

Effects of the pandemic on caregivers of individuals with neuropsychomotor disorders

Efeitos da pandemia em cuidadores de indivíduos com alterações neuropsicomotoras

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Date of first submission: June 11, 2022

Last received: September 14, 2022

Accepted: September 15, 2022

Associate editor: Clynton Lourenço Correa

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Abstract

Introduction: Since social isolation during the COVID-19 pandemic can influence a patient's and informal caregiver's health, the present study was carried out to understand and improve the latter's quality of life.

Objective: To analyze the physical, mental and quality of life effects on caregivers of patients with neurological sequelae and developmental delay during the COVID-19 pandemic.

Methods: Thirty informal caregivers divided into two groups (G1: Psychomotor disorders and syndromes; G2: Neurological sequelae) were evaluated using questionnaires on general data, burden and quality of life. Chi-square tests with Bonferroni post-hoc correction were performed to compare the response rate between the dependent variables and the level of burden. The student's t-test was applied to determine the correlation between groups and quality of life, obtaining significant findings ($p \leq 0.05$).

Results: No or minimal burden was found in 33.3% of the caregivers, and mild to moderate in 66.7% of each group, with no significant effect between them. In terms of quality of life, a decline was found in all domains, with a significant intergroup difference in social aspects and G1 exhibiting the highest declines (G1: $70.00 \pm 23.99\%$; G2: $86.66 \pm 20.84\%$).

Conclusion: There was a mild-to-moderate impact on physical burden, with a change in the quality of life of caregivers evaluated during the COVID-19 pandemic. Caregivers of children with psychomotor disorders and syndromes were the most affected in the social aspect domain.

Keywords: Caregivers. Quality of Life. SARS-CoV-2. Social Isolation.

Resumo

Introdução: O isolamento social durante a pandemia de COVID-19 pode influenciar a saúde do paciente e do cuidador informal. No intuito de compreender e orientar a melhora da qualidade de vida destes cuidadores, este estudo foi realizado.

Objetivo: Analisar os efeitos físicos, mentais e a qualidade de vida de cuidadores de pacientes com sequelas neurológicas e atraso do desenvolvimento durante a pandemia de COVID-19.

Métodos: Trinta cuidadores informais divididos em dois grupos (G1: distúrbios psicomotores e síndromes; G2: sequelas neurológicas) foram avaliados com questionários sobre dados gerais, sobrecarga e qualidade de vida. Foram realizados os testes qui-quadrado com pós-teste de Bonferroni para comparar a taxa de resposta entre as variáveis dependentes e o nível de sobrecarga. Para a correlação entre os grupos e a qualidade de vida, utilizou-se o teste t de Student não pareado, sendo significativo os achados com $p \leq 0,05$. **Resultados:** Encontrou-se ausência de sobrecarga ou sobrecarga mínima em 33,3% e sobrecarga leve a moderada em 66,7% dos cuidadores em cada grupo, sem efeito significativo entre estes. Na qualidade de vida foi encontrado déficit em todos os domínios, com diferença significativa entre os grupos no domínio de aspectos sociais, tendo o G1 apresentado maiores déficits (G1: $70,00 \pm 23,99\%$; G2: $86,66 \pm 20,84\%$). **Conclusão:** Conclui-se que houve impacto de leve a moderado na sobrecarga física, com alteração na qualidade de vida dos cuidadores avaliados durante a pandemia de COVID-19, sendo os cuidadores de crianças com distúrbios psicomotores e síndromes os mais acometidos no aspecto social.

Palavras-chave: Cuidadores. Qualidade de vida. SARS-CoV-2. Isolamento social.

