

Good health indicators in children with Down syndrome: High frequency of exclusive breastfeeding at 6 months

Buenos indicadores de salud en niños con síndrome de Down: Alta frecuencia de lactancia materna exclusiva a los 6 meses

Lorena Génova^{a,e}, Jaime Cerda^b, Catalina Correa^c, Natalia Vergara^c, Macarena Lizama^{a,d}

^aPediatric Department, Faculty of Medicine, Pontificia Universidad Católica de Chile, Santiago, Chile

^bPublic Health Department

^cSpecial Needs Health Care Program for Children and adolescents, Health Net UC CHRISTUS

^dUC Down syndrome Center, Pontificia Universidad Católica de Chile

^ePediatric resident

Received: 24-05-2017; Accepted: 19-10-2017

Abstract

Aim: To describe the frequency of exclusive breastfeeding at 6 months in binomial of mother and infants with Down Syndrome (DS) attending at the Health net UC CHRISTUS (PSSPSD-UC), and identify the main factors associated with exclusive breastfeeding cessation. **Patients and Methods:** Prevalence study of exclusively breastfeeding at 6 months of age that includes mother-child binomial of Chilean infants with (DS) aged 6-24 months, who attend the PSSPSD-UC. An on-line questionnaire was conducted, which included demographic data, child's background and experience in breastfeeding. **Results:** The total sample consisted of 73 binomials. Forty-six percent (34/73) of the mothers exclusively breastfed until 6 months or longer, 67.1% (49/73) of the infants had a disease or malformation that interfere with breast feeding. Among the 39 mothers who did not exclusively breastfeed until 6 months, 25 (64.1%) referred child factors. Hospitalization during the first 6 months was the most significant factor affecting the cessation of breastfeeding (OR = 6,13). **Conclusions:** First study in Chile that describes the frequency of exclusive breastfeeding at 6 months of age in children with DS, which shows a large rate of exclusively breastfeeding in the studied sample. The adequate support and education in breastfeeding could allow to achieve a better rate of exclusive breastfeeding in this vulnerable group.

Keywords:

Breast feeding,
Down syndrome,
lactation,
health promotion

Correspondence:
Macarena Lizama C.
mlizama@med.puc.cl

Introduction

Down syndrome (DS) corresponds to the most frequent chromosomopathy¹. In Chile, between 500 and 600 children are born with DS per year, an estimated figure according to annual births in Chile and the birth rate of children with DS of 2.5 per 10,000 live births, according to the Latin American Collaborative Study of Congenital Malformations (ECLAMC)¹.

Children with DS have characteristic phenotypic features and increased risk of congenital diseases and malformations, compared with the general population. It is known that those diseases and physical characteristics may interfere with breastfeeding (BF) in this group of patients. The conditions related to greater difficulty in initiating and maintaining BF are hypotonia, suction-swallowing disorders, congenital heart disease, macroglossia, gastrointestinal malformations, hypothyroidism, and intrauterine growth retardation or low birth weight²⁻⁵. Additionally, there are other circumstances that interfere with BF in infants with DS, such as the lack of BF education, prolonged hospitalizations, and the early milk formula indication^{4,6}. On the other hand, maternal feelings at the birth of a disabled child, such as stress, frustration, and depression, have been found to have a negative influence on BF^{2,7}.

The WHO defines the exclusive breastfeeding (EBF) as: "to give the infant only breast milk, without other liquids or solids, except for the administration of oral rehydration salts, vitamins, minerals or medications"⁸. The EBF in this group of patients presents the same benefits that in the general population such as risk reduction of recurrent chest infections, celiac disease, obesity, and cognitive developmental delay. However, it is important to consider that these conditions are more frequent in the population of children with DS, therefore the benefits are highly relevant. On the other hand, BF would help with the introduction of solid foods and would benefit the language development⁹⁻¹⁴.

The only data on the prevalence of EBF in children with DS in our country come from a nursing thesis study that estimates an EBF rate at six months of 6.25%¹⁵. International publications report variable rates of BF frequency in this group that is not comparable to our population^{6,12,16-19} or do not report the duration of EBF. In a research carried out in Mexico, it is described a start frequency of BF of 50%¹⁷, and in another study performed in Puerto Rico, the EBF prevalence was 45%¹⁶.

