





Original Article

Post-discharge home care of preterm infants during the Covid-19 pandemic

Cuidado domiciliar pós alta do prematuro durante a pandemia Covid-19 Atención domiciliaria tras el alta de bebés prematuros durante la pandemia de Covid-19

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Abstract

Objective: to understand how mothers experienced the care of their preterm infants at home in the midst of the COVID-19 pandemic. **Method:** qualitative, descriptive study, developed between January and December 2021, through remote interviews with 25 mothers of preterm infants, one month after hospital discharge, with thematic Content Analysis. **Results:** maternal reoccupations related to child care in the pandemic were revealed, as well as influences of the pandemic period on family routine; monitoring of children in discontinued health services; overload and fear. These aspects may expose the baby to a greater risk of developmental alterations, as well as affect maternal self-efficacy, since the fear of complications resulting from preterm birth was associated with the anguish of possible contamination by the coronavirus. **Conclusion:** the prematurity experienced in the midst of the COVID-19 pandemic had a negative impact both on the daily life of the family and on the health monitoring of preterm infants. **Descriptors:** Infant, Premature; Pandemics; COVID-19; Self Efficacy; Aftercare

Resumo

Objetivo: entender como mães vivenciaram o cuidado com seus filhos prematuros em casa em meio à pandemia da COVID-19. **Método:** estudo qualitativo, descritivo, desenvolvido entre janeiro e dezembro de 2021, mediante entrevistas remotas com 25 mães de prematuros, após um mês da alta hospitalar, com Análise de Conteúdo temática. **Resultados:** desvelaram-se preocupações maternas referentes ao cuidado com o filho na pandemia, além de influências do período pandêmico na rotina familiar;



acompanhamento do seguimento das crianças nos serviços de saúde descontinuado; sobrecarga e medo. Esses aspectos podem expor o bebê a maior risco de alterações do seu desenvolvimento, bem como afetar a autoeficácia materna, uma vez que o receio das complicações decorrentes do nascimento prétermo associou-se à angústia de possível contaminação pelo coronavírus. **Conclusão:** a prematuridade vivenciada em meio à pandemia COVID-19 repercutiu negativamente tanto no cotidiano da vida familiar como no acompanhamento de saúde do prematuro.

Descritores: Recém-Nascido Prematuro; Pandemias; COVID-19; Autoeficácia; Assistência ao Convalescente

Resumen

Objetivo: comprender cómo vivieron las madres el cuidado de sus hijos prematuros en el hogar en medio de la pandemia de COVID-19. **Método:** estudio cualitativo, descriptivo, desarrollado entre enero y diciembre de 2021, mediante entrevistas remotas a 25 madres de bebés prematuros, un mes después del alta hospitalaria, con Análisis de Contenido temático. **Resultados:** se revelaron preocupaciones maternas respecto al cuidado de los hijos durante la pandemia, además de las influencias del período pandémico en la rutina familiar; descontinuado el seguimiento de los niños en los servicios de salud; sobrecarga y miedo. Estos aspectos pueden exponer al bebé a un mayor riesgo de cambios en su desarrollo, así como afectar la autoeficacia materna, ya que el miedo a las complicaciones derivadas del parto prematuro se asocia a la angustia de una posible contaminación por el coronavirus. **Conclusión:** la prematuridad vivida en medio de la pandemia de COVID-19 tuvo un impacto negativo tanto en la vida familiar diaria como en el seguimiento de la salud de los bebés prematuros.

Descriptores: Recién Nacido Prematuro; Pandemias; COVID-19; Autoeficacia; Cuidados Posteriores

Introduction

Between 2020 and 2022, as a result of the COVID-19 pandemic, strategies such as social isolation and hygiene measures were implemented in an attempt to contain contamination, reduce hospitalization and deaths.¹ However, other aspects of the population's health care were not considered and these clients became vulnerable, resulting in negative effects due to the lack of adequate care.²

In this context, there was an increase in premature births and low birth weight, which increases the newborn's predisposition to morbidity and mortality, when compared to those born at term and of adequate weight, and who do not require complex care.³⁻⁴ Due to the hospitalization of the Preterm Newborn (PTNB), separation from their mother occurs, which influences the bond between them, in addition to interfering with the development of healthy parenting.⁵ Discharge from the hospital unit is the most expected moment for parents, but at the same time more feared, given the prospect of returning home, since the questioning about parenteral self-efficacy emerges. This is defined as a skill, characterized by the individual's perception of his capabilities in the exercise of a certain activity.⁶ In this sense, parents feel less

confident about caring for their preterm child without the help of the professional team and added to this feeling, there is the anguish and fear of parents in caring for the PTNB at home in the midst of a pandemic.

