

PERCEPTIONS OF SIBLINGS OF PEOPLE WITH TRISOMY 21 ON FAMILY RELATIONSHIPS^{1, 2}

PERCEPÇÕES DE IRMÃOS DE PESSOAS COM TRISSOMIA 21 SOBRE AS RELAÇÕES FAMILIARES

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ABSTRACT: The birth of a child with a disability brings implications, changes in the environment and family dynamics. The family goes through a process of overcoming until the child acceptance with disability and the establishment of a suitable family environment that includes and meets his/her needs. Trisomy 21 (T21) is the most frequent genetic anomaly among those diagnosed. This study aimed to identify the perception of a sibling group of people with T21 regarding their family and social relationships. The sample consisted of 18 adolescents aged between 11 and 16 years, siblings of people with T21, and 17 guardians. Data collection occurred through semi-structured interviews conducted by video calls, with an average duration of 10 to 15 minutes. The interviews were recorded, transcribed and analyzed qualitatively based on the creation of thematic nuclei and categories. The results reinforce the importance of family relationships as a security factor and acceptance of the siblings' needs.

KEYWORDS: Family influence. Down syndrome. Family. Psychology. Family relationships.

RESUMO: O nascimento de uma criança com deficiência traz implicações, mudanças no ambiente e na dinâmica familiar como um todo. A família passa por um processo de superação até a aceitação da criança com deficiência e a instalação de um ambiente familiar propício que a inclua e atenda às suas necessidades. A trissomia 21 (T21) é a anomalia genética mais frequente dentre as diagnosticadas. Este estudo teve como objetivo conhecer a percepção de um grupo de irmãos de pessoas com T21 quanto às suas relações familiares e sociais. A amostra foi composta por 18 adolescentes com idades entre 11 e 16 anos, irmãos de pessoas com T21 e 17 responsáveis. A coleta de dados ocorreu por meio de entrevista semiestruturada realizadas por meio de chamada de vídeo, com duração média de dez a 15 minutos. As entrevistas foram gravadas, transcritas e analisadas qualitativamente a partir da criação de núcleos temáticos e categorias. Os resultados reforçam a importância das relações familiares como um fator segurança acolhimento das necessidades dos irmãos.

PALAVRAS-CHAVE: Influência da família. Síndrome de Down. Família. Psicologia. Relações familiares.

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1 INTRODUCTION

The birth of a child with a disability, such as Trisomy 21 (T21), can generate within the family the need to redefine roles and change the lifestyle not only of the parents but of all members, including siblings (Alves & Serralha, 2019; Buscaglia, 2006; Navarousckas et al., 2010; Oliveira & Limongi, 2011; Yamashiro & Matsukura, 2013).

The family dynamics and routine of the house change with the birth of a child. For siblings, there is a need for sharing, division of physical space and parental attention toward the younger sibling (Batista et al., 2016; Navarousckas et al., 2010; Pereira-Silva et al., 2017; Yamashiro & Matsukura, 2013). In this situation, the impact is more significant since the demands of a sibling's disability and clinical and/or behavioral changes directly affect the others. These changes are experienced with increased intensity since the impact of alterations in a family organization tends to be greater due to the need for more attention and time spent by parents on medical follow-ups for the affected sibling, besides the feelings that accompany the discovery and acceptance of the diagnosis (Batista et al., 2016; Gau et al., 2008; Navarousckas et al., 2010; Pereira-Silva et al., 2017; Yamashiro & Matsukura, 2013).

In families with children with no disability among the siblings, the older sibling usually assumes the role of relationship leader and caregiver of the youngest (Dellazzana & Freitas, 2010; Pereira-Silva et al., 2017; Yamashiro & Matsukura, 2013). In contrast, in the case of families in which one of the siblings has a disability, the typically developing siblings play the role of caregiver, regardless of their age, gender and birth order (Almeida & Pereira-Silva, 2015; Kroeff, 2012; Pereira-Silva et al., 2017; Skotko & Levine, 2006; Soares et al., 2009).