Introduction

The Sars-Cov-2 virus was first reported in China in late 2019. The disease multiplied rapidly, and Brazil developed a contingency plan in addition to monitoring the epidemiological situation.¹ On March 11, 2020, the World Health Organization (WHO) declared the COVID-9 outbreak a global pandemic.¹

Infection by COVID-19 can cause a number of symptoms, such as cough, fever, throat inflammation, loss of smell and taste, pneumonia, hypoxia, dyspnea and respiratory failure, shock or multiorgan dysfunction in critical cases. The disease can affect healthy people,

regardless of age. However, there is a significant prevalence of complications in older adults with comorbidities such as diabetes mellitus, obesity, hypertension, cancer and pulmonary, kidney and chronic cardiovascular diseases.²

In order to combat COVID-19, radical changes in attitudes, conduct and social behavior, individually, socially, publicly and affectively, including social distancing, lockdowns and restricted movement of populations in different regions of the country were needed. These changes occurred over a short time frame without adapting and organizing the population, thereby compromising mental health, which was often exacerbated by economic and health problems, in addition to all the restrictions imposed on society.³

In an attempt at maintaining control over COVID-19 contagion, the number of people was restricted in closed spaces, such as physiotherapy clinics, which began to treat fewer people or conducted remote consultations, given that many of these patients belong to risk groups.⁴ This prolonged restriction period caused drastic changes in the lives of patients with chronic diseases, and those of their families and caregivers.⁵

Caregivers can be formal or informal, the former being a qualified professional trained in patient care. An informal caregiver, the focus of this study, is generally a family member or close friend who provides the necessary daily care.⁶ The fact that this caregiver usually has no prior knowledge or specific training may overburden the individual, which is manifested by negative feelings such as anxiety, stress, depression, insecurity, fear, concern and even loss of freedom.⁷ Moreover, when family members become caregivers, the sudden change requires them to reorganize their entire life in order to provide the best care possible, which demands dedication and may be exhausting.⁶

Thus, the pandemic increased caregiver burden, with the confinement and social distancing obliging individuals to stay at home and the cancellation of consultations that should be ongoing completely changing the routine of both patients and caregivers. In addition to promoting physical and social changes, altered routines also affect the patient's behavior and emotional well-being, which exacerbates burden and requires intense dedication from the caregiver.⁸

In this respect, the present study aimed to conduct an in-depth analysis of how the pandemic affected the mental, behavioral and physical health of the

caregivers of patients with neurological sequelae and developmental delay, which may have had a direct influence on their quality of life and the care provided. In addition, this research revealed aggravating factors, which could contribute to the creation of support, promotion and prevention protocols for this population.

Methods

Ethical aspects

This study was approved by the Research Ethics Committee (protocol no. 48247421.0.0000.5515), and after being informed of all the procedures, participants signed an electronic consent form, since there was no in-person contact.

Study site and population

This study was conducted online with the informal caregivers (parents or guardians) of patients undergoing physiotherapy at a clinic in São Paulo state. The sample consisted of 30 subjects of both sexes, caregivers of children and adolescents with neurological sequelae and developmental delay, such as Cerebral Palsy, Spinal Cord Injury, Down Syndrome and Psychomotor Developmental Delay.

The inclusion criteria were patients with neurological sequelae and/or developmental delay with internet access to respond to the study questionnaires, aged 18 years or older, and able to read and understand the instruments. Excluded were caregivers who did not complete all assessment stages and those with clinical diagnosis of any disease that could compromise the study findings, such as rheumatological or nervous system disorders.

Assessment instruments

The caregivers responded to all the questions at a single session. Initially, the caregivers signed the informed consent form, the first page of the Google Forms instrument. Next, they responded to the initial questionnaire, prepared by the researchers and containing questions on their relationship with the patient, time spent caring for the individual, work, sleep quality, stress and the presence of any concomitant disease.

An online questionnaire also evaluated the caregivers' quality of life and physical and emotional burden, assessed by the validated Brazilian version of the Burden Interview,⁹ which contains the following areas: affective, emotional, time spent on care, financial life, dependence, privacy, social life and health. The questions are scored on a 0-4 scale, where 0 = never, 1 = rarely, 2 = sometimes, 3 = frequently and 4 = always. The total score varies from 0 to 88 points, where higher scores indicate greater caregiver burden.

We applied the previously validated SF-36 Quality of Life Questionnaire,¹⁰ containing 36 items on functional capacity, overall health status, emotional aspects and physical and pain-related limitations, scored on a Likert scale. The total score is 100%, where the closer to this percentage, the better the quality of life; poor quality of life is indicated by lower values.¹⁰

Data analysis

The Excel® database of the online form completed by the participants was exported for data analysis. The groups were divided, according to the patients' clinical diagnosis, into G1 (psychomotor disturbances and syndromes) and G2 (neurological sequelae), defined as the dependent variables and submitted to analysis of proportions using the chi-square test with Bonferroni correction, to compare the response rate between the dependent variables and caregiver burden level by applying the Burden Interview questionnaire.

