

Neonatal transport, health outcomes, and psychosocial inequities among Black very preterm infants and their families: Protocol for a mixed-methods study to advance health equity

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Submitted to: JMIR Research Protocols
on: September 25, 2025

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Neonatal transport, health outcomes, and psychosocial inequities among Black very preterm infants and their families: Protocol for a mixed-methods study to advance health equity

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Abstract

Background: Despite medical advancements, preterm birth remains alarmingly high in the United States, contributing significantly to infant mortality and long-term health challenges. Black families are disproportionately affected by these high rates. Very preterm (VPT) infants- those born between 24 and 30 weeks' of gestation- are often delivered at community hospitals that lack specialized neonatal care. These infants require transport to tertiary-level NICUs, which can open the door for complications. In addition to medical complications, neonatal transport can create stress for families and affect parent-infant bonding during a crucial time. These problems are intensified by social vulnerability and perceived discrimination.

Objective: This study examines how neonatal transport affects both infant health outcomes and the psychosocial health of Black parents with VPT infants. It explores how structural inequities, and social vulnerability can shape parental experiences- from delivery and transport to NICU hospitalization.

Methods: Using a longitudinal, multiple-case study design with mixed methods, this research follows 10 cases of VPT Black infants transported from community hospitals in South Carolina between May 2023 and June 2024. Each case includes the infant and mother (with an invitation for partners to participate). Quantitative data includes infant health outcomes extracted from electronic medical records and neighborhood disadvantage assessed using the Area Deprivation Index. Parents complete validated surveys measuring stress, anxiety, depression, bonding, discrimination and access. Qualitative data comes from semi-structured interview guides based on an adaptation of the NIMHD Research Framework. Reflexive thematic analysis is used for to analyze these interviews. Data are integrated within and across cases to create detailed case summaries and cross-case comparisons.

Results: The study received National Institute of Nursing funding in July 2023. This protocol describes only the methods and the analytical approach. In accordance with our grant award, research results will be reported and disseminated through peer-reviewed publications and conferences.

Conclusions: This study is the first to explore the overlapping intersections of neonatal transport, infant outcomes, and psychosocial health in Black parents using a mixed-methods case study approach. The findings aim to inform future interventions that reduce disparities, improve parents' experiences, and promote better outcomes for both infants and maternal mental health.

(JMIR Preprints 25/09/2025:84626)

DOI: <https://doi.org/10.2196/preprints.84626>

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Original Manuscript

Introduction

Despite medical advancements, global preterm birth rates have remained largely unchanged over the past decade.¹ As survival rates of preterm infants have improved,² neonatal intensive care unit (NICU) admissions and length of stays have increased.³ Prematurity and low birth weight are the second leading causes of infant mortality in the US and major contributors to both short- and long-term morbidities. Annually, over 70,000 infants are transported from community hospitals to NICUs to manage complications related to preterm birth.⁴ These transports often create additional challenges for families, especially those living far from the NICU. Parents—particularly those from low socioeconomic backgrounds—face heightened stress,⁵ financial strain, higher rates of depression,^{6,7} and limited access to their infant.

The purpose of this paper is to report a study protocol designed to examine the association between neonatal transport, the health outcomes of Black very preterm (VPT) infants, and the psychosocial well-being of their parents. It also explored how social vulnerability contributes to the socioeconomic and racial inequities experienced by Black parents during birth, transport, and NICU hospitalization. A deeper understanding of these relationships is crucial for improving access to individualized, high-quality care and for advancing health equity.

METHODS

Setting

The study was conducted in South Carolina (SC), where the preterm birth rate for Black women is 55% higher than that of other racial and ethnic groups, and the infant mortality rate exceeds the national average.^{1,8} Recruitment took place at a tertiary Level III NICU at a local health system in a medium-sized, southeastern city. This health system includes a Children's Hospital and serves as the region's perinatal center, which covers many community hospitals and many counties, all of which are ranked moderate to high on the Centers for Disease Control & Prevention (CDC)

Social Vulnerability Index.⁹

Design

This descriptive, exploratory study employed a multiple-case study design and a mixed methods approach to describe the trajectory of Black preterm infants and their families from birth at a community hospital through transport to a referral center and subsequent NICU hospitalization. A case study design allows for the longitudinal understanding of complex and dynamic processes, from multiple perspectives and contexts across time,⁸ and describes, explains, or explores everyday phenomena in their natural settings.¹⁰ Case study research is appropriate for descriptive and exploratory studies, which investigate research questions that have not previously been studied in depth.¹¹ Multiple data collection methods provided a detailed investigation and an analysis of the context and processes involved in the phenomenon under study. An adapted version of the National Institute of Minority Health and Health Disparities (NIMHD) Research Framework¹² informed the research design and methods.¹³

Sample

The study was conducted between May 2023 and June 2024. Each case consisted of the anchor infant(s): a Black, very preterm (VPT) infant born between 24- and 30-weeks' gestational age (GA), transferred to the NICU, and the infant's mother, with an invitation to the other birthing parent to participate. Our aim was to enroll 10 infant cases using purposive convenience sampling with deliberate stratified sampling to ensure a range of GA across infant cases.