During the experience of living with a disability for a family, siblings are poorly attended to due to the demands of care and attention of the most vulnerable child. Like the parents who had to adjust to the disability, siblings also go through the same emotional states, such as frustration, fear, anger, guilt, and concern, among others (Batista et al., 2016; Gargiulo, 2003; Navarousckas et al., 2010). It is observed that the younger the age and the more restricted the information received about the disability are, the more challenging the child is in facing his/her feelings about his/her sibling's needs (Gargiulo, 2003).

The impact of disability on siblings can be categorized between gains and difficulties (Choi & Van Riper, 2014; Messa & Fiamenghi, 2010; Silva & Costa, 2018; Skotko & Levine, 2006). According to studies carried out by Silva and Costa (2018), the difficulties, also characterized as stressors, refer to the increase in responsibilities and functions related to caring for the disabled sibling and household activities; feelings of loneliness and resentment due to the greater attention of parents and health professionals towards him/her; lack of parental attention; jealousy when realizing the differential treatment and favoring related to the sibling; negative feelings such as fear of not having the parents' attention and that their brother/sister will die; guilt for having wished something terrible to happen to their sibling or for not being affected by the same condition or illness; shame and embarrassment at other children's question about their brother/sister's physical or behavioral differences and misinformation about his condition, in general. The characteristics related to gains are categorized as resilience, and the study also mentions that the siblings perceived the development of characteristics such as patience,

understanding and altruism, in addition to humanitarian attitudes and a higher sense of autonomy and independence (Fleitas, 2000; Messa & Fiamenghi, 2010; Skotko & Levine, 2006).

The presence of a sibling with a disability tends to cause early maturation in other siblings, regardless of whether they are older or younger (Alves & Serralha, 2019; Cid & Matsukura, 2008; Goitein & Cia, 2011; Lizasoain & Onieva, 2010; Messa & Fiamenghi, 2010; Navarausckas et al., 2010; Yamashiro & Matsukura, 2013). Batista et al. (2016) and Pereira and Fernandes (2010) add that this factor is related to the perception of responsibility towards the disabled brother/sister, aiming at his/her well-being. From a psychological perspective, such early maturation may not benefit the child, as he/she skips some of the necessary stages for healthy emotional development, which may lead to consequences in adulthood (Lizasoain & Onieva, 2010; Navarausckas et al., 2010).

The impairment may not be a source of stress for the sibling (Messa & Fiamenghi, 2010; Pereira-Silva et al., 2017). Relationships are influenced by the quality of family interaction and communication; besides the presence or absence of comorbidities peculiar to each disability, the personal characteristics of each sibling and their coping strategies added to the access to the support and care network. Even so, the literature indicates that siblings of children with various disabilities or mental disorders are more likely to present behavioral or psychological problems than siblings with typical development (Barnett & Hunter, 2012; Petalas et al., 2009; Rodrigue et al., 1993).

Thus, studies on fraternal relationships when one of the siblings has an intellectual disability, from the point of view of the brother/sister him/herself as an informant, become relevant to the extent that this knowledge may contribute to raising the emotional needs of the brothers/sisters of people with disabilities, due to the impact caused in their relationships and different areas of their lives. Therefore, this study aimed to understand the perception of a sibling group of people with T21 regarding their family and social relationships.

2 METHOD

This study was exploratory, cross-sectional, descriptive, and approved by an Ethics Committee, following national and international guidelines for scientific research involving human beings, under Opinion number 3.915.785.

The dissemination of the project and invitation to participate were carried out in existing groups on Social Networks, which aimed to bring together family members and others interested in T21. Those responsible for the participants filled in the link with the Participant Identification Form, Free and Informed Consent Form (FICT) and authorization for their child's participation.