Despite the acknowledged benefits of BF, it is presumed that the mother-child binomial with DS adherence is lower compared to the general population, thus it is necessary to know the prevalence of EBF in this group of patients and determine the factors that

influence their adherence, in order to generate recommendations and interventions for the promotion of EBF in this most vulnerable group.

The objective of this study is to describe the frequency of EBF at six months in mother-child binomial with DS attending at the Health Care Program for People with DS of UC CHRISTUS Health Network (PSSPSD-UC) and identify the main factors associated with EBF cessation.

Patients and Method

This study of prevalence performed in mother-child binomials included Chilean mothers whose children had DS and attend to PSSPSD-UC between October 2015 and September 2016.

Inclusion Criteria

Mothers over 18 years old whose children had DS diagnosis, and who were between six to 24 months old at the time of the study. The mothers signed an informed consent in order to voluntarily participate in the study.

Exclusion Criteria

Mothers who do not speak Spanish or those who could not read the questionnaire were excluded.

For the study, the following definitions were considered

Children with DS: clinical diagnosis by classic physical characteristics and/or definitive diagnosis by karyogram: free, translocation, or mosaic trisomy.

EBF: children fed to the mother's breast or with expressed breast milk, without the support of artificial milk, formulas, or solid foods. It was accepted the history of milk formula administration only once within the first six months, and the use of vitamin supplements and medications, as well as complementary solid fruit feeding from five months.

Mixed BF: children fed with breast milk and milk formulas in any proportion (milk formulas more than once within the first six months of life).

Exclusive milk formula: children fed only with milk formula, without breast milk.

Recruitment process and data registration

STAGE 1) In a first instance, an e-mail was sent, using the data recorded in the PSSPSD-UC database, to invite the mothers to participate in the study and request the submission of data to the research team.

STAGE 2) Mothers who agreed to be contacted, received an online questionnaire using the Google Drive form with anonymization code, which included the

following demographic variables of the mother and family: socioeconomic status according to average monthly family income²⁰, perinatal history of the child with DS, associated pathologies and/or malformations of the child, hospitalizations during the first six months of life, type of BF and time of EBF, BF education, specific reasons for BF cessation, and maternal experience in the postnatal period. The questionnaire was sent three times to those mothers that did not answer.

STAGE 3) Before answering the questionnaire, approval of informed consent was requested, which was sent through the same electronic platform. Along with the questionnaire, an anonymization code was sent in order to protect the mother-child binomial identity. The questionnaire was completed voluntarily by the mothers, and the answers were received electronically by the same means. The data were collected and stored using the anonymization code previously delivered.

The research protocol was approved by the School of Medicine Scientific Ethics Committee of the Pontificia Universidad Católica de Chile.

Statistical analysis

Continuous variables were expressed in medians and ranges, and the categorical ones were expressed in percentages. For the identification of associated factors to EBF at six months, a univariate analysis was performed through Fisher's exact test and a multivariate one through logistic regression, expressing its results as Odds Ratios (OR) and confidence interval (CI) of 95%. The multivariate analysis was performed based on three models (INTRO mode). Models 1, 2, and 3 included those independent variables which in the univariate analysis showed an absolute value of difference of 20 or more, 15 or more, and 10 or more percentage points among those have EBF at six months versus EBF < 6 months. The goodness of fit of the three models was assessed comparing the value of -2 log likelihood. It was considered statistically significant a value of $p < 0.05$. The statistical analysis was performed using the SPSS statistical software version 22.

Results

During the study period, out of a total universe of 130 patients invited to participate, 87 mothers who met inclusion criteria expressed that they wanted to participate. A questionnaire was sent to all of them, with a response rate of 83.9% (73/87). Figure 1 shows in detail the sample collection method and the total sample collected. Table 1 shows demographic characteristics of the 73 mothers surveyed and the background of their respective children with DS.

The frequency obtained of EBF at six months was 46.6% (N = 34), 30.1% (N = 22) received EBF less than six months, and 23.3% (N = 17) received milk formula from the first feeding opportunity, in other words, the child never received EBF. Figure 2 shows EBF frequency by child age. Out of the total mothers surveyed, 95.9% (N = 70) of them breastfed (exclusively or not) for at least one month, and the 71.2% (N = 52) breastfed for six months or more. The 75.3% (N = 55) of them breastfed directly from the breast.

