Disability and childbirth: meeting the challenges

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Education

Éducation

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As increasing numbers of women with physical disabilities and chronic illnesses choose to have children, physicians and other health care professionals will be faced with providing care and support in situations where they may have little experience. At the same time, a woman with a disability who becomes pregnant may have fears about how she will be perceived by her physician. Her fears arise because of our society's stereotypes about what constitutes a "good mother." Women with disabilities may be expected to forgo mothering because of fears that the disability will be passed on to the child or that the child may be psychologically deprived or burdened.[1] The purpose of this paper is to present an overview of the care issues faced by women with disabilities as they cope with the specific challenges of pregnancy, labour and birth and adapt to the role of mother, as well as to suggest strategies for physicians who care for these women.

Readers may question the legitimacy of speaking about and for women with disabilities when one does not have a disability and has not lived in the culture of disability. However, this paper is based on my practice over the past decade with approximately 100 women through the Childbearing and Parenting Program for Women with Disabilities and Chronic Illnesses, a Vancouver-based program that provides information and support to women and health care professionals. The paper is also based on the current literature on pregnancy, women's health, feminist theory and their intersection with disability.

The experience of disability, much like that of race and gender, is shaped by a complex interplay of social, cultural and political forces. However, the suggestions for health care made in this paper should be considered in light of each woman's particular circumstance. The examples chosen for illustration here (spinal cord injury, rheumatoid arthritis and multiple sclerosis) represent only a few of the many conditions physicians will encounter. However, these are the conditions about which I receive the most inquiries and about which there is a more coherent literature.

Defining "disability"

Why is the definition of disability important? For persons with disabilities there are the practical aspects of entitlements to education, housing, jobs, assistive devices and transportation. But of particular relevance to childbearing women and their physicians are the questions relating to attitudes and beliefs about impairment and disability that might shape a woman's health care experience. The literature describes 2 main perspectives on disability: the biomedical model, which focuses on the reduction of impairment, and the social model, which emphasizes decreasing the social and physical barriers to inclusion.[2] A focus on impairment results in persons with disabilities feeling different from the "norm." In fact, they often feel inadequate because of the prejudice they experience. The value of the social model is self-evident. However, as Jenny Morris, a disability activist, has pointed out, the social perspective is important, but within that perspective there is a tendency to downplay or deny the very real experience of the physical restriction or pain of the body.[3]

Wendell has said that "Good definitions of impairment and disability should recognize that normal (i.e., unimpaired) physical structure and function, as well as normal (i.e., non-disabled) ability to perform activities, depend to some extent on

the physical, social and cultural environment in which a person is living, and are influenced by such factors as what activities are necessary for survival in an environment and what abilities a culture considers most essential to a participant".[4] In my experience, women with disabilities who become pregnant desire care aimed at reducing the distance between their capabilities and the demands placed on them by their environment. Medical care, medications, lifestyle and behaviour changes may have an impact on their capabilities, whereas modifications of the physical environment, adaptive devices and personal assistance will reduce the demands of the environment. Consideration of all these factors can reduce anxiety and may improve outcome for the woman planning to become a parent.

Responding to the needs of women with disabilities

The few published articles about women's needs during the childbearing cycle are primarily anecdotal and derived from the clinical experiences of practitioners. Some review and research papers present clinical data about a particular disability and its relation to pregnancy. For this paper I considered information from both types of literature, along with data collected as part of the program evaluation of the Childbearing and Parenting Program for Women with Disabilities and Chronic Illnesses,[5] to identify 2 major concerns of women about becoming pregnant and strategies to assist with these concerns:

- concern about their ability to maintain their own health and their babies' health through pregnancy, labour, birth and the postpartum period
- fear of not being able to physically care for their babies.

The first concern is one shared by all mothers, but it has extra significance for women with disabilities because of the possible interactions between pregnancy and disability. The second brings with it many challenges for those supporting the woman, not only with respect to specific caregiving skills but also in relation to the woman's confidence and feelings about herself as a mother. Physicians can respond to these concerns in the following ways:

- by providing information
- by providing care in facilities that are physically accessible and psychologically supportive
- by putting in place a plan of care based on a thorough assessment of physical and psychosocial needs.

Meeting patients' information needs

In an ideal world all women would have a chance to discuss the timing of pregnancy with their doctor before becoming pregnant. However, we know this is not the case. The following discussion is relevant for providing care either before or during pregnancy. What is critical is that the physician determine how the woman feels about pregnancy before giving information and advice. Some women have reported being offered termination of the pregnancy before any assessment of their desires or abilities. Obviously, this could have a devastating effect on a woman's confidence. A neutral, open-minded and supportive approach will have the most positive impact.