Eighteen adolescents of both sexes were interviewed, aged between 11 and 16 years, siblings of people with T21, living in different states of Brazil, including Minas Gerais, Rio de Janeiro, Rio Grande do Sul e São Paulo. The participants' families consisted of two to four children. The socioeconomic level of the participants was calculated using the Brazilian Association of Population Studies (*Associação Brasileira de Estudos Populacionais* [ABEP]) scale, and the classification of the participants remained between class A and C2, with a higher concentration in classes C1 and C2 (66.7%), as described in Table 1.

Table 1
Characterization of the participants

Variables	Frequency	%
Sex		
Male	12	66.7
Female	6	33.2
Age		
11	1	5.6
12	4	22.2
13	2	11.1
14	1	5.6
15	7	38.9
16	3	16.7
Socioeconomic Level		
A	1	5.5
B1	2	11.1
B2	3	16.7
C1	5	27.8
C2	7	38.9
Residence		
Minas Gerais	2	11.1
Rio de Janeiro	3	16.7
Rio Grande do Sul	1	5.5
São Paulo	12	66.7
Number of children in families		
2	11	61.1
3	6	33.3
4	1	5.5

Of these adolescents, 11 (61.1%) had only one sibling with T21; six (33.3%) had one more sibling without T21, and one (5.5%) had two more siblings without T21. Siblings with T21 formed a group of 10 girls and seven boys, aged between one and 17 years, as described in Table 2.

Table 2
Sibling with T21 characterization

Variables	Frequency	%
Sex		
Male	7	38.9
Female	11	61.1
Age		
01 to 05	03	16.7%
06 to 10	11	66.6%
11 to 17	04	22.2%

Participants were instructed to be unaccompanied by their guardians. The explanations about the research were carried out with the reading of the Free Informed Assent Term (FIAT). The interviews were conducted using a video call via the WhatsApp application to meet the safety and social distancing recommendations arising from the COVID-19 pandemic in 2020 when data collection was carried out. Each interview lasted between 10 and 15 minutes, without interruptions. They were recorded, transcribed, and later, their content was qualitatively analyzed by creating thematic nuclei and categories. Content analysis is a set of research techniques that aims at their interpretation through an objective and systematic description of the manifest content of communications. The method proposes discovering the nuclei of meaning that make up a communication whose presence or frequency means something to the analytical objective studied (Bardin, 2011; Minayo, 2007).

The content organization phase of the interviews followed the Bardin's (2011) precepts, involving the "floating" reading, which represents the first contact with the interviews, which were transcribed for analysis. Exploring the material through readings and re-readings enabled us to highlight the richness of interpretations for analytical description. The records of the 18 participants were grouped according to the script that guided the interviews with the siblings observing the following topics:

a) Block 1: Discovery and knowledge about the sibling's disability

This block was composed of four questions. The objective was to understand how the participant discovered his/her brother/sister's disability and what is the knowledge about T21 from the period before the brother/sister's birth to the present moment. This block contained questions such as:

"What did they tell you about your brother/sister when he/she was born?";

"Do you know what Down Syndrome is?";

"Before your brother/sister was born, did you know anyone who looked like him/her?"

b) Block 2: Relationship and interaction with the sibling

Composed of five questions that aimed to investigate the form of interaction, relationship and help offered to and received by the brother/sister. The questionnaire items were based on questions such as:

“Can you play/talk to your sibling like you play/talk to other children?”;

“What do you most like to do with him/her? Why? / Is there anything he/she does that you don't like? Why?”

“What do you help your brother/sister with? / And does your brother/sister help you?”

c) Block 3: Perception of the relationship between parents and children

It consisted of questions that investigated the participants' relationship with their parents and the perception of their relationship with their disabled sibling, as follows:

“Tell me a little bit about how are your moments with your parents, what you do together”;

“What do you think your sibling is like with your parents?”

d) Block 4: Future perspectives:

Composed of questions that investigated the future perspectives of the participants, including possibilities of autonomy in the adult phase of their brother/sister with T21, as described below:

“How do you see you and your brother/sister as adults? (or in the future)”.