Regarding the reasons for EBF cessation before six months (N=39), 64.1% were because of factors associated to the child with DS (N = 25), 38.5% (N = 15) were due to factors associated to health care, and the 10.2% (N = 4) suspended EBF caused by maternal reasons. The 15.4% (N = 6) of the mothers related more than one reason of EBF cessation. Table 2 shows specific reasons for EBF cessation in each group.

All the mothers had the prenatal intention of BF her child, and all of them answered true to the statement that BF is the best food and it protects against diseases.

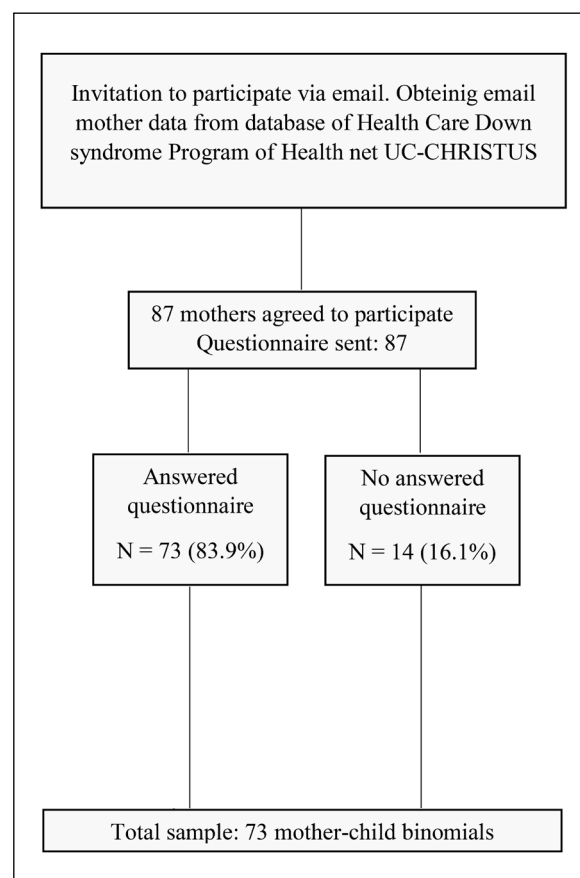


Figure 1. Sample collection method.

Out of the total of the mothers, 28.8% (N = 21) of them received prenatal education about BF, the 78.1% (N = 57) received education or support in BF during their stay in the maternity, and the 50.7% (N = 37) received postnatal support in BF, whether in breastfeeding clinic or in other support groups. Out of the mothers with previous experience in BF, the 71.7% (33/46) reported having a good previous experience in BF.

75% (30/40) of the mothers had paid work outside the home and had maternity leave of six months or more.

15.1% (N = 11) of the mothers had a medical diagnosis of post-partum depression, and the 46.6% (N = 34) of them had feelings of depression in the postnatal period. 41.1% (N = 30) of them reported stress or fear among the prevalent feelings during the first six months of life of their child.

Of the total sample, 67.1% (N = 49) of the children had some pathology or malformation associated. The most frequent pathology was congenital heart disease, which represents the 45.2% (N = 33) of the sample.

The 65.8% (N = 48) of the children were hospitalized in the neonatal period, and the 35.6% (N = 26) were hospitalized during the first six months of life.

According to univariate analysis, being only child ($p = 0.031$), the good previous experience in BF ($p =$

0.036), the hospitalization within the first six months ($p = 0.015$), and the use of nasogastric tube (NGT) in the first six months ($p = 0.013$), would be factors statistically significant for EBF cessation before the six months. Table 3 shows the univariate analysis of EBF frequency up to six months versus EBF frequency less than six months by reason of EBF cessation according to child, mother or health care system factors.

Table 4 shows the multivariate analysis by logistic regression with three statistical models of EBF frequency up to six months versus EBF frequency less than six months by reason of EBF cessation according to child, mother or health care system factors. According to multivariate analysis, the use of NGT and the hospitalization within the first six months would be factors statistically significant for EBF cessation before six months with an adjusted OR = 4.00 (CI 95% 1.24-12.94) and 6.13 (CI 95% 1.48-25.40), respectively.