Study Aims

Aim #1: Examine the impact of neonatal transport on infant health outcomes. Pathways resulting in poor infant outcomes are often complex and multifactorial. Community hospitals and staff vary greatly in their resources to stabilize and resuscitate VPT infants. Birth in community hospitals has been associated with increased morbidities such as hypothermia, severe intraventricular hemorrhage (IVH), chronic lung disease (CLD), and other poor outcomes from the physical stress

and lifesaving procedures.¹⁴⁻¹⁷ We wanted to examine cases for conditions that may have an association with the stabilization trajectory at the birth hospital or during the transport trajectory, which may negatively affect an infant's life in function or quality as well as pose challenges and costs to their families. Studies have shown that VPT infants born in a community hospital and requiring transport have significantly higher odds of morbidities, cognitive impairment, and mortality risk.¹⁸⁻²⁵ Morbidities of interest known to be higher in the VPT transported infant population were selected for data collection during NICU hospitalization. Any additional described morbidities were also noted to contextualize each case. Long term health outcomes are less than optimal for this population, as multiple studies reveal that infants requiring transport have a higher chance of developmental impairment, , cerebral palsy, and overall higher odds of death than those born in facilities with optimal capabilities.^{18-20,26}

Aim #2: Examine parent psychosocial health, social vulnerability, and socioeconomic or racial inequities. In the US, Black women are more likely to deliver preterm infants compared with White women.²⁷ Mothers of VPT infants are more likely to live in an area with a higher social vulnerability.²⁸ Further exacerbating these resource issues, VPT infants have considerably higher costs and use more health care resources in every health care service group than their full term peers during their first year of life.²⁹ Psychological morbidities in parents are common following childbirth, with depressive symptoms estimated to be 4.5-20% in mothers and 3-10% in fathers.³⁰⁻³² Research has shown that one partner's depressive symptoms can negatively affect the other partner's ability to bond with their child, and that stress experienced by one parent often contributes to increased stress in the other.^{31,33} Distance from the parent's home to the hospital NICU is another significant stress indicator,³⁴ also affecting parent-infant bonding, and further compounding stress and anxiety or leading to depression. Because structural racism in the health care system may also play an important role in racial disparities,³⁵ we investigated parents' perceptions of bias and racism in relationship to neonatal transport and NICU hospitalization.

Study Procedures

This project was supported by NIH/NINR award 1F31NR020731-01A, awarded in July 2023. Institutional Review Board (IRB) approval was obtained in advance from the hospital where the research was conducted. Mothers provided informed consent at the bedside or via the phone, both for themselves and on behalf of their infant(s). Inclusion criteria consisted of Black mothers and their infant(s) born between 24 and 30 weeks' gestation. Fathers were also invited to participate. Eligible infants had to be delivered at an outside hospital and transported to the NICU where recruitment took place. Infants with significant congenital anomalies and mothers who could not speak English were excluded. Enrollment took place between February and December 2023, with study procedures concluding in March of 2024.

To achieve the objectives of Aim 1, we used publicly available information to gather characteristics of the birth hospital. We performed an electronic medical record (EMR) data review to provide a complete picture of the infant's transport trajectory. The transport team provided records from the birth hospital and an admission summary that informed the case on stabilization procedures that were given directly after birth. A thorough review of EMR data from birth through 36 weeks corrected gestational age was conducted for any morbid health outcomes which may have critical impact on the health and well-being for each infant and their family.

To accomplish the goals of Aim 2, parents completed a series of surveys (see Table 1), via email. These surveys were previously published and validated instruments, apart from the Infant Access questionnaire, which the study team created. Surveys were administered 2 to 3 times (depending on infant's length of stay) to measure how responses changed over the course of NICU admission, and to understand experiences across multiple phases. Infant data collected from the EMR by the first author included infant's gestational age, sex, and home address. This address was used to obtain the Area Deprivation Index (ADI) on The Neighborhood Atlas website, a scientifically validated measure which shows socioeconomic disadvantage by neighborhood.^{36,37} The ADI is

composed of 17 education, employment, housing-quality, and poverty measures originally drawn from long-form Census data and updated to incorporate more recent American Community Survey (ACS) data.^{36,37} Scores from within a state are ranked from lowest to highest, then divided into deciles (1–10), with 10 being the most disadvantaged neighborhood groups. Research shows that socioeconomic status can be a fundamental cause of health disparities.³⁸