It has been documented that the physician is the primary source of information about the realities of pregnancy and parenting for a woman with a specific disability or chronic illness.[6] At the beginning of any discussion with the woman and her partner, it is important to acknowledge that she and her family have a sophisticated working knowledge of the disability and its effects and that their particular experience should be considered in the decision-making process.[7–9] The pre-pregnancy or early pregnancy discussion might include the following topics: how the pregnancy and disability will interact; the potential effect of the woman's medications on her health and that of her fetus; lifestyle modifications that might be required to maintain health during the pregnancy; points during the pregnancy and parenting periods when family adjustments may be necessary; coping with the reactions of family and strangers; and information on resources (see sidebar, p. 365).

Many factors influence the mutual impact of the pregnancy and the disability. Whether the disability is new or long-term, progressive or stable, needs to be considered, not just in terms of the physical implications, but also in terms of the woman's coping abilities and those of her family.[10] Information on physical impact is growing in the literature, but very little has been written about what helps some women manage better or to have a more positive experience than others. Spinal cord injury, rheumatoid arthritis and multiple sclerosis will be used to illustrate some of what we know about mutual impact. Review papers on these conditions provide more detailed information.[11–13]

Spinal cord injury

Relatively few cases of spinal cord injury and pregnancy have been reported, but generally the outcome has been good for both mother and baby.[11,14] Some of the common medical problems faced during pregnancy include an increase in urinary tract infection (as high as 100% in women with in-dwelling catheters and 50% in women who use a catheter intermittently), an increased tendency for formation of decubitus ulcers because of increased weight and the resulting difficulty with ambulation and transfer, difficulty in maintaining bowel regimen

because of increased constipation and autonomic hyperreflexia in up to 85% of patients with lesions above the fifth or sixth thoracic vertebrae. Most women with spinal cord injury have sensation of their contractions during labour, as backache, pressure or increased spasticity; evidence of a higher incidence of preterm labour has not been found. Cesarean rates are reported as 20–30%. Breastfeeding can be successful.

Rheumatoid arthritis

Approximately 75% of women with rheumatoid arthritis experience some improvement in their condition during pregnancy, usually in the first trimester. Up to 90% can expect the disease to flare within the first 3 months after the birth, and the flare may last from a few weeks to several months. Rheumatoid arthritis does not pose a threat to the outcome of the pregnancy. The most severe problem for the new mother is coping with pain and fatigue, which can interfere with all aspects of daily life including baby care.[12,15]

Multiple sclerosis

Women with relapsing multiple sclerosis do not experience an increase in relapse rate during pregnancy, and some studies have shown a lower relapse rate in the third trimester. However, some women experience an exacerbation of their symptoms during the first 3 months after the birth. Attacks occurring during pregnancy are reportedly less severe and during the postpartum period more severe than those usually experienced by the woman. Pregnancy does not seem to affect the long-term course of multiple sclerosis, and in some cases may result in improvement. Sadovnick has studied the genetic component of susceptibility to multiple sclerosis and has suggested that the risk is 50 times greater than in the general population for a daughter but substantially lower for sons, assuming a general population prevalence of 0.1 to 0.2%.[13,16,17]

Medications

A detailed discussion of the potential effects of the many medications used by women with various disabilities is beyond the scope of this paper. However, questions about medications are often raised by women as they think about pregnancy, and so it is important that physicians discuss the potential maternal and fetal effects of medications with all patients who have a disability and are of childbearing age. For example, women who are taking diazepam to control spasms[18] or methotrexate for rheumatoid arthritis[19] may be counselled to discontinue these medications because of the risk of congenital anomalies, but alternative medications or nonpharmacological means of controlling symptoms will need to be tried. It will be easier on the woman if the effectiveness of these alternatives is determined before she becomes pregnant.

Adjustments in the home

Lifestyle modifications and family adjustments during pregnancy and after the birth must be anticipated and discussed as part of the pre-pregnancy or early pregnancy discussion and assessment. For example, some studies have reported a higher incidence of anemia in women with spinal cord injury, and women with anemia have an increased risk of developing decubitus ulcers.[11] Because supplemental iron can interfere with a woman's bowel regimen, it should be given judiciously. Therefore, a change in diet may be required before or during preg-

Resources: disability and childbirth

Videos

Isobel's baby. London: Arrowhead Productions; 1990. Presents the emotional and practical adaptations to motherhood of a woman who uses a wheelchair because of multiple sclerosis.

