Restriction of follow-up of premature infants in the COVID-19 pandemic: a mixed approach

Restrição do acompanhamento de lactentes prematuros na pandemia da COVID-19: abordagem mista

Restricción del seguimiento de lactantes prematuros en la pandemia de COVID-19: enfoque mixto

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Abstract

Objective: To analyze the factors associated with restricting the follow-up of infants who were born premature and/or low birth weight during the COVID-19 pandemic and mothers' and health professionals' perception regarding this reality.

Methods: This is mixed methods research with a parallel convergent design, carried out with 14 mothers of infants who were born premature and/or low birth weight, followed up at a follow-up outpatient clinic of a maternity hospital in a municipality in Paraíba, and four health professionals from this service. Data collection was carried out from June to July 2020, concomitantly, in a secondary data source, consisting of all 140 medical records of the respective infants for a quantitative approach, through a semi-structured interview, for a qualitative approach. Quantitative analysis was performed using descriptive and inferential statistics, and qualitative analysis, according to inductive thematic analysis.

Results: There was a significant association between infant age and the restriction of their follow-up during the pandemic, with prioritization of one-to-one care for children under six months of age, occasional contacts with family members, via phone call or digital application, and gaps in updating the vaccination schedule of those whose follow-up was interrupted. This generated dissatisfaction on the part of mothers and fear of harm to the development of infants. There was also no continuity of care for these in the Basic Health Unit.

Conclusion: There were restrictions on follow-up of premature infants in the follow-up service during the pandemic, generating maternal dissatisfaction and fear of damage to the development of their children.

Resumo

Objetivo: Analisar os fatores associados à restrição do acompanhamento de lactentes que nasceram prematuros e/ou baixo peso durante a pandemia da COVID-19 e a percepção de mães e profissionais de saúde quanto a essa realidade.

Métodos: Pesquisa de método misto com delineamento paralelo convergente, realizada com 14 mães de lactentes que nasceram prematuros e/ou baixo peso acompanhados no ambulatório de *follow-up* de uma maternidade em um município da Paraíba, e quatro profissionais de saúde desse serviço. A coleta de dados foi realizada no período de junho a julho de 2020, concomitantemente, em fonte de dados secundários, constituída de todos os 140 prontuários dos respectivos lactentes para abordagem quantitativa, por meio de entrevista semiestruturada, para abordagem qualitativa. A análise quantitativa ocorreu por estatística descritiva e inferencial, e a qualitativa, conforme análise temática indutiva.

Resultados: Houve associação significativa entre a idade dos lactentes e a restrição do seu acompanhamento no *follow-up* durante a pandemia, com priorização do atendimento presencial dos menores de seis

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meses, contatos pontuais com os familiares, via ligação telefônica ou aplicativo digital, e lacunas na atualização do calendário vacinal dos que tiveram o acompanhamento interrompido. Isso gerou insatisfação das mães e receio de prejuízos ao desenvolvimento dos lactentes. Também não houve continuidade do cuidado desses na unidade básica de saúde.

Conclusão: Houveram restrições no acompanhamento dos lactentes nascidos prematuros no serviço de *follow-up* durante a pandemia, gerando insatisfação materna e receio de prejuízos ao desenvolvimento de seus filhos.

Resumen

Objetivo: Analizar los factores asociados a la restricción del seguimiento de lactantes que nacieron prematuros o de bajo peso durante la pandemia de COVID-19 y la percepción de madres y profesionales de la salud respecto a esta realidad.

Métodos: Estudio de método mixto con diseño paralelo convergente, realizado con 14 madres de lactantes que nacieron prematuros o de bajo peso atendidos en consultorios externos de *follow-up* de una maternidad en un municipio del estado de Paraíba, y cuatro profesionales de la salud de este servicio. La recopilación de datos fue realizada en el período de junio a julio de 2020, simultáneamente en fuente de datos secundarios, compuesta por las 140 historias clínicas de los respectivos lactantes para el enfoque cuantitativo, por medio de entrevista semiestructurada, para el enfoque cualitativo. El análisis cuantitativo se llevó a cabo por estadística descriptiva e inferencial, y el cualitativo mediante análisis temático inductivo.

