




Family care of children with chronic conditions in the context of the pandemic by COVID-19*

Cuidado familiar de crianças em condição crônica no contexto da pandemia pela COVID-19

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ABSTRACT

Objective: to describe how families experienced the care of children in chronic condition during the pandemic by COVID-19. **Methods:** qualitative study, guided by the Family Management Style Model, conducted with 24 families of children in chronic condition. The data, collected by telephone contact through semi-structured interviews, were submitted to thematic analysis. **Results:** data analysis resulted in three thematic categories: Changes in the routine of family members; Emotions triggered in family members and children due to the pandemic; and Implications of the pandemic by COVID-19 for the continuity of care. They highlighted: incorporation of hygiene care, social distancing concomitant to domestic and professional activities at home; and feelings of fear and concern about the children's health and development and the need for caregivers to provide rehabilitation and support for school activities. **Conclusion:** it was observed that the pandemic changed the family routine, produced negative feelings in families, modified care demands and compromised access to services. **Contributions to practice:** these results contribute to the identification of the repercussions of COVID-19 on families and children with chronic conditions and can help establish strategies to reduce the consequences of this pandemic and other future health emergencies.

Descriptors: Chronic Disease; Child Care; Family; COVID-19; Qualitative Research.

RESUMO

Objetivo: descrever como as famílias vivenciaram o cuidado da criança em condição crônica durante a pandemia por COVID-19. **Métodos:** estudo qualitativo, orientado pelo Modelo de Estilo de Manejo Familiar, realizado com 24 famílias de crianças em condição crônica. Os dados, coletados por meio de contato telefônico mediante entrevista semiestruturada, foram submetidos à análise temática. **Resultados:** a análise dos dados resultou em três categorias temáticas: Mudança na rotina dos membros da família; Emoções desencadeadas nos familiares e crianças devido à pandemia; e Implicações da pandemia por COVID-19 para a continuidade do cuidado. Destacaram-se: incorporação de cuidados de higiene, distanciamento social concomitante às atividades domésticas e profissional no domicílio; e sentimentos de medo e preocupação quanto à saúde e desenvolvimento das crianças e a necessidade de os cuidadores proverem a reabilitação e suporte para as atividades escolares. **Conclusão:** observou-se que a pandemia modificou a rotina familiar, produziu sentimentos negativos nas famílias, modificou as demandas de cuidado e comprometeu o acesso aos serviços. **Contribuições para a prática:** esses resultados contribuem para a identificação das repercussões da COVID-19 nas famílias e crianças sob condição crônica, podendo auxiliar o estabelecimento de estratégias para a redução das consequências dessa pandemia e de outras emergências sanitárias futuras.

Descritores: Doença Crônica; Cuidado da Criança; Família; COVID-19; Pesquisa Qualitativa.

Introduction

The emergence of coronavirus 2019 disease (COVID-19), caused by a virus with the potential to produce a severe acute respiratory infection, has produced social, economic, behavioral, and health changes in populations around the world⁽¹⁾.

As the number of confirmed cases and deaths due to the virus increased, protective measures such as social distancing were established to mitigate its spread⁽²⁻³⁾, leading to the interruption in the operation of schools, outpatient health services, and churches, among others^(1,4).

Initially, this rearrangement was necessary, however, the repercussions of the interruption of health care and school activities, especially those directed to children in chronic conditions, have not yet been measured, and it is likely that there are unknown impacts on this population with numerous negative effects⁽⁵⁻⁶⁾. The natural importance given to the physical dimension of health, however, has left uncovered other dimensions of people's health, particularly in the field of mental health, as shown by the research from this stage.

Chronic health conditions in children caused by congenital heart disease, asthma, obesity, and neurological alterations were considered risk factors for the development of the severe form of COVID-19 in this group⁽⁷⁻⁸⁾. It is also considered that the vulnerability determined by COVID-19 in these children was accentuated by pandemic control measures or reduced health protection, because, although unintentional, these are measures that were part of the pandemic context and that may have contributed to the increase of inequality^(4,9).

When present in childhood, chronic conditions impact directly on the family, bringing significant changes in family functioning. This may require that family members reorganize themselves and assume different roles to meet the child's care demands⁽¹⁰⁻¹³⁾. Besides the basic care of hygiene, feeding and surveillance, common to all children, for the group of

children in chronic condition, the performance of this care may need to be adapted and associated with the administration of medications, hospital admissions and specialized care⁽¹²⁾. The maintenance of this routine requires greater availability of time and financial resources to ensure the care of the child⁽¹¹⁻¹³⁾.

