



Quality of Life of Latin-American People with Neuromuscular Disorders and Their Families During the COVID-19 Pandemic

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Accepted: 15 March 2023 / Published online: 24 March 2023
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Abstract

Objectives The COVID-19 pandemic has affected the entire population, especially the population with chronic diseases. This study aimed to describe the quality of life of children and adults with neuromuscular diseases and their caregivers during the COVID-19 pandemic.

Methods A observational correlational study was conducted. Forty-seven participants, including adults with NMD and caregivers of children with NMD, took part in the study. The WHOQOL-BREF and PedsQL 4.0 GCS and FIM scales were used.

Results The PedsQL indicated a mean of 55.85 (SD = 22.05) for children, and a mean of 55.76 (SD = 16.72) for caregivers. Adults reported a mean of 67 (SD = 22.5) for their general perception of quality of life, and a M = 53 (SD = 28.25) for their perception on health.

Conclusions The results showed regular to low quality of life of all children, adults, and caregivers, mainly in the physical dimension for people with neuromuscular diseases, and in the concerns dimension for caregivers. These results warn about the physical and psychological vulnerability situation in which this population finds itself.

Keywords Quality of life · Family quality of life · Neuromuscular diseases · COVID-19

During past years, studies have focused on how chronic medical conditions affect quality of life of people with this type of diagnoses and their caregivers. Quality of life is a construct that describes a person's perception of their position in life in the context of their culture and value systems and considering their goals, expectations, and concerns (World Health Organization, 1995). Health related quality of life (HRQL), in contrast, considers the perception of the impact of health

on a multidimensional level, including physical, mental and social aspects of life (Quinceno & Vinaccia, 2013).

Due to improvement on therapeutical treatments and the increase on life expectancy on chronic conditions, such as Neuromuscular disorders (NMD), HRQL has become a central outcome. NMD consider a group of more than 150 diagnoses characterized by progressive muscle weakness. Other symptoms include muscle atrophy or hypertrophy, fatigue, myalgia and nerve and muscle degeneration. Due to their low prevalence rates, estimated between 1 and 10 per 100,000 population, NMD are also considered rare diseases (Aguerre, 2014; Deenen et al., 2015).

Since many of these conditions are diagnosed in childhood, it is important to study HRQL through lifespan. Previous studies have shown that HRQL is affected on people of all ages with NMD, including children, adolescents, and adults (Baiardini et al., 2011; Bendixen et al., 2012; Bhullar et al., 2019; Gocheva et al., 2019; Graham et al., 2011; Landfeldt et al., 2016; Ortega, 2020; Uzark et al., 2012). In children with NMD, it has been found that HRQL is lower than normative data on a general level and on physical, emotional, social, and school dimensions (Baiardini et al., 2011; Bendixen et al., 2012; Gocheva

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et al., 2019; Ortega, 2020). Regarding adults with NMD, they also report sleep and mental health problems, as well as an impaired HRQL on all its dimensions, especially on physical health (Cordeiro et al., 2014; Winter et al., 2010).

Furthermore, the chronicity and dependence that NMD generate, mark for the need of a caregiver. Caregiver role is often assumed by a family member, which causes an impact on caregiver's quality of life and family functioning. Psychosocial aspects of quality of life seem to be the most severely affected in caregivers of children and adults with NMD (Landfeldt et al., 2016; Ortega, 2020; Ortega et al., 2021; Ortiz et al., 2013; Soares de Moura et al., 2015; Zhi et al., 2019). In some cases, parents have even reported even lower levels of QoL than their children (Bhullar et al., 2019). Parents of children with NMD have also reported mental health problems, mainly internalizing problems like anxiety, depression and withdrawn (Ortega et al., 2021). Furthermore, families of children with NMD seem to have more difficulties related to family activities than families without children with NMD (Baiardini et al., 2011).

In addition, the relationship between children's HRQL and caregivers' burden and QoL has been previously explored. A worse child's HRQL in the psychological dimension was associated with greater emotional impact on parents and a greater familiar cohesion (Baiardini et al., 2011). Other study did not find significant correlation between child's HRQL and caregiver's QoL but did find a correlation between child's QoL and caregiver's burden (Soares de Moura et al., 2015).