Resultados: Hubo relación significativa entre la edad de los lactantes y la restricción de su seguimiento en el *follow-up* durante la pandemia, con priorización de atención presencial a los menores de seis meses, contactos puntuales con los familiares, vía llamada telefónica o aplicación digital, y vacíos en la actualización del calendario de vacunación de los que tuvieron el seguimiento interrumpido. Esto generó insatisfacción de las madres y temor de perjudicar el desarrollo de los lactantes. Tampoco hubo continuidad del cuidado de estos en la unidad básica de salud.

Conclusión: Hubo restricciones en el seguimiento de los lactantes nacidos prematuros en el servicio de *follow-up* durante la pandemia, lo que generó insatisfacción materna y temor de perjudicar el desarrollo de sus hijos.

Introduction

The year 2020 was marked by the emergence of the COVID-19 pandemic, bringing repercussions to the lives and health of people around the world. The number of new cases and deaths increases rapidly, in real time,[1] challenging all scholars and health professionals, who still do not have answers about the real impact of the virus and the disease on society.[2]

Although children are not considered a risk group, those born prematurely require a holistic look at their health needs during the pandemic.[3,4] However, child care services have weaknesses, putting their lives at risk and impacting 61% of neonatal deaths.[5] Furthermore, a study showed that 40% of children who were infected with the coronavirus and needed hospitalization were premature.[6]

It is noteworthy that preterm newborns (PTNB), after hospital discharge, are followed-up. This service consists of an outpatient follow-up with a multidisciplinary team, which must ensure a comprehensive child assessment, in order to reduce the number of infections and hospitalizations and promote healthy growth and development.[7]

Despite the importance of follow-up in premature child care, the COVID-19 pandemic caused restrictions in this follow-up.[8] This was due to changes in the care routine and in the number of professionals in this service, in order to prevent the spread of the virus, and, consequently, many pediatric outpatient services suspended their visits.[9,10]

With the temporary suspension of elective appointments at a follow-up outpatient clinic for asymptomatic premature children, as recommended by the Ministry of Health in 2020,[11] parents began to show anxiety and concerns about health, food, medication and the protection of their children.[12,13]

It is worth noting that children who do not attend follow-up have worse vital conditions and higher rates of disabilities.[14] Even in the face of the restrictions imposed by the pandemic, outpatient follow-up of PTNB and the establishment of the bond between health professionals and the family is urgent.[15,16]

Discontinuity in follow-up of PTNB can cause physical, psychological and neurological damage, intensifying the vulnerabilities resulting from the health condition and interfering with their quality of life.[17] A study points out that mothers' fear of exposing their children to the risk of contagion by the SARS-CoV-2 virus, especially when traveling to health services, also resulted in the discontinuation of child care.[18] As a result, distancing from the service and health professionals can generate in-

security in mothers regarding child care, because, in addition to not having the support from health professionals, restriction of meetings with family members limits the support they could provide in premature infant care.[19]

Exploring the aspects that are related to the restriction of follow-up in a specialized outpatient clinic, during the COVID-19 pandemic, of infants who were born preterm and/or low birth weight is essential. In addition to this, it is important to understand the repercussions for babies and their families, given this restriction of follow-up.

Because it is a complex topic that encompasses quantitative data, related to the characteristics of infants who were born premature and/or low birth weight with restrictions in follow-up, as well as qualitative data regarding health professionals' and mothers' perception, who are experiencing this whole process of change in outpatient care and in the care routine for infants, it is necessary to use mixed methods. It is believed that the combination of quantitative and qualitative approaches is an innovative option that may allow a broader and deeper understanding of this object of study.

Therefore, the present study seeks to answer the following question: How do factors associated with restricting the follow-up of infants who were born preterm and/or low birth weight during the COVID-19 pandemic converge and/or diverge with mothers' and health professionals' perception? What is their perception regarding the restriction of care for these children? To answer these questions, the objective was to analyze the factors associated with restricting the follow-up of infants who were born premature and/or low birth weight during the COVID-19 pandemic and mothers' and health professionals' perception regarding this reality.

