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Effects of Disability on Pregnancy Experiences Among Women with Impaired Mobility

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Abstract

Objective—Little is known about how functional impairments might affect the pregnancies of women with mobility disability. We aimed to explore complications that arise during pregnancy specifically related to physical functional impairments of women with significant mobility disabilities.

Design—Qualitative descriptive analysis

Setting—Telephone interviews with women from 17 USA states

Sample—22 women with significant mobility difficulties who had delivered babies within the prior 10 years; most participants were recruited through social networks.

Methods—We conducted 2-hour, in-depth telephone interviews using a semi-structured, open-ended interview protocol. We used NVivo software to sort interview transcript texts for conventional content analyses.

Main outcome measures—Functional impairment-related complications during pregnancy.

Results—The women's mean (standard deviation) age was 34.8 (5.3) years. Most were white, well-educated, and higher income; 8 women had spinal cord injuries, 4 cerebral palsy, and 10 had other conditions; 18 used wheeled mobility aids; and 14 had cesarean deliveries (8 elective). Impairment-related complications during pregnancy included: falls; urinary tract and bladder problems; wheelchair fit and stability problems that reduced mobility and compromised safety; significant shortness of breath, sometimes requiring respiratory support; increased spasticity; bowel management difficulties; and skin integrity problems (this was rare, but multiple women greatly increased skin monitoring during pregnancy to prevent pressure ulcers).

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Conflicts of Interests

The authors have no financial conflicts to report.

Conclusions—In addition to other pregnancy-associated health risks, women with mobility disabilities appear to experience problems relating to their functional impairments. Pre-conception planning and in-depth discussions during early pregnancy could potentially assist women with mobility disabilities to anticipate and address these difficulties.

Keywords

Pregnancy; disability; functional impairment; impaired mobility; wheelchair; falls; spasticity; respiratory support; pressure ulcers

Introduction

Increasing numbers of women with significant mobility disability are choosing to become pregnant. This represents a substantial shift from prior millennia – most notably from the early 20th century roiled by the eugenics movement – when these women were generally viewed as asexual or unfit to become mothers (1,2). Changing social mores, enactment of disability civil rights laws, and scientific advances in medical care for mothers and newborns have contributed to these shifts (3–6). Epidemiologic studies suggest that, after accounting for their older ages and other sociodemographic factors, even women with significant mobility disabilities are currently pregnant at the same rate as nondisabled women (7). An estimated 145,000 civilian, noninstitutionalized USA women with severe mobility disabilities are pregnant at some point every year (7).

A small but growing body of literature documents pregnancy experiences of women with specific disabling conditions, such as spinal cord injury (8–12), spina bifida (13–15), and cerebral palsy (16,17). These publications typically use case series, questionnaires, chart reviews, or clinical judgment to describe how physiological aspects of women's underlying health conditions affect pregnancies (3–6,18). Less is known about how women's functional impairments – defined by the World Health Organization as “problems in body function or structure such as a significant deviation or loss” (19) – are affected by or affect their pregnancies. Although diverse conditions cause mobility disability (20), the nature or consequences of the physical functional impairments is often similar.

Given the relative paucity of evidence on this topic, we used descriptive qualitative analysis methods to gather preliminary information about how women's functional impairments complicate – or are complicated by – their pregnancies. With this exploratory goal, we asked women with mobility disability wide-ranging, open-ended questions about their pregnancy experiences and used their reports to identify impairment-related complications. We did not review medical records or directly assess causality, and future research will need to characterize and quantify these complications. However, the reported concerns are all clinically plausible and make anatomical and physiological “sense” (i.e. have good “face validity”). Understanding and anticipating these complications could assist clinicians to provide better care to women with mobility disability during their pregnancies.

Material and methods

The Massachusetts General Hospital (MGH)/Partners HealthCare Institutional Review Board (IRB) approved this research. The IRB treated women's agreeing to be interviewed after being told about the interview process and protections as implied informed consent.

To qualify for our study, women at the time they became pregnant must have used an ambulation aid (cane, crutches, walker) or wheeled mobility aid (manual or power wheelchair or scooter) or have had significant difficulties using their arms or hands. They must also have delivered their youngest child within the past 10 years. We aimed initially to recruit 20 participants, generally considered a sufficient number to reach thematic saturation.

