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Adverse Birth Outcomes Among Women with Physical Disabilities: A Retrospective Cohort Study in South Carolina

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Adverse birth outcomes among women with physical disabilities: A
retrospective cohort study in South Carolina

by

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Submitted in Partial Fulfillment of the Requirements

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DEDICATION

I dedicate this to the Almighty Allah who has the power to make any action easier and has the control over everything – all praise be to Him. I am grateful to my mum for sacrificing everything for me and my dad for his continuous prayers for me.

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I would like to take this kind opportunity to express my humble gratitude to these people for making this thesis a reality. My earnest gratitude to my supervisor, Dr. Suzanne McDermott, for her invaluable support and strongest guidance throughout the course of this thesis. Thank you, Suzanne, for your kind patience and supporting words during all the hardship of this thesis work. I sincerely acknowledge all your ample encouragement and immense cooperation for which this work is successfully complete today.

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All of your endless support, prayers and inspiration have made this dream come true.

ABSTRACT

Motherhood is precious in women's lives. Among women, ages 21-64, 12.5% are living with a disabling condition, according to the Disability Status report: SC 2008. Although childbearing among women with disabilities is increasing, there are limited publications about the pregnancy outcomes. The objective of this study is to document the adverse neonatal outcomes of the pregnancies and to evaluate if early prenatal care is a protective factor for low birthweight and prematurity among the women with physical disabilities. This study used a retrospective cohort study design, with data from linked hospital discharge records and vital records (birth certificates) for all Medicaid insured births in South Carolina between 2007-2015. Women with disabilities were identified using ICD-9-CM codes from hospital discharge records and the neonate outcomes were ascertained from birth certificates. Birth outcomes included preterm birth and as low birth weight, and exploratory outcomes of small for gestational age (SGA) and admission to Neonatal Intensive Care Unit (NICU). In adjusted regression analysis, women with a physical disability were significantly more likely to have a preterm birth (aOR=2.35, 95% CI: 1.75-3.39), very preterm birth (aOR=2.29, 95% CI: 1.02-5.16), low birth weight (OR=1.90, 95% CI: 1.37-2.65), very low birth weight (aOR=2.65, 95% CI: 1.25-5.64) and admission to NICU (aOR=2.90, 95% CI: 1.70-3.40) compared to women without a physical disability. The association of SGA and maternal physical disability was not significant after adjusting with the covariates (OR=1.25, 95% CI: 0.89- 1.76). The study showed women with physical disability who delayed prenatal care were significantly more

likely to have adverse pregnancy outcome (preterm birth: aOR=2.06, 95% CI: 1.03-4.12; low birth weight: aOR=2.53, 95% CI:1.20-5.35) as compared those who started early care. We conclude that though there are some risks of adverse outcomes for physical disabled women these risks can be minimized by utilizing early prenatal care. These analyses provide insight into some challenges that need to be managed in order to improve outcomes for women with physical disability.

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LIST OF ABBREVIATIONS

ACS.....	American Community Survey
BM	Behavioral Model
FMA.....	Dermatomyositis and Fibromyalgia
ICD.....	International Codes for Diseases
IRB.....	International Review Board
NICU.....	Neonatal Intensive Care Unit
RA.....	Rheumatoid Arthritis
RFA.....	Revenue and Fiscal Affairs Office
SCI.....	Spinal Cord Injury
SGA.....	Small for Gestational Age

CHAPTER 1

INTRODUCTION

1.1 Background

More than one billion people have a disability around the globe(1-3). According to the U.S. census report in 2005, the prevalence of self-reported disabilities among civilian noninstitutionalized U.S women of childbearing age is 11.0%(3). The number of pregnancies is increasing among the women with mobility disabilities(4, 5) and epidemiological studies show the rate of pregnancy among women with physical disability the same as it is for nondisabled women, after controlling for age and other demographic factors associated with pregnancy(6-8).

Though more women with physical disabilities are becoming pregnant, they have limited knowledge about their reproductive health(9). Limited information exists to guide these women and their clinicians about how functional impairments affect pregnancy(6). Therefore, there is a need for information about maternal and newborn outcomes in this potentially vulnerable group. There are notable barriers such as social stigma and lack of awareness about risks which make the way harder for pregnant mothers with physical disabilities(7). These challenges have the potential to impact pregnancy outcomes(10). More data are needed about the pregnancy and childbirth experiences of the women with physical disability to improve the prospect for healthy motherhood(5).

1.2 Disability definition and overview

WHO defines disability as “Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions.” (11) Signore et al. in her survey defined disability as “difficulty with functional activities, activities of daily living, use of an assistive aid such as wheelchair or crutches, or limitations in the ability to work at a job or around the house.”(1) The later definition is more specific, and it suggests there is an interaction between physical traits and the environment. Thus, disability is a complex phenomenon and broad term from the public health perspective (11). Disability can be physical, mental, sensory, learning or intellectual, which can be recent or long-term, progressive or stable.

Disability is considered a large public health problem in the United States, affecting 54 million adults(12). The American Community Survey (ACS) estimates about 12.6% of the US population in 2015 is living with a disability(13). Statewide the rate of people with disabilities varies, as those vary by employment, poverty, earning, and health behaviors(13). The percentage of people with any disability is 25.5% in South Carolina(14). Most common causes of physical or mobility limitations are arthritis or rheumatism, back or spine problem, and heart trouble which account for about 35% of all disability(14). Women reported a higher prevalence of any disability(24.4%) than did men(19.8%)(14). Disabled women of childbearing age have the same desire to become mothers as other women(9). The impact of their disabling conditions can be managed through careful advanced planning and an interdisciplinary team approach(9).

1.3 Women with Disability and pregnancy

About 27 million women in the U.S. have a disability (15). According to the Disability Status report: SC 2008, approximately 12.5% woman of ages 21-64 are living with disabling conditions(16). Reports say, most women with physical disabilities have natural fertility and are capable of becoming pregnant (8). But these women and their families must receive guidance for better parenthood(8). According to the American College of Obstetricians and Gynecologists, “the more insidious barriers to health care for women with disabilities involve the ignorance, social prejudice and pervasive negative attitudes about living with disabilities”(17).

‘The Americans with Disabilities Act’ became law in 1990. It is civil rights legislation that describes the rights of the people with disabilities, and the responsibilities of society to ensure those rights(1). Before the late 20th century, people with disabilities were considered as ‘Passive receivers of help’ or ‘patients’; not capable of marriage or giving birth(1, 18). Family members and healthcare practitioners in the past discouraged many of these women from pursuing biologic motherhood(6). They believed disability itself was a barrier to pregnancy. This situation is improving with the advancement of medical knowledge, the self advocacy movement for people with disability, and technologyHealthy babies are born from many disabled women, and they have successfully become mothers(4).

Some of the persistent issues faced by women with disabilities are the stigma of pregnancy, lack of information, lack of referrals to other care professionals, and lack of obstetricians with expertise in disability(10). When the impediments are adequately

addressed, then they will be able to get the best outcome of pregnancy(10, 19). The combination of maternal fetal medicine specialists, specialized nurses, rehabilitation therapists, and support groups can provide appropriate care to women with disability during pregnancy(6).

