

**THE QUALITY OF LIFE, SITUATIONS AND EMERGING CONCERNS OF PARENTS OF CHILDREN WITH NEURODEVELOPMENTAL DISORDERS IN PHILIPPINE CHILDREN'S MEDICAL CENTER DURING THE COVID-19 PANDEMIC**

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**ABSTRACT**

**BACKGROUND:** COVID-19 resulted in a public health emergency and quarantine measures which may negatively impact vulnerable populations.

**OBJECTIVES:** This study intends to determine the quality of life, situations and emerging concerns of parents of children with neurodevelopmental disorders during the ongoing pandemic.

**METHODOLOGY:** A cross-sectional survey using a socio-demographic questionnaire, situations and emerging concerns during the coronavirus pandemic and WHOQOL-BREF (Filipino version) for parental quality of life was documented via Google Forms. Parents of patients aged 2-18 years seen at the PCMC Neurodevelopmental Pediatrics OPD during July to December 2019 were recruited.

**RESULTS:** Data from 115 respondents showed a lower score in the environmental domain. Child characteristics comparable with QoL scores include sex, severity of ID and ADHD while parent characteristics comparable with the QoL scores include educational attainment, monthly family income, father's employment status and family structure (P-value <0.05). Most respondents reported situations of physical distancing (82.61%) and curfew (80.87%). Inability to access essential services (43.48-74.48%) were further compounded by limited financial resources (51.30%) and public transport (60%). Government policy received included quarantine pass (90.43%), food allowance or relief package (86.09%), disinfection (60.87%), DSWD-SAP (42.61%) and cash distribution (41.74%).

Concerns include socio-environmental issues: no available transportation (73.04%), impaired ability to work or earn (70.43%), inadequate rations (50.43%), disruptions in basic social services (47.83%); and patient concerns: access to education (64.35%), medical (44.74%), developmental (33.04%), behavioral (31.3%), nutrition (20%) and sleep (19.13%).

**RECOMMENDATIONS:** Programs and policies should be planned accordingly to provide improvement of quality of life to parents and their child with neurodevelopmental disorder.

**Keywords:** Neurodevelopmental Disorder, Neurodevelopmental Pediatrics, Parental Quality of Life, WHOQOL-BREF, COVID-19, coronavirus

## INTRODUCTION

The coronavirus disease (COVID-19), a systemic infection caused by a novel strain of coronavirus emerged from an outbreak in Wuhan, China in December 2019 and in a matter of months has been declared a global pandemic and public health emergency.<sup>1</sup> Toward the end of October 2020, there have been more than 40 million cases of COVID-19 reported in 215 countries and territories resulting in more than one million deaths yet the numbers are still rising.<sup>2</sup> To respond to this crisis, the government and health agencies have recommended limitation of social contact, practicing proper personal hygiene and travel restrictions.<sup>3</sup> Beginning March 16, 2020, the Philippine Government imposed community quarantine measures covering strict

lockdown restrictions, suspension of mass public transportation, face-to-face school interactions, and closure of all private establishments, except for those providing essential goods and services.<sup>4</sup> In an effort to decongest health facilities and observe physical distancing, many outpatient services and private clinics were limited or closed during the lockdown, instead offering telehealth or remote consultation services.<sup>5</sup>

This encroachment affects not only social, economic and political resources but also instigates a sudden and drastic change in the life condition of families. Among vulnerable populations, children with neurodevelopmental disorders are of particular interest because of their unique and specialized needs. Children are dependent on

others to provide for food, shelter, transportation and medical care.<sup>6</sup> This is magnified with a concomitant neurodevelopmental disorder for whose spectrum of illnesses include ASD, ADHD, CP, GDD, ID, Learning Disorders and Sensory Impairments.<sup>7</sup> These diverse group of chronic conditions present with early onset neurocognitive deficits causing a disturbance in the developmental process and persisting throughout an individual's lifetime as a form of disability in personal, social, academic, or occupational functioning.<sup>8,9</sup> Other difficulties that may arise in the current public health situation include transport concerns, need for continuous medical assistance and support services, limitations in communication and trouble with transitioning to different situations.<sup>10</sup> They are also at risk for serious behavioral and emotional concerns that may be brought about by the stress and uncertainty of the quarantine measures implemented.

This burden is much more palpable and long-lasting to their parents who spend most of their time and resources in caring for a child with a neurodevelopmental disorder thereby impacting their psychosocial health. Studies indicate lower quality of life for these parents usually correlated to the functional

dependence of their child and increasing stress levels.<sup>11,12</sup> This high level of caregiving is in itself a daunting challenge on a day to day basis but add to that, a global medical phenomenon of disastrous proportions, may trigger a breaking point. The quarantine, health services and transport established for the COVID-19 response may fail to accommodate the needs of their children and even create obstacles to earn wages, access health and education services.<sup>13,14</sup> Discrimination and stigma already contribute to these systemic and societal barriers that may also negatively influence the psychosocial and environmental dynamics for their parents. The intersectionality of disability with demographic factors and exposure to disaster can multiply the stigma, discrimination and disadvantage that persons with disabilities experience.<sup>15</sup>

There is limited research as to the psychosocial effects of disaster and pandemics on this special population of pediatric patients and their families.<sup>13, 16, 17</sup> Since a pandemic of this scope and scale has not been experienced for more than a century, this becomes an opportunity to look into the varied and far-reaching impact that this global event has brought about. This study

aims to determine the quality of life, situations and emerging concerns of parents of children with neurodevelopmental disorders during the ongoing coronavirus pandemic. In this vein, the elicited quality of life scores will be correlated to the socio-demographic data. The knowledge gained from this study will benefit families of children with neurodevelopmental disorders as it will provide health care professionals with information regarding how the current global pandemic may impact the families of our patients, specifically the parents' quality of life, situations and emerging concerns. This knowledge may be used to create appropriate interventions and programs that may improve how families can adapt to the changes brought about by COVID-19 pandemic and assimilate into their "new normal" lives.

