

ORIGINAL ARTICLE

Mental health status and quality of life of people with disabilities in social isolation

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Abstract

Introduction: at this critical moment of the COVID -19 pandemic, we observe the social withdrawal and the break from the routine of individuals in society, for people with disabilities who need adequate support and a routine of more intense and effective activities may feel a greater need for care and attention of family support for solving everyday problems.

Objective: to identify factors associated with the impact of the pandemic on the quality of life of individuals with disabilities and their caregivers.

Methods: a virtual survey was carried out with parents and caregivers of people with disabilities to identify the main factors associated with the impact of the Pandemic on daily life and social relationships between family and community.

Results: of the parents and caregivers we had access to and answered the questionnaire, 90% are residents of the ABC region of São Paulo. Their children and adolescents with disabilities are between 4 and 18 years old. The main scores of caregivers on difficulties in care during the pandemic, 70% felt helpless at some point, 17% had difficulties in performing self-care activities, 42% had anguish and fear during the period, 83% have the greatest responsibility for household decisions, and about 50% can share those decisions.

Conclusion: the main complaints about the care of people with disabilities during the COVID-19 pandemic are related to the feeling of fear and anguish that affects decision-making and family relationships, which influences self-care activities and mental health of this population.

Keywords: health assessment, COVID-19 pandemic, mental health, quality of life, Occupational Therapy.

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Authors summary

Why was this study done?

To identify factors that can influence the mental health of people who live and live with people with disabilities during the COVID-19 pandemic period.

What did the researchers do and find?

A questionnaire was carried out to assess the quality of life and their mental health with the SF-36 questionnaire and closed questions that relate mental health, self-image perception and how they perceive their actions regarding the solution of conflicts and daily problems.

What do these findings mean?

Preliminary results indicate that participants do not observe major differences in mental health and daily relationships at home, although they perceive that there have been important changes in routine and in relation to self-image and the solution of daily problems.

INTRODUCTION

At the end of 2019, we witnessed an event that the world has not faced for a long time, a new scenario motivated by the pandemic of a hitherto unknown microorganism. The newly discovered new strains of the new coronavirus were able to transform world history in a short period.

Coronavirus, named for the structural conformation that gives it a coronal appearance belongs to a large family of positive single-stranded RNA viruses that parasitize and cause disease in mammals and birds, usually this class of virus, when it infects animals, it rarely affects humans¹. This family of viruses was first isolated in early 1931; the coronavirus in question was the infectious bronchitis virus (IBV) and caused an acute and extremely contagious respiratory infection in birds², already the first infection in people resulting from a coronavirus was identified in 1965 promoted by various strains of coronavirus and in almost 100% of cases involved upper airway infection².

Around 2003, a new variant of this virus family was responsible for an outbreak of severe acute respiratory syndrome, SARS-CoV. An individual admitted to the Prince of Wales hospital in Hong Kong was responsible for more than 100 minor disease cases. Other waves happened in the same country, at the Amoy Gardens housing complex, on Air China's flight from Hong Kong to Beijing, or at the Metropole Hotel, being the agent of the spread to Canada, Vietnam, and Singapore, resulting in hundreds of other confirmed cases of the disease³.

In December 2019, a new variant of this family of microorganisms appeared, the so-called SARS-CoV-2 (Severe Acute Respiratory Syndrome-coronavirus 2), responsible for the development of the so-called coronavirus disease, currently known as COVID-19 worldwide. This was first reported in China, in the state of Wuhan, Hubei province, spreading around the world extremely quickly, with less than three months, being declared a pandemic state by the World Health Organization (WHO) in March 2020^{4,5}.

During this critical moment of the COVID-19 pandemic, we observed the social withdrawal and the break in the routine of people in social life, considering that the person with a disability needs adequate support and a routine of activities, sometimes more intense and effective, and considering that researches point to a higher expectation of people with disabilities due to economic, social and affirmative policy advances.

Within the scope of health policies contemplated in Brazil, Health Promotion is the process that enables people to enhance control over their health. The central role of Public Health in confronting communicable diseases than communicable and others of a chronic nature, among other health threats^{6,7}.

When observing the numerous characteristics and comorbidities that can affect individuals with Cerebral Palsy and other disabilities such as Autism and Syndromes that cause some change in behavior and communication relationships, certain singularities of individuals affected by such conditions may feel the greater need of care and attention from family support for solving everyday problems⁸.

