REME • Rev Min Enferm. 2023;27:e-1508
DOI: 10.35699/2316-9389.2023.37077

RESEARCH

IMPACT OF THE DIAGNOSIS OF DOWN SYNDROME IN THE MATERNAL PERSPECTIVE

IMPACTO DO DIAGNÓSTICO DE SÍNDROME DE DOWN NA PERSPECTIVA MATERNA

IMPACTO DEL DIAGNÓSTICO DEL SÍNDROME DE DOWN DESDE LA PERSPECTIVA MATERNA

Danton Matheus de Souza[1]
Aurea Tamami Minagawa Toriyama[2]
Cecília Helena de Siqueira Sigaud[2]
Fabiana Lucélia de Miranda Campos[3]

[1]Universidade de São Paulo - USP, Unidade de Pediatria Integrativa do Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo - HCFMUSP. São Paulo, SP - Brazil.

[2]Universidade de São Paulo - USP, Escola de Enfermagem - EE. São Paulo, SP - Brazil.

[3]Universidade de São Paulo - USP, Faculdade de Medicina da Universidade de São Paulo - HCFMUSP. São Paulo, SP - Brazil.

Corresponding Author: Danton Matheus de Souza
E-mail*:* danton_souza@usp.br

Authors' Contributions:

Conceptualization: Cecília H. S. Sigarud, Danton M. Souza; ***Data Collection***: Danton M. Souza, Fabiana L. M. Campos; ***Investigation***: Cecília H. S. Sigarud, Danton M. Souza; ***Methodology***: Cecília H. S. Sigarud, Danton M. Souza; ***Project Management***: Cecília H. S. Sigarud; ***Supervision***: Aurea T. M. Toriyama, Cecília H. S. Sigarud; ***Validation***: Aurea T. M. Toriyama, Cecília H. S. Sigarud; ***Visualization***: Aurea T. M. Toriyama, Cecília H. S. Sigarud, Danton M. Souza, Fabiana L. M. Campos; ***Writing - Original Draft Preparation***: Cecília H. S. Sigarud, Danton M. Souza; ***Writing - Review and Editing***: Aurea T. M. Toriyama, Cecília H. S. Sigarud, Danton M. Souza.

Funding: No funding.

Submitted on: 12/02/2021
Approved on: 04/18/2023

Responsible Editors:
Bruna Figueiredo Manzo
Tânia Couto Machado Chianca

ABSTRACT

Objective: to understand maternal perceptions about the diagnosis of Down Syndrome (DS) of their children as children. **Method**: exploratory-descriptive study with a qualitative approach carried out with 9 mothers of children with DS in a tertiary public hospital in the city of São Paulo. Data collection took place through individual and semi-structured interviews, guided by a script of topics. Data were analyzed using thematic content analysis and considering the principles of anchoring and objectification of the Theory of Social Representations. **Results**: data were analyzed, and two main categories emerged: 1) maternal perceptions regarding communication of the child's DS diagnosis; and 2) maternal perceptions about the impact of the child's DS diagnosis, with interconnected subcategories. **Conclusion**: there was predominantly inadequate management by professionals when communicating the diagnosis of DS, which potentiated the emotional reactions of suffering, which were not restricted to the moment of the news. Reactions can be mitigated or enhanced with the experience of motherhood and with family and social interactions and with health professionals.

Keywords: Down Syndrome; Pediatric Nursing; Family Health; Health Communication; Qualitative Research.

RESUMO

Objetivo*: compreender as percepções maternas acerca do diagnóstico de Síndrome de Down (SD) de seus filhos quando crianças.* ***Método****: estudo exploratório-descritivo com abordagem qualitativa realizado com 9 mães de crianças com SD em um hospital público de nível terciário no município de São Paulo. A coleta dos dados ocorreu por meio de entrevistas individuais e semiestruturadas, guiadas por roteiro de tópicos. Os dados foram analisados por meio da análise temática de conteúdo e à luz dos princípios de ancoragem e objetivação da Teoria das Representações Sociais.* ***Resultados****: os dados foram analisados e emergiram duas categorias principais: 1) as percepções maternas em relação à comunicação do diagnóstico de SD do filho; e 2) as percepções maternas acerca do impacto do diagnóstico de SD do filho, com subcategorias interligadas.* ***Conclusão****: constatou-se manejo predominantemente inadequado dos profissionais ao comunicarem o diagnóstico de SD, o que potencializou as reações emocionais de sofrimento, que não se restringiram ao momento da notícia. As reações podem ser amenizadas ou potencializadas com a vivência da maternagem e com interações familiares, sociais e com profissionais de saúde.*

Palavras-chave*: Síndrome de Down; Enfermagem Pediátrica; Saúde da Família; Comunicação em Saúde; Pesquisa Qualitativa.*