1.4 Significance of the research

Although growing numbers of women with a mobility disability are becoming pregnant and desiring motherhood, they have insufficient knowledge about what to expect during their pregnancy(3). They must gather accurate information about pregnancy with their specific type of disability, having adequate support, identify clinicians with whom they feel comfortable, and manage their fears about pregnancy and delivery (20, 21). Recent studies suggest women with physical disabilities in United States are at risk for pregnancy complications and adverse birth outcomes compared to women without disabilities(6, 9, 22, 23). Additional insight is needed about what hallmarks are deemed to be indicators of quality of pregnancy-related health care for women with chronic physical disabilities. Previous studies have assessed some aspects of the sociodemographic, biophysical and psychosocial factors in the course of pregnancy period of these disabled mothers(3, 5, 10, 23, 24), but very few studies report birth outcomes from their pregnancies(25). There are no analyses published about disabled mothers and their birth outcomes in South Carolina. Our study will provide evidence of pregnancy outcomes among the women with physical disability in South Carolina. The findings of this study have the potential to shed light on some of the risk factors associated with low birth weight and prematurity among women with disability.

1.5 Purpose of the study

We aimed to quantify newborn health outcomes among women with physical disability in South Carolina. The purpose of this research is to better understand the association between pregnancy complications and birth outcomes, among women with disability. The analysis includes the role of early entry into pregnancy care to reduce the incidence of babies born small for gestational age and preterm infants among newborns of mothers with physical disability in South Carolina.

CHAPTER 2

REVIEW OF THE LITERATURE

2.1 Search Methods

A literature search was conducted through PubMed and Google Scholar to identify studies that evaluated the association between women with physical disabilities and birth outcomes. Searched criteria were bounded to the studies published in English, and performed on human subjects. Keywords and phrases used to identify relevant studies included “mothers with physical disability”, “physically disabled women”, “women with physical disabilities”, “pregnancy among women with physical disabilities”, “perinatal experience”, “disability and birth outcomes”, “childbirth”, “prenatal care”, “rheumatoid disease and pregnancy”, “low birth weight”, “Spinal cord injury and pregnancy”, “pregnancy experience”, “prevalence of women with disability”, as well as combination of these keywords and phrases. The initial search using ‘mothers with Physical Disability’ resulted in 307 studies. Then, when the search was restricted to ‘disability and pregnancy’ and ‘disability and birth outcome,’ and the specific disabling condition, e.g. rheumatoid arthritis(RA), spinal cord injury(SCI), dermatomyocitis and fibromyalgia(FMA), there were 54, 21, and 19 papers, respectively. The next step was title screening, and after reading the abstracts 43 papers were selected for complete review. These 43 papers assessed disability and pregnancy in broad aspects, from which only two evaluated the birth outcomes. Search criteria excluded women with intellectual or mental disability, as this study focused on mothers having only a physical disability. A limited number of

studies conducted outside of the USA were included and they were used to check citations from their reference list. Web-based searches of disability, low birth weight, and preterm birth included the World Health Organization(WHO), Centers for Disease Control and Prevention(CDC), Morbidity and Mortality Weekly Report(MMWR), and Women Watch websites. Figure 2.1 is a flowchart of the literature review search.

2.2 Maternal disability

Women with physical disabilities are experiencing pregnancy and they have a significant challenge in understanding the risks for positive outcomes of pregnancy(1). Failure to consider current knowledge, experience, and expertise of disabled women about their own disabilities can lead to the troublesome perinatal period(26). It is essential for women with disabilities to have opportunities to discuss reproductive health, childbearing desires, and associated concerns with their health care providers(27).

Mothers with physical disabilities had a higher prevalence of maternal risk factors which includes maternal age, obesity, pregnancy weight gain and current smoking status(5). Their physical limitations can add some risk for comorbidities like urinary tract infection, decreased mobility and independence, skin ulceration, respiratory compromise, bowel problem, interpersonal abuse, stress and mood disorders(1, 6). All these conditions are highly associated with adverse pregnancy outcomes(22). Women with some chronic diseases such as rheumatoid, arthritis and spinal cord injury have a greater risk for adverse pregnancy outcomes(1).

Some health care providers, including obstetricians and gynecologists lack appropriate information and training to adequately care for women with physical

disabilities during the perinatal period(21). At times, health care providers are also unprepared to provide the pregnancy-related care needed for these disabled mothers(18). Many women with physical disabilities report challenges obtaining care during the perinatal period, including the absence of ramps, physically inconvenience delivery rooms, narrow doorways, inaccessible ultrasound and examination tables and delivery beds(28). Patients who use wheelchairs and who have joint contractures, spinal or neuromuscular deformity, need to have accomodations to get physical examinations (27). Disabled mothers who use wheelchairs, face additional challenges dealing with regular bassinets, regular changing tables and cribs, after their infant is born(29). Women having affected upper extremities may need additional assistance for infant care and breastfeeding(27). Disabled mothers also suffer difficulties to get insurance coverage of their health care expenses (28). Due to their particular needs, a mother can have additional expenses for equipment, accessible transportation, and personal attendant services(28) and possibly they may also need more frequent visits and ultrasound scans (27, 30). Early prenatal care plays a vital role for better maternal and infant outcomes, and there is evidence women with physical disabilities start their prenatal care after the first trimester, compared to nondisabled women(22). Though they are at high risk for health challenges, mothers with mobility disabilities are enjoying satisfying lives because of ongoing medical advances and a focus on the quality of life.

2.3 Pregnancy, labor and delivery

Disabled mothers have some challenging issues regarding their specific disabilities which impacts their pregnancy(31). It is essential to get appropriate screenings and prenatal care for the expecting mothers with impaired mobility(27). Specific disabilities present

unique challenges for perinatal and obstetric health care providers(6). Most obstetricians who specialize in high-risk pregnancies have limited disability specific training about adaptations and accommodations (28). Inaccessible medical offices and equipment generate difficulties for the proper monitoring of pregnancy(29, 32). Physiological changes during pregnancy along with the physical limitations demand more frequent visits to the prenatal and postpartum care provider(33). Healthcare professionals must get specialized training to manage the special needs of women with physical disabilities(10, 30, 34). The challenges extend to the actual time of childbirth such as the choice of method of delivery, anesthesia and associated risk management(29). Guidance from the physicians potentially ensures that disabled women's various needs are met(28).

Few studies discussed the association of specific disabling conditions and the pregnancy outcomes. Women with spinal cord injuries(SCI) who become pregnant have increased risk of having life-threatening pregnancy complications, including hyperreflexia, thrombophlebitis, pyelonephritis and unattended delivery(35). Appropriate precautions can allow most patients with SCI a successful vaginal delivery at term(36). Women with rheumatoid arthritis(RA) have been reported to face a challenge to conceive and other management difficulties during the course of the pregnancy(37). Pregnant women having RA are at an increased risk for delivering preterm birth(34, 38), small for gestational age infants (34) and have higher rates of preeclampsia(39) and cesarean delivery(38, 39). Other autoimmune diseases have also been reported to have risk for adverse pregnancy outcome(34). Disease severity is the indicator for preterm birth for the pregnant mothers with rheumatoid arthritis(40). Better disease management, medication, and careful monitoring can improve pregnancy outcomes among women with RA (34, 40).

