# Lived Experiences and Support for People with Disabilities in the Pandemic World: An Interpretative Phenomenological Analysis in Brazil

## Experiências Vividas e Apoios para Pessoas com Deficiência no Mundo Pandêmico: Uma Análise Fenomenológica Interpretativa no Brasil

## Experiencias Vividas y Apoyos para Personas con Discapacidad en el Mundo Pandémico: Un Análisis Fenomenológico Interpretativo en Brasil

**RESUMO**

**Introdução**: A pandemia da COVID-19 causou mudanças abruptas, como a interrupção dos serviços de saúde e escolares. Entre os mais afetados estão as pessoas com deficiência, pois elas precisam constantemente e dependem de apoio especializado em saúde e educação. O apoio comunitário oferecido às pessoas com deficiência é fundamental para lidar melhor com situações adversas, como a pandemia. **Objetivo:** Assim, o objetivo deste estudo foi descrever qualitativamente a experiência da pandemia a partir da perspectiva das pessoas com deficiência e daqueles que as apoiam pessoal ou profissionalmente, bem como identificar o apoio comunitário oferecido às pessoas com deficiência no Brasil neste momento. **Método:** Os dados foram coletados por meio de entrevistas semiestruturadas com 27 participantes, sendo 23 mulheres e 4 homens; 8 das mulheres eram mães. A faixa etária variou entre 18 e 64 anos. Realizamos uma análise construtivista com abordagem descritiva, utilizando seis fases da análise fenomenológica interpretativa. **Resultados:** Entre aqueles que apoiavam pessoas com deficiência, foram frequentemente relatados impactos na saúde, tais como acesso a recursos de saúde, problemas mentais que surgiram devido à pandemia e perda de habilidades físicas nas atividades diárias. Em relação ao tipo de apoio recebido durante o período, cada participante relatou pelo menos uma fonte de apoio, principalmente psicológica e financeira. **Conclusão:** Em conclusão, emergiram aspectos importantes do apoio a indivíduos com deficiência durante a pandemia, alguns positivos e outros negativos, servindo como orientação para melhorar as políticas públicas para essa população.

**DESCRITORES:** pesquisa qualitativa, COVID-19, pessoas com deficiência, política.

**ABSTRACT**

**Introduction:** The COVID-19 pandemic caused abrupt changes, including the disruption of health and educational services. Among the most impacted groups are people with disabilities who continuously require specialized support in the areas of health and education. Community support is fundamental for this population when coping with adverse situations, such as the pandemic. **Objectives:** The objectives of this study were to qualitatively describe the experience of the pandemic from the perspective of people with disabilities and those who support them personally or professionally, as well as to identify the types of community support offered to this population in Brazil during this period. **Methods:** The interpretive phenomenological analysis (IPA) with six phases was used to understand how participants made sense of their experiences during the pandemic. Data were collected through semi-structured interviews with 27 participants, 23 women and 4 men, among whom 8 were mothers. The age ranged between 18 and 64 years. **Results:** Those who supported people with disabilities frequently reported the observed impacts on health: difficulties in accessing health resources, mental health problems resulting from the pandemic, and loss of physical skills in activities of daily living. Regarding the type of support received during the pandemic, each participant reported at least one source of support, predominantly of a psychological and financial nature. **Conclusion:** Positive and negative aspects of surviving the pandemic that emerged in our study can add to the broader understanding and guidance of the improvement of public policies aimed at this population.

**DESCRIPTORS:** qualitative research, COVID-19, people with disabilities, policy.

**RESUMEN**

**Introducción:** La pandemia de COVID-19 provocó cambios abruptos, como la interrupción de los servicios de salud

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y educativos. Entre los más afectados se encuentran las personas con discapacidad, ya que necesitan constantemente y dependen de apoyo especializado en salud y educación. El apoyo comunitario ofrecido a las personas con discapacidad es fundamental para afrontar mejor situaciones adversas, como la pandemia. **Objetivo:** Así, el objetivo de este estudio fue describir cualitativamente la experiencia de la pandemia desde la perspectiva de las personas con discapacidad y de quienes las apoyan personal o profesionalmente, así como identificar el apoyo comunitario ofrecido a esta población en Brasil en este momento. **Método:** Los datos se recolectaron mediante entrevistas semiestructuradas con 27 participantes, siendo 23 mujeres y 4 hombres; 8 de las mujeres eran madres. La edad osciló entre 18 y 64 años. Se realizó un análisis constructivista con enfoque descriptivo, utilizando seis fases del análisis fenomenológico interpretativo. **Resultados:** Entre quienes apoyaban a personas con discapacidad, se reportaron frecuentemente impactos en la salud, como dificultades de acceso a recursos de salud, problemas de salud mental derivados de la pandemia y pérdida de habilidades físicas en las actividades diarias. En cuanto al tipo de apoyo recibido durante el período, cada participante informó al menos una fuente de apoyo, principalmente de carácter psicológico y financiero. **Conclusión:** En conclusión, emergieron aspectos importantes del apoyo a las personas con discapacidad durante la pandemia, tanto positivos como negativos, que sirven como orientación para mejorar las políticas públicas dirigidas a esta población

**DESCRIPTORES:** investigación cualitativa, COVID-19, personas con discapacidad, política.

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## INTRODUCTION

The COVID-19 Pandemic brought profound impacts to society on a global scale. Many lives were lost[1], with a lot of sequelae of the disease [2], and eve+n after more than 2 years of its onset, its effects still remain. In this context, the population of people with disabilities needs to be highlighted, since they suffered devastating consequences[3]. Among these consequences were the absence of face-to-face therapies and increased barriers in accessing healthcare that resulted from the necessary social distancing[4].

Many challenges arose together with the needs of people with disabilities and their families to better cope with the pandemic situation. Adaptations in remote health[5,6] and education strategies[7,8] played important roles. Similarly, the relevance of community support for people with disabilities as an important facilitator for maintaining their functioning has been highlighted[10].

People with disabilities have specific needs that are essential to their quality of life, well-being and participation.

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Among them, access to health services entailing periodic medical consultations with specialists, and therapies, such as physiotherapy, speech therapy and occupational therapy[11,12]. In case a person attends school, individual monitoring is necessary, with activities and teaching strategies adapted to their particularities[13]. However, with the pandemic, this scenario changed, and much - or almost everything - was absent for a prolonged period of time[14].