Currently, the COVID-19 pandemic has put the population of people with disabilities in a vulnerable situation. Due to the complexity of symptoms that accompany these diagnoses, many of them have been considered at risk populations (Guidon & Amato, 2020). Some studies have studied how the COVID-19 pandemic impacted on people with intellectual and developmental disabilities. Results found a clear impact of the missing routine health checks and isolation, making the COVID-19 pandemic a potential source of stress and trauma for the disability community (Lund et al., 2020; Wanjagua et al., 2022).

Particularly, people with neuromuscular disorders have also been affected by the pandemic as they have suffered modifications in access to health and medical care. Patients reported cancellations and delays in medical appointments and having been forced to care via telemedicine (Li et al., 2021; Mauri et al., 2020). Some studies explored the impact of the pandemic on psychosocial aspects of rare diseases population. Results seem to show a decrease in general and mental health, reporting feelings of loneliness, worry, anxiety, stress and depression (Chung et al., 2020; Fiumara et al., 2020; Li et al., 2021).

Specifically, in NMD, some studies have explored HRQL during the pandemic. Findings show a decrease in physical

health and mental health, as well as reduced quality of life due to the pandemic in children and adults with NMD (Di Stefano et al., 2021; Gagliardi et al., 2021; Handberg et al., 2021). Even though these studies start to show how the pandemic has affected this population, none of them have used validated HRQL measures that are comparable to prepandemic studies. Also, no studies have been found in Latin America.

In order to contribute on understanding how the COVID-19 pandemic has impacted on families with NMD in Latin America, the present study aims to describe health related quality of life on children and adults with neuromuscular disorders. In addition, it aims to study family quality of life on caregivers of children with NMD and its correlation with the children's HRQL.

Method

Participants

The selection of the sample was non-probabilistic. Sample consisted of parents of children (1 to 18 years old) with a neuromuscular disease diagnosis, and adults with a neuromuscular disorder diagnosis from Latin America. Forty-seven (47) families with neuromuscular diagnoses participated in the study. Within these participants, 53,8% (n = 25) of them were adults with a NMD and 46,8% (n = 22) were parents of children and adolescents with NMD.

From the adults with NMD sample, 72% (N = 18) were women and 28% (N = 7) were men. Regarding their NMD, 68% (N = 17) of the participants had a diagnosis of Charcot Marie Tooth, the remaining had diagnoses of Spinal Muscular Atrophy (SMA) (N = 1), Duchenne Muscular Dystrophy (N = 1) or another muscular dystrophy (N = 6). The age range was 23 to 62 years, M = 36.08 (SD = 9.99). Regarding the level of education, 44% of the sample had completed university education, 12% incomplete university, 28% completed secondary education and the remaining percentage completed or incomplete tertiary.

Of the caregivers' sample, 86.4% were mothers and 13.6% were fathers. Their ages ranged from 26 to 52 years, with an M = 37.23 (SD = 5.99). Regarding their level of education, 36.4% of the sample had completed university education, 27.3% completed university education, and 22.7% completed high school. Regarding the children, 40.9% (N = 9) had a diagnosis of Charcot Marie Tooth, 36.4% (N = 8) Duchenne Muscular Dystrophy, 13.6% (N = 3) SMA and 9.1% (n = 2) another neuromuscular disease. 76.2% (N = 16) of the children were male, while 23.8% (5) were female. Mean age for children was calculated at M = 10.05 (SD = 4.18), where 13.6% (N = 3) belonged to the range of 2 to 4 years, another 13.6% (N = 3) in the range of 5 to 7 years, 40.9% (N = 9) in

the range of 8 to 12 years and 31.8% (N=7) in the range of 13 to 18 years.

Procedure

An online questionnaire containing both instruments (WHOQOL-BREF and PedsQL 4.0) and sociodemographic questions was elaborated. To be part of the study, participants were required to sign an informed consent form at the beginning of the questionnaire. Rare diseases' patient associations were contacted to collaborate with the study. Associations from Argentina, Perú, Chile, Honduras and Costa Rica accepted the invitation. Associations were the ones who sent the online questionnaire to their members, inviting them to participate on the study.

Ethical considerations were taken for this study. The study was carried out in accordance with Health Ministry's 1490/2007 Resolution on the guide to good research practices, and Law 3301, on the rights of subjects in health research. By coding the questionnaires identification data were kept confidential, according to Argentina's National Law 25,326 on Data Protection (*Habeas Data*).

