Impact of COVID-19 pandemic on healthcare utilitsation and psychosocial well-being of children with neuromuscular disorder (NMDs)

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INTRODUCTION

COVID-19 outbreak: Led to social distancing measures e.g., suspension of face-to-face learning in schools during 2020-21

Impact on children's psychosocial wellbeing: Decreased outdoor activities and social gathering with friends and family, especially difficult for children with special needs[1].

Impact on parents of children with NMD's psychosocial wellbeing: Decreased social gathering and isolation from working area led to higher chance of anxiety and depression[2].

What's not known: Impact on children with NMD their psychosocial wellbeing during Covid-19 outbreak.

OBJECTIVES and AIMS

1) To study the Health-related quality of life (HRQOL) of children with NMDs by comparing that of healthy children under COVID-19.
2) To find the factors that affect their psychosocial wellbeing

MATERIALS AND METHODS

Study Population: Children with NMDs aged 3-12 years old are invited to complete survey during school closure period in HK.

Information collected from the survey[3]: (1) Clinical information; (2) Children wellbeing (PedsQL^); (3) Children's habits; (4) Healthcare services utilization; (5) Parental stress scale (PSS); and (6) Parental-child interaction

Conduction of survey: Survey was conducted between September 2020 to March 2021 during the hospital appointment.

Matching: Each child of NMD was matched to four healthy control children by age, gender and socioeconomic status (SES).

Data analysis: 1) To study the PedsQL of children with NMDs comparing that of matched healthy children by unpaired t-test.
2) To study the PedsQL of children with SMA# (n=11) Pre- & during COVID-19 period by paired t-test.
3) To identify the factors affecting the PedsQL scores of children with NMDs by moderated multiple regression.

^**PedsQL** = Pediatric Quality of Life Inventory™ (PedsQL™) Generic core 4.0 survey
#Collected from another ethically approved study (UW19-418) at 2018/19.

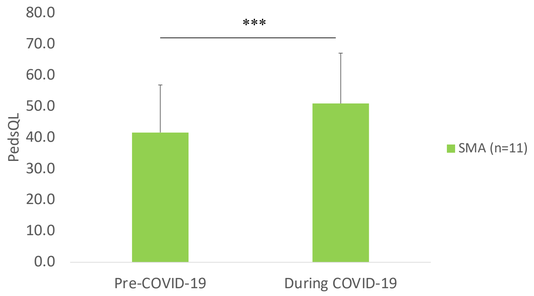
RESULTS

Demographic data & clinical characteristics of NMD participants (N=41)

	Mean	SD
Demographics		
Age (years)	7.46	2.96
Socioeconomic status index (SES)	-0.25	1.64
	Number	**%**
Male	24	58.5
Types of NMDs		
Spinal muscular atrophy (SMA)	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 (DMD)	6	14.6
Becker muscular dystrophy (BMD)	1	2.4
Congenital myopathy	7	17.0
Other NMD*	7	17.0
Medical Complex Need	27	65.9
Non-ambulatory	22	53.7
Feeding with assistance / dependent on NG or PEG tube	17	41.5
Ventilator support	11	26.8
Scoliosis	17	41.5

*Other NMDs included Congenital muscular dystrophy (n=3), myotonic Disorder (n=3), and ocular myasthenia gravis (n=1).
The mean age, mean SES and % male of the matched healthy control children were 7.46, 0.05 and 58.5%, and all these parameters are comparable to that of children with NMDs.