Due to the repercussions arising from the COVID-19 Pandemic⁹, which generated millions of deaths and hundreds of millions of infected people in the world, in Brazil, it highlighted the need for actions to contain the spread of the virus, with the application of social distancing to reduce transmission and this impacts the way we live and live, even with such measures we observe an important impact on the Unified Health System¹⁰.

For people with disabilities, some determinants can be enhanced, according to the severity of the comorbidities that affect them. In some cases, its repercussions on daily life become very important, including for people who live and live with the person with a disability. Given the above, it is necessary to identify the impacts of the pandemic on Quality of life, especially among individuals with disabilities and their caregivers.

METHODS

This is a descriptive study with people who live and live with people with disabilities. In the face of physical and social isolation, they find themselves without face-to-face assistance to carry out activities, whether for educational or recreational purposes.

A virtual survey was carried out with about 20 parents and caregivers of people with disabilities to identify the main factors associated with the impact of the Pandemic on daily life and social relations between family and community.

Among the different analysis models, we chose to use the quality of life assessment method, through the SF-36 (The Medical Outcomes Study 36 - has Short-Form Health Survey), this generic instrument of easy administration, widely used in the literature^{11,12}.

Currently considered a health-related quality of life assessment model. This survey is based on a multidimensional instrument composed of 8 domains, with a scale from 0 to 100, in which 0 (zero) corresponds to the worst and 100 (one hundred) to the best perception of the individual's quality of life.

Questions related to the survey carried out with parents and caregivers can be found in the link on the electronic form: <https://forms.gle/rQgpmreehbansZm1A>

As this study is restricted to parents and caregivers of a Special Education Unit of a Municipality in the Greater ABC region, registration with the Research Ethics Committee was requested to resolve any conflicts of interest and procedures that could cause damage to the health of the participants in this study. The number of the respective research ethics committee follows CAAE: 56553816.4.0000.0082.

RESULTS

Of the parents and caregivers, we had access to and answered the questionnaire, 90% are residents of the ABC region of São Paulo, their children and adolescents with disabilities are between 4 and 18 years old.

Of the findings related to the survey carried out with the SF-36 quality of life questionnaire, the analysis parameters present the following results, as shown in Table 1.

Table 1: Results of the domains observed by the SF-36 Quality of Life questionnaire with individuals who live and live with people with disabilities and their impact on health during the pandemic period.

Domains	Score
Functional capacity	48.60
Limitation of physical aspects	99.00
Ache	19.38
general health status	24.13
Vitality	19.30
Social aspects	24.25
Limitation by emotional aspects	98.33
Mental health	18.84

Source: authors

From the main points observed in the study, we found that the issues related to responsibility and decision-making were presented in the following question.

When questioned about trust for decision making, we observed the main answers shown in Figure 2, with 1 representing RARELY and 5 ALWAYS.

DISCUSSION

The main scores of caregivers on difficulties in care during the pandemic, 70% felt helpless at some point, 17% had difficulties in performing self-care activities, 42% had anguish and fear during the period, 83% have the greatest responsibility for household decisions, and about 50%

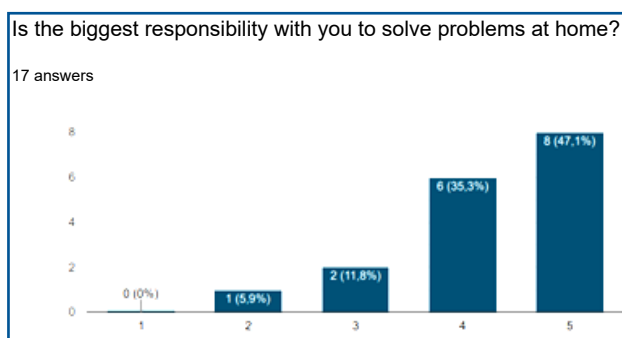


Figure 1: Questionnaire item carried out with families of people with disabilities, 1 represented with RARELY and 5 ALWAYS.

