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Understanding Loss to Follow-Up: The Role of Social Determinants of Health in Infants Referred After a Positive Newborn Screening – A Quantitative Analysis

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Abstract

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Dissertation Submitted in Partial Fulfillment

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Abstract

Newborn screening (NBS) is a vital U.S. public health initiative that identifies medical conditions shortly after birth. Patients with positive screenings are referred for medical follow-up or evaluation. However, many patients do not receive the recommended long-term follow-up, posing concerns for healthcare providers and public health professionals working to ensure timely treatment and care continuity. Based on the Social Determinants of Health framework, this quantitative, retrospective cohort study aimed to examine demographic and clinical factors associated with follow-up adherence among 691 infants identified through NBS in Colorado and Wyoming. The purpose of the study was to determine whether race, ethnicity, geographic location, language preference, insurance type, age, and NBS condition category significantly predicted being up to date on 2024 follow-up visits. Binary and multiple logistic regression were used to evaluate these predictors. Adjusted analyses indicated that infants with endocrine disorders (Adjusted OR = 2.91, 95% CI [1.44, 5.88], p = .003) had significantly higher odds of being up to date. In contrast, non-English language preference, Black/African American race, multiracial participants, and residence in smaller metro counties were not statistically significant predictors. Other variables, including age, ethnicity, and insurance type, also did not significantly predict follow-up adherence. These findings promote positive social change by identifying potential gaps in care and informing initiatives to improve long-term follow-up adherence and advance health equity among vulnerable infant populations.

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Dedication

This work is lovingly dedicated to Sandy Sue, my baby girl and faithful companion, who sat by my side throughout the process of earning two master’s degrees and during my PhD studies. Though she passed away just a few weeks before I completed this journey, her presence and unconditional support will always be part of this achievement and my heart.

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Chapter 1: Introduction to the Study

Introduction

Newborn screening (NBS) is a public health program conducted in every state in the United States. It is designed to identify neonates with a medical condition shortly after birth that can impact an infant's long-term health or survival. The program is based on the concept that early recognition leads to early treatment, which can prevent death or disability so that infants can achieve their optimal health potential. The term "condition" refers to impairments caused by multiple disorders or the diagnosis of a specific issue, with or without clinical manifestations (Singh et al., 2023). Early recognition followed by timely intervention has been associated with improved health outcomes (Deng et al., 2022). The newborn screening process in the U.S. has been recognized as a successful public health initiative. Infants with positive screenings are referred for further evaluation and often require long-term follow-up and care based on their condition, diagnosis, and the recommendations of their healthcare professionals. However, many infants do not receive adequate long-term follow-up, referred to as loss to follow-up, which can lead to adverse health outcomes and worsening of medical conditions, including increased mortality, because health risks frequently extend beyond the neonatal period (Gregorcyk et al., 2022).

Social Determinants of Health (SDOH) refer to non-medical factors in which individuals are born, live, learn, work, play, and age. These factors have a far-reaching impact on health, performance, quality of life outcomes, and risks (Islam, 2019). The SDOH are categorized into five categories: social context, economic context, education, physical infrastructures, and healthcare. Social aspects include demographic, social circles, and support. The economic component includes employment, income, and poverty. The educational aspect encompasses the quality of daycare facilities, schools, and adult education. Physical infrastructure encompasses housing, transportation, workplace environment, and safety. Healthcare needs to include access to high-quality care and insurance (Agency for Health Care Research and Quality [AHRQ], 2023). Understanding these factors is crucial for anyone involved in public health, as it can help to explain and address health disparities. Individuals have distinctive experiences based on numerous aspects of SDOH, and all are not equal. The SDOH can explain and exacerbate existing health disparities and continue future and ongoing inequities. Negative aspects of SDOH can be prevented and rectified (Roberts et al., 2016). Social determinants of health can be integral to whether patients receive appropriate long-term follow-up care. Identifying what social characteristics deter patients from receiving the suggested follow-up and treatment is crucial. Recognizing key social characteristics impacting long-term follow-up is a vital step that can assist public health professionals in addressing medical and social needs and providing adequate support to promote optimal health outcomes and eliminate health disparities (Guerrero et al., 2021).

This study will evaluate the social factors that explain and exacerbate inequities in access to healthcare services, leading to patients being lost to follow-up (Roberts et al., 2016). These factors are critical in understanding health disparities. The purpose of this study was to analyze whether insurance type, race/ethnicity, language preference, and geographic location influence whether an infant referred for follow-up care had a documented visit in 2024. Understanding these variables can assist public health professionals and policymakers in developing interventions to increase follow-up rates, eliminate disparities, and improve health outcomes for infants identified through newborn screening.

Background

Newborn screening, a highly successful public health initiative managed by state and territorial governments, is designed to identify neonates with 36 predefined medical conditions. With approximately four million infants born annually in the United States, more than 12,500 neonates are diagnosed with one of the core conditions (Dubay & Zach, 2023). The national participation rate for newborn screening stands at 97%, although there is a follow-up loss of up to 32% (Hunter et al., 2016). Newborn screening, which began more than 50 years ago with the test for phenylketonuria (PKU), a progressive health condition often resulting in brain damage, has been a life-saving breakthrough. Before the development of the PKU blood test, most children were not diagnosed until they developed irreversible brain damage, rendering treatment impossible. The PKU testing underscored the life-saving potential of early screening, enabling appropriate interventions and treatment to be initiated for patients, thereby maximizing their health outcomes (Dubay & Zach, 2023). The U.S. Secretary of Health and Human Services (HHS) has recommended that all newborns undergo newborn screening based on the Recommended Uniform Screening Panel (RUSP), a national guideline for NBS. The conditions included in NBS are primarily spinal muscular atrophy, cystic fibrosis, sickle cell disease and other hemoglobinopathies, endocrine diseases, inborn errors of metabolism, lysosomal storage diseases, severe combined immunodeficiencies, critical congenital heart defects, and hearing loss (Singh et al., 2023). Symptoms of the conditions are not always present at birth. Therefore, early detection enables the initiation of early treatment and long-term follow-up, thereby optimizing health outcomes (Dubay & Zach, 2023).

Infant Follow-Up Challenges

Although researchers have examined newborn screening and initial follow-up after a referral, a significant gap remains in understanding the characteristics that contribute to the loss of follow-up in the context of SDOH. Most studies have focused on the newborn screening process and the short-term outcomes after newborn screening, such as the initial referral. However, limited research has explored the social factors influencing long-term follow-up and continuity of care, particularly in populations facing social vulnerabilities (Health Resources and Services Administration, 2024).

Newborn screening is a critical tool in the early identification of medical conditions, allowing for timely intervention. However, the current long-term rates for infants diagnosed with disorders through NBS are insufficient, especially among socially vulnerable populations, which is a substantial public health issue. Failure to receive the appropriate care and long-term follow-up can lead to worsening conditions, unplanned hospitalization, and mortality (Cherestal et al., 2022). Research suggests that SDOH, including race, ethnic background, geographic location, language preference, and insurance type (private or state-funded), can significantly impact access to consistent follow-up care, potentially leading to adverse health outcomes. Despite existing research on short-term NBS follow-up, there is a pressing need to understand how these social determinants of health specifically impact being lost to follow-up rates (Sheingold, 2023).

While existing research has evaluated the NBS program and the initial referral after newborn screening, there is limited knowledge of how social determinants impact long-term follow-up status among pediatric patients with medical conditions (Sheingold, 2023). This quantitative study assessed how specific social determinants of health, geographic location, insurance type, race/ethnicity, and insurance type impact follow-up status in 2024 among a group of patients within a university health system in which ongoing follow-up is recommended. By understanding how the specific determinants impact health outcomes, specific interventions can be implemented to improve health equity (Weeks et al., 2023).

Long-term follow-up remains a significant challenge for pediatric patients with ongoing health conditions, affecting health outcomes and continuity of care across numerous conditions, including cardiology and oncology. Research indicates that insurance coverage, economic status, support systems, and geographic factors are barriers to follow-up. Sacharow et al. (2024) evaluated the lack of follow-up among Boston Children's Hospital phenylketonuria clinic patients who had not had a return visit for 5-50 years. The study sought to identify reasons for not attending follow-up visits. Findings identified being discharged from the clinic as a child, insurance barriers, financial barriers, lack of health provider or family support, and feeling uninvolved with the phenylketonuria community as the most common patient-reported reasons for not adhering to recommended follow-up visits. Similarly, Wright et al. (2024) evaluated 235 pediatric patients with congenital heart defects to identify factors contributing to being lost to follow-up, defined as no cardiology clinic visit for over 6 months. Results revealed that patients with comorbidities were more likely to seek care in non-cardiology clinics. Medicaid insurance correlated with a higher likelihood of receiving care outside the health system. Additionally, patients living closer to the clinic had higher return rates for follow-up visits.

Pediatric oncology patients enrolled in clinical trials have an approximately 15% decreased life expectancy, often with severe, life-threatening, and terminal health issues by age 50, compared to those who do not. This indicates the urgency of ongoing follow-up and management in this patient group. Puthenpura et al. (2023) conducted a retrospective study of more than 20,000 oncology patients to examine inequities in follow-up care. Findings revealed that adolescents and young adults, racial/ethnic minorities, and individuals from lower socioeconomic backgrounds were at the highest risk of being lost to follow-up.

The American Academy of Pediatrics and the National Institute of Child Health and Human Development emphasize the need for consistent follow-up in neonates with medical conditions due to the potential for long-term complications. Christner et al. (2023) examined the association between missed medical appointments and LTFU and found that 35% of participants were lost to follow-up. Additionally, each missed visit increased the likelihood of LTFU, with no-show appointments carrying the highest risk. These findings underscore the importance of early intervention strategies to ensure long-term continuity of medical care for high-risk pediatric patients. The studies illustrate the critical role of structural, social, and economic factors in determining adherence to follow-up. Addressing these barriers to care is vital to enhancing health outcomes in pediatric populations with chronic conditions.

Key Social Determinants of Health and Loss to Follow-Up

Insurance Type

Health insurance can impact whether a patient receives the recommended follow-up care. Patients with public insurance, like Medicaid, are at increased risk of being lost to follow-up compared to patients with private insurance (Roberts et al., 2016). Public insurance has been associated with financial instability, lack of health provider access, and limited access to health specialists (Sacharow et al., 2022).

Race and Ethnicity Disparities in Follow-Up Care

Racial and ethnic inequalities in healthcare access markedly contribute to variances in follow-up rates among infants referred to for ongoing care after newborn screening. Research has demonstrated that Black, Hispanic, and Native American infants experience higher rates of being lost to follow-up compared to White infants (Deng et al., 2022). These disparities can be related to socioeconomic barriers, healthcare professional bias, and systemic inequities in healthcare access (Kayle et al., 2024).

Language Preference and Communication Barriers

Language barriers play a critical role in follow-up adherence. Non-English-speaking families frequently experience issues obtaining health services due to language barriers. Scheduling medical appointments, understanding medical recommendations, and accessing health resources are commonly reported issues with non-English-speaking patients (Guerrero et al., 2021).

Geographic Location and Rural Disparities in Healthcare Access

Rural residence has been correlated with substantial challenges in accessing health services, including those recommended for follow-up care after a positive newborn screening. Disparities among infants from rural areas have been attributed to pediatric health specialists' limited availability, transportation, and long travel distances to an appropriate health facility (Weeks et al., 2023).

Problem Statement

The public health problem explored in this research is that, despite the recognized success of newborn screening NBS in the U.S. in identifying high-risk infants, a large proportion of children fail to receive the medically necessary long-term follow-up. Failure to ensure consistent follow-up, known as loss to follow-up, is closely linked to poor health outcomes, including the progression of untreated conditions and preventable complications (Sacharow et al., 2024). The specific problem is that social determinants of health often create barriers to care and ongoing monitoring of medical conditions, which is crucial for maximizing health potential (Kayle et al., 2020). Social Determinants of Health, such as socioeconomic status, access to healthcare, and linguistic or cultural barriers, along with broader social vulnerabilities like rural residence or insurance type, may exacerbate this issue by impeding access to care and continuity in monitoring and treatment. These factors disproportionately affect specific populations, resulting in increased rates of loss to follow-up and widening health disparities. Understanding the relationship between social inequality and long-term follow-up status in infants identified through newborn screening for medical disorders is crucial for developing targeted interventions that address these barriers and improve long-term health outcomes for this vulnerable population (Burlina et al., 2024).

The research will explore how social factors like ethnicity, socioeconomic status, geographic location, language preference, and type of insurance influence the ability of families to engage in long-term medical care for infants with a recognized medical condition. Understanding social factors that decrease loss to follow-up is critical to identifying barriers and developing interventions that promote continuity of care and improve health outcomes in this vulnerable population. The research problem is critical and time-sensitive because disparities in long-term follow-up status can result in worsening health conditions for the affected population, which can have implications for health inequities (Tong et al., 2023).

Purpose of the Study

This quantitative study aims to identify whether SDOH, ethnicity/race, geographic location, language preference, and type of insurance impact whether patients had a follow-up visit in 2024. The study takes a comprehensive view of the barriers to long-term monitoring and care, which could guide strategies to decrease loss-to-follow-up rates and improve health outcomes in infants identified through newborn screening. By focusing on the intersection of specific social factors and follow-up status, this research offers a comprehensive view of the barriers to long-term monitoring and care, which could serve as a guide for strategies to decrease loss to follow-up and improve health outcomes in infants identified through newborn screening. By exploring the relationship between the independent variables, ethnicity, race, geographic location, language preference, and type of insurance, and the dependent variable, long-term follow-up status, the purpose of the study was to identify which social determinants most significantly impact follow-up continuity. Covariates, such as healthcare access associated with each variable, will be controlled to isolate the effect of each determinant on long-term follow-up status. This research may provide insights into specific barriers affecting follow-up care, ultimately guiding public health strategies for improving long-term health outcomes in vulnerable pediatric populations.