It is assumed that the family is the primary caregiver for children with chronic conditions at home. The care actions performed by this social group suffer the variations determined by their life context. Considering that the pandemic caused changes in the life context of the entire population due to the limitations imposed, especially, by social distance, the family system was also modified, bringing changes to the care provided at home.

Knowing the care experiences of the families of children with chronic conditions during the pandemic by COVID-19 will or will not allow an approach to the changes in care and the identification of situations that may deserve professional attention during the period that follows the pandemic. Thus, the question that guided this investigation was: how was the care of children in chronic health condition experienced by their families during the pandemic by COVID-19? Therefore, this study aimed to describe how families experienced the care of children in chronic condition during the pandemic by COVID-19.

Methods

This is a study with a qualitative approach, guided by the referential Model of Family Management Style, which enables an analysis of the responses of families to the needs experienced by the existence of a chronic condition in childhood. It is composed of three main components: Definition of the Situation; Management Behaviors; Perceived Consequences) and eight dimensions: Child's Identity; View of the disease; Management Mentality; Mutuality between parents; Management Approach; Parents' Philosophy; Focus on the family; and Future Expectations, related to behavioral aspects of the family, indicating the

difficulties and facilities experienced for the care of the child in the family's daily life⁽¹⁴⁾. The preparation of this study met the recommendations of the Consolidated Criteria for Reporting Qualitative Research (COREQ).

For this study, the four dimensions of the Situation Definition component were used: I) child identity refers to the family's view of the extent to which their views focus on the child's ability or vulnerability; II) disease view encompasses the family's beliefs about the cause, severity, predictability, and course of the condition; III) management mindset refers to the family's views about the ease or difficulty of carrying out the treatment regimen and their ability to manage it effectively; IV) family mutuality, refers to caregivers' beliefs about shared or divergent views about the child, the condition, their parenting philosophy, and their approach to managing the condition. This component allows analyzing the subjective meaning that the family imposes on important elements of a lived situation⁽¹⁴⁾, here in this study, understood as the care of the child in chronic condition during the pandemic by COVID-19.

Attempts were made to contact 53 families of children in chronic condition who participated in a primary study⁽¹⁵⁾. Of these, nine families were not contacted due to lack of viable contact; 13 did not respond after three attempts to call, and four did not accept to participate. Therefore, 27 families were interviewed; however, three families participated in the pilot test and were not part of the analysis, totaling 24 families of children in chronic conditions.

Initially, a representative from each family was interviewed: 22 mothers, one father; and one aunt, considered the child's main caregivers. Later, to contemplate different perspectives of the family, these caregivers were asked to indicate another family member who was also involved in the child's care. In five families there was no other caregiver; three did not answer the researcher and 16 main caregivers indicated another relative. In nine families it was possible to interview another relative: six fathers, one

mother, one uncle and one grandmother. Therefore, 33 interviews were conducted. One of the participating mothers had twin children, both under the same chronic health condition. Thus, 24 families, 33 relatives and 25 children were included in the study.

The inclusion criteria for the participants were: being a family member of the child and involved in care; being over 18 years old; understanding the questions and being able to answer them; having telephone contact viability. The exclusion criteria consisted of not getting a response from the family member after three contact attempts by the researcher.

Although the research was not carried out with all the family members, the production of information referred to the family. Thus, the type of attachment of the family member to the child was mentioned only when necessary. The reference was to family or family members.

Data collection was conducted in the months of January and February 2021. Due to pandemic prevention measures, collection was done by telephone contact. As for the sociodemographic data of the main caregivers, the following were considered: age, time of study, ethnicity, religion, marital relationship, income, and receipt of assistance, which were collected before the beginning of the interview. We chose to use a semi-structured interview whose script was previously prepared based on the adopted referential and was guided by the question: how has it been caring for (name of child) at this time of the pandemic?

After acceptance was given and at the scheduled date and time, the interviews were conducted and audio-recorded using the "Voice Recorder" application of a mobile phone. The average length of the interviews was 15 minutes and 34 seconds. The audio files of the interviews and the answers to the informed consent form were stored on an external hard drive and on a password-protected personal computer.