Table 1. Outcomes and measures

Expected Outcome	Measure	Description
Parental bonding	Parent-to-infant Attachment Questionnaire (PAQ) ³⁹	25-item questionnaire uses a 6-point Likert scale, used to assess the occurrence of disturbances in postpartum bond formation between a mother and child
Barriers to infant access	Team Created Survey	8-item descriptive data (Distance & cost of travel, transportation & accommodations, visitation barriers or hardships)
Parental perceptions of bias, discrimination	Discrimination in Medical Settings (DMS) ⁴⁰	7-item instrument which asks about prior experiences of mistreatment while getting health care that persons attributed to race, ancestry or national origin. Responses were assessed with a 5-point Likert scale
Parental perceptions of bias, discrimination	Single Question from BRFSS ⁴¹	Within the past 12 months when seeking health care, do you feel your experiences were worse than, the same as, or better than for people of other races?
Parental perception of free choice to make informed healthcare choices	Adapted Medical Outcomes Study (MOS) ⁴²	1. If there were a choice between treatments, how often would your child's doctor ask you to help make the decision? 2. How often does your child's doctor give you some control over your treatment? 3. How often does your child's doctor ask you to take some of the responsibility for your treatment?
Parental Psychosocial Morbidities - Stress	Parental Stress Scale: Neonatal Intensive Care Unit (PSS:NICU) ⁴³	26-item questionnaire assessed with a 5-point Likert scale to quantify parental stress in the particular situation of preterm birth
Parental Psychosocial Morbidities - Anxiety	Beck Anxiety Inventory (BAI) ⁴⁴	21 self-reported items (four-point scale) used to assess the intensity of physical and cognitive anxiety symptoms during the past week
Parental Psychosocial Morbidities - Depression	Edinburgh Postnatal Depression Scale (EPDS) ⁴⁵	10-item questionnaire assessed with a 4-point Likert scale to see how women are coping with the life changes of pregnancy and childbirth
Socioeconomic status and disadvantage	Survey & ADI ^{37,46}	Multiple choice 8-item survey asking descriptive data Age, race, gender, marital status, education, paid leave, occupation, annual household income, insurance. & ADI rank for social disadvantage

To gain deeper insight into the psychosocial health of mothers—including their experiences during pregnancy, having a preterm infant, and navigating neonatal transport—the study team developed semi-structured interview guides informed by key constructs from an integrated theoretical framework. This framework is an adapted version of the NIH’s NIMHD Research Framework, which is described in detail in a separate publication.¹³ Probing questions were used to elicit deeper reflections on emotional support, staff interactions, perceived needs, etc. Sample questions from the interview guide is found below, in Table 2. To maximize participation, these interviews were conducted over the phone, or via Zoom teleconferencing.

Table 2. Sample Interview Questions

Interview Questions	Additional Probing Example
Tell me about your pregnancy experience over the last ___ months and what really stands out to you about this time in your life.	Who is the person or people you feel gave you emotional support during your pregnancy?
Tell me about your delivery experience with your baby at ___ hospital.	Are there any parts of your labor and delivery experience at the hospital that stick out to you, either good or bad?
The transport team brought your baby to this hospital. Did someone talk with you before your baby was taken away in the ambulance?	Tell me any ways the process of taking your baby away to another hospital might have been better for you?

Analysis

The case study approach allows in-depth, multi-faceted examination of an under-researched phenomenon in a real-life setting. Case study integrates well with mixed methods, which seeks a more complete understanding through the integration of qualitative and quantitative research.⁸ We chose this approach to address both aims over the trajectory of the case. This multiple case, longitudinal, within- and across-cases exploratory study used a personalized, concurrent mixed methods approach with repeated data collection points, as parental experiences are shaped by the unique trajectory of their infant’s NICU experience and their own experiences within the NICU.

Quantitative Analysis. Three types of quantitative data were collected: 1) surveys administered to the parents over sequential time points for variables of interest, 2) the ADI to measure neighborhood disadvantage, and 3) infant’s morbidity outcomes from the EMR. Research

Electronic Data Capture (REDCap) is a HIPPA compliant web-based application created to capture data for clinical research and to create databases and projects.⁴⁷ All data including surveys were uploaded as research capture tools into REDCap. Because this is exploratory and not powered for inference, we used descriptive statistics to analyze and summarize all data in each case.

