Revista Iberoamericana de Neuropsicología, Vol. 6, No. 2: 168-182, julio-diciembre, 2023.

Impact of the COVID-19 Pandemic in Children and Adolescents with Neurodevelopmental Disorders and their Families in Puerto Rico

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ABSTRACT

Objective: *The purpose of this study was to provide a broad description of the effects of social distancing in children and adolescents with neurodevelopmental disabilities (CAND) and their caregivers in Puerto Rico (PR). This was done by investigating (1) their sociodemographic characteristics; (2) changes in their daily life, education and mental health and (3) their caregiver's attitudes towards distance education and the emergency-response measures implemented.*

Method: *A descriptive research study was conducted; 612 parents of CAND living in PR were surveyed from October 23rd, 2020 to June 7th, 2021. Seventy-four of the 78 municipalities of the Island were represented in the sample.*

Results: *Mostly working mothers (76.6%) of a child (M^{age}=10) with cognitive and/or language disorders were represented. The most prevalent necessities found were related to therapies (73.9%) and recreation (63.6%). Virtual services were predominant during quarantine, and difficulties balancing work, household, parenting and caregiving were reported by parents. Findings suggest these families are struggling to adjust to distance education, and an increase in symptoms of anxiety and depression were reported in both CAND and caregivers.*

Conclusion: *Overall, results indicate that CAND and their caregivers are struggling to adjust to the changes brought by the pandemic; which is a cause for concern. It is recommended that governmental, private and nonprofit organizations should use these findings to support public policy and intervention programs to assist these families.*

Keywords:

COVID–19, disabilities, neurodevelopmental disorders, caregivers, Puerto Rico, mental health.

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INTRODUCTION

Two hundred and forty million children and adolescents with disabilities[1] (CAD) who already experience inequities in healthcare, schooling, future employment opportunities and governmental legislations[2]; are facing the COVID-19 Pandemic. These minors are 51% more likely to experience feelings of unhappiness, 32% more likely to be victims of disability-related abuse and 53% more vulnerable to acute respiratory infections[1]. This brings up the question: How are CAND and their families in PR coping during the pandemic? Since the WHO[2] declared COVID-19 a worldwide pandemic on March 11th, 2020; literature suggests that children and adults with disabilities and their families are experiencing greater symptoms of anxiety and depression[3-14], difficulties adapting to the changes in education[3,4,15-18], inaccessibility to healthcare, technology, adapted resources [3,16,19, 20] and government considerations during the emergency [21-25]. However, information continues to be limited on the effects of the COVID-19 pandemic on families of CAND, especially in PR.

Few literature is available on the needs, attitudes and challenges during quarantine, social isolation and distance education on the 54,000+ children living with neurodevelopmental disabilities in PR[26]. These children and their families live in a U.S. territory with and accumulated $72 billion in debt and 57% child poverty rates[27] therefore, not only do families of CAND in PR face general disability-related inequities, but also a higher economic hardship during the Pandemic compared to other territories or states, making this a unique population to study. They also continue to face the repercussions of two consecutive Category 5 Hurricanes Irma and María in September 2017, earthquake swarms (December 28th, 2019-present), and political turmoil; further supporting the need to investigate the effect COVID-19 has had in CAND and their families in PR. Also, there is limited research available on the families of children and adolescents with a variety of disabilities in the Island. This study mitigates this limitation in literature by including caregivers of children with sensorimotor, general developmental, cognitive, language, physical and eating disorders in PR in its sample. To our knowledge, it is the first study in PR to investigate how COVID-19 has affected CAND and their families in the Island.

The purpose of this descriptive study was to provide a multidimensional snapshot of families of CAND during the pandemic in PR by answering the following questions: (Q^1) Who are these families? (Q^2) What changes have occurred in CAND and their caregiver's daily routines, accessibility to services, education and mental health?, and (Q^3) What are the caregiver's attitudes towards distance education and the emergency response measures implemented during quarantine? The findings are analyzed using a sample composed of parents and caregivers of CAND.

METHOD

Participants

This study was aimed towards the parents or caregivers of CAND. To participate, the individuals needed to have the following characteristics: (1) be 21 years or older, (2) have at least one child with disability (CwD) in their care between ages 0 to 21 years, and (3) be currently living in PR during COVID-19. The exclusion criteria included the following: (1) They did not have the technology necessary to complete the online survey, (2) they were less than 21 years old, (3) they were CAND, and (4) they were not able to consent.

Participant Flow

A total of 1,111 people accessed the informed consent page in which 829 agreed to participate, 7 declined and 275 did not respond. From the 829 that agreed to participate, 552 parents and caregivers completed the survey in its entirety, and 277 completed it only partially. After careful revision of the responses, 18 surveys where eliminated due to not complying with the inclusion criteria [caregivers were less than 21 years old (n=3), participant was the person with disability (n= 1) or CAND were more than 21 years old (n=14)]. In addition, 151 surveys were excluded due to insufficient survey answers. The final sample was comprised of 612 caregivers of 74 of the 78 municipalities in the Island.

