
Exploratory Study: Barriers for Initiation and/or Discontinuation of Breastfeeding in Mothers of Children with Down Syndrome

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Background: The aim of the study is to identify the barriers associated with breastfeeding in mothers of Puerto Rican children with Down.

Method: A non-probabilistic sample (n=26) of mothers was used in the study. The sample was obtained in an institution in Puerto Rico specializing in care of infants with Down Syndrome [IDS]. A self-administered questionnaire was used consisting of six sections. Descriptive statistics were used for data analysis.

Results: The majority of interviewed mothers (80.8%) had 70.0% or higher correct answers regarding the benefits of breastfeeding. 84.6% of

the mothers who decided not to breastfeed or who discontinued breastfeeding reported as the main reason that the baby presented sucking problems and 50.0% of the participants were not allowed to have their baby with them during their stay in the hospital. 84.3% of the participants indicated having breastfed their IDS and 61.5% stated that they would not breastfeed in public places.

Conclusion: Active support, instruction, and collaboration among members of the health care team are essential for breastfeeding success.

Key words: Breastfeeding, Down syndrome, Barriers

Down syndrome is identified in 1/800 live births of all races and economic strata (1). In Puerto Rico it has been identified in 9/10,000 live births (2). Infants with Down syndrome (IDS) are difficult to feed since they present certain health conditions at birth that are barriers for breastfeeding (3). According to the National Institute of Child Health and Human Development [NICHD] (4), IDS have hypotonic or muscular tension deficiency. Also, due to this reduced muscular tension and a prominent tongue, breastfeeding of the IDS usually takes more time. Likewise, the hypotonic muscles can affect the digestive system, causing constipation. It is important that the IDS be breastfed frequently. Nevertheless, the mother should keep in mind that these IDS, due to their hypotonic condition, cry and kick less. Therefore, they can demand the breast less intensely than other children (5).

The suction problems related to hypotonia or heart defects can be problems in breastfeeding initiation, particularly in premature children (6). The IDS with heart defects may need to be fed frequently, but in shorter periods since they are more vulnerable to fatigue and shortness of breath (7). In addition, more than 50% of

these children have ocular and auditory problems such as strabismus, myopia, and hypermetropia (8).

From the digestive point of view, among 10 to 12% of IDS are born with intestinal malformations that will require surgical repair (8). Vomiting and the absence of depositions in the first days of life are characteristics which point toward that pathology. Breastfeeding can be difficult due to the hypotonia (8). An IDS is usually drowsy during the first weeks and may have a very weak suckling reflex; therefore, it is imperative that breastfeeders have additional patience (7).

The medical care of the IDS and breastfeeding will include the same pediatric care that healthy babies receive during the first year of life (4). However, in comparison with the general population, IDS have a mortality rate due to infectious diseases 12 times higher, if treatment is not obtained promptly (4). Also, IDS have a higher probability of developing chronic respiratory infections and otitis media infections. Pneumonia incidence is 62 times more likely in IDS than in the general population (4). In this regard human milk should be a priority for this population. The La Leche League International (9) informs that breastfeeding is the best way of feeding the IDS, just as it is to the rest of the children. Moreover, breastfeeding the IDS is even more important because it provides extra protection against the development of infections; it improves the coordination of the language and the mouth; it promotes the stimulation of tact and it maintains the baby's alertness. Nevertheless, many

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mothers face difficulties at the moment of breastfeeding their IDS.

The most recent statistical data of the Puerto Rico Department of Health reveals that 93.5% of Puerto Rican women express their intention to breastfeed, and that 65.5% breastfeed at the hospital (10). Several studies have presented some of the barriers for breastfeeding initiation among Puerto Rican women (11-13), but we did not find published literature on the barriers associated with breastfeeding in mothers of Puerto Rican children with Down syndrome, this being the principal purpose of this study.

Methodology

Human rights

This study was approved by the Institutional Human Subjects Review Committee of the Medical Sciences Campus at the University of Puerto Rico.