Discussion

This study shows a high frequency of EBF up to six months in the mother-child binomial with DS with a rate of 46.6% of EBF and 71.2% of BF (exclusive or not) up to six months. It is further emphasized that the 96% of the mothers breastfed for at least one month.

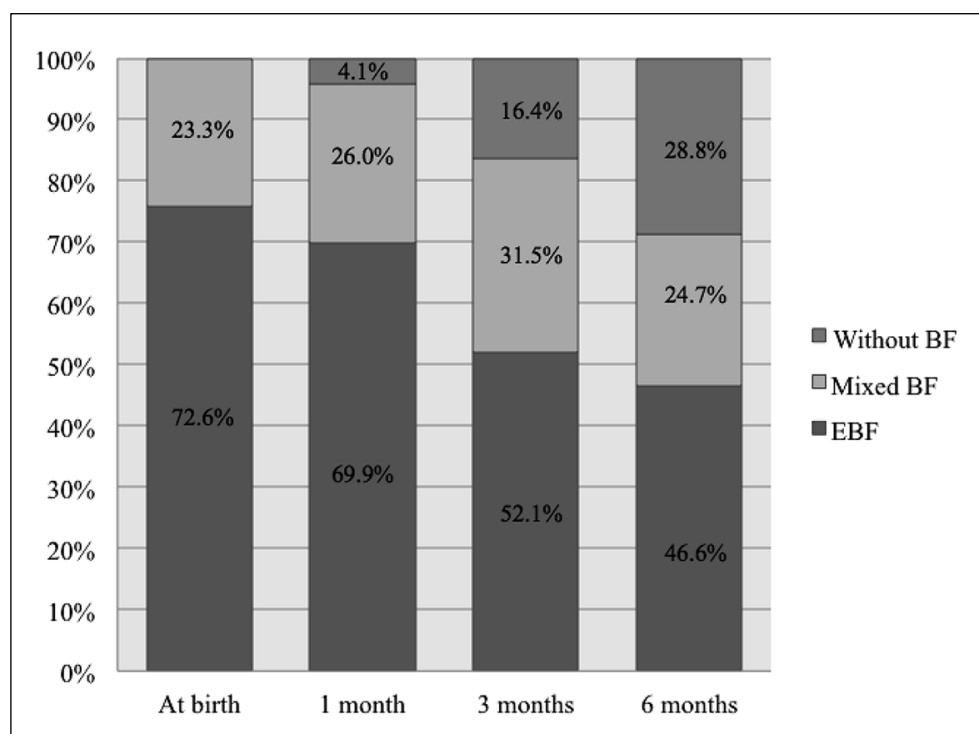


Figure 2. Exclusive, mixed or without Breastfeeding frequency by children age groups. BF Breast Feeding; EBF: Exclusive Breastfeeding.

Table 1. Demographic characteristics of population surveyed

Characteristics	n = 73	%
Child		
Gender Male	40	54.8%
Being only child	27	37%
Cesarean delivery	35	47.9%
Term Newborn ^a	45	61.6%
Birth weight grams average ^b (\pm SD)	3.029	(\pm 401)
Prenatal diagnosis (suspect or confirmed) of DS	21	28.8%
Malformation or associated disease	49	67.1%
Congenital heart disease	33	45.2%
Hospitalization during neonatal period	48	65.8%
Hospitalization during first 6 months	26	35.6%
NGT in the first 6 months	24	32.9%
Poor weight increase first 6 months	16	21.9%
Mother		
Age in years: median (range) ^c	37	(23-47)
Remunerated job	60	82.2%
Complete Higher Education ^d	64	87.7%
Good previous experience in BF	33	45.2%
Post-partum depression ^e	11	15.1%
Family demographic characteristics		
Capital city	60	82.2%
High socioeconomic status ^f	44	60.3%
Middle socioeconomic status ^f	27	37%
Low socioeconomic status ^f	2	2.7%
Mother-child binomials		
EBF at 6 months	34	46.6%
EBF less than 6 months	39	53.4%
Early skin contact ^g	43	58.9%
Prescription of EBF at discharging from maternity	32	43.8%
Postnatal education of BF ^h	37	50.7%

SD: Standard Deviation standard; DS: Down syndrome; NGT: Nasogastric tube; BF: breastfeeding; EBF: Exclusive Breastfeeding.

