Repercussions of the COVID-19 pandemic on the health of women mothers of autistic children

Repercussões da pandemia de COVID-19 na saúde das mulheres mães de crianças autistas

Repercusiones de la pandemia de COVID-19 en la salud de las mujeres madres de niños autistas

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Abstract

Objective: to understand the repercussions of the COVID-19 pandemic on the health of women who are mothers of autistic children. Method: qualitative study, participant action type, based on the theoretical and methodological assumptions of Paulo Freire. A virtual Culture Circle was held in January 2021. Participants were 12 women mothers of autistic children, members of an association in southern Brazil. Data analysis occurred with the participation of all those involved in the Circle of Culture, according to Freire's Itinerary. Results: women reflected on their physical and mental health; their social role as a mother and wife; and the reconciliation of domestic activities with the formal education of the child. Feelings also emerged: tiredness, discouragement, depression and fear of contracting COVID-19. Conclusion: the pandemic had an impact on the burden of women mothers of autistic children with a decrease in time for self-care and the need to reschedule their work environments and domestic routine.

Descriptors: Women's Health; COVID-19; Autistic Disorder; Social Isolation; Mother-Child Relations

Resumo

Objetivo: compreender as repercussões da pandemia de COVID-19 na saúde das mulheres que são mães de crianças autistas. Método: estudo qualitativo, tipo ação participante, fundamentado nos pressupostos teórico-metodológicos de Paulo Freire. Realizou-se um Círculo de Cultura virtual em janeiro de 2021. Participaram 12 mulheres mães de crianças autistas, membros de uma associação na região Sul do Brasil. A análise dos dados ocorreu com a participação de todos os envolvidos no Círculo de Cultura, conforme Itinerário Freireano. Resultados: as mulheres refletiram sobre a sua saúde física e mental; seu papel social enquanto mãe e esposa; e a conciliação das atividades domésticas com a educação formal do filho. Também emergiram os sentimentos: cansaço, desânimo, depressão e medo
COVID-19 pandemic: health of mothers of autistic children

Introduction

Autism Spectrum Disorder (ASD) is characterized by a dyad of symptoms and alterations in quantitative or qualitative media, as well as in restricted and repetitive behavioral changes, defined by diagnostic criteria currently used, being considered a global developmental disorder.\(^1\) Recent epidemiological data estimate the prevalence of ASD for 1 in 45 children.\(^2\) In developing countries, such as Brazil, studies addressing the incidence of ASD are scarce, however, a significant increase in diagnosis among Brazilian children can be observed. A study developed in the metropolitan region of Goiânia, Fortaleza, Belo Horizonte and Manaus identified a prevalence of 1% of ASD, including children and adolescents up to 16 years of age.\(^3\)

Despite the knowledge about the increasing number of ASD by health professionals, it is still a slow diagnosis and needs to be made from the multidisciplinary look. After diagnosis, families are deemed with specific care needs that are private and individualized, according to the degree of commitment and the need for support that the child needs.\(^3\)

Parents of children diagnosed with ASD typically experience higher levels of stress, depression, anxiety, and anger than other parents.\(^4\) There are a number of responsibilities related to ASD, and these contribute to parental stress that include problematic behaviors, financial obstacles, greater obstacles in access to education, such as day care centers, and...
community activities, among others.\(^5\) It is possible to infer that these aspects are experienced in a much more intense way in a pandemic situation, a reflection of the current scenario.

COVID-19 emerged as a serious global public health problem, which spread rapidly from China to other parts of the world.\(^6\) Thus, the need for reorganization of health, education, communication and transportation services for all people was imposed, resulting in the cancellation and/or postponement of indispensable activities in the context of children with ASD.

These changes had an impact on the physical and mental health of mothers who began to live with new demands and behavior of their children in the face of social restriction and longer stay at home. Although women understand the need for these measures, it may not be clear the impact on their children's development and health, given that in most cases care falls under the responsibility of women.\(^4,7-8\)

Considering that children with ASD require care or care throughout life, it is pressing to understand the experience of women, the main caregivers, in coping with the COVID-19 pandemic and seeking to assist them in this period. In this context, in which the virtual possibilities of establishing social relationships have gained a great age, the use of digital technologies was envisioned to bring these mothers closer together and stimulate reflection on the pandemic, the care of children and their own. Digital technologies provide listening and dialogue spaces and are promoters of learning and support. Nursing has been appropriating digital technologies and especially during the pandemic, there has been the opportunity to qualify meetings in a virtual way, so the proposal of the virtual meeting to women, mothers of children, can contribute to them reflecting on their challenges and being able to solve them.\(^9-10\)

Thus, the research question is: what are the repercussions of the COVID-19 pandemic on the health of women, mothers of autistic children? Since then, the aim of the study was to understand the repercussions of the COVID-19 pandemic on the health of women who are mothers of autistic children.

