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Prevalence of neonatal screening and associated factors in Brazil: a comparison of the 2013 and 2019 National Health Surveys

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Abstract *This study analyzed the prevalence of complete neonatal screening (CNS) of children aged under 2 years in Brazil and associated factors using data from the 2013 (n=4,442) and 2019 (n=5,643) national health surveys. We conducted a cross-sectional study to compare prevalence of CNS (eye, ear and heel prick tests) adopting 95% confidence intervals (95%CI) and a 5% significance level. Crude and adjusted Poisson regression was performed to estimate prevalence ratios (PR) and 95%CI to assess the association between socioeconomic, demographic and health variables and CNS. There was a statistically significant increase in CNS prevalence, from 49.2% (95%CI: 47.1-51.3) in 2013 to 67.4% (95%CI: 65.5-69.3) in 2019. However, large disparities persist across states and between sociodemographic groups. In both years, CNS prevalence was lowest among brown and black children, those from families in the three lowest income quintiles, children without health insurance, those from families registered in the Family Health Strategy and children living in the North, cities outside the state capital/metropolitan regions and rural areas. Despite the increase in prevalence of CNS, deep individual and contextual inequalities persist, posing challenges for health policies.*

Key words *Neonatal screening, Children's health, Health inequalities*

Introduction

Beginning in the 1960s in the United States (US)[1], neonatal screening seeks to ensure the early identification (from birth up to 28 days of life) of disorders and/or diseases in newborns in order to define appropriate interventions and guarantee treatment and follow-up during the life cycle[2,3].

Health problems identified by neonatal screening include congenital cataracts (the leading cause of child blindness, affecting 3-5 per 10,000 children in the US and UK and almost double this in low- and middle-income countries[4]), phenylketonuria (which causes severe brain dysfunction, epilepsy and behavioral problems, with a global prevalence of 1 per 10,000 live births[5]) and hearing impairment (with 34 million children under the age of 15 and 7.5 million under the age of 5 having disabling hearing loss[6]).

Worldwide, only one third of newborns undergo neonatal screening and various countries do not have screening programs[7]. In Latin America, coverage of neonatal screening policies in Cuba, Chile and Uruguay was more than 99% in 2015, while in Asia, South Korea and Japan have screening coverage rates of between 99% and 100%[8]. In China, where guidelines mandate screening for phenylketonuria and congenital hypothyroidism, coverage rates are high, reaching 99% in some cities[9]. In contrast, countries like Pakistan and Indonesia have only private neonatal screening programs, with coverage rates of below 1% and 2%, respectively[8].

In Brazil, neonatal screening was introduced late in 1992 and it was only in 2015 that a specific child health policy, the National Policy for Comprehensive Child Health Care (PNAISC), was created. The aim of the PNAISC is to promote child health through the provision of care during pregnancy and during the first nine years of life, focusing on early childhood and vulnerable populations. One of the key actions in the core area "humanized good quality pregnancy, labor, childbirth and newborn care" is neonatal screening[2].

Since 2016, to be discharged from hospital newborn babies must have undergone the heart and eye test and should do the ear test (during the first month of life) and heel prick test (ideally between the 3rd and 5th day of life), which are all provided free of charge[10]. Despite these recommendations, studies in Brazil have revealed regional, socioeconomic and racial disparities in testing[11,12]. A considerable proportion of children are not screened, and others have only partial access to testing, receiving incomplete neonatal screening. In 2019, only 2.2 million newborns from a total of 2,849,146 (77.2%) were screened by public health services in Brazil[13,14].

Given the sociodemographic, racial and geographic disparities in neonatal screening in Brazil and government interventions to improve access to testing, it is essential to estimate the prevalence of screening and associated characteristics in order to assess the effectiveness of the PNAISC over time[1]. In this sense, data from the 2013 and 2019 national health surveys are useful because they were undertaken before and after the creation of the policy and can therefore show advances and weaknesses in neonatal screening.

This study therefore analyzed the prevalence of complete neonatal screening (CNS) of children aged under 2 years included in the 2013 and 2019 national health surveys and associated factors.