Toward intimacy. Ottawa: National Film Board; 1993. A film about women with disabilities and sexuality.

Journal

Disability, Pregnancy and Parenting International. Arrowhead Publications, 1 Chiswick Staithe, London W4 3TP, England

A journal for professionals and parents to exchange information about experiences of pregnancy and parenthood with a disability.

Organizations

Barrier-Free Design Centre, 2075 Bayview Ave., Toronto ON M4N 3M5

Crane Library and Resource Centre (for the visually impaired), University of British Columbia, Vancouver BC V6T 1Z1

The Parenting Network, The Centre for Independent Living, 605–205 Richmond St. W, Toronto ON M5V 1V3; tel 416 599-2458

Through the Looking Glass (National Research and Training Center on Families of Adults with Disabilities), 2198 Sixth St., Suite 100, Berkeley CA 94710-2204; www.lookingglass.org (Web site has useful links)

Assistive devices

Tetra Development Society, Plaza of Nations, Box 27, 770 Pacific Blvd. S, Vancouver BC V6B 5E7

The Rehabilitation Centre, Rehabilitation Engineering Department, 505 Smyth Rd., Ottawa ON K1H 8M2

nancy. Other examples of lifestyle changes that may cause distress would be the need to use a wheelchair because of the shift in centre of gravity of a woman who previously managed with canes and, for some women with spinal cord injury, the need to change bladder management techniques to include catheterization during pregnancy or soon after the birth.

Family adjustments that may be required and deserve discussion include the need to accommodate the normal changes of pregnancy, which sometimes conflict with or are exacerbated by the disability (for example, maintaining independence as a person with a disability may conflict with the dependency needs of pregnancy). The normal ambivalence of early pregnancy may be exacerbated by fears of how pregnancy and motherhood will be managed, and changes in feelings of sexuality during pregnancy and the postpartum period may be experienced differently than is suggested in the literature. With respect to sexuality, some women have suggested that their partner's desire for them is especially important at this significant time in their lives, but some men, because of their fears of harming the fetus or hurting their partner, may need physician approval to engage in sex. Suggestions for preparation for sex will be appreciated by the couple. For example, for women with arthritis, suggestions might include using an analgesic to reduce discomfort, taking a warm bath or shower to reduce joint stiffness, and incorporating "range of motion" exercises and light massage into sexual pleasuring.[20] It is also important to do a family assessment to determine what kind of support will be available to the woman during the early months of parenting. If caregiver assistance might be required because of relapse, planning must begin early, since community agencies need time to put services in place.

Another aspect of the issue of planning for caregiver assistance is the importance of carrying out an assessment of the woman's child care abilities. This allows an early start in determining what kind of caregiver assistance might be necessary and purchasing or making the necessary equipment or assistive devices. The Child Care Abilities Survey[21] can be used to assist parents to determine what aspects of child care would present the most difficulty for them (Fig. 1). The survey is based on work by Cicenia and Stephenson,[22] the Parent Ability Committee of the National Childbirth Trust in England and experience working with women in the Childbearing and Parenting Program. The woman can complete the survey herself or can do so with the help of a physiotherapist, an occupational therapist or a childbirth educator. The physician will know which community worker would be most appropriate to work with a particular woman. After the assessment, the physician may wish to contact a volunteer organization such as the Tetra Development Society (see resource list), whose mandate is to design adaptive equipment.

In addition to breastfeeding, other areas assessed in the Child Care Ability Survey include formula and food feeding; diapering and toileting; managing clothing, crib, carriage or stroller; bathing; using high chair and car seat; playing; holding or carrying; and supervision.

Others' reactions

Once a woman has decided to embark on a pregnancy or comes to the physician already pregnant, she needs to be aware that family, friends and strangers are rarely neutral in their response to a woman with visible disabilities who is pregnant or caring for a child. Many react because of a prevalent societal view that persons with severe disabilities are asexual, others simply because they have never considered the notion of parenting with a disability. Women say they are often perceived as either superhuman for managing to parent with a disability or inadequate because they cannot do what "normal" mothers do. It is helpful if the physician can talk this over with the woman, encouraging her to anticipate her reactions and perhaps to formulate some responses she can feel comfortable with.

Physically accessible and psychologically supportive care

Physical accessibility

Close examination of the accessibility of the physician's office and the hospital where the woman plans to give birth should be undertaken so the barriers are known and can be taken into consideration during the course of care. Jones and Tamari[23] provide comprehensive guidelines for office-based physicians who wish to make their offices accessible to all patients, so I will address here only those aspects specific to the needs of the patient with a disability who is also pregnant.