## **METHODOLOGY**

### **a. Study Design and Participants**

With approval by the Institutional Research-Ethics Committee of PCMC (PCMC IR-EC 2020-036), this cross-sectional survey on parents of patients seen at the PCMC Neurodevelopmental Pediatrics OPD Clinic for the period of July

2019 – December 2019 due for a follow-up schedule were invited to join the study through phone call. To encourage participation, an advertisement was also sent to online support groups of PCMC patients. The patients' ages ranged from 2 to 18 years and had at least one confirmed neurodevelopmental disorder diagnosed at least 6 months prior to recruitment. Parents who had more than one child with a neurodevelopmental disorder, unable to understand conversational English or Tagalog and residing outside of the Philippines were excluded from the study.

Parents who agreed to join were given the option to fill up the same Google Forms either in the clinic, via phone interview or online survey to ensure their participation because of the community quarantine restrictions and technological limitation. A written consult was provided to all participants – for those who were interviewed over the phone, verbal consent was initially recorded but were subsequently sent written documents for signing via a courier service. There was no monetary compensation for participating but resources to psychosocial counselling were provided.

The number of participants was sufficient for the computed sample size of 85, based on 0.3 desired correlation coefficient of any parent's or child's characteristics as well as situations and emerging concerns of the children with neurodevelopmental disorders with the QoL scores of parents of children with neurodevelopmental disorders, 5% level of significance and 80% power.<sup>21</sup> This is based on the data of the previous study done in our center.

**b. Outcome Assessments**

**Socio-demographic questionnaire:**

A socio-demographic questionnaire was administered which included pertinent information such as parent demographics and patient characteristics.

**WHOQOL-BREF (Filipino version):**

The WHOQOL-BREF Filipino version was used to measure the quality of life of parents of children with neurodevelopmental disabilities. The WHOQOL-BREF is a condensed form of the WHOQOL-100 containing 26 items rated individually on a 5-point Likert scale

and identifying four domains: Physical Health, Psychological, Social Relationships and Environment. The Filipino version is cross-culturally valid and has been used for similar populations in local studies: particularly parents of children with special needs and parents of children with ASD.<sup>19,20,21</sup>

**Situations and Emerging Concerns during the COVID-19 pandemic:**

A survey on situations and emerging concerns was adapted from the online survey on the Needs and Situations of Children with Disabilities in the Context of COVID-19 by the Sub-committee on Children with Disability of the Council for the welfare of Children, a government agency to include specific developmental and behavioral concerns.<sup>22</sup> The members of this committee are experts in their field and represented agencies such as Commission on Human Rights, Department of Education, ECCD Council, UNICEF, Norfil Foundation and many others. Permission was obtained from the

members of the sub-committee to modify the questionnaire by adding specific concerns such as behaviors, sleep and nutrition. The survey included current measures implemented or services provided as a response to COVID-19, reasons and difficulties in accessing needs or services, and emerging issues or concerns which have surfaced. The questions had an option for open-ended responses if the participants had something to add aside from the choices presented.

The adapted survey was piloted by sending the Google Forms thru facebook messenger to 17 subjects – all parents who have children who were previously seen at the outpatient clinics of the Child Neuroscience Division. Item analysis was done resulting in a Cronbach's Alpha of .820.

**c. Statistical analysis**

Descriptive statistics was used to summarize the demographic and clinical characteristics of the patients. Frequency and proportion was used for categorical variables, median and

inter quartile range for non-normally distributed continuous variables, and mean and SD for normally distributed continuous variables. Independent sample T-test and One-way analysis of variance was used to determine the difference between two and three groups, respectively, in terms of Quality of Life scores. Pearson product moment or Spearman correlation was used to determine the linear and rank correlation between QoL scores of parents of children with neurodevelopmental disorders and different parameters. All statistical tests was two tailed. Shapiro-Wilk was used to test the normality of the continuous variables. Missing values was neither replaced nor estimated. STATA 13.1 was used for data analysis.

**RESULTS**

A total of 115 final respondents were culled from 198 parents after application of the selection criteria. Table 1 and 2 show the child and parent characteristics.

The proportion of the primary neurodevelopmental diagnosis in the child's

characteristics approximate the figures seen in the section's annual patient census which would further support an adequate sampling of subjects. Out of the patients whose primary neurodevelopmental diagnosis was either Global Developmental Delay or Intellectual Disability, there were 9 (7.8%) who had a neurologic malformation such as congenital hydrocephalus or Chiari 2 malfunction, 7 (6%) who had Down Syndrome or Trisomy 21, and 6 (5.2%) who had epilepsy.

There were 56 respondents (48.7 %) who reported that they had to discontinue interventions of their children due to the lockdown restrictions. The timing of data collection may have influenced the results of education as the resumption of classes in public schools occurred in the following month.

Most of the respondents were from the National Capital Region (66.08%) with 30 out of the 76 residing in Quezon City. Of those from Region III, majority (12 respondents) were from Bulacan province and of those from Region IV-A, majority (21 respondents) were from Rizal province.