**Method**

This is a qualitative study, of the type of participant action research,\(^{11}\) based on the theoretical-methodological assumptions of Paulo Freire. The Freire's Research Itinerary was
used, which is composed of three dialectical and interconnected stages: 1) Thematic research: dialogue that is initially established to identify the generating themes, which emerge according to reality; 2) Codification and Decoding: a moment when it is reflected about the generating themes, seeking to represent existential situations in a critical way about the reality experienced by the participants; 3) Critical Unveiling: a phase in which limits and possibilities are evidenced, it is the critical awareness of the existential situation of the reality of the participants. 12-13

The phases of the Freire's Research Itinerary develop in the Circle of Culture, which is a space in which the sharing of practices and knowledge is promoted, in search of the construction of knowledge. It is part of a group of people who discuss common themes in a dialogical, participative and horizontal-oriented way, which instigates the knowledge of all, in favor of the transformation of reality. 13-14

Faced with restrictions imposed by the pandemic, it became necessary to perform the Circle of Culture in a virtual way, using the digital platform Webex®, with the support of mobile phone and computer cameras, which allowed the interaction and integration of participants. In this sense, a Virtual Culture Circle (VCC) was held, with the participation of 12 women mothers of autistic children, living on the coast of Santa Catarina. The Snowball sampling method was used, 15 starting with two women, whose children attended a non-profit and charitable association, who were contacted by the researchers, by telephone, to integrate the research. After acceptance, they invited ten other women with the same characteristics to participate in the research. It was decided to participate 12 people with a view to favoring greater dialogue, interaction and active participation during the VCC.

The inclusion criteria were women over 18 years of age, who were the main caregivers of their children. Exclusion criteria were women, mothers of autistic children, who did not have internet access and electronic devices to participate in the VCC. All the guests agreed to participate in the study, with no refusals.

In the week before the VCC, a group was organized in a messaging application in order to facilitate communication between the study participants and the researchers. In this group, the day and time of the meeting were scheduled to perform the VCC. In addition, it was explained about the objective of the research and the need to sign the Informed Consent Form (ICF), which was forwarded to the study participants, who signed it and forwarded it to
the researchers.

On the afternoon of January 9, 2021, the VCC was developed, which was recorded in an electronic device, lasting approximately two hours. The participation of the 12 women and the mediator (nurse, doctor, with experience in conducting this type of approach) was counted.

To go through the phases of the Freire's Research Itinerary in a playful and integrative way, according to the reality of the participants, we asked in the application group what was the activity that their children most appreciated. The mothers decided to assemble blocks. Thus, an analogy of the stages of the Research Itinerary was made with the play of assembling the blocks of a house, representing the pandemic reality in view of the need to "stay at home" in isolation, as illustrated in Figure 1.

![Figure 1: Paulo Freire's Research Itinerary: analogy with building the Blockhouse](https://pt.dreamstime.com/ilustracao-curto-de-blocos-de-apartamentos-do-bebe-%E2%80%93-image45286382)

To instigate the dialogue and go through the first stage of the Freire's Research Itinerary, the mediator presented to the participants a house assembled with blocks. From then on, he stressed that it was necessary to investigate the best way to build the house, with the ideal pieces to be inserted in each location. It was reflected that the house was the place where the study participants, together with their families, remained during the pandemic, bringing repercussions for their lives. Then, he asked the following question: what are the repercussions of the COVID-19 pandemic on his health?

Each participant answered the question, while the mediator wrote their statements, through a keyword or phrase, on the computer's own shared screen. After all the participants
manifested themselves, the mediator read all the records, encouraging them to organize their statements according to the themes that were emerging. Thus, they organized two generating themes to reflect on the VCC: 1) Women’s health and 2) Mother and wife’s health.

For the second phase of the Freire’s Itinerary, Coding and Decoding, the mediator contextualized that to assemble the house, it was necessary to detail the door, window and roof with different colors and pieces. In such a way, it was necessary to contextualize the two generating themes, in which she questioned them: What are the repercussions of COVID-19 for her health as a woman? What are the repercussions of COVID-19 on your health as a wife and mother of an autistic child?

The women talked and reflected abundantly, having the opportunity to share their experiences. The meanings of their experiences were recorded in terms or phrases, which were codified and decoded, as shown in Figure 2.

![Figure 2: Representation of the Encoding and Decoding of the two generating themes](https://pt.dreamstime.com/ilustracao-stock-blocos-de-apartamentos-do-bebe-image45286382)

All records were read and validated with the study participants, seeking to motivate them to continue the reflections on the themes raised, in order to seal the process of action-reflection, instigating them to understand their ability to face shared challenges and together to visualize the possibilities to transform their reality.¹⁴

For Critical Unveiling, the last phase of the Freire’s Itinerary, it was pointed out that when assembling something with the blocks, the child develops his creativity, and when viewing the assembly, means its creation. Likewise, participation in the VCC brought meanings for women. In this sense, the mediator invited them to reflect on everything they talked and heard, in order to discover the real possibilities to live in health and overcome the challenges
imposed by COVID-19, strengthening each other. At this moment, the participants reflected on everything they had already dialogued and discussed, not inserting new debates, thus the saturation of the data. To end, was asked about the meaning of having participated in the VCC.