Previous studies highlight the importance of social support for quality of life and well-being[15]. Thus, community support is of great significance for better coping with the pandemic situation for the population with disability[13,16,17] by helping to achieve more positive results while living through the pandemic.

Given the importance of community support, Canadian researchers from CanChild - Centre for Childhood-onset Disability Research developed and administered a survey called “COVID-19 supports for people with disabilities and caregivers” to identify types of the community support received by them during the pandemic in several countries around the world through a standardized questionnaire[13]. To further understand the lived experience of people with disabilities during the pandemic in Brazil, the study team carried out a qualitative study presented in this paper.

This research follows the biopsychosocial approach indicated in the International Classification of Functioning, Disability and Health (ICF), proposed by the World Health Organization in 2001[18]. Based on this approach, the functioning of individuals with a health condition is determined by the multidirectional relationship between aspects of body structures and functions, activity and participation and contextual factors that include personal and environmental factors. Environmental factors have the potential to be a facilitator or a barrier to the functioning of individuals, and their role deserves to be explored during the COVID-19 pandemic. Therefore, this study conceptually is similar to perspectives espoused by community-centered care[19].

The study aimed to understand 1) what the experience of the pandemic was like for people with disabilities and those who support them in Brazil, and 2) how and what support was offered to them at this time? We expected to understand the experiences of living through a pandemic, as well as to identify which community support was available or not from the perspective of individuals with disabilities and perspectives of those who supported them personally and professionally. Thus, this study will provide unprecedented insight from this country and may assist in targeted and effective public actions to benefit individuals with disabilities during pandemics and beyond.

## METHODS

### Study design

This study was informed by an interpretative phenomenological analysis (IPA), which is a qualitative research approach that focuses on the examination of how people make sense of important life experiences[20]. As a qualitative approach, IPA aligns with the experiential nature of our study that sought to understand how people make sense of what happens to them, and in so doing, allows the researchers to apply their interpersonal and subjectivity skills and understanding to their research processes. IPA is ‘participant-oriented’ and explores the essence of "lived experiences" of interviewees as they express themselves in the way they see fit[21].

This qualitative study was envisioned by BHB (the first author), a PhD student at Federal University of São Carlos. BHB is a physiotherapist, and a sibling of a youth with Down syndrome. She is a member of an association of family members of people with Down syndrome in her hometown, and her thesis research focused on participation in the home of children and adolescents with Down syndrome before and during the pandemic period. Her research theme was delineated from her experience and her interest in the wellbeing of people with Down syndrome and other disabilities.

### Participants and recruitment

We used purposive sampling. The sample was obtained from the selection of participants in the initial survey (part 1). In part 1, participants were asked if they would like to participate in the second part. If so, they were invited to provide their name and telephone number or email address. From there, the researchers contacted the participants to schedule an interview. A semi-structured interview method was used to obtain information about the moment of the pandemic, using standardized questions (Appendix 1).

The inclusion criteria were based on those from the initial survey: the participants had to be over 18 years old; be a person with disability or have some relationship with a person with disability, personal or professional; residing in Brazil and being able to virtually complete the Consent Form and participate in an interview over Zoom. Therefore, the sample size was determined by the interest shown by the participants in part 1.

Before starting the interviews, the participants provided a verbal consent to participate and to the recording of the interview. Data collection took place between November and December 2020.

Out of 105 participants who completed a questionnaire (part 1), 37 participants expressed interest in participating in the qualitative study (part 2).

Figure 1 illustrates the flowchart of participants. The researchers contacted all of them but were able to schedule interviews with 27 participants.

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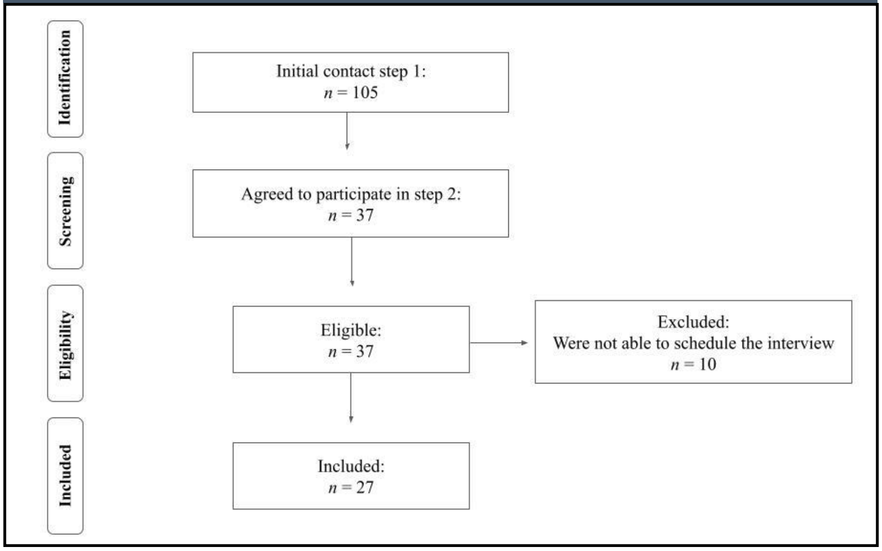
**Figure 1. Flowchart of participants**



Legend: n= number of participants.

## Procedures

The study was approved by the local ethics committee (#34904720.3.0000.5504). After completing the Consent Form, data were collected on the respondent as part 1 (age in completed years), gender (female, male, non-binary), perspective while responding to in relation to person with disability (what is the relationship with person with disability), area of residence (rural, urban, suburban), state of Brazil, as well as data on the person with disability (age in completed years) and gender (female, male, non-binary).

The researchers contacted the participants who expressed interest in participating in part 2 and scheduled the interview according to the participant's availability. Participants participated in a semi-structured interview, lasting approximately 1 hour, through a video conferencing platform Zoom®. The researcher conducted an individual interview with each participant asking 5 open-ended questions, in order to encourage participants to elaborate on the topic of interest. The questions were related to (1) experiences in taking care of themselves or others during the pandemic, (2) problems and challenges they faced, (3) needs and support received during the pandemic, (4) thoughts about the future, (5) ideas on how these needs can be better met by health managers. B.H.B conducted all interviews in order to maintain consistency. Only the researcher and participants individually were present during the interviews. The interviews were recorded and transcribed into text files, which were cross-checked with the audio recording transcriptions for accuracy and rigor. All data were kept confidential and all procedures strictly followed the rules of the local ethics committee regarding data collection and storage.