The interviewees were informed of their anonymity, the confidentiality of the information, and their freedom to stop calling and/or participating in the study at any time. The participants were named

according to the degree of kinship with the child, followed by the order number of the interview, in other words M24. M being for “mother”, F “father”, U “uncle”, and G “grandmother”.

The audios were transcribed by the authors and the accuracy of the transcriptions was checked by comparing their content to the audio of the recordings. The transcriptions were imported into the MAXQDA® software, version 22 (License: 373785049), which was used as support for data organization, coding, and exploration⁽¹⁶⁾.

Data were submitted to thematic analysis⁽¹⁷⁾ of the deductive type, guided by the referential. Considering that the object of study of this investigation was the care performed by the family and the objective of this study was to describe how they experienced the care of the child in chronic condition during the pandemic by COVID-19, the four dimensions of the situation definition component were defined as initial codes, considering the context of the pandemic.

The data analytic process followed the six stages of thematic analysis⁽¹⁷⁾: I) Familiarization with the data; II) Generation of initial codes; III) Searching for themes; IV) Reviewing themes; V) Defining and naming themes; and VI) Producing the final report.

To ensure credibility, the data were validated and discussed by a larger quantity of researchers. Reliability was met with coding, peer review and agreement, and with the resolution of disagreements by a third researcher⁽¹⁸⁾.

The information produced for the characterization of the participants was submitted to simple descriptive analysis with the presentation of absolute values and percentages.

This research was approved by the Research Ethics Committee under favorable opinion 3,508,414/2019 and Certificate of Ethical Appreciation Presentation: 12288919.0.0000.5149. It is worth noting that the present study was conducted in accordance with Resolutions 466/12 and 510/2016 of the National Health Council and the guidelines of Circular Letter No. 2/2021 of the National Research Ethics

Committee. Consent occurred through verbalization about the recording by the participant on audio. Participants received a printed or digital copy of the Informed Consent Form according to their choice. For the expansion of the investigation, considering the context of the pandemic by COVID-19, an amendment was submitted for consideration by this committee.

Results

It is considered that, as the main caregiver is the person who takes more intensively the child's care, he/she can offer information about the family's perspective. Thus, the information related to the sociodemographic characteristics which will be presented below refers to the children's main caregivers (Table 1).

Table 1 – Characterization of the main caregivers of the child in chronic condition (n=24). Belo Horizonte, MG, Brazil, 2021

Variables	n (%)
Age (years)	
20-30	4 (16.7)
31-40	17 (70.8)
41-50	3 (12.5)
Educational background (years)	
>15	7 (29.2)
11 to 14	8 (33.3)
8 to 10	6 (25)
1 to 7	3 (12.5)
Self-declared ethnicity	
Black	4 (16.7)
White	4 (16.7)
Other	16 (66.7)
Has religion	
Yes	21 (87.5)
No	3 (12.5)
Marital relationship	
Yes	18 (75)
No	5 (20.8)
Not informed	1 (4.2)
Main Caregiver	
Mother	22 (91.6)
Other (father/ aunt)	2 (8.4)
Family income (minimum wage - R\$1.100.00)	
< 1	6 (25)
1	8 (33.3)
>1	10 (41.7)
Did you receive aid during the pandemic period	
Yes	17 (70.8)
No	7 (29.2)

Most families received some type of aid during the period of data collection. The aid received consisted of emergency aid, offered because of the pandemic. *Bolsa Família* Program in Brazil (Family Allowance) and basic food baskets that were distributed by state and municipal schools when children were enrolled. Some received more than one benefit. It is worth mentioning that the values of the benefits received were computed in the calculation of family income.

In relation to the children, their ages varied between three and four years old. Seventeen were male. Regarding the birth condition, nine were born prematurely with a mean gestational age of 31.8 weeks. The medical diagnoses were: cerebral palsy (n=4); hydrocephalus (n=5); myelomeningocele (n=1); Tetralogy of Fallot (n=2); congenital heart disease (n=1); Klinefelter syndrome (n=1); Trisomy 18 (n=1); Goldenhar syndrome (n=1); congenital lathe foot (n=2); different leg dimensions (n=2); Autism Spectrum Disorder (n=2); necrotizing enterocolitis (n=1); laryngomalacia (n=1); and nephrotic syndrome (n=1).