Research Question

The study will seek to address four research questions.

RQ1: What is the relationship between ethnicity or race (independent variable) and the likelihood of having a medical appointment or visit in 2024, 0 did not have a follow-up or visit 1 did have a follow-up visit (dependent variable) among infants identified with a disorder through newborn screening when controlling for geographic location, insurance type, and preferred language (control variables)?

HO1: There is no statistically significant relationship between ethnicity or race and the likelihood of having a medical appointment or visit in 2024 0 did not have a follow-up or visit 1 did have a follow-up visit (dependent variable) among infants identified with a disorder through newborn screening when controlling for geographic location, insurance type, and preferred language.

HA1: There is a statistically significant relationship between ethnicity or race and the likelihood of having a medical appointment or visit in 2024 0 did not have a follow-up or visit 1 did have a follow-up visit (dependent variable) among infants identified with a disorder through newborn screening, when controlling for rural vs. geographic location, insurance type, and preferred language.

RQ2: What is the relationship between geographic location (independent variable) and the likelihood of having a medical appointment or visit in 2024 0 did not have a follow-up or visit 1 did have a follow-up visit (dependent variable) among infants identified with a disorder through newborn screening when controlling for rural vs. urban residence, insurance type, and preferred language (control variables)?

HO1: There is no statistically significant relationship between geographic location and the likelihood of having a medical appointment or visit in 2024 0 did not have a follow-up or visit 1 did have a follow-up visit (dependent variable) among infants identified with a disorder through newborn screening, when controlling for ethnicity, insurance type, and preferred language.

HA1: There is a statistically significant relationship between geographic location and the likelihood of having a medical appointment or visit in 2024 0 did not have a follow-up or visit 1 did have a follow-up visit (dependent variable), among infants identified with a disorder through newborn screening, when controlling for ethnicity/race, insurance type, and preferred language.

RQ3: What is the relationship between language preference (independent variable) and the likelihood of having a medical appointment or visit in 2024, 0 did not have a follow-up or visit 1 did have a follow-up visit (dependent variable) among infants identified with a disorder through newborn screening when controlling for ethnicity/race, geographic location, insurance type (control variables)?

HO1: There is no statistically significant relationship between language preference and the likelihood of having a medical appointment or visit in 2024, 0 did not have a follow-up or visit 1 did have a follow-up visit (dependent variable) among infants identified with a disorder through newborn screening, when controlling for ethnicity/race, insurance type, and geographic location (control variables).

HA1: There is a statistically significant relationship between language preference and the likelihood of having a medical appointment or visit in 2024, 0 did not have a follow-up or visit 1 did have a follow-up visit (dependent variable) among infants identified with a disorder through newborn screening, when controlling for geographic location, ethnicity/race, and insurance type (control variables).

RQ4: What is the relationship between insurance type (independent variable) and the likelihood of having a medical appointment or visit in 2024, 0 did not have a follow-up or visit 1 did have a follow-up visit (dependent variable) among infants identified with a disorder through newborn screening when controlling for ethnicity, geographic location, and preferred language (control variables)?

HO1: There is no statistically significant relationship between insurance and the likelihood of having a medical appointment or visit in 2024, 0 did not have a follow-up or visit, 1 did have a follow-up visit in 22024 (dependent variable) among infants identified with a disorder through newborn screening when controlling for ethnicity/race, language preference, and geographic location (control variables).

HA1: There is a statistically significant relationship between insurance and the likelihood of having a medical appointment or visit in 2024; 0 did not have a follow-up or visit, 1 did have a follow-up visit (dependent variable) among infants identified with a disorder through newborn screening when controlling for ethnicity/race, language preference, and geographic location (control variables).

Theoretical Framework for the Study

The study, which utilized the social determinants of health framework, serves as a call to action to address the urgent issue of social disparities in healthcare. Health and social inequalities in this pediatric population are substantial because they affect long-term health outcomes and quality of life (Weeks et al., 2023). By investigating how non-medical factors such as preferred language, ethnicity, geographic location, and insurance type influence the likelihood of patients receiving long-term follow-up care after a positive newborn screening and referral, the study underscores the interconnectedness of social characteristics and health systems in shaping health outcomes. In line with the study's objective, the social determinants of health framework plays a pivotal role in identifying key factors that can confront these disparities in this patient population.

By identifying structural and systemic circumstances, the foundation for interventions and policies can be established to bridge the disparities hindering follow-up care, thereby promoting equitable healthcare access for all infants (Thimm-Kaiser et al., 2023). The social determinants of health framework is appropriate for this study because it stresses the impact of more expansive societal and environmental characteristics on health disparities. The social determinants of health framework provides an adaptive model for initiating intervention opportunities to enhance population-level health outcomes (Wray et al., 2022). The framework enables researchers to pinpoint and evaluate structural and systemic challenges like access to health resources in rural areas, language barriers, and insurance type, further health inequities in long-term follow-up regimens. The alignment renders the framework relevant and critical for determining helpful intervention targets (Call et al., 2024).

The planned study stresses the importance of moving beyond individual explanations for health inequities by evaluating the specific social determinants affecting newborn follow-up. It is crucial to address system inequalities that sustain them. Identifying structural and systemic factors is essential to creating interventions and policies that address disparities and promote equitable health access for all pediatric patients, regardless of their social circumstances (Abbas et al., 2024). The research establishes a foundation for ongoing evidence-based methods to sustain follow-up care and enhance long-term health outcomes among vulnerable pediatric populations (Thimm-Kaiser et al., 2023).

Nature of the Study

This quantitative study used a retrospective cross-sectional design to examine whether infants referred after a positive newborn screening had a medical visit in 2024, using electronic health record (EHR) data from a partnering university. This design will allow the analysis of pre-existing data of infants with medical disorders identified through newborn screening. The study investigated the association between social determinants and long-term follow-up rates by examining race, ethnicity, geographic location, preferred language, and insurance type. The data analysis included statistical methods and logistic regression analysis to identify the characteristics most strongly associated with follow-up (Barroga & Matanguihan, 2022).

Definitions

Electronic health records (EHR): Digital records of patient health information, including medical history, diagnoses, medications, treatment plans, immunization dates, allergies, radiology images, and laboratory test results (CMS, 2024).

Geographic location: Categorized using the 2023 Rural-Urban Continuum Codes, which classify U.S. counties based on population size and proximity to metropolitan areas (United States Department of Agriculture [USDA], 2024).

Insurance type: Categorized as private (employer-sponsored or purchased independently) or public (Medicaid, Children's Health Insurance Program [CHIP], or other government-funded programs; "Type of health insurance," 2024).

Language preference: Categorized as English or non-English, based on the preferred language recorded in the electronic health record (U.S. Census Bureau, 2024).

Loss to follow-up (LTFU): Infants referred for follow-up after a positive newborn screening did not have the next recommended documented medical visit (Dubay & Zach, 2025).

Newborn Screening (NBS): A public health initiative that screens newborns shortly after birth for medical conditions to ensure early identification and intervention for those with positive results (Dubay & Zach, 2025).

Race/Ethnicity: Categorized according to U.S. Census classifications, including White, Black or African American, Asian, American Indian/Alaska Native, Native Hawaiian/Other Pacific Islander**,** and individuals identifying as *two or more races*. Ethnicity is classified as Hispanic/Latino or non-Hispanic/Latino (U.S. Census Bureau, 2024).

Sex: Categorized as male or female, as recorded in the electronic health record (National Academies of Sciences, Engineering, and Medicine, 2024).

Social determinants of health (SDOH): Non-medical factors influencing health outcomes, including economic stability, education, healthcare access and quality, neighborhood and built environment, and social/community context (CDC, 2020).

Assumptions

This study is based on fundamental assumptions essential to its validity and the interpretation of findings. It assumes that electronic health records accurately reflect medical visits, demographic characteristics, geographic location, and language preferences. Since the study focuses on identifying associations between social determinants of health and follow-up status, any inconsistencies or missing or inaccurate data could introduce bias, making it difficult to draw valid conclusions. Another assumption is that the infants in the dataset represent a broader population of patients who also require long-term follow-up after a positive newborn screening. This assumption ensures that findings can be applied to similar populations beyond this study. Furthermore, social and demographic factors—such as geographic location, language preference, insurance type, and race/ethnicity—can impact follow-up care by creating barriers to access. Understanding the impact of social and demographic circumstances is essential for identifying vulnerable individuals and populations who may benefit from targeted interventions to improve health outcomes. Lastly, this study assumes that social determinants of health factors significantly impact follow-up status, and any deviations from these assumptions could affect the validity of the results (Lopez et al., 2022).

Scope and Delimitations

The scope of this study focuses on understanding how social determinants of health, particularly geographic location (rural vs. urban residence) and preferred language (English vs. non-English), insurance type, and race/ethnicity, impact follow-up status for infants identified as having a medical condition through newborn screening. The study aimed to analyze retrospective data from electronic health records within a university health system to quantify disparities in follow-up status in 2024 associated with the independent variables. The findings of this study have the potential to provide actionable insights that can inform policy and interventions, leading to improved follow-up adherence and health equity. This focus was selected due to past research on newborn screening and the first referral process, leaving a gap in ascertaining characteristics impacting long-term adherence to follow-up. The study addresses critical barriers to healthcare access and continuity for vulnerable populations. While the current analysis is limited to data available within a partner university, the Colorado Department of Health, and Wyoming Department of Health, might generate insights into systemic barriers experienced by neonates and their responsible parties. The insights captured can be applied to similar groups, guiding further research and informing broader health policies to enhance health equity and follow-up.

This study includes participants from birth to 18 years of age from state newborn screening programs and is limited to Colorado and Wyoming. Patients were included if they had a positive newborn screening and were referred to a clinic within the health system or reported by the state Department of Health with pertinent demographic and follow-up data. Potential participants were excluded if they were not diagnosed with a medical condition, had a negative NBS examination, lived outside Colorado or Wyoming, or had insufficient electronic health documentation. Despite complementary perspectives, the study applied the SDOH framework but did not explore other frameworks, such as the Health Belief Model. The Social Determinants of Health framework guided the study, excluding factors unrelated to systemic health inequities.

Limitations

The study design, internal validity, external validity, and confounding variables can be considered study limitations. The study was based on existing data from electronic health records, which can lack variables of interest or not be uniformly collected. Efforts to identify and use only complete and consistent data will be made, and missing data will be analyzed for patterns to identify potential biases. Due to the lack of longitudinal data, only one year of information can limit the applicability scope. Using secondary data limits a researcher's control over initial data collection, introducing potential errors or inconsistencies (Baldwin et al., 2022). Data cleaning methods were applied to decrease data inconsistencies. Using one university health system can limit the generalizability of the findings. However, the study described demographic and related population characteristics, allowing future studies to replicate or compare conclusions. Confounding variables are considered a limitation. Circumstances like access to transportation can impact follow-up adherence but may not be captured in the data set (Mathur & VanderWeele, 2022).

Significance of the Study

Significance to Theory

This study contributed to the theoretical understanding of how specific social determinants of health affect follow-up for neonates with a health issue identified via newborn screening. The study can advance the knowledge of public health, health equity, and screening follow-up care by depicting how social determinants impact long-term health outcomes in this patient population. Grounding the research in the SDOH framework heightens the understanding of the association between external social characteristics and health outcomes. The findings can expand the theory by providing empirical evidence highlighting specific social circumstances that influence continuity of care. This study has the potential to advance knowledge in public health, health equity, and newborn screening follow-up care by demonstrating how social determinants of health (SDOH) affect patient follow-up status. The study addresses knowledge gaps about specific social factors that form health disparities (Park et al., 2022).

Significance in Practice

The study yields actionable insights for health professionals, public health programs, and policymakers to heighten long-term follow-up care for this pediatric population. Informing the design of health care models that are more inclusive in addressing social characteristics can address specific barriers like language and geographic barriers. Fostering the advancement of policies to allocate resources for underserved groups appropriately can improve healthcare access. The study has the potential to contribute to advancing health programs that integrate strategies to address social disparities, like rural outreach programs, and can prepare health professionals to recognize and address SDOH-related barriers in their practice.

Significance to Social Change

The study promotes positive social change by confronting health inequities in care access and quality to long-term follow-up care for infants identified by newborn screening. The findings might assist with decreasing disparities and empower public health strategies to prioritize enhancing continuity of care and health outcomes. The results may stimulate forward movement toward ensuring all infants receive timely and ongoing care and monitoring regardless of social circumstances like ethnicity or geographic location through generating data-driven insights and advocating for systemic healthcare changes promoting inclusivity and equitable healthcare systems, ultimately improving social conditions (Jindal et al., 2023).

Chapter 2: Literature Review

Introduction

Even with the recognized success of the newborn screening program in the U.S. for identifying high-risk infants, a substantial number of infants and children do not receive the medically necessary long-term follow-up. Inadequate ongoing follow-up and loss of follow-up are associated with poor health outcomes, including disease progression, mortality, and decreased life expectancy *(*Deng et al., 2022*).* The purpose of this quantitative study was to identify if specific social determinants of health, ethnicity, race, geographic location, language preference, and insurance type affect loss to follow-up among newborns identified as having a medical condition via newborn screening. The study's purpose is to comprehensively evaluate barriers to long-term care, which can be instrumental in decreasing the number of infants lost to follow-ups across various medical conditions and maximizing their health potential.