## Data analysis

**Data analysis followed the procedures of “Qualitative Handling Data: A Practical Guide”[22].**

The approach adopted was constructivist, assuming reality is subjective and varied, and is consistent with the Interpretative phenomenological analysis (IPA). In this context, an inductive thematic analysis was used to explore the experience of living through a pandemic as well as the community support during the pandemic consistent with the analysis process outlined by Braun and Clarke[23,24].

Several strategies were used to ensure rigor. Firstly, we followed six phases[24,25] illustrated in Table 1. Second, the positioning of the researcher who carried out the interviews was well described and explained. Third, as some of the participants knew the researcher previously, some measures were taken to minimize this bias, such as following the questions in the semi-structured interview and the researcher did not make comments about common topics, leaving only the participant to report what they would like. These measures helped to minimize the influence of this prior relationship in the analysis.

To minimize a possible loss of meanings during translation[26], all analyses were performed in the researchers' native language (Brazilian Portuguese), and only after completion where they were translated into English for writing the article. The co-authors discussed the findings at the various stages, in order to obtain a better understanding of the themes and subthemes.

We used the software Dedoose[27,28], a qualitative research software that allows the review of the codes extracted by the team. This tool facilitates the coding and data analysis organization.

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**Table 1: Phases of the thematic data analysis**

| Phase | Activities performed |
|---|---|
| 01: Familiarization with the data | Reading and re-reading the transcripts to familiarize with the data. |
| 02: Generating initial codes | Coding of data obtained related to open-ended questions performed.<br>Codes reviewed by senior researchers. |
| 03: Searching for themes | Review of codes and grouping into related themes and subthemes. |
| 04: Reviewing potential theme | Senior researcher revised the themes and subthemes. |
| 05: Defining and naming themes | Definition and naming of themes and subtopics. |
| 06: Producing the report | Production of the report and manuscript. |

## RESULTS

### Description of Participants

The majority of participants were female, aged between 35-44, residing in urban area and being a father/mother to a person with a disability as the most common relation registered. Table 2 shows the participants' demographics. Table 3 shows the frequency and percentage of demographic characteristic samples.

**Table 2: Participants demographics**

| Participant ID | Age range | Sex | relation to person with disability | Area of residence | State of Brazil | person with disability, age range | person with disability, sex |
|---|---|---|---|---|---|---|---|
| 1 | 45-54 | female | mother | urban | SP | 13-18 | male |
| 2 | 35-44 | female | therapist | urban | SP | 0-6 | non-binary |
| 3 | 25-34 | female | person with disability | urban | SP | 25-65 | female |
| 4 | 35-44 | female | mother | urban | RJ | 7-12 | male |
| 5 | 35-44 | female | teacher | urban | SP | 13-18 | non-binary |
| 6 | 45-54 | female | mother | urban | SC | 0-6 | female |
| 7 | 45-54 | male | person with disability | urban | SP | 25-65 | male |
| 8 | 35-44 | female | therapist | urban | SP | 0-6 | non-binary |
| 9 | 25-34 | female | mother | urban | SC | 0-6 | male |
| 10 | 35-44 | female | mother | urban | SP | 0-6 | male |
| 11 | 18-24 | female | researcher | urban | SP | 0-6 | non-binary |
| 12 | 35-44 | female | mother | urban | SP | 0-6 | female |
| 13 | 35-44 | female | pediatrician | urban | BA | 0-6 | non-binary |
| 14 | 25-34 | female | researcher | urban | SP | 0-6 | female |
| 15 | 55-64 | female | sister | urban | RN | 25-65 | male |
| 16 | 45-54 | female | mother | urban | SP | 13-18 | female |
| 17 | 18-24 | female | therapist | urban | SP | 25-65 | male |
| 18 | 25-34 | female | therapist | urban | SP | ≥ 65 | non-binary |
| 19 | 35-44 | female | mother | urban | PR | 7-12 | female |
| 20 | 35-44 | female | teacher | urban | SP | 13-18 | male |
| 21 | 18-24 | male | person with disability | urban | SP | 13-18 | male |
| 22 | 25-34 | female | therapist | urban | SP | ≥ 65 | male |
| 23 | 55-64 | female | therapist | urban | SP | 25-65 | male |
| 24 | 25-34 | female | researcher | urban | SP | 0-6 | non-binary |
| 25 | 35-44 | male | father | urban | RN | ≥ 65 | male |

| | | | | | | | |
|---|---|---|---|---|---|---|---|
| 26 | 35-44 | male | person with disability | urban | MG | 25-65 | male |
| 27 | 55-64 | female | teacher | rural | SP | 7-12 | non-binary |

Legend: SP= São Paulo; RJ= Rio de Janeiro; SC= Santa Catarina; BA= Bahia; RN= Rio Grande do Norte; PR= Paraná; MG= Minas Gerais.

**Table 3: Demographic characteristic of the sample by frequency and percentage**

| Demographic characteristic | Frequency (n) | Percentage (%) |
|---|---|---|
| Age range | | |
| 18-24 | 3 | 11.1% |
| 25-34 | 6 | 22.22% |
| 35-44 | 11 | 40.8% |
| 45-54 | 4 | 14.8% |
| 55-64 | 3 | 11.1% |
| ≥ 65 | 0 | 0% |
| Sex | | |
| Male | 4 | 14.8 |
| Female | 23 | 85.2 |
| Relation to person with disability | | |
| Father/mother | 9 | 33.4 |
| Therapist | 6 | 22.2 |
| Person with disability | 4 | 14.8 |
| Teacher | 3 | 11.1 |
| Researcher | 3 | 11.1 |
| Pediatrician | 1 | 3.7 |
| Sister | 1 | 3.7 |
| Area of residence | | |
| Rural | 1 | 3.7 |
| Urban | 26 | 96.3 |
| State of Brazil | | |
| SP | 19 | 70.4 |
| RJ | 1 | 3.7 |
| SC | 2 | 7.4 |
| BA | 1 | 3.7 |
| RN | 2 | 7.4 |
| PR | 1 | 3.7 |
| MG | 1 | 3.7 |
| Age, person with disability (age range) | | |
| 0-6 | 10 | 37.1 |
| 7-12 | 3 | 11.1 |
| 13-18 | 5 | 18.5 |
| 19-24 | 0 | 0 |
| 25-65 | 6 | 22.2 |
| ≥ 65 | 3 | 11.1 |