Methods

This is a mixed methods research, convergent parallel design (QUAN+QUAL), in which quantitative and qualitative data are collected simultaneously and then compared, in order to determine convergences and divergences between them.[20] The criteria established by the Mixed Methods Appraisal Tool (2018 version) were considered.[21] The quantitative design corresponded to a cross-sectional study, of the documentary type, and the qualitative investigation was of the exploratory-descriptive type.

The study site was at a public maternity hospital in a municipality in Paraíba, northeast region of Brazil, a reference in maternal and child care that provides assistance in the pregnancy-puerperal cycle and to prematurely discharged, up to two years of age.

The population consisted of mothers of infants who were born premature and/or low birth weight and were followed up at a follow-up outpatient clinic in a maternity hospital in a municipality in Paraíba and health professionals from this service.

The sample consisted of 14 mothers and four health professionals. Based on the number available in infants' medical records, 32 mothers were contacted, of which 19 met the following inclusion criteria: being the mother of infants who were born prematurely and/or low birth weight from the kangaroo mother unit of the aforementioned maternity hospital, who had their follow-up interrupted or restricted due to the COVID-19 pandemic, and being over 18 years of age. However, five mothers were excluded for refusing to participate in the research. As for professionals, from a list provided by the service manager with telephone numbers, four were contacted and included for following up the growth and development of infants in the follow-up service for at least 3 months.

Thus, the first approach took place by telephone and in a systematic way, so that, at the time, the research objectives were presented, the invitation to participate was made and, if so, the interview was scheduled according to availability. In cases of refusal, the next person on the list was contacted, and so on.

Since it is a census sample, i.e., all the records available in the follow-up service were used, the sample calculation was waived.

Quantitative and qualitative data collection was carried out from June to July 2020, concomitantly, as required by the convergent design.[22] In this way, quantitative collection was organized, in person at

the health institution, in a secondary data source with a total of 140 medical records of infants who were born preterm and/or low birth weight, who had undergone kangaroo mother care and who had their follow-up interrupted or restricted due to the COVID-19 pandemic.

A form was used as an instrument, filled in by previously trained collectors to collect information, referring to mothers' sociodemographic characteristics: age, marital status, number of children, works outside the home, education, family income, number of residents in the household, number of children under 5 years of age living in the household; and clinical and infant follow-up data: sex, age, weight and gestational age at birth, presence of comorbidity, type of diet and vaccination schedule at last appointment, and exclusive breastfeeding at discharge, contained in the medical record.

Qualitative data were collected through the semi-structured interview technique, through audio-recorded telephone call on digital media, in view of social isolation during the COVID-19 pandemic. The interviews lasted an average of twenty minutes and were fully transcribed for further analysis. To close the collection of mothers' statements, the sufficiency criterion was used, when it was possible to reflect on the multiple dimensions of the object of study.[23]

Quantitative data were tabulated in double entry to check for inconsistencies and analyzed using statistical software, using descriptive and inferential statistics.

For descriptive analysis, the absolute (n) and relative (percentage) frequency counts of the variables were used. For inferential analysis, Pearson's chi-square test and Fisher's exact test were used, with a significance level of 5% ($p<0.05$) being adopted. Prevalence ratios (PR) and respective confidence intervals were also calculated.

Qualitative data were interpreted according to inductive thematic analysis, which is not part of a ready-made grid of categories or themes, following six phases: Familiarization with the topic, interview transcription, exhaustive re-reading of data and annotation of initial data were carried out; Initial code generation, common data characteristics were coded in affine clusters; Theme search, classifying the different codes into potential themes, as well as grouping the relevant extracts to combine a comprehensive theme; Theme review and refinement, and thematic map design; Theme definition, the essence of each theme was identified, as well as their set, and it was determined which aspects of the data each theme captures; and Final textual production or writing of the report in a concise, coherent, logical, non-repetitive and interesting way of the data, with treatment and interpretation of results in the light of the literature relevant to the topic.[24,25]

Analysis was performed by a pair of researchers who, during the process, sought to ensure data internal homogeneity and external heterogeneity, making it necessary to exclude divergent codes at the end of the analytical process. Subsequently, data mixing was carried out, i.e., quantitative and qualitative analysis in a comparative way, in order to determine convergences, divergences and combinations,[20] as shown in Figure 1. Therefore, data codes were presented integrated, through the joint display strategy, which corresponds to the joint illustrative presentation of quantitative and qualitative data.[22]