Regarding the care needs. It was evident that all the children had the need for follow-up with specialists, and 52% required assistance from more than one specialty. The specialties reported were physiotherapy (60%), neurology (48%), speech therapy (28%), occupational therapy (28%), cardiology (12%), nephrology (12%), orthopedics (8%), endocrinology (8%) and nutrition (8%). Regarding technology dependence, the five children with the medical diagnosis of hydrocephalus had a ventriculoperitoneal shunt; the two children with congenital clubfoot used orthopedic boot, and one of the children with different leg sizes used orthopedic insole. The gastrostomy was a device used by two children.

The analysis of the interviews provided the definition of the highlighted themes: Change in the routine of family members; Emotions triggered in family members and children due to the pandemic; and Implications of the pandemic by COVID-19 for the continuity of care.

Change in the family members' routines

The interviews allowed the identification of changes in the families' routines. These changes corresponded to the adoption of new habits, directed to the prevention of infection by COVID-19. Hygiene care was incorporated. Social distancing and change in the work routine of family members, especially, its performance at a distance.

The incorporated care that were mentioned most frequently (58%) were related to the use of masks, alcohol gel and social distancing: *Now, with the problems that you have there I must avoid going out in public. use alcohol gel. clean as much as possible (M42). If you have to go out, you need the masks, you must be careful with alcohol gel (M53).*

Social distancing was another measure adopted by most family members (82%). The following expressions show that families created strategies to adapt to the conditions demanded by the pandemic reality: *I avoid leaving home (M45). We don't receive anyone at home (M15). We don't go out like before (M50).*

The need to incorporate remote work required more people to remain in the home space. With this, the care of the children and the domestic chores had to be performed together with the professional activities, producing an overlapping of the caregivers' functions, as evidenced by M35: *With the pandemic, came the remote work, so there are two children, plus the work that I must do. So, it was very hard for me, because I must wait for the children to sleep to be able to do my work (M35).*

Emotions triggered in family members and children due to the pandemic

The interviews revealed that the pandemic produced emotional changes in the families. Tension, signs of anxiety, fear, stress, concern and feeling of overload were mentioned. These feelings were mentioned by the participants when they were faced with the responsibility of ensuring the care demanded by their children, the sanitary protocols of contamination prevention, the remote work and the school tasks of their children.

Fear and concern were expressed, especially regarding the possibility of the child being infected by the virus, since they were considered more fragile and susceptible. The reports of M2 and M41 highlight this aspect: *I'm afraid of him getting Corona, I think it's a little easier for him to get it. It ends up that his immunity is lower* (M2). *The only fear I have is that I know that if she gets this COVID she can't stand it, because she already has a little problem that is why we are careful* (M41).

Stress was another repercussion mentioned by the participants resulting, mainly, from the need of the family to stay at home and the adoption of social restriction to contain the dissemination of COVID-19. It is expressed in the fragments of speech when they refer that: *We end up getting more stressed. You can't go out right. You can't have the freedom that we had* (M2). *Care must be tripled, right? Care and patience* (M9).

The repercussions were also identified in the children themselves. For example, we have the fragment of M9 describing her child as very nervous and M20 saying that they are more anxious because they stay at home: *He gets very nervous to stay indoors* (M9) and *the children stay at home more anxious* (M20).

Implications of the pandemic for COVID-19 for the continuum of care

The schools closing, health services and other welfare services led to the interruption of the children's care by different professionals. The children presented a need for specialized follow-up and interventions that contributed to their development. In her interview, M50 recognizes her child's need, stating that: *Wanting or not he [the child] needs this care* (M50). P35 reports the interruption of care by different professionals: *The issue of care that we felt the most was when the treatments were interrupted, isn't it, ALL OF THEM, any treatment no, ALL. Suspended neurologist, ophthalmologist, phono, physical therapist, equine therapy* (F35).

The participants emphasized that the interruption of the periodic care of children in the health services was a cause for concern. They recognize the

importance of these appointments for the children, and to ensure them, they themselves had to perform the activities accompanied from a distance by a professional. In the reports, attempts using video calls are indicated, however, they express the fear that they are not performing them in the best way. This can be evidenced in M25's statements that: *They call, make video call, then in the case of me having to do physical therapy. We don't know how to do it exactly like the professional, right?* (M25).

About two thirds of the interviewees evaluated that the interruptions of care can impair the child's development. What can be seen in M5's statement: *She needs to reinforce her steps, it's occupational therapy, it's physiotherapy, and until today nothing. She needs it* (M5).

