMD aged 3-12 years old were recruited from the Paediatric Neuromuscular Disorder Programme under the University of Hong Kong. They were given a questionnaire when their children were admitted to hospital for disease-modifying treatment or attended an out-patient consultation at the NMD clinics under the three university-affiliated hospitals (Queen Mary Hospital, Duchess of Kent Children's Hospital, and the Hong Kong Children's Hospital). The recruitment period was from September 2020 to March 2021, thus encompassing the period in which face-to-face lessons were suspended – January 2020 to mid-2021 – as a part of local social distancing measures. Information on demographics, NMD diagnosis, ambulatory status, respiratory status and feeding status were collected. All the recruited paediatric patients with NMD completed a survey that was developed in our previous study [6]. Survey data for the typically developed (TD) control children population was also retrieved from that previous study⁶. Each child with NMD was matched with four healthy children according to their household income, parents' education level, gender, and age for the comparison of HRQOL scores.

We also utilised data that was collected before the pandemic period. The HRQOL study data of our paediatric patients with SMA aged between 3 to 12 years had been collected before the pandemic period under another ethically approved study by the Institutional Review Board of the University of Hong Kong/Hong Kong West Cluster (HKU/HKW IRB) (Reference: UW19-418). This data was compared to the current study data from the NMD group collected during the pandemic. Pre-COVID-19 HRQOL study data of our paediatric patients with Duchenne muscular dystrophy was also obtained²⁵.

The study was approved by the HKU/HKW IRB (Reference: UW 20–177). Informed consent were obtained from parents upon participation. All procedures performed in this study involving human participants were in accordance with the relevant guidelines and regulations of the institutional research committee.

The survey questionnaire used in this study was the same as the one in our previous study completed by our population of typically developed children without chronic disease or special educational needs for a fair comparison⁶. The questionnaire was originally developed and validated by the Department of Paediatrics and Adolescent Medicine, the University of Hong Kong, with a multidisciplinary team of paediatricians, social scientists, public health and educational experts. Participants' demographic characteristics, including children's background information and parents' socioeconomic statuses (e.g. household income, educational attainment) were included. Locally validated scales were also adopted to measure children's and parents' behavioural and emotional functioning. To start with, children's wellbeing was measured by the Paediatric Quality of Life Inventory 4.0 Generic Core Scales (PedsQL), while the Strength and Difficulties Questionnaire (SDQ) was used to assess children's emotional and behavioural difficulties. Parental stress and parent-child interactions during the pandemic were also measured by the Parental Stress Scale (PSS) and the Chinese Parent-Child Interaction Scale (CPCIS)^{26,27}. Furthermore, children's lifestyle habits were also examined by asking parents to estimate the amount of time children spent on sleeping, physical activities, and the use of electronic devices during the pandemic. The level of parental guidance on various electronic device usage (Television, Game console, handheld gaming device, computer and mobile phone) was also interviewed. Moreover, children's routine medical services were also examined by asking whether their medical appointments and rehabilitation schedules were disrupted.

Statistical analysis was performed by R Statistical Software version 4.1.1 with 5% alpha levels. Distribution, outliers, and missing data of all variables were examined before data analysis. The assumption of a normal distribution was tested by skewness and kurtosis. Data with values greater than or equal to 3 standard deviations from the mean were considered outliers and removed. Each child with NMD was matched with four TD children according to their household income, parents' education level, sex and age for the comparison of HRQOL scores.

The characteristics of the recruited subjects and the measured variables were examined using descriptive statistics. An independent two-sample t-test was performed to compare the differences in SDQ, PedsQL and PSS scores between NMD and typically developed children. We calculated the correlation between SDQ, PSS, parental guidance of electronic device usage, parent-child interaction, and PedsQL using Pearson correlation. In addition, moderated multiple regression was performed to further explore the relationships between the HRQOL scores, e-device usage, parental stress, parent-child interaction, sleep and physical activities, contrasting NMD and control subjects. Process Macro (v 3.53) for R was used to perform the moderation analyses²⁸.