Pregnant women with axial spondyloarthritis have a higher risk of pregnancy complications (gestational diabetes, preeclampsia, infection, preterm premature rupture of membranes), small for gestational age and preterm deliveries(40). Women with inflammatory myopathies (dermatomyositis and polymyositis) are at increased risk of hypertensive disorders of pregnancy(41). Pregnancy outcomes of these mothers are reasonably good, through effective management of drug therapy and disease remission during pregnancy can alter the course of pregnancy(42). Women with fibromyalgia syndrome are experiencing lower rate of preterm deliveries but they are at higher risk for intrauterine growth restriction(43).

Women with a physical disability have less choice about place of birth and mode of delivery(1, 30). Despite preplanning and discussion of specific preferences with the physician, mode of delivery(vaginal or cesarean) and type of anesthesia(epidural or general anesthesia) depends on labor progression and obstetrical complications(23). Though most women with disabilities are capable of vaginal delivery, compared to women without disabilities, disabled women were more likely to have a cesarean delivery whether genuinely elective or medically indicated cesarean(1). Research suggests women with physical disabilities express dissatisfaction with their anesthesia care if they are not involved in the decisions (23). Again, physicians need specialized training to manage the care of women with physical disabilities(37). Technology intervention such as videos, telephone help lines, resources networks, the parent-to-parent support groups can be promising strategies in this regard(44, 45). Antenatal and intraoperative consultation are recommended throughout their pregnancy and during the labor(1). A multidisciplinary

team is needed to perform close monitoring of labor and delivery of mothers with impaired mobility(36).

2.4 Gestational age and Birth Outcome

Birth outcomes play a pivotal part in the future health of children. Various maternal facets and behaviors are associated with adverse birth outcomes. The most extreme measure of the birth outcomes is infant mortality(46) and birth weight and gestational age are the most important factor that predict neonatal mortality(46).

As the number of births increases in the United States, premature birth along with small for age gestational (SGA) continue to increase as well(47). According to WHO, small for gestational age (SGA) newborns are those who are smaller in size than normal for the gestational age, most defined as a weight below the 10th percentile for the gestational age(48). A related term of SGA is low birth weight (LBW), defined as a birth weight of an infant of 2,499 g or less, regardless of the gestational age(49). Normal weight at term is delivery is 2500- 4200 g (5 pounds 8 ounces to 9 pounds 4 ounces). Low birth weight can be subcategorized into very low birth weight (less than 1500 g) and extremely low birth weight (less than 1000 g). The rate of low birth weight is 8.2% and 9.6% of births in the United States and South Carolina , respectively, in 2016(50). Gestational age can be categorized as term pregnancy when gestational age anytime between 37 to 42 weeks, preterm is defined as babies born alive during 32-37 weeks of pregnancy and gestational age is less than 32 weeks of pregnancy considered as very preterm birth (51). In 2016, 1 in 9 babies (11.1% of live births) was born preterm in South Carolina(52).

Small for gestational age and preterm birth contribute to morbidity and mortality during infancy and in the long term these conditions may put adults at a risk for heart disease, high blood pressure, and type II diabetes (53, 54). Moreover, US health care system is spending at least \$26.2 billion each year to meet the need of special care and extra hospitalization of preterm infants (55). Mothers with significant physical disability are at increased risk of having preterm birth and babies born small for gestational age (22, 25). The association of disability during pregnancy and birth outcomes needs to be understood to quantify the factors required for better outcomes of pregnancy of women with disability and their infants.

2.5 Summary of the Literature

This review discusses the literature related to women living with physical disabilities and their pregnancy experiences. It includes pre-pregnancy status, labor, delivery, complications, and the newborns' conditions.

Emerging literature suggests disparities among women with disabilities in their health care utilization, health behaviors and health status before and during pregnancy and during the postpartum period (6, 28). Their struggles start with their home and family (32). Misconceptions exist among the family members, caregivers, health workers and society level about the capability of motherhood and parenthood issues of physically disabled women (4). Negative attitudes towards these pregnant mothers, hamper their quality of life during that period (1, 17). In addition to attitudinal and information barriers, many women with physical disabilities report unpleasant experiences during the perinatal period (28). Barriers include clinicians' lack of knowledge, negative attitudes, and lack of information

on how disability is affecting pregnancy(29). Lack of preparation and planning from health care providers, can lead to a unfavorable delivery and birth experiences for the disabled mothers(18). Studies report that many women with disabilities experience little or no guidance from nurses and doctors regarding whether or not they can safely have children(27). More open communication is required between these women and their clinicians to decrease dissatisfaction towards their care(23).

Women with physical disabilities experience more pregnancy-related complications compared to women without disabilities(33). They are at elevated risk for poor health and pregnancy complications throughout their pregnancy (3,6,8). Disabled mothers are prone to experience postpartum depression (9), physical abuse during pregnancy (10), and smoking before, during, and after pregnancy (11). Infants born to mothers with a disability had a higher proportion of cesarean birth and preterm birth, were small for gestational age, and had a low Apgar score (4,3,6). Disabled mothers were significantly more likely to report stressful life events and less likely to receive prenatal care in the first trimester compared to nondisabled women (3). Studies say, women with disability are as likely to have older age, longer hospital stays and less likely to breastfeed(30). Newborns of mothers with a disability comprise an at risk group for being small for gestational age, low birth weight, stillborn, perinatal death, having a neonatal infection(22, 30).

In qualitative studies ambivalence and uncertainty were expressed by the women with disabilities as to the use of medications during their antenatal period(31). Some medications have side effects on the fetus, but there is also as concern as to whether stopping these medications cause maternal health risks during pregnancy(31). In order to

manage medications during pregnancy, some experts recommend more frequent antenatal checks, scans, and screening during different phases of pregnancy(30). Some studies suggest individual and public health costs associated with pregnancy complications are likely to be high for women with disabilities(56).

Iezzoni et al.,2015 mentioned in her analyses, some recommendations from disabled mothers about successful pregnancies including selecting an appropriate clinician, seeking peer support from other mothers with disabilities, being an assertive self-advocate, prepare for pregnancy, childbirth, and postpartum challenges as much as possible(10). Physicians and other health care providers can also provide information and advice to educate these mothers about pregnancy events(8). Though the United States has comprehensive disability legislation, no national strategy addresses explicitly the needs of women with disability during their pregnancy(23). All of the studies identified unmet needs of women with disability related to their pregnancy. Knowledge, technical skills, and effective communication are essential components of care for women with physical disabilities during pregnancy. These would likely increase satisfaction with obstetric and anesthesia care and result in positive experiences and improve maternal and infant outcomes.

