Facilitating factors, main difficulties and strategies used in breastfeeding of Down syndrome infants: a systematic review

Fatores facilitadores, principais dificuldades e estratégias empregadas no aleitamento materno de bebês com síndrome de Down: uma revisão sistemática

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ABSTRACT

Purpose: To investigate in the literature the main difficulties related to breastfeeding in babies with Down syndrome, facilitating factors and indicated strategies. Methods: A systematic review was accomplished on PubMed, Scielo and VHL databases. The following descriptors were used: Down Syndrome and Breastfeeding and their correspondents in Portuguese and Spanish. Selection criteria: Original articles that addressed breastfeeding in Down syndrome, published in Portuguese, English or Spanish, between 1998 and 2018, were included. The following information was considered: year of publication, country of the research, sample, difficulties perceived in breastfeeding, facilitating factors, strategies, methodology and results. Results: 758 references were found, of which six contemplated the proposed selection criteria. Maternal emotional state due to the impact of the news, baby specifics, sucking difficulties, frequent hospitalizations and lack of support and knowledge on the part of health professionals were aspects that made breastfeeding difficult. The main facilitating factors cited were previous experience and family and professional support. As a direct strategy, stabilization of the baby’s head and mandible during feeding was pointed out. The indirect strategies cited were related to professional training and early multidisciplinary intervention. Conclusion: after analyzing the selected articles, it was concluded that breastfeeding difficulties in babies with Down Syndrome arise from the condition of the baby and the mother. Previous maternal experience and family support were cited as facilitators of breastfeeding. The main recommended strategies were indirect and related to the improvement of the health system.

Keywords: Breast feeding; Down Syndrome; Speech, language and hearing sciences; Counseling; Health education

RESUMO

Objetivo: Investigar, na literatura, as principais dificuldades encontradas no aleitamento materno de bebês com síndrome de Down, os fatores facilitadores e as estratégias utilizadas para melhorar a amamentação desses bebês. Métodos: Foi realizada uma revisão sistemática nas bases de dados PubMed, SciELO e BVS. Os termos utilizados foram síndrome de Down e aleitamento materno e seus correspondentes em inglês e espanhol. Critérios de seleção: Foram incluídos artigos originais que abordaram o aleitamento materno na síndrome de Down, publicados em português, inglês ou espanhol, de janeiro de 1998 a dezembro de 2018. Foram consideradas informações referentes ao ano de publicação, país de realização da pesquisa, amostra, dificuldades percebidas na amamentação, fatores facilitadores, estratégias, metodologia e resultados. Resultados: Foram encontradas 758 referências, das quais, seis contemplaram os critérios de seleção propostos. Estado emocional materno frente ao impacto da notícia, especificidades do bebê, dificuldades de sucção, internações frequentes e falta de apoio e conhecimento por parte dos profissionais de saúde foram aspectos que dificultaram a amamentação. Os principais fatores facilitadores citados foram experiência prévia e apoio familiar e profissional. Como estratégias diretas, foram apontadas a estabilização da cabeça e da mandíbula do bebê durante a mamada. As estratégias indiretas citadas relacionaram-se à capacitação profissional e intervenção multidisciplinar precoce. Conclusão: Concluiu-se que as dificuldades na amamentação são provenientes da condição do bebê e da mãe. Experiência materna prévia e apoio familiar foram citados como facilitadores do aleitamento. As principais estratégias recomendadas foram indiretas e relacionadas com melhoria do sistema de saúde.

Palavras chave: Aleitamento materno; Síndrome de Down; Fonoaudiologia; Aconselhamento; Educação em saúde
INTRODUCTION

The World Health Organization (WHO), endorsed by the Ministry of Health, recommends exclusive breastfeeding up to the sixth month of life and supplemented until 2 years old or older

Breast milk offers immunological support by its antibodies capable of enhancing the baby’s immunity; it is the complete food, both in nutritional and digestive aspects, besides promoting the bond between the mother and the child

Other benefits of breastfeeding for the baby include protection against diarrhea, respiratory infection, allergies, hypertension, high cholesterol and diabetes

Several campaigns to encourage breastfeeding have been carried out around the world, aimed at making families and professionals aware of adhering to this practice since due to the benefits of breast milk, the rate of breastfeeding can reduce infant mortality

The benefits of breast milk are for all babies. However, because it reduces the risk of infections, cardiac disease, and obesity, breastfeeding is especially important for babies with Down syndrome (DS), in which such clinical conditions are more frequent, promoting craniofacial, cognitive and language development, among other advantages

Breastfeeding also influences the development of the stomatognathic system musculature. During breast milk extraction, the newborn performs mandible and lingual movements, with an ideal force for the development of the musculature, providing the correct establishment of the functions performed by the phonoarticulatory organs. This is particularly important for babies with DS, who tend to have generalized muscular hypotonia, and directly affecting the stomatognathic system