RESUMEN

Objetivo*: comprender las percepciones maternas sobre el diagnóstico del niño con Síndrome de Down (SD).* ***Método****: estudio exploratorio-descriptivo con enfoque cualitativo, realizado con madres de niños con SD, en un hospital público de tercer nivel, en el municipio de São Paulo. La recolección se realizó a través de entrevistas individuales y semiestructuradas, regidas por un guión de temas. Los datos fueron analizados mediante análisis temático de contenido y a la luz de los principios de anclaje y objetivación de la Teoría de las Representaciones Sociales.* ***Resultados****: participaron 9 madres de niños con SD. Los datos se analizaron y surgieron dos categorías principales: 1) Percepciones maternas sobre la comunicación del diagnóstico de SD del hijo, y 2) Percepciones maternas sobre el impacto del diagnóstico de SD del hijo, con subcategorías interconectadas.* ***Conclusión****: se constató manejo predominantemente inadecuado de los profesionales en la comunicación del diagnóstico de SD, lo que potenció las reacciones emocionales de sufrimiento, que no se restringieron al momento de la noticia. Las reacciones se pueden mitigar o mejorar con la experiencia de la maternidad, las interacciones con los miembros de la familia, los profesionales de la salud y sociales.*

Palabras clave*: Síndrome de Down; Enfermería Pediátrica; Salud de la Familia; Comunicación en Salud; Investigación Cualitativa.*

How to cite this article:
Souza DM, Toriyama ATM, Sigaud CHS, Campos FLM. Impact of the diagnosis of Down Syndrome in the maternal perspective. REME - Rev Min Enferm. 2023[cited ____ ___ __];27:e-1508. Available from: https://doi.org/10.35699/2316-9389.2023.37077

INTRODUCTION

A Down Syndrome (DS) is a genetic syndrome caused by various forms of trisomy 21, which leads to cognitive impairment, determined from the configuration of genes, as well as favoring the presence of diseases(1). There is a worldwide incidence of approximately 1/1000 live births; in Brazil, this index is 1/700. For a syndrome, this number is high, making DS the most common genetic alteration(2).

In general, the experience of pregnancy brings multiple feelings, such as joy, fear, and anxiety. During this period, the woman experiences both the idealized and the real baby, the one she will know and which she will take care of after delivery. The imaginary and the real can come into conflict, especially when there is unexpected news, such as the DS(1).

When this condition is diagnosed, parents experience mourning for the "idealized baby" and there is little welcoming for the "real baby"(1,3). These reactions can be mitigated or strengthened according to the management of communication by healthcare professionals(4). After communicating the diagnosis, family members may experience the phenomenon known as "Flash Memory", in which, even after a long period of the event, there are memories of details, especially in relation to professional management(5). Thus, communication must be based on scientific evidence(3), such as the Health Care Guideline for People with DS.6 However, in the national literature, there are no studies that explore the management of professionals during the communication of the diagnosis of DS, not even the maternal experiences after the news.

Thus, the following concern emerged: "What are the maternal perceptions regarding the communication of the DS diagnosis and its impacts?". Knowing these perceptions allows the professional to act with a focus on providing the best communication to the mother, free of negative aspects, with embracement and active listening, to reframe emotions and empower the family in caring for the child, aiming to promote their development healthy and full. Given the above, this study aimed to understand the maternal perceptions about the diagnosis of DS of their children as children.

METHOD

This is an exploratory-descriptive study with a qualitative approach. To guide its writing, we used the Consolidated Criteria for Reporting Qualitative Research (COREQ) instrument as a guide(7).

The population consisted of 9 mothers of children with DS, selected for the study based on the following criteria: being over 18 years of age; being self-declared literate; to have preserved cognition and verbal communication; and having at least one child with DS, aged up to 6 full years. The following were excluded: teenage mothers; illiterate; with changes in cognition and communication; with children with DS over 6 years old - considering that the memories referring to the moment of communication of the diagnosis may suffer temporal influences and not be fully recalled.

The mothers participating in the study were approached at a tertiary-level public hospital in the city of São Paulo, where the children were hospitalized. It is noteworthy that all women approached by the researcher agreed to participate in the research.

Data were collected from July to September 2019 by the researcher, who is male, a third-year student of the Nursing course at the School of Nursing of the University of São Paulo (EEUSP) and previously trained by the main researcher to develop the study.