Qualitative Analysis. Research questions used for semi-structured interviews were guided by an adapted model of the National Institute of Minority Health and Health Disparities (NIMHD) Research Framework.⁴⁸ Parent interviews were recorded, typically lasting 20 to 40 minutes. Transcription was performed by the first author and were reviewed and compared to recordings to assure they represent participant utterances as accurately as possible. Reflexive thematic analysis, as outlined by Braun and Clark,⁴⁹ was used to explore the experiences of Black mothers navigating the emotional journey of giving birth to a VPT infant who required both neonatal transport and hospitalization in a NICU. Themes and subthemes were identified by the first author, RMD and RBD.

After quantitative and qualitative data analyses, data were integrated to comprehensively summarize each case and reviewed for deviations away from the interpretive summary by the first author and RBD. Data were then applied to a visual timeline trajectory comparing the infant's clinical status to the parent's psychosocial health to enhance interpretation. Across case analyses explored commonalities in participants' aggregate experiences. After case summarization, between-case comparisons were discussed by the entire research team. These results will be used to generate hypotheses for future studies.

Ethical Considerations

This study was approved by the Prisma Health Midlands IRB (1999826-1). All collected materials, including interviews, medical record information, and surveys were deidentified and entered into a password-protected database program stored on a secure server to protect participant privacy. Informed consent was obtained from all participants, who were informed they can withdraw

from the study at any time without consequence. Participants received financial compensation for each set of surveys or interview completed to acknowledge their time and reduce attrition (USD \$25).

RESULTS

This study examined the relationships between neonatal transport and both infant health outcomes and parental psychosocial well-being among Black families with VPT infants. It is expected to generate a comprehensive understanding of mother's experiences, and we anticipate identifying associations between neonatal transport experiences and maternal stress, anxiety and depression with infant outcomes. We further hope to identify barriers to care, and any instances of discrimination faced by mothers from their prehospital experiences to their infant's NICU discharge.

Dissemination plan

This project has met several key dissemination milestones. The doctoral dissertation was successfully defended, and the conceptual framework was published in a peer-reviewed journal.¹³ Continued efforts are underway to publish three additional peer-reviewed manuscripts, including case-study and qualitative findings. Preliminary dissemination has also included presentations at regional, national, and international conferences.

DISCUSSION

Important Implications for Practice

As mothers face numerous problems after premature birth, they require avenues of support to cope with the transition process. Health systems and social service networks have a significant opportunity to mitigate the psychosocial challenges of NICU mothers in the postpartum period. Patient-centered interventions are needed to improve experiences after preterm birth. Provider education on bias and awareness of the barriers these mothers face can decrease issues that are perpetuated in systems. Legislative solutions to improve maternal access and quality and to sustain funding for community-based maternal health could improve future outcomes for Black women and infants.

Limitations

Eligibility for this study was limited to a small population of Black mothers who delivered a preterm infant between 24-30 weeks' GA at a community hospital, requiring transport to a NICU. Recruitment of mothers for this study was within one perinatal center in the Southern United States; experiences of mothers in other regions may be different.

Conclusion

This multiple-case study design and mixed-methods approach has facilitated comprehensive and intensive data collection to gain a profound understanding of the real-life experiences of Black mothers following preterm birth and neonatal transport. To our knowledge, this is the first study to examine the experiences of Black women who have delivered a preterm infant in a community hospital that required neonatal transport through a mixed-methods case study lens. These maternal perspectives can highlight the challenges, and systemic barriers present within our healthcare system across all phases, from pregnancy to several months postpartum. This protocol outlines a small foundational study; however, a more extensive study is needed to provide evidence to generalize these initial results. There is a pressing need for future interventional research aimed at supporting mothers during this challenging and stressful period, tailoring interventions to reduce disparities, and improving maternal mental health. Ultimately, such efforts could improve health outcomes for both infants and their families.

Acknowledgments

This research project was funded by the National Institutes of Health (NIH)/ National Institute of Nursing Research (NINR) award number 1F31NR020731-01A. Generative AI was not used in the preparation of this manuscript.

Data availability

The data sets generated or analyzed during this study cannot be publicly shared due to ethical or legal reasons but are available from the corresponding author on reasonable request.

Authors' Contributions

KW and RBD contributed to the conceptualization, methodology and original draft writing. KW, RBD, TF, RMD and NB contributed to the validation, funding acquisition, supervision, review and editing of the manuscript.

Conflict of interest

The authors have no conflicts of interest to disclose.

Abbreviations

Area Deprivation Index (ADI)

Electronic Medical Record (EMR)

Gestational Age (GA)

Neonatal Intensive Care Unit (NICU)

Very Preterm (VPT)

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Supplementary Files

Multimedia Appendixes

NIH/NINR F31 summary sheets.

URL: <http://asset.jmir.pub/assets/195d399f7ce127f586f76a1c44c626b3.pdf>