Down syndrome is a genetic anomaly caused by a tripling of chromosome 21. It has an incidence of one in 600 to 800 births, regardless of ethnicity, gender or social class. It is often diagnosed at birth, causing frustration to parents who are not prepared to deal with a disabled baby

The literature shows few studies related to breastfeeding in infants with DS. Due to the specificities found in this syndrome, such as muscle hypotonia, macrognlossia, associated comorbidities and emotional aspects of the mother, greater support may be necessary. Mothers of babies with DS have difficulty breastfeeding. Studies on the prevalence of breastfeeding in babies with DS have identified lower rates than in the general population and a reduction in breastfeeding duration in these babies with DS

The reasons for these difficulties and which strategies can be used to assist mothers of babies with DS are little known. Thus, it is important to understand the factors that facilitate and hinder breastfeeding in this population, so health promotion actions, with appropriate recommendations, can elaborate effective strategies that can solve or minimize problems

Therefore, the aim of this study was to investigate the main difficulties encountered in breastfeeding infants with DS, the facilitating factors and the strategies that are used to improve breastfeeding of these infants in the literature.

METHODOLOGY

Research strategy

A systematic literature review was performed involving the following steps: the preparation of guiding questions, the establishment of keywords and criteria for inclusion/exclusion of the articles, the selection of articles and the critical evaluation of the articles.

The guiding questions of the study were: “What are the breastfeeding difficulties perceived by mothers of DS babies?”; “What are the facilitating factors for breastfeeding infants with DS?”; “What strategies are used to improve breastfeeding in infants with DS?”

Through these guiding questions, the facilitating and hindering factors of breastfeeding in babies with DS were understood, so this information can be used in the elaboration of strategies capable of solving the problems, promoting an increase in the breastfeeding rates initiation and the duration of breastfeeding of these babies.

A survey was conducted in the national and international literature, published in English, Portuguese or Spanish, using the PubMed, SciELO and VHL databases, as with a large number of publications related to health. The terms used in the research were: “Síndrome de Down” and “Aleitamento materno” in Portuguese; “Down syndrome” and “Breastfeeding” in English, and “Síndrome de Down” and “Lactancia materna” in Spanish.

Selection criteria

Original articles about breastfeeding in Down syndrome, published in Portuguese, English or Spanish, from January 1998 to December 2018 were included. Articles that did not address at least one of the following information were excluded: difficulties, facilitating factors and strategies for breastfeeding in babies with Down syndrome.

Data analysis

The material analysis was performed in stages. In the first stage, duplicate references in the queried databases were deleted. In the second stage, articles that did not meet the established inclusion criteria by reading the abstracts were excluded. Articles that met the inclusion criteria were obtained in full.

The third stage consisted on the analysis of the articles full texts, potentially relevant for the review, through a structured script. The following data were collected: year of publication, country of research, sample, perceived difficulties in breastfeeding, facilitating factors, strategies used, data collection methodology and results obtained. Articles that did not address at least one of these pieces of information were excluded.

Two speech therapists independently selected the articles after reading them fully and the abstracts. Data management was performed in Microsoft Excel and a spreadsheet was prepared which allowed the evaluators two answers for the selection: yes or no. Articles answered with “yes” from both evaluators were included for full reading and those answered with “no” from both researchers were excluded from the study. When there was a divergence of answers between the evaluators, a consensus meeting was held.
Results

Initially, 758 references were found, but 64 were excluded by duplicity and 686 were deleted after the title and the abstract being read. Eight articles were read in full, and 2 were excluded because they did not include the information established in the selection criteria. Thus, after the third stage, 6 articles remained in this study (Figure 1).

Data regarding the country of publication, sample, the methodology used, factors that hinder and facilitate breastfeeding in infants with DS and the strategies proposed for each of the selected articles are presented in Chart 1.

The articles selected in this research were published between January 1999 and December 2018. Brazil was the country that most participated in this type of research with participants ranging from 6 to 560.

The methodology that allowed data collection from the research analyzed consisted mainly of self-administered questionnaires and interviews, in which the mother answered according to her experiences. Only one research conducted an interview with doctors and the breastfeeding assessment was not performed in any of the researches.

![Figure 1. Flowchart of the study selection process](image-url)
The main difficulties in breastfeeding in the articles were related to the emotional aspects of the mother when she received the news of DS[12,14-16], the lack of preparation of the professionals to deal with this situation[14,17], the need for frequent hospitalizations due to comorbidities found in the baby with DS[4,12,16], and suction changes[4,12,17].

Only 2 strategies were mentioned as facilitators of suction: stabilization of the head and neck and stabilization of the baby’s mandible[17]. All the research highlighted the need for better education and support from health professionals.

DISCUSSION

Breastfeeding in babies with DS has been the subject of research in different countries. Studies highlighted the importance of properties against diseases in breast milk for babies with DS since they have predispositions for immunological diseases, allergies, obesity and infections[12].

Studies on different continents have been conducted to understand why many mothers of DS babies do not breastfeed or wean early. Research with the largest number of participants was conducted in Arabia[15] and Italy[12], in which there are greater financial resources compared to other countries that have published on this subject. In Brazil, studies were conducted with a small sample and qualitative approach[14,16].

