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A Perinatal Health Framework for Women with Physical Disabilities

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Abstract

Background—Studies suggest that women with disabilities experience health and health care disparities before, during, and after pregnancy. However, existing perinatal health and health care frameworks do not address the needs and barriers faced by women with physical disabilities around the time of pregnancy. A new framework that addresses the perinatal disparities among women with physical disabilities is needed.

Objective—To propose a framework for examining perinatal health and health care disparities among women with physical disabilities.

Methods—We developed a perinatal health framework guided by the International Classification of Functioning, Disability and Health (ICF) and the integrated perinatal health framework by Misra et al.

Results—The proposed framework uses a life span perspective in a manner that directly addresses the multiple determinants specific to women with physical disabilities around the time of pregnancy. The framework is based on longitudinal and integrated perspectives that take into account women's functional status and environment over their life course.

Conclusion—The perinatal health framework for women with physical disabilities was developed to inform the way researchers and health care professionals address disparities in perinatal health and health care among women with physical disabilities.

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Keywords

disability; pregnancy; perinatal health; framework; women with physical disabilities

INTRODUCTION

Approximately 12% of women of reproductive age report a disability and a substantial proportion report having a mobility or self-care limitation.¹ With advances in medical technology, growing community participation, and destigmatization of disability, an increasing number of women with disabilities are choosing to become pregnant.^{1,2} The nascent literature on pregnancy among women with disabilities suggests that they have higher risks than nondisabled women of complications and poor outcomes including urinary tract infections, inadequate prenatal care, delivery of low birth weight infants, and preterm birth.^{1,3,4} Compared with nondisabled women, women with disabilities are at an elevated risk for physical abuse before and during pregnancy⁵; smoking before, during, and after pregnancy⁶; and prenatal and postpartum depression.⁷ Women with physical disabilities often report that their clinicians: are ill-equipped to manage their pregnancies effectively; lack knowledge about their disability; possess negative views and stereotypes about the sexuality and reproductive preferences of women with disabilities; and disapprove of women with disabilities considering pregnancy and childbearing.^{2,8-16} In addition, clinical offices, examination tables, and weight scales may be inaccessible for women with disabilities, creating added barriers to prenatal care. Scant information is available to guide women with physical disabilities and their practitioners about pregnancy, its management, and transition through puerperium into parenthood.¹

One approach to systematically addressing disparities in perinatal care utilization and maternal and birth outcomes among women with and without physical disabilities, is to utilize a perinatal framework that considers the barriers to health and health care that are specific to women with physical disabilities. The integrated perinatal health framework developed by Misra et al.¹⁷ takes a life span perspective that acknowledges that the factors that affect pregnancy are linked to health-related behaviors and risks over time, and not simply during the time periods around pregnancy. In addition, their framework adopts a “multiple determinants” model that integrates the social, psychological, behavioral, environmental, and biological factors that influence perinatal health. Finally, it takes into account the changing demographics of pregnancy in the United States and includes both teen pregnancy and the biological and social issues related to women who delay their pregnancy.

The purpose of our paper is to propose a perinatal framework to assist in examining birth outcomes and experiences among women with physical disabilities. The proposed framework is based on longitudinal and integrated perspectives that take into account women's functional status and environment over their life course. Our approach recognizes the particular barriers and environmental factors that can influence maternal health and birth outcomes for women with physical disabilities. An integrated perinatal health framework for women with physical disabilities can guide the promotion of preconception and

interconception health and health care for these women. This framework applies to women with physical disabilities but many of the factors apply to women with disabilities generally.