^aGestational age equal or greater than 37 weeks, ^bWeight of Term newborns, ^cMaternal age at child birth, ^dTechnical or professional education, ^eDiagnosed by a Medical Doctor, ^fClassified according to average family income (CAsEN 2013), ^gAt child birth,

^hAt breastfeeding clinics or support groups.

Table 2. Reasons for cessation of exclusive breastfeeding before 6 months

Reasons	n = 39	%
Mother	4	10.2
Mother disease	2	5.1
Back to work or studies	2	5.1
Child	25	64.1
Poor weight increase	11	28.2
Suction-swallowing disorder	9	23.1
Associated disease	2	5.1
Baby was hungry	3	7.7
Health care	15	38.5
Hospitalization	7	17.9
Medical prescription of formula despite good weight increase	8	20.5

Table 3. Comparison between group that received EBF until 6 months and group with EBF less than 6 months (univariate analysis)

Variables	EBF 6 months N = 34	EBF < 6 months N = 39	Absolute value of difference of % points*	p value**
Preterm Newborn (< 37 weeks)				
Yes (28)	11 (32.4%)	17 (43.6%)	11.2	0.347
No (45)	23 (67.6%)	22 (56.4%)		
Being only child				
Yes (27)	8 (23.5%)	19 (48.7%)	25.2	0.031**
No (46)	26 (76.5%)	20 (51.3%)		
Good previous experience in BF				
Yes (33)	20 (58.8%)	13 (33.3%)	25.5	0.036**
No (40)	14 (41.2%)	26 (66.7%)		
Early skin contact				
Yes (43)	23 (67.6%)	20 (51.3%)	16.3	0.233
No (30)	11 (32.4%)	19 (48.7%)		
Suspect or confirmed prenatal diagnosis of DS				
Yes (21)	7 (20.6%)	14 (35.9%)	15.3	0.198
No (52)	27 (79.4%)	25 (64.1%)		
Malformation or associated disease				
Yes (49)	24 (70.6%)	25 (64.1%)	6.5	0.623
No (24)	10 (29.4%)	14 (35.9%)		
Congenital heart disease				
Yes (33)	16 (47.1%)	17 (43.6%)	3.5	0.817
No (40)	18 (52.9%)	22 (56.4%)		
Prescription of EBF at discharging from maternity				
Yes (32)	18 (52.9%)	14 (35.9%)	17	0.163
No (41)	16 (47.1%)	25 (64.1%)		
Postnatal education of BF				
Yes (37)	14 (41.2%)	23 (59.0%)	17.8	0.162
No (36)	20 (58.8%)	16 (41.0%)		
Hospitalization during neonatal period				
Yes (48)	19 (55.9%)	29 (74.4%)	18.5	0.138
No (25)	15 (44.1%)	10 (25.6%)		
Hospitalization during first 6 months				
Yes (26)	7 (20.6%)	19 (48.7%)	28.1	0.015**
No (47)	27 (79.4%)	20 (51.3%)		
NGT in the first 6 months				
Yes (25)	6 (17.6%)	18 (46.2%)	28.6	0.013**
No (49)	28 (82.4%)	21 (53.8%)		
Poor weight increase firsts 6 months				
Yes (16)	4 (11.8%)	12 (30.8%)	19	0.087
No (57)	30 (88.2%)	27 (69.2%)		
Post-partum depression				
Yes (11)	6 (17.6%)	5 (12.8%)	4.8	0.745
No (62)	28 (82.4%)	34 (87.2%)		

EBF: Exclusive Breastfeeding; DS: Down Syndrome, BF: Breastfeeding, NGT: Nasogastric Tube. *Absolute value of the difference of percentage points between the group with EBF up to 6 months and the group with EBF less than 6 months. **Significative p value ≤ 0.05 .