A majority (96.65%) of the respondents were mothers, most of whom were unemployed (64.91%) but were the primary caregivers (38.28%).

Table 3 details the WHOQOL-BREF scores across the different domains. A study using the WHOQOL-BREF proposed the critical value of 60 as a cut-off point for assessing QoL.<sup>28</sup> The parental quality of life showed acceptable scores in the physical, psychological and social relationships domains with a lower score (less than 60) for the environmental domain. The WHOQOL-BREF uses a Likert scale with 5 as the highest score; the first 2 questions reflect ratings for over-all quality of life (Mean=3.06) and over-all perception of health (Mean=3.37).

Table 4 relays the concerns of the parents caring for their children who have neurodevelopmental disorders during the pandemic. Most participants were concerned about social distancing (82.61%) and the curfew (80.87%) among the current measures being implemented during the COVID-19 pandemic. Of the 20 who answered Other: 9 participants named specific measures such as the wearing of face masks and face shields outside of the home; 7 named stricter

restrictions for minors and senior citizens; 4 named proper hand hygiene and disinfection while answers such as liquor ban, designated time for marketing or stricter security measures in private subdivisions were also mentioned.

When asked about how they had been affected by the quarantine measures, options on the inability to access rehabilitative, developmental, educational, and medical services were chosen (74.78%, 67.57%, 45.22% and 43.48% respectively). 75 respondents (65.22%) specified loss of income or employment as a consequence of the quarantine measures. Domestic and child abuse were rarely chosen with a frequency of 4.35% and 2.61% respectively. Of the 13 who answered “Other”: 7 mentioned the limitation of medical services; 2 respondents each elaborated on the decreased source of income, lack of recreational activities for their child and restrictions on public transport.

The majority of the reasons for limited access to services and necessities were those of limited or absence of financial resources and absence of public transport. Of the 20 who answered “Other”: 9 respondents mentioned the closure of many

establishments such as schools, clinics and therapy centers and 6 respondents mentioned fear of contracting the virus in public places.

The more common services or assistances received included quarantine pass (90.43%), food allowance or relief package (86.09%), disinfection of areas (60.87%), DSWD Social Amelioration Package (SAP) (42.61%) and cash distribution from City or Barangay (41.47%). Of the 9 who answered “Other”: 3 respondents each answered oral polio vaccination and other sources of cash assistance such as SSS and the 4Ps program; one respondent remarked that they were able to avail of the first round of SAP dole-outs but not the second.

Regarding issues or concerns that have surfaced during the implementation of quarantine measures, these options can be grouped into socio-environmental issues and patient concerns. For socio-environmental issues, respondents more frequently chose no available transportation (73.04%), effect of the quarantine on ability to work or earn (70.43%), violations on distancing (54.78%), inadequate food/medicine rations (50.43%), disruptions in basic social services (47.83%) and non-compliance to set



curfew time (40.87%). For patient concerns, the frequency of respondents' choices were as follows: access to education (64.35%), medical (44.74%), developmental (33.04%), behavioral (31.3%), nutritional (20%) and sleep (19.13%).

Table 5 shows the comparison of the child characteristics against the QoL mean score for each domain. P-value with <0.05 (**bold**) were significantly different between the group in their respective row (variable). Thus, there was a statistical difference seen in 2 variables in terms of their Environmental QoL score. Parents had higher QoL score in the environmental domain when their child was male ( $59.24 \pm 13.78$ ) compared to when their child was female ( $54.08 \pm 11.88$ ). This difference was also seen when a child with Intellectual Disability had severe classification ( $66.67 \pm 9.71$ ) compared to one classified to have moderate severity ( $51.71 \pm 6.68$ ). In terms of the QoL score under Social Relationships, there was a statistical difference seen in the classification of Attention-Deficit/Hyperactivity Disorder. Parents had a higher Social Relationships QoL score when their child with ADHD was classified with moderate severity ( $80.29 \pm 9.14$ ) compared to a child with ADHD having

a severe classification ( $59.5 \pm 13.44$ ). None of the other characteristics were seen to have a significant difference when compared against the QoL scores of the parents.

Table 6 shows the comparison of the parent characteristics against the QoL mean score for each domain. P-value with <0.05 (**bold**) were significantly different between the group in their respective row (variable). The variables marked with an asterisk (\*), shows positive correlation. Of these factors, educational attainment, monthly family income, father's employment status and family structure were significantly comparable with the WHOQOL-BREF scores. There is a positive but weak correlation with parents' educational attainment as compared to QoL scores in the psychological (0.1889) and environmental (0.2958) domain, as is with monthly family income compared to QoL environmental score (0.2977). The scores on the environmental domain was significantly higher when father was employed ( $59.77 \pm 13.4$ ) as compared with being unemployed ( $50.58 \pm 9.93$ ). The QoL scores on the psychological and social relationships domain were significantly higher with a 2-parent biologic family structure ( $70.08 \pm 11.79$ ,  $71.6 \pm 13.95$  respectively) compared

to other family structures ( $61.4 \pm 12.39$ ,  $53.7 \pm 18.87$  respectively).

## DISCUSSION

This was one of few local studies that explored the psychosocial and environmental impact that the COVID-19 pandemic may have on the parents of children with neurodevelopmental disorder.