Original plans to recruit from MGH obstetrical patients and local disability community groups identified only 2 participants. We obtained the IRB's permission to recruit participants beyond metropolitan Boston through networks of women with disabilities. Within several days of posting an IRB-approved flyer on social media (Facebook groups), 45 women from around the country contacted the project office seeking participation. We screened 27 women by telephone on a first-come-first-serve basis; 24 met inclusion criteria, and we scheduled 21 for interviews. One subsequently declined participation, saying she was too busy with childcare. The final sample of 22 women includes 2 from local sources and 20 from the nationwide social network.

Interview protocol and procedures

We designed a semi-structured, open-ended interview protocol for this study, drawing upon available literature and our prior research findings (18,21,22). The protocol (available upon request) covers 8 broad topics, including pregnancy, labor, and delivery experiences. After obtaining verbal informed consent, L.I.I. conducted all 22 telephone interviews, which averaged roughly two hours and occurred from October 2, 2013 to December 16, 2013. Participants received a \$50 gift card. A professional transcription service typed transcripts verbatim from the digital interview audio recordings. All names are pseudonyms.

Data analysis

Qualitative descriptive analyses provide summaries of experiences or events. These analyses adhere closely to the data and do not over-interpret what these experiences or events mean to the study participants (23,24). For this particular descriptive qualitative analysis, topic areas were straightforward, representing major problems mentioned by women (such as falls, bladder problems, breathing problems, and mobility aid difficulties). The researchers agreed upon basic topic areas for coding the texts by multiple readings of the interview transcripts and group discussion. A.J.W. used NVivo 10 (QSR International) qualitative analysis software to sort the transcript texts. Using conventional content analysis (25), the investigators independently reviewed the sorted texts within topic areas to identify major themes relating to these pregnancy complications, reaching consensus on themes through discussion. We selected quotations that exemplify each topic.

In the presentation below, we list the numbers of participants reporting particular complications. We recognize that our sample is not representative and these numbers are not

meant to imply the population prevalence of these problems. We provide these numbers simply to indicate clearly the frequency of these problems within our sample (i.e. rather than relying on general terms such as “many,” “a few,” or “several”).

Results

Table 1 presents characteristics of the 22 interviews. Most were white, non-Hispanic, and well-educated; during their most recent pregnancy, half had Medicaid health insurance (program for individuals with incomes below the federal poverty level); and they came from 17 states nationwide. Sixteen of the 22 women had at least one child age three or younger. Eight women had spinal cord injuries, four had cerebral palsy, and 10 had other conditions. Eighteen used wheeled mobility aids. Although this study is not about common complications of pregnancy among all women, we asked women about these problems. Four women had gestational diabetes, one developed eclampsia, and three reported pre-eclampsia, two with questionable diagnoses (Table 1). Fourteen women had cesarean deliveries; eight were elective.

Table 2 summarizes the seven complications women reported that appeared to be related to their mobility disabilities. We include conditions that commonly accompany significantly impaired mobility: breathing, urinary tract, and bowel difficulties (5,26). Although only one woman reported skin integrity problems, we include it because many other women explicitly heightened their vigilance for pressure ulcer detection during their pregnancies. A supplementary table, available on the journal’s website, presents selected quotations from women describing experiences with each condition.

Ten women reported falls during their pregnancies; two broke arms and several required monitoring by physicians. Weight gain and changes in the center of gravity as pregnancy advanced contributed to falls, which occurred: as women transferred into and out of wheelchairs; when women who still ambulated tripped and could not prevent the fall; and when their wheelchair tipped on uneven pavement and women late in pregnancy could not keep themselves from falling to the ground. Many falls were likely preventable as women tripped over younger children, pets, or items scattered around their households. Some women became so afraid of falling during pregnancy that they changed their behaviors, such as starting routinely to use transfer boards (a narrow board women slide across while transferring between two surfaces) or limiting their activities.

Many conditions, such as spinal cord injury (SCI), that cause movement disability also affect bladder function. Women learn over time how to manage voiding, with some requiring self-catheterization or indwelling urinary catheter devices. Ten women reported increased problems with bladder management during their pregnancies well beyond the frequent urination experienced by most pregnant women. Problems included: difficulties “straight cathing” the bladder because the gravid uterus blocked access to the urethra; indwelling Foley catheters and other techniques, such as the mitrofanoff method, failing to drain the bladder; almost continual incontinence; and repeated urinary tract infections (UTIs), sometimes requiring hospitalization. Some women confused incontinence with their

water breaking, leading to unnecessary hospital visits. One woman with a SCI T5 reported that pain “like an autonomic dysreflexia headache” heralded her frequent UTIs.