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| Sex, person with disability | Frequency (n) | Percentage (%) |
|---|---|---|
| Female | 6 | 22.3 |
| Male | 13 | 48.1 |
| Non-binary | 8 | 29.6 |

Legend: n = number of participants; SP= São Paulo; RJ= Rio de Janeiro; SC= Santa Catarina; BA= Bahia; RN= Rio Grande do Norte; PR= Paraná; MG= Minas Gerais.

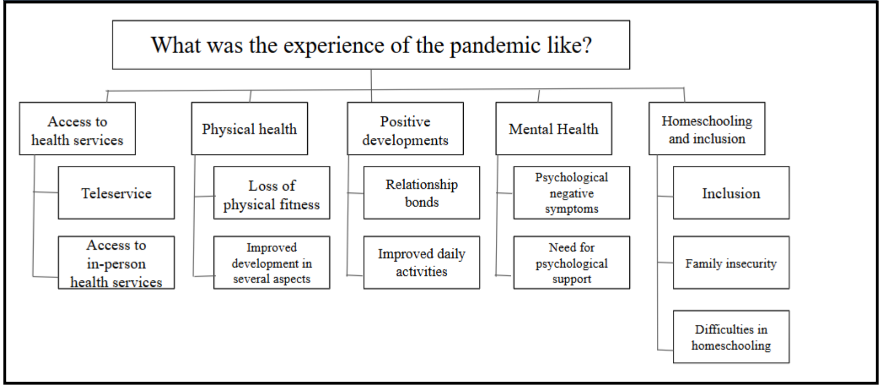
**Table 4: Sources of support**

| Support | Supporting quotes |
|---|---|
| Rehabilitation center | *“if you find it difficult to do any exercise, anything or have any difficulties, I contact the physiotherapist and she tells me what to do” (P-12, mother)*<br>*“I always turn to the team. So, they have very good support, the school does not give this support, like in society I don't know who to appeal to, but thanks to the association we have here they give you all this support”. (P-6, mother)* |
| School and university | *“The families, we call them and ask, ‘Look, do you need a prescription? Are you ill? Are you okay?’, and I gave them this opening, right? Anything that happened, they could contact me and I would pass it to the assistant, to the coordinator, and then we would reach a consensus to be able to solve it.” (P-20, teacher)*<br>*“There is the SAADE (General Secretariat for Affirmative Action, Diversity and Equity) site, which is the student assistance service. So, we found the psychologist there.” (P-7, person with disability)* |
| Community | *“Even in the health area, if we get sick, there are 2 or 3 apartments next door and we can ask for help. I think everyone here would help” (P-7, person with disability)* |
| Work | *“But it is one teacher helping another all the time.” (P-5, teacher)*<br>*“We do have technical support. Whenever they have any difficulties, we have a sector they can go to” (P-13, pediatrician)* |
| Family | *“Look, I hear them say that they ask for help for cousins, uncles... they ask for help for those around them, those close to them?” (P-27, teacher)*<br>*“In the case of the family itself, without any assistance, without any prospect of care. We have to take care of each other.” (P-25, father)* |
| Some healthcare professionals indicated lack of support from their hospital: | *“But emotional and psychological support, no. Not from the hospital. It is our preparation ...” (P-13, pediatrician)* |

## Results: Themes and subthemes

Participants offered a wide range of insights that are organized into three themes: Pandemic experience, Supports, and Messages for healthcare leadership. Figure 2 presents a thematic tree for the first theme, as the most elaborate one.

**Figure 2. Theme tree – Pandemic experience**



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### Theme 1: What was the experience of the pandemic like?

Participants described various facets of the pandemic experience: difficulties when accessing health services and medicines; the perceived loss of physical fitness and activity levels and yet some positive improvements. Some described the experience of the pandemic as a distressing moment for caregivers and for those with disabilities impacting their mental health. Some chose to focus on challenges with lacking supportive and inclusive education.

### Subtheme 1: Access to health services

The participants identified difficulties in accessing in-person health services. For example, one person shared:

*"I need an orthopedist (...), you can not get an orthopedist, because where is everyone located during the Coronavirus?" (P-26, person with disability)*

Some parents reported that the difficulty worsened compared to challenges before the pandemic:

"So, it only got worse. It is gotten much worse, much worse, because whether we like it or not, when there was no pandemic, we were able to get around, we were able to get around" (P-25, father/mother)

Some participants using telehealth care commented regarding the difficulties encountered:

"It is just that it is a very bureaucratic matter to install a new system in such a large institution, is it not? (...)but I understand that it is a new situation, that it is a situation that nobody knows how to deal with" (P-18, therapist)

Healthcare professionals agreed with people with disabilities and their families when they described challenges encountered using telehealth, as they showed their understanding of the difficulty for the caregiver of the disabled person:

"There are mothers who have other children and they say the demand is too great. They have to talk to us, do what we're asking, give us attention ... and they say that they know that if we are doing the video call, we are going to do an orientation, so there will be even more to do, right?" (P-8, therapist)

In addition, there were reports of challenges associated with accessing medications.