Children with neurodevelopmental disorders are steadily increasing in prevalence. In the United States, from 2009 to 2017, the overall prevalence among children aged 3 to 17 years was 16.93% which increased from 13.87% a decade prior.<sup>23</sup> In the Philippines, based on national health insurance agency estimates in 2017, there are 1 out of 7 Filipino children living with disabilities.<sup>24</sup> This supports the considerable number of patients who are susceptible to the negative effects of a global pandemic and the experience of being quarantined owing to physical and mental limitations, poverty, high likelihood for medical or life-threatening consequences and other social or psychological factors.<sup>25</sup> In the PCMC Neurodevelopmental OPD Clinic, there were 520 patients seen between the months of July to December 2019 who had at

least one diagnosis of a neurodevelopmental disorder.

The shutdown of various support services and schools have forced drastic and abrupt changes to the home environment and family dynamic. The parental role in the home environment has become even more crucial in this new normal. Parents who are already the caregiver and house manager are also forced to work from home and take on the role of teachers for those with children who are homeschooling. Previous support systems such as grandparents, friends, leisurely activities and therapy centers are not available. The situation may then result into psychological distress and negative emotions in parents which can cascade into that of their child with special needs.<sup>26</sup>

Parental quality of life, a more comprehensive assessment of parental adaptation and mental health, would also impact the ability of caregivers to notice changes in their child and how to properly respond to their healthcare needs.<sup>11, 12, 27</sup> QoL is a person's changing perception of one's life in relation to various domains relative to one's environment, showing an interplay of their goals, expectations, standards and

concerns to their culture and value systems. A study using the WHOQOL-BREF proposed the critical value of 60 as a cut-off point for assessing QoL.<sup>28</sup> As seen in the results, the parental quality of life showed acceptable scores in the physical, psychological and social relationships domains with a lower score (less than 60) for the environmental domain. In WHOQOL-BREF, the environmental domain is composed of items on money to meet needs, availability of information, leisure activity opportunity, conditions of living place, access to health services and means of transportation. These items are most affected by the quarantine measures that have been instituted due to the coronavirus pandemic. The environmental domain is also seen with the most significant comparisons to the child and parent characteristics in this study.

An analytical cross-sectional study done in Pakistan using WHOQOL-BREF during the COVID-19 pandemic compared parents of children with disabilities to those without and revealed statistically significant differences in the physical health and environmental domains.<sup>29</sup> This underscores outcomes in previous studies which highlight the greater caregiver burden of having a child

with neurodevelopmental disorders such as difficulty understanding the diagnosis of the child, stressful encounters with health professionals and the time it takes away from pursuing their own healthy habits.

There are previous studies conducted in different Asian countries showing that exposure to natural disasters may impair a person's quality of life.<sup>30, 31</sup> Some risk factors associated with poor QoL include being female, disadvantaged living conditions, lower socio-economic status, less educated and increased dependency on the activities of daily living.<sup>32, 33, 34</sup> In this study, parents had lower environmental QoL score in the environmental domain when their child was female and the father was unemployed. Lower educational attainment and monthly family income would correspond to lower environmental QoL scores. Unemployment and monthly family income factor into the financial resources of a family. A family with a child having a neurodevelopmental disorder are sure to have additional expenses for the specialized interventions that the child may require.

Severity of the neurodevelopmental disorder revealed significant differences. One of those identified was ADHD in the domain

of Social Relationships, Parental quality of life studies on ADHD have conflicting results on severity of symptoms.<sup>35, 36</sup> One study specifically identifies the child's academic performance as a predictor for physical, emotional and social domains of QOL.<sup>37</sup> Upon review of the subjects having severe classification in ADHD criteria, all had an associated learning disorder which would be a substantial liability during these times, as parents have to closely monitor and take on an active role in their child's education. The other finding was actually contrary to our expectations wherein the severe classification of Intellectual Disability was associated with a higher parental environmental QoL score. Upon review of the subjects having moderate classification of Intellectual Disability, the majority had at least 3 co-morbid conditions which would further add to the financial and emotional burden of their parents. This may be looked into further with a bigger sampling of subjects.

The outcome of the QoL scores on the psychological and social relationships domain being significantly higher with a 2-parent biologic family structure is also supported by the previous QoL study done in our center on parents of children with autism.

Having two parents living together was positively correlated with QoL score on social relationships and was attributed to family-centeredness and close family ties which is deeply ingrained in the Filipino culture.<sup>21</sup> There is a shared burden among family members and the strong social support can also be provided by friends and extended family members. Interestingly, in a recent study on the psychosocial and behavioral impact of COVID-19 in ASD, living with a separated or single parent was associated with better outcome in terms of intensity of behavior problems.<sup>38</sup>

A study was done in Liaoning Province in China to investigate the immediate impact of the COVID-19 pandemic on mental health and quality of life among local residents using an online survey distributed through a social media platform done last January and February 2020.<sup>39</sup> The results showed mild stressful impact, with 52.1% of participants reporting that they felt horrified and apprehensive due to the COVID-19 pandemic. However, the majority of participants (53.3%) did not feel helpless due to the pandemic.

Quarantine measures have implemented physical distancing restrictions and local government implemented curfews. Inability to access essential services were further compounded by limited financial resources and public transport. Government response that have been received by most respondents include quarantine pass, food allowance or relief package, disinfection of areas, DSWD SAP and cash distribution.

The online survey on the Situation of Children with Disabilities in the Context of COVID-19 which was fielded last April 2020 through social media platforms by the Subcommittee on Children with Disability of the Council for the Welfare of Children was open to parents and stakeholders and had more than 40,000 respondents in a span of few weeks.<sup>22</sup> When asked how children with disabilities have been affected, pertinent issues to more than 30% of the respondents include inability to access education services, day care centers, health clinic services, rehabilitation services and loss of income or employment. More than 40% of the respondents reported violations of social distancing, unavailability of transportation, effect of enhanced community quarantine on their ability to work/earn and reduced access

to education for their children as emerging concerns during the coronavirus pandemic. These were found to be consistent with the results of this study.

