

Covid-19 pandemic: experiences of mothers of infants who were born premature



Pandemia da Covid-19: vivências de mães de lactentes que nasceram prematuros

Pandemia Covid-19: experiencias de madres de bebés que nacieron prematuros

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ABSTRACT

Objective: To learn the experiences of mothers of infants who were born premature in the Covid-19 pandemic.

Method: Qualitative study based on the Bioecological Theory of Human Development, developed in a public maternity hospital in Paraíba, Brazil, between June and July 2020 with 21 mothers of infants who were born premature, through semi-structured interview. The data were submitted to inductive thematic analysis.

Results: Mothers know the measures for prevention, transmission, and symptoms of the disease, as reported in the media, but have different perceptions about social isolation. Their experiences were permeated by financial difficulties, reduced social support and emotional stress.

Final considerations: It is recommended to monitor child health and provide social support to the mother-child binomial remotely, so that there is no break in the continuity of the bond and care for the family in this moment of vulnerability.

Keywords: Coronavirus infections. Mothers. Infant, premature.

RESUMO

Objetivo: Aprender as vivências de mães de lactentes que nasceram prematuros na pandemia da Covid-19.

Método: Estudo qualitativo fundamentado na Teoria Bioecológica do Desenvolvimento Humano, desenvolvido em uma maternidade pública da Paraíba, Brasil, entre junho e julho de 2020, com 21 mães de lactentes que nasceram prematuros, por meio de entrevista semiestruturada. Os dados foram submetidos à análise temática indutiva.

Resultados: As mães conhecem as medidas de prevenção, de transmissão e os sintomas da doença, conforme divulgado na mídia, mas possuem percepções distintas sobre o isolamento social. Suas experiências foram permeadas por dificuldades financeiras, redução do apoio social e estresse emocional.

Considerações finais: Recomenda-se o acompanhamento da saúde infantil e o apoio social ao binômio mãe-criança de modo remoto, a fim de que não haja quebra na continuidade do vínculo e cuidado à família nesse momento de vulnerabilidade.

Palavras-chave: Infecções por Coronavírus. Mães. Recém-nascido prematuro.

RESUMEN

Objetivo: Conocer las experiencias de madres de bebés que nacieron prematuros en la pandemia de Covid-19.

Método: Estudio cualitativo basado en la Teoría Bioecológica del Desarrollo Humano, desarrollado en una maternidad pública en Paraíba, Brasil, entre junio y julio de 2020 con 21 madres de bebés que nacieron prematuros, mediante entrevista semiestruturada. Los datos se sometieron a análisis temático inductivo.

Resultados: Las madres conocen las medidas de prevención, transmisión y síntomas de la enfermedad, según se informa en los medios, pero tienen diferentes percepciones sobre el aislamiento social. Sus experiencias estuvieron impregnadas de dificultades económicas, menor apoyo social y estrés emocional.

Consideraciones finales: Se recomienda monitorear la salud del niño y brindar apoyo social al binomio madre-hijo de manera remota, para que no se rompa la continuidad del vínculo y el cuidado de la familia en este momento de vulnerabilidad.

Palabras clave: Infecciones por Coronavírus. Madres. Recien nacido prematuro.

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INTRODUCTION

Prematurity represents the main reason for infant and neonatal mortality⁽¹⁾. Data reveal that in 2017, in the world, approximately two thirds of newborns (NBs) who died were premature. Annually, about 15 million babies are born preterm, that is, before 37 weeks of gestation, and that number is increasing. Thus, it is understood the need for full monitoring of premature children, as a strategy to guarantee their right to life⁽²⁾.

One of the ways of coping with prematurity is the follow-up of newborns after hospital discharge, through follow-up, a modality of outpatient consultation at a maternity hospital, carried out by a multidisciplinary team. In the case of premature infants, it is recommended that the first follow-up visit occurs seven to ten days after discharge. Up to six months of corrected age, monthly revisions are made, and up to 12 months, bimonthly. Follow-up must ensure a comprehensive assessment of the premature infant, which will lead to a reduction in the number of infections, hospitalizations and more favorable rates of growth and development⁽³⁾.