Measures

The protocol consisted of an informed consent, a sociodemographic data questionnaire, the World Health Organization Quality of Life (WHOQOL-BREF) and the Pediatric Quality of Life Inventory 4.0 (PedsQL 4.0) Generic Core Scale and Family Impact Module.

Adult's HRQL was assessed using the WHOQOL-BREF. This questionnaire is an abbreviated version of the WHOQOL-100. It is composed by 26 Likert-type items. The instrument provides an Overall Quality of Life score, a Health Perception score, and scores for the physical, psychological, social relationships, and environment domains. Scores range from 0 to 100, where a higher score means a better quality of life (Skevington et al., 2004). Internal consistency of this instrument for this sample showed $\alpha = 0.92$.

Children's HRQL was evaluated through the PedsQL 4.0 Generic Core Scale (Varni et al. 2001). The PedsQL 4.0 GCS contains 23 items that assess 4 domains: physical functioning, social functioning, school functioning and emotional functioning. In addition, summary scales for Physical Health and Psychosocial Health can be calculated. Parental report forms were used for this study, including versions for children aged 2–4, 5–7, 8–12, and 13–18 years (Roizen et al., 2008; Varni et al., 1999). The obtained measurement of internal consistency for this sample was $\alpha = 0.30$ for ages 2–4, $\alpha = 0.91$ for ages 5–7, $\alpha = 0.92$ for ages 8–12 and $\alpha = 0.95$ for ages 13–18.

Finally, the PedsQL Family Impact Module (Varni et al., 2004) was used to study impact of pediatric conditions on the family. This module was developed as a parental reporting instrument and contains 36 items. These items are divided into the subscales of impact on the parent's quality of life: a) Physical Functioning, b) Emotional Functioning, c) Social Functioning, d) Cognitive Functioning, e) Communication, f) Concerns; and two subscales measuring impact on family functioning: g) Daily Activities, and h) Family Relations. (Varni et al., 2004). Both PedsQL modules take scores from 0 to 100, where higher scores indicate better quality of life (Roizen et al., 2008). The internal consistency was measured for this sample, with Cronbach's alpha, $\alpha = 0.91$.

Data Analyses

All statistical analyses were performed using statistical software SPSS Statistics-25 (Statistical Package for the Social Sciences version 25, IBM SPSS Inc, Chicago, IL, USA). In order to describe HRQoL on children, adult and caregivers, means and standard deviations were calculated for the descriptive analysis of the WHOQOL, PedsQL GCS and PedsQL FIM. The normality of the sample was checked using the Shapiro–Wilk method and since it had a normal distribution (PedsQL GCS $p = 0.62$, PedsQL FIM $p = 0.237$), it was decided to use Pearson's r statistic to study the correlation between children's HRQoL and family QoL. Correlations were calculated both for the total scores and dimensions of the instruments.

Results

Health Related Quality of Life in Children and Adolescents with NMD

The PedsQL GCS total score for HRQL indicated a mean of 55.85 (SD = 22.05). For summary scales, a $M = 41.67$ (SD = 33.25) was found for physical health, and a $M = 64$ (SD = 22.33) for the psychosocial health. When analyzing the HRQL dimensions, results showed $M = 64.77$ (SD = 23.22) for the emotional dimension, $M = 60.9$ (SD = 28.89) for the social dimension and $M = 66.06$ (SD = 25.24) for the school dimension.

Health Related Quality of Life in Adults with NMD

Descriptive analysis for the WHOQOL scale showed that adults reported a $M = 67$ (SD = 22.5) for the general perception of their quality of life, and a $M = 53$ (SD = 28.25) for their perception on health. Regarding adult's QoL

dimensions results indicated a $M = 53.57$ ($SD = 20.46$) for physical health, a $M = 65.6$ ($DE = 18.45$) for psychological health, a $M = 63.33$ ($DE = 24.06$) for social relations, and a $M = 61.12$ ($DE = 21.35$) for environment.