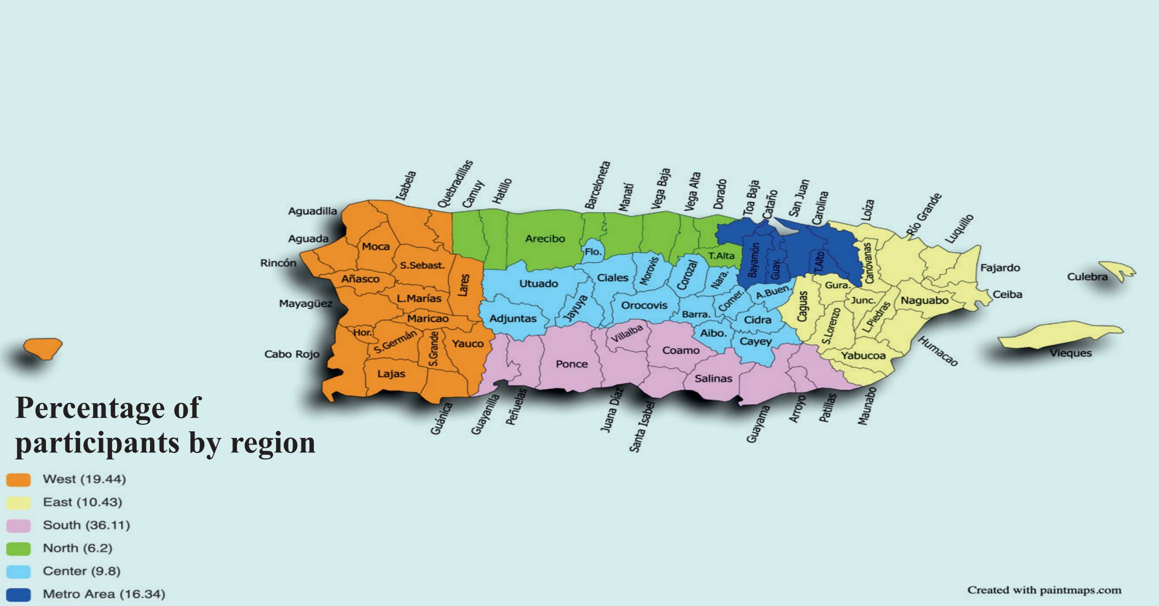

Figure 1. Percentage of participants by Region of PR (n= 612)

Note. This figure shows the distribution of participants throughout the Island by regions of Puerto Rico (n=612). The Metro Area was included to better represent the population distribution. The majority of participants are from the southern (n_1=221), western (n_2= 119) and metropolitan (n_3= 100). This image was adapted from "[Color Puerto Rico Map]", by Paintmaps, 2022. Copyright 2014 by Paintmaps.com.

The majority of the subjects lived in the southern (36.1%), western (19.4%) and metropolitan (16.3%) regions (Figure 1). Municipalities most represented were Ponce (19.4%), San Juan (6.8%) and nearby cities. More details on the sociodemographic characteristics of our participants are discussed in the results section, since it is data relevant to answering Q^1 of our investigation.

Measures

After carefully revising the current literature in COVID-19 and CAND, an instrument directed to parents and caregivers was created by a team composed of two neuropsychologists, a medical geneticist and a clinical psychology doctoral student using survey design procedures recommended by Creswell & Creswell[28] on quantitative research design. Figure 2 shows the questionnaire's components. Content validity for the instrument was established using three external professors with doctoral degrees who practice within the fields of developmental psychology, health psychology, autism, neuroscience and education. The survey was administered in an online format through the REDCap platform, a HIPAA compliant software for clinical research[29]. It included 33 multiples choice or multiple selection questions, two mental health scales, one for parents and the other for the children, one parental attitudes scale towards distance education, and another attitudes scale towards disability-inclusive response measures.

Demographics

To answer Q^1 of this study, exhaustive demographic information was collected including the participants' gender, age, marital status, relation with child with disability, education level, employment status, household income, household number and place of living in PR. A section was also included to specify the number of children with disabilities in their care, the child's age, their disability type and school level.