However, this follow-up may have suffered from the consequences of the new coronavirus (SARS-CoV-2) pandemic, which started with Covid-19 disease, in December 2019, in the city of Wuhan, China, and quickly spread with associated deaths worldwide, which led the World Health Organization (WHO) to declare a public health emergency of international interest, which subsequently raised it to pandemic status⁽⁴⁾.

Up to August 22, 2020, were reported worldwide 22,970,240 cases of Covid-19 and 800,060 deaths from this disease. In Brazil, up to that date, 3,582,362 cases of Covid-19 and 114,250 deaths were confirmed. In the state of Paraíba, in the same period, there were 100,970 cases, with 2,288 deaths. In relation to children, nationwide, from the total of 2,393 confirmed cases in children under five years old, up to May, 441 died⁽⁵⁾.

People of all ages are susceptible to contracting Covid-19, however the elderly, immunocompromised and individuals with comorbidities belong to the risk group, which can progress to severe conditions and even death. Newborns, especially premature infants, because they have immaturity of the immune system, are also considered to be at high risk for developing severe symptoms of the disease⁽⁶⁾.

In view of the exponential growth of Covid-19 and the number of individuals who evolve to severe conditions, several countries, in order to prevent or delay the spread of the virus, have been implementing mass social isolation, quarantine and operation of only essential services⁽⁷⁾. However, social isolation has been increasing the prevalence of

anxiety, depression, reduced family income and stress in the home environment⁽⁸⁾.

Adding up to the social restrictions imposed by social isolation, in order to protect the child, health services were reorganized, with provisional suspension of follow-up consultations with clinically stable premature NB, as well as suspension of childcare consultations in the Basic Health Units (BHU).

It is important to emphasize that the vulnerability of premature NB is often the main responsible for the deficits in neuropsychomotor development in the long term, in this population. Therefore, the non-monitoring of these children can contribute to delays or deficiencies in the preschool phase, mental and intellectual delays, neurological sequelae and the development of behavioral, psychological and emotional dysfunctions⁽¹⁾.

Given the above and considering the fragility of health services and the impacts of the pandemic on mothers and premature NBs, the question is: What is the experience of mothers of infants who were born premature, in the Covid-19 pandemic? Therefore, the objective was to apprehend the experiences of mothers of infants who were born premature in the Covid-19 pandemic.

METHOD

This is a descriptive-exploratory research, with a qualitative approach, carried out in a public maternity hospital in a municipality in Paraíba, Brazil. Twenty-one mothers participated in this study, who met the inclusion criteria: being a mother of infants born prematurely, discharged from that maternity who had their follow-up interrupted or spaced due to the Covid-19 pandemic; being over 18 and accept to participate in the research remotely. The mothers were only included after accepting to participate in the research, remotely, and having access to cell phones during the data collection period.

Data collection took place in the months of June and July 2020, through semi-structured interviews, using a telephone call, in view of the impossibility of physical approach due to the social isolation resulting from the Covid-19 pandemic. The selection of participants occurred systematically, based on the telephone contact number available in the child's medical record, following the scheduling of the interview according to the availability and consent of each mother, so that, in case of refusal, the next one was contacted of a list. It is noteworthy that each consent was recorded verbally, after reading the informed consent form, before each telephone interview started.

The interviews, later transcribed for analysis, were guided by the following guiding questions: 1) What is your opinion about social isolation?; 2) Have you heard of Covid-19?; 3) Can you tell me what you know about this disease?; 4) How is your routine and that of the whole family during social isolation?; 5) Talk a little about it.

The closure of the collection followed the sufficiency criterion, when it was possible to reflect on the multiple dimensions of the object of study⁽⁹⁾, making a total of 21 interviews. The analysis of the empirical data was performed using the technique of inductive thematic analysis⁽¹⁰⁾, following six phases: Familiarization with the theme (active reading of the empirical material before the search for codes and meanings); Generation of initial codes (identification of similar sets and production of initial codes manually); Search for themes (selection of different codes on potential themes); Review of the themes (refinement of the themes by reading all the data extracts that are part of each theme and visualizing the relationship between the themes); Definition of themes (clear identification of themes); and Production of the final text.

The theoretical foundation was based on the Bioecological Theory of Human Development, developed by Bronfenbrenner. This theory postulates that, in order to better understand human development, it is essential to consider the entire bioecological system around the individual⁽¹¹⁾.