These concerns are very critical to the subset of pediatric patients seen in PCMC Neurodevelopmental Pediatrics OPD as limitations in finances, closure of face-to-face and absence of public transport has brought about changes in how medical consults and therapeutic interventions are being implemented. Even the modification to the educational system are very substantial concerns to children who have many academic and cognitive limitations.

The findings of this study should be received discerningly due to its limitations. The study design of a cross-sectional survey may be able to reveal associations among factors but a longitudinal study may be more predictive to define relationships of the parent and child characteristics with the parental quality of life. This may also offer comparison in the results depending on the timing of data collection to the current social and public health milieu. A qualitative study design with focused group discussions or structured interviews may provide more depth regarding the concerns of parents of

children with neurodevelopmental disorders. The data may also be enriched with a bigger sample size to improve on representation of the population and more reliable results. As this study provided for different options to accomplish the questionnaire, the phone interview was more prone to response bias as opposed to those that were self-administered. Item analysis of the different options can be done to investigate for the possible biases. The questionnaire on situations and emerging concerns may also be refined to better organize these concepts in the context of the evolving nature of the coronavirus pandemic and the measures being implemented.

In conclusion, this study highlighted how the ongoing COVID-19 pandemic has challenged families of children with neurodevelopmental disorders. Parental quality of life scores showed a lower score in the environmental domain. The child characteristics that are statistically comparable with the QoL scores include sex, severity of ID and ADHD while the parent characteristics that are statistically comparable with the QoL scores include educational attainment, monthly family income, father's employment status and family structure. The quarantine measures

have disrupted employment, financial gains and availability of supports that these families need such as medical, rehabilitative and educational services. Inability to access essential services were further compounded by limited financial resources and public transport. Government responses received include quarantine pass, food allowance or relief package, disinfection, DSWD-SAP and cash distribution. Concerns encountered include socio-environmental issues and patient concerns.

Children with a multitude of health, developmental and behavioral concerns are at risk to present with more intense and frequent problems and at present, may not have the infrastructure to address these accordingly. Even with the shift to telemedicine and teletherapy platforms, many of these families are struggling to cover for their basic needs and adjust to the many changes that this public health emergency has brought about. A reframing of current programs and policies need to be taken into account to provide opportunities for the improvement of the quality of life of both the parents and the child with a neurodevelopmental disorder. The government should be able to provide for subsidy and specific interventions that these

children and adolescents require which would greatly lift some of the burden from their parents. Hospitals and service providers should organize parent trainings and empower support groups to address specific needs and concerns of parents and patient; these can be made easily accessible through online platforms or face-to-face interactions once restrictions allow for them. Interventions should also take into account the mental health and surveillance of the psychosocial wellbeing of these families.

Parents and pediatric patients with neurodevelopmental disorders have an innate resilience from the situation and experience that they go through but this can be extinguished by the overwhelming burden of their circumstance. Future efforts at designing more inclusive and comprehensive intervention programs will aid in their transition of a post-pandemic society, one that turns challenges into opportunities.

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**Table 1. Child Characteristics (n=115)**

	<b>Frequency (%); Mean <math>\pm</math> SD</b>
<b>Age</b>	5 (3.58 to 7.58)
<b>Years since diagnosis</b>	1.92 (0.92 to 3.25)
<b>Sex</b>	
Male	75 (65.22)
Female	40 (34.78)
<b>Primary neurodevelopmental diagnosis</b>	
<b>ASD</b>	<b>51 (44.35)</b>
Level 1	3 (5.88)
Level 2	7 (13.73)
Level 3	41 (80.39)
<b>ADHD</b>	<b>9 (7.83)</b>
Mild	0
Moderate	7 (77.78)
Severe	2 (22.22)
<b>CP</b>	<b>16 (13.91)</b>
GMFCS level 1	0
GMFCS level 2	3 (18.75)
GMFCS level 3	0
GMFCS level 4	1 (6.25)
GMFCS level 5	12 (75)
Global Developmental Delay	27 (23.47)
<b>ID</b>	<b>10 (8.70)</b>
Mild	0
Moderate	7 (70)
Severe	3 (30)
Profound	0
Sensory Impairments	1 (0.87)
Communication Disorder	0
Specific Learning Disorder	1 (0.87)
<b>Number of comorbid conditions</b>	<b>1.6 (0 to 3)</b>
<b>Number of medications</b>	
0	74 (64.35)
1	32 (27.83)
2	8 (6.96)
3	1 (0.87)
<b>With ongoing/history of intervention</b>	
Ongoing	37 (32.17)
Discontinued	56 (48.7)
Never	22 (19.13)
<b>Education</b>	
Enrolled in SPED	25 (21.74)
Enrolled in regular school	26 (22.61)
None	64 (55.65)