3 RESULTS AND DISCUSSION

3.1 BLOCK 1: DISCOVERY AND KNOWLEDGE ABOUT THE SIBLING'S DISABILITY

Responses varied among the participants. The discovery of T21 for the sibling may have been influenced by the birth order in the family or by their age at the time of the sibling's birth. In three cases (P1, P18 and P15), the parents did not communicate the fact at birth.

I don't remember because I was three years old. My mother always said that she was different when she was little. As I grew older, she explained it better. (P1)

According to Batista et al. (2016) and Petean and Suguilhura (2005), for parents, the most common reactions facing the discovery of a disability were shock, guilt, anger and sadness, while for the siblings, the news seemed to have a less active effect for a possible psychological disruption, with few manifestations of extreme feelings. Paul et al. (2013) add that for siblings the main manifestations include sadness, jealousy or happiness, associated with the perception of the need to care for and help the brother/sister.

Batista et al. (2016) question in their study the need for research on the timing of the communication of the diagnosis of disability to the brother/sister, pointing out that, for the typical sibling, unclear information about the disability may generate fantasies or prejudices about the disabled sibling's condition, compromising the fraternal bond.

Concerning *Communication and Information*, Alves and Serralha (2019) analyzed the feelings and needs of siblings of people with disabilities in the literature, highlighting the importance of communication and dialogue about the brother/sister's disability.

Nine participants were informed by their parents about their brother/sister's disability, and in these cases, corroborating data from the studies by Batista et al. (2016) and Petean and Suguihura (2005), who emphasize the importance of the informant to communicate the diagnosis to the sibling, highlighting the importance of the communication being given by a person in whom the child trusts and can have the freedom to express his/her feelings, because doubts and anxieties may arise, requiring guidance and emotional acceptance.

On the occasion of the communication of the disability, among these participants who received the news from their parents, three reported the use of the terms "different/special" (P9, P11, P16). For other siblings, the naming of the diagnosis itself was used, as described:

They said she was special, a little different from other children. My mother said she had Down syndrome, and I researched beyond what they told me. (P9)

Almeida and Pereira-Silva (2015) warn that the way parents explain the characteristics of T21 to the sibling can impact family dynamics and relationships. Diagnostic information should be provided according to the child's level of understanding, with appropriate vocabulary according to their age and developmental stage (Alves & Serralha, 2019; Lizasoain & Onieva, 2010; Petean & Suguihura, 2005; Yamashiro & Matsukura, 2019; 2013), not minimizing or omitting information and providing an opening moment for possible doubts, which must be resolved when they arise (Petean & Suguihura, 2005).

At the time of the discovery of the disability, two participants also brought up the need to help their sister, as described below:

That she was special, different from the other kids, and that she would need my help. (P17)

When I was born, she already existed. But I remember that they said that I had to help C. (P18)

Studies on the relationships among siblings of people with disabilities bring in their entirety the relationship on the care of the typical sibling towards the other. Although the issue of care between siblings is not just a finding of the relationship among brothers with atypical development or a disability, as proposed by Yamashiro and Matsukura (2013). In the event of a disability, the perception of care is more evident, even in an early way, regardless of the typical sibling being the oldest or youngest, resulting in an early maturation in these siblings due to the constant perception of responsibility towards the disabled sibling (Alves & Serralha, 2019; Batista et al., 2016; Cid & Matsukura, 2008, 2016; Goitein & Cia, 2011; Lizasoain & Onieva, 2010; Messa & Fiamenghi, 2010; Navarousckas et al., 2010; Pereira & Fernandes, 2010; Yamashiro & Matsukura, 2013).

Batista et al. (2016) and Alves and Serralha (2019) mention that the issue related to disability is permeated with stereotypes and can bring a feeling of insecurity, discomfort and concerns about facing the possibility of bullying or prejudice related to disability, as in the following reports:

They said she had T21 (...). Sometimes I'm afraid of her being bullied because that happens a lot, doesn't it? (...) I always want to have her close to me, and I will always protect her. (P13)

Messa and Fiamenghi (2010) add that the perception of the vulnerability of the disabled sibling can lead to an attitude of overprotection and dependence, as can be seen in the previous report.