Some of the participants reported already identifying a worsening in the child's conditions with the closing of services such as schools and specialized care: *It will be a year without physical therapy. He was already having difficulty walking. I already saw that his musculature is already having difficulty* (M9). *She won't be able to go to school and will miss it, because it is a very important moment in her development, motor and psychological, the interaction with other children that she won't have* (M44).

This interruption of the school's participation as a partnership in meeting part of the children's needs transferred to the home environment and to the caregivers the function of maintaining the children's education. Although they sought to maintain this function that, also, contributes to the change in the family's routine, the participants consider that: *At home I teach a little bit, but it is not the same* (M45). *When she was at school her development was different* (M34). *School was making all the difference* (M20).

Discussion

For the families of children with chronic conditions interviewed, the difficulty of continuous care allied to protection against the virus accentuated their vulnerabilities and the challenges faced in the pandemic. The speeches evidenced the uncertainty about what the virus could produce in the children's health,

the feeling of insecurity and the need to reinvent themselves as caregivers.

Uncertainty in disease is a central phenomenon in nursing⁽¹⁹⁾. Similarly, safety has always been considered a “basic human need”, which also constitutes the scientific focus of nursing. The uncertainty and insecurity, verified in this study, thus, appeal to a scientific nursing perspective about the results obtained. Of the various perspectives of analysis that can be object, the different experiences of people in the face of the pandemic situation as well as the analysis from the scientific field of nursing emerge, equally, as evidence in the present study.

The daily care of a child with a chronic condition already requires extra efforts, regarding maintaining safety and reducing injuries⁽¹⁰⁻¹²⁾. In this scenario, as new situations of vulnerability arise, such as the risk of becoming ill due to COVID-19 or the impossibility of maintaining care, it is necessary that families adapt continuously to meet the demands of the child⁽²⁰⁾.

The adaptation to the new epidemiological scenario demanded the incorporation in the routine of prevention measures against COVID-19 such as social distancing, the use of masks, increased frequency of hand washing, use of alcohol gel and cleaning of surfaces with disinfectant products⁽²⁻³⁾. The adoption of these measures occurred, maintaining the existing care routine.

For most of the interviewed families, the fact that their child was living with a chronic condition increased their vulnerability to COVID-19. The family's focus on the child's vulnerabilities due to his health condition modified the caregiving behaviors and consequences perceived by caregivers. This understanding corroborates the literature⁽²¹⁾, by the evidence that families had to face fear and concern for their children during the pandemic because they believed that they were more susceptible to infection and that, contracting the virus, the consequences of the disease would be more severe.

From the perspective of these families, with the pandemic scenario there was a loss or decrease in the

sharing of childcare because schools and outpatient clinics interrupted their in-person care. With this, it was necessary to (re)organize the family's entire routine, since new tasks, such as remote work, school teaching, online care, among others, had to be incorporated into the daily demands⁽²²⁾.

Due to the variety and complexity of needs of children with chronic conditions, providing comprehensive care has been identified as challenging in different settings^(9,20). With the pandemic by COVID-19, the health system scenario has become even more complex, accentuating the difficulties in ensuring continuity of care due to the reduction of care and adequate support to this risk group^(21,23).

To provide care for cases of COVID-19 illness and to contain the spread of the virus, one of the health system's strategies was to interrupt routine services⁽²⁾. Services provided in outpatient clinics were considered nonessential⁽²⁾. Therefore, follow ups with specialists such as physical therapists had their activities suspended indefinitely⁽²⁴⁾.

The delayed development was an aspect evaluated by the caregivers because of this lack of care. It is known that the interventions made by health professionals are designed according to the evolution of the child's development. Thus, children dependent on rehabilitation therapies, when for a long period they do not receive the previously continuous stimuli, they may present functional declines that have already been achieved over time^(20,23).

Because the interviewed families knew the limitations of the children and the importance of these services, this context brought even more implications for care. In addition to being concerned about adopting measures to prevent infection by the virus, they also began to worry about the compromised development of the child, because besides not attending school, the child was deprived of periodic health interventions. More studies evidenced the caregivers' concern with child development, evaluating such situation as a factor causing anguish, fear, and psychic suffering for the caregivers^(3,21).

The restriction to home deprived the child of social interaction, a factor that produces potential losses to learning and child development⁽²⁵⁾. The children were cut off from friends and teachers, and distanced from loved ones who shared their care with their caretakers. The isolation restricted their environment to the home, and these modified routines brought limitations to their life routines^(4,25-26). Moreover, the need for confinement and the incorporation of new routines disproportionately affected the child population, especially those already vulnerable⁽⁴⁾, being able to accentuate reactions of irritability, fear, and behavioral changes⁽²⁶⁾.