2.6 Conceptual framework:

I applied the Andersen's Behavioral Model (BM) of Health Services Use(57) to conceptualize the enabling, predisposing and need based factors associated with child outcomes, for pregnant women with physical disability. The severity of the disability, pregnancy complications, accessibility of health care services, and sociodemographic factors are associated with and influence the receipt of prenatal care. Andersen's

Behavioral Model(BM) was originally developed in 1960's to investigate the conditions that facilitate or interfere the health services utilization(58, 59). Based on the original prototype of Andersen's BM, I developed a model (figure 2.2), provides the framework of relationship between population characteristics of disabled mothers and utilization of prenatal care and pregnancy outcomes. The association between each of the predisposing factors, enabling resources, need and outcomes are described in the literature review. Predisposing factors include a number of socio-cultural characteristics of individual that exists prior to their pregnancy (58). Socio-cultural characteristics such as age, education, occupation, health beliefs, knowledge about pregnancy are predisposing factors(59, 60). Enabling factors are the ability to obtain obstetric care(58). Enabling factors consists of financial elements (income, health insurance), social support (from family and professionals) and organizational characteristics (accessibility of health services, transportation), health system characteristics (availability of facilities, health care personnel)(59-61). Perceived need is the woman's belief that professional care during pregnancy will improve her and her baby's outcome (60), it is the woman's perception about the severity of her disability and it's impact on the pregnancy (61, 62), and her sense that specific treatments, supplies and equipment will improve her outcome (63). Evaluated need is a measure of the components of care that are provided during the pregnancy, based on standards of care for each disabling condition (59). All these factors influence the outcome of pregnancy (63).

2.7 Gaps in the Literature

A growing field of study within disability science focuses on the barriers to access the information and health services needed during the time of pregnancy for

women with impaired mobility(7, 27, 29). The literature examining the relationship between women with physical disabilities and birth outcomes is insufficient. Our literature search identified only two epidemiological studies on this specific topic. The other studies were mostly qualitative interview studies with limitations of small, nongeneralizable sample size. Their analysis was based on recall from the disabled mothers where the experiences are not recent. The researchers did not explicitly address the effect of socioeconomic status and racial discrepancy on the accessibility of getting health care facilities for disabled mothers. Most of the literature describes pregnancy experiences among women with disabling conditions more generally and broadly. The review indicates the substantial gaps to identify the prenatal care and their evaluation to improve the outcome of pregnant women with disability.

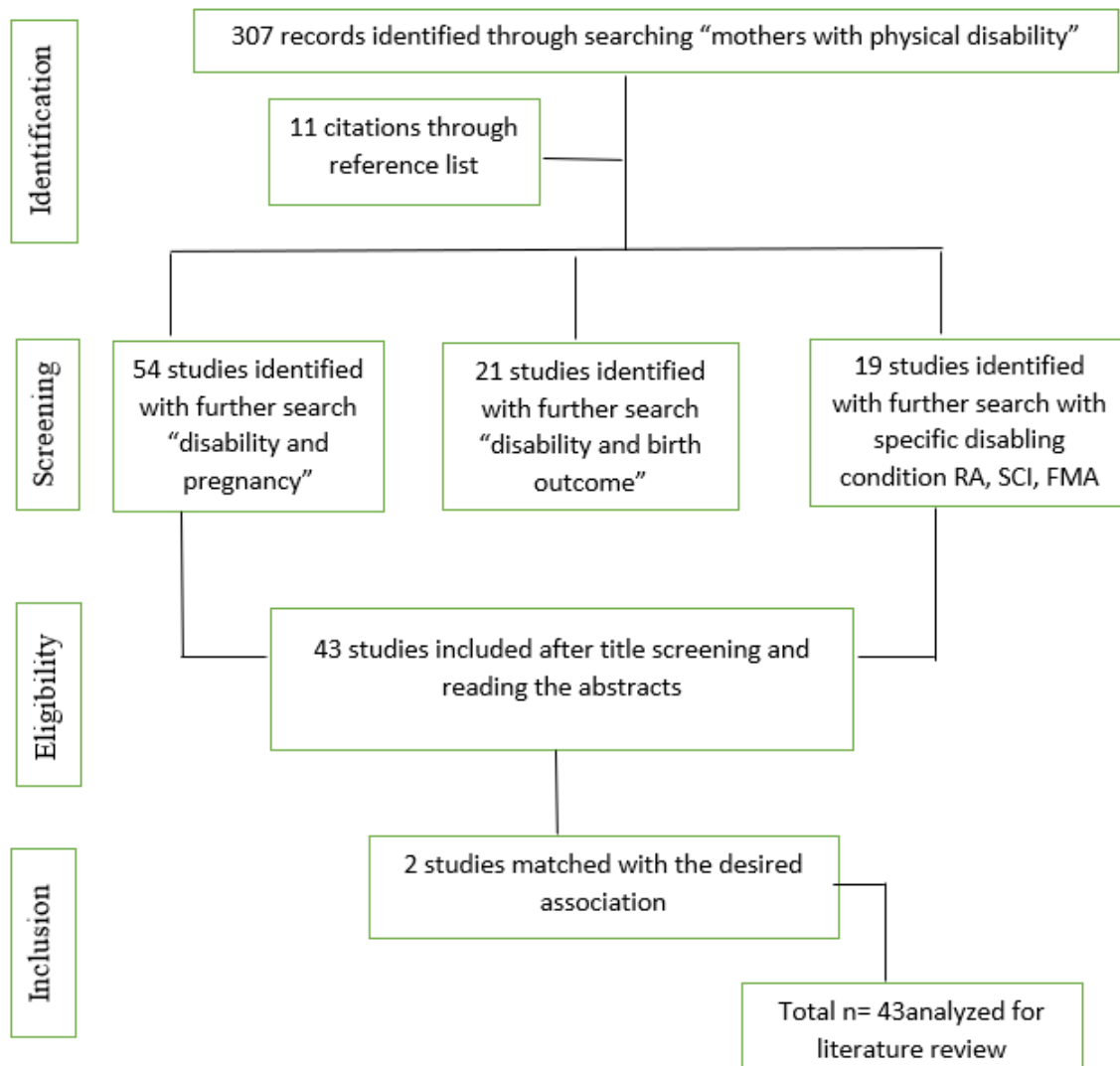


Figure 2.1: Flowchart of literature review.