Literature Search Strategy

An extensive literature search was conducted using PubMed, Ebsco Host, ProQuest, and CINAHL, focusing on publications from 2015 to 2023. The period captures relevant advancements in NBS practices, policy changes, and trends related to long-term follow-up care. Numerous sources were used to ensure a comprehensive understanding of the topic. The search strategy employed combinations of keywords and phrases: *newborn screening, disparities, inequalities, inequities, morbidity, pediatric, health outcomes, race, ethnicity, geographic location, urbanicity, rural, healthcare access, insurance type, language barriers, barriers, social determinants of health,* *pediatric, infant*, and *congenital disorders*. The search strategy included peer-reviewed published articles in reputable journals like the Journal of Pediatrics. Proceedings from relevant conferences were included to collect findings and expert opinions. Reports from authoritative entities like the Centers for Disease Control and Prevention and the Health Resources and Services Administration were used to collect information regarding policies and current recommendations. The inclusion of international literature provided a global perspective on long-term follow-up. The search was expanded to include related topics like general healthcare follow-up and barriers to healthcare access. The broad-based approach provided a refined understanding of the multifactorial circumstances involved with loss to follow-up. Integrating different types of literature, the study aims to pinpoint gaps in current evidence and emphasize needed future research. Studies published in English between 2000 and 2023 focused on infants and children recognized via NBS and evaluated characteristics related to loss to follow-up. Articles unrelated to healthcare and lacking empirical data were excluded.

Theoretical Foundation

The concept of poor working and living conditions leading to bad health outcomes originated in the 19th century and has evolved into the present-day Social Determinants of Health framework. Based on the idea that non-medical factors significantly influence overall health, this framework has four pillars: economic stability, education, social and community context, and healthcare access and quality. These pillars, neighborhoods, and built environments all impact health outcomes. The World Health Organization (WHO) has been a key influence in highlighting social and economic disparities in health outcomes. In 2008, the WHO developed the report Closing the Gap in a Generation: Health Equity through Action on the Social Determinants of Health, emphasizing the upstream issues affecting population and individual health. The SDOH framework integrates ideas from epidemiology, sociology, and public health (Nikora & McFarlane, 2010). The SDOH framework posits that there is more involved in health outcomes than merely healthcare access or medical treatment. Macro-level structural determinants encompass policies, culture, and governance, while intermediary determinants include physical factors like housing and psychological characteristics like stress and behaviors that shape health outcomes. Social gradients impact health due to worsening health outcomes with an associated decline in socioeconomic status. Adverse outcomes frequently arise from preventable inequalities (Goldacre & Hood, 2022).

Theoretical, methodological, and contextual assumptions based on the SDOH align with the current study. Theoretical assumptions apply to the concept that factors like geographic location, type of insurance, and ethnicity influence loss to follow-up and that loss to follow-up is impacted by systemic inequalities. The methodological assumption is that the variables of interest are consistently measured, and a contextual assumption involves the idea that there is a difference between rural and urban areas for follow-up (Merz et al., 2023). This study is derived from the assumption that ethnicity, geographic location, insurance type, and language preference play a role in cultural barriers to healthcare.

The SDOH framework has been broadly used in public health research to evaluate disparities and their impact on health. Studies have evaluated how SDOH characteristics like language preference, insurance type, and ethnicity have impacted health outcomes and follow-up for pediatric patients. Pilarz et al. (2023) evaluated lengths of hospital stay and discharge times among pediatric patients with English-speaking, Spanish-speaking, and non-Spanish language preferences. The authors found that patients who preferred a language other than Spanish or English had a 50% longer stay and later discharge than those who spoke English or Spanish. Bettenhausen et al. (2021) explored disparities, socioeconomic status, insurance type, race, and geographic location among children who reside in rural areas. The authors found children from rural areas to be a distinct, vulnerable pediatric population with more healthcare disparities than their urban counterparts. Rural children had decreased access to primary care and even more so to specialty care, and transportation barriers to obtaining health care were based on geographic location. It was recognized that one in five rural children lived in poverty, a higher rate than urban children. According to the American Community Survey, more than 17% of non-Hispanic whites, nearly 44% of non-Hispanic blacks, 37% of American Indian and Alaskan Natives, and 31% of Hispanic children from rural locations live below the federal poverty line. Additionally, research indicates that rural children are more likely to be uninsured or receive state insurance, contributing to healthcare access barriers (Bettenhausen et al., 2021).

The SDOH framework is particularly relevant to the current long-term follow-up study. It emphasizes how characteristics beyond medical illnesses affect health outcomes, takes an inclusive approach, and considers various social and environmental factors in healthcare use and services. This framework allows tailored actions based on specific

SDOH to improve health equity. The SDOH framework is directly related to the quantitative study's research questions, which correspond with preferred language, social and community context, ethnicity, social community context geographic location, neighborhood, built environment, insurance type, health care access, and quality (Van Cleave et al., 2025).

Emphasizing structural inequities demonstrates how geographic location can affect long-term care. The focus on cultural competency evaluates how language and ethnicity impact the ongoing follow-up for the patient group. The quantitative approach encompasses individual-level information to evaluate loss to follow-up, adding to the existing body of knowledge by focusing on a specific health outcome and pinpointing specific areas for targeted health promotion interventions that can be implemented. The SDOH influence on long-term follow-up in the specified population provides a deeper understanding of how the characteristics impact pediatric care and health outcomes. Evaluating the intersection between SDOH and recommended follow-up allows the study findings to enhance healthcare access and utilization among vulnerable

Literature Review Related to Key Variables and/or Concepts

Loss to Follow-Up

Long-term follow-up is necessary for managing chronic medical conditions in infants diagnosed with a condition. Although ongoing care has well-known advantages, many patients do not receive adequate follow-up, worsening their health outcomes. The American Heart Association reports that 70% of patients with critical congenital heart defects (CHD) and 95% of patients with non-critical CHD survive into adulthood, necessitating ongoing cardiology care (Gregorcyk et al., 2022). However, research indicates that up to 50% of pediatric CHD patients are lost to follow-up before transitioning to adult care, highlighting significant barriers (Gregorcyk et al., 2022).

Wright et al. (2024) evaluated follow-up trends among pediatric cardiology patients across multiple health clinics that served rural and underserved communities. Patients were considered lost to follow-up if they had not attended a pediatric cardiology visit six months past the recommended date. Among 235 patients, more than 40% received care outside the cardiology clinic, most frequently in specialty clinics (N=46), emergency departments (N=44), primary care (N=40), and hospitals (N=12). Patients with Medicaid (public insurance) were more likely to receive care at another clinic (HR = 1.60, 95% CI: 1.02, 2.51, $p = .038$). Additionally, patients living farther from the clinic were less likely to return for follow-up (HR = 0.77 per 10 km, 95% CI: 0.71, 0.83, $p < .001$).

Similarly, Gregorcyk et al. (2022) conducted a retrospective cohort study of nearly 9,000 pediatric cardiology patients to identify risk factors for being lost to follow-up. They found that 46% of patients were lost to follow-up, with higher odds among non-Hispanic Black patients, patients with severe congenital heart disease, and those with longer follow-up intervals. Patients with follow-up schedules of two or three years were at a heightened risk of being lost to follow-up compared to those with shorter follow-up times. The authors recommend shortening follow-up intervals to improve adherence and reduce care disruptions. La Roux et al. (2021) investigated loss to follow-up rates among pediatric patients transitioning to adult care for endocrine and metabolic conditions. In their longitudinal cohort study of 500 patients, nearly 90% adhered to regular follow-up visits, 9% had irregular follow-up, and 7% required intensive case management support. Patients with rare obesity-related conditions required the most case management interventions, emphasizing the need for individualized transition planning.

Swearingen et al. (2020) examined follow-up rates among premature infants, a patient population at high risk for developmental delays and medical complications. Their retrospective cohort study found that 62% of the 237 neonates were lost to follow-up within 24 months. Risk factors were identified as maternal smoking, gestational age of 31–32 weeks, and mothers of African American race. Parental scheduling issues (76.2%) were the leading reported reason for missed follow-up appointments, followed by provider scheduling issues (18.4%) and insurance-related barriers (1.4%). The findings emphasize the need for interventions targeting social determinants of health to reduce barriers to receiving long-term follow-up care in this vulnerable population.

Ulnes et al. (2023) assessed factors contributing to the loss of follow-up among pediatric patients with celiac disease. The retrospective cohort study included 162 Swedish children referred for follow-up programs. The data were collected from pediatric gastroenterology clinics, general pediatric outpatient clinics, laboratory records, and questionnaires. Loss to follow-up was defined as no celiac disease-related follow-up or tissue transglutaminase test within two years. Results indicated that 14% of the cohort was lost to follow-up, with a higher proportion among boys (61%) than girls (39%). The patients lost to follow-up had a longer disease duration (5.8 years vs. 5.2 years, $p = 0.11$). The results depict gaps in adherence to follow-up recommendations, suggesting a need for targeted interventions to improve follow-up retention. Hunter et al. (2016) evaluated loss to follow-up rates among infants undergoing newborn hearing screening to compare follow-up rates for infants participating in Women, Infants, and Children (WIC) programs to those who were not. Results indicated that WIC-eligible infants had a significantly lower loss to follow-up rate (<10%) compared to non-WIC infants (>28%). The average age at hearing confirmation was lower in the WIC group (~35 days) than in non-WIC infants (~62 days). The study suggests that targeted interventions, like participation in the WIC program, can improve follow-up adherence in newborn screening programs.

West et al. (2023) conducted a literature review and case study to evaluate social vulnerabilities impacting follow-up care for sickle cell patients. Housing insecurity, food insecurity, and lack of transportation were the most frequent reasons for not receiving timely medical treatment. A case study of a 12-year-old girl with sickle cell disease indicated that her mother did not have a phone or mailing address or methods of contact after a positive newborn screening test. These circumstances prevented communication of her abnormal screening results, which delayed treatment; consequently, her disease progressed during this time. The study highlights the importance of considering social vulnerabilities and early interventions for at-risk populations. Starosta et al. (2021) examined long-term follow-up rates for patients with congenital disorders of glycosylation (CDG), a rare metabolic disorder. Their study included 39 patients with progressive liver injury patterns, indicating the need for ongoing liver function monitoring through liver function tests, ultrasounds, and elastography. The authors advocate for individualized follow-up protocols for CDG patients to optimize care. Kyrklund et al. (2020) reviewed follow-up care for Hirschsprung's disease (HSCR), a congenital condition requiring bowel resection, with many patients experiencing complications after surgery. The study stressed that postoperative complications frequently require lifelong monitoring, but consistent guidelines are lacking. The authors concluded that all patients, including those who are considered to be stable, should continue receiving care into adulthood to prevent adverse health outcomes.

Thomas et al. (2023) conducted a systematic review to identify unmet supportive care needs among pediatric patients with chronic conditions (excluding cancer). Their findings indicated that the most common unmet needs were lifestyle, treatment information, and emotional support. The study stresses the importance of comprehensive support programs for patients and families managing chronic pediatric medical conditions. Kellar-Guenther et al. (2024) evaluated long-term follow-up rates using data from 672 children across four newborn screening programs. Results revealed that 92% had an initial specialist visit, and 87.7% received appropriate care. The study suggests standardizing long-term follow-up tracking and data-sharing systems to improve the efficacy of newborn screening programs. Similarly, Kemper et al. (2019) identified gaps in long-term monitoring after positive newborn screenings and referrals. The authors emphasized the lack of a national tracking system and suggested coordinated care, data sharing, and policy changes to ensure long-term follow-up care.

Lucena and Cavalcanti (2023) depicted another example of being lost to follow-up in newborn hearing screening. The authors evaluated the percentage of patients lost to follow among 604 infants in Brazil. Results demonstrate that approximately 60% were lost to follow-up. Few prenatal visits and a family history of hearing loss were identified as significant risk factors for being lost to follow-up. Powell (2020) conducted a meta-analysis to determine follow-up issues in newborn screening programs. They found limited data tracking and elevated loss rates to follow up due to relocation. Based on the findings, the authors recommend establishing national registries to heighten long-term care.

Sacharow et al. (2022) researched barriers to long-term follow-up in patients with phenylketonuria at Boston Children's Hospital. Fifty-three patients were eligible, but only 16 participated in follow-up interviews, and only five returned to the children's clinic. The key barriers were insurance issues, financial constraints, and lack of community support. The most common issues were insurance, financial instability, and lack of community support. The study recommends telemedicine as a potential solution to overcome follow-up challenges. To ascertain follow-up rates, Sheller et al. (2020) evaluated newborn screening follow-up in patients with two rare conditions. Their study found that 54% of newborn screening programs discontinued follow-up post-diagnosis, with only 16% monitoring patients from infancy to adulthood. The findings demonstrate the need for improved patient education and clinician coordination in rare diseases for follow-up. Baertling et al. (2019) analyzed malonic aciduria, a rare genetic disorder, follow-up in four Turkish siblings diagnosed through newborn screening. Results demonstrated biochemical variability and undiagnosed cardiomyopathy risk, highlighting the need for lifelong metabolic screening. The study stresses early intervention and structured follow-up processes for rare metabolic disorders. Hays et al. (2024) reviewed the Arkansas Newborn Screening Long-Term Follow-up (ArNBSLTFU) Database, a longitudinal study funded by the Centers for Medicare and Medicaid Services that tracked NBS-diagnosed neonates until age 21. Findings demonstrated that only 20% of children with special needs received ongoing services, 78% had emergency department visits, and 80% had hospitalizations. The study underscores the need for increased access to specialized medical care with the idea that it would decrease emergency department visits and improve patient outcomes.

