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Obstetric Clinicians' Experiences and Educational Preparation for Caring for Pregnant Women with Physical Disabilities: A Qualitative Study

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Abstract

Background—Women with physical disabilities (WPD) experience major barriers to care during pregnancy. Lack of education about disability in health professionals' education is a pervasive barrier to quality care. In an effort to explore this issue, this study examined the issue from the perspective of obstetric clinicians who provide care to WPD.

Objective—This qualitative descriptive study explored perspectives of obstetric clinicians who provide perinatal care for WPD to inform the educational preparation of clinicians to care for women with disabilities.

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A brief report of the study described in this manuscript will be presented in a poster session at the November 2017 American Public Health Association conference

Method—We contacted 33 obstetric clinicians who care for pregnant WPD. Thirteen obstetricians and one nurse midwife participated in semi-structured telephone interviews. Interview transcriptions were content analyzed to identify initial themes. Investigators discussed and revised the themes as additional transcripts were reviewed and new themes were identified.

Results—Themes identified from transcript analyses included: lack of education at any level including during postgraduate residency and fellowship on care of pregnant WPD, unplanned career pathway, educating other clinicians, and positive and negative experiences providing obstetrical care to women with physical disability. Several clinicians provided this care because of requests from other clinicians and did not begin their careers with the goal of providing obstetric care to women with physical disabilities. None had received formal education or training including during their residencies or fellowships. The clinicians described very rewarding experiences caring for WPD.

Conclusions—The experiences reported by this study's participants suggest the need to include disability in undergraduate and postgraduate education and training to improve obstetric care to WPD.

Although the Americans with Disabilities Act was passed in 1990, individuals with disabilities continue to report difficulty obtaining quality health care[1–2], including perinatal care.[3–8] A growing body of research has documented unmet needs among pregnant women with disabilities, negative attitudes, bias, and stereotyping by clinicians toward them and their pregnancy, clinicians' lack of knowledge about their perinatal health care needs, and failure to consider women's expertise about their disability.[3–8] A recent study indicated that among all sub-specialties, gynecology was least likely to accept women with physical disabilities (WPD) as patients.[9] Failure of subspecialties to accommodate WPD during pregnancy is likely to increase the risk of poor outcomes,[10] including maternal complications, low birth weight and preterm birth,[11–15] heightening the need for quality care for them.

Background

Multiple calls have been issued to reduce health disparities affecting persons with disabilities by improving the knowledge, skills and attitudes of health care professionals,[16–22] through education and training.[23–26] Responses to these calls have been sporadic at best. Although many WPD have recounted negative obstetrical experiences,[3–8] some women have reported positive experiences from which clinicians could learn.[6]

This study was conducted to describe clinicians' experiences in providing perinatal care to WPD. To capture clinicians' descriptions of those experiences, we asked clinicians who provide such care to WPD about their professional pathway, the education and training they received to prepare them for providing care to WPD, and memorable experiences the clinicians experienced in providing such care. It is anticipated that the study's findings could be useful to guide the preparation of obstetrical clinicians to provide quality care to pregnant WPD.

Methods

Procedures

A qualitative study, designed to describe rather than quantify experiences from the perspective of study participants,[27–29] explored the experiences of obstetrical clinicians and their preparation to care for WPD. Quantitative approaches would preclude follow-up questions about clinicians' experiences reported via survey. Further, because this topic has not been studied in any depth, a qualitative approach with data obtained through interview was indicated to obtain information directly from participants with potential to guide future quantitative studies. A qualitative descriptive approach was appropriate because our intent was to capture descriptions of the participants about issues of interest to clinicians without over-interpretation of data.[27–29] This is part of a mixed-method study that examined unmet needs of WPD.[30–31] The Institutional Review Boards of Brandeis University, University of Massachusetts Medical School and Villanova University approved the study.

We conducted telephone interviews with obstetrical clinicians with experience caring for pregnant WPD. To identify candidates, we approached disability-related organizations, the American Congress of Obstetrics and Gynecology (ACOG), and the American College of Nurse Midwives; we also reviewed relevant publications and clinicians' online professional profiles indicating work with women with disabilities. Once identified, clinicians were contacted and invited to participate in interviews. We identified 33 potential interviewees. We were unable to reach 16 candidates; 3 did not have the requisite experience; and 14 agreed to participate. To be eligible to participate, clinicians had to have provided perinatal care to women with mobility disabilities.