Caregiver's Quality of Life and Family Functioning

Considering the importance of knowing not only the level of quality of life of the person who has an NMD, but also that of their caregivers, it was sought to describe the impact on the quality of family life. A mean of 59.12 ($SD = 15.55$) was found for the total impact scale. For the summary scale of caregiver's functioning, an $M = 55.76$ ($SD = 16.72$) was found. For the family functioning summary scale, a $M = 62.50$ ($SD = 21.59$) was found. Scores obtained for specific dimensions were calculated. Results showed a $M = 53.03$ ($SD = 22.9$) for physical dimension, $M = 58.64$ ($DE = 26.6$) for emotional dimension, $M = 66.48$ ($DE = 16.95$) for the social dimension, $M = 58.18$ ($DE = 16.65$) for cognitive dimension, $M = 65.53$ ($DE = 23.47$) for the communication dimension, $M = 40.45$ ($DE = 31.35$) for worry dimension, $M = 54.92$ ($DE = 28.82$) for daily activities, and a $M = 67.04$ ($DE = 28.18$) for the family relationships dimension.

Relationship Between Children's HRQoL and Family's QoL

Lastly, correlations between the PedsQL GCS dimensions and total score, and PedsQL FIM dimensions and total score were drawn. A significant positive correlation was found between children's HRQoL and family impact total score ($r = 0.75$, $p = 0.00$, $N = 22$). Table 1 shows correlations between dimensions from both instruments.

Discussion

Families of people with NMD have been considered a population at risk of greater vulnerability during the COVID-19 pandemic. Results of this study showed an impaired quality of life in all groups studied: adults, children, and adolescents with neuromuscular diseases, and their caregivers. Previous studies aimed to explore quality of life of NMD population during the pandemic, but this is the first study to do so using validated instruments, and to study Latin American population.

According to the results of the present study, the physical dimension of quality of life seems to be the most affected, whether in pediatric or adult population. These results are similar with results from studies prior to the pandemic (Baiardini et al., 2011; Bendixen et al., 2012; Ortega, 2020; Uzark et al., 2012; Winter et al., 2010), meaning people with NMD had implications in

their quality of life prior de pandemic. Nonetheless, the COVID-19 pandemic seem to have worsened this situation, especially in physical health, due to the difficulties in accessing therapies and treatments that many patients have reported during the pandemic (Li et al., 2021; Mauri et al., 2020).

Children and adolescents who participated on this study seem to have a diminished health related quality of life. Physical, social and school aspects seem to be then most affected dimensions. Children who participated in the study reported similar and even lower HRQL than previous studies before the COVID-19 pandemic (Bendixen et al., 2012; Ortega, 2020). This decrease on HRQL scores could be accounted by the pandemic impact on daily life. When comparing age groups, lowest HRQL was found in the 8 to 12 years old group, followed by the 2 to 4 years old group. Due to the progressive nature of NMD, age has been hypothesized to be related to HRQL, but other studies have also not found age as a determinant factor in HRLQ (Baiardini et al., 2011; Bendixen et al., 2012). In relation to the pandemic, the 8 to 12 years old group is expected to be the most affected group in terms of changes in daily life activities, since this group is composed of school-aged children.

Regarding adults with NMD, their quality of life and general perception of health seem to be impaired. In addition, participants reported difficulties on social relationships, environmental aspects and mental health. These results are similar to those reported by Di Stefano et al. (2021), which point out that this population is more affected than the general population.

One of the main results of the study indicated that caregiver's quality of life and family functioning on families of children with NMD is affected. Specifically, caregiver's quality of life seems to be primarily affected in the concerns and physical dimensions. Low scores on the concerns dimension may relate to the feelings of worry that many caregiver's of children with rare diseases have reported during the pandemic (Fiumara et al., 2020). Regarding family functioning, daily activities seem to be the most diminished dimension, similar to the results reported prior the pandemic (Baiardini et al., 2011). These results highlight the importance of considering caregivers health when evaluating people with complex diagnoses (Ho et al., 2021; Soares de Moura et al., 2015).

Moreover, child's HRQL was associated with caregiver's QoL. Particularly, child's HRQL was associated to parental's physical, emotional and social functioning, as well as worry dimension. These correlations were positive, meaning better the child's HRQL better the parent's QoL. Associations between children's HRQL and parental and family functioning were previously explored by Baiardini et al. (2011) and Soares de Moura et al. (2015). Results from the present study go in line with these studies in terms of the impact a chronic condition may have on the family group.