Badawi et al. (2019) assessed the practicality of using pediatric primary care data to follow the long-term outcomes in 14 pediatric patients who had sickle cell disease or were deaf or hard of hearing (DHH). The study identified gaps in knowledge among healthcare providers about early intervention services, vaccine status, and genetic counseling. Results indicated that primary care data alone is inadequate for following long-term newborn screening outcomes, highlighting the need for national data-sharing processes.

A systematic review of 101 studies was conducted by Mackey et al. (2022) to evaluate the characteristics and long-term follow-up rates of newborn screening programs. The systematic review demonstrated that involvement with an audiologist, no-cost services, and affiliation with national programs increased follow-up rates. The review reflects the importance of considering cultural and demographic circumstances when designing newborn screening initiatives. Malesci et al. (2022) reflect another example of high lost-to-follow-up rates by analyzing long-term hearing screening follow-up in 350,178 infants born in the Campania region of Italy (2013–2019). Results demonstrated a 20.14% loss-to-follow-up rate, with syndromes, craniofacial abnormalities, ototoxic drug exposure, and family history as key risk factors. The authors concluded that Campania's screening program met the desired quality benchmarks, but additional measures should be employed to improve rates in identified at-risk groups. Powell (2020) conducted a meta-analysis to assess long-term follow-up in newborn screening programs. Tracking challenges due to relocation, electronic health record limitations, and lack of standardized national processes to increase being lost to follow up. Based on the results, the authors suggest that national registries and electronic health record integration be implemented to track patients across regions and improve health outcomes.

Insurance Type

Health insurance type is a significant determinant for follow-up adherence. The study by Wright et al. (2024) recognized that Medicaid patients were more likely to receive care at alternative clinics than the recommended one, contributing to fragmented care. Christner et al. (2023) similarly identified public insurance as a predictor of being lost to follow-up in a retrospective study of more than 260 neonatal intensive care unit patients who had been discharged and referred for follow-up, in which 35% of patients failed to return for follow-up care. Publicly insured patients also had higher rates of missed appointments, increasing the likelihood of being lost to follow-up. Roberts et al. (2016) evaluated 5,856 patients discharged from a neonatal intensive care unit in Nebraska to examine disparities in follow-up completion. The study found that infants with private insurance were 2.65 times more likely to complete follow-up than those on Medicaid ($p < 0.05$). Additionally, White patients were 1.8 times more likely to complete follow-up compared to minority patients, and high-risk infants were 1.36 times more likely to adhere to follow-up than low-risk infants. The results highlight the role of insurance status and racial disparities in completing follow-up care.

Heckenlaible et al. (2024) explored socioeconomic factors impacting follow-up care for pediatric glaucoma patients, a condition responsible for more than 5% of pediatric blindness globally. Their retrospective study included 99 pediatric glaucoma patients (2015–2021.) They analyzed visit attendance, treatment outcomes, and optical testing rates. Results revealed that only 22% of the sample received the recommended annual optic exam. Patients living closer to the clinic, 0–29.9 miles, had significantly lower follow-up rates than those residing farther away, and those with state-based insurance had significantly lower follow-up rates than patients with private insurance. The study stressed the need for targeted interventions to improve follow-up adherence among publicly insured patients.

Tran et al. (2022) performed a meta-analysis of 65 studies, which included 546,981 patients and 34,080 deaths, to review the impact of SDOH on congenital heart disease mortality. Results indicated that Black patients with CHD had a higher mortality risk, particularly infants with non-critical congenital heart disease (($OR = 1.62$) and neonates with critical congenital heart disease ($OR = 1.27$). Other high-risk factors included public/state insurance, maternal age under 18, and maternal education of less than 12 years. The authors stress the need for social interventions and policies to mitigate mortality disparities in this patient population. McKenna et al. (2024) evaluated the social needs of 2,400 pediatric patients with chronic health conditions. They found that families of patients with chronic health conditions reported higher unmet social needs (20%) than those without chronic health conditions (14%). The study also found increased social needs among Medicaid recipients and Spanish-speaking families. The results emphasize the intersection of chronic illness and socioeconomic vulnerabilities and affirm the importance of targeted social support programs.

Geographic Location

Geographic location is pivotal in obtaining healthcare access and adherence to follow-up care. Wright et al. (2024) found that patients living farther from the clinic were significantly less likely to return for follow-up visits. This aligns with Gregorcyk et al. (2022), who found that patients in rural areas faced more significant barriers to follow-up due to transportation issues, limited healthcare access, and lower socioeconomic status. Weeks et al. (2023) performed a retrospective analysis at the county level to evaluate health disparities from 2015 to 2019 across five health domains: social determinants of health (SDOH), health outcomes, clinical care, health behaviors, physical environment, and economic characteristics. Analysis of variance (ANOVA) depicted that counties with lower socioeconomic status had significantly poorer health indicators compared to counties with higher socioeconomic status ($p < 0.001$ for all measures). There was a reduction in all domains between 2015 and 2019, suggesting socioeconomic factors in the county represent an indicator for community health outcomes. Based on the findings, Weeks et al. (2023) stressed the importance of public health initiatives to target underserved areas to improve health outcomes.

To understand SDOH's role in healthcare gaps for pediatric patients with congenital heart disease, Abbas et al. (2024) conducted a retrospective single-center study of 8,554 children with moderate to severe congenital heart disease 2013 to 2015. Results demonstrated that approximately 30% of patients experienced a gap in care for more than 3.25 years. Patients aged 14 to 29, non-Hispanic black patients, those with low maternal education, minimal caregiver contact, those living further from the hospital, and those with a low child opportunity index were at the most significant risk for experiencing gaps in care. The authors concluded that healthcare improvement initiatives to address SDOH are necessary to improve outcomes in this vulnerable patient group. Burdick et al. (2023) assessed U.S. healthcare access inequities by evaluating intensive care unit bed availability within a 60-mile radius. Almost 2% of Americans had no intensive care unit bed access, and 26.8% had below-average access. Racial disparities were apparent, with 12.6% of American Indians/Alaska Natives and 29% of Hispanics having no access or limited intensive care unit bed access. Rural populations (41.2%) had worse access than urban groups (26.8%). The study stresses the impact of geographic location on healthcare accessibility.

Race/Ethnicity

Multiple studies indicate the presence of racial and ethnic disparities in obtaining needed long-term follow-up adherence. For example, Gregorcyk et al. (2022) found that among pediatric oncology patients, non-Hispanic Black patients were at higher risk of being lost to follow-up compared to White patients. Similarly, Christner et al. (2023) identified Black race as a significant indicator for missed follow-up visits among neonatal intensive care unit patients who had been discharged and referred for long-term follow-up. Maternal substance use, younger maternal age, and single-parent households were indicators for being lost to follow-up. The findings indicate that systemic barriers contribute to disparities in follow-up care, stressing the need for targeted interventions to improve healthcare access for historically underrepresented groups. Additionally, Swearingen et al. (2020) found African American race to be associated with an increased risk of being lost to follow-up among premature infants. The study suggested that parental scheduling issues and perceived barriers to care significantly affected these disparities.

Sheingold et al. (2023) analyzed the effect social determinants of health have on health disparities during the COVID-19 pandemic to develop a framework for addressing health inequities. They categorized health influencers into three domains: individual factors, system drivers, and policies. Individual factors were economic status, insurance coverage, and healthcare access, while system drivers included geographic location, provider discrimination, and local policies. Policy-level influences involve government initiatives, medical outreach programs, and medical and social services integration. The study emphasizes the disproportionate impact of the COVID-19 pandemic on Native American, Black, and Hispanic populations, who experienced higher rates of infection, hospitalization, and mortality rates compared to their White populations. Sheingold et al. (2023) stressed that policy-driven interventions are needed to mitigate health disparities and improve health equity. Kayle et al. (2024) studied racial and social disparities among patients with sickle cell disease, a condition included in newborn screening. The cross-sectional study used the Social Vulnerability Index to evaluate socioeconomic risk factors in a cohort of 3,305 newborns. Results revealed that those who lived in high or very high social vulnerability areas were Black or African American (90%) and single mothers (70%). The most common barriers in the communities were housing insecurity and limited transportation access. The authors suggested including social support initiatives in care plans for patients with sickle cell disease to decrease disparities and ultimately improve health outcomes. Peyvandi et al. (2018) investigated racial and socioeconomic disparities in one-year outcomes for infants with hypoplastic left heart syndrome (HLHS) and dextro-transposition of the great arteries (d-TGA), congenital heart defects. The population-based cohort study included 1,315 infants from 2007–2012. The researchers identified that Hispanic infants had significantly higher odds of mortality or unplanned hospital readmission compared to non-Hispanic White infants (*OR* = 1.72, 95% CI: 1.37–2.17). Higher maternal education (>12 years) and private insurance were associated with better outcomes. The study depicts maternal education and insurance status to mediate racial disparities in pediatric patient outcomes.

Holmes et al. (2024) investigated racial disparities among pediatric renal cell carcinoma, a rare and aggressive form of cancer. Their retrospective study from 1973–to 2015 included 174 cases and discerned that black children had a threefold higher mortality risk and a fourfold increased risk for those who lived in urban areas. Additional findings revealed that male patients had a 20% higher mortality risk than females. The study emphasizes that geographic and racial disparities play a part in outcomes and survival rates for pediatric patients with renal cell carcinoma. After a newborn has a positive screening test, they are referred for formal evaluation and diagnosis. Deng et al. (2022) conducted a retrospective cross-sectional study that included 754,613 infants born in 2017 across nine U.S. states to understand punctuality from birth diagnosis better. Study variables encompassed screening and diagnostic methods, maternal education, race/ethnicity, and socioeconomic factors like Women Infant Children recipient status. Results indicated that infants admitted to the neonatal intensive care unit, lower maternal education, and being from a racial minority group impacted early completion of newborn hearing screening and follow-up adherence. The results highlight the need for targeted outreach measures to support racial/ethnic minority mothers, those with lower education levels, and neonatal intensive care unit-admitted infants to decrease delays in diagnosis and treatment.

Language Preference

Language barriers have a substantial impact on obtaining healthcare services and follow-up adherence. Guerrero et al. (2021) presented a case study of a 12-year-old girl with Van Wyk-Grumbach syndrome, a rare pediatric endocrinological disorder requiring ongoing specialized care. The patient faced numerous care interruptions due to language barriers, lack of insurance renewal, and difficulty rescheduling appointments. These challenges resulted in delayed diagnosis, treatment disruptions, and LTFU, underscoring the immediate need for language access programs and culturally competent care. Similarly, Christner et al. (2023) found that non-English-speaking households were less likely to adhere to follow-up recommendations, likely due to communication barriers, lower health literacy, and challenges navigating the healthcare system. La Roux et al. (2021) stressed the importance of case management support for patients with complex medical needs, suggesting that language-access programs and culturally competent interventions could significantly improve follow-up rates.

Farrell et al. (2020) examined parental perspectives on their experience with newborn screening (NBS) follow-up. The study included 426 sickle cell hemoglobinopathy patients and 288 cystic fibrosis carrier infants. Results showed that 27.5% of parents with a child with sickle cell hemoglobinopathy and 7.8% of cystic fibrosis parents did not remember being informed of abnormal results. The study identified limited health literacy, younger parental age, and race/ethnicity as significant predictors of misunderstanding about newborn screening results and further recommendations. The authors concluded that language barriers and literacy limitations contribute to parental misunderstanding but also highlighted the urgent need for improved communication measures in newborn screening programs to enhance healthcare outcomes.

Summary and Conclusions

The literature reviewed highlights critical barriers to long-term follow-up and disparities in healthcare access among infants with a positive newborn screening and referred for follow-up. Critical findings demonstrate that race/ethnicity, language preference, geographic location, and insurance type significantly impact follow-up rates and overall health outcomes. Studies consistently illustrate that Black, Hispanic, and other minority populations experience higher rates of LTFU, often due to systemic inequities, social vulnerabilities, and access barriers (Deng et al., 2022; Kayle et al., 2024; Holmes et al., 2024). Insurance type has also been recognized as a strong predictor of follow-up adherence, with publicly insured patients less likely to receive continuous care (Roberts et al., 2016; Heckenlaible et al., 2024; Sacharow et al., 2022). Geographic disparities further exacerbate loss to follow-up rates, with patients from rural and those living in low-opportunity areas facing higher gaps in care due to transportation challenges and reduced healthcare access (Weeks et al., 2023; Abbas et al., 2024; Burdick et al., 2023). Parental factors, like language barriers, maternal education, and socioeconomic status, further influence follow-up rates. Families with limited English proficiency, lower health literacy, and financial instability are at increased risk for missed follow-up visits, leading to delayed diagnoses and poorer health outcomes (Farrell et al., 2020; Guerrero et al., 2021; Medeiros et al., 2023).

Despite the well-established benefits of early detection and intervention, the lack of standardized national long-term follow-up guidelines remains a significant challenge. Research stresses the need for structured follow-up protocols, multidisciplinary care coordination, data-sharing initiatives, and targeted outreach initiatives to enhance long-term follow-up and improve health outcomes (Powell, 2020; Kellar-Guenther et al., 2024; Kemper et al., 2019). This body of research stresses the need for timely systemic modifications in healthcare policy, social support systems, and patient-centered interventions to decrease inequities and ensure access to long-term follow-up care for all infants diagnosed through newborn screening programs. Future research should focus on developing standardized long-term follow-up frameworks, addressing social determinants of health, and leveraging technology to improve patient tracking and care continuity. The current study addresses gaps in the literature by evaluating intersections, using the SDOH framework, and including individual-level consideration. Ethnicity, insurance type, geographic location, and language preference are assessed to determine how they impact the likelihood of being lost to follow-up, which offers the opportunity to comprehend multifaceted disparities. Individual-level information for follow-up instead of total rates provides perspectives on individual barriers to care. The SDOH framework is used uniquely by consolidating population-based factors to evaluate the specified variables. The study adds to the current body of knowledge by contributing a detailed understating of how the variables impact being lost to follow-up among vulnerable patients through a new perspective.