The study coordinator confirmed clinicians' eligibility, reviewed informed consent, and scheduled interviews, which occurred between February and April of 2015. We interviewed 14 of 33 clinicians identified. One investigator (author #1), a health care clinician with doctoral preparation and experience conducting qualitative interviews, conducted all 14 interviews. The interviews averaged 45 minutes in length. A semi-structured interview guide addressed clinicians' perspectives on barriers for WPD and for clinicians providing perinatal and childbirth care for them, and strategies they would recommend to others caring for WPD during pregnancy. This report focuses specifically on clinicians' education, practice and experience related to caring for WPD during pregnancy. Following verbal informed consent, the interviewer again explained the purpose of the study and asked about each participant's practice, education or training to care for WPD, and experiences in providing perinatal care to WPD. When interviewed, the clinicians were in their offices. Interviews were audio-recorded and professionally transcribed. No transcript or summary of the results was sent to the participants for their correction or comment.

Traditional content analysis[32] was used to analyze transcripts from the 14 interviews. Four members of the research team reviewed several interview transcripts independently and then discussed them to generate initial topics related to the study's purpose. Additional topics were identified as other interview transcripts were reviewed. Codes were developed for the topics and revised repeatedly; one member of the research team used Atlas.ti version 7, in collaboration with the principal investigator to code the remaining transcripts and identify

themes. All researchers reviewed transcripts using the final themes to verify the accuracy of coding and to establish trustworthiness of the findings.

Sample

The specialties of the 14 clinicians interviewed included obstetrics/gynecology, maternal-fetal medicine (MFM), nurse midwifery, and medical genetics. All but two clinicians were male. One clinician was a nurse midwife; the remaining were obstetricians with seven identifying subspecialties (i.e., genetics or maternal-fetal medicine). Clinicians cared for pregnant WPD for an average of 22 years, ranging from 6 to 40 years, with the number of women ranging from five or more WPD per month to only several per year. The clinicians practiced in hospitals, university practices, solo practices, and specialty clinics for women with disabilities. The women had diverse physical disabilities: multiple sclerosis, muscular dystrophy, cerebral palsy, spinal cord injury, amputation, and dwarfism, and others. All 14 clinicians, from 9 states across the country, have provided care for WPD in their practices, although several currently do not.

Results

The themes identified through data analysis include: 1) pathway to providing perinatal care for women with disabilities with three subthemes, and 2) clinicians' experiences in providing perinatal care to WPD with two subthemes. Salient comments from the clinicians related to these themes and subthemes are provided below and in Table 1.

Pathway to Providing Perinatal Care for Women with Disabilities

Three subthemes related to the theme of becoming a provider of perinatal care for WPD were identified: unplanned career pathway, lack of formal training in perinatal care for WPD, and educating other obstetric clinicians.

Unplanned Career Pathway—None of the clinicians began their careers intending to provide care for WPD. Several reported that once in obstetric practice, they were asked by a colleague, neighbor or spouse from another area of practice to provide obstetrical care to that clinician's patient population. One became involved in providing care for WPD because of a friend: "I got started about 25 years ago, when a friend…a researcher in MS…came up to me one day and grabbed me by the arm and said, 'You are now going to become a specialist in MS.' So I kind of fell into this."

In several cases, clinicians followed in the footsteps of practice partners who cared for patients with disabilities because of personal interest or professional obligation ("the right thing to do"). One indicated that when his department head learned that he was seeing patients with disabilities and patients on ventilators, he decided that the practice should market this fact. Subsequently, a small clinic group was created, he received funding and has continued this focus in his practice ever since.

Another clinician indicated that proximity to a school for the Deaf and the interest of a practice partner in caring for hearing-impaired individuals resulted in attracting women with other disabilities to the practice. He searched the literature and discovered little information

available to guide care. He stated, “the topic was ripe for the pickings…there was a knowledge deficit and a population that desperately needed informed and concerned providers.”

Other clinicians indicated that it was an expectation in their practice setting that they provide care to this population. One stated, “My former partners, who are now all retired, had been forward-thinking 40 years ago…they had gone to an ACOG meeting and saw an electric examination table that rose and fell as needed.” He provided care to WPD for many years, lectured others on the topic, and joined an advisory board that included women with disabilities. Another clinician stated that the birth center where she practiced accommodated wheelchairs. She explained that women from group homes who received care at the birth center did not have “friendly places” to go for care and their experiences were often very traumatic. The center director, dedicated to the care of women with disabilities, decided to provide gynecologic and perinatal care in a comfortable home-like setting. When clinicians joined the birth center staff, they received an orientation to perinatal care to WPD.