METHODS

Rationale for a perinatal health framework for women with physical disabilities

Built upon the health framework originally articulated by Evans and Stoddart,¹⁸ Misra et al.¹⁷ developed a perinatal health framework that made an important contribution to the literature by acknowledging the influence of factors affecting women throughout their lives, reflecting the reality that healthy outcomes for women and infants are a result not only of good prenatal care, but of a multitude of factors influencing women throughout their lives. Misra et al. categorized these factors into three groups: Distal determinants, proximal determinants, and outcomes. Distal determinants include those factors that put women at a greater risk for the proximal risk factors. Included among the distal determinants are genetic factors, the physical environment such as pollution and the physical, social, political and economic environments. The proximal determinants category includes biomedical (e.g. chronic diseases, infections) and behavioral factors (e.g. smoking, alcohol and drug use). Outcomes in this framework are divided into short- and long-term maternal and infant diseases and complications, maternal and infant health and functioning, and maternal and infant wellbeing. Although useful in many ways, this framework does not adequately address the determinants of maternal and infant health among women with physical disabilities. For example, the framework underemphasizes the immediacy of concerns regarding the physical environment, such as physical access to health care, and the social and policy environments, including the availability of social support, personal care assistance and the impact of disability-related stigma. The lack of emphasis on factors with a substantial impact on women with physical disabilities is also demonstrated in the description of factors in other categories. For example, Misra et al.¹⁷ included the issue of maternal functioning only in the outcomes category, thereby overlooking the importance of functional abilities for women with physical disabilities before, during, and after pregnancy.

Yet another model relevant to women with disabilities can be found in the work of Lu and Halfon¹⁹ who applied a life course perspective to birth outcomes among African American women. They posited that the cumulative effects of poor living conditions and chronic stress experienced by African American women as a result of racism over the course of a lifetime was an important contributor to poorer birth outcomes. Similarly, women with disabilities experience the negative impact of inaccessibility and disability-related stigma in their daily lives and a framework that seeks to fully address the factors that impact their perinatal experiences and outcomes must account for these issues.

Aday and Andersen²⁰ incorporate the concept of stigma along with other environmental factors into their framework explaining access to health services. Access to health services is a critical component of any examination of the experiences of women with disabilities with perinatal care. However, equally important to the perinatal care experiences of this population is quality of health care services. Therefore, a framework explaining the perinatal care experiences and outcomes of women with disabilities must, of necessity, take a broader approach.

Nosek et al.²¹ proposed a model of factors contributing to reproductive health maintenance among women with physical disabilities. Similar to the model of Misra et al.,¹⁷ Nosek et al.'s model²¹ made a substantial contribution to the literature, but does not fully address the factors relevant to the experiences of women with physical disabilities around the time of pregnancy. Nosek et al.'s model describes disability as “a context within which the interrelationship of all the variables . . . are substantially altered” and which “conditions the manner in which women perceive themselves . . . as well as the manner in which society responds to them and makes its resources available to them”.^{21(p513)} Nosek et al. divided the relevant factors into two categories – internal factors and environmental factors, with sociodemographic characteristics included in the model as moderating the relationship between the factors and reproductive health maintenance among women with disabilities.

A major contribution of Nosek et al.'s model is its emphasis on the role of knowledge, both as an internal factor pertaining to women and as an environmental factor related to the knowledge of health professionals. Similarly, the model acknowledges the importance of women's internal psychological factors and the attitudes of health professionals. Another important contribution of Nosek et al.'s model is its explicit inclusion of environmental access and the characteristics of health care systems. Yet, although Nosek et al. acknowledged the importance of functional abilities and other disability-related characteristics as part of the broader context for reproductive health maintenance, they did not explicate in detail how certain disability-related characteristics, such as body structure and function, interact with internal and environmental factors to lead to health-related outcomes among pregnant women with physical disabilities and their infants.

Body structure and function are incorporated explicitly in the model of the International Classification of Functioning, Disability and Health (ICF) articulated by the World Health Organization.²² This ICF framework also incorporates some of the factors described in the model posited by Nosek et al.,²¹ such as internal and environmental factors. The ICF attempts to articulate the impact of health conditions on participation in societal roles. Although it is possible to infer how the ICF framework might apply to women with physical disabilities in and around the time of pregnancy, a search of the literature did not yield any articles describing how it would be applied with regard to pregnancy.²³⁻²⁷ This gap in the literature suggests the need for a framework that applies a life span perspective in a manner that directly addresses the multiple determinants specific to women with physical disabilities around the time of pregnancy.