**Table 2. Parents' characteristics (n=115)**

	<b>Frequency (%); Mean <math>\pm</math> SD</b>
<b>Age</b>	36.72 $\pm$ 6.71
<b>Sex</b>	
Female	110 (96.65)
Male	5 (4.35)
<b>Location</b>	
NCR	76 (66.08)
Region III	14 (12.17)
Region IV-A	24 (20.86)
Region IV-B	1 (0.88)
<b>Primary caregiver</b>	
Myself	41 (38.28)
Myself and partner	61 (53.98)
Other family members	8 (7.08)
Friend/Neighbor	1 (0.88)
Yaya/helper	2 (1.177)
<b>Parents' educational attainment</b>	
Elementary undergraduate	1 (0.88)
Elementary graduate	1 (0.88)
High school undergraduate	6 (5.31)
High school graduate	28 (24.78)
Vocational undergraduate	2 (1.77)
Vocational graduate	8 (7.08)
College undergraduate	14 (12.39)
College graduate	51 (45.13)
Post graduate degree	2 (1.77)
<b>Mother's employment status</b>	
Employed	31 (27.19)
Self employed	9 (7.89)
Unemployed	74 (64.91)
<b>Father's employment status</b>	
Employed	75 (67.57)
Self employed	12 (10.81)
Unemployed	24 (21.62)
<b>Monthly family income</b>	
< P5,000	20 (17.39)
P5,000 to P9,999	33 (28.7)
P10,000 to P19,999	40 (34.78)
$\geq$ P20,000	22 (19.13)
<b>Family structure</b>	
Two parent biological	105 (91.3)
Two parent adopted	4 (3.48)
Single mother, no father	5 (4.35)
Others	1 (0.87)
<b>Number of children in the household</b>	2 (1 to 3)

**Table 3. WHOQOL-BREF Filipino Version domain scores (n=115)**

WHOQOL-BREF FV Transformed Scores		Physical	Psychological	Social Relationships	Environmental
	Mean	67.71	69.42	70.04	57.44
	Median	69	69	75	56

**Table 4. Situations and Emerging Concerns during the Coronavirus Pandemic (n=115)**

	Frequency (%)
<b>Current measures being implemented during the COVID-19 Pandemic</b>	
Social distancing	95 (82.61)
Curfew	93 (80.87)
Mandatory quarantine	35 (30.43)
Other	20 (17.39)
Unsure about the situation in my area	1 (0.87)
<b>Impact of the quarantine measures brought on by COVID-19 pandemic</b>	
<ul style="list-style-type: none"> <li>• Unable to access habilitation and rehabilitation services (physical therapy, speech therapy, occupational therapy)</li> </ul>	86 (74.78)
<ul style="list-style-type: none"> <li>• Unable to access Child Development Center/ Day Care Centers, Supervised Neighborhood Playgroup, National Child Development Center, Early Learning Center</li> </ul>	75 (67.57)
<ul style="list-style-type: none"> <li>• Loss of income or employment</li> </ul>	75 (65.22)
<ul style="list-style-type: none"> <li>• Unable to access education services / learning resource</li> </ul>	52 (45.22)
<ul style="list-style-type: none"> <li>• Unable to access health clinic services (including public health services, immunization, nutritional screening, medical consultations)</li> </ul>	50 (43.48)
<ul style="list-style-type: none"> <li>• Decline in mental health and well-being (example: fear, anxiety, stress)</li> </ul>	37 (32.17)
<ul style="list-style-type: none"> <li>• Unable to access medicines</li> </ul>	25 (21.74)
<ul style="list-style-type: none"> <li>• Unable to buy essential supplies (food, basic commodities, hygiene products)</li> </ul>	25 (21.74)
<ul style="list-style-type: none"> <li>• Unable to access mental health/psychosocial services and counselling support</li> </ul>	24 (20.87)
<ul style="list-style-type: none"> <li>• Unable to access bank, money remittance services/financial Institutions</li> </ul>	15 (13.04)
<ul style="list-style-type: none"> <li>• Others</li> </ul>	13 (11.3)
<ul style="list-style-type: none"> <li>• Domestic abuse/ violence is now more frequent                             <ul style="list-style-type: none"> <li>• Physical</li> <li>• Sexual</li> <li>• Verbal/Emotional</li> <li>• Online/Cyberspace</li> <li>• Not applicable</li> </ul> </li> </ul>	5 (4.35)
<ul style="list-style-type: none"> <li>• Child abuse is now more frequent                             <ul style="list-style-type: none"> <li>• Physical</li> <li>• Sexual</li> <li>• Verbal/Emotional</li> <li>• Online/Cyberspace</li> <li>• Not applicable</li> </ul> </li> </ul>	0
<ul style="list-style-type: none"> <li>• Limited supply or absence of clean water</li> </ul>	5 (4.35)
<ul style="list-style-type: none"> <li>• None of the above</li> </ul>	0
<ul style="list-style-type: none"> <li>• Child abuse is now more frequent                             <ul style="list-style-type: none"> <li>• Physical</li> <li>• Sexual</li> <li>• Verbal/Emotional</li> <li>• Online/Cyberspace</li> <li>• Not applicable</li> </ul> </li> </ul>	3 (2.61)
<ul style="list-style-type: none"> <li>• Limited supply or absence of clean water</li> </ul>	0
<ul style="list-style-type: none"> <li>• None of the above</li> </ul>	3 (2.61)
<ul style="list-style-type: none"> <li>• Limited supply or absence of clean water</li> </ul>	0
<ul style="list-style-type: none"> <li>• None of the above</li> </ul>	112 (97.39)
<ul style="list-style-type: none"> <li>• Limited supply or absence of clean water</li> </ul>	3 (2.61)
<ul style="list-style-type: none"> <li>• None of the above</li> </ul>	1 (0.87)
<b>Reasons for limited access to services and necessities</b>	
<ul style="list-style-type: none"> <li>• Absence of public transport</li> </ul>	69 (60)
<ul style="list-style-type: none"> <li>• Limited or absence of money to buy</li> </ul>	59 (51.30)