Seven women reported difficulties with wheelchair fit, maneuverability, or stability. These problems affected women by: reducing their mobility; increasing their risks of wheelchair tipping, expelling the woman and causing injurious falls; difficulties transferring from one surface to another, heightening falling risks; and problems with fit, which could produce pressure ulcers at vulnerable pressure points. The supplementary table describes the practical consequences of these difficulties. Although some problems should be easily solved with a new wheelchair, interviewees described substantial delays and difficulties obtaining new mobility aids or modifying existing equipment because of USA insurance payment policies and delivery system complexities. One woman with Charcot-Marie-Tooth disease started trying to get a wheelchair when she became pregnant but only received the equipment after her daughter was born.

Breathing difficulties accompany many movement disabilities, with a variety of causes including: anatomic limitations compromising the ability to fully inflate lungs; musculoskeletal problems relating to muscle strength and skeletal structures; and neurological factors affecting respiratory function. Many women reported shortness of breath during their pregnancy, which was bothersome but relatively easily handled. However, four women (two with SCI, one with congenital myasthenia, one with muscular dystrophy) reported significant problems, sometimes requiring mechanical ventilatory support. The woman with congenital myasthenia, for example, was already using a ventilator nightly while sleeping but when pregnant used it throughout the entire day. She was hospitalized three weeks prior to delivery because of concerns both about breathing and significant swallowing difficulties, which increased aspiration risks.

Cerebral palsy, SCI, and other neurologic conditions are often complicated by spasticity, but the three interviewees who reported significant spasticity problems during pregnancy all have cerebral palsy. These women said their spasticity increased dramatically during pregnancy, sometimes causing tripping and falls, and they started using new mobility aids or stayed in bed to prevent injuries from spasticity-related falls (see supplemental table). Several women with other disabling conditions worried that baclofen, a common anti-spasmodic drug, could affect their fetus. One woman with SCI rejected the baclofen pump recommended by her physician and used exercise and acupuncture to manage increasing spasticity before becoming pregnant. A woman with spina bifida continued taking baclofen during her pregnancy, convinced that “the benefit outweighed the risk.”

Limited bodily movement and disorders causing mobility disability frequently compromise bowel function. In particular, bowel management for persons with SCI requires constant attention and is highly individualized (27,28). SCI level determines the bowel motility pattern, either: reflexive bowel (injury generally above T12), where persons cannot control the exact timing of bowel movements; or flaccid bowel (injury below T12), where bowels do not move independently and stool is often removed manually. Persons with a reflexive bowel generally manage bowel movement timing with suppositories, mini-enemas, and/or digital stimulation of the rectum. Persons with flaccid bowels may need to empty their

bowels more than once daily, using digital stimulation and manual disimpaction. Diet, fluid consumption, and products such as stool softeners help control bowel function. Applying external pressure to the abdomen assists some persons in moving stool. Rarely, in persons with high SCIs, problems such as constipation can trigger autonomic dysreflexia, with dangerously elevated blood pressures often preceded by severe headache.

Three interviewees with SCI noted substantial difficulties with bowel management (Table 2 and supplementary table). Their gravid uteruses complicated efforts to exert external pressure and other physical maneuvers they used to evacuate stool. One woman reported having worried at one point that constipation was about to trigger autonomic dysreflexia.

Persons who sit virtually all waking hours and especially those with difficulties moving in bed confront risks of developing pressure ulcers, most commonly over ischial and sacral areas. Pregnancy heightens these risks, as expected weight gains exert additional pressure on vulnerable sites. Interviewees, particularly women with SCI, seemed well aware of these risks and took steps to avoid ulcer development and ensure early detection. Only one woman, born missing all four limbs, developed a pressure ulcer, which she detected early and treated without difficulty. Women reported strategies to avoid pressure ulcers, including: heightened monitoring of vulnerable areas; changing seat cushions to reduce pressure; performing pressure relief maneuvers more often, by slightly elevating the body briefly or shifting seated position; and using tilt and leg elevation features available on high-tech power wheelchairs.