Table 4. Multivariate analysis for factors that influence in Exclusive breastfeeding up 6 months or less than 6 months

	Model 1*	Model 2*	Model 3*
Built- in variables	<ul style="list-style-type: none"> • Being only child • Good previous experience in BF • Hospitalization during first 6 months • NGT in the first 6 months 	<ul style="list-style-type: none"> • Being only child • Good previous experience in BF • Hospitalization during first 6 months • NGT in the first 6 months • Early skin contact • Suspect or confirmed prenatal diagnosis of DS • Prescription of EBF at discharging from maternity • Postnatal education of BF • Hospitalization during neonatal period • Poor weight increase firsts 6 months 	<ul style="list-style-type: none"> • Being only child • Good previous experience in BF • Hospitalization during first 6 months • NGT in the first 6 months • Early skin contact • Suspect or confirmed prenatal diagnosis of DS • Prescription of EBF at discharging from maternity • Postnatal education of BF • Hospitalization during neonatal period • Poor weight increase firsts 6 months • Preterm Newborn
Goodness of fit (-2 log likelihood)	83.329	75.095	74.731
OR significative variables	<p>Hospitalization during first 6 months Adjusted OR = 3.34 (CI 95% 1.07 -10.47)</p> <p>NGT in the first 6 months Adjusted OR = 4.00 (CI 95% 1.24 – 12.94)</p>	<p>Hospitalization during first 6 months Adjusted OR = 5,62 (CI 95% 1.41-22.48)</p>	<p>Hospitalization during first 6 months Adjusted OR = 6,13 (CI 95% 1.48-25.40)</p>

EBF: Exclusive breastfeeding, DS: Down Syndrome, BF: Breastfeeding, NGT: Nasogastric Tube. *Multivariate analysis using 3 logistic regression models (INTRO mode): The Model 1 considered those variables that as a result of univariate analysis presented an absolute value of difference of 20 or more percentage points between those who presented EBF at 6 months versus EBF < 6 months. Model 2 considered those variables that presented an absolute value of difference of 15 or more percentage points. Model 3 considered the variables with absolute value of difference of 10 or more percentage points.

Although the EBF frequency in our population was significantly higher than the one reported in the thesis of Quezada in 2001 of 6.25%¹⁵, it is less than the one reported in Chile for the general population that, according to the last National Survey on BF in Primary Health Care (ENALMA), 2013, would reach a 56.3%²¹. ENALMA was conducted after the implementation of the postnatal parental leave Law of 5.5 months, showing an increase of 11.4% since the entry into force of the Law²¹. Such intervention could be also positively affecting the study group due to the inclusion of patients in this study after the implementation of the legislation.

International publications report frequency of BF (exclusive or not) in children with DS lower than the one obtained in our population. Rendon-Macias described that, in Mexico, only the 50% of children with DS start BF, and other studies report EBF prevalences close to 45%, without specifying the length of EBF^{2,16}. Studies that compare BF between children with DS and the general population have shown mixed results. In Italy, Pisacane reported that the 45% of the children with DS are breastfed with an average of 56 days versus

an 85% in the controls, with an average of 154 days⁶. On the other hand, in the Netherlands, no significant differences were found in BF frequency in children with DS versus the general population, with a 67% versus a 78% respectively¹².

Recent studies have shown that over time, the frequency of BF in children with DS increase. In 2015, Glivetic reported an increment of 10% from 2009 to 2012, concluding that there are interventions that can be carried out to favor BF in this group¹⁸.

The last report on global prevalence of BF in 2016²², showed an average frequency of EBF up to six months of 37% in low-and middle-income countries, being even lower in the more developed countries. Comparing it with our results, we obtained a higher frequency than the reported in both EBF and non-exclusive BF up to six months, which makes this indicator considered a very good result.

Studies in the general population and at-risk populations show that the intention of the mother of BF is decisive in order to achieve EBF^{16,23}. In this study, all the mothers had the antenatal intention of BF and they recognized the benefits of BF. The fact that the

child was an only child was a factor that significantly influenced the EBF cessation before six months and despite not obtaining a statistically significant difference, we observed that having a good previous experience in BF was associated with a higher frequency of EBF up to six months, which is consistent with what was reported for the general population²¹.

With regard to EBF cessation, the mothers reasons were the less relevant in this study. In relation to the medical diagnosis of post-partum depression, the prevalence was similar to the reported for the general population²⁴ and it was not a determining factor in the EBF frequency. On the other hand, the antenatal diagnosis or suspicion of DS that could positively affect due to the anticipation and preparation of the mother to the diagnosis, was not a factor that favors the BF, by contrast, in the group with prenatal suspicion or diagnosis there was a lower frequency of EBF at six months, which may be determined by other added factors in that group such as the presence of congenital malformations associated to DS that led to suspicion of chromosomopathy in the fetal period²⁵.