About prior knowledge of T21, three participants (P3, P9 and P11) reported the initiative to research the subject together with the family or on their very initiative after discovering the diagnosis.

My mother said she had Down syndrome, and I researched beyond what they told me. And even they didn't know much. (P9)

The family must have the necessary clarifications about the disability. Besides the technical information received by professionals, the literature on families of people with disabilities highlights the importance of therapeutic interventions. It also describes the benefits of specialized support groups for parents and siblings, which serve as a possibility for exchange and learning (Alves & Serralha, 2019; Batista et al., 2016; Cezar & Smeha, 2016; Graff et al., 2012; Lobato et al., 2011; Loureto & Moreno, 2016; Pereira & Fernandes, 2010; Ronca et al., 2019).

Among the respondents, only two participants (P13 and P7) had contact with or knew another person with T21 before their brother/sister was born. As for the current knowledge of T21, there was agreement on the part of the interviewees regarding the perception of delay, difficulties in acquisitions and learning.

Some things that prevent him from learning like the others, speaking like the others, some difficulties... (P15)

Participants recognize that T21 is related to a chromosomal/genetic condition, and two participants (P8 and P17) add the recognition of phenotypic traits.

One more chromosome, and that leaves people with difficulties (...) [I identify] the little eye and the mouth (P17)

The main characteristics of people with T21 are intellectual disability, global developmental delay and easily recognizable phenotypic characteristics. Thirteen interviewed siblings know these characteristics of T21 and the association with a genetic condition. Regarding the issue of siblings of people with disabilities, the literature is unanimous in stating that knowing the needs of the sibling's disability helps to create a healthy fraternal bond.

Finally, this block brings the importance of adequate dialogue, effective communication and knowledge of the particularities of the disability as facilitators for the sibling to demystify any erroneous fantasy about his/her sibling with T21 in the adjustment of current and future expectations, contributing to the formation of the bond and the maintenance of a healthy fraternal relationship.

3.2 BLOCK 2: RELATIONSHIP AND INTERACTION WITH THE SIBLING

Regarding the perception of interaction among siblings, only one (P1) of the 18 participants answered that he could not interact with his sister with T21 in the same way he interacts with another teenager of the same age. In addition, five mentioned difficulties in speech intelligibility (P3, P7 and P18) or behavior (P5 and P8) as the main factors that hinder interaction, although they do not prevent it. In fact, speech-language pathology difficulties, which are characteristic of people with T21, have already been identified as an interference factor in the relationship between siblings (Alves & Serralha, 2019).

Table 3 presents the participants' speeches showing the primary forms of interaction among the siblings, divided into three groups: Playing, watching TV, and helping. The first two were considered favorite activities among the interviewees. The activities considered less positive among them varied according to the sibling's age, being related to behavioral problems, which may or may not be connected to characteristics of intellectual disability.