PedsQL Change with Disease-modifying treatment for SMA



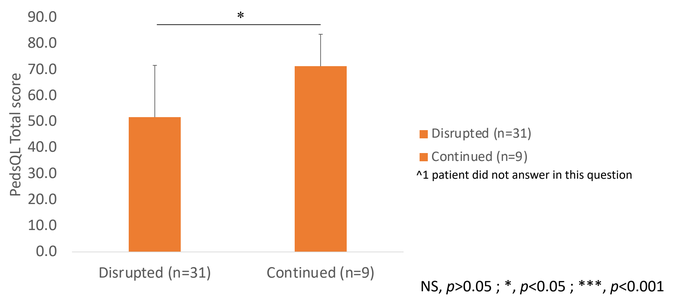
- SMA Typing: I (N=3) ; II (N=8) ; III (N=1)
- **Children with SMA with regular Nusinersen treatment even had higher PedsQL score** during COVID-19 pandemic.

Comparison of HRQOL and lifestyles between children with NMDs and control

	NMD (n=41)		Healthy (n=164)		
	Mean	SD	Mean	SD	*p*-value
PSS					
Total score	43.10	7.83	44.61	7.33	0.267
PedsQL™ 4.0					
Physical functioning	41.48	29.15	83.35	11.61	**<0.001**
Emotional functioning	75.25	19.45	78.96	16.58	0.222
Social functioning	59.65	21.90	81.49	14.52	**<0.001**
Psychosocial functioning	67.30	19.29	80.23	14.35	**<0.001**
Total score	**55.66**	**19.85**	**81.61**	**12.00**	**<0.001**
E-device usage					
Time spent on Social media (hours)	**0.94**	**2.55**	**0.27**	**0.49**	**0.002**
Parental guidance on E-device usage	**2.15**	**3.22**	**5.80**	**3.53**	**<0.001**
Habits of daily activities					
Time on Sleeping (hours)	10.53	2.46	11.29	3.30	0.109
Time on Physical exercises (hours)	**1.11**	**1.16**	**2.04**	**3.88**	**0.009**

- **41 children with NMDs completed the survey** (mean age:7.46 ± 2.96 years old). 65.9% of patients have medical complex needs.
- **Children with NMDs had significantly lower PedsQL scores** when compared to healthy control (55.66 vs 81.61, *p*<0.001).
- **Children with NMDs had less physical exercise** (*p*=0.009) ,but **spent more time on social media** per day (*p*=0.002)
- **Parents of children with NMDs had lower level of guidance on E-device usage** (*p*<0.001).

Impact of Disrupted Rehabilitation Training on PedsQL for NMDs



^1 patient did not answer in this question

NS, *p*>0.05 ; *, *p*<0.05 ; ***, *p*<0.001

- **Majority of children with NMDs** experienced disruptions on rehabilitation training under COVID-19 (73.8%, n=31/41)**.**
- **Those who continued the rehabilitation training had significantly higher PedsQL scores** (71.29 vs 51.75, *p*=0.012).

RESULTS

Moderated multiple regression

- There is positive correlation between parental guidance level on E-device usage and PedsQL scores (PCC=0.354, *p*=0.025)
- After adjusting age, gender, and SES, we found a **significantly stronger positive correlation between PedsQL scores and parental guidance on E-device usage in children with NMDs** compared to normal control children (*p*=0.007).

DISCUSSION

- **Children with NMDs had lower HRQOL** compared to healthy control children **during COVID-19 era** when more social distancing measures were being applied.
- **Interruption of rehabilitation services affects psychosocial well-being in children with NMDs**. Telerehabilitation program may support the children and the families better.
- **Continuation of disease-modifying treatment improves HRQOL in patients with SMA so must not be interrupted.**
- **Children with NMDs spent less time on physical exercise but more time on E-device use on social media.** More studies on how this habit can affect the child's psychosocial well-being, and how to recommend to family the weekly exercise plan and the preferred time on E-device use, will give more insight.

CONCLUCION

Children with NMDs have lower HRQOL compared to matched healthy control children. Uninterrupted rehabilitation and drug treatment, and parental guidance on E-device usage, are positive factors that improve their psychosocial wellbeing.

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Ethics: This study was approved by the University of Hong Kong/Hospital Authority Hong Kong West Cluster IRB Committee (IRB No: UW 20-177). Informed consent was obtained from legal guardians.

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