Table 1 Correlations between PedsQL CGS and PedsQL FIM dimensions

	PedsQL FIM total	PedsQL FIM parent functioning	PedsQL FIM family functioning	PedsQL FIM physical functioning	PedsQL FIM emotional functioning	PedsQL FIM social functioning	PedsQL FIM cognitive functioning	PedsQL FIM communication	PedsQL FIM worry	PedsQL FIM daily activities	PedsQL FIM family relationships
PedsQL GCS total	Pearson's r 0.68*	0.75*	0.07	0.67*	0.71*	0.67*	0.18	0.37	0.58*	0.23	-0.06
	<i>p</i> 0.00	0.00	0.75	0.000	0.00	0.00	0.42	0.09	0.00	0.29	0.79
	N 22	22	22	22	22	22	22	22	22	22	22
PedsQL GCS physical dimension	Pearson's r 0.50*	0.53*	0.06	0.56*	0.46*	0.42	-0.001	0.25	0.47*	0.17	-0.03
	<i>p</i> 0.02	0.02	0.79	0.01	0.03	0.060	0.99	0.27	0.03	0.46	0.89
	N 21	21	21	21	21	21	21	21	21	21	21
PedsQL GCS emotional dimension	Pearson's r 0.71*	0.75*	0.14	0.65*	0.81*	0.71*	0.17	0.38	0.53*	0.11	0.11
	<i>p</i> 0.00	0.00	0.54	0.00	0.00	0.00	0.45	0.077	0.01	0.63	0.66
	N 22	22	22	22	22	22	22	22	22	22	22
PedsQL GCS social dimension	Pearson's r 0.47*	0.53*	0.04	0.30	0.49*	0.55*	0.18	0.22	0.48*	0.26	-0.11
	<i>p</i> 0.03	0.01	0.85	0.17	0.02	0.01	0.43	0.33	0.02	0.24	0.64
	N 22	22	22	22	22	22	22	22	22	22	22
PedsQL GCS school dimension	Pearson's r 0.69*	0.76*	0.10	0.63*	0.74*	0.67*	0.38	0.51*	0.42*	0.30	-0.06
	<i>p</i> 0.00	0.00	0.65	0.00	0.00	0.00	0.08	0.01	0.05	0.17	0.79
	N 22	22	22	22	22	22	22	22	22	22	22

*Significant correlations < 0.05

Limitations and Future Research

The results of the study should be considered considering its limitations. First, even though neuromuscular disorders are considered rare diseases, a larger sample should be recruited. The size of this sample may have limited the power to identify significant correlations between variables. In addition, neuromuscular diagnoses may vary between them on level of disability and motor functioning, variables that have been related to HRQL, and were not measured on this study. Regarding instruments, the PedsQL GCS for ages 2–4 showed low levels of internal consistency for this sample, possibly due to the sample size for this age group, but previous studies have shown acceptable internal consistency (Roizen et al., 2008; Varni et al., 1999). Moreover, it would be interesting to explore how the COVID-19 pandemic has affected social inclusion for people with NMD, as well as studying other variables that may be related to quality of life such as pain, treatment adherence and caregiver burden.

Some relevant conclusions may be drawn from this study. First, children with NMD have an impaired HRQL, mainly on its physical dimension, even more than prior the pandemic. Second, adults with NMD reported a low QoL and perception of health during the pandemic. Also, caregivers of children and adolescents with NMD reported an impaired quality of life for themselves, affecting mainly their physical health and worry. Family functioning was also altered, mainly on aspects related to daily activities. Finally, caregiver's HRQL is associated with children's HRQL. Daily life changes and modifications on medical assistance may have had an impact on people with neuromuscular conditions. The present research highlights the need to take into account the populations considered risk groups with chronic conditions when considering interventions during the pandemic.

Acknowledgements Authors would like to thank every family that agreed to participate in this study and shared their experiences.

Author Contributions JO, NV, and IAC designed and executed the study; JO and NV collected the data and analyzed the results; JO wrote the draft of the manuscript; JO, NV and IAC revised the manuscript.

Funding No funding was received.

Data Availability The data that support the findings of this study are openly available in OSF at <https://doi.org/10.17605/OSF.IO/47PMN>.

Declarations

Ethics Statement This study derives from a superior project that has been approved by the Ethics and Teaching and Research Committee of the Dr. Ricardo Gutiérrez Children's Hospital (HNRG) (CEI n19.04).

Informed Consent Statement All participants of the study were informed of its purpose and signed an informed consent in order to participate on the study. Participant's personal data was protected under the Habeas Data Law.

Conflict of Interest Statement The authors declare no competing interests.

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