Table 3

Activities with the brothers

What do you most like to do with your brother/sister?	What does your brother/sister do that you don't like?	Participant
I like watching movies with her. (...). We make popcorn and watch movies together, and I like that.	She doesn't like being with me much. Sometimes, she's more stressed, and she doesn't let me get close to her, she doesn't let me sit on the same bench... (...) I don't like it when she ignores me.	P2
I like singing songs, and she dances, I laugh, and she laughs along. It's really cool	I wouldn't say I like when she slaps me. I know it's not her fault because she doesn't think, but nobody likes to be slapped, right?	P13
Basically, I like to do everything... because it's a feeling that I can't explain, I feel happy, glad to be by her side (...).	I'm not particularly eager to watch her favorite cartoons on my cell phone. I don't like when she hits me.	P15
I like watching with her, and I play a lot too... we keep playing... My brother, she and I...we have a lot of fun... because I always see her laughing a lot (...).	Sometimes she gets angry and irritated... she screams a little... there are other times when I'm doing something important, and she wants to play around, and I say I can't, and I don't like it very much	P16
When we were little, it was kind of a crazy idea. Each one had in his hand a piece of wood to play.	I'm not patient. I don't like drawing, painting... He grinds his teeth a lot, and it's agonizing; you can hear it from far away. When he's angry about something, he gets jealous, he throws things at us.... he's special. He needs more treatment. But... he's ten years old and very needy, emotionally, physically, it's kind of hard to keep up.	P4
Normal... To play video games, to walk around...	Put the food for her sometimes. I don't like it because she knows how to do it and gets lazy. Then I go there and put it on some-times.	P18

The relationship between siblings is permeated by experiences such as rivalry, affection, complicity and responsibility for the other, with models that tend to be reproduced throughout family life. Thus, experiencing feelings and divergences throughout the coexistence and

intimacy of family life characterizes the relationship among siblings and other family members and should not be attributed to the fact that one of the siblings has T21 (Silva & Lucas, 2020; Yamashiro & Matsukura, 2013).

The forms of help given to siblings with T21 varied according to their age. Fourteen participants (P1, P2, P8, P9, P15, P3, P7, P12, P4, P11, P5, P14, P16 and P18) help siblings with specific daily tasks such as feeding, helping with the bathroom and changing clothes.

When my parents are sleeping, or if I wake up early, I give her food, juice. And I help her in the bathroom. (P2)

Although the participants in this study help their siblings to carry out some routine tasks, these situations also occur in relationships of siblings without disabilities, in which the firstborn usually assumes the role of caregiver for the younger ones (Dellazzana & Freitas, 2010; Pereira- Silva, 2017; Yamashiro & Matsukura, 2013).

Alves and Serralha (2019) and Silva and Costa (2018) highlight an increase in responsibilities and roles related to the accumulation of tasks and care for a sibling with a disability. However, one cannot conclude on such an issue with the results found in the present study, as there was no significant variability regarding the variables of birth order and gender since most of the study participants were composed of male adolescents (12 participants being P1, P9, P3, P12, P4, P11, P6, P5, P13, P14, P16 and P18). Only two participants (P13 and P14) were older than their brother/sister with T21.

In the interviewed group, three participants were younger than their brother with T21. Their reports about offering help to their brother/sister are described below:

To do the homework. (P8 and P12)

To go to the bathroom and go down the stairs, sometimes I also help her eat and put on her shoes. (P14)

Concerning the help that the participant receives from his/her brother/sister with T21, the answers varied between Yes and No, regarding the division of tasks in the household routine.

When I'm putting the toys in their correct place, and she sees what I'm doing, she comes to help me. When I'm sweeping, she tries to help sweep, too. (P6)

Unlike the other participants, two did not bring help reports in the routine. Their discourse is permeated with an affective/emotional nature, related to how his/her brother/sister with T21 helps him/her, as in the following reports, corroborating the literature on the subject, which is conclusive when it comes to the development of subjective aspects in siblings. The authors point out that living with a disabled sibling enhances cognitive, affective and social skills (Alves & Serralha, 2019; Fleitas, 2000; Messa & Fiamenghi, 2010; Navarausckas et al., 2010; Petean & Suguihura, 2005; Skotko & Levine, 2006).

Sometimes when I'm sad, she makes me laugh. This helps me, too. (P13)

She helps me... in everything, in playing, when I'm sad, she goes there to cheer me up. (P10)

3.3 BLOCK 3: PERCEPTION OF THE RELATIONSHIP BETWEEN PARENTS AND CHILDREN

The answers varied among the respondents. Participants reported data related to family routine and leisure time among them. In table 4, there is the report of the interviewees who considered the perception of their relationship with their parents similar to their brother/sister's relationship with T21 and their parents, not bringing themes and differentiation.