<ul style="list-style-type: none"> <li>• Shops or pharmacies are only opened for a limited time</li> <li>• Physically unable to leave the home and there is no caregiver to provide the support</li> <li>• Other</li> </ul>	40 (34.78) 32 (27.83) 20 (17.39)
<b>Services or assistances received during the implementation of the quarantine measures</b> <ul style="list-style-type: none"> <li>• Quarantine pass</li> <li>• Food allowance or supply or relief package</li> <li>• Disinfection of areas</li> <li>• Information on COVID-19 prevention and treatment</li> <li>• DSWD Social Amelioration Package</li> <li>• Cash distribution from City/Municipality/ Barangay</li> <li>• Vitamin C / Dietary Supplements</li> <li>• Transportation Services</li> <li>• Testing for COVID-19</li> <li>• Medical and health needs</li> <li>• Other</li> <li>• Training on how to do therapy for my child (physical, occupational, speech therapy)</li> <li>• Provision of medicines</li> <li>• None of the Above</li> <li>• Psychosocial and counselling support</li> </ul>	104 (90.43) 99 (86.09) 70 (60.87) 59 (51.3) 49 (42.61) 48 (41.74) 21 (18.26) 9 (7.83) 17 (14.78) 14 (12.17) 9 (7.83) 6 (5.22)  3 (2.61) 2 (1.74) 1 (0.87)
<b>Issues or concerns that surfaced during the implementation of the quarantine measures</b> <ul style="list-style-type: none"> <li>• Violations on social distancing</li> <li>• Effect of enhanced community quarantine on our ability to work / earn</li> <li>• No available transportation</li> <li>• Inadequate food and/or medicine ration</li> <li>• Disruption in education and other basic social services</li> <li>• Non-compliance to set curfew time</li> <li>• LGU does not prioritize Persons and Children with Disabilities in relief distribution</li> <li>• No access to test kits</li> <li>• Inaccessible information</li> <li>• No designated area for medical consultation and isolation of patients</li> <li>• Prejudices, stigma, and discrimination toward persons with disability</li> <li>• Non-issuance of quarantine pass</li> <li>• Increased risk of domestic violence</li>   <li>• Effect of enhanced community quarantine to our children's access to education.</li> <li>• Medical concerns</li> <li>• Developmental concerns</li> <li>• Behavioral concerns</li> <li>• Sleep concerns</li> <li>• Nutrition concerns</li> <li>• Others</li> </ul>	84 (73.04) 81 (70.43) 63 (54.78) 58 (50.43) 55 (47.83) 47 (40.87) 43 (37.39) 37 (32.17) 29 (25.22) 24 (20.87) 15 (13.04) 12 (10.43) 2 (1.74)  74 (64.35) 51 (44.74) 38 (33.04) 36 (31.3) 23 (20) 22 (19.13) 13 (11.30)

**Table 5. Child characteristics data against the QoL scores of parents of children with neurodevelopmental disorders**

	Overall QoL	Physical health	Psychological	Social relationships	Environment
	Correlation coefficient; Mean $\pm$ SD				
Age	0.0332	0.0206	-0.0886	0.0902	0.0900
Years since diagnosis	0.0453	0.1065	-0.0849	0.1165	0.1165
Sex					
Male	71.77 $\pm$ 8.64	68.61 $\pm$ 12.67	70.67 $\pm$ 12.98	70.15 $\pm$ 15.64	59.24 $\pm$ 13.78
Female	69.23 $\pm$ 6.49	66.53 $\pm$ 9.52	66.8 $\pm$ 9.71	69.85 $\pm$ 14.56	54.08 $\pm$ 11.88
P-value	0.106	0.363	0.101	0.921	<b>0.047</b>
<b>Primary neurodevelopmental diagnosis</b>					
ASD					
Level 1	75.6 $\pm$ 6.42	73.33 $\pm$ 13.05	75 $\pm$ 6	75	64.67 $\pm$ 9.61
Level 2	68.1 $\pm$ 7.81	61.57 $\pm$ 13.65	67.85 $\pm$ 9.21	58.86 $\pm$ 11.35	55.43 $\pm$ 18.17
Level 3	70.08 $\pm$ 7.85	67.20 $\pm$ 12.36	68.54 $\pm$ 12.27	70.39 $\pm$ 14.7	55.73 $\pm$ 12.99
P-value	0.383	0.364	0.639	0.110	0.545
ADHD					
Moderate	73.23 $\pm$ 5.68	68.71 $\pm$ 10.21	68 $\pm$ 8.31	80.29 $\pm$ 9.14	61.71 $\pm$ 12.19
Severe	71.5 $\pm$ 9.76	59.5 $\pm$ 21.92	78.5 $\pm$ 21.92	59.5 $\pm$ 13.44	59.5 $\pm$ 4.95
P-value	0.747	0.391	0.285	<b>0.034</b>	0.816
CP					
GMFCS level 2	68.43 $\pm$ 2.66	69 $\pm$ 10.39	69	70.67 $\pm$ 13.05	48 $\pm$ 3.46
GMFCS level 5	72.39 $\pm$ 8.43	69.33 $\pm$ 9.63	71.33 $\pm$ 14.32	74 $\pm$ 11.97	58.42 $\pm$ 13.32
P-value	0.447	0.959	0.788	0.678	0.213
ID					
Moderate	66.87 $\pm$ 5.45	64.43 $\pm$ 6.16	66.14 $\pm$ 12.36	59 $\pm$ 20.94	51.71 $\pm$ 6.68
Severe	73.53 $\pm$ 5	67 $\pm$ 6.93	69 $\pm$ 6	73 $\pm$ 3.46	66.67 $\pm$ 9.71
P-value	0.109	0.574	0.719	0.280	<b>0.021</b>
Number of comorbid conditions	0.0290	0.0381	-0.0739	0.0171	0.0607
Number of medications	-0.0138	0.0091	-0.1316	0.0559	-0.0293
With ongoing intervention					
Ongoing	72.11 $\pm$ 8.86	69.32 $\pm$ 12.24	71.03 $\pm$ 13	71.46 $\pm$ 16.05	59.56 $\pm$ 14.09
Discontinued	69.53 $\pm$ 7.06	66.11 $\pm$ 11.32	67.86 $\pm$ 11.44	68.29 $\pm$ 14.77	55.02 $\pm$ 12.39
Never	72.25 $\pm$ 8.63	70 $\pm$ 11.40	70.18 $\pm$ 12	72.14 $\pm$ 15.04	60.04 $\pm$ 13.84
P-value	0.214	0.277	0.435	0.480	0.163
Education					
Enrolled in SPED	73.21 $\pm$ 7.05	69.56 $\pm$ 10.81	71.12 $\pm$ 11.04	73.56 $\pm$ 14.65	62.6 $\pm$ 11.52
Enrolled in regular school	70.75 $\pm$ 6.87	67 $\pm$ 11.36	68.88 $\pm$ 11.95	70.12 $\pm$ 13.47	58.04 $\pm$ 13.11
None	70.03 $\pm$ 8.71	67.59 $\pm$ 12.21	68.80 $\pm$ 12.56	68.64 $\pm$ 16.06	55.19 $\pm$ 13.67
P-value	0.245	0.707	0.704	0.394	0.059