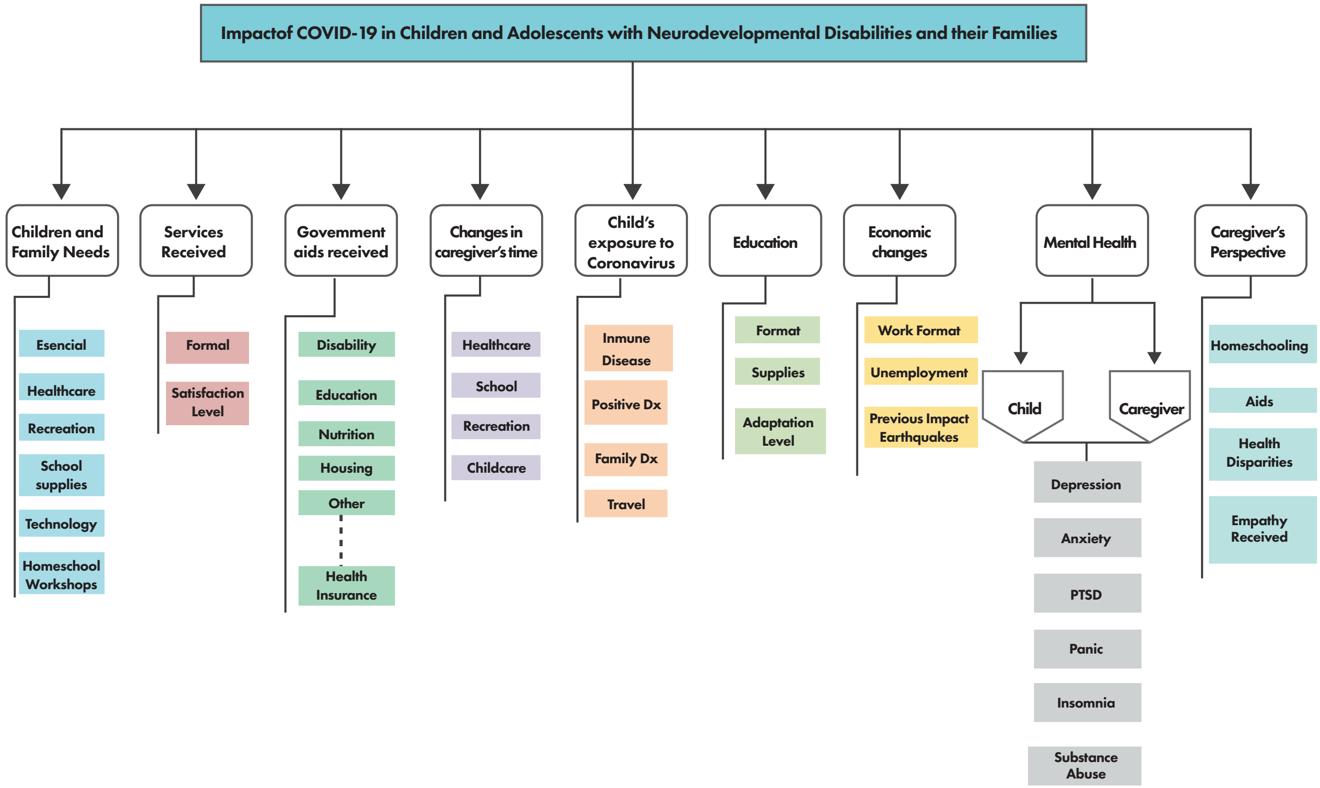

Figure 2. Components of the "COVID-19- Neurodevelopmental Questionnaire"
Note. This figure shows the diverse descriptive variables explored throughout this study.

Changes in Daily Routine

Thirty-three multiple choice and multiple selection questions were used to explore the changes in CAND and caregiver's daily routine during the Pandemic. Variables assessed include essential, economic and educational necessities; format of health services received and parent's level of satisfaction, and changes in work, time-management, and education. The items were carefully created based on the needs frequently reported in children and adults with disabilities during quarantine and social distancing measures in various studies[3,6,8,11,12,16,19,20,21,22,30,31].

Mental Health

To answer Q^2 of this study, researchers developed a 26-item Likert scale to measure the psychological effects of the pandemic in both caregivers and CAND, based on the recent psychological symptoms reported worldwide[32,33] and in persons with disabilities (PwD)[3-14] during quarantine. Symptoms related to depression, anxiety, sleep, panic, substance abuse and Post Traumatic Stress Disorders (PTSD) were included in the scale based on the diagnostic criteria in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5)[34]. The scale obtained a Cronbach's alpha of 0.93, reflecting an excellent internal consistency reliability coefficient.

Parental Attitudes: Distance Education

For Q^3, researchers developed a nine item Likert scale to measure the attitudes of the caregivers of CAND towards virtual education during COVID-19, based on the recent literature available[3, 4, 15-18, 21,22] on the difficulties students with disabilities face during change from in-class to distant education. The scale obtained a Cronbach's alpha of 0.773, reflecting a good internal consistency reliability coefficient. Since some CAND may not be currently enrolled in distant education due to their age, a "Does not apply" item was added in the education section of the study.

Parental Attitudes: Emergency-Response Measures

A seven-item Likert scale was development to measure the attitudes of the caregivers of CAND towards the emergency response measures implemented during the pandemic by the government and institutions (Q3). Since there were limitations in literature on this topic, emphasis was put in trying to determine if parents thought the response-measures were disability-inclusive and if they thought they and their CwD were taken into consideration during the emergency. The scale obtained a Cronbach's alpha of 0.55 indicating a low level of internal consistency. This was taken into consideration during the results analysis and discussion.

Procedure

This exploratory study was reviewed and approved as exempt by the Institutional Review Board of the [Ponce Health Sciences University (IRB-PHSU), Study ID: 2007042948]. A self-paced online questionnaire was created and administered in Spanish to the caregivers of CAND through REDCap and had the approximate answer time between 10 to 15 minutes. Participants were recruited through social media (WhatsApp, Instagram and Facebook) and collaborations with non-profit organizations. Before participating, caregivers were asked to read and accept an online consent form that included the purpose of the study and the benefits and risks of participating. Furthermore, participants were given brief instructions on how to answer the questionnaire. Names were not solicited, and the publication or presentation of results does not identify the person answering the survey.

Data collection and storage was also done online through REDCap between October 23rd, 2020 and June 7th, 2021. Although, most responses were collected between October 23rd and the month of January 2021. Only the investigators and IRB-PHSU could inspect and have access to the confidential data for quality control and data analysis purposes.

Data Analysis

Descriptive statistics were conducted to analyze the results. Demographics, necessities, services received, mental health symptoms of CAND, educational and attitudes towards emergency-response measures. IBM SPSS 28.0 Statistics was used to compute the descriptive analyses. Microsoft Excel 2021 was also used to present the data in tables and figures.

RESULTS

Who are these families during the pandemic in PR?

Of the 612 participants, most of them were mothers of CAND of 40 years of age (SD_{age} - 9.19), married (49.5%) with only one CwD (92.2%). Most were full-time working mothers (41.8%) with a bachelor's degree (43.3%), living in a family of four (39.36%) with a household income between $10,001-$30,999 (39.1%). These working mothers selected cognitive/learning disorders as their child's principal disability (70.5%) however, most children had comorbidities with other disabilities, such as sensorimotor and language disorders (Table 1). The M_{age} of the child with special needs was 10.31 (SD= 4.88, 5.3%) and most were enrolled in elementary school (38.0 %).