Chapter 3: Research Method

Research Design and Rationale

This quantitative, retrospective, cross-sectional study evaluated the relationships between the independent variables (race, ethnicity, geographic location, language preference, and insurance type) and whether patients were current on their follow-up visits (dependent variable). The design aligns with the study's goal of investigating potential factors associated with receiving follow-up care in the specified pediatric patient population. The independent variables of interest are race/ethnicity (minority versus non-minority groups), geographic location (metropolitan versus non-metropolitan), preferred language (English versus non-English), and insurance type (private versus state-sponsored). The dependent variable is long-term follow-up status, defined as no touchpoints (visits, calls, communication) in the Epic system for 2024. Electronic health records were used to capture demographic data and determine whether patients received their recommended follow-up in 2024. The study design is deemed appropriate because it uses archival data and historical electronic health records to evaluate follow-up patterns based on demographic and social determinants.

Using a retrospective cohort design is suitable for ascertaining associations with receiving follow-up care, particularly in population health analyses. Basing the study on the SDOH framework enhances the current knowledge around individual characteristics and how they intersect with systemic inequities. The design fosters information for targeted interventions to improve long-term follow-up and health equity for vulnerable groups.

Methodology

Population

The study population consisted of 691 pediatric or adolescent patients, after excluding cases with incomplete or missing data, who were born in Colorado or Wyoming on or after January 1, 2020, and had a positive newborn screening result, and who were referred to or seen as patients in one of the partner university-affiliated clinics. Patients with a medical diagnosis identified via a positive newborn screening test were included. Exclusion criteria included deceased infants who moved out of the region, refused care, received care elsewhere, or transitioned to adult providers. Patients who have undergone bone marrow transplants or are awaiting bone marrow transplants were excluded due to different follow-up requirements in this patient group, which could impact the results.

Archival Data

Electronic health records (EHRs) from hospitals or clinics and newborn screening data from public health databases are considered archival data. The study utilized archival data from EPIC to evaluate patients lost to follow-up among infants identified as having a condition via newborn screening. The data were extracted from a partner university's EHR by their research team. This comprehensive electronic health record system maintains records of patients evaluated at their affiliated clinics, which include clinical and demographic information pertinent to the study. The Institutional Review Board (IRB) granted permission to gain access to de-identified patient records. The work has been deemed non-human subject research, and activities related to analyzing the de-identified data are being used to inform systems and quality improvement work. No additional approvals are needed.

Procedures for Gaining Access to the Data

The partner university's data researcher accessed and captured electronic health data, and the de-identified data were provided. To ensure compliance with ethical standards and patient privacy, de-identified data were used, and unique identifiers were removed in a process that involved removing identifiable information, such as medical record numbers, names, dates of birth, and social security numbers, if listed prior to being provided to the student. Institutional policies for data security and storage will be adhered to in order to safeguard protected health information. Copies of exemptions and permissions are included in the study's Appendices A and B. The Walden IRB approval number is 05-13-25-1038024. Walden IRB will oversee the student capstone data analysis and reporting of results.

Reputability and Justification for Data Use

The archival data from EPIC were deemed an appropriate source for the study due to their broad use and validated program across healthcare settings. The information from the EHR enabled the capture of patient outcomes, reduced associated biases, and facilitated self-reported information. The data set is a thorough and reliable source for examining follow-up patterns. This reliability instills confidence in the research methodology and the validity of its findings.

Sampling and Sampling Procedures

A retrospective cohort sampling strategy was useful to identify infants who met the inclusion criteria. The university's electronic health record (EHR), Epic, was employed to search for patients with positive newborn screenings, which were then filtered based on inclusion and exclusion criteria. Infants were categorized based on their follow-up status, identifying those who were lost to follow-up or not current with their recommended medical visits in 2024. Demographic characteristics, race/ethnicity, geographic location, insurance type, and language preference were extracted from the Epic records. To access the data, Epic's reporting tools were used to search for missed medical visits by querying appointment records, race, ethnicity, and language preference, and collected from patient demographic fields. Insurance type was filtered by payor source and coverage details to identify those with private and state-provided insurance.

The geographic location of patients was determined by querying using the patient's county of residence. The collected data was exported to a spreadsheet where identifiable information was not included to safeguard patient privacy. The raw dataset was assessed for completeness, accuracy, and consistency before undergoing statistical analysis, which evaluated patterns of missing data, incomplete demographic fields, and missing patient visit records. Reviewing the data for consistency included ensuring follow-up records are documented for the patients and validating that follow-up status is accurately captured. The data set was cleaned and patient demographics were reviewed to pinpoint patients who did not have a follow-up visit in 2024, permitting further evaluation of barriers based on SDOH, language preference, insurance type, geographic location, and race/ethnicity.

Power analysis was performed using the International Business Machines (IBM) Statistical Package for Social Sciences (SPSS) version 28.01 to determine the minimum sample size necessary for ample statistical power. An alpha level of 0.05, a power of 0.80, and an estimated large effect size (*OR*=3.0) were used. The sample size calculation was conducted using SPSS software. The effect size was based on previous literature evaluating disparities in similar populations, indicating that approximately one-third of pediatric patients are lost to follow-up (Amat et al., 2022). By clearly defining the study population, sampling strategy, and classification system, this methodology ensures transparency and replicability for future research on the social determinants of health that influence follow-up rates in newborn screening programs. This study includes independent variables, insurance type, language preference, geographic location, race, and ethnicity, which will be categorized based on their characteristics and coding structure.

Study Variables

Loss to Follow-Up

Loss to follow-up is the study's dependent categorical, binary variable coded as follows: 0 = not up-to-date in 2024 and 1= up-to-date for the 2024 follow-up visit. This variable was determined by querying electronic health records in Epic to identify whether an infant referred for follow-up after a positive newborn screening had a documented medical visit in 2024. Loss to follow-up is a vital predictor of gaps in long-term care, as infants who do not receive timely follow-up may experience worsened health outcomes due to delayed diagnosis and treatment (Christner et al., 2023; Powell, 2020). This study enhances replicability and methodological transparency by establishing clear coding and classification. This will enable future research to investigate factors influencing long-term follow-up rates in newborn screening programs.

Geographic Location

Geographic location, one of the study's independent variables, is a categorical, multinomial independent variable that will be analyzed. It was categorized based on the 2023 rural-urban continuum codes, delineating metropolitan counties by population size, non-metropolitan counties by urbanization, and proximity to a metropolitan area. According to the 2023 Office of Management and Budget, counties are categorized as urban or non-metropolitan. Areas are further divided into three metropolitan and six non-metropolitan regions. Based on census data, one of the nine codes is assigned to a county. The categories are (1 Metropolitan - Counties in metro areas of 1 million population or more; 2 Metro - Counties in metro areas of 250,000 to 1 million population; 3 Metro - Counties in metro areas of fewer than 250,000 population; 4 Nonmetro - Urban population of 20,000 or more adjacent to a metro area; 5 Nonmetro - Urban population of 20,000 or more, not adjacent to a metro area; 6 Nonmetro - Urban population of 5,000 to 20,000, adjacent to a metro area; 7 Nonmetro - Urban population of 5,000 to 20,000, not adjacent to a metro area; 8 Nonmetro - Urban population of fewer than 5,000, adjacent to a metro area; 9 Nonmetro - Urban population of fewer than 5,000, not adjacent to a metro area. The patients will be categorized using the nine codes for this study. Using county codes allows researchers to view county-level data, evaluate patterns and trends, and systematically analyze rural versus urban disparities in follow-up care and health outcomes among newborns identified through state screening.

Insurance Type

Insurance type is an independent categorical variable in this study, classified as private or public insurance. This variable was be coded as 1 = private and 2 = public insurance. Data was extracted from Epic electronic health records (EHR) using a structured query to categorize patients based on their documented insurance provider. Insurance type was included as a variable because prior research suggests that public insurance is associated with decreased healthcare access, longer wait times, and higher loss-to-follow-up rates compared to private insurance (Roberts et al., 2016; Sacharow et al., 2022).

Race and Ethnicity

Race and ethnicity data, self-reported by patients and patient family members, were extracted from Epic electronic health records. This variable was included due to documented disparities in healthcare access and follow-up rates among racial and ethnic groups (Deng et al., 2022; Roberts et al., 2016). Race was defined and coded based on the standardized U.S. Census categories: White, Black or African American, Asian, American Indian/Alaska Native, Native Hawaiian/Other Pacific Islander, and individuals identifying as two or more races. Ethnicity was categorized as Hispanic/Latino or non-Hispanic/Latino. Race is a categorical, nominal variable and was coded as 1 white/Caucasian, 2 black/African American, 3 Asian, 4 American Indian/Alaska

Native/other, 5 more than one race. Ethnicity is a categorical, binary variable and was coded as 1 for Hispanic/Latino or 2 for non-Hispanic/Latino.

Language Preference

Language preference is an independent categorical, binary variable coded as follows: 1 = English preference, 2 = non-English preference. This self-reported variable was extracted from electronic health records (EHR) in Epic based on the preferred language recorded during patient visits. Language preference was included due to its potential impact on healthcare access, communication barriers, and follow-up rates in newborn screening programs (Guerrero et al., 2021; Farrell et al., 2020). By clearly defining the study population, sampling strategy, and classification system, this study ensured methodological transparency and replicability for future research on the social determinants of health influencing follow-up rates in newborn screening programs.

Data Analysis Plan

Descriptive Statistics

Descriptive statistics were used to summarize the distribution of individual variables. They help provide an overview of the data by providing a description or summary and can also reflect trends. Frequencies and 95% confidence intervals depict categorical variables, such as geographic location, insurance type, race/ethnicity, and language preference. Frequencies and 95% confidence intervals (CIs) were used for categorical variables like geographic location, insurance type, race/ethnicity, and language preference to calculate how common each category was within the sample (Kaliyadan & Kulkarni, 2019). Cross tabulation was performed to evaluate the relationship between categorical variables in table format for each independent variable and covariate with the dependent variable, follow-up visit in 2024. Cross tabulation provides a method for grouping variables to identify patterns and associations before performing binary logistic regression or multivariate regression (Bauer et al., 2021).

Bivariate Analysis

Simple logistic regression was deemed appropriate because the dependent variable, follow-up in 2024, is a binary categorical variable (yes or no). Simple logistic regression evaluated the association between each independent and dependent variable before adjusting for confounders, which assisted in identifying significant individual predictors for follow-up status without adjusting for other variables. Results were reported as an unadjusted odds ratio (UAOR) to measure the strength and direction of associations, a 95% confidence interval to reflect the range of possible *OR* values, and *p*-values to assess statistical significance, with a value of <0.05 considered significant (Harris, 2021). The odds ratio for each independent variable reflects the likelihood of completing follow-up per dependent variable category. A 95% confidence interval (CI) for each odds ratio examined the precision and reliability of the estimates. Probability values (*p*-values) were interpreted to test the null hypotheses, and results were considered statistically significant if the p-value is less than 0.05. The Hosmer-Lemeshow goodness-of-fit test was appropriate for binary regression due to its ability to evaluate how well the logistic regression model fits the observed data to assess if the observed events match the expected events based on model prediction. A non-significant result of $p > 0.05$ is considered a good model fit. The *p*-value indicates whether the observed and expected counts are statistically significant. A high *p*-value, >0.05, indicates no statistically significant difference, indicating that the model fits well, and a low *p*-value, <0.05, depicts that the model is not a good fit (Bewick et al., 2005).

Multiple Logistic Regression

Numerous circumstances can impact follow-up medical visits, so adjusting for covariates helps ensure that other factors like age or newborn screening conditions do not alter the observed associations between the independent variables and follow-up status. Adjusting for covariates helps isolate the actual effect of each independent variable on the likelihood of having a follow-up visit in 2024. Therefore, multiple logistic regression was performed to answer each individual research question while controlling for possible covariates, age group, and newborn screening condition. The model evaluated the relationship between independent variables and the dependent variable, adjusting for covariates like age group and newborn screening condition. Adjusted odds ratios, 95% confidence intervals, and *p*-values (a <0.05) will be reported for each independent variable. For this analysis, the adjusted odds ratio, 95% confidence intervals, and *p*-values were reported to gauge the independent association of each variable with follow-up status in 2024 (Zapf et al., 2024).

Interpretation

In multiple logistic regression, the adjusted odds ratio (*AOR*), *p*-value, and 95% confidence interval (CI) reflect the strength, direction, and significance of associations between independent variables and the dependent variable (follow-up visit in 2024: Yes/No). The *AOR* indicates the strength and direction of the effect. If the *AOR* is less than 1, the independent variable was interpreted as a decrease in the odds of having a visit in 2024, and an *AOR* of 1 was considered as having no association between the independent variable and having a visit in 2024. An *AOR* greater than 1 indicates an increase in the odds of the independent variable and having a follow-up visit in 2024. The *p*-value reflects if the effect is statistically significant; p-<0.05 is considered to be significant. The 95% confidence interval depicts the precision of the estimate. If the confidence interval excludes 1.0, the effect was considered statistically significant.