The Neonatal Intensive Care Unit (NICU) by itself is characterized as an environment that generates situational stress for parents and can have long-term negative consequences on parent-child interaction and child development. Thus, experiencing this context associated with a contagious disease, such as that triggered by coronavirus type 2, exacerbates this stress. It was evidenced that most parents of babies admitted to the NICU during isolation due to COVID-19, considered this period stressful, among other things due to restricted visitation rules.8 Thus, experiencing the birth of a preterm child and all its demands in the midst of the pandemic can imply repercussions not only in home care after hospital discharge, but also throughout childhood. And despite the resoluteness of the pandemic period, the population is not free to experience similar situations again.

Thus, understanding how the possible difficulties faced by mothers in the hospitalization of preterm newborn with the advent of COVID-19 interfere in family daily life and in the care of Preterm newborn is a knowledge gap in the neonatal area. Therefore, it is important to record the consequences of this situation in postnatal care, due to the implicit long-term bonding problems and the psychosocial implications for parents, which will allow subsidies to propose policies of care and participation and adequate support to parents in the NICU, in case of a new pandemic.

Among the possible repercussions, there is the possibility of the non-development of the bond between mother and child resulting from the separation due to the need for hospitalization, which leads to the lack of "positive affection" for the baby. This is understood as the baby's response to the mother's interactions. 10 Thus, the limited or non-existent connection in the face of hospitalization psychologically affects the mother, who experiences stress, anxiety and worry, impairing maternal and parental self-efficacy for care, which will hinder the development of healthy parenting of PTNB parents.⁶⁻¹¹

Preterm birth generates anguish and affliction for mothers. And when the baby is discharged, especially in the midst of a critical situation such as that experienced since 2020, it is necessary to deal with the care inherent to prematurity and with those related to the contamination prevention measures imposed by the pandemic. With the strategies of social isolation and restrictions, fear and insecurities became part of the daily lives of mothers and families. The new rules established prevented some care in the NICU, such as the kangaroo method and skin-to-skin contact, impairing the bond and development of the child, having the effect of reducing maternal self-efficacy for care, creating situations of stress and depression in the puerperium period.¹²⁻¹³

Therefore, the objective was to understand how mothers experienced the care of their preterm children at home in the midst of the COVID-19 pandemic.

Method

Qualitative, descriptive research with mothers of preterm infants born from January to December 2021, in a university hospital in Paraná.

Participation in the study was of the convenience type, in which mothers (over 18 years old) of preterm infants were included, with no report of use of psychotropic drugs, without a medical diagnosis of anxiety and/or depression. After three unsuccessful attempts at contact by instant message or call, mothers of preterm infants with congenital malformations and those whose preterm children died of PTNB after hospital discharge were excluded.

Data collection was conducted by the researcher, a nursing student trained for this purpose. The semi-structured interviews took place through a quick messaging app. The mothers signed the Informed Consent Form in the first week of hospitalization of the PTNB in the NICU, when they were enrolled in the study. In this face-to-face contact, they were informed that, one month after hospital discharge, they would receive a phone call and/or an instant messaging app message to schedule the interview, which should happen as soon as possible after the completion of that month. The participants were informed about the reasons why the investigation was being developed – to bring feedback on the follow-up to the NICU health team and to make records on the relationship of home care for preterm infants in the pandemic environment for future studies and comparisons in relation to the development of these children, from the maternal perspective. The collection was terminated based on the criterion of theoretical data saturation, ¹⁴ that is, when the research question and the objectives were answered.

The leading questions of the interviews were: How is the care of your preterm child at home? How is it going for you to take care of your child in the midst of the COVID-19 pandemic?

When such questions were answered superficially, there were new questions from the interviewer, guided by the interview script, in order to obtain more in-depth answers. Pilot testing was not used, as these are comprehensive questions that allowed for individualized and detailed experience reports.