In this investigation, delay to school entry or disruption of school routine was a hindering factor. In the latter case, school activities were added to the daily routine and started to be developed exclusively at home. The closing of schools for children with special educational needs and disabilities can negatively impact, the learning and emotional well-being of this population⁽²⁷⁾.

The transfer of the educational environment to the home, which occurred during the pandemic, was considered one of the biggest challenges for families of children with chronic health conditions⁽²⁸⁾. Especially, the caregiver's time demand and the fact that they considered that they could not develop the activities with the same quality as the educators were verified in this study.

The pandemic by COVID-19, also, exacerbated the global economic crisis, especially, of the most vulnerable populations. This resulted in unemployment, disarticulation of the support network and overcrowding of homes⁽²⁹⁾. Of the interviewed families, 70.8% revealed that they had relied on different financial support. Seven of them received the financial support offered by the government due to the pandemic.

As this population is formed by caregivers, it can be inferred that the home was already considered a workplace. Therefore, the manifestation of inferences of work that, due to the pandemic, started to be performed at home was not considered frequent.

However, the manifestations presented signaled the transition from work to home as a factor capable of increasing the caregivers' burden. A study developed with parents of children with autistic spectrum disorder corroborated this finding by indicating an increase in the overload of demands in parents who took their jobs home⁽³⁰⁾.

It was evidenced that the impacts of the pandemic transcend virus infection and disease. The measures adopted in public health will have unintended consequences that will probably affect the entire population, by social, health or financial consequences with exponential threat to children and families living with a chronic health condition^(9,20-22).

Study limitations

The study has an essentially exploratory nature, which makes it necessary, as productions advance, to invest in research that has an explanatory design. The data were collected in a period of more intense social isolation, making it impossible for the researcher to have contact with the participants and their life context, considered a limitation since the reports can bring data with less richness of details.

Contributions to practice

In view of the above, and considering the importance of the family in the care of children in chronic conditions, it is believed that this work will contribute to the identification of the repercussions of the pandemic by COVID-19 on children and their families and to the identification of the additional demands experienced, as well as providing information that can guide nursing professionals in the development of strategies capable of helping families and children in chronic conditions in their real needs, as well as contributing to the reduction of the negative repercussions of the pandemic by COVID-19 and other health emergencies that may come to exist.

Conclusion

It was found that the situations experienced by families for the care of their children during the pandemic by COVID-19 indicated that these families were overwhelmed to meet the pre-existing needs of children in chronic conditions plus those arising from the change in their living context. The need to intensify hygiene measures, adopt new behaviors, such as wearing masks, and maintain social distance were highlighted. Fear and concern were present feelings, mainly related to the possibility of infection of the child.

The families experienced the interruption of health care and the closing of schools, which they evaluated as capable of bringing harm to the child's development. The maintenance of rehabilitation care and teaching activities provided by the caregivers during the period of social distance reinforced their centrality in care. The challenges faced allowed us to consider that these families need to be prepared and supported to assume this function beyond periods of sanitary emergencies.

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Authors' contribution

Conception and design or data analysis and interpretation: Macêdo MML, Duarte ED.

Writing of the manuscript or relevant critical review of the intellectual content: Macêdo MML, Henriques NL, Deodato S, Duarte ED.

Final approval of the version to be published: Deodato S, Duarte ED.