The technique used for data collection was the semi-structured interview, guided by a script of topics developed by the authors, consisting of identification data and 21 open questions: When did you find out about the DS diagnosis? Which professional provided you with the information? Was he/she alone or accompanied by another professional? Accompanied by whom? Where were you at the time of the news? Were you accompanied by anyone? If yes, who? How was the information presented to you? Had you already seen your son before being informed of the diagnosis? What was your reaction when you learned of the diagnosis? How did you feel? What were your main concerns? Did you know what DS was at that time? Did you have questions? Which? Have your doubts been clarified? Did you feel supported by the professional who told you? And for your family? And for other people? Which? In view of what happened when you learned of the diagnosis, what do you highlight as positive? And negative? What would you like to have been different at the time of diagnosis?

The interviews were carried out in a reserved and private space in the hospital, lasting from 30 minutes to 1 hour and 30 minutes. It was not necessary to approach the participants again to clarify doubts or repeat the recording of the interview. The audios of the interviews were recorded and transcribed and were not shared with the participants. The main researchers read the testimonies together, to monitor the progress of the collection and the speeches obtained. From the reading of the 9th interview, it was observed that the main ideas were being repeated, with theoretical saturation of data(8), without the addition of new information. Thus, it was decided to end the collection.

After completing the collection, the data were analyzed using the thematic content analysis method, proposed by Bardin(9). The method consists of the steps of: 1) pre-analysis, with floating reading of the material, constitution of the corpus and formulation of hypotheses; 2) exploration of the material, with categorization, codification and organization of the collected data; and 3) data interpretation, correlating the collected information and the research objective.

To complement the analysis and extract new meanings from the speeches, it was decided to make use of the principles of objectification and anchoring of the Theory of Social Representations, by Serge Moscovici.(9) Anchoring consists of the subject integrating new conceptions based on experiences and the social context in which he/she is immersed, turning the unfamiliar into the familiar. In the case of this study, the anchorage is to integrate the child with DS into the reality of being a mother, permeated by representations of women as a maternal and protective figure. In objectification, abstract notions are concretized in reality. In the case of the present study, the experience of motherhood and its expectations are transformed into emotional reactions that prevail throughout the context. These principles allow understanding the beliefs, symbols, knowledge, and behavior of the subject before the phenomenon, as shown in the results of this study. For the treatment and discussion of the findings, we based ourselves on the scientific literature and on the Health Care Guideline for People with DS(6).

This study was conducted based on Resolution 466/12 of the National Health Council. The study was approved by the Research and Ethics Committee of EEUSP and the co-participating institution, under opinion reports No. 3,342,175, issued on May 22, 2019, and No. 3,440,118 of July 5, 2019, respectively. Participants were informed about the development of the study, with joint reading of the Free and Informed Consent Form and signature in two copies after agreeing to participate. In the results, the mothers' statements are presented with the letter M (mother) followed by the number of their respective interview (M1, M2...), to maintain the anonymity of the research participants.

RESULTS

Characterization of the participants

Nine women aged between 20 and 43 years old participated, most of whom were over 30 years old. Eight children were between 18 days old and 2 years old, and one was 5 years old. Mothers' education varied, with three having completed higher education. Regarding marital status, four were separated. As for occupation, five claimed to have some paid work activity, while four were housewives by choice, to take care of the child. The number of children ranged from one to nine, with five children with DS being the youngest and three daughters being the only child. When asked about the support network, seven women mentioned the family, in addition to specialized child and family care services, friends, healthcare professionals and other mothers of children with DS. Some even mentioned reading books and spirituality as a source of strength.

Through the analysis of the reports, two main categories were organized: 1) The maternal perceptions regarding the communication of the child's DS diagnosis; and 2) Maternal perceptions about the impact of the child's DS diagnosis, composed of subcategories, presented below.

The maternal perceptions regarding the communication of the child's DS diagnosis

This category refers to the professional's handling of the communication of the diagnosis, as well as the positive and negative points of the professional approach, with two subcategories

Communicating the child's DS diagnosis

Diagnosis was communicated between the child's birth and the 17th day of life. The medical professional was the main informant. Two mothers heard the news from their own mother or from the nurse. Five informants were accompanied by other healthcare professionals and/or undergraduate students. The conversation took place in the unit where the mother and/or child were hospitalized, such as Rooming-in, Nursery and Neonatal Intensive Care Unit. One of them was informed at the Obstetric Center right after delivery, even before meeting the newborn. All the others received the diagnosis after having contact with the child.

> *While my son was with me in the room, nobody told me anything.* [...] *My mother went to the maternity ward and the doctor who was there told her what he had, and my mother arrived* [in the room her daughter was] *and told me.* (M1)

> *When the pediatrician came by, she didn't say anything to me, there was she and her assistant. They passed by, examined,*

> *and left. From then on,* [medical] *resident by resident began to come in, about 10 came, all of them just to see my son. It scared me.* [...] *There were two more mothers in the room, and they started to get scared. At that point, I started to cry desperately and, when everyone had passed by, the doctor came back and said that there was an 80% chance that he* [the son] *had DS.* (M4)

> *I found out in childbirth; it was a cesarean section. The pediatrician came around the stretcher and said: 'Oh mom, it's here, she's fine and has DS, as you already know'. So I said, 'No, I didn't know'.* (M2)

Only three participants were accompanied when they received the news, all by a sister-in-law, without the option of requesting another companion or receiving the news without the family member being present. Two received the news in front of other mothers of hospitalized children, without receiving support.