The answers were sent by written and audio messages by the mothers, without a size or time limit, being transcribed and checked by a second researcher, validated by the participants by the consent of the transcription via communication by the instant messaging app. The analytical process conformed the themes inductively following the guidelines of Content Analysis, in the thematic modality. 15 This process involved the search for repeated patterns of meaning, in a constant back and forth movement in the data set. First, repeated readings of the data were made, looking for meanings, patterns, allowing familiarization with the data. Subsequently, the initial codes were produced, identifying the characteristics of the data to be considered in relation to the analyzed phenomenon, whether semantic or latent. From the double coding of all data and their grouping, the code list was obtained, generating potential themes. With the revision of the themes, in which the refinement of these was made, the thematic map of the data was obtained and the denomination of the final themes was passed.15

The confidentiality of the information was maintained based on the following coding: "I" of interviewee, the position number in the interviews, and right after "G" in case of twin or "TG" in case of triplets (Ex: I1G, I2, I25TG...). The names mentioned by the participants were replaced only by the initial (Ex: John = J). The consolidated criteria for reporting qualitative research -COREQ for the preparation of this manuscript were followed.

This research was conducted in accordance with the ethical standards described in Resolutions 466/2012 - 510/2016 - 580/2018, of the Ministry of Health, and is part of the project "Repercussions of prematurity: maternal stress and metabolic programming after hospital discharge/stress and maternal role after an educational intervention", approved by the Research Ethics Committee by opinion 5.078.538, CAAE 16348813.7.0000.0107 on November 4, 2021.

Results

During the study period, a total of 90 mothers had their children hospitalized in the NICU, of which 38 were eligible and enrolled in the initial research sample according to the inclusion or exclusion criteria of the research. However, in the contact one month after the preterm infant was discharged to schedule the interviews, there was success in contacting 25 mothers, the others did not answer the phone call or did not return the requested information via instant messaging application, even after numerous attempts to contact them.

Of the 25 participants, five of them were mothers of twins and one of triplets, aged between 19 and 41 years. The participants were mainly characterized by having had a cesarean section, being multiparous, having completed high school, being inserted in the labor market, living with their companions, who worked outside and participated very little in care, with a mean monthly income of up to two minimum wages, and one reported that she was only maintaining emergency aid. The total number of preterm infants was 31, of which 14 were extreme preterm infants (up to 31 weeks and 6 days), nine were moderate preterm infants (31 to 33 weeks and 6 days) and two were late preterm infants (34 to 36 weeks and 6 days).

From the analysis of the research corpus and after reviewing the themes and their refinement, the thematic map was obtained, and two thematic categories were extracted: "Maternal concerns with care in the pandemic" and "Influences of the pandemic and the care of preterm infants".

In the category maternal concerns with care in the pandemic, the following subcategories were identified: fear of prematurity; not knowing how to care after hospital discharge; difficulties in home care; possible complications; lack of support that caused maternal overload.

The mothers demonstrated the feeling of fear in the face of the child's prematurity, from the moment of rupture of the membranes to concerns about the development and possible sequelae arising in the baby.

> My water had broken, and I was a little afraid [...] they were going to be born prematurely. (I1G, multiparous)

> Greater concern is about his psychomotor development, and possible sequelae associated with prematurity. (I19, multiparous)

The reports also showed the fear of not knowing how to care for the PTNB after hospital discharge and how the mothers faced this situation, demonstrating doubts, skills, and selfconfidence for care.

> I confess that the care of preterm infants is much stricter, [...], but nothing that we cannot go through. (I1G, multiparous)

> I had the impression that it wasn't going to work out, that I wasn't going to be able to (take

In the home context, mothers experienced difficulties in PTNB care due to size and lack of knowledge about how to care and how to observe nursing care during hospitalization in the NICU helped in self-efficacy.

[...] I had never even bathed P., and you imagine, he was not even two kilos, I was very worried. (I2, primiparous)

At first it was more fear, I didn't know what it was like to take care of a preterm baby, but as the days went by, everything went smoothly. (I5, multiparous)

At the hospital I was thinking about how I'm going to do with her so tiny small [...], but I'm doing very well thank God. I paid attention to the nurses in the hospital, I followed the rhythm with the care, it's working. (18, multiparous)

Regarding fear, the mothers also mentioned possible complications, such as respiratory arrest, broncho aspiration, respiratory diseases, gastrointestinal disorders and difficulty in identifying the cause of murmurs and guttural sounds, thus not adequately developing the maternal role.