The correlation between the groups and caregiver quality of life using the SF-36 questionnaire was expressed as mean and standard deviation, and the unpaired student's t-test was applied. Findings with $p \leq 0.05$ were considered significant. The Statistical Package for the Social Sciences (SPSS, IBM Corporation, Armonk, NY, USA), version 22.0, was used.

Results

The sample was composed of 30 individuals of both sexes, with an average age of 37.03 ± 10.81 years. Most caregivers in both groups were mothers of the patients themselves, whom they cared for for more than 12 hours a day. Although most do not work outside the home, in both groups there was an increase in care time and stress during the pandemic (Table 1).

Table 1 - Sample characterization

Characteristics	Group 1	Group 2
Age (years)	38.00 ± 10.69	36.06 ± 11.22
Family relationship		
Mother	12	15
Father	1	0
Aunt	1	0
Grandmother	1	0
Daily time spent on caregiving (hours)		
1 - 2	1	3
2 - 4	0	1
8 - 10	2	1
10 - 12	1	0
> 12	11	10
Hours of sleep		
< 3	0	1
3 - 4	2	0
4 - 5	3	2
6 - 7	4	6
7 - 8	4	6
> 8	2	0
Increased stress during the pandemic n (%)	12 (84.61)	13 (91.66)
Increased caregiving time n (%)	15 (100)	10 (66.66)
Number of individuals working outside the home n (%)	3 (23.07)	5 (33.33)

Note: Group 1 = psychomotor disturbances and syndromes (n = 15); Group 2 = neurological sequelae (n = 15).

No significant intergroup effect was observed for caregiver physical and emotional burden. Homogeneity was found between the caregivers of both groups in terms of burden, neither classified as moderate to severe or severe. The data are illustrated in Table 2.

With respect to quality of life, a significant intergroup difference was found for social aspects, with caregivers of individuals with psychomotor disturbances and syndromes exhibiting greater impairment in this domain (Table 3).

Table 2 - Burden level according to the Burden Interview x group

Burden Interview	Group 1 n (%)	Group 2 n (%)
Absence of burden or minimal burden	5 (33.3)	5 (33.3)
Mild-to-moderate burden	10 (66.7)	10 (66.7)

Note: Group 1 = psychomotor disturbances and syndromes (n = 15); Group 2 = neurological sequelae (n = 15).

Table 3 - Percentage of quality-of-life analysis using the SF-36 x group questionnaire

Domains	Group 1	Group 2	p-value
Functional capacity	72.66 ± 19.44	71.00 ± 28.85	0.85
Physical limitation	46.66 ± 38.80	63.33 ± 38.80	0.24
Emotional limitation	37.75 ± 39.55	53.30 ± 37.37	0.27
Social aspects	70.00 ± 23.99	86.66 ± 20.84	0.05
Pain	69.26 ± 18.14	77.20 ± 15.91	0.21
Mental health	53.86 ± 22.05	68.53 ± 24.88	0.09
Vitality	46.00 ± 18.72	55.66 ± 28.77	0.28
Overall health status	51.66 ± 17.49	52.33 ± 9.72	0.89

Note: Group 1: psychomotor disturbances and syndromes (n = 15); Group 2 = neurological sequelae (n = 15). Data expressed as mean and standard deviation. Values in bold indicate a significant difference ($p \leq 0.05$).

Discussion

Given the possible consequences of the COVID-19 pandemic on the quality of life of people, the present study was conducted to assess its impact on the informal caregivers of patients with neurological sequelae and developmental delay, with a view to informing them regarding the impact on their health and highlighting the importance of providing them with the necessary care.

Most of the sample of both groups were more stressed and spent more time providing care during the COVID-19 pandemic, with a minority working outside the home. Caregivers of patients with psychomotor disturbances and syndromes (G1) were more compromised in the social aspect domain. However, no interference of diagnosis type was found for caregiver burden, where both groups obtained low levels, classified as absent or minimal, and mild to moderate.