> *The doctor came alone and spoke in front of everyone. The other mothers saw it, other professionals saw it, and they felt sorry for me.* (M3)

Positives and negatives of the child's DS diagnosis

Only one mother reported favorable aspects of professional management: the professional's calmness and clear explanations about the DS.

> *The doctor was a very calm person, and when she came to talk to me, she conveyed this to me in a very beautiful way.* [...] *I think her calmness was the most positive thing as well as her knowledge.* [...] *She started to show me the striking features, like the little ears, the little eyes.* (M4)

The negative points referred to the fact that the news was communicated by third parties (maternal grandmother and partner); the maternal feeling of helplessness; the lack of clarification about DS, causing more anguish; the lack of privacy in the place; the high number of professional informants; tone of voice and words used in a negative way; and references to other people with DS, removing the focus from the individual maternal experience, even if the intention was to reassure the mother.

> *The doctor didn't sit down with me and explain: 'I'll tell you what's going on', no.* [...] *I thought it was a lack of respect on her part, especially since she didn't even look at my face.* [...] *I didn't feel supported. I even felt helpless by the team.* (M5)

> *I didn't understand what DS is, and I hope you can explain to me why it is born that way.* (M7)

> *When they talk about the DS, they don't explain reality. 'But today there is a person with DS who has a degree, is a lawyer', but I don't want to know what she will be like in 30 years, I want to know her condition now.* [...] *The mother must see that she is not alone, because they throw the diagnosis and say: 'Look mom,* [he/she] *is going to be a doctor'; 'You won a box of surprises that in 20 years it* [he/she] *will become a doctor'.* [...] *Nobody says that they are not to blame for being like this.* (M2)

Maternal perceptions about the impact of the child's DS diagnosis

This category deals with the emotional impacts of the DS diagnosis and the maternal experiences with the child, comprising three subcategories.

Maternal emotional reactions to the child's DS condition

Mothers mentioned the following feelings when discovering the DS diagnosis: shock; despair and anger, accompanied by the attempt to blame something or someone; sadness and anguish expressed by crying; rejection of the child, experienced by discomfort and estrangement in contact with her; and frustration due to the mourning of the idealized child. Some were very precise when expressing dissatisfaction with the child's condition, referring that, if they could change something at the time of communication of the diagnosis, they would withdraw the DS. One of the mothers reported that, after discovering that the child had DS, she did not want to carry another one, afraid of also having a disability. In one statement, it was possible to observe ambivalence of feelings towards the child.

> *NDuring pregnancy, we do not expect this from the child. I imagined he was going to call me Mom, that I was going to see the first steps, but when they told me about the Syndrome, the language she used, wow! It looked like a seven-headed animal. I cried, cried, cried.* [...] *I no longer had the courage to see him. Then I got up. I had already cried a lot; my eye was all swollen. Then I remember that I looked at him, took him in my arms, I had already passed that conscience relief. I thought: 'he is my son; I will not reject him'. I picked him up, but it felt uncomfortable, because I looked at him and saw him as nothing, you know? I kept thinking about what the doctor told me.* (M3)

> *At that moment, if I could change anything, I would want him to have nothing* [such as the DS]. (M3)

> *My biggest dream was to be a mother, I always imagined that.* [...] *I found out that I was pregnant, I was already 4 months old, so I thought that my dream was coming true.* [...] *But now? I have a little bit of trauma from having another child.* (M3)

> *I don't like people saying things that blind the mothers. Isn't it beautiful to be a mother of a disabled person, because nobody wants to have a disabled child to begin with, nobody dreams of having a disabled child. I love my son; I love him so much. But for me it would be a gift if he was normal, because only a mother who has a disabled child understands when you speak.* [...] *We love our children, but they could be normal. Why aren't they? It's not our fault, it's not their fault.* [...] *People in society mystify this a lot, passing on the idea that it is beautiful to have a child with Down Syndrome. It's a lie!* (M2)

Some women reported that they hoped that the diagnosis would not be confirmed, especially in the first months of the child's life, a period in which laboratory confirmation is awaited. One of them mentioned the hope that there would be a vaccine to cure DS.

> *She was so cute, that until the exam to confirm it, I was hoping it was negative. Because we don't want to, it's no use. But it was there, chromosome 21.* [...] *Later, I searched the internet for a cure and a vaccine appeared. But I imagined that people were already advanced in the matter. It is a hope that remains.* (M2)

In addition, there were questions about why the child had DS and concerns about the child's future, such as physical and cognitive development and access to health services.