Declarations

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Author contributions

M.K.L. recruited the patients, collected the data and drafted the manuscript. W.W.Y.T. supervised the data interpretation and drafted the manuscript. W.H.S.W. supervised the data analysis. K.M.Y and O.K.F.Y. performed the statistical analysis. Y.L.W. and L.K.L. performed multiple regression and moderation analyses. G.C.F.C. supervised the study design. P.I. and S.H.S.C. designed and supervised the study. All reviewed the manuscript.

Competing interests

The author(s) declare no competing interests.

Additional information

The datasets generated during and/or analysed during the current study are available from the corresponding author on reasonable request.

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Tables

Table 1: Clinical and demographic characteristics of the 41 children with NMD (3-12 years old) and the 164 typically developed children as healthy control included in the study

	NMD (<i>n</i> =41)		TD (<i>n</i> =164)		<i>p</i> -value
<u>Demographics</u>					
Gender	Number	%	Number	%	
Male	24	58.5	88	58.5	1.000
Female	17	41.5	76	41.5	1.000
	Mean	SD	Mean	SD	
Age (years)	7.46	2.96	7.46	2.96	1.000
Socioeconomic status index	-0.25	1.64	0.05	1.53	0.294
			-		-
Types of NMD					
			-		-
Spinal muscular atrophy	20	48.8			
Type I	5	12.2			
Type II	13	31.7			
Type III	2	4.9			
Dystrophinopathy	7	17.0			
Duchenne muscular dystrophy	6	14.6			
Becker muscular dystrophy	1	2.4			
Congenital myopathy	7	17.0			
Myotonic Disorder	4	9.7			
Congenital muscular dystrophy	3	7.3			
Ocular Myasthenia gravis	1	2.2			
-					
Medical conditions					
Feeding with assistance / dependent on Ryle's tube or PEG**	17	41.5			
Non-ambulatory	22	53.7			
Scoliosis	17	41.5			
Ventilator dependence	11	26.8			

NMD: Neuromuscular disorders; TD: Typically developed; PEG: Percutaneous endoscopic gastrostomy

p -value <0.05 was considered statistically significant.

Table 2: Impact on COVID-19 on rehabilitation training for the 41 children with NMD (3-12 years old) in Hong Kong

Disruption of rehabilitation training	Yes	No	p -value	No data
Number of NMD children (%)	31 (73.8%)	9 (22.0%)	NA	1 (2.4%)
PedsQL™ 4.0 total score : mean (SD)	51.75 (19.89)	71.29 (12.29)	0.012	

PedsQL™ 4.0: Paediatric Quality Of Life Inventory 4.0 Generic Core Scales

p -value <0.05 was considered statistically significant.

Table 3: Comparison of health-related quality of life questionnaires and time spent of daily activities between children with NMD and age and gender matched TD children

	TD (n=164)		NMD (n=41)		
	Mean	SD	Mean	SD	<i>p-value</i>
SDQ					
Emotional symptoms	1.79	1.79	2.30	2.35	0.263
Conduct problems	1.97	1.40	1.63	1.47	0.289
Hyperactivity/inattention	4.49	2.02	4.48	2.63	0.994
Peer relationship problems	2.78	1.85	3.38	1.99	0.114
Prosocial behaviour	6.73	1.77	6.81	2.22	0.822
Total difficulties	11.02	5.21	12.36	6.67	0.276
PSS					
Total score	43.10	7.83	44.61	7.33	0.267
PedsQL™ 4.0					
Physical functioning	83.35	11.61	41.48	29.15	<0.001
Emotional functioning	78.96	16.58	75.25	19.45	0.222
Social functioning	81.49	14.52	59.65	21.90	<0.001
Psychosocial functioning	80.23	14.35	67.30	19.29	<0.001
Total score	81.61	12.00	55.66	19.85	<0.001
Parent Child Interaction					
Teaching	1.75	0.83	1.82	0.95	0.643
Recreation	1.42	0.69	1.55	0.84	0.292
Total score	1.59	0.65	1.69	0.72	0.387
E-device usage (hours)					
Learning	1.81	2.37	2.42	3.20	0.258
Gaming	2.39	2.65	1.94	3.20	0.410
Social	0.27	0.49	0.94	2.55	0.002
Parental guidance on E-device usage	5.80	3.53	2.15	3.22	<0.001
Total time spent (hours)	4.47	3.35	5.30	7.88	0.511
Habits of daily activities					
Sleeping duration (hours)	11.29	3.30	10.53	2.46	0.109

Physical activity duration (hours) 2.04 3.88 1.11 1.16 **0.009**

The data from typically-developed (TD) children was drawn from Tso et al. ⁶.