Table 4

Similar perception between the relationship with the parents and the disabled sibling with the parents

Perception of the relationship with their parents	Perception of the disabled sibling's relationship with their parents	Participant
We went out a lot but not anymore. Now we stay in the living room from time to time, and I help with some things at home (...).	It's good. Talk to my parents and play with them.	P5
When I'm with my father we usually go out to different places... travel a lot, when I'm with my mother I go to the shopping, we buy pizza and stay more at home.	It's good.	P7
As my father works almost all day (...) from Monday to Friday. At the weekend I have the idea to watch a movie together, make popcorn and go to the park.	The same thing, G. always eats a little junk on the weekend. We order hamburgers and pizza. She always gives ideas too	P16
Normal, we talk to ourselves. She goes out, works... then stays here at home.	Normal, like any mother. Being careful with her. She treats her like us, normal, that sort of thing.	P12
My family and I are very close. Everything that happens, I tell them, everything I do too. I always have my family with me. I play basketball, and my father and mother always watch me play. My sisters have only been there once, but my parents are always there.	They get along really well.	P9

According to Alves and Serralha (2019), while some siblings report a more distant relationship with their parents, others claim greater family unity caused by living with a disability. Five participants do not consider that their relationship with their parents is different from that of their siblings and do not bring up themes that suggest advantages, disadvantages or different forms of contact, as shown in Table 4.

Three participants (P8, P18 and P14) added that their brother/sister with T21 draws much attention from their parents or "throws a tantrum", as shown below:

Perception of the relationship with their parents

My parents work a lot, and sometimes I am alone. But we sometimes go out on the weekend.
(P8)

We are very close. When it was possible to go for a walk, we would go. (P18)
I'm in class most of the time, so we can't do much together, and my father works, and my mother went back to work (...). (P14)

Perception of the disabled sibling's relationship with their parents

Normal, he asks for a lot of attention, and sometimes he won't let me talk to them. (P8)
Just like ours, but she's sweet and very needy. She throws a tantrum... so my mom does whatever she wants. (P18)

It's a normal relationship; she sometimes throws a tantrum, but it's a normal relationship. (P14)

Despite the signaled behaviors, the participants do not notice differences in the parents' performance and consider their parents' relationship with their brother/sister to be "normal/equal" to theirs. It is worth noting that the behaviors mentioned are not specific to the demands of T21. Only one of the 18 participants brought the perception of closer proximity from the mother to his disabled brother due to the routine of treatments, as described below,

I think he is close to both of them. My mother stays more with him because she needs to go out with him to speech therapy... and when she is at home, he stays with my father. (P12)

It is pretty common for the sibling to have the perception that his parents spend more time with the disabled brother/sister due to the need for treatment and care imposed by the disability (Batista et al., 2016; Gau et al., 2008; Messa & Fiamenghi, 2010; Navarouskas et al., 2010; Pereira-Silva et al., 2017; Yamashiro & Matsukura, 2013). The low frequency of such perception may be related to the requirements of social isolation during the collection period, in which care services for people with disabilities were suspended due to the COVID-19 pandemic.

The nature of the speech of two participants differed from the others when dealing with details regarding the perception of the parents' relationship with the sibling with T21. The perception of their relationship with their parents is based on specific aspects of the family routine and management in education, but for P10 and P11, the parents' relationship with their brother/sister encompasses terms such as affection and closeness as described below:

Perception of the relationship with their parents

In this pandemic, we are not doing that much now. My father works a lot and travels. I stay more with my mother, we ask for something to eat, watch a series together, a movie.... but I do the same thing with my father when he is at home (...). (P11)

I have a good relationship with my mother. She is constantly correcting me for what is right and playing with me. (P10)

Perception of the disabled sibling's relationship with their parents

I think it's much more about love. When they take him, hug him, and play... They give him a lot of affection and love. (P11)

She has a closer relationship with my mother. She knows that my mother is always, always, always there. She knows that she will help her with everything. (P10)

Such reports fit into the negative characteristics of sibling relationships of people with disabilities, as described by Silva and Costa (2018) and also categorized by Messa, Fiamenghi

(2010) as feelings of loneliness, resentment and jealousy when perceiving the differentiated treatment and favoring of the brother/sister.

