



SPECIAL ISSUE: Sexual and Reproductive Health of Women with Disability

Research paper

Reproductive healthcare experiences of women with cerebral palsy



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ABSTRACT

Background: Little is known about pregnancy rates in women with disabilities in general and even less is known about women with child-onset disabilities such as cerebral palsy (CP).

Hypothesis: We hypothesized that discussions about pregnancy with healthcare providers and pregnancy rates for women with CP would be related to their functional levels.

Methods: Survey methodology was used to gather information about demographics, function, whether women were asked about their desire for children, pregnancy outcomes, and services offered during pregnancy and postpartum.

Results: Of the 375 women with CP who participated in the survey, 76 (20%) reported 149 pregnancies resulting in 100 live births. Using Chi square statistics, mobility, manual dexterity, and communication function were significantly higher in women who were queried about or who experienced pregnancy. More than half of the women experienced a loss of mobility during pregnancy but few received referrals for physical or occupational therapy. Few reported screening for postpartum depression. A higher rate of Cesarean sections (50.4%), preterm births (12.1%), low birth weight infants (15.7%), and very low birth weight infants (7.1%) was reported by women with CP compared to national statistics.

Conclusions: Pregnancy rates and discussions were related to functional levels. As 20% of women with CP surveyed experienced pregnancy, there is a need to increase awareness, education, support, and advocacy for achievement of optimal reproductive health. More research is needed to identify factors contributing to maternal and infant health in women with CP.

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Misperceptions regarding the sexuality of women with disabilities are pervasive, and can affect the pregnancy experience as well as care received. Decades of research continues to show that people with disabilities are perceived as uninterested in sex, asexual, not sexually active, or unable to have sex.^{1–6} There appears to be genuine incredulity that a woman with a disability would have sex and want to be a mother.^{2,5,7} Furthermore, women with disabilities are discouraged from having children, and have their ability to care for a child and competence as a parent questioned.^{1,2,8} Once

pregnant, immediate termination has been offered based on these assumptions.^{9,10} Women with disabilities are so accustomed to negative reactions about their pregnancy that a lack of negative comments is perceived as a positive response.²

Contrary to these beliefs, women with disabilities do experience sexual relationships and pregnancy.¹¹ It is estimated that there are 4.1 million parents with disabilities who have children under age 18 and living at home with them.¹² Recent data from a national survey estimated that 163,732 women with chronic physical disability ages 18 to 49 (2%), including 44,200 women with a severe mobility disability, are pregnant in a given year.^{2,13,14} The limited existing literature suggests that the majority of women with physical disabilities have normal fertility, are capable of becoming pregnant, and are capable of a vaginal delivery.^{6,9} Women with disabilities, however, continue to encounter barriers to receiving the education and services they need for pregnancy planning, pregnancy, and

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postpartum care.

During pregnancy, women with disabilities may have difficulty finding obstetricians to follow their pregnancy for multiple reasons. One of the most common barriers to monitoring pregnancy is a lack of elevating exam tables and accessible scales.^{15,16} Women with disabilities have frequently reported not being weighed during their pregnancy.^{8,17} In interviews with ten women with cerebral palsy (CP), mobility related to walking, balance, and/or transfers worsened in 13 of 16 pregnancies in their third trimester.¹⁸ Therefore, accessible exam rooms become more important as the pregnancy progresses.

Health care providers often lack knowledge and experience in treating women with disabilities.^{8,17,19} There appears to be a general perception that physical disabilities are associated with pregnancy complications and poor outcomes. For example, women with physical disabilities who lack high risk medical conditions are commonly referred to maternal-fetal medicine physicians.^{9,10,18,20} Additionally, women with physical disabilities appear to have an increased frequency of Cesarean births (C-sections).⁹ The few existing studies of women with CP, however, indicate positive pregnancy outcomes. There were no significant differences in the number or type of pregnancy complications or delivery complications compared to nondisabled controls.²¹ In a separate study of 38 pregnancies of women with CP, 27 were live births, 10 terminated (8 = induced abortion, 2 = spontaneous abortion), and 1 was stillborn.²² Rogers found that 16 of 18 pregnancies resulted in live births; two were miscarriages.¹⁸ Approximately one-third of these deliveries were C-sections.^{18,22}