Method

We conducted a cross-sectional study using secondary data from the 2013 and 2019 national health surveys (NHSs). These data were used to identify inequalities in neonatal screening in Brazil.

The surveys were conducted by the Brazilian Institute of Geography and Statistics (IBGE) in partnership with the Ministry of Health and Oswaldo Cruz Foundation (Fiocruz)[15]. Both were nationwide population-based household surveys undertaken to obtain a set of validated data on lifestyle and health indicators that is representative of the Brazilian population.

The target population of the surveys was individuals living in permanent private households in Brazil. The survey questionnaire contained questions about the households and residents. One-third of the items covered specific information about a single resident randomly selected from a list of the people living in the household[15,16].

The NHS uses complex samples selected from clusters of sampling units from selected areas (individual census tracts or tract clusters called primary sampling units (PSUs) selected across all states and representing a subsample of the master sample that makes up IBGE's Integrated Household Survey System (SIPD).

The study used three-stage cluster sampling stratified by primary sampling unit, where the secondary units were the households and the tertiary units were the randomly selected residents who responded the individual section of the

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questionnaire. The census tracts or tract clusters were selected using sampling with probability proportional to the size of the master samples and probability equal to proportion. The households and residents were selected using simple random sampling[15,16].

The 2013 NHS included 64,348 households, with 205,546 residents responding the individual section of the questionnaire, compared to 94,115 households and 279,382 residents in the 2019 survey. For the purposes of the present study, we only analyzed the answers to the items in module "L", which contains questions about children living in the household aged under 2 years[17]. We analyzed data on 4,442 children with information on neonatal screening born between 28/07/2011 and 27/07/2013 from the 2013 NHS and 5,643 children born between 28/07/2017 and 27/07/2019 from the 2019 NHS. Further details on the survey methodology can be found in previous studies on the respective NHSs[15,16].

We used a set of socioeconomic, demographic and health variables for the analysis. The socioeconomic and demographic variables were as follows: color/race (white, brown, black, other); number of people living in the household (1, 2 and ≥3); per capita household income quintiles (1st quintile, 2nd quintile, 3rd quintile, 4th quintile, 5th quintile, where median income in the lowest and highest quintiles in 2013 and 2019 was R$ 113 and R$ 2,976 and R$ 117 and R$ 1,333, respectively); region of residence (North, Northeast, Midwest, Southeast and South); state of residence; place of residence (urban, rural); city of residence (capital, metropolitan region and outside capital/metropolitan region). The health variables were as follows: underwent the heel prick test, ear and eye tests, respectively (yes, no); has health insurance (yes, no); household registered in the Family Health Strategy (FHS) (yes, no).

The data in each neonatal screening test were aggregated to determine the number of tests performed per child in each survey. The outcome variable complete neonatal screening (CNS) refers to children who underwent all three tests mentioned above. The study was limited to these tests because the 2013 NHS did not ask about the heart test, which was only included in the questionnaire in 2019.

We estimated national and state prevalence of neonatal screening and associated 95% confidence intervals (95%CI) in both NHSs for each socioeconomic, demographic and health variable. Differences in prevalence between variables were considered statistically significant when the p-value was <0.05 with non-overlapping 95%CIs. Pearson's chi-squared test was used to confirm these differences between the 2019 and 2013 surveys.

Crude and adjusted Poisson regression with robust variance was used to calculate prevalence ratios (PRs) and respective 95%CIs to determine the association between socioeconomic, demographic and health variables and CNS.

All analyses were performed using RStudio version 2022.2.3.492 (R Foundation for Statistical Computing, Boston, USA) and incorporated all the complex sample design features of the 2013 and 2019 surveys.

The 2013 and 2019 NHS data are available in the public domain. The 2013 and 2019 survey protocols were approved by the National Research Ethics Committee/National Health Council (reference numbers CAAE 10853812.7.0000.0008 and CAAE 11713319.7.0000.0008, respectively). All participants signed an informed consent form[15].