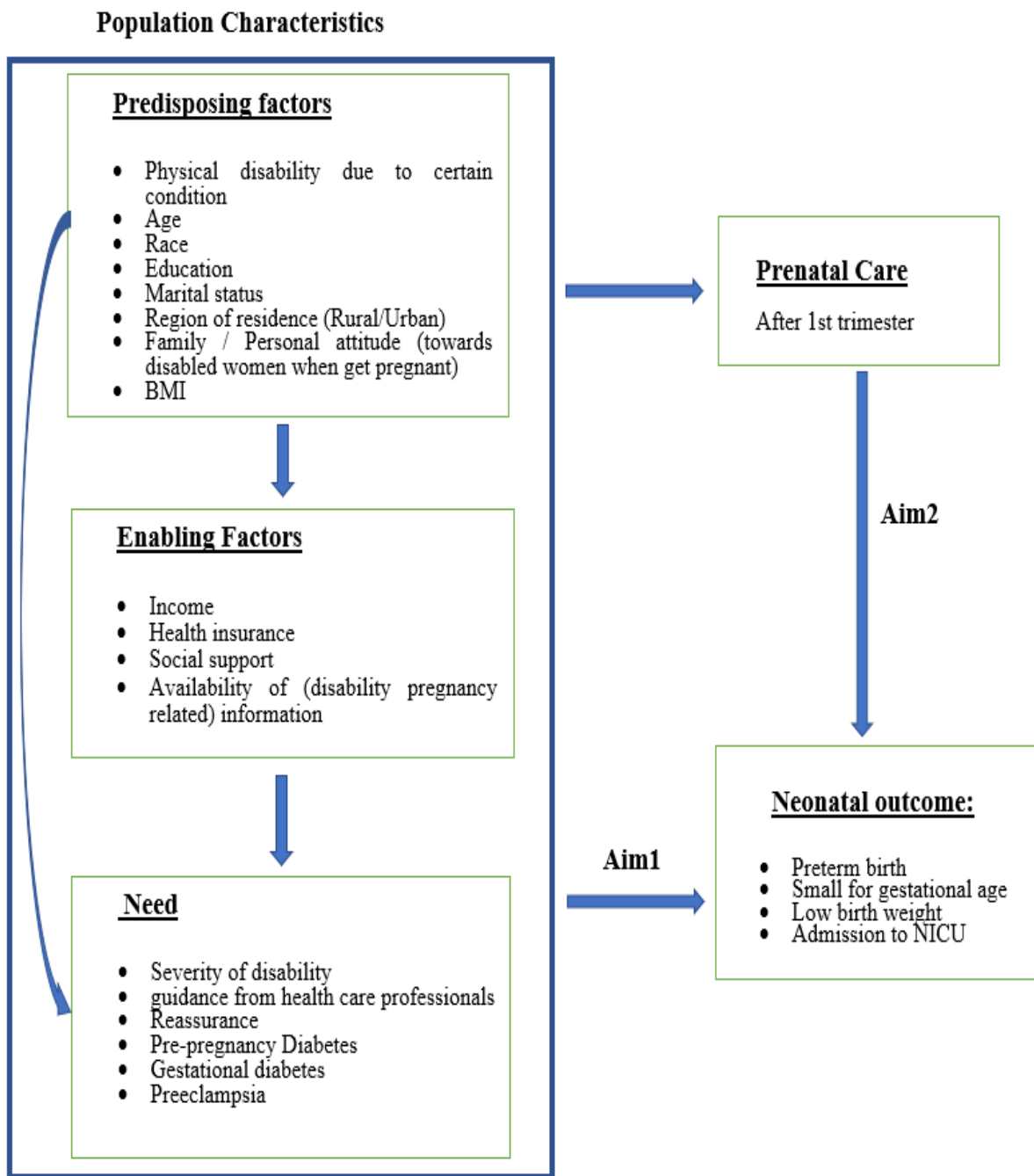


Figure: 2.2 Conceptual framework of maternal disability and pregnancy outcome based on Anderson’s Behavioral Model of Health Care Use.

CHAPTER 3

METHODOLOGY

3.1 Study Design

The study is designed as a retrospective, population-based, cohort study. The cohort is defined as pregnant women (age 18 – 44) insured by Medicaid and living with or without any physical disability in South Carolina during the time frame of 11/1/2007 to 10/31/2015.

3.2 Data sources

This study uses a linked dataset of women and neonates, provided by the South Carolina Revenue and Fiscal Affairs Office (RFA). The data source consists of linked hospital discharge and vital records (birth certificates) for all Medicaid births in South Carolina between 2007-2015. Medicaid is a public insurance system that uses federal and state funds to provide care for women and children, in South Carolina, who are at or below 185% of the Federal Poverty level. Thus the data for this study are representative of the experience of both low income and poor women in South Carolina.

Application for Medicaid outpatient encounter data and a signed Data Use Agreement were sent to RFA with the specification of the datasets to be used. Inpatient Hospitalization data element files and Emergency Department data elements files were requested for the identification of pregnant women aged 18-44. Vital Statistics records of mothers and neonates born within 2007-2015 were derived from Office of Public Health

Statistics and Information services, DHEC. Birth Certificate data provided the information for gestational age, parity of the current pregnancy, month entered to prenatal care, maternal age, maternal race/ethnicity, education level and some medical and health information of these mothers. Birth certificates also provide information for the neonate outcomes, date of birth, birthweight, clinical estimates of gestational age at delivery. South Carolina Medicaid encounter data, Inpatient hospitalization data and Emergency Department data were linked with South Carolina Birth certificates. Then the final dataset consists of the de-identified data for mother and child pairs selected from the maternal and child hospitalization records and respective birth records. University of South Carolina International Review Board (IRB) exempt status was obtained for this study.

3.3 Study Participants

A total of 198,460 mother-neonate pairs from 2007-2015 who were identified following hospital discharge for delivery in South Carolina and merged with the birth certificate data to derive the sample (flow chart 3.1). The neonatal outcomes were ascertained from birth certificates.

3.21 Inclusion Criteria

The dataset consists of de-identified data for mother and child pairs who were insured by Medicaid. All women with a pregnancy that resulted in a live birth(singletons only) were included. Participants were eligible for the study if they were female, pregnant, living in South Carolina, insured by Medicaid, aged in between 18 to 44 and delivered babies within the year 2007 to 2015. We identified physically disabled mothers using ICD-9 codes (Table 3.1).

3.22 Exclusion criteria

We excluded mothers aged less than 18 and above 44 years and those who had a fetal death or stillborn infant. Women with breech presentations and birth of neonates before viable gestational age (less than 18 weeks) were excluded from the study.

3.4 Study aims and objectives

Specific objectives of this study are

- To examine the association between maternal disability status with child birth outcomes such as preterm birth and SGA.
- To assess the early prenatal care as a protective factor for SGA and prematurity among the women with physical disabilities.

3.5 Hypothesis

Hypothesis 1: Women with physical disabilities would have a higher risk for delivering babies small for gestational age (SGA) and preterm births compared to those women without any disability.

Hypothesis 2: Women with physical disabilities who started their prenatal care in later pregnancies have a higher risk for preterm and SGA compared to women with physical disabilities who began their care earlier.

3.6 Variables

3.6.1. **Outcomes of Interest:** We have included preterm birth and SGA as two main outcomes of interest in this study. Other exploratory variables are prenatal care, admission to NICU and birth Injury.

A baby is considered preterm if the baby is born before 37 weeks of pregnancy. Variable ‘Gestational age’ is categorized into three categories: 1) preterm (gestational age less than 37 weeks); 2) term (gestational age anytime from 37 to 42 weeks), and 3) post-term (gestational age 42 weeks or beyond). Small for gestational age is considered as birth weight below the 10th percentile of gestational age. Small for gestational age was identified using ICD-9 codes 656.50, 656.51, 656.53.

3.6.2. **Primary Exposure Variable:** Women having physical disability were identified using the International Classification of Disease, Ninth Revision, Clinical Modifications (ICD-9 codes). From hospital discharge files we identified the mothers with physical disability determined as ‘primary diagnosis’ by using ICD-9-CM codes. Women with ICD-9-CM codes for Multiple sclerosis, hemiplegia, infantile cerebral palsy, paralytic syndrome, myasthenia gravis, muscular dystrophies, myopathies, rheumatoid arthritis, spinal cord injury and its late effects (Table 1) were our case group. Our disability algorithm was adapted from the ICD-9 code book revised by Centers for Medicare and Medicaid Services(64).