### Subtheme 2: Physical health

Some participants reported a loss of physical fitness for the disabled person and the related drop in physical activity levels:

*"I think I have noticed a loss of physical fitness, resistance to exercise, tolerance to activity in patients?" (P-18, therapist)*

*"When will these patients be comfortable enough to actually go outside again and practice what we advise them to do? Exploring the community, walking with a cane in the street?" (P-18, therapist)*

Family members concurred when describing difficulties in performing everyday motor activities:

*"I found it harder for him to get out of bed, I found it harder for him to lie down in a hammock, to get out of a hammock(...), we even talked, maybe it was also the lack of physiotherapy." (P-15, sister)*

### Subtheme 3: Positive developments

These challenges notwithstanding, both parents and therapists reported some positive improvements in the development in various aspects, such as speech and gait:

"[Child's Name] could barely speak and he started to say a lot of new words" (P-9, mother)

"She has developed spectacularly during this period! In terms of speech, because she always has to speak, express herself[M3] ... and so, for me it is also been a learning experience with her" (P-6, mother)

This mother clearly articulated how the time spent with her child building a trusting relationship helped her daughter develop her walking skills:

"The pandemic began in March and [Child's name] started walking in June. So, I think she needed spend more time with me, her mother, that she trusts, so she can have the security to start her walking" (P-12, mother)

Some therapists reported that they were able to focus more on activities of daily living during the pandemic.

### Subtheme 4: Mental health

Quite a few participants reported negative psychological symptoms regardless of their role and ability. Quotes below capture the range of mental health issues:

"It is distressing for me! You are isolated. I have colleagues who have anxiety attacks, who have already been treated for anxiety and now with Covid it has gotten worse. Students also have this issue of some parents complaining about anxiety, about not being able to cope, about the child being different" (P-5, teacher)

"But even me in this pandemic, in the psychological area, I had a downturn." (P-7, person with disability)

"Then, during this period, there was anxiety, there was anger, there was sadness, discouragement ...a little bit of each emotion, each feeling came out, right? ?A lot of anxiety at first, right?" (P-23, therapist)

"I have seen that she has become a little more aggressive, a lot more nervous." (P-19, mother)

"Ah, this moment has really messed my anxiety, has it not? As I said at the beginning, I was already very anxious because of the competitions and the training, and now I am getting more anxious, wanting it to be over soon so I can get back to my normal routine,

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right??" (P-21, person with disability)

Parents and healthcare professionals agreed about the need for psychological support:

"I think the support is more… more… how can I use the word "psychologically"speaking, I did miss it a little. Because it was a shock, something that has not ended yet and sometimes we still can not organize our 'head'." (P-9, mother)

"Every family needs psychological support; there are times when we have a shock. I try to bring him along in everything, I try to do my best and it is exhausting (…)" (P-10, mother)

"I think that, focusing on my family and the institution, this part of psychology was very important. Very important! Because it was a new situation, the child was totally out of their routine - child, young person or adult, they were totally out of their routine - they no longer saw their friends and they have a great affection for the whole therapy team" (P-20, teacher)

### Subtheme 5: Homeschooling and Inclusion

Regarding education during the pandemic, the participants reported insecurity on the part of their families in terms of being able to perform the activities proposed by the school at home:

"[Parents said to me:] Will I succeed? Will I not succeed?" (P-20, teacher)

"I think that the most difficult thing for parents is to follow these children pedagogically, because this is a habit that has been lost over the last few years of mothers homeschooling their children" (P-27, teacher)

Teachers reported the lack of family engagement when homeschooling:

"And when we do not receive [the completed homework from families], we have to follow up on the delivery, because it is as if it is missing: If I do not have the material of this student then it means that is missing". (P-5, teacher)

Some parents emphasized the need for inclusion and adaptation to their child's individual needs that apparently became more pronounced during the pandemic when they were involved and could witness the process:

"For inclusion even. (…)Every child is unique! And now, especially when it comes to inclusion, it is a different look, a look with affection, knowing that they need more individualized attention (…)" (P-19, mother)

"One example is adapting the proposed activities, which does not mean he will not learn, he will learn a little more slowly, more slowly than the other children, so I think one of the needs would be this, the adaptation". (P-9, mother)

## Theme 2: What were supports like during the pandemic?

### *Subtheme 1: Source of support*

Participants identified various sources of support during the pandemic, including rehabilitation center, school, university, work, and family. Table 4 presents sources of support with related quotes.

### Subtheme 2: Type of support

Participants also identified two major types of support: psychological and financial.

*Psychological*

Some parents resorted to therapy during the challenging time:

"Nowadays, I started therapy during the pandemic even to help me cope during this period" (P-4, mother)

A therapist described the nature of the support they offered, noting the *initial* intensity of the demands:

"I provided all the support online. I have been doing online support for seven months now (…) it is more of a conversation, it is not therapy, it is a welcome and support for the moment of greatest difficulty. In the beginning, the demands were much stronger, right? Today it is more certain." (P-23, therapist)

"Psychologists talk a lot about anxiety, about depression, about accepting yourself at this time, right?" (P-20, teacher)

Financial

"We put together food parcels… So those families that we know have been through and are going through more needs, they received and are still receiving this help." (P-20, teacher)

"Aid from the athlete scholarship that helps us" (P-21, person with disability)

## Theme 3: Messages for healthcare leadership

The participants shared messages to the health managers in their country, suggesting priorities that ranged from healthcare to inclusion in schools.

### Primary care and public health

"So, I think we have to prioritize primary care" (P-13, pediatrician)

"This situation we are experiencing (pandemic) makes us think about the needs of the public health system, especially in primary care". (P-23, therapist)

### Telehealth

"I think it is necessary to strengthen policies aimed at access to remote care technologies, since we have no idea how long it will last, right? And not even if we are going to live with it in the long term" (P-13, pediatrician)

"I would stay in telemedicine (…). I can see benefits that extend beyond the pandemic period, you know?" (P-18, therapist)

### Equitable access to therapies

"What we need are therapies (…). So, it is the obligation of the government to offer this so that there is not this discrepancy between the child

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who was born into a rich family and the child who was born into a poor family, right?" (P-1, mother)

"It needs to be made available in the public health system, in the SUS (Unified Health System), targeted care, care with a psychologist, family groups, right?" (P-20, teacher)

### Consistent and reliable health information

*"I think the first is for the health manager, for example, to have control not only of the children. I think this is done, but I think that now we see so many patients lost in the system who don't have any information about what they can do (...)" (P-4, mother)*

*"I would talk precisely about this passing on of information about Covid, because I, for example, am an undergraduate student and I know what reliable information, I know where to look for this kind of information. It is just that people like, for example, my parents, some relatives, they just accept what is shown on television, which is often unreliable. Or what a friend has told them, right? So, I think bringing in public policies, right??" (P-11, researcher)*