> *I kept looking at other moms' kids and wondering why they were normal and mine wasn't.* [...] (crying) *I kept thinking: 'Why did my son have to be born like this?'.* (M3)

> *I thought, 'How am I going to deal with this?'* (M9)

> *I was worried and afraid with these issues of walking, talking, playing. Of being able to develop properly, without difficulties.* (M3)

Only one mother had a favorable perception of the child's DS after learning about the diagnosis but did not offer more elements for understanding the speech.

> *The doctor said there was an 80% chance of him having Down. Thank God! That's what I said to her. I have always, always, always been passionate about children with DS.* (M4)

The news also affected the child's father and family. Among the paternal reactions, prejudice, rejection, sadness, fear, insecurity for care and hope were observed. Regarding the family, there were reactions of support for the mother, comforting her and uniting the family, but there was also rejection, prejudice, and an attempt to blame something or someone.

> *I feel prejudice and rejection from his father.* (crying) *But I'm not worried about him* [the father], *I'm not worried about what he thinks or doesn't think.* (M5)

> *My husband's family did not react well to the news. They thought he would be a retarded child, full of problems, those prejudices we deal with in society.* (M2)

Living and learning with the care of a child with DS

There were reports that, over time, the initial reactions diminished, giving way to other feelings, such as love, empathy, strength, maturity, and the desire to dedicate oneself to care. The feeling of personal transformation stands out, with maternal empowerment and the struggle for the child's development.

> *When you are the mother of a disabled person, you change as a human being, you start to see everything differently. He/she* [the child] *changes us. I thought I knew how to love, but I didn't, until he was born.* [...] *They are victories, each advance is a party, then you leave behind everything that happened there.* [...] *Each of his conquests will be a celebration.* (M9)

Also, there were positive expectations regarding the future of the child, especially regarding development. Associated with dedication, some mothers recognized that the child with DS is their life project, reporting a feeling of overprotection.

> *I imagine him like that, grown up, playing, running, super well, well developed.* (M5)

> *Over time I changed the way I treat my son. The love just grew.* [...] *When I had the diagnosis I thought: 'My life is going to change completely', and it did. Nowadays, not that it's negative, but my life depends on his.* [...] *With time you realize that everything you went through was worth it.* [...] *But in the*

> *beginning it is very difficult, it was something that you did not imagine.* (M3)

> *I will continue to overprotect him. Do you have to treat it normally? But I will spoil my son no matter what.* (M9)

It is observed, in the statement of a mother, that dedication to the child limited her entry and performance in the work market, due to the difficulty of reconciling employment and the child's appointment schedule in health and education services

> *I still haven't thrown myself into the work market because it's difficult to find a job, especially in education and having flexible schedules for speech therapy, physio, school. It is difficult.* (M2)

Social attitudes and behaviors towards children with DS

There were statements that, after the birth of the child, women assumed the position of mother and main responsibility for the child, which led to the belief that they could not despair or show weaknesses, with concerns about their longevity.

> *We mothers have a role, we are caregivers, we solve everything. So, I struggled a lot with that. If there is anyone who is going to solve things for my disabled daughter, it's me: understanding it will be me, taking care of it will be me, taking it to the professionals will be me, so I can't despair.* (M2)

> *The negative point of being the mother of a child with DS is the fear of dying* [the child]. *I never had that fear, but now I do.* [...] *Of course, in my family there will be many people to take care of him, but no one will take care of him like me, I am a mother.* (M9)

The mothers stated that, in everyday life, people show prejudice through excessive attention and judgmental looks towards the child, considering them fragile and limited. In addition, they also reported that they felt inferior and victimized. It was pointed out that, with time, there was a "normalization", and that the child started to be accepted in social contexts.

> *The diagnosis draws unnecessary attention, the type of attention I don't like.* [...] *In this period of 5 years, it is the reaction of others that sometimes bothers me, this excessive attention they give her.* [...] *It offends me, she has special treatment.* (M2)

> *Of course, there are people who don't talk about it, but you know that they victimize you, that put you in a victim position. 'There, poor thing, she has a sick, retarded son'.* (M4)

The mothers recognized the importance of specialized health services in the care of children with DS, highlighting the welcome, support, care and information provided by professionals, and the nurse was especially remembered in the statements.

> *Nurses have always supported me and continue to do so.* [...] *The nurses fell in love with him, they took good care of him, they always told me everything that happened.* (M1)

> *Only professionals* [Nursing] *to hear the anguish is very good. Many think that it's people's whining, that it's exaggeration. Anyone from the area knows, but not us mothers.* (M8)

It is noteworthy that, due to frequent visits to health services, there was an opportunity to interact with other families with children and/or people in the same condition. This interaction promoted a strong identification and complicity between the women, building a bond, understanding, support and security for the care of the child.