The study complied with the ethical precepts of Resolution 466/12 of the Brazilian National Health Council (CNS – *Conselho Nacional de Saúde*), with approval by the Research Ethics Committee, under Opinion 4,045,340. All study participants signed the Informed Consent Form (ICF). Anonymity was guaranteed by coding the speeches with the letter "M" (mother) and "P" (professionals), both followed by the number corresponding to the order of the interview, namely: M1, M2 [...]; P1, P2 [...]. It is noteworthy that each consent was verbally recorded, after reading the informed consent, before the telephone interviews began.

Results

Premature born infants' sociodemographic, clinical and follow-up characteristics are shown in table 1. It is observed that 54.3% were male, 68.6% were over six months old, 59.0% were born late preterm and 57.1% were low birth weight. It is evident that

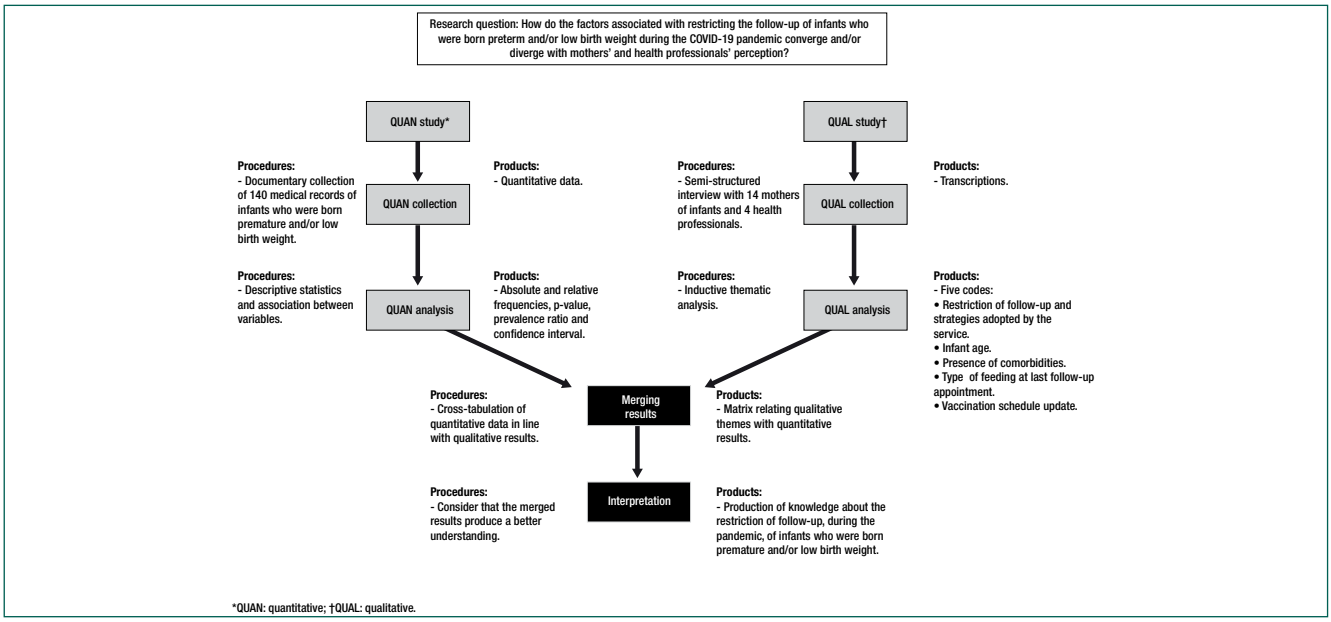

Figure 1. Representative diagram of the study design

58.5% of infants were not being followed up during the COVID-19 pandemic.

In the bivariate analysis, there was a statistically significant association between infant age and follow-up during the pandemic period (p<0.001). Those younger than six months had a follow-up prevalence at follow-up that was 2.37 times higher than those older than six months. Infants with comorbidities had a 1.39-fold higher follow-up prevalence compared to those without comorbidities (Table 1).