This theory anchors human development in four dimensions that interact with each other: the Process, the Person, the Context and the Time (PPCT Model). The Process corresponds to the interactions between the person in development and other people, objects and symbols present in their close environment. The Person is the developing individual interacting with the context, according to his biopsychosocial characteristics. The Context is characterized by any event or condition outside the organism, which can influence or be influenced by the person in development. The Time is the structure that contemplates the changes and stability of the development of the Person in the course of life and of the generations⁽¹¹⁾.

This study is linked to the project entitled "Maternal and child care in the face of the Covid-19 pandemic: a proposal for remote care", approved in Notice No. 003/2020 - FAPESQ/SEECT project for monitoring, analysis and recommendations for rapid implementation faced with Covid-19 pandemic, in the State of Paraíba, and approved by the Research Ethics Committee of the Health Sciences Center, of *Universidade Federal da Paraíba* (UFPB), under statement No.4,045,340, CAAE 31353220.3.0000.5188 as recommends the Resolution 466/12 of the National Health Council (NHC). The Free and Informed Consent Term was presented through reading, during

the telephone call, and all mothers agreed to participate. To guarantee the anonymity of the participants, the records of the statements were coded with the letter "M", referring to "Mother", followed by the number corresponding to the chronological order of the interviews, namely: M1, M2 [...].

■ RESULTS

Among the 21 mothers participating in the study, thirteen claimed they were in a stable relationship, five were single, two were married and one was a widow, aged between 18 and 38 years old. Regarding the number of children, nine had a child; seven, two children, and five, three children or more. As for years of study, fourteen women were between five and ten years old, and seven had more than ten years of study. With regard to the average family income, fourteen women had an average family income of up to one minimum wage, and two had the emergency aid granted by the Federal Government as their sole income. As for occupation, twelve were employed, seven were homemakers and two were students.

From the analysis of the empirical material, two themes emerged: Theme I: Maternal knowledge and perception about Covid-19 and social isolation; Theme II: Experiences of mothers of premature infants in the Covid-19 pandemic. Each theme was built from initial codes, according to Chart 1.

Theme I: Maternal knowledge and perception about Covid-19 and social isolation

The maternal experience during the new coronavirus pandemic and the care for a premature baby at home are influenced by the maternal understanding of Covid-19 and social isolation. From the reports, it was possible to apprehend that the knowledge of mothers of premature infants about Covid-19 is consistent with what is reported in the media:

I know that it is a respiratory disease that, if you have contact with the infected person, you can get it [...] Is that they actually say that you get it from the 4th day; others say it gets worse only if you already have a disease, if you are hypertensive, diabetic. Several people have died who do not have any of these diseases. (M10)

Which is a very resistant virus and when it gets to the lung, right? it is [...] you stop breathing, you have to breathe with a device, all of that. (M12)

Given the excess of information about Covid-19 transmitted on social and television networks, the mothers revealed in their speeches:

Main themes	Initial codes
<p>Theme I: Maternal knowledge and perception about Covid-19 and social isolation</p>	Positive perception of social isolation
	Negative perception of social isolation
	Difficulties in relation to social isolation
	Knowledge about Covid-19
	Prevention
	Contagion
	Symptoms
<p>Theme II: Experiences of mothers of premature infants in the Covid-19 pandemic</p>	Socioeconomic condition
	Unemployment
	Restrictions on leaving home
	Maternal and child stress
	Distancing from family
	Fragile support network
	Psychic suffering

Chart 1 – Main themes and initial codes. João Pessoa – PB, 2020
 Source: Research data, 2020.

There is so much going on television that I can't say for sure what COVID is. I think it's just a passing virus. (M1)
Look, I see it on television. Every day is on television. It is a contagious disease, and this disease catches easily, right?! (M11)
It's been on TV so much that it's disgusting. This disease is very terrible because it has already killed a lot of people out there, and we are afraid to take this thing. Every night it's coronavirus, it's Covid-19. (M20)

It is noteworthy that the importance of adopting preventive measures and the forms of transmission of the virus were found to be recurrent in maternal speeches, when asked about their knowledge about the disease.