> *No one better than mothers to understand what I'm going through, what each step, each thing, each evolution means. When my son sat for the first time with support, everyone cheered. But they* [mothers of children with DS] *celebrated even more, because they knew what that first breakthrough meant, how much we fought for that breakthrough to happen.* (M4)

DISCUSSION

About the communication of the diagnosis of DS, although many mistaken actions were observed in this study, it should be noted that, at the national and international level, professional conduct is guided by recommendations and guidelines(6,10), such as availability, communication after consensus of the team and after the mother has already seen the child and initiated the bond. Furthermore, communication must be carried out using essential information, the presence of a companion chosen by the woman, taking place in a private place and indicating the defining characteristics of DS(6). In addition to the aforementioned, a welcoming and supportive attitude on the part of the informant is recommended, communication still suspect, with clear and professional language with experience in the subject(10,11).

However, this study demonstrated that, lots of times, the professional reporting the news did not follow the recommendations, presenting unethical handling and behaviors disapproved by women, which contributes to their dissatisfaction and obscures the joy of the birth of a child(10-12).

Regarding the time to communicate the news, in the case of the first days of the child's life, it is noted that the technologies for prenatal diagnosis were not accessible, despite studies portraying that mothers would be emotionally more prepared to deal with the situation if they knew about the condition during pregnancy(11-14). In an investigation involving 345 mothers of children with DS in Chile, 55% considered the professional management inadequate, and, almost always, the news was given after delivery. Only 34 mothers stated that there was a suspicion of DS during pregnancy, perceived by ultrasound changes. However, none underwent amniocentesis to confirm the suspicion, due to fetal risk or medical contraindication(11).

Inadequate communication practices, such as an inappropriate location and an excessive number of professional informants, were also reported in other studies,[6,10,11] which demonstrated that the need for privacy and freedom of expression of feelings were not considered. It is known that the presence of a trusted companion at the time of communication is crucial, with the opportunity for both the mother and the companion to be informed together, clarifying doubts and supporting each other(4,6,10,12). There are reports that, when a mother receives the news alone, her anguish is heightened by loneliness and the lack of emotional and physical support(14), this context is seen in this study.

The international literature brings experiences that corroborate the results of this study regarding the transmission of scarce, negative, and even wrong information. There is, for example, communication with a strictly clinical approach, in which DS is seen as a disease and cause of pathologies, with emphasis on the delay in cognitive, physical and motor development and condemnation of the child to the condition of early death(4,5, 10.12). It is noteworthy that the future image of the child with DS is influenced by the way the condition is presented, especially if it is “monstrous”.

The emotional reactions reported by the mothers in this study are a consequence of the beginning of the conflict between the child's idealizations and reality(1,3,13,15). These reactions are also experienced with motherhood and with feelings of incompetence and impotence in meeting the demands of child care.[15] There are concerns and doubts regarding the child's future, especially regarding their development(2,3) and social roles, such as attending university, being a father and getting married(14), proving to be a source of anguish. Due to this suffering, mothers are afraid that the experience of DS will be repeated, so they avoid a new pregnancy(16).

The impact of DS is also of a socioeconomic nature. In Turkey, of 129 mothers of children with DS, 84% stated that having a child with this condition affected their marriage, 37.3% said that there was an increase in expenses, 8% experienced less participation in social activities and 2% perceived a decrease in the time dedicated to taking care of themselves(17), And this impact also affects the family, which starts an adaptive struggle to restore the previous balance(1), which is particularly important, since family members are the main support network stated by mothers.

Society as a whole also reacts with discrimination based on prejudice and misinformation, restricting the child to the condition(1,9,18). There is use of pejorative terms(19) and maternal victimization.(9) Such pejorative and stereotyped attitudes do not only affect the person with DS, but also the family, which is ignored for their efforts and achievements, being forced to share the discredit of the stigmatized person(1,9,18,20,21). This can lead to family to hide the child and keep him away from social life(1), a fact that is detrimental to his development.

Despite the challenges, as well as this study, other studies indicate that living with the child helps to ease feelings and enhance learning, maturation and maternal strengthening, with appreciation of the child's individuality(20). Mothers experience a journey of acceptance similar to a puzzle: little by little, the pieces come together, working on emotions and finding beauty in their children(14).

The mother's overprotective behavior towards the child with DS is observed, perceived as a vulnerable being and incapable of carrying out activities by herself(18). Erving Goffman(21), a scholar on stigma, portrays that the family tends to create a capsule protector for the “different” individual since birth, as a way of demonstrating that he is accepted. It is noted that the family pays more attention to the differential quality than to the individual.