The biggest fear was apnea but thank God everything goes well. (I5, multiparous) My concern is only that he drowns with breast milk, but this I am taking good care of and if this happens, I already know how to do the maneuver to vent him. (I11, primiparous) It makes me worried when he grumbles a lot I don't know if it's pain or something else. (I7, multiparous)

The biggest concern is her catching some respiratory disease. (I22, primiparous) My biggest difficulty so far is adapting them to the milk formula, they have constipation, so it ends up causing persistent cramps and vomiting, as a result they end up drowning. (I25TG, multiparous)

Measures to prevent contamination by COVID-19 prevented mothers of PTNBs from having family and social support for care at home. This condition led to maternal overload, as it was difficult to adapt to the baby's routine, in addition to loneliness and fatigue.

I take care of him alone [...] so it's more difficult (I13G, primiparous).

The routine has been a little tiring. Only I take care of him. (I21, primiparous)

So the care for them at home is well drawn because they are three children, they need attention at all times. (125TG, multiparous)

The biggest difficulty was adapting to their schedules, but I'm doing well. (I14G, multiparous)

The experience lived by the mothers demonstrated a risk of greater cumulative stress caused by a combination of factors related to the health of the preterm baby and stressors related to COVID-19. Themes present among them included fear of infecting the baby, loneliness and fears caused by restrictions that disrupted daily routines. These feelings can

interfere with maternal self-efficacy for home care, as they allow mothers to feel less confident in their ability to care, requiring adequate support from health services throughout the first years of life of the PTNB, to minimize the seguelae arising from the pandemic period.

In the category Influences of the pandemic and the care of preterm infants, the following subcategories emerged: changes in routine at home, fear of taking the PTNB to health services and changes in health service care.

In the context of prematurity and the pandemic, the participating mothers reported changes in the routine at home, due to the indication of social isolation due to the risk of contamination in COVID-19, preventing the receipt of visits to adhere to preventive measures.

> The pandemic is affecting our routine. I'm not getting any visits from friends, just their grandparents. (I13G, primiparous)

> When M. was discharged from the hospital, we chose not to receive visits at home, so we stayed at home for a couple of months, we only went out to go to the pediatrician, with all the care, washing our hands, using alcohol gel, wearing a mask always and to this day we have this care. Now, as soon as we started going out, going to the grandparents' house, to the aunts' house, but always with the same care, , every time someone picks him up I ask them to use hand sanitizer, wear a mask, especially because he is premature, I believe he is a little more fragile than other babies born after 40 weeks. So, all the care we received at the hospital that nurses gave me, I'm trying to provide at home too, because this pandemic is still very worrying. (124, multiparous)

The experience of the pandemic moment and the care of a preterm child at home generated concerns for mothers associated with both contexts, in which the possible consequences of a premature birth for the development of the child, as well as the complications that could occur and the performance of routine care tasks such as bathing and fear of caring for a preterm child due to low weight are factors that led mothers to experience the feeling of fear. In addition, the care provided to preterm infants was only provided by the mother, as the requirement of physical distancing due to the pandemic prevented the support network from being activated, which led to maternal overload. The way of caring for preterm infants underwent changes due to the period of distancing and the restriction of physical contact between family members who did not live in the same household was one of the important elements to modify the routine at home.

Mothers who had their children born prematurely, when discharged from the NICU, reported fear of taking them to the health service due to the risk of contamination by COVID-19. In addition, mothers reported changes in the care of health services.

I was more or less afraid to go to the physician with him. (I4, multiparous).

Ah, I'm even afraid to take him to the hospital, but I have to. And that's all I go out with *him for, for consultations that are not few.* (I20, primiparous)

The monitoring of preterm infants in health services, both in primary care and in the monitoring outpatient clinic, changed with the pandemic, as the fear of contamination contributed to the mother not attending consultations periodically. In addition to the monitoring in the hospital outpatient clinic, this monitoring should take place in primary health care, but was prevented due to the overcrowding of the units for restricted Covid-19 care, leaving the PTNB population and the puerperal women without coverage.

Discussion

As in other studies that analyze the relationship between prematurity and maternal emotions, in this investigation mothers showed fear and concerns due to their child's prematurity. Faced with the need for hospitalization of the preterm child, maternal expectations are deconstructed, generating fears and feelings of guilt, impotence and incompleteness. Since, in the NICU, the PTNB depends on professionals and technologies to survive, the mother feels completely powerless in the face of the perception that it is no longer a safe home for her baby, to be a coadjuvant in her care. 16-17 However, the mothers reported relief at being discharged from hospital, synonymous with the child's evolution and improvement.