Issues of Trustworthiness

Threats to Validity

External Validity

External validity, a key component of the study, refers to how the findings can be generalized beyond this study's specific sample population or other situations or settings. The potential threats to external validity, including study selection bias, differences in healthcare between geographic regions, and changes in healthcare policy, have been carefully considered in the study design. The study results from infants in Colorado and Wyoming might not be generalized to other areas or states. Still, the thorough approach to defining the inclusion and exclusion criteria, as well as comparing the sample population characteristics with those of larger datasets, ensures the representativeness of the findings. Healthcare differences exist, with access for follow-up varying across geographic areas, which can impact the applicability of our findings to other states. Using rural-urban continuum codes to consider variations in care access can assist with mitigation. Newborn screening and follow-up policies change over time, impacting findings. Policy changes can be addressed by explicitly defining the study period and accounting for policy changes when interpreting results.

Internal Validity

Internal validity is the extent to which a study minimizes alternative explanations for the observed effects or is free from bias or systematic errors. Possible threats to internal validity are confounding variables and selection bias. Performing multiple regression addresses possible confounding by including multiple variables, including well-known confounders. Data cleaning procedures were implemented to address selection bias and missing data. It is essential to note that sensitivity analyses were also employed to detect bias, a crucial step in maintaining internal validity.

Construct Validity

Construct validity reflects how accurately a test estimates the concept it was meant to evaluate. Measurement errors and geographic location categorization can threaten construct validity. It is possible that ethnicity, language preference, and follow-up status might not have been consistently or accurately captured in the EHR. Using standardized definitions and valid coding to classify variables was crucial to maintain construct validity, as these practices can help address measurement errors. Rural-urban categories might streamline healthcare access differences. However, the use of 2023 Rural-Urban Continuum codes for locations can address this issue (United States Department of Agriculture [USDA], 2024).

Ethical Procedures

The partner university's electronic health records system, Epic, served as the primary and trusted source for the data in this study. Official agreements for accessing the archival data were secured with supporting documentation, a component of the IRB application. The university's authorized researcher provided the student researcher with de-identified data. The required permissions were obtained before accessing or analyzing the data. The Institutional Review Board approval was obtained from Walden University to collect and analyze archival data.

Data access was limited to only the data necessary for the study, without direct contact with participants, thereby safeguarding patient privacy. Identifiable data was excluded. The researcher adhered to organizational guidelines for securing and handling data and reported any inconsistencies to the IRB if they occurred. The data was de-identified before being given to the student researcher, and prior to data analysis, as a measure of safeguarding patient information, data coding will be performed. Data will be stored on a password-protected, encrypted hard drive, with access restricted to the researcher only.

Study results will be disseminated as a summation, with no individual identifiers divulged. The dissertation presents data tables that summarize demographic characteristics and provide statistical analyses. The data retention period will be five years, congruent with ethical guidelines. The records will be deleted after the retention period using secure erasure software that strictly adheres to organizational and federal mandates, ensuring the highest level of data security. Data will be stored on a password-protected, encrypted hard drive, with access restricted to the researcher only. Study results will be disseminated as a summation, with no individual identifiers given.

Chapter 4: Results

Introduction

The purpose of this retrospective quantitative cohort study was to comprehensively identify social and clinical factors associated with follow-up adherence to recommended medical visits. This study specifically sought to evaluate the unadjusted and adjusted effects of predetermined social and clinical independent variables. The independent variables included race/ethnicity, socioeconomic status (as indicated by insurance type), geographic location (county of residence), and language preference. These social determinants were analyzed for their influence on the dependent variable and whether patients were current for their 2024 follow-up visit. By identifying specific characteristics, such as racial background or linguistic preference, or county-specific resources that can impede follow-up adherence, this study provides actionable insights that can empower health policymakers to make informed decisions, improve health equity, and enhance health outcomes.

Data Collection

This study employed a quantitative, retrospective cohort design to examine the characteristics of patients who had a positive newborn screening test and to determine whether they were up-to-date on their recommended follow-up visits in 2024. Data for this research were collected from Epic, the university's EHR, by an authorized university researcher. A de-identified dataset was provided to the student researcher, allowing for the analysis of existing archival data, including historical electronic health records.

Sample and Participants

The study's sample population included 691 infants from Colorado and Wyoming who were born on or after January 1, 2020. Eligible infants were identified based on the inclusion and exclusion criteria. The inclusion criteria consisted of patients under 25 years who had a positive newborn screening result and were referred to the partner university's medical clinics, born in Colorado or Wyoming. Exclusion criteria for this study included deceased infants, those who moved out of the study region, refused care, received care elsewhere, or transitioned to adult providers. Additionally, patients who had undergone or were awaiting bone marrow transplants were excluded due to their specific follow-up requirements.

Data Collection Procedures

The university's electronic health record (EHR) system, Epic, was utilized to search for patients with positive newborn screenings. The records were then filtered to identify those who were lost to follow-up or not current with their recommended appointments in 2024. Demographic information, including race/ethnicity, geographic location, insurance type, and language preference, was extracted from the EHR. Data completeness and consistency were assessed through an evaluation of the raw dataset to ensure the presence of all variables of interest. Data were uploaded into SPSS for statistical analysis, including descriptive statistics, cross-tabulations, binary logistic regression, and multiple logistic regression to evaluate associations between the independent variables and follow-up status while controlling for covariates such as age and NBS condition.

Representativeness and External Validity

Non-probability sampling was employed due to the secondary nature of the study, which utilized secondary archival data. The detailed description of the demographic and population characteristics of the sample aims to enhance the study's applicability, allowing for replication or comparison in future research. I assumed that the sample is representative of a broader patient population requiring long-term follow-up, which is vital for the study's validity. The study findings are intended to be applied to similar patient groups, providing a foundation for future research and contributing to the development of broader health policies that aim to foster health equity and optimize continuity of care.

Covariates

Newborn screening conditions and age were included as covariates in the analysis due to their role as demographic and clinical characteristics that impact health outcomes and adherence to follow-up. Age is a well-known demographic factor that can affect health practices and healthcare access. Specific newborn screening conditions were included because they define a patient's specific needs for long-term follow-up and may have varying implications for patient engagement and care requirements. The inclusion of covariates helps account for their potential impact on follow-up status, thereby providing insight into the effect of the primary independent variables (race, ethnicity, geographic location, language preference, and insurance type).

Results

Descriptive Statistics

Race

A total of 691 valid cases were included in the analysis, as shown in Table 1, with a small number of missing cases for specific variables. The majority of participants (76.8%, n = 531) were categorized as being up-to-date on their 2024 follow-up visit, while 23.2% (n = 160) were not up-to-date on their 2024 visit. The largest racial group in the study was White/Caucasian (65.6%, n = 453), followed by Black or African American (15.8%, n = 109), The Native/other group represented (10.3%, n = 72) and more than one race group (4.9%, n=34) and Asian (3.2%, n=22). White/Caucasian was used as the reference category in the regression analyses.

Cross-tabulation (further detailed in Table 1) revealed that the majority of participants who were up-to-date on their 2024 visits were white/Caucasian (64.0%, n=340), followed by black/African American (n=96, 17.5%), and those of more than one race (n=25, 4.7%). Among those who were not up-to-date on visits were Caucasian/white (71.1%, n=453). A Pearson Chi-Square test was performed to evaluate the association between participant race and their visit status for 2024. The analysis, which included 690 valid cases, revealed no statistically significant association between these two variables, $\chi2(4, N = 690) = 6.70, p = .152$. All expected cell counts were greater than 5, satisfying the assumption for the chi-squared test.

Age

The largest age group was category one, comprising individuals aged up to 12 years (62.7%, n = 437), and the category for those over 12 years was category 2 (36.4%, n = 254). Cross-tabulation of participant age group by their visit status as reflected in Table 1 shows that most of the study sample was zero to 12 years (63.2%, n=437), with 36.4% (n=254) aged 12 or greater. Both age groups showed similar proportions of participants being up-to-date on visits (63.5% for 'age to 12' vs. 62.5% for '12 to 25') and not up-to-date on visits (36.5% for 'age to 12' vs. 37.5% for '12 to 25'). A Pearson Chi-Square test was performed to assess the association between participant age groups and visit status. The analysis included 691 valid cases and revealed no statistically significant association between these two variables, $\chi 2(1, N = 691) = 0.05, p = .824$. All expected cell counts were greater than 58, satisfying the assumption for the chi-squared test.

Newborn Screening (NBS) Category

Patients in category 1, cystic fibrosis represented (31.9% n=222), category 2 endocrine disorders (12.2%, n=85), category 3 hemoglobinopathy (18.8%, n-131), category 4 metabolic conditions (30.7%, n=214), category 5 severe combined immunodeficiency (SCID) or trec related (1.9%, n=13) group 6 spinal muscular atrophy (3.7%, n=26). Cross-tabulation of Newborn Screening Category ('NBS Category') by up-to-date on visit status reflected in Table 1, variations in visit status across NBS categories. A substantial proportion of patients with metabolic conditions (59.4%, n=95) were not up-to-date on 2024 visits compared to other categories. Patients in the 'Cystic

Fibrosis' group, 38.0% (n=202), were up-to-date on 2024 visits. A Pearson Chi-Square test was conducted to examine the association between Newborn Screening Category ('NBS Category') and up-to-date on 2024 visits status. A statistically significant association was found between NBS Category and up-to-date on 2024 visits status, $\chi 2(5, N = 691) = 91.21$, $p < .001$. This suggests that the proportion of individuals up-to-date on 2024 visits varied significantly across different NBS categories. One cell (8.3%) had an expected count less than 5 (minimum expected count = 3.01).

Ethnicity

Ethnicity was labeled as 'Ethnicity new' and coded as 1 for Hispanic or Latino and 2 for not Hispanic or Latino. Most participants identified as non-Hispanic/Latino (78.3%, n = 540), while 21.7% (n = 150) identified as Hispanic/Latino. Hispanic/Latino was used as the reference category in dummy coding. The cross-tabulation of 'Ethnicity new' by up-to-date 2024 visit status, as reflected in Table 1, shows that most of the study sample (78.3%, n = 540) fell into the 'Ethnicity new' category 2 (not Hispanic or Latino). Very similar proportions of individuals in both ethnic categories (Hispanic/Latino and non-Hispanic/Latino) were found to be up-to-date on 2024 visits (21.7% vs. 22.0%) and not up-to-date on visits (78.3% vs. 78.0%). A Pearson Chi-Square test was conducted to examine the association between ethnicity and the patient's 2024 visit status. No statistically significant association was found between these variables, $\chi 2(1, N = 690) = 0.01$, $p = .924$. All expected cell counts were greater than 5, satisfying the assumption for the Chi-Square test.

Preferred Language

Preferred language was labeled as 'Language new'. Most participants (91.6%, n = 633) preferred English, while 8.4% (n = 58) preferred a non-English language. The cross-tabulation of participant preferred language by 2024 visit status, as shown in Table 1, reveals that the majority of the study sample (91.6%, n = 633) reported being in language category 1. Among those up-to-date on 2024 visits, 92.3% (n=490) were in language category 1, compared to 89.4% (n=143) of those not up-to-date on 2024 visits who were in language category 1. A Pearson Chi-Square test was conducted to examine the association between participant language and their up-to-date on 2024 visit status. No statistically significant association was found between these variables, $\chi 2(1, N = 691) = 1.35$, $p = .246$. All expected cell counts were greater than 5, satisfying the assumption for the Chi-Square test.

Insurance Type

Insurance type was labeled as 'Insurance recoded' and coded as 1 for private insurance and 2 for public insurance. Public insurance (category 2) accounted for 66.4% (n = 459) of participants, and private insurance (category 1) accounted for 33.6% (n = 232). Cross tabulation, Table 1, of insurance type and 2024 visit status reflected a slightly higher percentage of patients not up-to-date on 2024 visits were from category 1 (38.8%, n=62) compared to those who were up-to-date (32.0%, n=170)." A Pearson Chi-Square test was conducted to examine the association between 'Insurance Recoded' and up-to-date on 2024 visit status. No statistically significant association was identified between these variables, $\chi 2(1, N = 691) = 2.50$, $p = .114$. All expected cell counts were greater than 5, satisfying the assumption for the chi-squared test.

County Code

Patient county of residence was labeled as 'County code' and categorized as (1 Metropolitan - Counties in metro areas of 1 million population or more; 2 Metro - Counties in metro areas of 250,000 to 1 million population; 3 Metro - Counties in metro areas of fewer than 250,000 population; 4 Nonmetro - Urban population of 20,000 or more adjacent to a metro area; 5 Nonmetro - Urban population of 20,000 or more, not adjacent to a metro area; 6 Nonmetro - Urban population of 5,000 to 20,000, adjacent to a metro area; 7 Nonmetro - Urban population of 5,000 to 20,000, not adjacent to a metro area; 8 Nonmetro - Urban population of fewer than 5,000, adjacent to a metro area; 9 Nonmetro - Urban population of fewer than 5,000, not adjacent to a metro area.