Source: authors

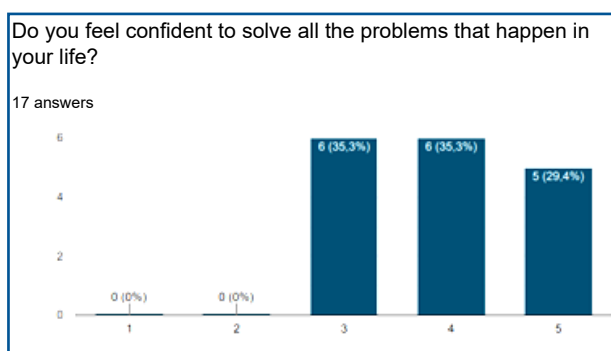


Figure 2: Item of the questionnaire carried out with families of people with disabilities, 1 represented with RARELY and 5 ALWAYS.

Source: authors

can share those decisions. 88% say they have a healthy relationship with their children and feel confident to solve domestic problems. However, 58% of the participants say they are mentally well at the time of the survey.

Translated and adapted for the Brazilian¹³ instrument encompasses generic data about the quality of life, its 36 items distributed in domains such as functional capacity related to the performance of daily activities (DA)¹².

These domains include self-care, dressing, bathing and climbing stairs, physical aspects that involve the impact of physical health on the performance of AD and/or professionals, Pain and refers to the level of pain and the impact on the performance of AD and /or professionals, general health status and their subjective perception of the general health status, vitality that refers to the perception of the individual's energy and fatigue level, social aspects that show the reflection of the physical health condition in social activities, aspects emotional conditions and how their emotional conditions affect the performance of AD and/or professionals, mental health that assesses their perception of mood and well-being¹².

This survey also involves a question of comparative assessment between the current health condition concerning the previous year¹². Among these issues related to the quality of life, questions were also included at this time questions, topics related to sociodemographic data, and specific questions about their perception of mental health, decision-making and family relationships, so we can analyze more broadly their perception of pandemic

and the social isolation of this population and what is the impact of this unhealthy condition on people.

Considering the results observed by the SF-36 instrument, in our study, we can identify that the main aspects in issues related to mental health and in the resolution of family conflicts are quite important and indicate that there may be a tensioning of the issues and at the time of the pandemic, but, it does not bring evidence about the difficulties in settling conflicts. These issues can influence the mental health of individuals when they are unable to solve problems in family relationships.

We observed in the analysis parameters the following results: functional capacity (48.60 points), a value far from the most important quality of life goal, considering that values closer to 100 points are as higher quality of life conditions, by example. The condition of limitation of physical aspects with 99 points indicates that, in general, this sample indicates that physical problems are not more important at the time of social isolation.

Limitation by emotional aspects (98.33 points) indicates that these findings demonstrate that the ability to solve problems and resolve family conflicts may not be affected to the detriment of social isolation, as observed in other studies such as the findings by Bezerra (2020)¹⁴ in which shows us which issues of social isolation influence the behavior of individuals.

Mental Health (18.84 points) about the low value concerning the parameters of a better quality of life in terms of mental health (close to 100) indicate that factors influencing the progress of the pandemic and the fear proven by the possibility of the contamination may exert influence on this indicator.

The aspect related to pain (19.38 points) reveals important evidence regarding pain during this moment of the pandemic. For the general health status (24.13 points) it also indicates that there are problems that influence the health of individuals.

Vitality (19.30 points) shows that during this time of pandemic it also indicates that there are problems that influence the health of individuals, as we observed in Social Aspects (24.25 points) that influence the health of individuals, especially if we observe that social relationships were greatly affected due to the restrictive measures to contain the COVID-19 pandemic and its escalation of deaths.

Effects are resulting from the pandemic, such as anxiety and depression problems due to job loss, death of family, friends, and colleagues, financial insecurity, and social isolation, culminating in reduced quality of life and activities of daily living¹⁵. In addition, although clinical symptoms are predominantly respiratory associated with severe pneumonia, direct and indirect involvement of other organs is common. The main target after the lungs

is the cardiovascular system, which makes heart disease a powerful group of risk, increasing the probability of developing severe infection¹⁶.

Gao *et al.*³ looked for relationships between mental health problems and excessive social media exposure during the COVID-19 outbreak. Compared to national data, there was a higher prevalence of depression, anxiety, or even the combination of these two psychological disorders during the outbreak of COVID-19. In the same direction, Zhang *et al.*¹⁷ investigated the immediate impact of COVID-19 on the mental health and quality of life of patients in China. An association of the disease with a mild level of stress was found.