RESULTS

Perinatal framework for women with physical disabilities

Guided by the ICF, we developed a perinatal health framework for women with physical disabilities. The ICF defines disability as an “umbrella term for impairments, activity limitations or participation restrictions,” conceiving “a person's functioning and disability ... as a dynamic interaction between health conditions (diseases, disorders, injuries, traumas, etc.) and contextual factors.”^{22(p3)} Our framework (Figure 1) reflects the short- and long-term outcomes of pregnancy for women with physical disabilities as a result of the interaction of a number of factors. These factors include those present at various points

throughout the women's life as well as around the time of pregnancy. In formulating these constructs, our work is also informed by the reproductive health maintenance framework articulated by Nosek et al.²¹ and the life span approach developed by Misra et. al.¹⁷

Individual Factors

Individual factors in our framework include (1) demographic factors, such as age, race/ethnicity, and income, and (2) health conditions, such as the nature of the primary disabling condition, comorbid conditions, or secondary conditions (Table 1). Comorbid conditions include those that are concomitant with, but unrelated to the disability, such as complications of pregnancy that could occur in anyone, regardless of whether the woman has a disability,²⁸ e.g., diabetes.²⁹ Secondary conditions refers to those preventable conditions for which a person with a pre-existing disability is at higher risk in general, including those that may or may not be more common in pregnancy, i.e., pressure ulcers, urinary tract infections.^{28,30-32} There can be some overlap between what we describe as “comorbid conditions” and “secondary conditions” as a pregnancy may increase an already high risk, due to the underlying disability, of developing certain secondary medical conditions, e.g., urinary tract infections; (3) body structures and functions, which refer to anomalies and the operation of body systems, for example skeletal anomalies of the hips and pelvis such as those often experienced by women with achondroplasia, which may complicate delivery³³; (4) impairments refers to deviation from generally accepted population standards for body structures and functions exemplified by the inability to walk; (5) genetic factors are those that may affect any woman and also those that are condition-specific, such as an inheritable condition like spinal muscular atrophy; (6) activities in the framework include the execution of tasks or actions such as dressing or bathing independently, and (7) participation, which is involvement in a life situation such as employment and intimate relationships that may lead to pregnancy and birth.

Mediating Factors

The framework also illustrates the role of factors mediating the relationship between the environmental and individual factors and the outcomes (Table 1). These include the following four categories identified in the literature with the potential to affect perinatal health and health care for women with disabilities: (1) access to information and resources, such as preconception counseling,³⁴⁻³⁶ prenatal education and personal assistance with the tasks of mothering,^{12,34} (2) health care-related factors ranging from physical access to communication and attitudinal barriers interfering with relationships with health care professionals,^{21,34,37-41} (3) psychosocial factors ranging from women's beliefs about childbearing and motherhood to increased risk for physical abuse around the time of pregnancy,^{12,42,43} and (4) social support and connection-related factors such as the degree of family support, attitudes toward women's pregnancy, and relationships with partners/spouses and peers.^{12,43}

A recent study by Mitra et al.³ found that women with disabilities were nearly twice as likely as nondisabled women to begin prenatal care after their first trimester, and more likely to report inadequate prenatal care than women without disabilities. Another study conducted in the United Kingdom indicates that fewer women with disabilities attended prenatal