Nearly half of the sample resided in county category 1(Metropolitan - Counties in metro areas of 1 million population or more([49.9%, n = 345], followed by category 2 (Metro - Counties in metro areas of 250,000 to 1 million population) [32.9%, n = 227] and the fewest residing in county code 4 (Nonmetro - Urban population of 20,000 or more adjacent to a metro area) [3.4%, n=5]. Cross-tabulation of patient 'County code by their 2024 visit status was performed. Most participants resided in County Code 1 (49.9%, n = 345) and County Code 2 (32.9%, n = 227). The proportions of participants who were up-to-date on 2024 visits varied slightly across counties, with County Code 1 depicting 48.8% (n=259) of its residents being up-to-date, compared to 53.8% (n=86) among those not up-to-date. Several county codes had very small (n = 5, category 4) numbers of participants in specific visit categories, which were considered in the statistical analysis. A Pearson Chi-Square test was conducted to examine the association between participants' County code and their 2024 visit status. The analysis, which included 691 valid cases, as reflected in Table 1, showed no statistically significant association between these two variables, $\chi 2(7, N = 691) = 4.64$, $p = .703$. However, it should be noted that four cells (25.0%) had expected counts less than 5, with a minimum expected count of 1.16, which may affect the reliability of the chi-squared result.

Table 1

Descriptive Statistics for Predictor Variables by Up-to-Date Status in 2024

	Up-to-date		Not Up-to-date	
	n (%)	95% CI	n (%)	95% CI
Characteristics	531 (76.2)	72.8-79.3	160 (23)	20.7-36.3
NBS Category: Cystic Fibrosis	222 (31.9)	28.1-35.8	20 (12.5)	5.4-13.1
NBS Category: Endocrine	85 (12.2)	9.90-14.9	20 (12.5)	15.3-32.9
NBS Category: Hemoglobinopathy	131 (18.8)	15.9-21.9	21 (13.1)	9.9-22.9
NBS Category: Metabolic	214 (30.7)	27.2-34.5	95 (59.4)	37.9-50.9
NBS Category: SCID or TREC-Related	13 (1.9)	1.0-3.2	4 (2.5)	7.7-53.8
NBS Category: Spinal Muscular Atrophy	26 (3.7)	2.4-5.5	0 (0.0)	0.0-0.0
County Code: 1	259 (48.8)	70.4-79.4	86 (53.8%)	20.6-9.6
County Code: 2	180 (33.9)	74.0-84.6	47 (29.4)	15.4-26.0
County Code: 3	21 (4.0)	68.0-96.0	4 (2.5)	4.0-32.0
County Code: 4	4 (0.8)	40.0-100.0	1 (0.6)	0.08-60.0
County Code: 5	20 (3.8)	66.7-95.8	4 (2.5)	4.20-33.3
County Code: 6	14 (2.6)	55.6-94.4	4 (2.5)	5.6-44.4
County Code: 7	22 (4.1)	51.5-81.8	11 (6.9)	18.2-48.5
County Code: 9	11 (2.1)	57.1-100.0	3 (1.9)	0.0-42.9
Age: Up to 12	337 (63.5)	73.2-81.0	100 (62.5)	19.0-26.8
Age: 12 to 25	194 (36.5)	71.3-81.5	60 (37.5)	18.5-28.7
Race: White	340 (64.0)	70.9-78.8	113(71.0)	21.2-29.1
Race: Black	93 (17.5)	77.5-90.8	16 (10)	9.2-22.5
Race: Native American	54 (10.2)	63.9-83.6	18 (11.3)	16.4-36.1
Race: Asian	19 (3.60)	66.7-95.3	3 (1.90)	4.7-33.3
Race More than one race	25 (4.70)	56.9-85.4	9 (5.70)	14.6-43.1
Ethnicity: Hispanic	80 (15.5)	72.7-87.9	19 (11.9)	12.1-27.3
Ethnicity: Non-Hispanic	449 (65.1)	72.5-79.5	141 (88.1)	20.5-27.5
Insurance: Public	342 (62.2)	74.5-82.3	94 (58.8)	17.7-25.5
Insurance: Private	189 (36.4)	68.6-79.2	66 (41.3)	20.8-31.4
Language: English	491 (92.5)	75.2-81.6	135 (84.4)	18.4-24.8
Language: non-English	40 (7.5)	49.2-73.8	25 (15.6)	26.2-50.8

*Note**. N = 691. CI = Confidence Interval. Percentages may not sum to 100 due to rounding.

Binary Logistic Regression Analysis

Individual binary logistic regression analyses were conducted to assess the unadjusted association between each independent variable and the likelihood of being up-to-date on visits in 2024, as shown in Table 2. For these analyses, the dependent variable "up-to-date on visits" was coded as 1 for up-to-date visits and 0 for not up-to-date visits in 2024. An odds ratio (*OR*) greater than 1 indicates increased odds of being up-to-date on 2024 Visits, while an odds ratio less than 1 indicates decreased odds of being up-to-date on 2024 Visits.

Age

Age was labeled as 'Age final' and coded as 1 for individuals aged 0 to 12 years and 2 for those aged 12 to 25. The univariate binary logistic regression for age, as shown in Table 2, was not statistically significant (*OR* = 1.08, 95% CI [0.72–1.63], p = .703). This indicates that, when considered alone, the age group was not significantly associated with the odds of being up-to-date on visits in this study sample.

Race

Race was labeled 'Race final'. Table 2 shows that Black participants had 1.85 times higher odds (Unadjusted *OR* = 1.85, 95% CI [1.12–3.07], p = .017) of being up-to-date on visits compared to White/Caucasian participants (the reference group). Those who identified as more than one race demonstrated a near-significant trend with 2.73 times greater odds (Unadjusted *OR* = 2.73, 95% CI [1.00–7.44], p = .05) of being up-to-date on visits than White/Caucasians.

Newborn Screening Category Condition

Newborn Screening Category Condition was labeled as Recoded NBS Category: Category 1 (cystic fibrosis) was used as the reference group. As depicted in Table 2, participants in Category 2 (endocrine disorders) had 0.23 times the odds (Unadjusted O*R* = 0.23, 95% CI [0.14–0.37], $p < .001$) of being up-to-date on visits compared to those in Category 1. This indicates patients with conditions in Category 2 were considerably less likely to be up-to-date on visits (or, equivalently, approximately 4.35 times more likely to be not up-to-date on visits).

Preferred Language

Preferred Language was labeled as ‘‘Language new’’ and coded as 1 for English preference and 2 for non-English preference. The univariate binary logistic regression for ‘‘‘Language new’’’ was statistically significant (Table 2). Those who preferred non-English languages had 0.37 times the odds (Unadjusted *OR* = 0.37, 95% CI [0.20–0.68], $p = .001$) of being up-to-date on visits in 2024 compared to those who prefer English. This suggests that non-English speaking participants were less likely to be current on 2024 visits than English-speaking participants.

Ethnicity

Ethnicity was labeled as ‘Ethnicity new’ and coded as 1 for Hispanic or Latino and 2 for non-Hispanic or Latino. The univariate binary logistic regression for ‘Ethnicity new’ Table 2, was not statistically significant (Unadjusted *OR* = 1.02, 95% CI [0.59–1.77], $p = .958$). So, when considered alone, ‘Ethnicity new’ (Hispanic vs. Non-Hispanic) was not significantly associated with the odds of being up-to-date on visit

County Code

County Code: As previously mentioned, predetermined county codes were used to reflect geographic location and urbanicity. Overall, univariate binary logistic regression for County code failed to demonstrate statistical significance. As shown in Table 2, all individual County Code categories were not statistically significant predictors of being up- to-date on 2024 visits compared to County code 1 (the reference group). For example, County code 3 (Metro - Counties in metro areas of fewer than 250,000 population) had 0.574 times the odds (Unadjusted *OR* = 0.574, 95% CI [0.191–1.719], $p = .321$) of being up-to-date on 2024 visits than those from the reference county, code 1

Insurance Type

Insurance Type was labeled as ‘Insurance new’ and coded as 1, private insurance, and 2, public insurance. The univariate binary logistic regression for Insurance type (Table 2) did not demonstrate statistical significance (Unadjusted *OR* = 0.71, 95% CI [0.51–1.00], $p = .051$). In this study, when considered alone, insurance status was not significantly associated with the odds of being up-to-date on 2024 visits.

Table 2

Bivariate Analysis of Predictor Variables for Up-to-Date Follow-Up Status (N = 691)

Characteristics	Unadjusted OR (95% CI)	p-value
Age		
0–12 (Ref)	1.00b	
12–25	1.08 (0.72–1.63)	0.703
Race		
White (Ref)	1.00b	
Black	1.85 (1.12–3.07)	.017*
More than one	2.73 (1.00–7.44)	0.05
Ethnicity		
Non-Hispanic (Ref)	1.00b	
Hispanic	1.02 (0.59–1.77)	0.958
Insurance		
Public (Ref)	1.00b	
Private	0.71 (0.51–1.00)	0.051
County Code		
County Code 1 (Ref)	1.00b	
County Code 2	0.786 (0.525–1.178)	0.243
County Code 3	0.574 (0.191–1.719)	0.321
County Code 4	0.753 (0.083–6.828)	0.801
County Code 5	0.602 (0.199–1.812)	0.367
County Code 6	0.860 (0.276–2.688)	0.796
County Code 7	1.506 (0.701–3.233)	0.294
County Code 9	0.821 (0.224–3.011)	0.767
Language		
English (Ref)	1.00b	
Non-English	0.37 (0.20–0.68)	.001**
NBS Category		
Cystic Fibrosis (Ref)	1.00b	
Category 2	0.23 (0.14–0.37)	<.001***

Note. OR = Odds Ratio; CI = Confidence Interval. N = 691. * *p* < .05. ** *p* < .01. *** *p* < .001.

Multiple Binary Logistic Regression Analysis

A multiple binary logistic regression analysis was conducted to assess the adjusted associations between the independent variables and the likelihood of being current at the 2024 follow-up visits, shown in Table 3. Up-to-date on visit status was coded as 1 for 'up-to-date' and 0 for 'not up-to-date'. Therefore, adjusted odds ratios

(Exp(B)) greater than 1 indicate increased odds of being up-to-date on visits, and values less than 1 indicate decreased odds of being up-to-date on visits.

Overall Model Fit and Classification

The full model containing all predictors (Table 3) was statistically significant, $\chi 2(13, N=691) = 76.719$, $p < .001$. This indicates that the set of independent variables significantly predicted the odds of being up-to-date on visits in 2024. The model explained approximately 14.0% of the variance in the outcome (Nagelkerke R-squared = .140). The classification table for the model indicated an overall correct prediction rate of 76.8%. An important component of the model's performance reflected that the model correctly predicted 0.0% (0 out of 160) of cases that were not up-to-date on visits, but accurately predicted 100.0% (531 out of 531) of cases that were up-to-date on visits (see Table 3 for details).

Newborn Screening Category Condition

Newborn Screening Category Conditions were coded and labeled as 'NBS recoded', with the following codes: 1, cystic fibrosis; 2, endocrine disorders; 3, hemoglobinopathy; 4, metabolic conditions; 5, SCID or Trek-related conditions; 6, spinal muscular atrophy. After adjusting for all other variables (see Table 3 for full model results), patients in Category 2 (endocrine disorders, compared to Category 1, cystic fibrosis) had significantly higher odds of being up-to-date on visits (Adjusted $OR = 2.91$, 95% CI [1.44, 5.88], $p = .003$). This finding indicates patients in Category 2 were approximately 2.91 times more likely to be up-to-date on visits compared to those in Category 1, holding all other variables constant.

Race

Race was labeled ‘Race final’. After adjusting for other variables, Black/African American participants had lower odds of being up-to-date on visits (Adjusted *OR* = 0.42, 95% CI [0.17, 1.03], p = .057) compared to White/Caucasians (the reference group), a finding that approached but did not reach statistical significance at the $p < .05$ level (see Table 3 for full results). Similarly, patients who identified as more than one race had lower odds of being up-to-date on visits (Adjusted *OR* = 1.15, 95% CI [0.46, 2.90], p = .764) compared to White/Caucasians, after adjusting for other factors, and this was not statistically significant. Asian (Adjusted *OR* = 0.34, 95% CI [0.08, 1.39], p = .135) and Native Hawaiian or Other Pacific Islander (Adjusted *OR* = 0.61, 95% CI [0.30, 1.26], p = .181) racial categories were also not statistically significant predictors in this adjusted model.

Language Preference

Language preference was labeled ‘‘Language new’’ (Reference group: Category 1) and coded as 1 for English preference and 2 for non-English preference. Participants in Category 2, who had a non-English preference (compared to Category 1), were not a statistically significant predictor in the adjusted model (Adjusted *OR* = 1.99, 95% CI [0.94, 4.18], p = .071). This indicates that individuals in Category 2 had approximately 1.99 times higher odds of being up-to-date on visits compared to those in Category 1, adjusting for other variables. However, this finding was not statistically significant.

Geographic Location by County Code

County code 3 (metro-counties in metro areas of fewer than 250,000 population) was not a statistically significant predictor in the adjusted model (Adjusted *OR* = 0.47, 95% CI [0.15, 1.54], $p = .213$). This indicates that participants from County code 3 had lower odds of being up-to-date on 2024 visits compared to County code 1 (metropolitan - counties in metropolitan areas of 1 million population or more), holding other variables constant, though this finding was not significant. Similarly, County codes 2 (metro - counties in metropolitan areas of 250,000 to 1 million population) and other county codes were not statistically significant predictors in this adjusted model (see Table 3 for full results).

Non-Significant Predictors

As detailed in Table 3, all age categories (compared to reference, $p > .05$), Insurance Recoded (all categories compared to reference, $p > .05$), and 'Ethnicity new' (Hispanic compared to non-Hispanic, $p = .288$) were not identified as being statistically significant predictors for being up-to-date on 2024 visits in this multiple regression model.