### Addressing mental health needs of the population

*"For the mental health of the people. I think that is something that has been affected a lot in this pandemic and that people are not taking into consideration". (P-5, teacher)*

*"Psychiatric care, because people need it a lot!" (P-20, teacher)*

### Promoting school inclusion

"Inclusion in schools has to be worked better, right?" (P-1, mother)

"I would like everyone to pay attention to special education itself, because I have been working in this area for a long time and it is always pushed to the back, there are always other priorities, you know??" (P-27, teacher)

"They could use the school as a support, build a bridge, since the school is in the neighborhood, and have more effective inclusion". (P-10, mother)

## DISCUSSION

This qualitative study sought to understand the experience of the COVID-19 pandemic and the community support offered to people with disability from their perspectives. Our findings include three themes and subthemes that emerged from the interviews, providing important insights on what it was like to live with disability during the pandemic, what supports were afforded, and what suggestions were offered for healthcare professionals. First, it was apparent that the pandemic experience was very stressful for many participants who identified ways the disrupted access to healthcare and education impacted their lives, with the impact on physical and mental health given special attention. While there were some reports of the silver lining of the pandemic parenting experience and regained focus on daily living, it was clear that disability magnified various adversities during the pandemic. Another pre-pandemic study has shown that personal factors with disability among them are related to vulnerability and marginalization[29]. Second, participants identified important sources of support such as rehabilitation centers in addition to their families, school and work communities, with psychological and financial types of support as the main ones. Finally, based on their lived experience, participants were able to offer a wide range of suggestions for health managers, which included prioritizing primary care, strengthening telemedicine, making therapies more accessible and equitable, providing reliable information to the public, focusing on mental health, and supporting more effective inclusion in schools.

When the population affected by disability is asked about access to health services in Brazil, we see that the issues reported refer to teleservices, access to in-person health services and basic resources. We observed that during the pandemic, health demands persisted, and this prompted the sudden need to have reliable telehealth care, to meet the necessities of the population during this period. However, bureaucracy seems to have been a barrier, which slowed down the implementation and execution of teleservices. Furthermore, telecare services that require actions from caregivers, for example, during teletherapy, overload caregivers and several issues may be implicit, such as difficulty for caregivers in carrying out activities with people with disabilities at home. In addition, caregivers' fear of harming or hurting people with disabilities, and the idea, still persistent, that only therapists and their techniques can help people with disabilities.

It was clear that many health needs continued to require in-person services, with the great demands specific to COVID-19, other essential services were hampered: highly complex exams and administrative actions, such as issuing reports for disability retirement, and renewals of government aid for people with disabilities. The necessary resources such as medicines and specific guidance were reported to be difficult to access.

The findings about physical health revealed that individuals with disabilities experienced some loss of physical fitness, a drop in the level of physical activity and difficulties in carrying out daily motor activities. Other researchers observed that the mandatory need for social distancing was sometimes exacerbated for people with disabilities due to their particularities and needs, and made them cloistered in their homes, with

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a reduced level of physical activity [30,31] and scarcity or absence of therapies[30]. The limitation of physical activity and reduction in daily activities resulted in a loss of physical conditioning, sometimes associated with a reduction in the level of physical activity[31]. As a result, many people with disabilities reported more difficulties in carrying out daily activities, which generates a cycle of loss of physical fitness-reduction in the level of physical activity and reduction in daily activities. On the other hand, positive aspects were reported, such as improved speech, acquisition of gait and improvement in skills involved in activities of daily living. Due to the need to stay at home, many of the people with disabilities were able to use this time to develop skills, without the rush of everyday life that they usually have.

The findings about mental health suggested negative psychological aspects and the need for psychological support. Several studies have reported emotional difficulties, stress and depression in different populations, including people with disabilities[30] and family members of people with disabilities[32]. Unsurprisingly, one of the messages to health leaders focused on addressing mental health issues for those affected by disability, the emerging understanding in the pre-pandemic world [33, 34].

Education was a topic frequently raised by participants during the interviews and also made on the list of recommendations for healthcare professionals. Difficulties in adapting to the new remote teaching format generated a significant burden on people with disabilities, family members, caregivers and teachers, which may have added to the negative psychological impact on one's overall functioning. Both families and teachers agreed on how the lack of support generated family insecurity in carrying out activities at home and lack of adherence. The same would apply to adherence to therapeutic recommendations, which is a known challenge recognized by researchers and therapists. These findings suggest the need for psychological and financial support to function effectively with this new teaching modality, routine and adaptations, while exposing inequities and inaccessibility of education to those with disabilities especially during the pandemic. The findings also reveal and underscore the nexus among education, health and well-being.

This study illustrates a very strong need for diverse and multi-dimensional supports for individuals with disabilities, especially during the acute pandemic time. Among the important sources of support identified were institutions and rehabilitation centers that already had links with people with disabilities; the fate of others affected by disability is unknown. The importance of family and one's various communities, including schools and work, became particularly pronounced. While most participants reported receiving some support, it was clear that it was very limited and insufficient. Support was reported to be restricted to psychological and financial. Patients' reports suggest that general information and guidance, specific training and other types of support in need for this specific population with disabilities may not have been provided during COVID-19, and there were not any tools to assist relatives or extended family. Some participants reported receiving no support, thus illustrating the exacerbated vulnerability of individuals with disability or their support teams, especially during such critical societal upheavals as pandemics. The messages for healthcare managers from participants offer important lessons and recommendations for supported, equitable, inclusive and accessible lived experience during a pandemic and beyond.

In this study emerged the need for discussion in political and social agendas, so that changes can be made and encompass perspectives of the participants. For example, one can use the patient and public involvement matrix[35] as a strategy to involve stakeholders in a co-construction of public policies. Bringing a sense of belonging to public health processes for people with disabilities and their caregivers may result in more meaningful engagement and effective policies and may regain the public's trust and interest in reliable health information while offering a sense of empowerment.

## Limitations

This study has some limitations. First, considering the size of our sample, we cannot consider the sample as representative of the Brazilian population, but the qualitative information might provide insights about how people with disabilities experienced the COVID -19 pandemic in Brazil, and the support they received from the community. Second, this study occurred during the first year of the pandemic in Brazil, that means that after that, new challenges or advances could have occurred. Further studies should explore the after and the current experience and community support for this population in Brazil.