Discussion

Interviews with 22 women with significant mobility disabilities who had delivered babies within the prior 10 years identified complications during pregnancy that appeared to be related to their underlying functional impairments. Women without mobility disability often experience certain similar problems during pregnancy: shortness of breath, urinary tract difficulties (urinary frequency, UTIs), and bowel management problems. However, drawing from clinical experience, the nature and morbidity of these difficulties reported by the women with mobility disabilities likely differ substantially from the experiences of nondisabled pregnant women. Our research design prevents us from explicitly determining causality or frequency of these difficulties or comparing pregnancy experiences of women with versus without mobility disabilities. Nonetheless, the seven broad types of problems identified by the 22 interviewees seem clinically plausible and consistent with physiological and anatomical considerations, lending face validity to these findings.

Given limited scientific evidence about how functional impairments affect pregnancy, our qualitative study has important strengths. Descriptive qualitative analysis is an excellent method for exploring events or experiences and providing useful insights (23,24). Our conventional content analysis approach adheres closely to the data (25). Qualitative studies can inform speculation about why observed events occur, especially in complicated contexts.

A small but growing literature describes pregnancy experiences among women with specific disabling conditions and women with disabilities more generally (3–6,8–17). Typically, this literature relies upon case series, medical record reviews, questionnaires, or the authors' clinical experience to describe how disability affects pregnancy. These publications provide important information for clinicians caring for pregnant women with these disabilities. Nonetheless, when studies derive from data gathered by clinicians and documented in charts, they may miss aspects of pregnancy experiences that are not addressed in standard history taking and that women with mobility disability do not mention to their clinicians, such as wheelchair problems. Such studies also typically do not reflect the woman's perspective or consider activities of daily living performance, which might critically affect pregnancy outcomes.

Our study identified seven broad concerns that make “clinical sense” and therefore merit consideration when caring for pregnant women with significant mobility disabilities. Some issues, such as wheelchair technologies and ventilation management, are clearly outside the expertise of typical obstetricians. Other concerns, such as urinary tract problems, are common among all pregnant women but can raise specific difficulties for women with mobility disability. This highlights potential benefits of interprofessional teams in caring for disabled women during pregnancy (3), including specialist physicians, nurses expert in urinary tract instrumentation and bowel management, and rehabilitation therapists.

Preconception planning with interprofessional teams can assist both women and their clinicians to anticipate needs and marshal resources to meet those concerns. Standard clinical issues will need attention, such as evaluating women's medications and determining whether changes are necessary prior to conception. Altering medication regimens may significantly affect some woman's physical functioning and compromise her ability to perform daily activities during pregnancy. Rehabilitation therapists can help anticipate these problems and find possible solutions, such as methods for safe transfers with advancing gestation. Home visits by occupational therapists could identify environmental safety risks that should be mitigated before pregnancy. Women who require new wheelchairs or mobility devices should initiate efforts to obtain this equipment far in advance. Requirements for obtaining mobility technologies vary across countries; clinicians caring for these women should learn about acquisition requirements and what clinicians must do to advocate for their patients.

Our study shares limitations of other qualitative interview studies with small, non-generalizable samples, in our case recruited through social networks. Researchers are increasingly using social networks to recruit research participants, especially persons with relatively rare conditions (29,30). Although we aimed to enroll racially and ethnically diverse women, the vast majority of our participants were white; furthermore, all interviews were conducted in English. We did not validate women's assertions about their conditions or experiences. Nevertheless, the consistency and authenticity of women's reports throughout the two-hour interviews suggests the interview data accurately represent the women's “lived experiences.” For several interviewees, nine or 10 years had passed since their pregnancy, but 16 women had had their youngest child within the prior three years, suggesting that pregnancy memories were relatively fresh. Although we present numbers of women

reporting specific complications, we provide these numbers only for clarity about the interviewees' experiences; these figures do not represent the population prevalence of these conditions.

Finally, we could not explicitly determine causality of the problems women described. However, their detailed descriptions gave considerable insight into likely explanations, and some causes seemed clear cut. For instance, changes in the center of gravity and women's physical inability to compensate for these shifts in later pregnancy almost certainly contribute to falls, especially during transfers and from tipping wheelchairs.