**Table 6. Parents' Socio-demographic data against the QoL scores of parents of children with neurodevelopmental disorders**

	Overall quality of life rating	Physical health	Psychological	Social relationships	Environment
	Correlation coefficient; Mean $\pm$ SD				
Age	0.0675	0.1393	0.0832	0.0445	-0.0691
Sex					
Male	76.26 $\pm$ 13.5	70.2 $\pm$ 17.88	79 $\pm$ 16.75	67.6 $\pm$ 20.45	67.6 $\pm$ 18.45
Female	70.64 $\pm$ 7.7	67.78 $\pm$ 11.42	68.88 $\pm$ 11.7	70.15 $\pm$ 15.04	56.98 $\pm$ 12.98
P-value	0.126	0.652	0.066	0.715	0.081
Primary care giver					
Myself	71.02 $\pm$ 7.15	68.85 $\pm$ 11.77	68.24 $\pm$ 10.79	69.32 $\pm$ 16.13	57.73 $\pm$ 12.74
Myself and partner	70.89 $\pm$ 8.06	66.08 $\pm$ 11.68	70.15 $\pm$ 11.81	71 $\pm$ 12.79	58.08 $\pm$ 13.11
Others	70.72 $\pm$ 11.6	73.54 $\pm$ 10.74	68.27 $\pm$ 18.4	67.64 $\pm$ 24.5	54.73 $\pm$ 17.18
P-value	0.993	0.119	0.713	0.744	0.746
Parents' educational attainment	0.2248*	0.1640	0.1889*	0.0486	0.2958*
Mother's employment status					
Employed	69.81 $\pm$ 8.41	67.45 $\pm$ 11.53	70.45 $\pm$ 13.77	66.94 $\pm$ 16.34	54.1 $\pm$ 13.59
Self employed	75.68 $\pm$ 8.88	73.56 $\pm$ 12.83	77.89 $\pm$ 8.91	76.44 $\pm$ 17.4	61.22 $\pm$ 15
Unemployed	70.67 $\pm$ 7.67	67.36 $\pm$ 11.65	67.81 $\pm$ 11.31	70.5 $\pm$ 14.44	58.15 $\pm$ 12.87
P-value	0.149	0.320	0.051	0.232	0.237
Father's employment status					
Employed	71.94 $\pm$ 7.94	68.69 $\pm$ 11.84	70.16 $\pm$ 10.96	71.25 $\pm$ 14.31	59.77 $\pm$ 13.4
Self employed	71.56 $\pm$ 8.51	67.83 $\pm$ 13.97	69.42 $\pm$ 13.58	72.92 $\pm$ 11.44	57 $\pm$ 14.07
Unemployed	67.8 $\pm$ 7.15	64.71 $\pm$ 10.63	68.04 $\pm$ 13.32	69.2 $\pm$ 15.06	50.58 $\pm$ 9.93
P-value	0.081	0.360	0.744	0.733	<b>0.011</b>
Monthly family income	0.2418*	0.1760	0.1645	-0.0730	0.2977*
Family structure					
Two parent biological	71.3 $\pm$ 7.92	68.03 $\pm$ 11.98	70.08 $\pm$ 11.79	71.6 $\pm$ 13.95	57.73 $\pm$ 13.09
Others	66.57 $\pm$ 8.21	66.4 $\pm$ 7.96	61.4 $\pm$ 12.39	53.7 $\pm$ 18.87	54.4 $\pm$ 16.09
P-value	0.075	0.675	<b>0.029</b>	<b>&lt;0.001</b>	0.452
Number of children in the household	-0.0050	-0.0175	-0.0918	0.0112	-0.0700

\* - Significant at 5% level of significance