Third, we recognize that our sample had specific characteristics that make it difficult to generalize the results for all Brazilian populations. For example, the majority of our sample was female, in an age range of 18-64 years old. All of our sample lived in an urban area, except for 1 participant who lived in a rural area. Finally, we understand that the pandemic period in which the research was done could make people more sensitive and critical of the topic, influencing their thoughts during the interviews. On the other hand, this period may also have exacerbated feelings that could

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be "dormant" in this population before the pandemic. Thus, we reiterate the need for continuous research in relation to this topic in the country.

## CONCLUSION

Our study captured varied, yet often recurrent, themes and messages relevant to participants. The experience of the pandemic lived by people with disabilities and those who support them personally or professionally was complex in different aspects. Despite the government's measures to provide support for people with disabilities in Brazil during the pandemic, there were reports of adversities exacerbated by one's disability status.

On the other hand, there were also positive aspects, which suggest that it is possible to have community support for people with disabilities in Brazil, even in very uncertain situations such as the COVID-19 pandemic. This paper highlights the needs of not only people with disabilities , but also those who support them.

### Future Directions

For instance, it was noticed that some participants were reluctant to do any of the exercises or activities via telehealth sessions. This fact could be an indication of a significant dependence on the therapist and with that patients need to be more empowered in general to feel comfortable in doing these kinds of activities on their own. Therefore, we invite people with disabilities, their families, clinicians, therapists, politicians and the civil population to encourage discussions on this topic, aiming to develop public and social actions and policies that can be put into practice based on the needs reported.

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## REFERENCES

1. Hadj Hassine I. (2022). Vacinas contra a Covid-19 e variantes de preocupação: uma revisão. Reviews in medical virology, 32(4), e2313. https://doi.org/10.1002/rmv.2313

2. Ceban, F., Ling, S., Lui, L., Lee, Y., Gill, H., Teopiz, K. M., Rodrigues, N. B., Subramaniapillai, M., Di Vincenzo, J. D., Cao, B., Lin, K., Mansur, R. B., Ho, R. C., Rosenblat, J. D., Miskowiak, K. W., Vinberg, M., Maletic, V., & McIntyre, R. S. (2022). Fadiga e comprometimento cognitivo na síndrome pós-COVID-19: uma revisão sistemática e meta-análise. Brain, behavior, and immunity, 101, 93–135. https://doi.org/10.1016/j.bbi.2021.12.020

3. Park, J., Sung, C., Fisher, M. H., Okyere, C., & Kammes, R. R. (2022). Impactos psicossociais e vocacionais da COVID-19 em pessoas com e sem deficiência. Psicologia da reabilitação, 67(3), 381–390. https://doi.org/10.1037/rep0000420

4. Dimitriou, D., & Esposito, G. (2022). Gestão e apoio a pessoas com deficiências de desenvolvimento durante a pandemia de COVID-19. Research in developmental disabilities, 125, 104228. https://doi.org/10.1016/j.ridd.2022.104228

5. Hamadi, H. Y., Zhao, M., Haley, D. R., Dunn, A., Paryani, S., & Spaulding, A. (2022). Medicare e telessaúde: O impacto da pandemia de COVID-19. Journal of evaluation in clinical practice, 28(1), 43–48. https://doi.org/10.1111/jep.13634

6. Miller, M. J., Pak, S. S., Keller, D. R., & Barnes, D. E. (2021). Avaliação da implementação pragmática da fisioterapia por telessaúde durante a pandemia de COVID-19. Fisioterapia, 101(1), pzaa193. https://doi.org/10.1093/ptj/pzaa193

7. Mahapatra, A., & Sharma, P. (2021). Educação em tempos de pandemia de COVID-19: Estresse acadêmico e seu impacto psicossocial em crianças e adolescentes na Índia. Revista Internacional de Psiquiatria Social, 67(4), 397–399. https://doi.org/10.1177/0020764020961801

8. Klosky, J. V., Gazmararian, J. A., Casimir, O., & Blake, S. C. (2022). Efeitos da educação à distância durante a pandemia de COVID-19 na aprendizagem e no comportamento acadêmico de crianças pequenas na Geórgia: percepções de pais e administradores escolares. The Journal of school health, 92(7), 656–664. https://doi.org/10.1111/josh.13185

9. Hunt, X., Bradshaw, M., Vogel, S. L., Encalada, A. V., Eksteen, S., Schneider, M., Chunga, K., & Swartz, L. (2022). Apoio comunitário a pessoas com deficiência em países de baixa e média renda: uma revisão exploratória. Revista Internacional de Pesquisa Ambiental e Saúde Pública, 19(14), 8269. https://doi.org/10.3390/ijerph19148269

10. Novak, I., & Honan, I. (2019). Eficácia da terapia ocupacional pediátrica para crianças com deficiência: uma revisão sistemática. Revista australiana de terapia ocupacional, 66(3), 258–273. https://doi.org/10.1111/1440-1630.12573

11. Russell, C. J., & Simon, T. D. (2014). Cuidados a crianças com complexidade médica no ambiente hospitalar. Anais pediátricos, 43(7), e157–e162. https://doi.org/10.3928/00904481-20140619-09

12. Tannús-Valadão e Mendes, 2018: INCLUSÃO ESCOLAR E PLANEJAMENTO EDUCACIONAL INDIVIDUALIZADO: UM ESTUDO COMPARATIVO SOBRE PRÁTICAS DE PLANEJAMENTO EM DIFERENTES PAÍSES. Gabriela Tannús-Valadão e Enicéia Gonçalves Mendes. Revista Brasileira de Educação v. 23 e230076 2018

DOI: 10.36489/saudecoletiva.2026v17i107p19818-19843

13. Brugnaro, B. H., Vieira, F. N., Camargo, O. K. de, & Rocha, N. A. C. F. (2023). Qual foi o apoio comunitário oferecido às pessoas com deficiência durante a pandemia de COVID-19 no Brasil? Um estudo piloto como parte de uma pesquisa global. International Journal of Health Science, 3(32), 2–22. https://doi.org/10.22533/at.ed.1593322328045