Lack of Formal Education and Training—The second subtheme was lack of formal education and training for the role. None of the 14 clinicians received training about caring for women with disabilities when they were students, residents, or fellows. All clinicians learned on the job, including those whose specialty was maternal-fetal medicine (MFM). One MFM clinician stated that MFM clinicians become experts by default. He indicated that if obstetricians or midwives have no experience with patients’ underlying disability, they usually refer those patients to MFM, “so by default you become the expert.” He added: “I can’t say that during my fellowship I had any specific training in it. It’s mostly on-the-job training.” Another MFM clinician stated, “Well…the MFM subspecialty probably spends more time thinking about that than a general obstetrician. And since many disabilities affect how pregnancy progresses…that’s why this subspecialty has a little bit more experience.”

One obstetrician stated, “I did not have formal training beforehand, but I had an active interest in the topic, so I was seeking literature and reading whatever I could…I was teaching myself.” Another referred to the dearth of literature on the topic: “And I started to realize that there was no literature…to guide us when we were seeing people with a variety of disabilities and looking at reproductive health care.” Another clinician learned about caring for pregnant WPD from his patients and by listening to them stating: “I’ve been very grateful because I learned to talk with my patients. I remember one patient…with spinal cord injury…she taught me a lot on how to care for people like her.”

Educating Other Clinicians—The third subtheme is educating other clinicians to ensure that other clinicians will be better prepared to care for pregnant WPD. Clinicians assumed the role of teacher and provided lectures to other clinicians to increase their knowledge, awareness and sensitivity about the topic. Their lectures were based on what they had learned from their patients and through providing care to women with disabilities.

One clinician arranged to spend one day each week on the issue because he convinced the director of his practice that programs such as the one at his institution are needed across the country. He planned to seek funding to support his effort. All clinicians interviewed

indicated that formal education or training to care for WPD is warranted and would be very useful. One of the clinicians noted, “It would be really great if during fellowship there was something, or even during residency there was some sort of…educational tool to…kind of help us out.”

Clinicians’ Experiences Providing Care to Women with Disabilities

The second overall theme refers to clinicians’ experiences of providing care to WPD during pregnancy. In order to describe the care provided by these clinicians to WPD during pregnancy, we asked about memorable positive and negative experiences caring for these women.

Clinicians’ Positive Experiences—Without further prompting, six clinicians immediately identified how rewarding their experiences were caring for WPD. Several identified this role as the ultimate care a physician can provide. One stated: “I’m always reminded on a personal note about my most rewarding (role) as a physician and the word physician, not doctor, not healthcare provider, not caregiver, but truly as a physician. I’ve been delivering cord-injured patients who were told all the negative things and now they have…not one, but sometimes…two or three (children)…and they deliver vaginally.”

Another clinician explained that when he gives lectures about caring for WPD, he explains “how easy it is to do and how gratifying it is. Yes, there are some challenges…but the rewards far exceed the effort. We talk about how gratifying it is to get involved with these people, and how appreciative they are…and if you…really take your role as a physician healer seriously.”

The sense that providing care to women with disability during pregnancy is not only rewarding but also the moral thing to do was identified by several clinicians. One stated, “You don’t get paid any extra. You do this because it’s the right thing to do and you want to do it and you love to do it and the patients appreciate it. And that’s why you do it. You don’t do it for money. It’s a money loser. No insurance company…commercial, state, or federal… is going to pay me more.” Another stated, “My most rewarding experiences have been with patients (with) disabilities who get pregnant and deliver. Part of that is they were told…the usual stereotypes…they don’t have sex, can’t have sex, can’t get pregnant, and if they get pregnant they should abort. All of which is usually not true.” One clinician indicated that his experiences were, “not very different than caring for anybody else. The pleasure of working with women with disabilities was that they’re just like everybody else.”

Clinicians’ Negative Experiences—The clinicians did not identify negative experiences related specially to the women themselves; rather, any negative experiences were frustrations related to “systems issues, such as lack of information and continuity from other providers”. In response to the question about negative experiences, one clinician explained that there is an intellectual component associated with caring for women with disabilities because, “you’re responsible for these people.” He described the stress of taking care of patients in a high-risk situation, but added, “but it’s all part of medicine, you know.”

In describing the inclination of some clinicians to consider all WPD to be high risk, one clinician summarized it this way: “Actually… almost any pregnant woman…is at increased risk compared to the non-pregnant state…so they all have risks. The question is…what unique risks do WPD have and what’s the best way to care for it.” Additional systems issues contributing to negative experiences included inaccessible facilities, time required to provide appropriate care for WPD, and lack of availability of accurate information for WPD and clinicians themselves.