I know that it is a virus that is spread through touch and that it has already killed a lot of people. So, the only thing we can protect ourselves from is washing hands well, not

going out without a mask, avoiding touching things and putting the hand on face, whenever you go out, come back, bathe and wash everything. (M6)

That is a virus, right? and it catches in the air and has to use a mask and alcohol gel and that a lot of people are dying and getting sick (M4)

Among the preventive measures of Covid-19, social isolation was seen by mothers as important to reduce the contagion of the disease, but they had different perceptions, sometimes positive sometimes negative and pointed out the difficulties to maintain it.

My opinion is that it is very important because, as there is no vaccine or medicine, the only way we have to prevent the spread of the virus is with isolation. Although we know that the economic/financial issue weighs a lot, but I think that this isolation is extremely important, to avoid

as much as possible, only to go out in very emergency circumstances. (M6)

Isolation is the most important right now at the time of the pandemic, precisely because of the easy contagion of the virus, and it is what must be done at the moment. (M21)

My opinion is that it is very difficult to maintain isolation. We really need to go to hospitals to consult. It's been really difficult. (M19)

It is very difficult because, as my boys are all at home, without having a class, here at home are those city hall apartments, right? very tight. (M17)

In addition, participants identify the main symptoms of Covid-19:

I know that the coronavirus is contagious [...] The symptoms are dry cough, fever, diarrhea, headache and shortness of breath. (M2)

Generally, when we have some symptoms such as shortness of breath, fever, headache, it loses the taste and there are people who enter the risk group, right? Which are cardiovascular, hypertensive and diabetic. (M14)

Theme II: Experiences of mothers of premature infants in the Covid-19 pandemic

The advent of the new coronavirus pandemic has increased the vulnerability of mothers and families of premature infants in different contexts. One of the aspects affected in the family nucleus was the socioeconomic condition, resulting from unemployment.

My husband was self-employed, but because of this pandemic, he stopped going. (M20)

The routine is very difficult because it is difficult to get around, go to the doctor; everything has changed, our life has changed. The financial issue has changed, it has changed a lot. (M2)

In addition to the socioeconomic changes, it was possible to verify that the mothers experienced restricted encounters with family members and, thus, received minimal support in the care of the premature infants.

Woman [...] It's complicated! Because I practically live alone. My sister comes in the evening to help me. Then afternoon is the time when I finish fixing my things, taking a shower, eating, fixing the house, you know what I mean?! Then, when night comes, I'm tired. (M5)

Everyone is isolated, right?! We live close by, but only communicate by cell phone. (M16)

Regarding the visit, since she left the maternity ward, she has not received any visit. Both my husband's family and mine only know her by photo. It was a very different thing, because usually, when a baby is born, the staff will visit with about 15 days or even a week, and she had none of that. (M6)

In view of the restriction on family support and, consequently, of the proximal processes with the child, a mother reported that there were changes in her psychological condition.

My whole family is from the countryside of Recife, you know?! And I am unable to visit them, and they cannot come to visit me. My psychological has changed a lot, mainly, in these last days because my brother tested positive in the countryside. I am feeling very sad. (M3)

Another experience pointed out was maternal stress, since, in addition to the care of the premature, women have other children who demand attention and who, in this pandemic period, are idle at home due to the closing of schools and leisure environments.

Isolation totally changed the routine in relation to solving my things, the issue of children who are very agitated at home because they have nothing to do, accustomed [...] Oh! there is already a boy crying (laughs). - Easy boy. They are used to the school, the classmates, going to a beach to be distracted, so, this type of thing that we really miss. (M6)

Accustomed to having a normal life, going out to places, being able to go to the mall, to the beach, to go out [...] And today we can't do anything else, so it's kind of complicated! The psychological one gets a little shaken, sometimes, without being able to go anywhere. (M5)

Furthermore, the data revealed that, due to social isolation, mothers limit their leaving home, giving priority to essential services and aimed at child health care.

We just stay at home, go out with the babies even just for the pediatric consultation and, if it is necessary to go to the pharmacy or something and there is no way to leave them at home, they go, stay in the car, but we are going out as little as possible. (M21)

My routine is only inside the house, if I go out, it is for consultation with her. (M7)

DISCUSSION

The extracts from the interviews bring relevant aspects to the apprehension of the experiences of mothers of infants who were born premature in the Covid-19 pandemic. Based on Bronfenbrenner's theory of human development, it is considered that maternal experiences, immersed in peculiar Processes and Contexts, can interfere in the development of these children, through the care that will be offered⁽¹¹⁾.