Fear, a feeling present among the interviewed mothers, can compromise the development and growth of the PTNB, given the complexity of his care due to unhealthy parenting, which results from the abrupt separation of the child and the situational stress experienced by the birth of the preterm child. It is clear, therefore, that the importance of follow-up after the discharge of these preterm infants is essential to identify the possible complications due to the prematurity itself, as well as those related to the fact that they did not become parents adequately. 18 However, during the COVID-19 pandemic, this activity did not occur.

To minimize these feelings, the health team must carry out the practice of mothering with the mother in the NICU, so that she becomes more confident in her parental role. ¹⁹ When she is not offered, the feeling of powerlessness and uselessness can be generated, potentially harmful to perceptions and the development of the maternal role. 6,20

The greater complexity in care after discharge generated insecurities for home care. The

lack of professional support can lead to doubts for the mother regarding her ability to deal with possible situations in the routine of home care, ²¹ contributing to impaired parental self-efficacy. However, when the NICU team is careful to include mothers in the routine during hospitalization and manages to stimulate the bond between PTNB and mother, it provides security and encourages them to learn about child care, especially through observation. In this way, the development of the baby is benefited, since the level of stress is reduced, reflecting on the increase in self-efficacy for care, which influences breastfeeding and the creation of a bond between the baby and the mother, reducing the length of hospital stay.²² The Social Cognitive Theory, ⁶ describes learning by observation and, later, imitation, in which the level of self-efficacy and confidence in activities is established according to the frequency of successes and failures in carrying them out, with the environment and resources as influencers.

The testimonies refer to self-comfort, hope and confidence that everything remains under their control, in which self-efficacy for care is apprehended. The context of the study was formed by primiparous and multiparous mothers, a fact that was not indicative of less or greater concern with the care of the preterm child. Since the arrival of a preterm baby at home causes changes in virtually all areas, physical and emotional health, finance, structural and social, they can be seen as challenges by the family.²³

The COVID-19 pandemic devastated the world with a high rate of contamination and deaths.²⁴ In addition, the rate of preterm and low birth weight childbirths increased, probably not due to the pathology, but due to the decrease in coverage for monitoring and assistance to pregnant women, causing an increase in the mortality rates of pregnant women and preterm babies.¹³

This pandemic context influenced the perception of the mothers of preterm infants, who identified the changes in routine at home with the arrival of the child after hospital discharge, the non-receipt of visits to the baby, going from frequent to sporadic and with a lot of preventive care. The pandemic, therefore, affected one of the most common and expected practices from the birth of a baby, that of receiving friends and relatives at home to meet the new member of the family, something that stopped happening or became less frequent and depended on many care, such as the use of masks and hand hygiene. In addition, the need to leave the house with the baby, whether for consultations or other activities, was a factor that generated fear of contagion. These aspects reflected in the lack of support for mothers by other

family members, leading them to overload with the care of the preterm child and the other routines of the house, as well as not monitoring the health of the preterm baby in the follow-up outpatient clinic.

Thus, return consultations at the hospital outpatient clinic were replaced by monitoring in primary health care, but as this sector was suffering saturation by the demands of the pandemic, routine monitoring of childcare was not being offered. Thus, not monitoring the health of preterm infants makes them more prone to risks and changes in development compared to those who are assisted.²⁵

Monitoring was hampered in the pandemic by lower adherence to consultations to avoid contamination of preterm infants and by the absence of professionals due to illness or because they are from risk groups and their relocation to other sectors of COVID-19 care. This situation made it difficult to assist other cases, which was mitigated by the use of teleconsultations, video calls, messages, in order to contribute to the bond of the family and the baby with the local health facilities.²⁶⁻²⁷

In the absence or reduction of monitoring the health of preterm infants, many feelings of fear about complications with the child became present and could not be clarified by professionals. It is known that preterm infants are susceptible to the risk of aspiration and gastroesophageal reflux due to their immaturity.²⁴ The greatest concern of mothers is about possible drowning, but some report having already learned the maneuver and care. Other fears mentioned were apnea, which is not an unrealistic situation, since neonatal apnea is quite common, prevalent in newborns with craniofacial anomalies, neurological disorders and airway malformations.²⁸ Therefore, in the face of maternal fears, it is important monitoring at the follow-up outpatient clinic or in primary care health units so that the family feels welcomed and safe in the face of the possibility of these complications. In hospitalization, parents must be prepared through health education about the danger signs that can endanger the baby's life and those that require outpatient consultation, to prevent family stress with the fear of what may occur and prevent harm to the baby's health.²⁹