Most children were enrolled in the Government's Special Education Program (66.0%) and 38.4% of these families received support to buy food supplies through the Puerto Rico Nutritional Assistance Program (PAN). Ninety-six percent of caregivers indicated that neither them nor their children had been exposed to someone with COVID-19 during sample recollection. Similarly, the majority indicated that they had not been diagnosed with the coronavirus (84.4%) nor has their child presented symptoms related to COVID-19 (94.4%). Only 130 participants (21.2%) indicated their family had been affected by the earthquake swarms from December 28th to the present in PR, and 177 indicated their child has a condition that compromises their immune system (67.5%). An interesting finding is that 50.3% of participants have opted to not take their child to therapies for fear that they might contract COVID-19.

What changes have occurred?

Necessities

The most prevalent necessities reported by caregivers of CAND during COVID-19 were related to therapies (73.9%) and recreation (63.6%). Other neces-

Table 1. Type of neurodevelopmental disabilities as reported by the parent

Category	Examples[a]	N	%
Sensorimotor	Palsy, apraxia, motor coordination disorder, motor delay/hypotonia, tics, Tourette's, sensory disorder, among others	172	28.1
Developmental Disorder	Developmental delay, intellectual disability, global developmental delay, among others	127	20.8
Language Disorder	Speech delay, dysphasia, apraxia of speech, mutism, mixed receptive/ expressive disorder, among others	254	41.5
Cognitive disorder	Dyslexia, dysgraphia, dyscalculia, ADHD, autism, among others	425	69.4
Physical disorder	Metabolic disorders, genetic disorders (Rett, Down, Muscular dystrophy; Prader Willi/Angelman; phenylketonuria; cystic fibrosis; Hirschsprung's disease) developmental malformations (spina bifida); perinatal strokes, blindness, deafness, among others	83	13.6
Eating disorder	Dysphagia, swallowing disorders, eating disorders, anorexia, among others	95	15.5

Note. Caregivers were asked to select all that applied to their child from a list.
[a] Each category provided examples of disorders to further assist the parent in choosing the right classification.

Table 2. Necessities of children and adolescents with neurodevelopmental disabilities during COVID-19, as reported by the caregiver

Variable	N (%)
Therapy	452 (73.9)
Recreation	389 (63.6)
Technology	205 (33.5)
Educational materials	199 (32.5)
Daycare services	134 (21.9)
Medical services	118 (19.3)
Medications	97 (15.8)
Specific nutritional necessities	94 (15.4)
Hygiene Products	73 (11.9)
Nutritionist	58 (9.5)
Delivery services	41 (6.7)
Transport services	38 (6.2)
Water	30 (4.9)
Medical equipment	29 (4.7)
Cleaning services	25 (4.1)
In home health carer	14 (2.3)
Nurse services	8 (1.3)

Note. Caregivers were asked to select all the necessities that applied to their child from a list.

Table 3. Necessities during distance learning, as reported by the caregiver

Variables	N (%)
Technology	203 (33.2)
Internet	155 (25.3)
Training services for parents	134 (21.9)
School books	118 (19.3)
Arts and crafts, projects	101 (16.5)
Writing and drawing materials	86 (14.1)
Paper, folders, index cards	75 (12.3)

Note. Caregivers were asked to select all the necessities that applied to their child from a list.

sities reported were educational materials (32.5%), technology (33.5%) and internet services (25.3%). Twenty-two percent of caregivers reported the need for training services for parents providing distance education to their children (See tables 2 and 3).

Services received and Parental Satisfaction Level

The most common in-site service received were medical services (23.9%). However most services during quarantine, as expected were in an online/virtual format, with the highest reported service being distance education (69.6%). Other than virtual schooling, 27.9% of participants indicated that their child received online speech and language therapy and 21.6% of CAND received virtual psychological interventions. In terms of satisfaction levels for the most prevalent services received, most parents agreed they were satisfied with the in-site medical service received (*M*= 3.68, *SD*= 1.30), compared to those who received physician consultations via telehealth for their child, who felt neutral (*M*= 3.32, *SD*= 1.22). In terms of education, parents expressed feeling neither satisfied nor dissatisfied for both virtual and in-site education for their children (M= 2.60, $SD_{\text{in-site education}}$= 1.43, M= 2.88, $SD_{\text{virtual education}}$= 1.17). Similarly, they had a neutral position for speech, language and psychological therapies received in virtual formats (M= 3.38, $SD_{\text{virtual speech therapy}}$= 1.30, M= 3.12, $SD_{\text{virtual psychology}}$= 1.30).

Work and life changes. Overall, 52.3% of parents indicated that they experienced changes in their employment since the start of quarantine including a loss or decrease in income, that makes it difficult for them to cover their child with special needs' expenses (40.4%). The most common changes in work format during social distancing were changes in work hours (20.9%) and the format of their employment (18%), for example, from in-site to online format. Changes in time dedicated by parents to their children were also reported. Most parents expressed time spent for therapies and essential services for their child was reduced in quarantine, while 53.1% reported their time spent to their child's schooling increased. About 48% of parents agreed that their time dedicated to their child for recreation purposes was reduced.