NMD: Neuromuscular disorders; TD: Typically developed

SDQ: Strength and Difficulties Questionnaire

PSS: Parental stress scale

PedsQL™ 4.0: Paediatric Quality Of Life Inventory 4.0 Generic Core Scales

E-device: Electronic-device usage

p-value <0.05 was considered statistically significant.

Table 4: Comparison of PedsQL™ 4.0 findings of children with Spinal Muscular Atrophy (SMA) and Duchenne Muscular Dystrophy (DMD) before and during COVID-19 pandemic

Period	Pre COVID-19 (2018-2019)		COVID-19 pandemic (2020-2021)		
SMA	n=11		n=11		
PedsQL™ 4.0	mean	SD	mean	SD	<i>p-value</i>
Physical functioning	21.02	13.63	26.14	26.78	0.567
Emotional functioning	65.00	19.36	78.18	17.36	0.021
Social functioning	51.36	19.12	63.53	21.92	0.111
Psychosocial functioning	58.18	15.66	70.85	17.63	0.016
Total score	41.67	12.89	50.98	15.29	0.012
Period	Pre COVID-19 (2014-2015)		COVID-19 pandemic (2020-2021)		
DMD	n=11		n=6		
PedsQL™ 4.0	mean	SD	mean	SD	<i>p-value</i>
Physical functioning	51.70	17.49	62.50	27.31	0.409
Emotional functioning	74.55	18.06	83.33	10.33	0.221
Social functioning	62.27	21.86	58.33	6.83	0.591
Psychosocial functioning	68.41	16.16	70.83	7.53	0.680
Total score	68.41	16.16	67.13	15.26	0.874

The Pre-COVID-19 PedsQL™ 4.0 data of children with SMA were collected from our ongoing prospective study examining the health-related quality of life of children with SMA before and after disease-modifying treatment. Eleven children with SMA receiving nusinersen treatment had pre-Covid-19 pandemic PedsQL™ 4.0 data collected at 2018-2019 before they started treatment. Paired t-test was performed to compare the pre-Covid-19 to the Covid-19 pandemic PedsQL™ 4.0 data. Among the 11 patients, 3 of them had SMA type 1 and 8 of them had SMA type 2. The mean (+/-SD) and median ages of the patients with SMA started on nusinersen was 5.57 +/- 2.10 years and 5.70 years old.

The Pre-COVID-19 PedsQL™ 4.0 data for children with DMD was collected from 2014/2015 from our earlier study²⁵. The mean (SD) and median ages of patients with DMD in the Pre-COVID period was 7.06(+/-4.18) and 8.00 years old. The pre-COVID-19 data was compared to the data collected during

COVID-19 pandemic by unpaired t-test. The mean (\pm SD) and median age of patients with DMD at the pandemic period were 8.03(\pm 2.7) and 9.88 years old.

PedsQL™ 4.0= Paediatric Quality Of Life Inventory 4.0 Generic Core Scales

p -value <0.05 was considered statistically significant.