Women predominated in the present study and mothers were the main caregivers in both groups, exhibiting compromised quality of life during the pandemic (Table 3), given that all the instrument domains obtained percentages of less than 100%. This finding may be culturally related, since women are generally considered to be more sensitive caregivers of disabled individuals.¹¹⁻¹³ Men usually participate more indirectly, that is, financially or as drivers when needed.¹¹ In this respect, studies that assess the effect of burden on the quality of life of the caregivers of children and adolescents with syndromes¹¹ and neurological sequelae^{12,13} found that mothers were the most prevalent caregivers. For

example, Barros et al.¹¹ reported a percentage of more than 95%, a finding similar to that of the present investigation.

Since children with psychomotor disturbances, neurological sequelae and syndromes have difficulty performing their activities of daily living, their caregivers must spend a considerable amount of time every day caring for them (Table 1), which may directly affect the social aspect because the caregiver does not have enough time to socialize. Due to its high contamination potential, the COVID-19 pandemic became an aggravating factor, since social isolation further restricted social interaction and hindered caregiver socialization owing to their concern about having contact with other individuals.

The effect on the social aspect of quality of life may be related to the fact that these informal caregivers of children with psychomotor disorders or syndromes decreased their social contact, both at work and during leisure time. Aimed at greater time flexibility in order to give their full attention to the child, caregivers often seek work-from-home jobs, thereby reducing overall social contact, which may be related to G1 individuals' increasing their caregiving time by 100% (Table 1) during the pandemic. In addition, necessary care-related expenses decrease family income, resulting in a decline in leisure activities and a social impact on these caregivers.¹¹ According to Ribeiro et al.,¹⁴ in an attempt at protecting children from prejudice, primarily discrimination, caregivers often restrict their socialization and that of the child, resulting in a decline in their social aspect.

As mentioned before, most caregivers were mothers, which may be directly related to the absence and minimal or mild-to-moderate burden found in this study, given that these findings may be associated with the more affective relationship between mothers and children, thereby increasing the mothers' desire to protect their offspring. Since mothers typically do not delegate this function to other people,¹³ it may have directly changed their perception of burden.

However, the presence of burden, albeit mild, and the negative effect on the quality of life of the study sample may have been directly influenced by the pandemic and the time available to care for the patient (Table 1), given the reported increase in time spent on care and stress level during the pandemic, which may have reduced leisure, relaxation, entertainment and amusement time.¹⁴ Furthermore, changes in caregiver burden can accumulate over time and influence their quality of life. In this respect, Souza et al.¹⁵ assessed the quality of life of 15 mothers of children with psychomotor disorders and concluded that physical or psychic dependence caused them to forego leisure activities, which may exacerbate caregiver burden. Barros et al.¹¹ evaluated the burden of 84 caregivers of children and adolescents with Down syndrome, observing predominantly a moderate level, similar to that found here.

A limitation of this study was not including marital status as one of the factors, which could have influenced the results. According to Souza et al.,¹⁵ a partner can help in transport, meal, clothing and leisure costs, and may have an impact on the burden and quality of life of single mothers. Other important factors not considered were the caregivers' profession and salary, since mothers with higher incomes may exhibit better quality of life.¹⁵

Conclusion

Although most of the caregivers were mothers, spending more time on care during the pandemic and experiencing high stress levels, the impact on their physical burden was mild to moderate, albeit with a decline in quality of life. In an attempt at decreasing the burden caused mainly during the pandemic and improving the quality of life of these caregivers, it is essential to give them the necessary care. We recommend multiprofessional measures that encompass health and

emotional aspects, from guidelines to facilitate and optimize daily patient care to social assistance to help caregivers under specific conditions, such as financial problems, aimed at improving the impact on their overall health.

Authors' contributions

GAE, MLP, RGVNR and MTAPD conceived and designed the study, and all the authors analyzed and interpreted the data. GAE, MLP and RGVNR wrote the manuscript and LAS, MHST, DCGLF and MTAPD revised it. All the authors approved the final version.

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