Table 3

Multiple Logistic Regression Predicting Being Up-to-Date on 2024 Visits (N = 691)

Characteristics	Adjusted OR (95% CI)	*p*-value
NBS Category		
Endocrine (vs. CF)	2.91 [1.44, 5.88]	.003**
Hemoglobinopathy (vs. CF)	3.16 [1.24, 8.04]	.016*
Metabolic (vs. CF)	8.86 [5.08, 15.47]	<.001***
SCID/TREC (vs. CF)	4.98 [1.33, 18.69]	.018*
Spinal M (vs. CF)	0.00 [0.00, inf]	.998
Race		
Black (vs. White)	0.42 [0.17, 1.03]	.057
Asian (vs. White)	0.34 [0.08, 1.39]	.135
Native/Other (vs. White)	0.61 [0.30, 1.26]	.181
More than one (vs. White)	1.15 [0.46, 2.90]	.764
Age		
12–25 (vs. 0–12)	1.09 [0.72, 1.64]	.684
Insurance		
Private (vs. Public)	0.86 [0.56, 1.31]	.486
Language		
Non-English (vs. English)	1.99 [0.94, 4.18]	.071
Ethnicity		
Hispanic (vs. non-Hispanic)	1.25 [0.71, 2.19]	.447
County Code		
County Code 2 (vs. 1)	0.75 [0.47, 1.18]	.211
County Code 3 (vs. 1)	0.47 [0.15, 1.54]	.213
County Code 4 (vs. 1)	0.33 [0.03, 3.30]	.345
County Code 5 (vs. 1)	0.58 [0.17, 1.98]	.389
County Code 6 (vs. 1)	1.35 [0.39, 4.75]	.639
County Code 7 (vs. 1)	1.55 [0.65, 3.67]	.322
County Code 9 (vs. 1)	0.93 [0.23, 3.74]	.916

Note. AOR = Adjusted Odds Ratio; CI = Confidence Interval. N = 691. * *p* < .05. ** *p* < .01. *** *p* < .001.

Chapter 5: Discussion, Conclusions, and Recommendations

This quantitative, retrospective cohort study aimed to assess demographic and clinical factors influencing adherence to follow-up visits among infants identified with medical conditions through newborn screening. The purpose of the study was to address the issue of patients lost to follow-up, a critical public health concern, and to improve continuity of care by promoting health equity. The study's findings, derived from binary and multiple logistic regression on a de-identified dataset of 691 infants from Colorado and Wyoming, revealed several predictors of being up-to-date on 2024 visits. The study's findings are significant, as they provide valuable insights into the factors influencing adherence to follow-up visits.

Pertinent findings from the adjusted model indicated that individuals with endocrine disorders had significantly higher odds of follow-up adherence. Contrarily, Black/African American participants and those identifying as more than one race demonstrated no statistically significant association with being up-to-date on 2024 visits in the adjusted model. Similarly, those whose preferred language was not English and County code (3) also demonstrated no statistically significant association with adjusted odds of follow-up adherence. Age, ethnicity, and insurance were not found to be significant independent predictors. While the model achieved high overall accuracy, a considerable limitation was its inability to classify cases that were not up-to-date correctly. These results highlight the complex interconnection between social and clinical factors and patient adherence to pertinent follow-up visits. While the model achieved high overall accuracy, a considerable limitation was its inability to classify cases that were not up-to-date correctly. These results highlight the complex interconnection between social and clinical factors and patient adherence to pertinent follow-up visits.

Interpretation of Findings

This study's findings provide vital information regarding the characteristics that impact follow-up adherence among the specified population of infants identified with a medical condition through newborn screening. The SDOH framework served as a foundation, and findings were interpreted from that perspective, positing that non-medical factors greatly influence health outcomes, which encompass SDOH pillars such as economic stability, education, social and community context, and access to and quality of healthcare. By evaluating SDOH elements and clinical factors, the current research aims to determine if and how these factors align with existing knowledge.

The present study results regarding language preference and follow-up adherence demonstrated no statistically significant independent association in the adjusted model. Participants with a non-English language preference had nearly twice the odds of being up-to-date on their 2024 medical visit (Adjusted $OR = 1.99$, 95% CI [0.94, 4.18], $p = .071$), although this difference was not statistically significant. Chapter 2 emphasized that language barriers have a strong and well-documented impact on healthcare access and adherence to follow-up. While the current findings did not reveal a statistically significant barrier to continuity of care due to language preference in this adjusted model, the observed trend suggests that further investigation into the specific linguistic and cultural contexts within this study's population may be warranted. This finding, while not significant, still relates to the SDOH pillars of Social and Community Context and

Healthcare Access and Quality by suggesting a nuanced relationship that may differ from generalized literature or that other factors in the model mediate its effect.

The results for race in this adjusted model differed from some existing literature on racial and ethnic disparities in follow-up adherence. While Chapter 2 recognized racial and ethnic disparities in receiving follow-up care, the adjusted results of this study indicated that Black/African American participants had lower odds of being up-to-date on 2024 visits (Adjusted *OR* = 0.42, 95% CI [0.17, 1.03], $p = .057$) compared to White/Caucasians, after controlling for other SDOH factors and the newborn screening conditions. This finding approached but did not reach statistical significance at the $p < .05$ level. Similarly, participants identifying as more than one race also had no statistically significant difference in their odds of being up-to-date on 2024 visits (Adjusted *OR* = 1.15, 95% CI [0.46, 2.90], $p = .764$) compared to White/Caucasians in this adjusted model. These findings suggest that the relationship between race and follow-up adherence within this specific health system or region is complex and may not align with broad assumptions of across-the-board disparities or protective factors, highlighting the importance of nuanced, context-specific research within the SDOH framework. This finding might reflect specific patient subgroups or systemic factors within the study's context.

The association between patients from County code 3 (Metro - Counties in metro areas with fewer than 250,000 population) and 2024 visit status was not statistically significant in the adjusted model (Adjusted *OR* = 0.47, 95% CI [0.15, 1.54], $p = .213$). This finding, which showed lower odds of being up-to-date compared to County code 1 (the reference), aligns more with generalized findings from the literature. Chapter 2 included research by Wright et al. (2024) and Gregorcyk et al. (2022), which demonstrated that a greater distance from clinics and residence in rural areas was associated with a decreased likelihood of follow-up due to barriers such as transportation, limited healthcare access, and lower socioeconomic status. The lack of significance for County code 3 in the adjusted model suggests that while some localized factors might be at play, they did not reach independent statistical significance in promoting follow-up adherence when accounting for other variables. This finding still contributes to understanding the influence of local and regional factors on the Social Determinants of Health (SDOH) pillars of Neighborhood and Built Environment and Healthcare Access and Quality, by showing where previously assumed other factors might mediate significant effects.

Patient insurance did not demonstrate statistical significance. It was not identified as an independent predictor of status for 2024 follow-up visits in the multiple regression model (Adjusted $OR = 0.86$, 95% CI [0.56, 1.31], $p = .486$), contrary to some existing literature. Chapter 2 discussed findings by Wright et al. (2024) indicating that Medicaid patients were more likely to receive care from alternative clinics, thereby disrupting the continuity of care, which aligns with existing research. The present study findings disconfirm a direct, independent effect of insurance type on follow-up adherence when controlling for other factors (race, ethnicity, geographic location, language preference, age, and newborn screening condition). This study suggests that the type of insurance did not have a direct effect on whether patients were current on their 2024 visits, which could be mediated by other social and systemic characteristics in the model. The result aligns with the Economic Stability and Healthcare Access and Quality pillar, illustrating how other Social Determinants of Health (SDOH) influence outcomes, making their independent effect insignificant when accounting for various factors.

Newborn screening conditions were found to be independent predictors of being current on 2024 visits, with category two (endocrine disorders) reflecting higher odds of being up-to-date (Adjusted *OR* = 2.91, 95% CI [1.44, 5.88], $p = .003$). The current finding adds to the existing literature that the specific condition presents follow-up issues, indicating clinical complexity can create care barriers. This highlights the interconnectedness between clinical conditions and the extended Social Determinants of Health (SDOH) concepts. Reciprocally, age was not a significant predictor in the adjusted model (Adjusted *OR* = 1.09, 95% CI [0.72, 1.64], $p = .684$), indicating that the age group did not independently impact follow-up adherence in this patient population.

The study's findings indicate that while some social and community context factors (such as NBS condition) are significantly associated with follow-up adherence, others, like race, language preference, and county code, did not demonstrate independent significant associations in the adjusted model. Similarly, the economic stability pillar (insurance type) did not reflect an independent impact in the adjusted model. Other SDOH factors might mediate its influence. The complex interconnectedness and often non-significant or varied results for some social and demographic factors stress the importance of not focusing on single SDOH components in isolation. This current study augments the literature by examining the adjusted and independent effects of key social and clinical determinants. The inferences drawn from the findings are limited to empirical data, highlighting the observed associations and refraining from concluding the study's scope and the statistical evidence.

Limitations of the Study

This study offers valuable insights but also has several limitations, including classification imbalance, a lack of longitudinal data, a limited patient population, and the use of observational data. The retrospective nature of the study impedes the ability to establish causation and assess outcomes at a single point in time. Therefore, this study offers valuable insights, but it also has several limitations. These include classification imbalances, a lack of longitudinal data, a limited patient population, and the reliance on observational data. The retrospective nature of the study hampers our ability to establish causation and assess outcomes at a single point in time. Thus, we can only identify associations between social determinants of health (SDOH) and follow-up status in 2024. Longitudinal studies, on the other hand, are capable of tracking patients over time, giving a more comprehensive view of their health status.

Capturing a patient's status at just one point in time does not reflect whether the patient had previously been up-to-date on their care or sporadicity in follow-up adherence. Additionally, the study's multiple logistic regression model had a significant limitation; it failed to accurately classify cases that were not up-to-date on visits in 2024, achieving 0% accuracy in identifying these cases. As a result, the model's overall accuracy was 76.8%. This indicates an imbalance in the outcome variable, where all participants were classified as up-to-date. Consequently, the model's effectiveness in identifying patients who are not up-to-date is limited.

Furthermore, the study's findings are based on data from a restricted population in only two states, Colorado and Wyoming, which can hinder the generalizability of the results to the broader population or other geographic regions. Only associations between SDOH and follow-up status in 2024 can be made. However, longitudinal studies can track patients over time. Capturing a patient's status at a single time point does not reflect whether the patient had previously been up-to-date or why they might not have been. There was a substantial limitation of the multiple logistic regression model, as it failed to correctly classify cases not up-to-date on 2024 visits (0% accuracy), resulting in an overall accuracy of 76.8%. This finding reveals an imbalance in the outcome variable, where all participants are classified as up-to-date. Therefore, the model's use in identifying patients at risk of not being up-to-date is limited. The study results are based on information from a limited population in only two states, Colorado and Wyoming, which can limit their generalizability to the broader population or other geographic regions.

Recommendations

Based on the study results, it is recommended that future research utilize study designs for imbalanced datasets, like stratified sampling, to enhance the model's ability to identify at-risk patients. Future research should prioritize and perform qualitative studies to deeply understand specific patient experiences, perceptions, and barriers from language category two (non-English preference) and factors among patients and families with endocrine disorders, and black/African American and more than one race. Longitudinal studies would offer the opportunity to track trends in patient adherence over time, capturing changes in adherence patterns.

Implications

Several key findings from this study have implications for advancing public health initiatives that aim to enhance adherence to pediatric and adolescent follow-up. The consistently significant positive association with patients with endocrine disorders ($AOR = 2.91$, $p = .003$) suggests that, for this specific condition, patients had higher odds of being up-to-date on follow-up, which may indicate specific patient- or system-level factors related to managing this condition. Further investigation is warranted to understand what aspects might contribute to this higher adherence, which could then inform strategies for other conditions. For non-English-speaking individuals, the adjusted model did not show a statistically significant association with follow-up adherence ($AOR = 1.99$, $p = .071$). While not significant in this model, language barriers are well-documented in the literature as impacting healthcare access. Therefore, from a public health perspective, culturally and linguistically appropriate communication and educational methods remain crucial. Providing educational materials in the patient's and family's preferred language, and using translators, can help address the needs of diverse patients and their families, potentially enhancing their understanding of health recommendations and available resources, regardless of this study's specific findings.

Regarding geographic location by county code, County code 3 ($AOR = 0.47$, $p = .213$) did not show a statistically significant association with follow-up adherence in the adjusted model. This suggests that the assumed geographic strengths were not independently significant in this particular population when other factors were controlled for. Further research may be necessary to investigate localized factors that influence follow-up in different county types. The adjusted odds for Black/African American patients (*AOR* = 0.42, $p = .057$) and those who were of more than one race (*AOR* = 1.15, $p = .764$) did not demonstrate statistically significant associations with being up-to-date on 2024 visits. Therefore, this study does not provide direct evidence to support higher adherence rates in these specific groups based on the adjusted model. Further qualitative or mixed-methods research could explore the nuanced experiences of racial and ethnic groups in follow-up adherence within this context, as well as factors that might facilitate or impede care, consistent with broader literature on health disparities.

Conclusion

The principal conclusion arising from this study is that promoting consistent patient follow-up requires a multifaceted understanding of the complex interplay between social and clinical factors that either foster or impede adherence to follow-up. While the Newborn Screening Category was confirmed to have a significant effect on follow-up, with some conditions showing higher odds of adherence, other factors often cited as "traditional barriers" like language differences, racial background, and geographic location did not reach statistical significance as independent predictors in this adjusted model. This underscores the urgency and importance of developing effective targeted interventions focused on this vulnerable pediatric population, which may need to consider the specific context and interaction of factors rather than relying on generalized assumptions. Optimizing the findings to detect adherence issues to inform health policies and methods can improve health outcomes and increase health equity for every child.

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