3.1 BLOCK 4: FUTURE PERSPECTIVES

Regarding future perspectives, the theme of the answers suggests aspects referring to the concerns affecting sibling relationships due to the limited views of autonomy of the disabled person.

The findings are consistent with the literature. Concerning perspectives, some siblings believe in the possibility of independence for the sibling with a disability. At the same time, others have no such perspective, foreseeing that the future will entail having to take over the care of the sibling, either in the supervision of tasks or in financial matters (Silva & Costa, 2018; Messa & Fiamenghi, 2010).

In the present study, four participants (P1, P7, P14, and P3) perceived the need to help their siblings. They included plans to live with them, reinforcing the protective relationship established in the family life.

It will depend a lot on how my family will live, because if it's just her and me in the world... I'll have to work... I'll need to take shame in the face.... to work and take care of her. (P7)

Of those interviewed, four participants (P16, P10, P7 and P18) have a future expectation that their sibling may be independent and not need support.

I imagine that it will be fine... I imagine that she will be independent... that she will do things by herself. (P10)

For two participants (P17 and P15), even with the expectation that the sibling is independent, they believe in a need for surveillance.

I don't know. I think even though she doesn't need it, I'll always be around to help her with whatever she needs. I think it'll go something like this. (P15)

Lizasoain and Onieva (2010) and Alves and Serralha (2019) report that siblings of people with disabilities place themselves as responsible for caring for their brother/sister in the future. Such a situation was found in studies with adult siblings or in late adolescence (Batista et al., 2016; Cezar & Smeha, 2016), which may justify the oscillation in the answers of the participants' group, which is composed of siblings who meet both at the beginning and the end of adolescence. Even believing in the possibility of autonomy, the participants placed themselves in a supporting role in the relationship, being present to offer the necessary help and care.

In light of these considerations, it is clear that siblings' relationships may be affected from birth to future life planning, with a frequent concern about "caring". These findings reinforce the need for studies and support programs for families of people with disabilities, including all their members, such as the father, the mother and the siblings.

4 CONCLUSIONS

Although the study presented some limitations and was carried out with a small number of participants and in an atypical world context, such as the COVID-19 pandemic, the results presented are relevant for higher knowledge on the subject addressed to siblings of people with T21. The discourse analysis made it possible to identify common points in the verbal report of adolescents, allowing the creation of categories to understand better the impact of having a disabled brother/sister.

The study highlights that an adequate dialogue and effective communication about the particularities of the disability contributes to the knowledge and adjustment of the sibling's current and future expectations and collaborates with forming the bond and maintaining a healthy fraternal relationship.

Relationships among siblings are permeated by affection, complicity, rivalry and disagreements. However, feelings of rivalry and disagreements should not be attributed to one of the brothers/sisters having T21. The literature on siblings of people with disabilities highlights that such siblings tend to increase responsibilities and roles associated with caring for the disabled brother/sister. This question cannot be conclusive in the present study, as there was not enough sample variability for comparisons according to birth order and sex to be performed. The present sample mainly consisted of male siblings older than their brother/sister with T21.

Finally, due to the requirement of social isolation, the need for a homestay, with school and therapeutic activities remotely occurring, it is essential to consider this atypical context of the COVID-19 pandemic, which caused a change in social and family interactions being a variable to be considered in understanding the results found in the present study.

The fraternal relationships established in the families of people with T21 can be rethought based on the considerations recorded in this study. However, the expansion of data considering a more significant number of participants, birth order and age of siblings may bring new information to the understanding of family dynamics. From the discussions and reflections contextualized in this article, new studies may bring other contributions to this theme.

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