

Research Paper

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 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. © 2015 Elsevier Inc. All rights reserved.

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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, Guyer, and Allston¹⁷ takes a life span perspective that acknowledges that the factors that

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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,

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