classes (among those wishing to attend) than those without disabilities.⁴⁴ Inadequate or delayed access to health care for women with disabilities are a result of multiple issues that affect the potential to obtain health care services as well as the actual receipt of services.³⁴ Access considerations are not limited to physical access; rather, access also includes women's access to health information and appropriate communication with health care professionals. Challenges to access to health care services have been categorized as physical, attitudinal, communicational, informational and financial.⁴⁵ Barriers to health care services for women with physical disabilities are related to location of services and model of health care, transportation, physical environment (access to buildings, internal architecture of health-related facilities, inadequate collaboration of services, lack of suitable equipment, and lack of assistance with the physical environment). Additional barriers include limited availability of health information and ineffective communication between health care professionals and women with disabilities. Barriers to access are further related to attitudes of health care professionals, attitudes and behaviors of staff toward women with disabilities (e.g., hostility, sympathy, and pity) and to the idea of pregnancy and motherhood in this population. Health care providers might possess negative stereotypes about the sexuality of women with disabilities and disapprove of their pregnancy and question their ability to care for their child.^{9,12,21,37,40,46-56} These attitudes and negative responses can be manifested by increased scrutiny and questioning of the ability of women with disabilities to interact with and care for their infants. These damaging experiences with health care providers could prevent women with disabilities from seeking timely preconception, interconception, prenatal, and postpartum care.

In addition, lack of knowledge about disabilities among health care providers and staff may result in inadequate management of pregnancy among women with disabilities or avoidance of these women, which may both result in inappropriate care, increased medicalization of childbearing, and poor postnatal care.³⁴ Given that disabilities are more prevalent in women beyond reproductive years, it will be relatively rare for an OB to see women with certain disabling conditions who are pregnant. As a result proactive solutions are needed to ensure that clinicians are prepared when pregnant women with physical disabilities seek prenatal care. Other factors that further limit these women's access to prenatal care include mental health issues, violence victimization, poor social and professional relationships, transportation or travel problems, and the expectation of negative attitudes and experiences in their interactions with health care providers.⁴³

Maternal and Infant Outcomes

We divide outcomes into two categories: (1) maternal outcomes including maternal health, wellbeing and functioning, and (2) infant outcomes, such as low birth weight, preterm birth, hospital use, congenital anomalies, maternal-infant bonding, and clinical complications (Table 1). Most maternal and infant outcome indicators such as low birth weight, preterm birth, and infant mortality rate are well-documented in the general obstetric population.^{57,58} While a few studies have explored disability-related disparities in adverse birth outcomes including preterm birth, low birth weight and admission of the infant to the neonatal intensive care unit (NICU),^{3,4} the research on the relationship between maternal disability and pregnancy-related outcomes is still in its infancy.

In addition to the generally accepted indicators of maternal outcomes, we have included maternal health and functioning as an additional outcome in our framework.¹⁷ Maternal functioning, also used in Misra et al.'s framework, is particularly important for women with physical disabilities for whom changes in functioning are potentially greater compared to women in the general population. The general health status of mothers was also included as an outcome for women with physical disabilities given the already fragile relationship between disability and health. Women with disabilities during preconception and during pregnancy are more likely to self-report fair to poor health compared to those without disabilities.^{59,60} For instance, delayed prenatal care may potentially have a greater impact on the health status of women with physical disabilities compared to women in the general population. In addition, other mediators unique to women with physical disabilities such as unmet needs for personal care assistance, inaccessible examination tables, and weighing scales may have an added impact on the health and functioning of women with disabilities and their infants.

Environmental Context

All of these interactions occur within the larger environmental context, which has an indirect impact on the perinatal health of women with disabilities. The environmental context impacts the individual level factors, mediating factors and maternal and birth outcomes. Similar to the distal level of factors in Misra's framework,¹⁷ the environmental context includes risk factors that increase or decrease the vulnerability of women with disabilities to the “mediating factors” in this framework. The environmental context includes the (1) cultural and social norms such as opportunities for intimate relationships and degree of social connectedness, (2) attitudinal factors including the attitudes of the broader community toward childbearing among women with physical disabilities, (3) physical environment includes the design and accessibility (or lack thereof) of the built environment including accessibility of the transportation network, parks, schools, healthcare settings, and (4) the legal/policy context within which women with disabilities reside. The legal/policy context includes the laws, policies and the service delivery systems within which these other factors interact. For example, in the United States, it includes the Americans with Disabilities Act, the Social Security Act (including Titles XVIII and XIX, Medicare and Medicaid, respectively), the Affordable Care Act, and policies and regulations promulgated to implement these laws. These laws and policies affect women's access to accessible and appropriate health care, equipment to assist in caring for themselves and their children, access to paid personal assistant services, their education, income and employment, and virtually every other aspect of a their lives throughout childhood and young adulthood and in their role as a mother with a disability.