Mental Health of Child

In regard to CAND's mental health, caregivers generally reported sometimes observing an increase in sleeping difficulties (*M* = 1.93, *DS* = 0.76), hyperphagia (*M* = 1.88, *SD* = 0.81), stress (*M* = 1.97, *SD* = 0.74) and anhedonia (*M* =1.78, *SD* = 0.77) in their child with special needs (Table 4). They also informed sometimes noticing feelings of anxiety or exaggerated preoccupations (*M* = 1.74, *SD* = 0.77, fear of being alone, irritability (*M* = 1.99, *SD* = 0.77), and an intolerance to changes (*M* = 1.84, *SD* = 0.73). They also occasionally observed concentration difficulties (*M* = 2.21, *SD* = 0.76) and a decrease in academic performance (*M* = 1.91, *SD* = 0.77).

Mental Health of Caregiver

Parents generally reported sometimes experiencing an increase in anxiety (M = 2.29, DS = 0.68), sleeping difficulties (M = 2.19, DS = 0.72), sadness (M = 2.16, DS = 0.71), muscular tension (M = 2.14, DS = 0.77) and a reduced desire to participate in social activities (M = 2.08, DS = 0.78). They also occasionally experienced fear (M = 2.05, SD = 0.72), concentration difficulties (M = 2.02, DS = 0.76), an increase in appetite (M = 1.94, DS = 0.80), nervousness (M = 1.92, DS = 0.74), irritability (M = 1.89, DS = 0.73) and difficulties adapting to the changes brought by the Pandemic (M = 1.83, DS = 0.69). See table 5.

Education

Of the 612 caregivers surveyed, 403 parents (65.8 %) reported offering distant education to their children during the pandemic. Ninety-two percent reported schools continued services during quarantine, with the most used learning formats being videoconferences (55.7%) and assignments delivered by email correspondence (41.3%).

Caregivers' Attitudes

Distance education

On average, the majority of parents somewhat agreed on having difficulties employing distant education to their children with special needs (*M* = 3.08, *SD* = 0.99) and indicated they preferred regular

Table 4. Child mental health observations as reported by parent during social distancing and quarantine

Statement	Have not noticed n (%)	Sometimes n (%)	Frequently n (%)	M (SD)
Difficulties in concentrating	113 (20.7)	204 (37.4)	228 (41.8)	2.21 (0.76)
Irritable or anger (tantrums)	167 (30.6)	217 (39.7)	162 (29.7)	1.99 (0.78)
Increase in appetite	280 (51.4)	183 (33.8)	146 (26.9)	1.88 (0.81)
Stress	157 (28.9)	245 (45.0)	142 (26.1)	1.97 (0.74)
Decreased academic performance	189 (34.6)	217 (39.7)	140 (25.6)	1.91 (0.77
Difficulties sleeping	178 (32.6)	230 (42.1)	138 (25.3)	1.93 (0.76)
Fear of being alone	253 (46.5)	174 (32.0)	117 (21.5)	1.75 (0.79)
Stopped participating in activities that he/she previously enjoyed	244 (44.8)	188 (34.5)	113 (20.7)	1.76 (0.77)
Anxiety or exaggerated preoccupations	253 (46.2)	184 (33.6)	111 (20.3)	1.74 (0.77)
Was intolerant to changes	191 (35.3)	244 (45.1)	106 (19.6)	1.84 (0.73)
Decreased desire to participate in social activities with peers or adults	268 (48.8)	193 (35.2)	88 (16.0)	1.67 (0.74)
Presents obsessive, constant thoughts of crisis	333 (61.6)	147 (27.2)	61 (11.3)	1.40 (0.67)
Has difficulty expressing positive emotions or affect recently	331 (60.5)	157 (28.7)	59 (10.8)	1.50 (0.68)
Feelings of sadness or depression	213 (39.3)	208 (38.2)	57 (10.5)	1.59 (0.67)
Has had nightmare related to the Pandemic	382 (70.9)	101 (18.7)	56 (10.4)	1.22 (0.51)
Decrease or loss of appetite	329 (60.3)	170 (31.1)	47 (8.6)	1.48 (0.65)
Expressed having physical pain without apparent cause	406 (74.2)	98 (17.9)	43 (7.9)	1.34 (0.62)
Avoids conversations, activities or places that remind him/her of COVID-19	406 (74.8)	94 (17.3)	43 (7.9)	1.33 (0.62)
Night enuresis (bed wetting)	448 (82.8)	56 (10.4)	37 (6.8)	1.24 (0.57)
Increase of risk behaviors	415 (76.4)	93 (17.1)	35 (6.4)	1.30 (0.58)
Reacts abruptly or presents psychological stress with thoughts or conversations of COVID-19	399 (73.1)	113 (20.7)	34 (6.2)	1.33 (0.59)
Ocasionally looks disoriented in space and time	377 (69.2)	136 (25.0	32 (5.9)	1.37 (0.59)
Increase in aggressive/disruptive behaviors	450 (82.7)	70 (12.9)	24 (4.4)	1.50 (0.69)
Has difficulties remembering events related to the Pandemic	471 (86.3)	54 (9.9)	21 (3.8)	1.18 (0.47)
Negative thought of self or the world	431 (79.7)	90 (16.6)	20 (3.7)	1.24 (0.51)
Games involve pandemic or natural disaster related themes	462 (85.6)	66 (12.2)	12 (2.2)	1.17 (0.43)