This overprotection brings, between the lines, the idea of permanent disability of the person who needs frequent care, due to not being able to meet their own needs. It is believed that it may be a personal emotional regulation strategy, in which the parents avoid exposing the child to new and challenging situations, controlling the anxiety produced by the fear of child failure. In addition, overprotection makes mothers give themselves to the child, making it their life project and moving away from professional and social experiences(3,19).

It should be noted that, in the present study, a mother (M2) dared to expose her ambivalence towards the child: even feeling love for the child, there is a desire for him to be different. It is believed that this experience is more frequent, although rarely revealed, to protect oneself from attacks by people who demand ideal feelings and attitudes of "good mothers". In Western society, the social representation of women is linked to the maternal role, understanding that the feminine nature makes them capable of loving and caring for their children and family(22), causing them to hide other non-loving feelings towards their children.

In addition, mothers of other children with DS were cited as sources of support, evidencing the importance of frequent visits to specialized health services, where, in addition to attending to the DS condition, it is possible to build a support network and mutual recognition of strengths through the exchange of knowledge and experiences. In Spain, in an investigation with 352 mothers of children with DS, only 11.6% had contact with services, although all of them defined the experience as positive(4).

There is a need for greater dissemination of guidelines and more scientific evidence to guide better practices in communicating the diagnosis of DS, through professional training and continuing education. In addition, the importance of a broad support network and truly intersectoral public policies with adequate interventions is noted, so that the impacts provided by the DS condition are re-signified.

Although the data collection script for this study does not include questions about the experiences of mothering a child with DS, they were portrayed by the mothers to exemplify their social representations in view of the feelings and difficulties of daily care. It is relevant for health professionals to recognize the need to welcome, support, respect and integrate families into care, respecting their individualities and providing a conducive environment for people with DS to reach their development potential and contribute to society.

The limitation of this study is the impossibility of generalizing the data as representative of the general population of mothers of children with DS, with results referring to individual experience and the context in which it is inserted. However, it should be noted that the participants' speeches were similar in many aspects. We hope that the results make health professionals aware of the importance of welcoming family members of children with DS and light care technologies as a tool that can be used in welcoming, permeating from diagnosis to the course of care.

CONCLUSÃO

The management of the communication of the diagnosis of DS proved to be very inappropriate. It is expected that the health professional knows how to behave and communicate appropriately. To this end, the issue of communication must be addressed during the training and continuing education of healthcare professionals, addressing both the most common errors and appropriate conduct. In addition, it is desirable that health students can participate in successful communication experiences.

Nursing professionals who work in child and family care are essential in the maternal experience. Although this professional class is not legally supported for communicating the diagnosis, it is important that they understand the best form of management. In this study, even without being questioned about the performance of the Nursing professional, the mothers were clear about how this professional can make a difference after the news of DS, constituting not only a source of information, but also of support and acceptance.

REFERÊNCIAS

1. Z. Zani AV, Merino MFGL, Marcon SS. The feelings and experience of a mother facing Down syndrome. Acta Scientiarium [Internet]. 2013[cited 2021 May 9];35(1):67-75. Available from: https://www.redalyc.org/pdf/3072/307226203010.pdf

2. Bermudez BEBV, Medeiros SL, Bermudez MB, Novadzki IM, Magdalena NIR. Down syndrome: prevalence and distribution of congenital heart disease in Brazil. São Paulo Med J [Internet]. 2015[cited 2021 May 9];133(6):521-4. Available from: https://doi.org/10.1590/1516-3180.2015.00710108

3. Chan GK, Lim KA, Ling HK. Care demands on mothers caring for a child with Down Syndrome: Malaysian (Sarawak) mothers' perspectives. Inter J Nurs Practice [Internet]. 2015[cited 2021 May 9];21:522-31. Available from: https://doi.org/10.1111/ijn.12275

4. Aldecoa TV, Conty JLM, Serrano RSC, Pérez CF. Communication of the diagnosis of Down Syndrome: Mother's stories. Cuad Bioét [Internet]. 2018[cited 2021 May 9];29(96):147-58. Available from: https://pubmed.ncbi.nlm.nih.gov/29777603/

5. Crombag NM, Christiaens GCP, Skotko BG, Graaf G. Receiving the news of Down Syndrome in the era of prenatal testing. Am J Med Genet [Internet]. 2019[cited 2021 May 9];182(2):1-12. Available from: https://doi.org/10.1002/ajmg.a.61438

6. Ministério da Saúde (BR). Secretaria de Atenção à Saúde. Departamento de Ações Programáticas Estratégicas. Diretrizes de atenção à pessoa com Síndrome de Down. Brasília: Ministério da Saúde; 2013[cited 2021 Oct 9]. Available from: https://www.portaldaenfermagem.com.br/downloads/diretrizes_atencao_pessoa_sindrome_down.pdf

7. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. Int J Qual Health Care [Internet]. 2007[cited 2021 May

9];19(6):349-57. Available from: https://doi.org/10.1093/intqhc/mzm042

8. Fontanella BJB, Ricas J, Turato ER. Saturation sampling in qualitative health research: theoretical contributions. Cad Saúde Pública [Internet]. 2008[cited 2021 May 9];24(1):17-27. Available from: https://doi.org/10.1590/S0102-311X2008000100003

9. Minayo MCS. O desafio do conhecimento: pesquisa qualitativa em saúde. 10ª ed. São Paulo: HUCITEC; 2007. 406p.

10. Aldecoa TV. Ethics in the Communication of Down Syndrome diagnosis. Cuad Bioét [Internet]. 2019[cited 2021 May 9];30(100):315-29. Available from: https://www.researchgate.net/publication/336614552_Ethics_in_the_communication_of_down_syndrome_diagnosis

11. Paul MA, Cerda J, Correa C, Lizama M. Receiving the diagnosis of Down Syndrome: what do the parents think? Rev Med Chile [Internet]. 2013[cited 2021 May 9];141:879-86. Available from: http://dx.doi.org/10.4067/S0034-98872013000700007

12. Buyukavci MA, Dogan DG, Canaloglu SK, Kivilcim M. Experience of mothers with Down syndrome children at the time of diagnosis. Arch Argent Pediatr [Internet]. 2019[cited 2021 May 9];117(2):114-9. Available from: https://www.sap.org.ar/docs/publicaciones/archivosarg/2019/v117n2a09e.pdf

13. Camargo MM, Silva MFF, Cunha MC. Impact of Down Syndrome diagnosis on mothers and its repercussions on the language development on children. Distúrb Comun [Internet]. 2012[cited 2021 Oct 9];24(2):165-72. Available from: https://revistas.pucsp.br/index.php/dic/article/download/11984/8667/28740

14. Pillay D, Girdler S, Collins M, Leonard H. "It's not what expecting, but it's still a beautiful jorney": The experience of mothers of children with Down Syndrome. Disabi Rehabil [Internet]. 2012[cited 2021 May 9];34(18):1501-10. Available from: https://doi.org/10.3109/09638288.2011.650313

15. Rodriguez FT, Carneiro TF. Babies with Down syndrome and their parents: new proposals for intervention. [Internet] Estud Psicol. 2012[cited 2021 Oct 9];29(Supl.):831s-841s. Available from: https://www.scielo.br/pdf/estpsi/v29s1/19.pdf

16. Almeida BR, Pereira-Silva NL. Living with a sibling with Down's syndrome. Psicol Pesq [Internet]. 2015[cited 2021 Oct 9];9(1):10-9. Available from: http://pepsic.bvsalud.org/pdf/psipesq/v9n1/v9n1a03.pdf

17. Dinc GS, Cop E, Tos T, Sari E, Senel S. Mothers of 0-3 years old children with Down Syndrome: effects on quality of life. Pediatr Int [Internet]. 2019[cited 2021 May 9];61:865-71. Available from: https://doi.org/10.1111/ped.13936

18. Lou S, Lanther MR, Hagenstjerne N, Petersen OB, Vogel I. "This is the child we were given": a qualitative study of Danish parents' experiences of a prenatal Down Syndrome diagnosis and their decision to continue the pregnancy. Sexual Reproductive Healthcare [Internet]. 2020[cited 2021 Oct 9];23:1-6. Available from: https://doi.org/10.1016/j.srhc.2019.100480

19. Miranda ACRL, Barreto MS. Children with Down Syndrome: quotidian experiences of the families. Rev Par Enferm [Internet]. 2019[cited 2021 Oct 9];2(1):13-22. Available from: https://www.researchgate.net/publication/347948260_CRIANCAS_COM_SINDROME_DE_DOWN_EXPERIENCIAS_QUOTIDIANAS_VIVENCIADAS_PELAS_FAMILIAS

20. Takataya K, Yamazaki Y, Mizuno E. Perceptions and Feelings of fathers of children with Down Syndrome. Arch Psychiatr Nurs. 2016[cited 2021 Oct 9];30(5):544-51. Available from: http://dx.doi.org/10.1016/j.apnu.2016.04.006

21. Goffman E. Estigma- Notas sobre a manipulação da identidade deteriorada. 4ª ed. Rio de Janeiro: LTC; 1981. 124p.

22. Badinter E. Um amor conquistado: o mito do amor materno. 2ª ed. São Paulo: Nova Fronteira; 1985. 293 p.