Results

The findings show that there was a statistically significant increase in the overall prevalence of CNS in Brazil, from 49.2% (95%CI: 47.1-51.3) in 2013 to 67.4% in 2019 (95%CI: 65.5-69.3; p-value=0.001), and a statistically significant reduction in the prevalence of children who underwent only two, one or no tests (p-value=0.001). There was a statistically significant increase in the prevalence of CNS in 17 of the 26 states and in the Federal District (p-value<0.01). However, large disparities remained between some states, with CNS prevalence rates in the states of Amapá and Maranhão in 2019 being lower than those in São Paulo and Pará in 2013 (Figure 1).

In both the 2013 and 2019 surveys, prevalence of CNS was highest among whites, children from families in the 5th income quintile, children who had health insurance, and children living in households not registered in the FHS, urban areas, capital cities, metropolitan regions and in the South. There was a statistically significant increase in the prevalence of CNS in white and brown children across all income quintiles, regardless of whether the children had health insurance or lived in a household registered in the FHS, and across both places of residence, all types of cities, and all regions. Despite these increases, significant disparities remained in 2019.

CNS prevalence rates in 2019 among brown children, children from families in the 1st income quintile, those who did not have health insurance, and children living in rural areas, outside capital cities and in the North were lower than those in 2013 among white children, children from families in the 5th income quintile, those with health insurance, and children living in urban areas, capital cities and the South and Southeast. The only variable that did not show disparities in 2019 was being registered with the FHS (Table 1).

The results of the crude analysis (Table 2) show that, in 2013, the chance of undergoing CNS was lowest among brown children, children from families in the 1st income quintile, those who did not have health insurance, children from families registered in the FHS and those living in the North, cities outside the state capital/metropolitan regions and rural areas. The same results were found for the adjusted analysis of the 2013 data and the crude analysis of the 2019 data. The only variable that showed a change in the adjusted analysis of the 2019 data was color/race, with black children having the lowest chance of undergoing CNS. The last column of Table 2 shows the consolidated data for 2013 and 2019 controlled for year effect and the other variables. The results show that the chance of undergoing CNS increased by 37% and 39% in the crude and adjusted analysis, respectively (PR: 1.37; 95%CI: 1.29-1.46 and PR: 1.39; 95%CI: 1.32-1.46) (Table 2).

When the variables were adjusted by year, the results of the crude analysis show that the chance of undergoing CNS was lowest in brown children, children from families in the four lowest income quintiles, those who did not have health insurance, children from families not registered in the FHS and those living in cities outside the state capital/metropolitan regions and rural areas. In the adjusted analysis, the variables that continued to be associated with a lower chance of undergoing CNS were being brown (PR: 0.94; 95%CI: 0.89-0.99), being from families in the 1st (PR: 0.75; 95%CI: 0.68-0.82), second (PR: 0.80; 95%CI: 0.73-0.87) and 3rd (PR: 0.88; 95%CI: 0.82-0.95) income quintiles, not having health insurance (PR: 0.83; 95%CI: 0.79-0.88) and living in cities outside the state capital/metropolitan regions (PR: 0.84; 95%CI: 0.80-0.89) and rural areas (PR: 0.81; 95%CI: 0.75-0.88). Chances were highest in children from families not registered in the FHS (PR: 1.08; 95%CI: 1.03-1.13) and children living in the Midwest (PR: 1.33; 95%CI: 1.21-1.47), Southeast (PR: 1.64; 95%CI: 1.51-1.80) and South (PR: 1.77; 95%CI: 1.61-1.94) (Table 2).

Discussion

The results reveal that there was an increase in the prevalence of CNS between 2013 and 2019, leading to a reduction in the proportion of children who underwent isolated neonatal screening tests. However, 32.6% (95%CI: 30.7-34.5) of children in the 2019 survey had not undergone CNS and only the heel prick test was almost universal (data not shown). The disparities in CNS between regions and groups highlight the challenges faced by the PNAISC in increasing prevalence rates and reducing inequalities to guarantee the right to neonatal care for all in Brazil.