Regarding data mixing, the codes and the respective extracts of the qualitative data were mixed with the quantitative results, i.e., data were analyzed and compared, aiming to find points of correlation, making it possible to indicate differences and similarities for a better understanding of the aspects related to restrictions in follow-up of preterm infants during the pandemic period, according to the joint display provided in chart 1.

Discussion

The limitation of this study is related to the cross-sectional design, of the quantitative component, which made it impossible to carry out a longitudinal analysis of the population, as well as several

Table 1. Sociodemographic, clinical and follow-up characteristics of infants born preterm and/or low birth weight linked to follow-up at a public maternity hospital and bivariate analysis with follow-up in the pandemic period

	Follow-up in the pandemic period				
Variables	Total n(%)	Yes n(%)	No n(%)	PR	p-value
Sex					0.25†
Male	76(54.3)	34(45.9)	40(54.1)	1.27	
Female	64(45.7)	22(36.1)	39(63.9)		
Age					<0.001†
≤ 6 months	44(31.4)	28(70.0)	12(30.0)	2.37	
> 6 months	96(68.6)	28(29.5)	67(70.5)		
Birth weight					0.124†
Low weight	80(57.1)	25(33.3)	50(66.7)	-	
Very low weight	31(22.1)	18(58.1)	13(41.9)		
Extremely low weight	11(7.9)	5(45.5)	6(54.5)		
Normal weight	18(12.9)	8(44.4)	10(55.6)		
Gestational age					0.401†
Extreme preterm	1(0.7)	0(0.0)	1(100.0)	-	
Very preterm	21(15.7)	10(47.6)	11(52.4)		
Moderate preterm	33(24.6)	16(48.5)	17(51.5)		
Late preterm	79(59.0)	26(35.1)	48(64.9)		
Presence of comorbidities					0.11†
Yes	72(52.9)	34(47.9)	37(52.1)	1.39	
No	64(47.1)	22(34.4)	42(65.6)		
Type of food at last appointment					0.653‡
Exclusive breastfeeding	34(25.2)	16(47.1)	18(52.9)	-	
Breastfeeding	59(43.7)	25(42.4)	34(57.6)		
Without breastfeeding	42(31.1)	15(36.6)	26(63.4)		
Vaccination schedule at last appointment					0.23‡
Updated	105(89.7)	39(39.0)	61(61.0)	0.67	
Not updated	12(10.3)	7(58.3)	5(41.7)		
Exclusive breastfeeding at discharge					0.65 †
Yes	116(95.1)	47(42.3)	64(57.7)	1.27	
No	6(4.9)	2(33.3)	4(66.7)		

PR - Prevalence Ratio; †Fisher's Exact Test; ‡Chi-square test

Chart 1. Data mixing on sociodemographic, clinical and follow-up characteristics of infants who were born premature and/or low birth weight in the follow-up of a public maternity hospital during the COVID-19 pandemic

Codes	Quantitative investigation	Qualitative investigation
Restriction of follow-up in the follow-up and strategies adopted by the service	58.5% of preterm infants in the follow-up were not followed up during the pandemic period.	I think it's terrible because he already has slow development, and not having a follow-up with a professional ends up being even worse for him. When the suspicions started (of COVID-19), the doctor told me to stay with him at home without going out, and since then, it has been 90 days since he has gone anywhere, except for a vaccine or somewhere else. (M9) She was going to see a neurologist, but she didn't have it because of the thing (COVID-19), everything stopped. (M17) I give my phone number to some (mothers) that I am controlling the child's weight. When the mother has any doubts, she is low on milk, I ask her to make a video to see how she is sucking, if that is the case, I guide her in a better position. (P4).
Infant's age (p<0.001)	Infants younger than six months had a 2.37 times higher prevalence of being followed up during the pandemic period, compared to older infants.	The criteria are children who are still under one year of age and are being followed up monthly [...]. (P1)
Presence of comorbidities	52.1% of preterm infants with comorbidities were not being followed up during the pandemic.	We always give priority to extremely premature babies, those who have neurological problems or any sequel of prematurity. (P2)
Type of food at last follow-up appointment	43.7% of babies were on complementary breastfeeding; 25.2% were on EB and 31.1% were not breastfed.	She turned six months, but I don't know, it's like four. Can I or can't I give her food? Can I give her juice? I could not tell. I'm not going to feed her. I'm scared, all of a sudden I give and she gasps, that's it, I go crazy. So, I'm not going to do that, then I didn't introduce it it, she's still in the milk. (M6)
Vaccine calendar update	41.7% of infants whose vaccination schedule was delayed were not being followed up.	My son has delayed vaccines, the health centers here don't have vaccines either, I'm really worried about that. (M16) There (at health unit) they are only assisting urgent care cases. Only if you have a case of COVID; even vaccines there were late, I didn't want to apply. (M7)