- Women who might not normally have access to a dis-

	No difficulty	Manage with some difficulty	Manage with great difficulty	Unable to manage
Breastfeeding				
Unfasten nursing bra	[ ]	[ ]	[ ]	[ ]
Mouth to breast	[ ]	[ ]	[ ]	[ ]
Support child	[ ]	[ ]	[ ]	[ ]
Position for burping	[ ]	[ ]	[ ]	[ ]
Fasten bra	[ ]	[ ]	[ ]	[ ]

Fig. 1: A sample section from the Child Care Abilities Survey.[21] The respondent is asked to indicate the level of difficulty of the various activities according to the scale given.

ability sticker (e.g., women with chronic fatigue syndrome or fibromyalgia) might require a special request from the doctor to obtain a sticker for use during the pregnancy and postpartum period.
- An examining table that can be lowered for easy access or for easy transfer from wheelchair to table will be appreciated by all patients. The Midmark Electric Power Chair/Table (Midmark Corp., Versailles, Ohio) allows the woman to sit down with more ease; the chair converts easily to an examination table and takes many positions.
- Showers without lips or sills or accessible tubs in labour and birth rooms allow women with physical disabilities to enjoy the potential benefits of water therapy during labour.
- Labour, birth and postpartum rooms that are large enough for an extra bed allow partners or attendants to stay overnight and assist with special requirements for care.
- A baby bassinet with side hinges allows women with limited arm mobility to access their babies independently from the side of the bed using the bassinet side as a transfer device.
- Maternity units need to think about how they can accommodate seeing-eye dogs.

Psychologically supportive care ("attitudinal" accessibility)

Women with disabilities say they feel invisible in the health care system. They stress that their problems are more than medical — they are also social and political — and that access means more than physical accessibility.[24] Care that is psychologically supportive recognizes the complexity of the issues faced by people with disabilities in their daily lives and requires that care providers develop the requisite knowledge, skills and attitudes. The following suggestions are examples of ways in which physicians can provide psychologically supportive care.
- Every patient should be asked, when she is first seeking services from a physician or hospital, if she has any special needs. In this way care can be delivered in a sensitive way from the beginning. For example, a woman with limited mobility or limited vision could be offered to be met at the door of the facility by a volunteer or a porter.
- Communicating directly to the woman, rather than to her attendant, and recognizing her skills in managing her own condition reflect a sensitive approach. It is also important not to touch a woman's wheelchair, canes or other prostheses without permission, as some see these devices as parts of their bodies.
- Planning for extra time or alternative times for visits to the physician's office may be required. Prenatal visits could be scheduled at a time when the office is least busy if, for example, the woman needs extra time to obtain a urine specimen by self-catheterization or if special preparation is required to carry out a pelvic examination. With respect to the pelvic examination, the physician might encourage a woman with mobility difficulties to bring a support person to assist with transfer or support of her limbs. A willingness to carry out the examination in a position that eases the woman's discomfort or spasticity (e.g., sidelying, on hands and knees) will enhance the woman's confidence in her doctor's sensitivity to her specific needs.[25] Also important during a pelvic exam is an awareness of the possibility of previous sexual abuse because "social devaluation places [women and girls with disabilities] at high risk for abuse, even from those [who are relied] on for assistance in daily activities"[24] (p. 9). Extra time might also be required for women who are nonverbal and may use a Blissymbolics board (Blissymbolics Communication International, Toronto) or a laptop computer. Patients who are hard of hearing may be able to schedule an appointment only when an interpreter is available.
- Offering some aspects of prenatal care in the patient's home at a time when other family members can meet the doctor and are also available to provide child care is a good strategy.
- Physicians will benefit from working closely with a specific childbirth educator in the community, who, over time, can develop expertise with this population of women.

All of these approaches recognize the contextual realities of a woman's life.

Well-planned care

Because many women with disabilities face unpredictability in their symptoms and their abilities day by day, they desire care that is well planned and helps to eliminate surprises. After the physician has carried out the initial assessment, a written plan of care should be provided to the woman and to the hospital where she plans to give birth. Early in the pregnancy a referral to the clinical nurse specialist or the head nurse on the unit would be helpful so the various requirements outlined in the plan of care can be put into place. The hospital may need to order a special mattress, an adapted toilet seat or attachments for the bed to help with lifting and transfer. Organization of training sessions about the plan of care may be required for a team of nurses . With enough lead time, the hospital may be able to organize a nursing schedule so that the same team of nurses can provide continuity of care to the

woman throughout her hospital stay. An interdisciplinary team conference with the public health nurse and community occupational therapist can ensure the plan of care is relevant to home care as well as hospital care.