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References

1. Stephen WP, Henkhaus LE, Zickafoose JS, Lovell K, Halvorson A, Loch S, et al. Well-being of parents and children during the COVID-19 pandemic: a national survey. *Pediatrics*. 2020;146(4):e2020016824. doi: <https://doi.org/10.1542/peds.2020-016824>
2. Organização Pan-Americana da Saúde (OPAS). Histórico da pandemia de COVID-19 [Internet]. 2020 [cited Nov 15, 2022]. Available from: <https://www.paho.org/pt/covid19/historico-da-pandemia-covid-19>
3. Grumi S, Provenzi L, Gardani A, Aramini V, Dargenio E, Naboni C, et al. Rehabilitation services lockdown during the COVID-19 emergency: the mental health response of caregivers of children with neurodevelopmental disabilities. *Disabil Rehabil*. 2020;43(1):27-32. doi: <https://doi.org/10.1080/09638288.2020.1842520>
4. Fegert JM, Vitello B, Plener PL, Clemes V. Challenges and burden of the Coronavirus 2019 (COVID-19) pandemic for child and adolescent mental health: a narrative review to highlight clinical and research needs in the acute phase and the long return to normality. *Child Adolesc Psychiatry Ment Health*. 2020;14(20):1-11. doi: <https://doi.org/10.1186/s13034-020-00329-3>
5. Malta DC, Gomes GS, Silva AG, Cardoso LSM, Barros MBA, Lima MG. Use of health services and adherence to social distancing by adults with Noncommunicable Diseases during the COVID-19 pandemic, Brazil, 2020. *Ciênc Saúde Coletiva*. 2021;26(7):2833-42. doi: <https://doi.org/10.1590/1413-81232021267.00602021>
6. Hefferon C, Taylor C, Bennett D, Falconer C, Campbell M, Williams JG, et al. Priorities for the child public health response to the COVID-19 pandemic recovery in England. *Arch Dis Child*. 2021;106(6):533-8. doi: <http://doi.org/10.1136/archdischild-2020-320214>
7. Tsankov BK, Allaire JM, Irvine MA, Lopez AA, Sauvé LJ, Vallance BA. Severe COVID-19 infection and pediatric comorbidities: a systematic review and meta-analysis. *Int J Infect Dis*. 2021;103:246-56. doi: <https://doi.org/10.1016/j.ijid.2020.11.163>

8. Kompaniyets L, Agathis NT, Nelson JM, Preston LE, Ko JY, Belay B. Underlying medical conditions associated with severe COVID-19 illness among children. *JAMA Netw Open*. 2021;4(6):e2111182. doi: <https://dx.doi.org/10.1001/jamanetworkopen.2021.11182>
9. Lignou S, Greenwood J, Sheehan M, Wolfe I. Changes in healthcare provision during Covid-19 and their impact on children with chronic illness: a scoping review. *J Health Care*. 2022;59:469580221081445. doi: <https://dx.doi.org/10.1177/00469580221081445>
10. Aydon L, Hauck Y, Murdoch J, Siu D, Sharp M. Transition from hospital to home: Parents' perception of their preparation and readiness for discharge with their preterm infant. *J Clin Nurs*. 2018;27(1-2):269-77. doi: <https://dx.doi.org/10.1111/jocn.13883>
11. Vaz JC, Milbrath VM, Gabatz RIB, Krug FR, Hirschmann B, Oliveira MM. Care for families of children with chronic disease. *Rev Enferm UFPE on line*. 2018;12(5):1397-408. doi:<https://dx.doi.org/10.5205/1981-8963-v12i5a230852p1397-1408-2018>
12. Tavares TS, Duarte ED, Sena RR. Repercussions of chronic conditions in children's health needs egresses from neonatal unit. *Rev Enferm Cent Oeste Min*. 2018;8:e2686. doi: <https://doi.org/10.19175/recom.v8i0.2686>
13. Dias BC, Ichisato SM, Marchetti MA, Neves ET, Higashi IH, Marcon SS. Challenges of family caregivers of children with special needs of multiple, complex and continuing care at home. *Esc Anna Nery*. 2019;23(1):e20180127. doi: <https://doi.org/10.1590/2177-9465-EAN-2018-0127>
14. Knafel KA, Deatrck JA, Gallo AM, Skelton B. Tracing the use of the family management framework and measure: a scoping review. *J Fam Nurs*. 2021;27(2):87-106. doi: <https://dx.doi.org/10.1177/1074840721994331>
15. Felizardo MJA, Silva JB, Neves ET, Duarte ED. Ability of management of families of children with chronic conditions for care at home. *Esc Anna Nery*. 2022;26:e20220071. doi: <https://dx.doi.org/10.1590/2177-9465-EAN-2022-0071en>
16. Souza Neto RA, Dias GF, Silva RR, Ramos ASM. Efeitos dos softwares de análise de dados qualitativos na qualidade de pesquisas. *Rev Adm Contemp*. 2019;23(3):373-94. doi: <https://dx.doi.org/10.1590/1982-7849rac2019170357>
17. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. 2008;3(2):77-101. doi: <https://doi.org/10.1191/1478088706QP0630A>
18. Guba EG, Lincoln YS. Do inquiry paradigms imply inquiry methodologies? In: Fetterman DM. *Qualitative approaches to evaluation in education: the silent scientific revolution*. London: SAGE; 1988. p. 89-115.
19. Bora ST, Buldukoglu K. Using the Uncertainty in Illness Theory to provide care for the caregiver: a case report. *J Psychiatric Nurs*. 2020;11(1):70-7. doi: <https://doi.org/10.14744/phd.2019.44365>
20. Cacioppo M, Bouvier S, Bailly R, Houx L, Lempereur M, Mensah-Gourmel J, et al. Emerging health challenges for children with physical disabilities and their parents during the COVID-19 pandemic: the ECHO French survey. *Ann Phys Rehabil Med*. 2021;64(3):101429. doi: <https://doi.org/10.1016/j.rehab.2020.08.001>
21. Medeiros JPB, Neves ET, Pitombeira MG, Figueiredo SV, Campos DB, Gomes ILV. Continuity of care for children with special healthcare needs during the COVID-19 pandemic. *Rev Bras Enferm*. 2022;75(2):e20210150. doi: <https://doi.org/10.1590/0034-7167-2021-0150>
22. Houtrow A, Harris D, Molinero A, Levin-Decanini T, Robichaud C. Children with disabilities in the United States and the COVID-19 pandemic. *J Pediatr Rehabil Med*. 2020;13(3):415-24. doi: <https://doi.org/10.3233/PRM-200769>
23. Bettger JP, Thoumi A, Markevich V, Groote W, Battistella LR, Imamura M, et al. COVID-19: maintaining essential rehabilitation services across the care continuum. *BMJ Global Health*. 2020;5(5):e002670. doi: <http://doi.org/10.1136/bmjgh-2020-002670>
24. Savassi LCM, Reis GVL, Dias MB, Vilela LO, Ribeiro MTAM, Zachi MLR, et al. Recommendations for Home Care in COVID-19 pandemic period: joint recommendations - SBMFC Home Care Working Group and ABRASAD. *Rev Bras Med Fam Comunidade*. 2020;15(42):2611. doi: [https://doi.org/10.5712/rbmf15\(42\)2611](https://doi.org/10.5712/rbmf15(42)2611)