Note. 1= Have not noticed, 2= Sometimes, 3= Frequently

school for their CwD (*M* = 316, *SD* = 1.09). Similarly, most caregivers somewhat agreed they had difficulty using materials and educational platforms to teach their children (*M* = 2.65, *SD* = 1.02), although they were fairly able to make reasonable accommodations for their children's education in the COVID-19 Pandemic (*M*= 2.53, *SD*= 1.06). Generally, caregivers slightly disagreed their child's academic performance during the pandemic was excellent (*M* = 2.22, *SD* = 0.99) and they accomplished the learning goals for his/her grade levels (*M* = 2.19, *SD* = 0.95). On average, caregivers fairly disagreed their CwD adapted well to the changes in education brought by the pandemic (*M* = 2.19, *SD* = 1). The majority of parents totally disagreed their CwD completed their assignments without requiring aid (*M* = 1.69, *SD* = 0.96), and fairly disagreed their child's school answered their questions regarding distance learning (*M* = 2.20, *SD* = 1.08). Most parents rated their CwD's adaptation to the changes in education as fair (*M* =3.23, *SD* = 1.14). For more information on this data, see Table 6.

Emergency-response measures

On average, the majority of parents totally agreed that few people understand the difficulties of caring for

Table 5. Parents' Self-reported Mental Health Symptoms during the Pandemic

Statement	Have not experienced n (%)	Sometimes n (%)	Frequently n (%)	M (SD)
Anxiety	70 (11.4)	254 (41.5)	233 (38.1)	2.29 (0.68)
Muscular tension	132 (21.6)	116 (35.3)	210 (34.3)	2.14 (0.77)
Difficulties sleeping	102 (16.7)	248 (40.5)	207 (33.8)	2.19 (0.72)
Reduced desire to participate in social activities	148 (24.2)	215 (35.1)	195 (31.9)	2.08 (0.78)
Feelings of sadness	102 (16.7)	264 (43.1)	191 (31.2)	2.16 (0.71)
Concentration difficulties	152 (24.8)	235 (38.4)	164 (26.8)	2.02 (0.76)
Increase in appetite	195 (31.9)	195 (31.9)	162 (26.5)	1.94 (0.80)
Fear	130 (21.2)	267 (43.6)	155 (25.3)	2.05 (0.72)
Preference to being alone instead of with others	180 (29.4)	234 (38.2)	142 (23.2)	1.93 (0.76)
Restlessness or nervousness	175 (28.6)	253 (41.3)	130 (21.2)	1.92 (0.74)
Difficulties in relationships with friends or family	227 (37.1)	205 (33.5)	123 (20.1)	1.81 (0.77)
Irritability/anger	185 (30.2)	250 (40.8)	122 (19.9)	1.89 (0.73)
Tension in my close relationships	232 (37.9)	211 (34.5)	111 (18.1)	1.78 (0.76)
Physical ailments without apparent cause	267 (43.6)	178 (29.1)	107 (17.5)	1.71 (0.77)
Hopelessness	220 (35.9)	222 (36.3)	107 (17.5)	1.79 (0.74)
Depression	226 (36.9)	222 (36.3)	107 (17.5)	1.79 (0.75)
Feeling useless	283 (46.2)	168 (27.5)	104 (17.0)	1.68 (0.77)
Low self-esteem	323 (52.8)	155 (25.3)	72 (11.8)	1.54 (0.72)
Fatigue	288 (47.1)	166 (27.1)	97 (15.8)	1.65 (0.76)
Difficulties accepting/adapting to the changes or what has happened	187 (30.6)	273 (44.6)	93 (15.2)	1.83 (0.69)
Confusion/uncertainty	275 (44.9)	190 (31.0)	89 (14.5)	1.66 (0.74)
Hyperactivity	368 (60.1)	127 (20.8)	56 (9.2)	1.43 (0.67)
Reduction or loss of appetite	284 (46.4)	216 (35.3)	56 (9.2)	1.59 (0.67)
Feeling of guilt	377 (61.6)	123 (20.1)	55 (9.0)	1.42 (0.67)
Increased alcohol, cigarette, drug or sleep pills consumption.	458 (72.8)	62 (10.1)	34 (5.6)	1.23 (0.55)
Thoughts of death	494 (80.7)	42 (6.9)	18 (2.9)	1.14 (0.43)

Note. 1= Have not noticed, 2= Sometimes, 3= Frequently

a special needs' child during the Pandemic (*M* = 4.17, *SD* = 1.23). However, most took a fairly neutral position in relation to questions about disability sensibility and considerations in school, work, therapy sessions, information received during COVID-19, governmental response measures and ableism questions.

DISCUSSION

The purpose of this study was to create a multidimensional profile of families with CAND in Puerto Rico during the COVID-19 pandemic. This was done by (1) finding out the sociodemographic characteristics of the caregivers and children with disabilities in the Island, (2) collecting data on the changes the pandemic has brought in their accessibility to needs and health services, changes in work/life balance, mental health and education, and (3) exploring the attitudes of parents towards distance education and the emergency measures implemented. Overall, the three research questions were answered successfully and a broad snapshot of CAND and their families during the pandemic was described.