Depression and anxiety are intrinsically linked to the loss of quality of life, and the decrease in activities of daily living, which can worsen the prognosis of COVID-19 since psychological disorder and depression can affect the immune system's response¹⁸. In addition, depressed patients may have negative attitudes towards antiviral therapy, reducing treatment adherence and individual recovery¹⁹⁻²¹.

These comorbidities, linked to COVID-19, are powerful indicators for compromised quality of life, whether due to psychological disorders related to the disease or even to decreased physical activity caused by social isolation, this association of events related to decreased health of the patient with coronavirus disease.

This study presents an outline of a specific group of parents and caregivers of people with disabilities, so we cannot emphasize that these results represent a larger group or class of individuals, as no statistical treatment was applied to evidence their expression in the population. Furthermore, the quality of life indicators present us with an overview of the perception of individuals in social isolation and may bring us new hypotheses for approaches to reduce the impact of the pandemic on the daily lives of these individuals.

CONCLUSION

One of the main complaints about the care of people with disabilities during the COVID-19 pandemic is the feeling of fear and anguish that affects decision-making in family relationships, which influences self-care activities and the physical and mental health of this population.

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■ REFERENCES

1. Madabhavi I, Sarkar M, Kadakol N. COVID-19. A review. *Monaldi Arch Chest Dis* [Internet]. 14 de maio de 2020 [citado 1o de outubro de 2021]; 90 (2). Disponível em: <https://www.monaldi-archives.org/index.php/macd/article/view/1298>
2. Arber W, Braun W, Haas R, Henle W, Hofschneider PH, Jerne NK, et al. Current topics in microbiology and immunology: ergebnisse der mikrobiologie und immunitätsforschung volume 59. Softcover Reprint of the Original 1st 1972 ed. edição. Berlin, Heidelberg: Springer; 2011.
3. Wong G, Liu W, Liu Y, Zhou B, Bi Y, Gao GF. Mers, sars, and ebola: the role of super-spreaders in infectious disease. *Cell Host Microbe*. 14 de outubro de 2015; 18 (4): 398–401.
4. Long B, Brady WJ, Koyfman A, Gottlieb M. Cardiovascular complications in COVID-19. *The American Journal of Emergency Medicine*. julho de 2020; 38 (7): 1504–7.
5. Kochi AN, Tagliari AP, Forleo GB, Fassini GM, Tondo C. Cardiac and arrhythmic complications in patients with COVID-19. *J Cardiovasc Electrophysiol*. maio de 2020; 31 (5): 1003–8.
6. Judicialização da Saúde Pública [Internet]. [citado 1o de outubro de 2021]. Disponível em: <https://clubedeautores.com.br/livro/judicializacao-da-saude-publica-2>
7. Liporoni AAR de C. Os caminhos da participação e do controle social na saúde: estudo das realidades do Brasil e Espanha. 11 de junho de 2014 [citado 1o de outubro de 2021]; Disponível em: <http://educapes.capes.gov.br/handle/11449/106131>
8. Monteiro CB de M. Realidade Virtual na Paralisia Cerebral [Internet]. São Paulo; 2011. Disponível em: <https://repositorio.ufsc.br/handle/123456789/127730>
9. Pfefferbaum B, North CS. Mental health and the covid-19 pandemic. *New England Journal of Medicine* [Internet]. 13 de abril de 2020 [citado 1o de outubro de 2021]; Disponível em: <https://www.nejm.org/doi/10.1056/NEJMp2008017>
10. Almeida C, Luchmann L, Martelli C. A pandemia e seus impactos no Brasil. *MARLAS*. 30 de junho de 2020; 4 (1): 20.
11. Wengert M, Suzano D da S, Almeida MCS, Bernardo LDB. A importância da qualidade de vida em pacientes hipertensos. In 2021 [citado 1o de outubro de 2021]. p. 21–32. Disponível em: <http://www.editoracientifica.org/articles/code/201001851>
12. Sette CP, Capitão CG. Investigação do suporte social e qualidade de vida em pacientes com câncer. *SaudPesq*. 2 de maio de 2018; 11 (1): 151.
13. Ciconelli RM. Tradução para o português e validação do questionário genérico de avaliação de qualidade de vida medical outcomes study 36-item short-form health survey (SF-36). 1997 [citado 1o de outubro de 2021]; Disponível em: <https://repositorio.unifesp.br/handle/11600/15360>
14. Bezerra A, Silva CEM da, Soares F, Silva JAM da. Fatores associados ao comportamento da população durante o isolamento social na pandemia de covid-19 [Internet]. 2020 abr [citado 1o de outubro de 2021]. Disponível em: <https://preprints.scielo.org/index.php/scielo/preprint/view/123/version/128>
15. Mikolajewska A, Witzernath M. Ambulant erworbene Pneumonie bei Erwachsenen. *Dtsch med Wochenschr*. março de 2020; 145 (06): 359–70.
16. Alexandre J, Cracowski J-L, Richard V, Bouhanick B. Renin-angiotensin-aldosterone system and COVID-19 infection. *Annales d'Endocrinologie*. junho de 2020; 81 (2–3): 63–7.
17. Ma Y-F, Li W, Deng H-B, Wang L, Wang Y, Wang P-H, et al. Prevalence of depression and its association with quality of life in clinically stable patients with COVID-19. *Journal of Affective Disorders*. outubro de 2020; 275: 145–8.
18. Correction to *Lancet Infectious Diseases* 2020; published online April 29. [https://doi.org/10.1016/S1473-3099\(20\)30064-5](https://doi.org/10.1016/S1473-3099(20)30064-5). *The Lancet Infectious Diseases*. julho de 2020; 20 (7): e148.
19. Xing Y, Mo P, Xiao Y, Zhao O, Zhang Y, Wang F. Post-discharge surveillance and positive virus detection in two medical staff recovered from coronavirus disease 2019 (COVID-19), China, January to February 2020. *Eurosurveillance* [Internet]. 12 de março de 2020 [citado 1o de outubro de 2021]; 25 (10). Disponível em: <https://www.eurosurveillance.org/content/10.2807/1560-7917.ES.2020.25.10.2000191>
20. Abreu LC. The path of humanity in the pandemic of COVID-19: the choice of the realistic, optimist or pessimist scenario. *J Hum Growth Dev*. 2021; 31(1):05-08. DOI: 10.36311/jhgd.v31.11683
21. Ferreira T, Figueiredo TC, Bick MA, Langendorf TF, Padoin SMM, de Paula CC. Opportunities in child motor development at home: bibliometric and scientometric review. *J Hum Growth Dev*. 2021; 31(1):125-144. DOI: 10.36311/jhgd.v31.10691