Brazil stands out from other Latin America countries such as Paraguay, Guatemala and Haiti when it comes to neonatal screening. However, nations such as Argentina, Cuba, Chile and Uruguay have higher CNS coverage rates.

Asian countries such as China, South Korea and Japan have always had high coverage rates, while in Europe neonatal screening started slowly and gradually increased, first in western Europe and then in countries in the eastern bloc. Poland stands out from other countries, having had almost 100% coverage since 2004. Other countries in Asia, such as Pakistan and Indonesia, have much lower coverage rates than Brazil[8,9,18,19].

In Brazil, health care was enshrined as a right for all and duty of the state in the 1988 Federal Constitution. The creation of the country's public health system, *o Sistema* Único *de Saúde* (SUS) or Unified Health System in the 1990s, one of the largest health systems in the world, placed Brazil in the spotlight. However, progress towards guaranteeing the right to health has been shaky[20], especially when it comes to vulnerable groups.

Between the 2013 and 2019 NHSs, Brazil went through a political and socioeconomic crisis that impacted all spheres of society, deepening individual and contextual inequalities. This situation aggravated barriers to access to public health services, contributed to the dismantling of institutional rights, amplified threats to the SUS, and led to increase in the number of people in poverty and vulnerable situations that persist today[20].

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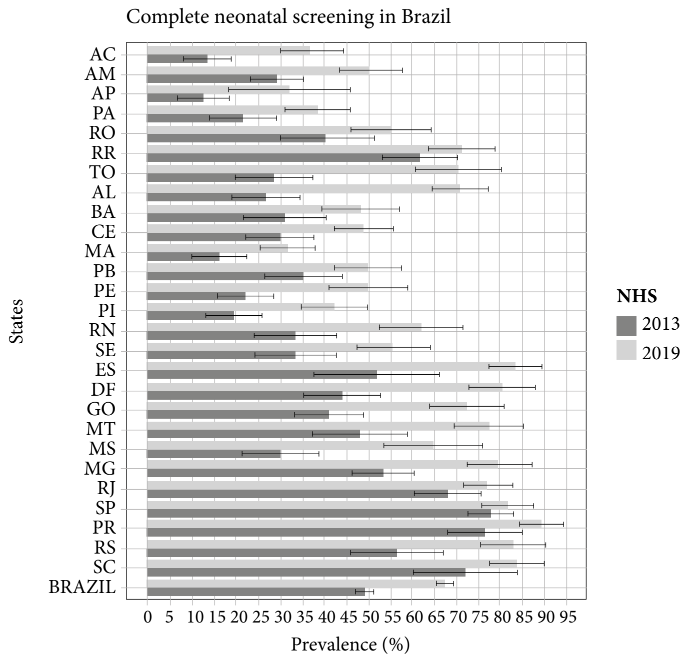

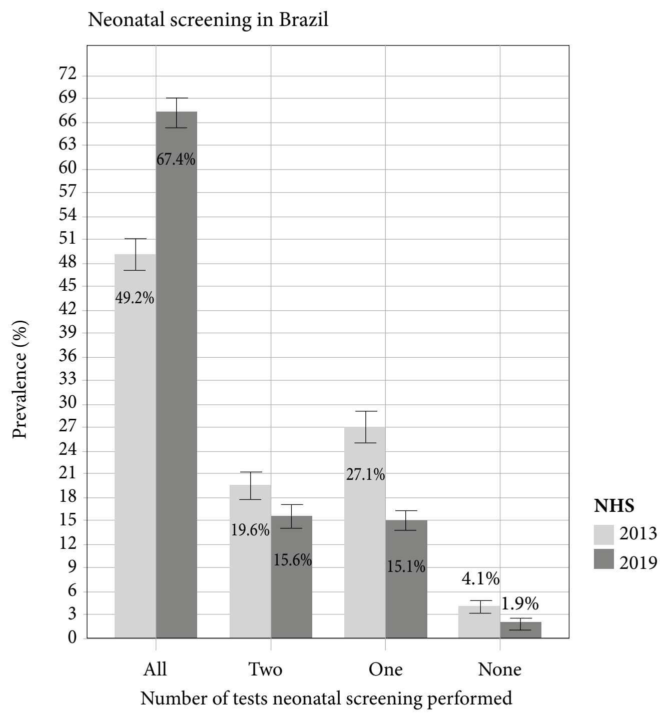

Figure 1. Prevalence of complete neonatal screening at national and state level and number of tests performed based on data from the National Health Survey 2013-2019.