3.6.3. **Covariates:** Covariates included in the model for mothers with and without physical disability and adverse outcome were as follows: mother’s age (18-21, 22-30, 31-44), mothers’ education (less than high school diploma, high school diploma and

beyond), prenatal care began (first trimester, 2nd trimester, 3rd trimester), smoking during pregnancy (yes/no), infection (yes/no), gestational diabetes (yes/no), preeclampsia and hypertensive disorder (yes/no), BMI (<18.5(underweight), 18.5-24.9 (normal weight), 25-29.9(overweight), >30(obese)). All the variables were ascertained from inpatient hospital data, except the entry of prenatal care which was derived from the birth certificate data.

3.7 Statistical Methods:

All data analyses conducted using SAS software, version 9.4. Descriptive statistics were calculated for demographic information. Bivariate analysis for dependent variables with selected independent variables to check for the positive or negative association. Multivariate analyses were conducted to find the best fitting model to describe the relationship between the selected outcome variable and independent variables. We considered p-values less than 0.05 to be statistically significant. Logistic regression was conducted to describe the relationship between the outcome variable and independent variable using Odd Ratios (OR). Further analysis is performed separately for disabled and non-disabled comparison by variable 'prenatal care began'. We present point estimates and 95% confidence interval of all indicators by disability status.

For Aim1(to determine the association between having preterm births and babies with SGA and maternal disability status) we calculated descriptive statistics compared between to study groups: women with physical disability and women without disabilities. Logistic regression models will be used to evaluate unadjusted rates for adverse birth outcomes like SGA, preterm birth, low birth weight, admission to NICU for each group. We tested for bivariate differences in the proportion of SGA and preterm birth between

women with disability and no disability, presented in the framework of the Mantel-Haenszel approach.

For Aim2 multiple logistic models are used to compare between groups while adjusting for maternal age, BMI, smoking during pregnancy, previous poor pregnancy outcome and admission to NICU. Stratification by the variable ‘prenatal began’ will be used to compare the difference between the strata. Separate multivariate logistic regression models are developed for disability and no disability status controlling for maternal covariates.

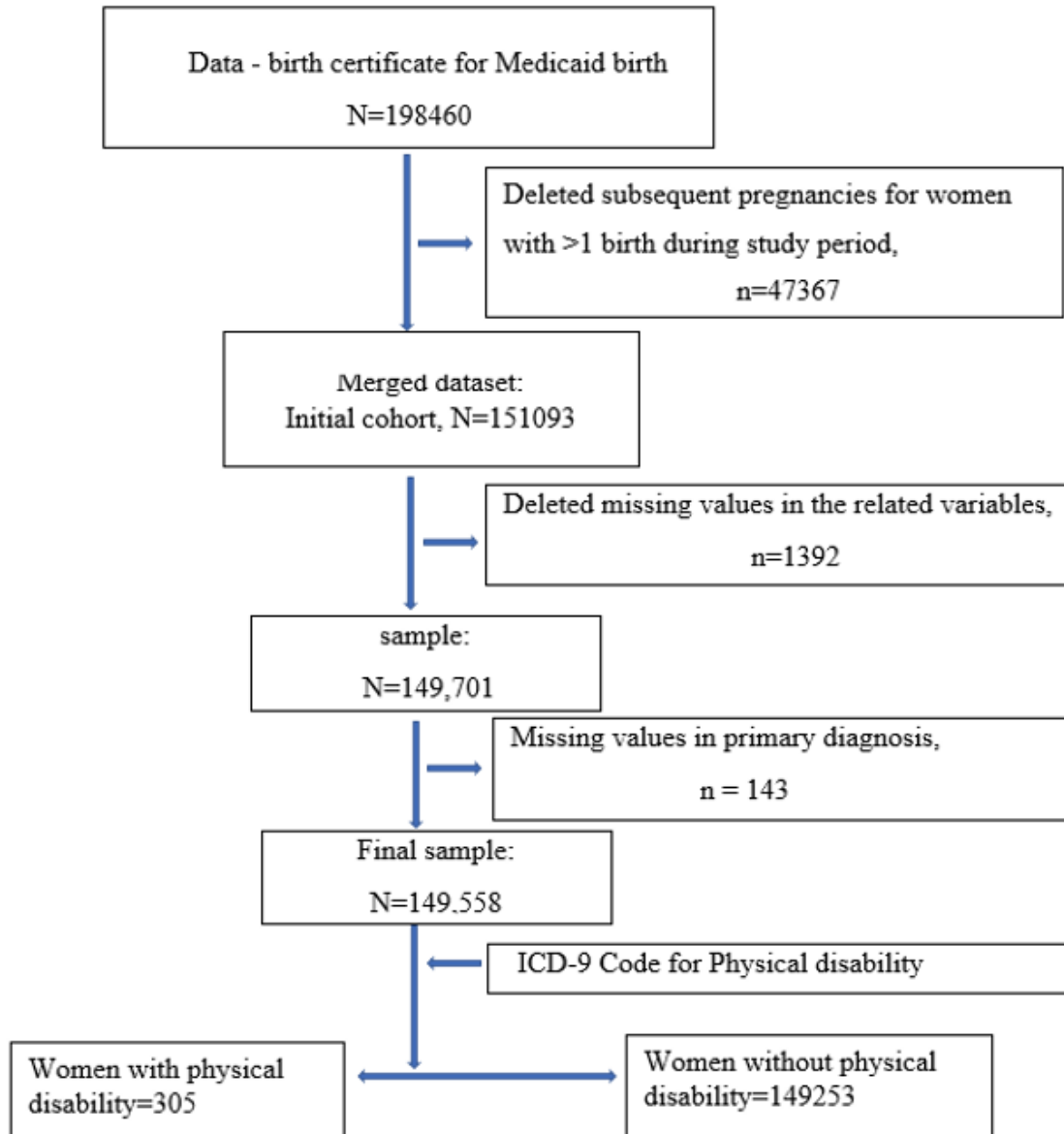


Figure 3.1: Sample selection from linked medical and birth data, SC, 2007-2015.

Table 3.1 : Classification of Physical disability by ICD-9 codes used in this study.

ICD-9 code	Physical disability	N of unique women (N= 305)
340	Multiple Sclerosis	75
342.00, 342.90	Hemiplegia and Hemiparesis	9
344.0, 343.2, 343.9	Infantile cerebral palsy	15
344.0, 344.00, 344.09, 344.1, 344.3, 344.9	Paralytic syndrome	13
358.00, 358.01, 359.0, 359.1, 359.21, 359.3, 359.5, 359.89, 359.9	Myasthenia gravis, muscular dystrophies and myopathies	17
714.0, 714.1, 714.30, 714.4, 714.89	Rheumatoid arthritis	59
806.00, 806.20, 806.29, 907.2, 928.20, 950.00, 952.16, 952.2, 952.3, 952.9	Spinal cord injury and its late effects	117

CHAPTER 4

RESULTS

The study population included 149,558 pregnancies among which 305 were identified as women with physical disability. Table 1 summarizes the demographic characteristics of women who had given live birth in South Carolina, 2007-2015. Most of the women became mother in their age between 18 to 21 years for both the group, but women with physical disabilities having their babies at advanced age between 31 to 44 years (23.93% vs 14.93%) compared to the mothers without physical disability. We found more women with physical disabilities having preeclampsia and hypertensive disorder compared to the women without physical disability (14.43% vs 11.74%). The percentage of receiving early antenatal care for pregnant women with physical disability was less (71.15% vs 73.01%) than women without physical disability. There were more mothers having physical disability, started their care during 3rd trimester than nondisabled mothers (5.57% vs 3.92%). Physical disabled women tend to be more obese (36.39% vs 33.03%) than women without physical disability. We found more women with physical disabilities having previous poor pregnancy outcome (considering still birth, neonatal death, preterm birth) comparing women without disability (10.16% vs 7.06). There were equal proportion within both the groups for gestational diabetes (5.25% vs 5.17%) and smoking during pregnancy (17.38 vs 17.34).