Figures

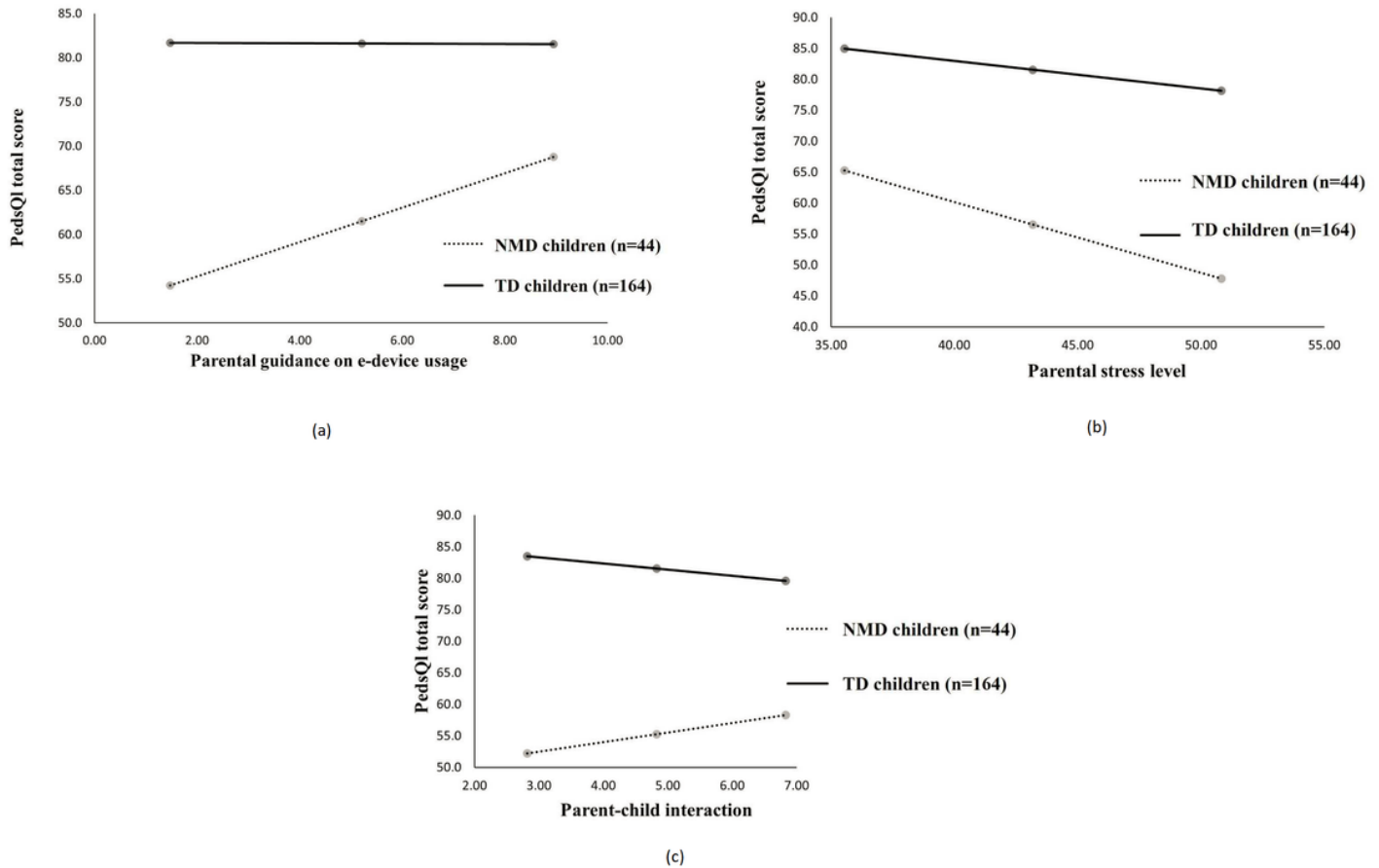


Figure 1

a. PedsQL total score as a function of parental guidance on e-device usage in NMD and TD children, after adjusting for gender and SES. We found a significant stronger interaction between the PedsQL score and parental guidance on E-device usage in NMD group compared to TD group ($p = 0.007$). The parental guidance on e-device usage levels was measured by the sum of 6 3-point Likert scales on the parental guidance level of different e-devices (television, game console, handheld gaming device, computer and mobile phone).

b. PedsQL total score as a function of parental stress levels in NMD and TD children, after adjusting for gender and SES. We found a stronger interaction between PedsQL score and parental stress in NMD

group compared to the TD group ($p = 0.043$). Parental stress was measured by the Parental Stress Scale (PSS).

c. PedsQL total score as a function of parent-child interaction level in NMD and TD children. We found that parental-child interaction played a more important role in affecting the PedsQL score in NMD group compared to the TD group ($p = 0.030$). The parent-child interaction levels were measured by the Chinese Parent-Child Interaction Scale (CPCIS).