Maternal overload, as the mother is the only full-time caregiver, is added to the restriction of visits and, thus, to the support of the support network that this mother could count on if there were no pandemic installed. Prematurity causes care to be provided with greater dedication, requiring more time in these tasks.²³ Thus, mothers experience a lack of

time for rest, recovery and sleep, and increased family support would reduce maternal burdens and improve their mental health.²⁷

The experiences reported by the mothers in this study are similar to those evidenced in the literature regarding the experience of prematurity in times of COVID-19, in which it was indicated that restrictions on entry into neonatal units to prevent the transmission of the virus limited interaction with the preterm child and with the healthcare team. In addition to increasing demands for care that was discontinued, communication failures, lack of guidance and delays in the application of vaccines increased.³⁰

This study sought to present contributions to professional practice in the NICU, especially to the clinical practice of nurses, who should consider in their evaluations and planning of the care of mothers of preterm infants the assessment of maternal self-efficacy for care and greater vulnerability to child development of preterm infants born in the pandemic period, due to the conviviality between disabled peers and the need for isolation and social distancing, as well as the overload of maternal attributions that can lead to the reduction of moments of stimulation to child development.

The restrictions reported by the mothers and the emergence of exacerbated fear in relation to contamination were due to the lack of knowledge that the COVID-19 disease could affect the baby, who is already considered fragile under normal conditions, being an imminent risk within a pandemic. This lack of knowledge, in addition to causing insecurity, constant concerns and affecting the mental health of caregivers, who returned to their lives to daily care and constant fear of possible contamination, also affected families in relation to wear and tear, due to social isolation.

This context should be considered as a possible factor that interferes with maternal self-efficacy for care, since when mothers feel safe and confident in their care skills, they tend to reduce anxiety and offer more fruitful care. Also, as during the pandemic mothers had less contact with the NICU team, the preparation for discharge and home care did not occur effectively. This lack of adequate preparation contributed to mothers experiencing feelings of fear and insecurity, implying decision-making based on these feelings and ignorance. These mothers may have, in the long term, reduced self-efficacy and compromise child care.

The continued monitoring of those born during the pandemic period should be one of the care of the health teams of both the risk newborn outpatient clinic and primary care, as these children and their families, in addition to prematurity, have experienced moments of greater stress, which is one of the factors that generate changes in maternal self-efficacy for care and this influence on the parental role and, thus, may have repercussions on the development and growth of these children.^{11,21}

The research limit is the type of methodological design, considering that it was necessary to conduct the interviews remotely due to the pandemic period, which may interfere with the mothers' responses and prevented the non-verbal dialogue that emerges in face-to-face contact. This is because, in addition to participating online, the mothers were alone to take care of the PTNB.

Conclusion

The pandemic and prematurity influenced the family routine, modifying the way of caring for the preterm infant, since, as a result of prevention and restriction measures, there was a greater maternal burden due to the lack of support from friends and extended family, as well as increased difficulty in monitoring the preterm infant, due to the excessive demand for health services.

Despite this, the study contributes to the understanding that the experience of mothers in the care of PTNB during the pandemic can further interfere with maternal self-efficacy. In addition, it demonstrates the need for monitoring by health services, which can be carried out through the use of technologies, such as online consultation, the adequacy of specialized services for face-to-face care, when necessary, and the improvement of staff sizing and the work process in the care devices for PTNB and their families, at different levels of health care. In addition, the strengthening of primary health care for this specificity of care with regard to the active search and monitoring of this clientele in the territory.

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Chief Scientific Editor: Cristiane Cardoso de Paula **Associate Editor:** Rosane Cordeiro Burla de Aguiar

How to quote this article

Martinelli EC, Silva AD, Machineski GG, Reis ACE, Viera CS. Post-discharge home care of preterm infants during the Covid-19 pandemic. Rev. Enferm. UFSM. 2023 [Access at: Year Month Day]; vol.13, e37: 1-16. DOI: https://doi.org/10.5902/2179769283804