Sample characteristics of newborn infants are shown in table 2. More children of women with physical disability compared with women without disability were born preterm (17.05% vs 7.83%) and small for gestational age (12.46% vs 10.35%). Labor complication was less for the mothers having physical disability than mothers without physical disability (47.21% vs 53.84%). Over 13% of women with physical disabilities had a low birth weight infant compared with 7.53% among women without disabilities. Women with disabilities were more likely to have infant admitted in NICU than their nondisabled peers (13.11% vs 6.54%).

Table 3 describes the adjusted analysis of the outcome variables between deliveries to women with and without physical disability. We used binary logistic regression adjusted for maternal education, maternal age, BMI, smoking during pregnancy, Previous poor pregnancy outcome, and fetal complications. Women with physical disability had higher risk of having preterm birth, SGA and low birth weight babies. Preterm birth and very preterm birth among physically disabled mothers were twice than that of without physical disability (OR=2.45,95% CI:1.815-3.306, OR=2.36,95% CI:1.048-5.310, respectively). Women with physical disability had higher odds of having SGA compared with women without physical disability (OR=1.23,95% CI:0.877-1.732). Odds of having low birth weight infants was significantly higher among physically disabled women than nondisabled women (OR=1.95,95% CI:1.399-2.711). Women with physical disability had more than twice risk of having very low birth weight than those without physical disability (OR=2.74,95% CI:1.292-5.825). Physically disabled mothers were significantly more likely to have infants at NICU compared with nondisabled mothers (OR=2.49,95% CI:1.763-3.512). When controlling for covariates, the adjusted odd ratios

remained almost unchanged for all dependent variables. We observed deliveries to women with physical disabilities were significantly more likely than other deliveries to have worse birth outcomes, including having preterm birth (aOR=2.35,95% CI: 1.742-3.392), very preterm birth (aOR=2.29,95% CI: 1.016-5.155), low birth weight (OR=1.90, 95% CI: 1.366-2.654), very low birth weight (aOR=2.65, 95% CI: 1.249-5.641), and admission to NICU (aOR=2.90, 95% CI: 1.698-3.396). The association of SGA and maternal physical disability was not significant after adjusting with the covariates (OR=1.25, 95% CI: 0.885-1.761). So, there is no justification to include SGA for further analysis.

Table 4 reports an unadjusted and adjusted comparison of the effects of delayed prenatal care across the multivariate model. There were no significant association of adverse birth outcomes and delayed prenatal care among physically disabled mothers except low birth weight. Unadjusted analysis showed, women with physical disabilities who had their prenatal care later in their pregnancy, had two-fold higher odds of having preterm births (uOR=2.10, 95% CI: 1.078-4.090) compared who had the care early. Similar results concerning delayed prenatal care were still evident after adjustment for covariates (previous poor pregnancy outcome, BMI, maternal age, admission to NICU) except results for preterm birth. Women with physical disability who had delayed prenatal care, were significantly more likely to have adverse pregnancy outcome (preterm birth: aOR=2.06, 95% CI: 1.030-4.121; low birth weight: aOR=2.53, 95% CI:1.200-5.348) as compared those who started early care. We found significant association of adverse pregnancy outcome and delayed prenatal care among nondisabled mothers throughout the crude and adjusted analysis.

Table 4.1 Demographic characteristics of women with live births, by physical disability status, SC,2007-2015.

	Women with physical disability (n=305)	Women without physical disability (n=149253)	p-value
	Frequency (%)	Frequency (%)	
Mothers age (years)			
18-21	123(40.33)	65490(43.88)	< .0001*
22-30	109(35.74)	61473(41.19)	
31-44	73(23.93)	22290(14.93)	
Mothers education			
Less than high school	177 (58.03)	86863(58.20)	
Highschool and above	128(41.97)	62012(41.55)	.6748
Prenatal care started at(months)			
1 st trimester (0-3)	217(71.15)	109063(73.01)	
2 nd trimester (4-6)	71(23.28)	34341(23.01)	.3183
3 rd trimester (7-9)	17(5.57)	5849(3.92)	
Smoking during pregnancy			
No	252(82.62)	123379(82.66)	
Yes	53(17.38)	25874(17.34)	.8926
Infection			
Absent	272(89.18)	134176(89.90)	
Present	33(10.82)	15077(10.10)	.6776
Gestational diabetes			
Absent	289(95.75)	141537(94.83)	
Present	16(5.25)	7716(5.17)	.9522
Preeclampsia ^a and hypertensive disorder			

absent	261(85.57)	131738(88.26)	
present	44(14.43)	17515(11.74)	.1447
	Women with physical disability (n=305)	Women without physical disability (n=149253)	p-value
	Frequency (%)	Frequency (%)	
BMI			
Underweight (<18.5)	31(10.16)	9992(6.69)	
Normal weight (18.5-24)	95(31.15)	54418(36.46)	.0272*
Overweight (25-30)	68(22.30)	35545(23.82)	
Obese (>30)	111(36.39)	49298(33.03)	
Previous poor pregnancy outcome ^b			
No	274(89.84)	138711(92.94)	0.0348*
Yes	31(10.16)	10542(7.06)	

*Statistically significant p-value

^a Preeclampsia is a pregnancy related condition characterized by maternal hypertension, various vascular abnormalities and poor placental function.(65)

^b Previous poor pregnancy outcome includes abortion, perinatal mortality, preterm birth, infant death.(65, 66)

Table 4.2

Demographic characteristics of newborn infants, by maternal physical disability status, SC 2007-2015.

	Women with physical disability (n=305) Frequency (%)	Women without physical disability (n=1787572) Frequency (%)	p-value
Birth weight(gm)			
Normal birth weight (2500-4200)	249(81.64)	132892(89.04)	
Low birthweight (1500-2500)	41(13.44)	11236(7.53)	<.0001*
Very low birth weight (<1500)	7(2.30)	1362(0.91)	
High birth weight (>4200)	8(2.62)	3763(2.52)	
Small for gestational age ^a			
No	267(87.54)	133799(89.65)	0.2282
Yes	38(12.46)	15454(10.35)	
Clinically estimated gestation (weeks)			
Very preterm (<32)	6(1.97)	1400(0.94)	
Preterm (32-36)	52(17.05)	11683(7.83)	<.0001*
Term (37-42)	247(80.98)	135946(91.08)	
Post Term (>42)	-	224(0.15)	
Labor complications (induction and augmentation)			
No	161(52.79)	68894(46.16)	0.0204*
yes	144(47.21)	80359(53.84)	
Admission to NICU			
No	265(86.89)	139491(93.46)	<.0001*
Yes	40(13.11)	9762(6.54)	

*Statistically significant p-value

^a Weight below the 10th percentile of gestational age

Table 4.3

Crude odds ratio (95% confidence interval) and adjusted odds ratio (95% confidence interval) for pregnancy outcomes in women with physical disability compared with women without physical disability.