Resumo

Introdução: neste momento crítico da pandemia de COVID -19, observamos o afastamento social e a quebra da rotina dos indivíduos na sociedade, para a pessoa com deficiência que necessita de suporte adequado e uma rotina de atividades mais intensas e efetivas podem sentir maior necessidade de cuidado e atenção do suporte familiar para resolução que problemas cotidianos.

Objetivo: identificar os fatores associados ao impacto da pandemia na Qualidade de vida dos indivíduos com deficiência e seus cuidadores.

Método: foi realizado um inquérito virtual com pais e cuidadores de pessoas com deficiência no para identificar os principais fatores associados ao impacto da Pandemia no cotidiano e nas relações sociais entre família e comunidade.

Resultados: dos pais e cuidadores que tivemos acesso e responderam ao questionário, 90% são residentes da região do ABC de São Paulo, suas crianças e adolescentes com deficiência têm entre 4 e 18 anos de idade. As principais pontuações dos cuidadores sobre as dificuldades no cuidado durante a pandemia, 70% se sentiram desamparadas em algum momento, 17% tiveram dificuldades para realizar atividades de autocuidado, 42% tiveram angústias e medo durante o período, 83% tem a maior responsabilidade nas decisões do lar, e cerca de 50% conseguem compartilhar tais decisões.

Conclusão: das principais queixas para o cuidado da pessoa com deficiência durante a pandemia de COVID-19, estão relacionadas a sensação de medo e angústia que afeta a tomada de decisão e as relações familiares, o que influencia as atividades de autocuidado e na saúde mental desta população.

Palavras-chave: avaliação de saúde, pandemia de covid- 19, saúde mental, qualidade de vida, terapia ocupacional.

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