medical records with incomplete records. In the qualitative component, conducting the interviews remotely restricted the identification of participants' non-verbal expressions.

By highlighting the restrictions on follow-up of infants born preterm and/or low birth weight, the findings support strategies for following this group up during and after the pandemic, as well as in other contexts of crises that may happen. Moreover, actions to support caregivers and raise awareness among health professionals are encouraged so that they recognize the importance of child health surveillance and begin to fully follow children's growth and development up in their daily practice.

The pandemic caused by the new coronavirus brought several social changes so that children's appointments were seriously affected.[26,27] In this study, most infants born prematurely (58.5%) were not being followed up, which was corroborated by maternal dissatisfaction and fear that this circumstance could result in greater harm to the development of their children.

This reality is worldwide, as a study carried out with 1120 health professionals and managers from 62 countries found that following up PTNB and/or with health problems has been affected by the COVID-19 pandemic, with the lowest number of professionals in the service, the reduction in the number of appointments and the interrupted home visits.[28]

Health professionals reported that one-to-one follow-up was prioritized in the follow-up of infants under six months of age, as well as those with comorbidities, extreme prematurity and/or low birth weight. However, according to the mother's report, the restriction of following up premature infants hampered support regarding food, especially in relation to complementary feeding introduction.

Contrary to the present study, research highlighted that health professionals clarified doubts and provided guidance on infant feeding in the pandemic, through online and app meetings. This strategy made it possible for mothers to remain informed, empowered and able to start complementary feeding for their children, at the opportune moment, without fear and uncertainty.[29]

With regard to breastfeeding recommendations, during the pandemic, the World Health Organization (WHO), the United Nations Children's Fund (UNICEF) and the Center for Disease Control and Prevention (CDC), from the United States, guide the non-interruption of breastfeeding if there is a suspected or confirmed infection by COVID-19, considering the benefits of breastfeeding and the tiny findings regarding the transmission of other respiratory viruses through breast milk.[30]

Another aspect identified was the agreement between the qualitative and quantitative data related to vaccination, since 41.7% of infants who were not in follow-up had a delayed vaccination schedule, which was reinforced by the mother's report that she was not able to vaccinate her children in PHC. This scenario contradicts the guidelines on continuity of childhood immunization in the pandemic,[31] given that vaccine-preventable deaths outweigh the risk of contagion and death from COVID-19.[32]

In this context, nurses' role in promoting breastfeeding and immunization is highlighted, considering them to be one of the main actors in child care and that can mitigate the damage arising from restrictions in follow-up of PTNB. Thus, it is essential that these professionals strengthen their care practices for this population with vulnerabilities, with more intensity, especially in times of crisis.

Conclusion

Fragility in following up infants with a history of prematurity, during the pandemic, can enhance their vulnerabilities, since, for caregivers to face the new demands of child care at home, support from health professionals is essential. Therefore, in the follow-up service investigated, follow-up was limited to infants younger than six months, restricting appointments with other children, which resulted in failure to update the vaccination schedule and punctual contacts with family members, via phone call or digital application, in order to resolve some doubts about the child. This generated dissatisfaction on the part of mothers and fear of damage to the development of their children. There was also no continuity of care in PHC for infants born prematurely.

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Collaborations

Reichert APS, Soares AR, Guedes ATA, Brito PKH, Bezerra ICS, Santos NCCB and Collet N contributed to study design, data interpretation analysis, article writing, relevant critical review and final approval of the version to be published.

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