More research will need to characterize further and quantify pregnancy complications relating to functional impairments among women with mobility disability. However, even without additional generalizable information, our study suggests clinically plausible factors that obstetricians should consider when caring for pregnant women with mobility disabilities, including fall risks, urinary tract and bladder problems, wheelchair fit and stability concerns, significant shortness of breath, increased spasticity, bowel management difficulties, and concerns about skin integrity. Ideally, working with interprofessional clinical teams prior to pregnancy could assist these women in anticipating their needs during pregnancy and help ensure good outcomes. Although today about 145,000 USA women with severe mobility disability are currently pregnant at least some time during the year (7), epidemiologic trends suggest this number will rise in coming decades. Obstetricians should expect to see women with mobility disability in their practices and be prepared to offer them high-quality care, informed by the experiences of other women with mobility impairments who have successfully given birth.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Abbreviations

MGH	Massachusetts General Hospital
IRB	Institutional Review Board
SCI	spinal cord injury
T followed by number	thoracic vertebra level (for example, T5 indicates fifth thoracic vertebra)
UTI	urinary tract infection

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Key Message

Pregnant women with significant mobility disabilities report complications relating to their functional impairments, including falls, significant urinary tract and breathing problems, and difficulties safely operating wheelchairs. Addressing these issues during pre-pregnancy counseling and prenatal care may assist women with mobility disabilities to better anticipate potential complications and improve their pregnancy experiences and outcomes.

Table 1**Participant Characteristics and Pregnancy Outcomes**

Characteristics and pregnancy outcomes	n
Age in years at time of interview (mean, standard deviation)	34.8 (5.3)
Age category at time of interview	
25–29 years old	1
30–34 years old	13
35–39 years old	4
40–49 years old	4
White race ^a	20
Hispanic ethnicity	2
Geographic region at time of birth ^b	
Northeast	7
Midwest	7
South	5
West	3
Number of children	
One	16
Two	4
Three	2
Condition causing disability	
Cerebral palsy	4
Spinal cord injury	8
Other condition ^c	9
More than one condition ^d	1
Mobility aid(s) or other assistive technology used at time of most recent pregnancy ^e	
Cane or crutches	4
Walker	2
Manual wheelchair ^f	12
Scooter	1
Power wheelchair	5
Leg braces or ankle-foot-orthotic	2
Gestational diabetes	4
Eclampsia	1
Pre-eclampsia ^g	3
Cesarean delivery	14
Elective cesarean delivery	8
Nonelective cesarean delivery	6

^aBlack = 1; Native American = 1

^bStates include: Arizona, Georgia, Illinois, Maine, Massachusetts, Minnesota, Missouri, New Hampshire, New Jersey, New Mexico, North Carolina, Ohio, Oklahoma, Rhode Island, South Carolina, Texas, and Utah.

^cArthrogryposis (2 women); Charcot-Marie-Tooth (1); congenital myasthenia (1); missing all four limbs, congenital (1); multiple bone injuries from car crash many years ago (1); NARP (neuropathy, ataxia, and retinitis pigmentosa) (1); osteogenesis imperfecta (1); spina bifida (1)

^dIncomplete spinal cord injury and mitochondrial disease

^eAll women used at least one mobility aid or assistive technology, and some used different aids in different settings; some women started using mobility aids during their pregnancy and continued use post-partum

^fTwo women used a manual wheelchair with power assist

^gClinicians disagreed about one woman's pre-eclampsia diagnosis; one woman mentioned only high blood pressure that led to early delivery

n = 22

Table 2**Disability-Related Complications During Pregnancy**

Complications	N ^a	Description
Falls	10	Tripping and not being able to recover balance, falls during transfers, falls when wheelchair tipped; two women broke arms during falls and several were monitored by obstetricians after falls
Urinary tract and bladder problems	10	Difficulties emptying bladder, problems positioning catheter during straight cathing, recurrent urinary tract infections, difficulties draining bladder through indwelling catheters and other approaches, almost continual incontinence, and recurrent urinary tract infections
Wheelchair fit and stability	7	Difficulties self-propelling manual wheelchair, no longer fitting comfortably into wheelchair, increased risks of tipping or other difficulties as pregnancy advanced
Shortness of breath	4	Significant shortness of breath increasing during pregnancy and sometimes requiring more continuous use of ventilator or intermittent positive pressure ventilation
Increased spasticity	3	CP: increased spasticity during pregnancy, resulting in frequent falls
Bowel management problems	3	SCI: disruptions in bowel management, sometimes raising threats of autonomic hyperreflexia
Skin integrity	1	Stage 2 pressure ulcer. Other women increased skin inspections, increased efforts to relieve pressure on ischial tuberosities and other pressure points

CP = cerebral palsy; SCI = spinal cord injury

^aWe present these number to clearly reflect the reports from the 22 interviewees; these numbers are not intended to represent population prevalence of these conditions.

N = 22