14. Hassanein, E. E. A., Adawi, T. R., & Johnson, E. S. (2021). Apoio social, resiliência e qualidade de vida para famílias com crianças com deficiência intelectual. Pesquisa em deficiências do desenvolvimento, 112, 103910. https://doi.org/10.1016/j.ridd.2021.103910

15. Lapierre, N., Olatona, O., Labrie, D., Gagnon, M., Paquette Raynard, E., Mortenson, W. B., & Routhier, F. (2022). Prestação de serviços comunitários para pessoas com deficiência durante a pandemia de COVID-19: uma revisão exploratória. Saúde e assistência social na comunidade, 30(6), e3746–e3760. https://doi.org/10.1111/hsc.14050

16. Valderrama, A., Lajoie, X., Armstrong, M., Luizar-Obregon, A., & Kraus de Camargo, O. (2022). Perspectivas relatadas pelas próprias pessoas sobre a disponibilidade de apoio para pessoas com deficiência durante a pandemia de COVID-19 em Quebec. Canadian Journal of Public Health. https://doi.org/https://doi.org/10.17269/s41997-022-00671-3

17. OMS (2001). OMS; Organização Mundial da Saúde. [Acessado em 2 de dezembro de 2021]. Disponível em: http://www.who.int/classifcations/icf/en/

18. Nacoti, M., Ciocca, A., Giupponi, A., & Brambillasca, P. (2020). No epicentro da pandemia de Covid-19 e das crises humanitárias na Itália: Mudanças nas perspectivas sobre preparação e mitigação. NEJM Catalyst, 21 de março, 1–5. https://doi.org/10.1056/CAT.20.0080

19. Smith, J., Flowers, P., & Larkin, M. (2009). Análise fenomenológica interpretativa: Teoria, método e pesquisa. Sage.

20. Alase, A. (2017). A Análise Fenomenológica Interpretativa (IPA): Um guia para uma boa abordagem de pesquisa qualitativa. Revista Internacional de Estudos sobre Educação e Alfabetização, 5(2), 9. https://doi.org/10.7575/aiac.ijels.v.5n.2p.9

21. Lyn Richards. Livro: Tratamento de Dados Qualitativos: Um Guia Prático, segunda edição, SAGE, 2009

22. Braun, V., & Clarke, V. (2006). O uso da análise temática em psicologia. Pesquisa Qualitativa em Psicologia, 3(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

23. Braun, V., & Clarke, V. (2019). Reflexões sobre a análise temática reflexiva. Qualitative Research in Sport, Exercise, and Health, 11(4), 589–597. https://doi.org/10.1080/2159676X.2019.1628806

24. Byrne, D. Um exemplo prático da abordagem de Braun e Clarke à análise temática reflexiva. Qual Quant 56, 1391–1412 (2022). https://doi.org/10.1007/s11135-021-01182-y

25. Van Leeuwen K, Rousseau S, Hoppenbrouwers K, et al. Crianças pequenas, preocupações pequenas? Necessidades de apoio dos pais com bebês em relação às características dos pais, da criança e da família. Em: Onderzoek SB, editor. Leuven: SWVG, 2010

26. Dedoose. 2017. Versão 4.5, aplicativo web para gerenciar, analisar e apresentar dados de pesquisa qualitativa e de métodos mistos (2013). Los Angeles (CA): SocioCultural Research Consultants, LLC

27. Dedoose Versão 8.0.35, aplicativo web para gerenciar, analisar e apresentar dados de pesquisa qualitativa e de métodos mistos (2021). Los Angeles, CA: SocioCultural Research Consultants, LLC. https://

28. Potter, L., Zawadzki, M. J., Eccleston, C. P., Cook, J. E., Snipes, S. A., Sliwinski, M. J., & Smyth, J. M. (2019). As interseções de raça, gênero, idade e status socioeconômico: implicações para a denúncia de discriminação e atribuições à discriminação. Stigma and Health, 4(3), 264–281. Recuperado de https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6741774/

29. Jesus, T., Bhattacharjya, S., Papadimitriou, C., Bogdanova, Y., Bentley, J., Arango-Lasprilla, J., & Kamalakannan, S. (2021). Disparidades relacionadas ao lockdown vividas por pessoas com deficiência durante a primeira onda da pandemia de COVID-19: revisão exploratória com análise temática. International Journal of Environmental Research and Public Health, 18(12), 6178. https://doi.org/10.3390/ijerph18126178

30. Helena Santana Dalla Déa, V., Paulo Batista Dalla Déa, V., & Duarte, E. (2022). Atividade física, alimentação e distanciamento social de pessoas com síndrome de Down durante a pandemia da COVID-19. Pensar a Prática, 25(19806183). https://doi.org/10.5216/rpp.v25.69540

31. Navas, P., Verdugo, M. Á., Martínez, S., Amor, A. M., Crespo, M., & Deliu, M. M. (2021). Impacto da COVID-19 na carga de cuidados das famílias de pessoas com deficiências intelectuais e de desenvolvimento. Journal of Applied Research in Intellectual Disabilities, 35(2). https://doi.org/10.1111/jar.12969

32. Hanes, J. E., Hlyva, O., Rosenbaum, P., Freeman, M., Nguyen, T., Palisano, R. J., & Gorter, J. W. (2019). Além dos estereótipos da paralisia cerebral: explorando as experiências vividas por jovens canadenses. Criança: Cuidados, Saúde e Desenvolvimento, 45(5), 613–622. https://doi.org/10.1111/cch.12705

33. Cree, R. A., Okoro, C. A., Zack, M. M., & Carbone, E. (2020). Sofrimento mental frequente entre adultos, por situação de deficiência, tipo de deficiência e características selecionadas — Estados Unidos, 2018. MMWR. Relatório Semanal de Morbidade e Mortalidade, 69(36), 1238–1243. https://doi.org/10.15585/mmwr.mm6936a2

34. Jesus, C. C. A. F. et al. Tradução da ferramenta Matriz de Envolvimento para o português do Brasil. Fisioterapia em Movimento, 36, 2023. DOI: 10.1590/fm.2023.36130. Disponível em: https://www.scielo.br/j/fm/a/yJQfpYHrqdTM77dwdjHZ4ck/?lang=en.

DOI: 10.36489/saudecoletiva.2026v17i107p19818-19843