Results showed that most participants were mothers of CAND with cognitive disabilities, living in

Table 6. Perspective of parents who offered distance learning during COVID-19

Statement	Totally disagree n (%)	Somewhat disagree n (%)	Somewhat agree n (%)	Totally agree n (%)	M (SD)
I had difficulty employing distance education to my child with disability.	46 (11.9)	38 (9.8)	141 (36.4)	162 (41.9)	3.08 (1.0)
My child's academic performance was excellent.	114 (29.2)	118 (30.0)	115 (29.5)	43 (11.0)	2.22 (1.0)
My child adapted well to the changes in education.	124 (31.9)	109 (28.0)	115 (29.6)	41 (10.5)	2.19 (1.0)
My child accomplished the learning goals for his/her grade level.	113 (29.3)	120 (31.1)	121 (31.3)	32 (8.3)	2.19 (1.0)
I prefer regular school than distance education for my child with disability.	52 (13.4)	47 (12.1)	76 (19.5)	214 (55.0)	2.16 (1.1)
I was able to make reasonable accommodations necessary for my child.	87 (22.5)	87 (22.5)	132 (34.1)	81 (20.9)	2.53 (1.1)
I had difficulty using materials and educational platforms to teach my child.	74 (19.1)	71 (18.3)	161 (41.5)	82 (21.1)	2.65 (1.0)
My child mostly did assignments alone without needing help.	229 (58.7)	79 (20.3)	54 (13.8)	28 (7.2)	1.69 (1.0)
I received help from the school/institution with my questions of distance learning.	138 (36.0)	84 (21.9)	106 (27.7)	55 (14.4)	2.20 (1.1)

Note. 1= Totally disagree, 2= Somewhat disagree, 3= Somewhat agree, 4= Totally agree

the metro, southern and southwestern areas of the Island. The distribution of participants is consistent with the population's higher densities in the Municipalities of San Juan in the metro area (2.722/Km^2), Ponce in the southern region (454.5/Km^2), as stated by the U.S. Census Bureau[35]. Also, the majority were married, worked full-time and lived in a household of four with a family income of less than $31,000 during the COVID-19 pandemic. The fact that the majority were mothers is not surprising since culturally, their role is usually associated with caregiving and nurturing their children. However, their biological sex, household income classified as living in poverty, and their child's disabilities all cause higher vulnerabilities to suffering mental health symptoms during social distancing and health disparities, according to literature[32,33]. Also, the most common disability type in our sample, cognitive disability, reflects the most common disability type in children and adolescents in PR[26]. In general, one of the objectives of our study was to provide a detailed picture these families living in PR during the pandemic, and it was accomplished.

In relation to the changes brought by social distancing, results in our study showed a high necessity for therapies and recreational activities during COVID-19 in CAND in Puerto Rico, consistent with findings early on in the start of the pandemic in other countries[8,19,30,36]. It is clear that social isolation due to quarantine limits the amount of recreational activities to indoors, and findings in this study suggest that accessibility to specialized therapies such as psychological, occupational, physical and speech therapies continue to be limited, similar to those reported in the starting months of the pandemic[4, 9]. However, essential necessities such as specialized nutrition, water, daily essentials and access to physician consultation were not prevalent during sample recollection, in contrast to one of the few studies done in the months of March through May, 2020[3].

Results in our investigation also indicated that most CAND that received services during quarantine did so in an online format, especially distance learning and therapeutic services. However, findings suggest that parents' level of satisfaction was neither satisfied nor unsatisfied. This is consistent with previous literature that states that, both telehealth and distance education, are good emergency-response measures to prevent the spread of COVID-19, however, they still have many limitations to PwD, including delayed services, internet connectivity and accessibility problems[3,4,19,20].

Data in our study showed that 40% of families of CAND have had economic loses, and parents are struggling to cover expenses for their child's special needs, although they work full-time during quarantine. This information is concerning because, economic hardship positively correlates to the mental health of these individuals[32,33] and should be taken seriously for the wellbeing of the parents and their children, whom depend mostly on their caregivers for their needs. The prevalence of changes in work format reported by parents is not surprising, since most services have transferred to an online format during quarantine[19,20]. And, in relation to changes in routine during social distancing; the reduction of time spent on therapies, services and recreation reported by caregivers in our study correlates to school closures, and the emergency response-measures implemented; that greatly reduce the accessibility to these services. Also, it is congruent to the widespread need for therapies and recreation reported by parents in our study. On another note, our data indicated that the time spent by caregivers educating their children increased, which is consistent with literature that indicates that parents are taking the role of teaching their children during quarantine[15].

In relation to changes in education, most parents answered that schools continued services during quarantine using videoconferences and assignments delivered by email, consistent with the increased use of technology to safeguard families of contagion. As stated by Jeste et al.[20] the use of technology has been of benefit to PwD during COVID-19, although it still has much to improve, and services have been delayed.

An increase of anxiety, stress and depression symptoms were reported by parents in themselves and in their special needs' children during the pandemic in our investigation, consistent with what has been reported worldwide and in families of children with disabilities[6,12,13,16,21]. Interestingly, most parents self-reported and observed in their child the symptoms occasionally, and not frequently. The only symptom that parents observed in their children frequently was an increase in concentration difficulties. This may correlate to the difficulties adapting to distance education and their reduced academic performance reported in this study, and supported by previous literature[16,17, 37]. This data on the overall necessities, services received, changes in work/life balance, changes in education and mental health answered Q[2] of this study.

In relation to parental attitudes (Q 3), the results obtained in our study support that both parents and CAND are having a hard time adapting to distance education, and the overall academic performance of special need's students has been reduced, consistent with previous studies early in quarantine[16, 37]. Data in our study indicate that parents are having difficulties using materials and educational platforms, and they are in the need of resources, materials, training and aid to teach their special needs' children. This suggests there may be a lack of guidelines available, poor implementation of virtual courses and a lack of accessibility during distance learning, as stated in previous literature[16,17]. Previous research also indicates that some parents feel overwhelmed and unqualified to teach their special needs' children during distance learning[15] consistent to what parents reported in our findings, which may contribute to the difficulties in adapting to distant education found in our study.