The most frequent reason referred by mothers to discontinue the EBF was for reasons of the child, mainly associated with sucking-swallowing disorders and poor weight gain, which coincides with those described by Colón et al. in Puerto Rico¹⁶. Poor weight gain during the first six months was one of the non-statistically significant factors that negatively affected the BF. On the other hand, the use of NGT (associated with the sucking-swallowing disorder) significantly interfered with EBF in our population, consistent with what was described in the mentioned studies. Although the factors of the child are the most difficult to intervene, it is possible to optimize the BF with an appropriate support and using individualized techniques for each patient and associated pathology or malformation^{26,27}.

Factors associated with health care, such as the medical indication of initiation of formula or the mother-child separation due to hospitalization, have been described as relevant to the EBF cessation. In our study, 36% of the children were hospitalized during the first six months, being this a significant antecedent, both in the univariate and multivariate analysis in all models analyzed, in the EBF cessation. During hospitalization, mainly in the Intensive Care Unit, the severity of the pathology and the stress of the mother can negatively impact in the EBF. However, it is possible to promote the maintenance of EBF in the hospital environment through education, promotion of milk extraction and avoiding separation of the mother-child binomial during the stay^{28,29}. Considering the above, this factor is the most modifiable with educational interventions and changes in the pediatric hospital services policies,

where facilities could be optimized to maintain the EBF in this group of patients.

One of the main limitations of our work is that the studied population does not represent the national reality since it corresponds to a specific population with a medium-high socioeconomic status, which has access to multidisciplinary care specialized in patients with DS and early referral to a lactation clinic. Despite this, it is important to note that this limitation allows us to infer that targeted and early interventions allow strengthening the EBF in this group of children with special needs. Another limitation is that the mothers who agreed to participate and answered the survey could be those who precisely had the best experience in BF and for this reason were more interested in expressing it. Finally, to reduce memory bias, we included mothers whose children were two years old or younger at the time of entering the study, however, it is possible that at two years of age, mothers did not reliably remember the events that occurred during the first six months of life.

We can infer that is possible to achieve a higher frequency of EBF up to six months in children with DS, overcoming barriers and limitations of this population through specific techniques and appropriate support to the mothers. There is clear evidence that the support in BF in both, antenatal and postnatal, is effective in order to achieve the EBF in the general population³⁰⁻³³, and there are specific techniques that can be used in children with DS³⁴⁻³⁶ such as: encourage the early skin-to-skin contact, initiation of BF in the first hours of life, educating on positioning techniques with an adequate head and chin support, favoring tongue protrusion, education and exercise through non-nutritive sucking and manual and pumped milk extraction techniques and storage specifications³⁷.

In the future, new studies are required to assess the efficacy of promotion techniques and the support in BF in this group of patients, and thereby encourage the development of intervention methods by health professionals, both in outpatient and inpatient settings.

Conclusions

This study shows the high frequency of EBF in children with DS. As a healthcare team, we must be convinced that children with DS are capable of receiving EBF and with appropriate BF support and education, it can be successful with high exclusivity frequency up to six months.

We recognize that the prevalence of EBF could be even better, so we recommend promotion in BF and generate changes in the main factor described in this study and that is also modifiable, for this we propose:

to optimize the comprehensive care of the child with DS that allows to prevent hospitalizations, and in the inpatient environment to educate health professionals about the benefits of the BF in this group, in order to promote it and allow access to BF (direct or expressed), considering the creation of BF rooms and to avoid interfering with the BF process.

Ethical responsibilities

Human Beings and animals protection: Disclosure the authors state that the procedures were followed according to the Declaration of Helsinki and the World Medical Association regarding human experimentation developed for the medical community.

Data confidentiality: The authors state that they have

followed the protocols of their Center and Local regulations on the publication of patient data.

Rights to privacy and informed consent: The authors have obtained the informed consent of the patients and/or subjects referred to in the article. This document is in the possession of the correspondence author.

Financial Disclosure

Authors state that no economic support has been associated with the present study.

Conflicts of Interest

Authors declare no conflict of interest regarding the present study.

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