Notes: 1- States: AC - Acre, AM - Amazonas, AP - Amapá, PA - Pará, RO - Rondônia, RR - Roraima, TO - Tocantins, AL - Alagoas, BA - Bahia, CE - Ceará, MA - Maranhão, PB - Paraíba, PE - Pernambuco, PI - Piauí, RN - Rio Grande do Norte, SE - Sergipe, ES - Espírito Santo, DF - Distrito Federal, GO - Goiás, MT - Mato Grosso, MA - Mato Grosso do Sul, MG - Minas Gerais, RJ - Rio de Janeiro, SP - São Paulo, PR - Paraná, RS - Rio Grande do Sul, SC - Santa Catarina. 2- Complete neonatal screening defined as having undergone all three tests (eye, ear and heal prick).

Source: Brazil, NHS, 2013 and 2019.

Table 1. Prevalence of complete neonatal screening in Brazilian children aged under 2 years based on data from the National Health Survey 2013-2019.

Variables	Complete neonatal screening			
	2013		2019	
	%	95%CI	%	95%CI
Color/race				
White	59.7	(56.6-62.7)	75.9	(73.3-78.4)
Black	44.5	(35.2-53.8)	60.7	(53.0-68.3)
Brown	38.1	(34.8-41.3)	59.3	(56.4-62.1)
Other	49.9	(20.5-79.3)	65.4	(49.7-81.1)
Per capita household income				
1st quintile (lowest)	24.2	(20.0-28.3)	47.4	(42.9-51.8)
2nd quintile	35.3	(30.1-40.5)	49.3	(44.9-53.8)
3rd quintile	41.3	(36.4-46.3)	64.4	(59.6-69.1)
4th quintile	61.0	(56.5-65.4)	76.8	(72.9-80.7)
5th quintile (highest)	74.6	(70.0-79.2)	85.3	(82.4-88.2)
Health insurance				
Yes	75.5	(71.5-79.6)	86.5	(83.7-89.3)
No	37.9	(35.4-40.4)	60.0	(57.7. 62.3)
Household registered in the FHS				
Yes	42.2	(39.4-45.0)	63.8	(61.4-66.2)
No	58.8	(55.3-62.2)	74.6	(71.5-77.7)
Place of residence				
Urban areas	53.6	(51.3-55.9)	71.8	(69.6-73.9)
Rural areas	25.8	(21.3-30.3)	44.9	(41.8-48.0)
City				
Capital	60.5	(57.3-63.6)	78.2	(75.4-81.1)
Metropolitan region	57.4	(52.9-61.8)	76.7	(72.7-80.7)
Outside capital/ metropolitan regions	42.3	(39.3-45.4)	61.0	(58.2-63.7)
Region				
North	26.1	(22.0-30.2)	46.3	(42.2-50.4)
Northeast	26.6	(23.5-29.8)	48.5	(45.3-51.7)
Southeast	68.7	(65.1-72.4)	80.4	(76.7-84.0)
South	68.8	(63.1-74.6)	85.7	(82.0-89.4)
Midwest	41.0	(36.4-45.6)	72.7	(67.8-77.5)

Source: Brazil, NHS, 2013 and 2019.

The findings of this study reveal various types of inequality. Despite a reduction in racial disparities in screening over the study period, white people have historically enjoyed proportionally better access to health services than black or brown people[21,22].

