

Facilitators and barriers to breastfeeding among mothers with physical disabilities in the United States

Introduction

The benefits of breastfeeding are well-established and an increasing number of mothers in the United States choose to breastfeed, at least short-term. Although a growing number of women with physical disabilities are becoming mothers, there is a dearth of information available about breastfeeding practices among these women. Existing research suggests that mothers with disabilities often encounter a lack of postpartum supports, health care professionals with limited understanding of disabilities, and limited availability of adaptive parenting equipment. The children of mothers with physical disabilities should benefit from breastfeeding just as children of nondisabled mothers do. Our goal with this study was to identify the facilitators and barriers to breastfeeding that is encountered by mothers with physical disabilities.

We conducted interviews with 25 mothers with physical disabilities from across the United States. To participate, mothers must have had a physical disability or condition that affected her ability to walk or to use her arms or hands at the time of her pregnancy, delivered a child within the last 10 years in the United States, and between 18 and 55 years old. We recruited participants through national disability organization, email lists, and social media. Reported here are findings related to factors that support or impede breastfeeding among mothers with physical disabilities.

Results

Participant characteristics

- The average age of the participants at time of the youngest child's birth was 32
- Fourteen of the mothers had one child at the time of interview and two were pregnant
- Most of the participants were white and not Latina
- Fifteen of the mothers had planned pregnancies and 10 had unplanned pregnancies
- Participants reported range of disabilities: multiple sclerosis, spina bifida, spinal cord injury, amputation, cerebral palsy, osteogenesis imperfecta, stroke, and muscular dystrophy

Facilitators to breastfeeding

The interviews revealed four factors that assisted or supported breastfeeding among mothers with physical disabilities.

1. Adaptations and equipment

Many mothers reported that they used adaptations and equipment to enable them to breastfeed. Some of the mothers described the importance of finding the right position to breastfeed, which some said can take time and creativity. In addition, some of the mothers explained the need for breastfeeding pillows, such as "Boppy pillows," and other types of adaptive parenting equipment. Moreover, some of the mothers modified how they used breastfeeding pillows and other equipment to meet their specific needs. For example, some mothers reported laying down while others were able to sit while breastfeeding.

2. Use of breast pump

Some of the mothers we spoke to did not have the physical strength their babies long enough to breastfeed and others were unable to find a position that worked for them. However, because it was important for them to still feed their infant human milk, some mothers chose to use a breast pump, which they could do independently or with help. By using a breast pump, these mothers still were able to provide their infants breast milk using a bottle.

3. Physical assistance from others

Breastfeeding posed many physical challenges for some of the mothers. Some participants were unable to hold their babies while breastfeeding and others could not a breast pump on their own. As such, a few of the mothers reported receiving physical help from others, primarily the other parent or a family member.

4. Peer support

Many of the mothers reported receiving information about breastfeeding from their peers, particularly those with similar disabilities. Some mothers connected with other mothers using social media and others attended disability conferences. Receiving advice and information from mothers who had similar experiences was very important for several of the mothers we spoke to.

Barriers to breastfeeding

The interviews revealed five factors that impeded mothers with physical disabilities from breastfeeding.

1. Lack of supports

Several of the mothers told us there is a lack of available supports related to breastfeeding. Some of the mothers encountered lactation consultants who did not have experience supporting mothers with physical disabilities. Moreover, some of the mothers wished there were more in-home supports available for breastfeeding mothers with physical disabilities.

2. Disability-related health considerations

A few of the mothers explained that they chose not to breastfeed because of disability-related considerations. For example, some mothers were worried about how medication they took would interact with breastfeeding. Other mothers were concerned that breastfeeding may exasperate symptoms of their disabilities (e.g., bone density). Finally, a few of the participants reported not breastfeeding because they were physically unable.

3. Limited information

Many of the mothers expressed frustration with the lack of information about breastfeeding among mothers with physical disabilities. A few mothers told us that their doctor did not know if their disability would be impacted by breastfeeding. Other mothers explained that most of the information available to mothers about breastfeeding does not address the specific needs and experiences of those with physical disabilities.

4. Difficulties with milk supply

Several of the mothers reported difficulties related to their milk supply. Although challenges with milk supply can also be a problem for nondisabled mothers, for many of the mothers in this study, the issue was often disability-related. For example, some of the mothers were delayed in initiating breastfeeding because they had problems finding the right adaptations or equipment. These delays sometimes resulted in mothers "drying up."

5. Difficulties with latching

Some of the mothers experienced difficulties getting their babies to properly latch. While latching can be challenging for many mothers, for the mothers in this study it was usually exasperated because of their disabilities, namely problems with positioning. Moreover, delays in initiating breastfeeding often led to difficulties with latching.

Limitations

As with all research, there are limitations to our study. The first limitation is selection bias; the mothers who we spoke with are connected to the disability community and may not represent those who do not receive disability-related services. Moreover, our study sample is small and does not reflect the diversity of mothers with physical disabilities, meaning that the findings cannot be generalized. Finally, because we interviewed some mothers who had given birth several years ago, they may not remember certain experiences accurately.

Implications for policy and practice

Findings from our study have important implications for policy and practice. To increase breastfeeding rates for mothers with physical disabilities, greater attention should be given to addressing facilitators and barriers. Below are specific changes we believe are needed.

- Health care providers, including lactation consultants, need appropriate training and quidance on how to support mothers with physical disabilities
- Personal supports, personal assistance, and adaptive parenting equipment must be readily available for parents with disabilities
- Information and other resources about breastfeeding by mothers with disabilities must be developed and disseminated to people with disabilities and health care providers

Adapted from Powell, R.M., Mitra, M., Smeltzer, S.C., Long-Bellil, L.M., Smith, L.D., Rosenthal, E., & Iezzoni, L.I. (in press). Breastfeeding among women with physical disabilities in the United States. *Journal of Human Lactation*.