DISCUSSION

This study was innovative because we explored the perspectives of clinicians who provide care during pregnancy to WPD. Although many studies have addressed perspectives of pregnant WPD,[3–8] few studies have addressed clinicians’ perspectives. This study’s findings are relevant to clinicians caring for pregnant WPD, as well as faculty involved in the training of beginning clinicians, residents, and fellows to prepare them to care for this population. None of the clinicians received education or training at any time on caring for women with disabilities during their medical or undergraduate education, residencies or fellowships. Despite their lack of training and the barriers they encountered in providing care, they found caring for WPD deeply rewarding. Given the increasing number of women with disabilities who become pregnant and have children,[20,33] these findings are also relevant to clinicians who are increasingly likely to encounter pregnant women with disabilities in their practice in the future.

Studies have identified lack of knowledge on the part of clinicians about health issues of WPD.[5,6,30] Most health professions’ education programs devote little time to disability.[20,23–24,35–36] Further, clinicians in this study reported inadequate attention to disability during their graduate medical education. As a result, clinicians are generally unprepared to meet the needs of individuals with disabilities, including during pregnancy.[23–26] Further, attitudes of clinicians toward pregnant women with disabilities have been described as negative and stereotypical.[3–6] These attitudes have been attributed to clinicians’ lack of knowledge, comfort and confidence in caring for individuals with disabilities because of sparse interaction with individuals with disabilities during their education and lack of training in providing care.[16–20] The lack of training resulting in lack of knowledge was verified by this study’s participating clinicians. Instead, they learned how to care for these women because of their own interest and willingness to “learn on the job.” Although most participants had completed their education and training a number of years ago, recent studies and commentaries indicate continuing lack of attention to disability in health professionals’ education.[10,23–24,36] Although medical educators are beginning to develop core competencies for students to care for individuals with disabilities, it remains rare for physicians to receive training to address the diverse needs of persons with disabilities.[24]

Several clinicians indicated that women themselves were often their best teachers, if clinicians listened to them. This finding supports those of other studies in which women with disabilities explicitly recommended that clinicians ask WPD what works and what does not, rather than discount or shrug them off. They recommended that clinicians learn from

women who may have lived with their disabilities for years.[5,6,8] Although valuable, this approach should not replace educational preparation of clinicians to provide appropriate care to WPD. The consistent failure of clinicians to receive education and training to provide care for WPD during pregnancy supports the need for the health professions educational programs to prepare clinicians to care for individuals with disabilities, including WPD.

Of particular importance is the response from many of the clinicians that caring for WPD was one of the most rewarding experiences a clinician can have. Clinicians also described caring for WPD as the essence of the physician role as a healer, a professional responsibility and a mission. The interest of the clinicians in providing high-quality perinatal care to WPD was obvious in their responses. They recounted positive aspects of caring for pregnant WPD and had difficulty identifying negative experiences related to the women themselves. Instead, they described "systems issues" that are discussed elsewhere.[37] The clinicians recommended that education and training programs begin to address care of WPD for all clinicians. Several models to do so have been developed.[36,38–41] Examination of curricula of medical and other health professions' education programs would be useful to determine gaps related to caring for WPD.

Several participating clinicians reported a professional, ethical or moral obligation to provide care to women with disability. Although several organizations and agencies[1,16–20] have identified a mandate for clinicians to provide full and equal access to individuals with disabilities including health care, the care provided by many clinicians to WPD falls short of this mandate. Although it is unknown if the clinicians who reported an obligation to care for WPD differ in any meaningful way from other clinicians, participants in this study who reported this obligation may have developed this perspective only after their experience caring for them. Further research would be useful to explore factors that might lead to this perspective with the goal of developing strategies to capitalize on this sense of obligation.

Limitations

As with all qualitative studies, this study had several limitations that need to be acknowledged. Selection bias was a limitation because clinicians responded to invitations after being identified as having experience providing obstetric care to women with disabilities. The number of clinicians identified, contacted, and interviewed was small and others with these experiences may not have been identified or contacted and otherwise missed. Further, other clinicians may not have had experiences or career pathways similar to those reported by study participants. Although there was consistency in clinicians' responses, suggesting data saturation, further research is needed to determine if the findings would be found with other participants. Bias is an additional possible limitation if clinicians provided only responses considered socially desirable.