DISCUSSION

Policy and research implications

Broad measures to improve the health and wellbeing of women with physical disabilities specifically, and among women generally, are both necessary to produce optimal maternal and infant outcomes in this population. Misra et al.¹⁷ noted that these measures must begin in childhood and suggested a focus on primary prevention efforts related to nutrition and

other risk factors. Public health initiatives to improve the health and wellbeing of women with physical disabilities must encompass such efforts and must also include secondary prevention, i.e., the prevention of co-morbid and secondary conditions, to which women with physical disabilities may be prone.

Efforts to improve access to health care must not only include those that benefit women generally, but must address the specific physical, programmatic and communication barriers that affect women with physical disabilities. Lagu et al.³⁸ documented high rates of refusal to see patients who used wheelchairs among specific subspecialty practices; gynecologists had the highest rates of refusal to provide care for women with physical disabilities. This finding is consistent with the experiences of women with disabilities and underscores the need for provider education to ensure access to prenatal care. Efforts to improve access must begin before pregnancy and must be part of the effort to improve health care for all persons with disabilities. Not only must the offices of obstetricians/gynecologists be accessible, but the primary care clinicians' and specialists' offices and other clinical facilities must also be accessible. The U.S. Department of Justice has recently bolstered its efforts to improve physical access by issuing proposed standards on access to medical equipment such as weight scales.

In addition to improving physical access, efforts must be made to improve programmatic access. Better training of health care professionals to provide care to women with physical disabilities during pregnancy and in the preconceptional and interconceptional stages is critical. Such training and preparation would need to address the medical aspects of care, along with beliefs and attitudes held by health care professionals that may interfere with their ability to provide quality care. An important step to providing comprehensive reproductive care and preconception counseling to women with physical disabilities is to improve the knowledge and attitudes of clinicians regarding the reproductive rights of women with disabilities, including their perspective on the sexuality of women with physical disabilities whom some may view as asexual, unable to participate in intimate relationships and bear children.. The Patient Protection and Affordable Care Act of 2010 included a requirement that health care organizations document their efforts to train clinicians about working with individuals with disabilities and this may help to broaden the availability of such training.⁶¹

Women with physical disabilities must be educated at age-appropriate points in their lives about their sexuality, not only including their potential for motherhood, but also contraception, risks for sexually-transmitted diseases, and unintended pregnancy. At the point when they begin to contemplate motherhood, they should be provided with accurate information about the benefits and risks of pregnancy and childbirth. Unfortunately, knowledge about the implications of various disabling conditions is in its infancy.¹ Further research is needed to enable clinicians to give women with physical disabilities the information they need to make informed decisions about their reproductive health.¹

Public policies also need revision to improve access to assistive technology that may maximize women's ability to care for their infants combined with better access to assistance with child care to supplement their efforts are important components of a strategy to support

women in their role as mothers. These efforts to improve the health and health care of women with disabilities must be embedded within a strategy of improving the economic and social opportunities available to women and men with disabilities overall. Improvements in education, employment, and social opportunities can only help to improve the likelihood that mothers with physical disabilities and their infants will be able to achieve optimal outcomes. A review of policies for care of women with disabilities related to pregnancy, childbirth, and early motherhood in ten developed countries reveals that the United Kingdom has the most developed strategy for addressing maternity care for women with disabilities. In contrast, although the United States has comprehensive disability legislation, no national strategy specifically addresses the needs of women with disabilities related to pregnancy, childbirth, and early motherhood.²¹