Design and sample

The design used for this study was pre-experimental and cross sectional to identify the barriers associated with breastfeeding in mothers of Puerto Rican children with Down syndrome. A universe of 26 Puerto Rican mothers whose infants were receiving health services in one specialized institution for IDS participated in this study.

All mothers participating in this study signed an informed consent form. Participants were recruited by the institution's staff personnel.

Inclusion and exclusion criteria

Eligibility for participation in this study for mothers was determined by means of the following inclusion criteria: a) biological mothers of Down syndrome babies of 12 months of age or less; b) who could read and write Spanish; and c) only had one child diagnosed with Down syndrome.

Data collection procedure

Data was gathered by means of a semi-structured questionnaire that included closed and open-ended questions in the Spanish language. The interviews were carried out by one interviewer. The data gathered by means of the interview included data related to: a) the sociodemographic characteristics of the mother; b) information on the infant and his/her condition; c) information on the pregnancy and birth of the IDS; d) knowledge of breastfeeding benefits; e) mother's breastfeeding experience; f) barriers encountered for initiation of breastfeeding; and g) attitudes toward breastfeeding in public places.

Each interview session was 20 to 30 minutes long. The completed questionnaire was revised by the principal investigator before being entered into the computerized database. Double entry of data was carried out to minimize data entry errors.

Description of instruments

The questionnaire was designed from previous instruments used by the authors' research team in this type of community and other researchers in the breastfeeding field. Two scales were included in the questionnaire:

- *Knowledge Scale on Breastfeeding Benefits.* This scale was comprised of 13 premises regarding breastfeeding benefits with a nominal scale (Yes, No, and I do not know). This scale showed a Cronbach alpha of 0.83.

For the purpose of analysis, knowledge premises were categorized as (1) correct and (0) incorrect, and were then added up. The "I do not know" premise was considered as an incorrect answer in the analysis. Knowledge was considered adequate when 70% of the premises were correct and inadequate otherwise (14). The type of breastfeeding was defined as per Labbok and Krasovec (15).

- *Attitudes toward breastfeeding in public places.* This scale was comprised of 16 premises with a nominal scale (Yes and No) regarding public places where the participants would breastfeed. This scale showed a Cronbach alpha of 0.70.

For the purpose of analysis, premises regarding attitudes were categorized as (1) Yes and (0) No, and were then added up. To more punctuation in the scale more positive is the attitudes toward public places breastfeeding (16).

Statistical analysis

All data was entered and analyzed by means of SPSS for Windows 11 (17). Being an exploratory study consisting of a small number of participants, only descriptive statistics such as frequency distributions and percents were applied to data analysis.

Results

The mean age of mothers was 33 years (SD=5.17) with a range from 23 to 45 years of age and 65.4% of mothers were 33 years or older. The median school years completed was 13 years (SD=1.4) with a range between 9 and 16 years. We found that 57.7% of participants had a bachelor degree or higher (Table 1).

We found that 53.8% of interviewed mothers reported the pregnancy lasted 8 or 9 months. Primiparas accounted

for 30.8% of the mothers; 38.5% indicated they knew in advance that their baby would be born with Down syndrome. The mean postpartum days of hospitalization was 3 days (SD=0.90). Hospital stay was between 2 and 3 days for 88.5% of the mothers (Table 1).

Among participants, 84.3% indicated having breastfed their IDS. Breastfeeding of the child with Down syndrome had begun in the hospital in 72.7% of the mothers who breastfed and breastfeeding initiation occurred 1-3 weeks after birth in 90.9% of the cases. Feeding directly from the breast was carried out by 82.4% of mothers who gave their milk to their babies. Of those who fed directly from the breast, 54.5% did it on a daily basis (Table 1).

Forty five point five percent (45.5%) of the participants breastfed their child exclusively. It should be pointed out that 78.6% of the mothers weaned their babies between 1 and 6 weeks of age. Likewise, mothers reported that 53.8% of their babies were female (Table 1).