A fear of not being able to physically care for the baby has been expressed by some women. Therefore it is critical to provide information about the various adaptations to equipment that are available on the market or that can be made. This discussion needs to occur early in the pregnancy to allow time for preparations.

Mobility impairment

For women with mobility impairment, many options are available:

- Velcro or snap closures on maternity clothes, nursing bras and baby clothes and diapers
- slings or cloth-covered tube supports (Fig. 2) for breastfeeding
- bottle attachments for ease of handling (Fig. 3)

Fig. 2: Cloth-covered tube supports make breastfeeding easier.

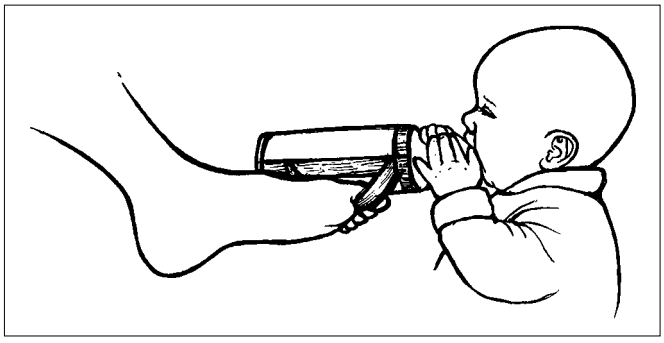

Fig. 3: Novel bottle attachments can be used if the mother cannot hold the bottle in her hand.

- castors attached to a high chair for easy movement around the home
- child carrier attachment for a wheelchair, so that a car seat can be attached to the front forks of the wheelchair
- wheelchair-accessible baby cribs with doors that slide open sideways (Fig. 4)
- wall-mounted change table that allows for wheelchair access.

Visual impairment

Women with visual impairment may benefit from these devices:

- stroller with swivel wheels (the stroller should be pulled instead of pushed; the seeing-eye dog can be trained to compensate for the stroller when making turns)
- electronic leash, transmitter and receiver to signal when a toddler has moved a certain distance away.

Hearing impairment

Tools are also available for those with hearing impairment:

- sound-activated visual alarm and reading lamp: the caregiver can learn to distinguish from the pattern of the flashes the baby's sounds (e.g., singing or crying) and sounds from other sources.

The resources listed in the sidebar may have other suggestions for patients and may be able to provide the names of women who have "been through it" and are willing to share their experiences.

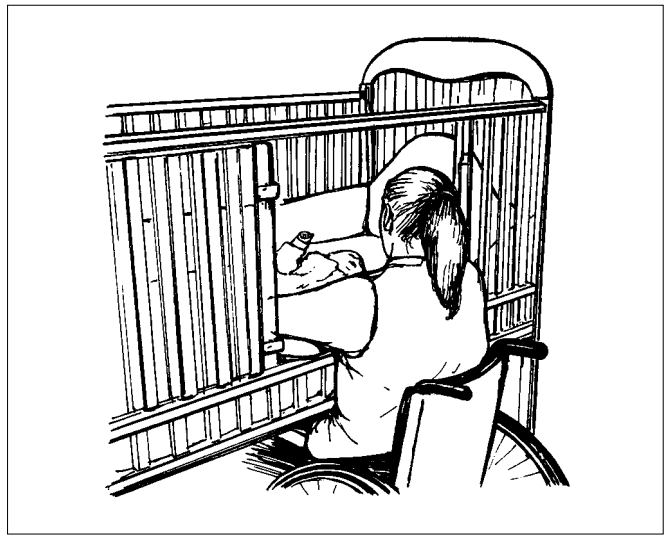

Fig. 4: Cribs with doors that slide open sideways are accessible for mothers in wheelchairs. Adapted with permission of the ROHCG/The Rehabilitation Centre, Ottawa.

Conclusion

Because physicians and other health care providers rarely have training in the accessibility and sociopolitical aspects of disability and chronic illness, it is hoped that the material presented here will prevent the problems sometimes described by women with disabilities: inappropriate language, incomplete assessment and sometimes irrelevant interventions.[26] We are challenged by this kind of care, but my experience is that women with disabilities are excellent teachers. They wish to be visible and to have a care provider who listens. They want practical information and support. However, much more research and resource development is needed for the benefit of these mothers and their families.

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