There are several barriers to researching disability-related disparities in pregnancy-related maternal and infant outcomes. A primary barrier is the exclusion of maternal disability identifiers in surveillance systems that are used to assess these outcomes in the United States. Despite Section 4302 of the Affordable Care Act⁶² which established a set of six questions as the minimum standard for measuring disabilities in all population health surveys, the Pregnancy Risk Assessment and Monitoring System (PRAMS), which is the primary population-based surveillance system used to monitor behaviors, experiences and conditions before, during and after pregnancy in the United States, does not include these questions. Given the disparities in the health and health care utilization of mothers with disabilities as well as the adverse pregnancy outcomes, it is vital that the PRAMS survey and other datasets, such as the National Vital Statistics System-Natality (NVSS-N), used to assess obstetric outcomes, include the full set of disability questions to enable systematic identification and monitoring of the health of mothers with disabilities across the United States. Finally, this framework can enhance public health surveillance of perinatal health and birth outcomes of women with physical disabilities through the systematic collection, analysis and interpretation of data on the risk factors, barriers, consequences, and health service requirements that are specific to women with disabilities.

CONCLUSION

In this article we present a perinatal health framework for women with physical disabilities that incorporates the specific needs and unique barriers faced by pregnant women with disabilities. It provides a context from which to examine the interplay between women's disability status and perinatal experiences and provide a much-needed construct for furthering our understanding of both specific and general relationships between perinatal health and disability status. We anticipate that this framework will facilitate enhanced public health surveillance of pregnancy among women with disabilities, facilitate future research towards a greater understanding of the needs, barriers, and outcomes of pregnancy among women with physical disabilities, development of interventions that reduce barriers to care, and improve perinatal and neonatal health outcomes, and finally the development of clinical recommendations and practice guidelines for perinatal care among women with disabilities.

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Figure 1.
Perinatal Health Framework for Women with Physical Disabilities

Table 1

Perinatal Health Framework for Women with Physical Disabilities: Individual, Mediating, Maternal and Infant Outcomes and Environmental Context

Individual factors	Example
Demographic	Age Race/ethnicity Income Education Country of origin Marital status Sexual orientation Culture
Health condition	Primary disabling condition Co-morbid conditions (e.g. asthma or diabetes) Secondary conditions (e.g. pressure ulcers, UTIs) Stability of condition
Body structure and function	Structural anomalies (e.g. spinal cord injury, amputation)
Impairments	Limited mobility Limited dexterity
Genetic factors	Inheritable condition like spinal muscular atrophy, achondroplasia
Activities	Self-care including dressing, bathing, eating (ADLs and IADLs)
Participation	Employment Community and social interactions Intimate relationships
Mediating Factors	Example
Access to information and resources	Preconception counseling Prenatal education Assistive technology Access to information on pregnancy Financial support Transportation access Access to nutrition Personal assistance with mothering tasks
Health care-related factors	Physical, communication, programmatic and attitudinal barriers to health care Provider knowledge Health insurance status Reproductive care experiences Sexuality education
Psychosocial factors	Women's knowledge, beliefs and attitudes about childbearing and motherhood Self-efficacy Stress Depression/anxiety Risk for physical abuse
Social support	Family support Family and peer attitude towards pregnancy among women with physical disabilities Relationship with spouse/partner and peers
Maternal and Infant Outcomes	Example
Maternal outcomes	Maternal health Maternal well-being Maternal functioning Cesarean delivery
Infant outcomes	Low birth weight Preterm birth NICU admissions Congenital anomalies Clinical complications Maternal-infant bonding

Environmental Context	Example
Physical	Physical accessibility of woman's home and clinicians' office Accessibility of transportation
Social	Opportunities for intimate relationships Degree of social connectedness
Attitudinal	Attitudes of broader community towards pregnancy among women with physical disabilities
Legal/policy	Americans with Disabilities Act Social Security Act (Medicare, Medicaid, cash benefits) Affordable Care Act Maternal and child health policy