While the FHS aims to reduce socioeconomic inequalities in access to services, be a model for the expansion and reorganization of the SUS, and ensure care continuity and longitudinality[23], our findings show that prevalence of CNS was higher in children from families not registered in the program. These children are also from families that have *higher purchasing power* and health insurance. FHS coverage may therefore be a marker of unmet health needs among more vulnerable populations, who have historically been characterized by higher FHS adherence rates.

In a study by Mallmann *et al.*[11], prevalence of test seeking and neonatal screening was higher among children with health insurance, while Pilotto and Celeste[24] reported that the utilization of medical services is higher among this group. This factor therefore reduces barriers to access and facilitates disease prevention.

Geographical inequalities (place of residence, city and region) are related to purchasing power, quality of facilities, infrastructure and health system organization, and level of health workforce training and development[11,25]. There are also differences in the organization of the health care network across all levels of care between regions, weakening health services, especially in more disadvantaged areas[26].

Although notable progress was made in CNS over the study period, efforts to reduce inequalities in Brazil need to be intensified as they persist even after the expansion of the PNAISC. Intersec-

Table 2. Crude and adjusted prevalence ratios showing the association between socioeconomic, demographic and health variables and complete neonatal screening1 in children under two in Brazil based on data from the National Health Surveys, 2013 and 2019.

Variables	2013 (n=4.442)				2019 (n=5.643)				2019/2013 (n=10.085)			
	Complete neonatal screening				Complete neonatal screening				Complete neonatal screening			
	Crude analysis		Adjusted analysis[1]		Crude analysis		Adjusted analysis[1]		Crude analysis[2]		Adjusted analysis[3]	
	PR	95%CI	PR	95%CI	PR	95%CI	PR	95%CI	PR	95%CI	PR	95%CI
Year (2019)	‘	---	1.00	---	1.00	---	1.00	---	1.37	1.29-1.46	1.39	1.32-1.46
Color/race												
White	1.00	---	1.00	---	1.00	---	1.00	---	1.00	---	1.00	---
Brown	0.64	0.57-0.71	0.90	0.81-0.99	0.78	0.74-0.83	0.96	0.91-1.02	0.73	0.69-0.77	0.94	0.89-0.99
Black	0.75	0.60-0.71	0.95	0.79-1.14	0.80	0.70-0.91	0.89	0.79-1.00	0.78	0.70-0.87	0.91	0.82-1.01
Other	0.84	0.47-1.50	0.96	0.58-1.56	0.86	0.68-1.10	0.98	0.76-1.25	0.85	0.66-1.11	0.97	0.75-1.24
Income quintile												
1st quintile (lowest)	0.32	0.27-0.39	0.65	0.53-0.79	0.61	0.57-0.66	0.80	0.72-0.89	0.46	0.42-0.51	0.75	0.68-0.82
2nd quintile	0.47	0.41-0.55	0.79	0.67-0.93	0.86	0.80-0.93	0.79	0.71-0.88	0.54	0.50-0.58	0.80	0.73-0.87
3rd quintile	0.55	0.48-0.64	0.76	0.66-0.88	0.98	0.91-1.06	0.93	0.85-1.01	0.68	0.63-0.73	0.88	0.82-0.95
4th quintile	0.82	0.74-0.90	0.98	0.88-1.09	0.95	0.87-1.03	1.03	0.97-1.11	0.87	0.83-0.92	1.03	0.97-1.09
5th quintile (highest)	1.00	---	1.00	---	1.00	---	1.00	---	1.00	---	1.00	---
Health insurance												
Yes	1.00	---	1.00	---	1.00	---	1.00	---	1.00	---	1.00	---
No	0.50	0.49-0.55	0.76	0.69-0.84	0.69	0.66-0.73	0.88	0.83-0.94	0.62	0.59-0.65	0.83	0.79-0.88
Household registered in the FHS												
Yes	1.00	---	1.00	---	1.00	---	1.00	---	1.00	---	1.00	---
No	1.39	1.27-1.53	1.11	1.02-1.21	1.17	1.11-1.24	1.05	0.99-1.11	1.25	1.19-1.31	1.08	1.03-1.13
Region												
North	1.00	---	1.00	---	1.00	---	1.00	---	1.00	---	1.00	---
Northeast	1.02	0.84-1.24	1.04	0.86-1.25	1.05	0.94-1.17	1.07	0.96-1.18	1.04	0.94-1.15	1.06	0.97-1.16
Midwest	1.57	1.29-1.91	1.25	1.04-1.50	1.57	1.41-1.75	1.36	1.22-1.52	1.58	1.43-1.74	1.33	1.21-1.47
Southeast	2.63	2.23-3.11	1.98	1.68-2.33	1.74	1.57-1.92	1.48	1.34-1.64	2.01	1.84-2.19	1.64	1.51-1.80
South	2.64	2.220-3.15	2.07	1.72-2.49	1.85	1.68-2.04	1.62	1.46-1.80	2.09	1.91-2.29	1.77	1.61-1.94
City of residence												
Capital	1.00	---	1.00	---	1.00	---	1.00	---	1.00	---	1.00	---
Metropolitan region	0.95	0.86-1.04	0.91	0.83-0.99	0.98	0.92-1.04	0.97	0.91-1.03	0.97	0.92-1.02	0.95	0.89-1.00
Outside capital/ met. regions	0.70	0.64-0.76	0.80	0.73-0.88	0.78	0.74-0.83	0.86	0.81-0.91	0.75	0.71-0.79	0.84	0.80-0.89
Place of residence												
Urban area	1.00	---	1.00	---	1.00	---	1.00	---	1.00	---	1.00	---
Rural area	0.48	0.40-0.58	0.78	0.66-0.92	0.63	0.58-0.67	0.82	0.75-0.88	0.57	0.53-0.62	0.81	0.75-0.88