Caring for an infant born prematurely is a challenge for families, since prematurity is a risk factor for infant morbidity and mortality⁽²⁾. In this context, the child may be affected by health problems and developmental delays, and must be monitored regularly, in the first year of life⁽¹²⁾; later, from the second year, she will be followed in childcare, with more spaced consultations, according to the calendar proposed by the Ministry of Health.

Concomitant to the challenges of caring for children born prematurely and in the face of the new pandemic scenario, the need for new maternal knowledge about Covid-19 and new ways of caring emerges in order to provide comprehensive care to the child. In view of the reports presented, it is clear that maternal knowledge is related to preventive measures, ways of transmitting the virus and social isolation, as reported on social and television media.

Thus, by appropriating knowledge about the needs of premature infants, based on the prevention of Covid-19 and health promotion, mothers can reframe the way of caring for their children in the context of the pandemic. A study carried out in China showed that knowledge about Covid-19 is associated with a lower likelihood of negative attitudes and potentially dangerous practices in relation to the epidemic of the new coronavirus⁽¹³⁾.

Thus, the importance of a consolidated maternal knowledge about the disease is revealed, in order to favor the development, the reduction of vulnerability and the protection of the child in its microsystem, which corresponds to the place where the child directly establishes patterns of activities, social roles and interpersonal relationships, through face-to-face interactions⁽¹¹⁾.

Child development is directly affected by the environment in which the child is inserted, as well as by his family relationships. Furthermore, according to Bioecological theory, development is influenced by elements that run through the following systems: microsystem, which refers to the family nucleus; mesosystem, evidenced by the environment in which the child is inserted and the interaction between them, such as family and school; exosystem, in which the child is not inserted, but influences its microsystem; and

macrosystem, in which socioeconomic and cultural conditions are included⁽¹¹⁾.

Considering that the biological and social vulnerabilities of the premature infant and his family nucleus can be enhanced by the pandemic context of Covid-19, obtaining coherent information is essential to face the pandemic. However, the present study reveals that the excess of information transmitted by the media about the coronavirus is a reality experienced by the study participants.

The exponential increase of information, true or not, about a specific subject in a short period of time is called Infodemia. This profoundly affects different aspects of life, such as human health, as it also allows the circulation of inaccurate information, resulting in misinformation and stress⁽¹⁴⁻¹⁵⁾.

It is noteworthy that, from the perspective of the PPCT model of the Bioecological Theory⁽¹¹⁾, the current conjuncture of excessive information about Covid-19 can affect the environment in which the child lives and influence the maternal knowledge about the real needs of the Person/child health.

In view of the pandemic context, some measures were adopted by the authorities to control the disease, among them, social isolation⁽⁸⁾. However, in the present study, divergent maternal opinions were found in relation to social isolation, with regard to its importance, which, depending on their knowledge about the severity of Covid-19, the strategies they use to protect can be modified to protect their family and the community.

The literature highlights that the perception of individuals in relation to social isolation is different, according to schooling, income, age and gender; however, most people see social isolation as an effective strategy for controlling the pandemic⁽⁸⁾. On the other hand, social isolation accentuates the vulnerability that premature infant experience at home, since it can increase financial difficulties, affect mothers' mental health and make the home environment stressful⁽¹⁶⁾.

It is observed that one of the consequences of social isolation was the discontinuity of care for premature infants by health services, a scenario that can compromise the full development of these children. Therefore, it is necessary to ensure mothers of premature babies a support network, in order to guarantee comprehensive care to the child and, thus, minimize the risks of infant morbidity and mortality.

As evidenced in the findings of the present study, the Covid-19 pandemic brought some damage to the health and well-being of families, as well as a marked financial insecurity, since it intensified the existing poverty, due to the increase in the rates of unemployment, with an increase in socioeconomic, racial and ethnic inequalities⁽¹⁷⁾.

Such aspects can reflect both immediately and in the long term, on the emotional and physical integrity of children, due to the negative repercussions on access to diversified and nutritious food, health care and other basic needs, which represent important risks for their biopsychosocial well-being and for their development⁽¹⁸⁻¹⁹⁾.