Associated health conditions affected 53.8% of the babies and the most frequently associated conditions were: cardiovascular problems, respiratory illness, gastrointestinal disease, among others. The median duration of NICU stay was 3 days with an interval ranging from 2 to 48 days, and the mean number of daily visits by mothers to the NICU was two. The number of visits fluctuated between one and 6 daily visits. Specifically, 63.6% of interviewed mothers visited the NICU twice daily and 27.3% did so once daily (Table 1).

Breastfeeding Benefits Knowledge

The majority of interviewed mothers (80.8%) had 70.0% or higher correct answers regarding the benefits of breastfeeding. Analysis of the premises showed that 100% of the participants knew that human milk provides benefits to the baby, including antibodies against diseases. We also found that 73.1% knew that breastfeeding reduces breast cancer risks in the mothers (Table 2).

Nevertheless, the participants were unaware that: 1) human milk protects the baby against respiratory illness (53.8%); 2) breastfeeding can serve as a contraceptive method during the first 6 months if babies are fully breastfed and postpartum amenorrhea persists (53.8%); 3) human milk provides the best nutrition to the baby (92.3%); 4) the quantity of human milk production does not depend on breast size (96.1%); and 5) human milk should not be alternated with artificial milk (84.6%) (Table 2).

Barriers for Initiation of Breastfeeding

84.6% of the mothers who decided not to breastfeed or discontinued breastfeeding reported baby sucking

problems as the principal reason for this decision. Other barriers identified in the study were issues related to health care personnel. It was observed that 50.0% of the participants were not allowed to have their baby with them during their stay in the hospital. Also, 30.8% of the participants stated they received no support from hospital personnel on breastfeeding a baby with Down syndrome.

Attitudes toward breastfeeding in public places

Among study participants, 61.5% stated that they would not breastfeed in public places. Among the reasons mentioned for not breastfeeding in public were: lack of knowledge, uncomfortable, preference for the use of bottle.

Table 1. Characteristics related to Mothers and Down Syndrome.

Variable	N	%
Mother's age (years)		
< 27	06	23.1
28-32	03	11.5
> 33	17	65.4
Education		
< Bachelor degree	11	42.3
> Bachelor degree	15	57.7
Duration of Pregnancy		
7 months	02	46.2
8 or 9 months	24	53.8
Previous Births		
Primiparous	08	30.8
Multiparous	18	69.2
Days of Postpartum Hospitalization		
2-3 days	23	88.5
> 4 days	03	11.5
Knowledge of Down Syndrome		
Diagnosis before delivery		
I know	10	38.5
I do not know	16	61.5
Down Syndrome Child Breastfeeding		
Yes	22	84.3
No	04	15.4
Type of Breastfeeding*		
Exclusivity	10	45.5
Partially	12	54.5
Infant's gender		
Female	14	53.8
Male	12	46.2
Others Infant's Health Conditions		
Yes	14	53.8
No	12	6.7
Number of daily visits to NICU (n=26)		
1-5	17	65.4
6-10	02	7.7
11-15	01	3.8
16-20	01	3.8
> 21	05	19.3

*Missing cases = 4

Table 2. Knowledge by mothers of infants with Down Syndrome about the benefits of breastfeeding (n=26).

Items	Correct		Incorrect	
	n	%	N	%
Human milk provides benefits to the baby (True).	26	100.0	0	0.0
Human milk provides antibodies that protect the baby against diseases (True).	26	100.0	0	0.0
Human milk protects the baby against gastrointestinal diseases (True).	19	73.1	7	26.9
Human milk protects the baby against respiratory illness (True).	12	46.2	14	53.8
Breastfeeding can serve as a contraceptive method during the first 6 months if babies are fully breastfed and post partum amenorrhea persists (True).	12	46.2	14	53.8
Lactation is not possible when you return to the job or school (False).	10	38.5	16	61.5
Artificial milk provides the best nutrition to the baby (False).	2	7.7	24	92.3
The quantity of human milk production depends on breast size (False).	1	3.8	25	96.1
Breastfeeding helps the mother lose weight (True).	22	84.6	4	15.4
Breastfeeding reduces the risk of breast cancer (True).	19	73.1	7	26.9
Human milk should be alternated with artificial milk (False).	4	15.4	22	84.6
You can breastfeed a baby with Down Syndrome using special techniques (True).	19	73.1	7	26.9
Babies with SD are capable of achieving an effective suction when breastfeeding (True).	21	80.8	5	19.2