In relation to the attitudes towards emergency response measures, most parents reported a neutral stance, neither satisfied nor dissatisfied in all except one statement. This neutrality could be related to the social desirability component in the formulation of the statements. However, in the deviating statement, parents totally agreed that few people understand the difficulties of caring for a special needs' child during the pandemic. When comparing families of CAND with others with neurotypical children, their special needs and additional vulnerability can make them more susceptible to suffering health disparities and mental health symptoms, as supported by previous literature[2,5]. So, it is valid that the majority of parents feel that few people understand the difficulties of caring for a special needs' child during the pandemic. Although this scale had a low reliability, taking this statement alone shows that caregivers may often feel unrecognized, unappreciated and invalidated while covering their many roles as therapists, teachers, caretakers and parents for their kids with special needs during social distancing.

Significance of the study and future implications

Overall, this is one of the few studies that assesses the necessities, mental health and education of CAND and their caregivers, and the only one to our knowledge in PR that provides a multidimensional descriptive profile of these families during the COVID-19 pandemic. This study has provided a voice to the families of these children and youth in the Island, who have passed through unique circumstances other than COVID-19, including hurricanes, earthquakes and political turmoil; and who continue to face unique challenges during this emergency that their neurotypical peers do not experience.

With this study, organizations that provide services to this population and the governmental agencies of Puerto Rico can make a difference and take into consideration the voice of the parents and the children with disabilities living in the Island, to bring forth more inclusive emergency-response measures, to continue to reinforce the Individuals with Disabilities Education Act (IDEA Law), the Americans with Disabilities Act of 1990 (ADA Law) and the Section 504 of the Rehabilitation Act of 1973 (Public Law 93-112).

Clinicians can take into consideration and be aware of the most common mental health symptoms experienced by both minors and caregivers to help create a more systemic-based intervention and promote the mental health and wellbeing of both caregiver and child. Public policy can be made to support these families during this and future emergencies to assist in the essential and educational necessities, provide emotional support and spread awareness to endorse inclusion in society during COVID-19 and beyond. Educational institutions can take the data on distance learning as feedback to better their provision of services and provide aid for parents of CAND, whom, according to these findings had difficulty adapting to teaching their children during distance learning. The SARS-CoV-2 virus constantly mutates, and new variants will inevitable arise, thus distance learning and other emergency-response measures will continue to thrive. Therefore, this study provides a valuable tool for organizations, clinicians and families to create a more disability-inclusive response, tailored to the necessities of these Puerto Rican families, in the present and in future emergencies.

Limitations

Although this study provides a significant contribution to literature on CAND during the pandemic, and this data can be applied to better emergency response-measures, and to provide more inclusive services during quarantine, the study has some limitations. One limitation is that, although it considers a variety of disabilities, individual disorders were not analyzed. This is a limitation because, children may classify in a category for a disorder (ex. Cognitive Disorders), but the necessities for their particular diagnosis may be different. For example, autism spectrum disorders (ASD) may not have the same necessities, effects on mental health and adaptation to distance education as children with attention deficit hyperactivity disorder (ADHD) or specific learning disorders (SLD). Another limitation is that the necessities, attitudes towards education, and mental health of CAND are being reported by the parents and not directly through the child. Children with disabilities may have other perspectives of distance learning and other mental health symptoms. Furthermore, the sample was limited to those parents who had access to internet and computers to answer the questionnaire, excluding those families of CAND who do not have internet access. In addition, changes during the pandemic may vary through time throughout the continued course of the emergency.

Recommendations for Future Research

To expand the findings in this study, further research is suggested on seeking the necessities, perspectives of education and mental health of

CAND of individual disorders such as ASD, intellectual disabilities (ID), ADHD, SLDs or Down Syndrome during COVID-19. Also, it is recommended that researchers continue to monitor, investigate and compare how the changes in necessities, education and mental health vary over time.

Overall, a multidimensional profile of CAND and their caregivers was investigated and described in this study; including sociodemographic characteristics, and the effects of social distancing in these families' daily life, education and mental health. Results indicate that CAND and their caregivers are struggling to adjust to the changes brought by the pandemic. This study supports public policy and intervention programs that assist these families for the areas of education, mental health, financial aids, accessibility to therapies and recreation.

Declaration of Interests

The authors were not financially or personally affiliated with any person or entity, neither directly nor indirectly, that could influence the creation and results of this work.

Acknowledgements

We thank Dr. A. Ramos, Dr. G. Medina and Dr. A. Landivar (Ponce Health Sciences University) for providing their expertise to establish inter-rater content reliability in our survey. We also thank the following people and organizations that aided in spreading the word of our study: Apoyo a Padres de Niños con Impedimentos (APNI), Centro Ponce Ponceño de Autismo (CEPA), Dr. J. Córdoves (Interamerican University of PR, Ponce), Mrs. I. Colón (Madre Fajona), Ms. N. Candelaria (El Vocero de Puerto Rico), Medical Reserve Corps of PR (MRCPR), Dr. J. Jiménez (Ponce Health Sciences University, Tu Salud Informa), Mrs. MdC Rodríguez, Igualmente Diversos and Alianza de Autismo de PR. Finally, we acknowledge all the caregivers of CAND in PR who took the time to answer the questionnaire and share their experiences during the pandemic.

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