It should be noted that the data analysis process occurred during the development of all stages of Paulo Freire's Research Itinerary, according to its precepts, which provides for the analytical process. Therefore, it developed continuously, with the participation of all people involved in the Circle of Culture. After the end of the VCC, the dialogues were transcribed and organized, according to the two generating themes.

It was explained about the importance of maintaining the privacy and confidentiality of the participants, who, when they realized that they were in 12, they chose to be named for the 12 months of the year. The study obtained approval from the Human Research Ethics Committee from a Public University of Southern Brazil, with opinion number 4.068.387, with CAAE 32239220.7.0000.5564, on June 3, 2020.

Results

The twelve study participants were between 29 and 45 years old. Five of them worked outside the home (four teachers and a hairdresser), two resigned during the pandemic, in order to be able to dedicate themselves with higher quality to the care of their autistic child and five were housewives. As for marital status, nine were married to men and three were divorced, and eight women had more than one child. All autistic children of the participants were male and aged between four and nine years.

When they talked about the first generating theme, in which they discussed women's health, the presence of tiredness, discouragement and depression was pointed out in coping with COVID-19. In addition, they showed fear of acquiring the disease in the family:

- I feel very tired and discouraged, like never before. (January)
- In this pandemic I had to go to the doctor and I saw myself depressed, having to take medication. It affected my mental health. (April)
- I'm too afraid to catch COVID. So far we remain more at home and in care and no one in our family has taken it. (March)

Due to the pandemic, some women had the need to resign from their jobs in order to care for their autistic children with higher quality. But with the whole family indoors, the
accumulation of work emerged:

*I had to quit my job. I could not leave my son at home alone during the pandemic, and I quit.* (February)
*With the family at home, my work has only increased* [...]. (May)

The participants reported little time to take care of themselves, in which they were unable to perform routine tests, emerging the lack they feel about going out with friends and going to church. They also regret the lack of doing different things on a daily life, having to cancel holiday trips due to the pandemic:

*We ran out of time to take care of ourselves. Everything has been very busy in this pandemic.* (June)
*This year I could not even do my annual routine exams.* (August)
*I miss hanging out with my friends and talking, laughing with them.* (July)
*I miss going to church and doing different things like walking around at ease.* (September)
*We had no vacation in July, it was all cancelled due to the pandemic.* (October)

Faced with the need for social distancing, imposed by the pandemic, emerged the feeling of longing of family members as well as their parents and in-laws, also reflecting on the lack of face-to-face support in the care of autistic children, because they were the ones who most helped them:

*I miss being with my family, my parents and my in-laws.* (December)
*In addition to the longing I feel about my parents, they were the ones who helped me take care of my autistic son. And now, even this support I have due to the pandemic, which ended up driving us away.* (November)

During the discussion of the second theme generator, health of the mother and wife, the women unveiled that in the pandemic had to be mother, wife, housewife and therapist. Thus, they highlighted the lack of time to take care of the partner and the house:

*Besides being a woman, mother, wife and housewife, I also had to be a therapist in this pandemic.* (April)
*I have no time to take care of my husband and my house, which lives all disorganized.* (June)

The women revealed to feel trapped inside their own homes due to COVID-19 and that their autistic son became more nervous. They showed a feeling of sadness at seeing their son without therapy and regressing in the pandemic conjuncture. They pointed out that the autistic son had difficulty following online classes, having to devote himself entirely to him, with a lot of patience and resilience to face all these situations:
I feel trapped inside my own house. You cannot get out like you used to, and that complicates everything when you have an autistic son. (December)
My son was much more nervous about the pandemic. (February)
It is very sad to see my son not being able to go to therapy in person because I see him regressing every day. (March)
My son could not keep up with online classes. That was really bad. So I had to dedicate myself to my son in full. (January)
All these changes due to the pandemic made us have to have a lot of patience and resilience to move on. (May)

During the pandemic context, women reprogrammed some daily actions, seeking to promote family health with creativity and playfulness:

- Back home, we had to reprogram a few things: time to stay on the internet, time to watch the sunset, to talk as a family, to reading and games. (September)
- As a family, we organize to maintain everyone's health. (November)
- With creativity and playful games, we were dealing with our son, elaborating different schedules for him, indoors. (August)

The women reported that the use of leisure time in the family was important and positive in the management of social isolation and maintenance of the health of all.