Notes: 1Adjusted for the following variables: color/race, income quintile, health insurance, household registered in the FHS, region, city of residence, place of residence; 2Analysis considering the year of the NHS; 3Adjusted for the following variables: color/race, income quintile, health insurance, household registered in the FHS, region, city of residence, place of residence and year of the NHS.

Source: Brazil, NHS, 2013 and 2019.

toral strategies should be developed to promote coordination and cooperation between different spheres of government, with health, finance and social service departments and agencies working together to provide well-structured services and comprehensive newborn and children's health care[11].

In view of the positive long-term health and socioeconomic benefits of neonatal screening, it is necessary to strengthen the PNAISC by increasing investment and improving the availability of tests on the SUS.

Despite providing important findings, this study has some limitations. First, the fact that testing was self-reported by the child's mother or guardian during the interview means that the data may be subject to recall bias, including confusing the names of the tests. Second, the NHS questionnaire does not ask about the action taken after carrying out the tests. Information on whether the family received the results of the tests or if timely appropriate treatment was provided and child referral through the health system was not available. The 2019 survey questionnaire asked about tests that were not available in 2013, meaning that for the purposes of this study screening was deemed to be complete when the child had undergone the three tests included in both surveys.

Study strengths included the use of nationally representative data for two different periods, providing a broad overview of the situation in Brazil and progress made by neonatal health policies in a country with deep and wide-ranging individual and contextual inequalities. Our findings also revealed stark disparities and the main barriers to CNS, providing important insights to inform further research and the development of strategies to expand the coverage of CNS in Brazil.

In conclusion, this study revealed an increase in the prevalence of CNS in recent years in Brazil. However, large individual and contextual disparities remain, posing challenges for the PNAISC in the pursuit of wide-scale and even CNS coverage in the country.

This study provides important findings that show the progress made by the country's neonatal screening policy, revealing weaknesses in and opportunities to improve health policies and social and economic policies that have an impact on health.

Collaborations

WS Melo and LCS Brito worked on conceptualization, data curation, formal analysis, investigation, and writing – original draft. BLCA Oliveira worked on methodology, project administration, supervision, validation, visualization, and writing – review and editing. LP Barbosa worked on conceptualization, formal analysis, project administration, supervision, validation, and writing – review and editing. MVLML Cardoso worked on supervision, validation, visualization, and writing – review and editing.

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