CONCLUSIONS

The obstetrical clinicians in this study learned about caring for pregnant WPD through on-the-job training and from their patients; none had received formal training prior to caring for these women, including during obstetrical or maternal-fetal medicine residencies and fellowships. No interviewees entered their obstetrical career planning to care for WPD, but

all indicated that such formal training is important to incorporate into current training programs. The interviewees' positive descriptions of caring for these women could encourage medical students, obstetrical residents and fellows, and other health professions' students to serve the growing population of pregnant WPD.

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Table 1

Themes and Subthemes of Perspectives of 14 Obstetric Clinicians who Care for Women with Disabilities

Themes and Subthemes	Sample Quotes from Clinicians
Theme 1 – Professional Pathway to Providing Care to Women with Disabilities during Pregnancy	
Subtheme 1: Unplanned career pathway	• Well, many years ago there's someone that was just a business acquaintance, a medical director of a school or home for adults with severe mental and physical handicaps…he asked if I would be the gynecologist and I was for 10 years. I went out there and actually did exams and the Pap smears at the facility. And then they switched over to having the exams not done at the facility, but that had given me some experience so when the past gynecologist of our clinic was promoted, he asked me to take over…and have been doing it ever since. • About 24 years ago when I moved to current city, the neighbor next door to me was a doctor and assistant director for a free-standing rehab hospital….he couldn't get any gynecologists to see the patients. But since I lived next door to him, I said, "I'll see them." So for the past over two decades I've been going every month…to see patients in their clinic….so that was my connection with patients with disabilities and injuries like cord injuries.
Subtheme 2: Lack of formal training	• I can't say that during my [MFM] fellowship I had any specific training in it. It's mostly on-the-job training. • I did not have formal training beforehand, but I had an active interest in the topic, so I was seeking literature and reading whatever I could… So I was teaching myself. • I don't think people are really particularly given any background…just wasn't a specific focus…It just was one of those things, as you got someone who had the needs we just sort of figured it out.
Subtheme 3: Educating Other Clinicians.	• In fact about three or four months ago I was thinking…"Why don't we have this in our area?" I'm thinking well, maybe I can do something about that…I'm going to dedicate myself to reaching out to hospitals and medical centers throughout the country and see if I can help them and convince them to open a clinic just like ours….I'm really looking forward to it. • The main message I give [when teaching other clinicians] is actually taking care of disabled patients even though sometimes it's awkward and difficult and labor intensive, it's very rewarding and when physicians do take care of these patients – I'd say a physician who has no experience with it, that should not discourage them. They should be fine. They'll figure out how to examine the patient.
Theme 2 – Clinicians' Experiences Caring for Women with Disabilities During Pregnancy	
Subtheme 1: Clinicians' Positive Experiences	• It was just really nice taking care of her (a patient with a SCI). She had a really good outcome. I sort of get emotional, because…some providers didn't want to take care of her. But we did a good job… it was very complex, because we didn't really know, like is the fetal blood sampling going to trigger autonomic dysreflexia or not? What kind of anesthesia should we provide for this, because usually we don't really give anything? It was clinically challenging. • It's very, very rewarding to care for people with disabilities because they just…they are able to navigate what's a difficult situation for anyone to try to get health care…and so we found it incredibly rewarding… It developed into a real mission for us, especially at the birth center. If other providers knew that and had any kind of sense of that they might go out of their way to incorporate these women into their practice because it's so, it's such a good thing to do. It's the right thing to do, you know, and it's rewarding and the people are so grateful. • I think…when people with disabilities want to have children, they're so excited when it actually happens. It really is very rewarding for everybody. So the time is worth it, in that sense, you know? Though sometimes you say, oh my gosh, how is this going to work? • This one patient who lived [nearby]… insisted that she wasn't going home by car. Because she goes everywhere…in her motorized wheelchair, and she insisted on taking her son home in her lap. Now, I watched her…she put her baby in a harness around her neck, and she motored out of the hospital, went down the sidewalk, and I walked to the corner and waved her goodbye. I'll never forget that… everything worked out just fine. That was a career highlight.

Themes and Subthemes	Sample Quotes from Clinicians
	• It's just so rewarding. Patients all seem to be very pleasant and in good spirits and they're happy that someone is treating them with dignity and more than that, just taking care of them. And so, gosh, it's just, the whole thing is extremely rewarding… Our practice is one of the few that has a dedicated clinic…when they find us they're very happy.
Subtheme 2: Clinicians' Negative Experiences	• System-related issues…those were the frustrations that we had. It was never a negative experience with the patients themselves. • So I think that…the only negatives, like I said, are the systems things.