25. Brooks SK, Webster RK, Smith LE, Woodland L, Wessely S, Greenberg N, et al. The psychological impact of quarantine and how to reduce it: rapid review of the evidence. *Lancet*. 2020; 395(10227):912-20. doi: [https://dx.doi.org/10.1016/S0140-6736\(20\)30460-8](https://dx.doi.org/10.1016/S0140-6736(20)30460-8)
26. Givigi RCN, Silva RS, Menezes EC, Santana JRS, Teixeira CMP. Efeitos do isolamento na pandemia por COVID-19 no comportamento de crianças e adolescentes com autismo. *Rev Latino-am Psicopatol Fundam*. 2021;24(3):618-40. doi: <https://doi.org/10.1590/1415-4714.2021v24n3p618.8>
27. Barnejee T, Khan A, Kesavan P. Impact of lockdown and school closure on children in special schools: a single-centre survey. *BMJ Paediatr Open*. 2021;5(1):e000981. doi: <https://doi.org/10.1136/bmjpo-2020-000981>
28. Van Lancker W, Parolin Z. COVID-19, school closures, and child poverty: a social crisis in the making. *Lancet Public Health*. 2020;5(5):e243-e244. doi: [https://dx.doi.org/10.1016/S2468-2667\(20\)30084-0](https://dx.doi.org/10.1016/S2468-2667(20)30084-0)
29. Berron GC, Laryea-Adjei G, Vike-Freiberga V, Abubakar I, Dakkak H, Devakumar D, et al. Safeguarding people living in vulnerable conditions in the COVID-19 era through universal health coverage and social protection. *Lancet Public Health*. 2022;7(1):e88-92. doi: [https://doi.org/10.1016/S2468-2667\(21\)00235-8](https://doi.org/10.1016/S2468-2667(21)00235-8)
30. Eshraghi AA, Li C, Alessandri M, Messinger DS, Eshraghi RS, Mittal R, et al. COVID-19: overcoming the challenges faced by individuals with autism and their families. *Lancet Psychiatry*. 2020;7(6):481-3. doi: [https://doi.org/10.1016/S2215-0366\(20\)30197-8](https://doi.org/10.1016/S2215-0366(20)30197-8)



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