Discussion

The principal barrier for initiation and/or discontinuation of breastfeeding among study participants was related to suckling problems. Infants with Down syndrome are likely to have hypotonia and frequent drooling which makes more difficult the achievement of an adequate seal, adequate negative pressure, and an adequate suckling mechanism (3). Nevertheless, this should not be a reason to deprive the infant of the benefits of breastfeeding. Moreover, one study of 59 babies with Down syndrome recorded that 31 infants had no problem establishing breastfeeding, although a severe cardiac anomaly was associated with ineffective suckling (5). Merewood and Phillipp (5) explained different strategies to manage the suckling problems in Infants with Down syndrome. In terms of position, the clutch or football hold can be useful. These positions allow an upright baby, the baby is more likely to remain awake, the mother can see the infant's mouth clearly on the breast, and she can support the head well.

Other barriers to initiation and/or prolongation of breastfeeding were identified among participants such as: poor support by NICU personnel (18) and physical distance between the mothers and infants during their stay in the hospital (19). Orientation should be provided to those closest to the mother in areas such as: the NICU routines, the importance of the closeness to the mother's room, number of daily visits allowed to the NICU, and the proper environment in NICU (20). It should be noted that the participants had an adequate knowledge about the benefits of breastfeeding.

A negative attitude toward breastfeeding in public places was observed. Donelda (21) and Forrester, et al. (22) observed a decrease in the percent of support

for breastfeeding in public places. Cultural, social and religious factors could explain this negative attitude among participants. It is important to develop research in this area to try to explain this finding.

This study was limited by sample size (n=26) of the mothers of infants with Down syndrome and may not be generalizable to the whole population. Infants with Down syndrome can breastfeed. These infants usually exhibit poor muscular tone at birth and breastfeeding helps them to strengthen muscle tone. It is important to be patient when breastfeeding these babies, since the process can be difficult due to the multiple health problems, especially suction problems, presented by these babies.

Various interventions, largely aimed at overcoming the difficulties associated with hypotonia, would improve the breastfeeding experience (23). In order to initiate and maintain breastfeeding, these mothers need early and effective assistance in the initiation of the process. This should include special techniques for latch-on and extraction of mother's milk. Also, stabilizing the head and the neck is particularly important in infants with Down Syndrome, because there might be malformations or laxity of the ligaments of the first two cervical vertebrae (atlanto-axial instability) that can put pressure on the brainstem or spinal cord with head flexion or excessive extension (24). The Dancer hand position can benefit many of these babies because it stabilizes the jaw and supports the masseter muscle, which decreases the intra-oral space and enhances the generation of negative pressure (23). In order for the mother to develop a good milk supply it is usually necessary that she pump or express her milk frequently if the baby is not taking the breast well (23). Active support, instruction, and collaboration among members of the health care team are essential for breastfeeding success.

Resumen

Objetivo: Identificar las barreras asociadas con la lactancia materna en madres puertorriqueñas de niños/as con Síndrome Down. **Método:** Una muestra no probabilística (n=26) de madres participaron en el estudio. La muestra fue obtenida de una institución especializada en el cuidado de infantes con Síndrome Down en Puerto Rico. Un cuestionario auto-administrable de seis secciones fue utilizado. Estadísticas descriptivas fueron utilizadas para el análisis de los datos. **Resultados:** La mayoría de las madres entrevistadas (80.8%) tuvieron 70.0% o más de respuestas correctas relacionadas a los beneficios de la lactancia materna. El 84.6% de las madres que decidieron no amamantar o discontinuar la lactancia materna reportó como la razón principal el que su bebé presentaba problemas de succión. **Conclusión:** Apoyo activo, instrucción, y colaboración entre los miembros del equipo de salud son esenciales para una lactancia materna exitosa en niños/as con Síndrome Down.

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