Questionnaires and interviews with mothers were the sources of information from the research analyzed. One limitation of this type of methodology was the application months or even years after the baby was breastfed, needing to consider the mother’s memory of her past experiences. No research was found that included breastfeeding assessment by a trained professional. The assessment of breastfeeding, through an appropriate tool and competent professional, would enable the research of behaviors of mothers and babies favorable to breastfeeding or suggestive of difficulties, factors related to body position, grip, suction efficiency, among others that would allow an effective aid.

Emotional aspects were one of the main difficulties reported by the mother, described as news impact[14], frustration[15], depression[12] and difficulty in accepting[16]. The diagnosis of Down syndrome is often informed by the provider after delivery, and since the birth of a disabled child is not expected by the parents, the way the provider addresses the suspicion or diagnosis of DS makes all the difference and may or may not extend the mother’s suffering[12]. In one research, 56% of parents of infants with DS considered the manner they received the diagnosis inadequate[18].

Some diseases such as congenital heart disease[12] are common in individuals with DS discovered at pregnancy or at birth, with an estimated prevalence of 79% of the population with DS[19]. These babies often require surgeries[12] and hospitalizations[4,12,16], delaying their approach to the mother[17] and causing a decrease in milk production due to the lack of suction stimulus[4,12]. Added to these factors, there are also suction difficulties[4,17], characteristic of the muscular hypotonia of the syndrome, which also contributes to the low maternal milk production.

The unpreparedness of health professionals to deal with this situation and the lack of support from the health team were also difficulties reported in the research[14,17], not only when informing the diagnosis, but also in the management of breastfeeding. Training for professionals is extremely important to gain knowledge of strategies that solve the difficulties presented by mothers[20].

The baby with DS has global hypotonia, which includes stomatognathic system structures such as tongue, lips, cheeks, and jaw-lifting muscles, and consequently causes suction difficulties, since it is important to have compression and veiling to suckle lip movement, movement of the masseter muscles and mandible and anteroposterior movements of the tongue[21]. Although there is the difficulty of sucking caused by muscle hypotonia, it is necessary that these babies perform suction for the development of this musculature. Other factors hindering breastfeeding are the use of the nasogastric tube[4] and low weight gain[4] related to the difficulty of sucking, and also the beliefs about the benefits of formula and bottle feeding[15] that further contribute to early weaning.

Some factors were reported as facilitators of suction in different researches. The experience with breastfeeding in previous pregnancies[4,14] was a facilitating condition, increasing intention, affective bonds and desire to breastfeed[22]. Other facilitators mentioned included family support[16], which provides security and a positive attitude of the mother regarding breastfeeding[23]. Also, support from the health team[14,16] when they are properly trained, they have favorable breastfeeding attitudes and help the formation of the mother-child bond. More facilitators are religion, beliefs[16] and breastfeeding in the first hour after birth, which may not occur due to complications that some babies with DS present soon after birth[19].

All articles mentioned professional and/or health system support as strategies for improving breastfeeding of infants with DS. Professionals should be trained, educated and updated to talk with parents and clarify any doubts about DS, leaving them comfortable and respecting the feelings of shock, denial and grief that many of them go through during this period of adaptation and acceptance of the new baby, helping and supporting the mother during breastfeeding[20]. However, it is an indirect strategy. Through this research, it was expected to obtain direct strategies related, for example, to the handling of the baby. Only one study[17] pointed at head and neck stabilization as a facilitating strategy for breastfeeding. The authors explained that stabilization is important in infants with DS, who are more likely to have malformations or ligamentous laxity in the first two cervical vertebrae (atlandoaxial instability[24]), which can put pressure on the brain stem or spinal cord during flexion or excessive extension of the head. Another strategy cited by the authors[17] to provide stability to the baby’s jaw and masseter support is to position the U-shaped hand with the index finger and thumb forming the U, and the baby’s chin must be positioned in the concavity of the U.

A limitation of this study was the lack of separation of the studied aspects, according to the age of the baby. The difficulties in initiating breastfeeding in newborns are different from those found in continuing breastfeeding in infants. Because they had methodologies based on questionnaires and interviews with the parents after the breastfeeding period, the studies addressed in this research did not show such distinction.

Studies about breastfeeding in Down syndrome are scarce. Research is needed with larger numbers of babies. These researches should point out direct strategies to improve breastfeeding and perform breastfeeding observation, so professionals can understand what happens during this process.
CONCLUSION

Babies with Down syndrome have specificities that can cause difficulties in breastfeeding, such as stomatognathic system changes and frequent hospitalizations. However, the main complaints of mothers were the lack of support from the health team and emotional changes at the impact of the news. The main facilitating factors in the articles were previous experience and family and professional support. As direct strategy, there was stabilizing the baby’s head and jaw during breastfeeding and as indirect strategies there were professional training, early multidisciplinary intervention and improved support offered by the health system.

REFERENCES