Characteristic	Women with Physical disability Vs women without physical disability			
	Crude OR	95 %confidence interval	Adjusted OR ¹	95% confidence interval
Clinically estimated gestation(weeks)				
Preterm	2.45	1.815 - 3.306	2.35	1.742 - 3.392
Very preterm	2.36	1.048 – 5.310	2.29	1.016 - 5.155
Small for gestational age	1.23	0.877 – 1.732	1.25	0.885 – 1.761
Birth weight(gm)				
Low birth weight	1.95	1.399 - 2.711	1.90	1.366 – 2.654
Very low birth weight	2.74	1.292 – 5.825	2.65	1.249 – 5.641
Admission to NICU	2.49	1.763 – 3.512	2.90	1.698 – 3.396

¹ Adjusted maternal education, maternal age, BMI, smoking during pregnancy, poor pregnancy outcome, fetal complications

Table 4.4

Odds ratio of delayed prenatal care and birth outcome (preterm birth and low birth weight), by maternal disability status

	Birth Outcome	Women with physical disability		Women without physical disability	
		Crude OR	Adjusted OR¹	Crude OR	Adjusted OR¹
		OR (95% confidence interval)		OR (95% confidence interval)	
Delayed Prenatal Care*	Preterm birth	1.69 (0.924-3.104)	2.06 (1.030 -4.121)	1.38 (1.327 – 1.432)	1.40 (1.343 -1.455)
	Very preterm birth	1.01 (0.182 – 5.640)	0.23 (0.11 – 4.607)	1.58 (1.423 – 1.757)	1.67 (1.491 –1.875)
	Birth Outcome				
	Low birth weight	2.10 (1.078 – 4.090)	2.53 (1.200 -5.348)	1.10 (1.057 - 1.144)	1.09 (1.048 – 1.137)
	Very low birth weight	1.50 (0.326 – 6.858)	3.14 (0.299- 42.95)	1.39 (1.249 – 1.547)	1.31 (1.196 –1.473)

*prenatal care started after first trimester

¹ Adjusted with previous poor pregnancy outcome, BMI, maternal age, admission to NICU

CHAPTER 5

DISCUSSION

This study explores the association between mothers with physical disabilities and their risk of adverse birth outcomes. The main findings of this study indicate that mothers with physical disability were more likely to have infants born preterm. A higher proportion of infants of physically disabled mothers were born with low birth weight and risk for admission to the Neonatal Intensive Care Unit (NICU).

Mothers with physical disability who delivered live births were more likely to have a previous poor pregnancy outcome, preeclampsia, obesity, and delayed prenatal care. Previous studies have suggested that maternal body mass index and weight gain have a negative impact on birth outcome(9, 25). We observed labor complications during induction and augmentation were lower for the women with physical disability than those without having physical disability. We did not have information about mode of delivery (vaginal delivery or cesarean section) among the mothers in this study, thus we did not know if the lower proportion of labor complications among physically disabled women was the result of planned cesarean sections. Studies showed that women with spinal cord lesions and rheumatoid arthritis are less likely to deliver vaginally (25, 39). Other studies have also reported a higher proportion of cesarean deliveries among women with physical disability as compared with women with no disability(34, 37, 40, 41).

Similar to previous studies, we encompassed a significant association of women with physical disability and higher rates of preterm birth (aOR=2.35) and low birth weight (aOR=1.90). In addition, we found women with physical disabilities were more likely to have a very preterm birth (aOR=2.29) and very low birth weight (aOR= 2.65). Researchers comment that stressful life, less social support and physical limitations potentially have an impact on their adverse birth outcome(6, 28, 67). Research on the association of smoking and gestational diabetes and pregnancy outcome suggests that smoking and gestational diabetes are important risk factors for adverse birth outcome(68). These adverse outcome which is observed in general population could have greater impact for pregnant women with physical disability(25). We had similar proportion for smoking during pregnancy and gestational diabetes among women with and without physical disability.

Based on our analysis women with disability were more likely to delay prenatal care to the second or third trimester (22, 25). Other researchers reported that disabled women were more likely to enter the antenatal care after the first trimester due to inadequate knowledge, emotional stress, and unsatisfactory experiences with health professionals (30, 69). As a result, this group of women is more likely to miss screening tests, early assessment of their pregnancy status, and information about self-management during pregnancy. Previous Studies reported that delayed prenatal care among pregnant women with physical disability was associated with higher risk for low birth weight, preterm birth, long hospital stay, infant admission to the NICU(22, 61). In our study, We reported increased likelihood of preterm birth and low birth weight among women with physical disability who had late prenatal care compared with who received early prenatal

care. But when we compared effect of prenatal care among women with physical disability and women without physical disability, we observed delayed prenatal care had a greater risk for preterm birth and low birth weight for pregnant women having physical disability. So we can conclude that, by utilizing prenatal care from the beginning of their conception, some risks of adverse outcomes for physical disabled women which can be minimized.

5.1 Strength of the study

A major strength of this study is that it is a retrospective population-based study with a large sample of mothers who were at highest risk for adverse outcomes based on their relatively low family income which qualifies them for Medicaid in South Carolina. All the women had singleton births between 2007-2015. The Medicaid data used for this survey were linked with the birth certificate data. We assessed the risk of adverse pregnancy outcome among the women with physical disability compared to women without these disabilities. In South Carolina, no other study has assessed maternal physical disability and adverse pregnancy outcome. In addition, we examined whether delayed prenatal care has an impact on pregnancy outcome, for the mothers with and without physical disability.

5.2 Limitations of the study

There were a number of limitations to our study. As a retrospective study we must rely on the information available in the Medicaid billing record, which was not always complete. We restricted our exposure group to women with a specific set of diagnoses known to be associated with physical disability which limits the generalizability

of the results to only those diagnoses. In addition, the size of the physical disability group was small compared to the comparison group of women without physical disability. We did not have all the data that would have been desirable such as the type of delivery (vaginal versus caesarian), fetal growth measures throughout pregnancy, number of prenatal visits, test results during pregnancy, and longer term developmental and physical outcomes of the children.

5.3 Conclusions

We found significant differences in birth outcomes between women with and without physical disability who were insured by Medicaid. Women with physical disability were significantly more likely than women without physical disability to have preterm birth, a low birth weight infant and an infant admitted to the NICU. We also identified evidence that delayed prenatal care among women with disabilities, results in higher risk for preterm birth and low birth weight newborns. Despite the increased risk of adverse outcomes, this study can inform both obstetricians and women with disability about the importance of early entry into prenatal care for mothers with physical disability.

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