Discussion

The women in this study had the opportunity to reflect on learning from the experience of the VCC and on the meaning of experiencing the coping of COVID-19 in the management of self-care and care for their children with ASD. The occurrence of the pandemic has given rise to different feelings, and many have reported the increase in fear, anxiety, anguish and depression. These may be related to lack of knowledge about the disease, information overload and fake news, as well as economic uncertainty, because many caregivers have compromised family income.

Considering that COVID-19 is a new situation in the world scenario, with research still being carried out, many reflections on its confrontation are based on personal experiences and experiences. All these aspects can influence the conduct of the family context and bring even more impacts to mental health, not only of children with ASD, but also of their caregivers, represented mostly by the figure of the woman.
As a woman, isolation and social distancing have made it difficult to maintain quality of life and regular control of health, either because of changes in the dynamics of the family context or uncertainty about safety in seeking care. Although the effects of the health crisis on women's health cannot be measured, it is known that there has been a change in the network of elective, essential and emergency services. This difficulty in accessing services, associated with the need for social isolation, can generate a complex situation of difficulties in self-care and restriction of rights already conquered, limiting their search for better health conditions.

In this context, women have increasingly occupied work spaces and prestige in society, although this fact has not decreased their workload at home, including care for family members. The occurrence of the pandemic has aggravated a situation that was already evident in double and triple work days and reflects gender inequalities in Brazil. The responsibility for formal or non-domestic work is still exclusively destined to women, a result of the macho rooted culture prevalent in Brazil, which reflects gender inequality.

This situation is more evident when the woman assumes for her the role of caregiver in the face of a diagnosis of ASD from a family member, especially a child. Socially and culturally, they represent 70% of the health workforce and are the majority at the forefront of responsibility for care, whether domestic or institutional.

The need to maintain social distancing due to COVID-19 also led to tiring childcare journeys, as well as family dynamics. The women, mother and wife present in this study presented weaknesses in the conduct of care in this context. Especially in the organization of activities with the child with ASD diagnosis, which has become a challenge to assist in maintaining learning with remote classes during the closing of schools. This situation has led to significant changes in family routines, with marked repercussions on the child's behavior.

In addition, it is important to reflect on the role of each subject at home, and it is essential to share obligations and tasks, reviewing family dynamics beyond care.

The sudden change in the learning process of children with ASD causes stagnation and/or involution of intellectual, motor and coexistence development, directly impacting the well-being and quality of life of the whole family. Furthermore, the suspension of therapeutic practices can result in worsening of aggressive behavior and loss of basic skills previously acquired for these children.

Such specific demands of children with ASD, associated with work activities, home and
attention to other family members requires the woman/mother/wife, in addition to time, patience, resilience and reorganization of the family scenario and the needs of all involved. For the women in this study, the experience and coexistence in the pandemic context has been challenging and limiting, since they present difficulties in mediating these behaviors, in offering adequate stimuli for each child at home, including the reconciliation of domestic activities.

Reinventing daily life and the way of relating at home has become necessary for the preservation of mental, physical and social health, especially in times of pandemic.\textsuperscript{25} There have been successive displacements between families and the use of technologies, with school and in the relationship with children, and creativity is needed to rethink daily life.\textsuperscript{26} Thus, it is necessary to reflect on the impacts of long-term isolation and how children with ASD are adapting to these processes of changes in society in coping with the pandemic and also in the post-COVID-19 scenario.

As a limitation of the study, there is the challenge of reconciling a schedule in the participants' agenda for performing the VCC, given the accumulation of activities that women had, especially in the care of their child with ASD. In addition, access to communication technologies, such as the computer and the Internet network itself, was another limiting factor for replicating this experience with some groups of mothers.

The VCC allowed a meeting to share experiences, with qualified listening and mutual learning, being a powerful opportunity for health care. The use of this methodological instrument in the field of research is innovative, especially for Nursing, and can promote the development of various activities during the pandemic in a welcoming, creative and humane way, without offering risks of contamination to professionals, as well as to the participants.

**Conclusion**

The study revealed how the COVID-19 pandemic is influencing the health of women mothers of children with ASD, who revealed the presence of tiredness, discouragement and depression, as well as the fear of acquiring the disease in the family during this period. The participants shared that in the pandemic they had to be a mother, wife, housewife and therapist, referring sadness in showing the regression of the child without face-to-face therapies, with increased workload, lack of time to take care of themselves and reconcile the
educational actions of learning special children with domestic activities.

It is noteworthy that the VCC, mediated by a nursing professional, enabled, in addition to the sharing of congruent experiences and motivations among peers, care collectively, reinforcing the role of nursing also in this space of mediation and resilience. Thus, the need for strengthened support for women, mothers of children with ASD, is unveiled, highlighting the relevance of mandatory nursing participation with dialogue and attentive listening, including actions in the virtual environment.

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