The pregnancy and postnatal experiences of women with CP can be enhanced through access to services including physical and occupational therapy. Women with CP have reported mobility losses during pregnancy.¹⁸ Additionally, they may be at risk for falls due to impaired balance and coordination that are exacerbated by changes in center of gravity as their pregnancy progresses.^{10,18} Physical therapists (PTs) can help women improve or maintain strength and balance¹⁷ and can recommend assistive devices (walker, wheelchair) for use during periods of reduced mobility.⁹ Additionally, occupational therapists (OTs) can link new mothers with disabilities with accessible baby equipment and other parenting resources.^{8,17–19}

Another service important for all mothers is postpartum depression screening and counseling. Risk factors for postpartum depression include, but are not limited to a history of depression, difficulty breastfeeding, stress, and a weak support system.²³ A study performed in the Netherlands found a significantly higher prevalence of depressive symptoms in adults with CP, age 25–45 years, as compared to the general population (25% versus 12%, respectively).²⁴ Women with CP may be particularly vulnerable for postpartum depression given this increased risk and the additional stress associated with parenting with a disability.

This study is part of a larger, multi-site project to identify the barriers that women with CP face in accessing women's health care. This paper focuses specifically on the reproductive life planning and pregnancy outcomes of women with CP. The pregnancy rate of women with CP is unknown and there is little research about pregnancy and neonatal outcomes in this population. We imagined that women with CP, like other women with physical disabilities, would encounter biases in their efforts to become parents. Specifically, we hypothesized that discussions about desire for children and pregnancy rates of women with CP would be related to their functional and cognitive level.

Methods

Participants were included in this study if they were diagnosed

with CP and were ≥ 18 years of age. CP describes a group of permanent disorders of the development of movement and posture, that can be associated with cognitive and communication difficulties, due to non-progressive disturbances that occurred in the developing fetal or infant brain.²⁵ Participants were recruited from CP Centers and clinics at four large university-based medical institutions. In addition, flyers were distributed to CP organizations. Efforts were made to include individuals with significant physical and communication difficulties through outreach to nurses serving individuals with CP in the community. Caregivers were invited to complete the survey as proxies for women who were unable to participate due to their inability to comprehend the questions. This allowed their needs to be addressed in the survey. The study was approved by the Human Subject Protection Committees from participating sites. Potential participants were sent an email with a link to the survey and study information sheet using a secure server. Alternatively, women could choose to participate via paper survey or telephone. Survey data were collected over a one-year period.

Participant survey

As no formal questionnaire existed, an online 52 question survey was developed. The survey was estimated to take 10–15 min to complete. In addition to demographic questions, the survey included four sections related to each institution's area of focus: transition and adolescent sexual health, gynecological care, mammography, and reproductive health and pregnancy. Survey questions relevant to this paper queried demographic information, educational level, employment, income, functional abilities, pregnancies, childbirth, and service referrals.

Individuals with CP may have difficulty with physical and communication functions; therefore, they were asked to rate their ability in these areas. Existing measures developed for CP were used to rate mobility and manual dexterity. The Gross Motor Function Classification System (GMFCS) Expanded and Revised version²⁶ was used to describe mobility: I) walk independently and use stairs without a railing; II) walk independently and have difficulties on uneven surfaces, stairs, or in crowds; III) walk using an aid (e.g. walker or crutches) but may use a wheelchair for distances or to travel faster; IV) use a power chair for self-mobility, significant support for walking; and V) difficulty sitting independently and controlling head and trunk posture.²⁶ The Manual Ability Classification System (MACS)²⁷ was used to describe arm and hand function: I) handle objects easily and successfully; II) handle most objects but with somewhat reduced quality and/or speed; III) handle objects with difficulty; need help to prepare and/or modify activities; IV) handle a limited selection of easily managed objects in adapted situations; and V) do not handle objects and have severely limited ability to perform even simple actions. A 6-point scale developed by the investigators was used to evaluate expressive communication skills: 1) no difficulty speaking; 2) speak with minor limitations; 3) speak with some difficulty, speech may be slow or somewhat difficult to understand by a new listener; 4) speak with very significant difficulty, speech may be slow or very difficult to understand by a new listener; 5) communicate using adapted techniques such as signing or an augmentative communication device; and 6) communication is severely limited even with the use of an augmentative technology. A 5-point scale developed by the investigators was used to rate the ability to understand speech: 1) no trouble understanding conversation; 2) mild difficulty understanding conversation; 3) understand my name and short sentences, but have difficulty understanding conversations; 4) can respond to voice but unable to understand speech; and 5) unresponsive to voice and unable to understand

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