Premature newborns have increased risk for disorders of neuropsychomotor development, which can possibly be affected according to changes in the external environment. After birth, factors such as socioeconomic and cultural level are at risk for problems in the development of preterm infants⁽¹⁾, due to the influences of their micro and macrosystem, in this case, the family and structural conditions, respectively⁽¹¹⁾.

The healthy development of a child depends, among other factors, on his social interactions, however the isolation caused by the pandemic was responsible for breaking up the bond with family, friends and the community. In the midst of this, in order to limit the circulation of people, the essential components of the microsystem of institutions and groups - such as school, family, neighborhood, friends and religious institutions - were heavily harmed by the pandemic⁽¹⁷⁾.

With regard to the broad measures applied to control the Covid-19 pandemic, social interaction is a heavily impaired aspect. Social distance is responsible for reducing the transmission of the disease, for reducing social contacts by at least 60%; however, it can have a negative effect on the family, which loses the support network in the child care⁽⁷⁾.

Added to this is the fact that the elderly, being part of the risk group for severe cases of Covid-19, are distant from families, so, due to this restriction on family meetings, grandparents are unable to offer help, security and emotional support for children⁽¹⁷⁾, which leads to an increase in the physical and mental burden of mothers of premature children.

Thus, the scenario imposed by Covid-19 established new stress spots in the routine of mothers of children who were born premature, in view of the changes that occurred in their daily lives. This aspect was corroborated in a survey⁽⁸⁾ that addressed the social isolation imposed by the Covid-19 pandemic and identified that the majority of participants suffered an impact on their livelihoods, resulting in increased family stress.

Maternal stress is associated with other difficulties arising with the pandemic, such as the overload of daily demands with other children, in view of the closure of schools and leisure environments, which hinders the proximal processes between the child and the family nucleus, which may impact negatively their development during the pandemic⁽²⁰⁾.

In addition, mothers of preterm infants may have problems with their mental health, such as depression and anxiety, factors that negatively influence the social, emotional and

functional development of children. Therefore, it is necessary to minimize the contextual influences of vulnerability to premature babies, through proximal processes with the family and the interaction with health services and professionals, for acting in the promotion of child care and development⁽¹⁸⁾.

The study highlighted that the Covid-19 pandemic is often accompanied by a feeling of fear, anxiety, depression, impotence, uncertainty, boredom, worry, causing psychological and emotional damage⁽¹⁹⁾. In this context, mothers are afraid of becoming ill, since, during treatment, they may become unable to provide attentive care to their children, whether due to their own hospitalization or to their other children⁽²⁰⁾.

This reality represents a risk factor for premature infants, since parents who are psychologically affected may find it difficult to provide care for their children, making them more vulnerable to violence, exploitation, and abuse. Furthermore, the decrease in maternal care can also generate stress for the child, which, depending on the time, frequency, and intensity of exposure, may have its development⁽²⁰⁾ impaired.

Therefore, the changes in the child's macrosystem resulting from the pandemic and the socioecological impact of Covid-19 represent important risks, which may have consequences for the well-being, development and protection of children, making the experiences of mothers of premature infants even more challenges in the Covid-19 pandemic.

■ FINAL CONSIDERATIONS

The study allowed us to apprehend that the experiences of mothers of infants born prematurely in the face of the Covid-19 pandemic were affected by social isolation, potentiating their vulnerabilities and the premature child's family nucleus, as well as causing direct impacts in social, financial, emotional, and psychological contexts. Thus, the need for social support for these women/mothers emerges, with professional responsibility for remote contact, due to the conditions imposed by the pandemic.

As a limitation, it is highlighted the difficulty to carry out some interviews that, due to the fact that they took place by telephone, some mothers temporarily interrupted their speeches to meet some demands arising from domestic activities or childcare.

However, looking at the experience of these mothers contributes to the theoretical advancement of the topic in question, which has been little explored by national and international literature. In addition, the scientific evidence pointed out from this reality allows nursing to reflect on their practices in the work process and expand the strategies for continuity and integrity of care for this population, even at a distance.

Therefore, it is recommended to monitor child health and provide social support to the mother-child binomial remotely, so that there is no break in the continuity of the bond and care for the family in this moment of vulnerability.

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