



Psicologia em Estudo

ISSN: 1413-7372

ISSN: 1807-0329

Universidade Estadual de Maringá

Ronca, Roberta Pasqualucci; Rocha, Marina Monzani; Pozzi,
Denise Campos; Cymrot, Raquel; Blascovi-Assis, Silvana Maria
SÍNDROME DE DOWN: IRMÃOS FAZEM DIFERENÇA NA QUALIDADE DE VIDA DOS PAIS?
Psicologia em Estudo, vol. 24, e44238, 2019
Universidade Estadual de Maringá

DOI: <https://doi.org/10.4025/psicolestud.v24i0.44238>

Disponível em: <https://www.redalyc.org/articulo.oa?id=287162798033>

- Como citar este artigo
- Número completo
- Mais informações do artigo
- Site da revista em redalyc.org



Sistema de Informação Científica Redalyc
Rede de Revistas Científicas da América Latina e do Caribe, Espanha e Portugal
Sem fins lucrativos acadêmica projeto, desenvolvido no âmbito da iniciativa
acesso aberto

DOWN SYNDROME: SIBLINGS MAKE DIFFERENCE IN THE QUALITY OF LIFE OF THEIR PARENTS?

Roberta Pasqualucci Ronca^{1 2 3}, Orcid: <http://orcid.org/0000-0002-9929-2255>

Marina Monzani Rocha¹, Orcid: <http://orcid.org/0000-0003-4995-7906>

Denise Campos Pozzi⁴, Orcid: <http://orcid.org/0000-0001-8417-4873>

Raquel Cymrot¹, Orcid: <http://orcid.org/0000-0001-9874-4507>

Silvana Maria Blascovi-Assis¹, Orcid: <http://orcid.org/0000-0002-5437-891X>

ABSTRACT. The objective of this study was to evaluate and to discuss the influence of the presence of siblings with typical development on the quality of life (QoL) of parents of adolescents with Down Syndrome (DS). It was a qualitative, cross-sectional, descriptive and exploratory study. The sample consisted of 25 families represented by the caregiver with children aged from 10 to 19 years old. These families were divided in two groups: a) a group of parents with single child with DS (GDSU) and b) group of parents with children with DS and other(s) with typical development (GDSI). Participants answered the semi structured interview whose script focused on topics such as family planning, the presence of the sibling in the family, relationships among the siblings (for GDSI), the future of the child with DS, and aspects related to the parents' feelings about the birth of the child and of the news on his coming to their family. Data were collected, individually, in a single meeting with approximately 30 minutes of duration. The results indicate that the presence of siblings with typical development can change the family structure and dynamics, but not in order to influence a better QoL, since the reports of both groups were very similar.

Keywords: Down syndrome; quality of life; caregivers.

SÍNDROME DE DOWN: IRMÃOS FAZEM DIFERENÇA NA QUALIDADE DE VIDA DOS PAIS?

RESUMO. O objetivo deste estudo foi avaliar e discutir a influência da presença de irmãos com desenvolvimento típico na qualidade de vida (QV) de pais de adolescentes com síndrome de Down (SD). Tratou-se de um estudo qualitativo, transversal, descritivo e exploratório. A amostra foi formada por 25 famílias representadas por um cuidador, com filhos em idade entre dez e 19 anos. Essas famílias foram divididas em dois grupos: a) grupo de pais com filhos únicos com SD (GSDU) e b) grupo de pais com filhos com SD e outro (os) filho (os) com desenvolvimento típico (GSDI). Os participantes responderam à entrevista semiestruturada, cujo roteiro focalizava temas como o planejamento familiar, presença do irmão na família, relações entre os irmãos (para GSDI), o futuro do filho com SD e aspectos referentes aos sentimentos dos pais

¹ Universidade Presbiteriana Mackenzie, São Paulo-SP, Brazil.

² E-mail: roronca7@gmail.com

³ Faculdade de Fisioterapia da Universidade Paulista (UNIP), São Paulo-SP, Brazil.

⁴ Faculdade Anhanguera de Campinas (FAC), Campinas-SP, Brazil.



diante do nascimento do filho e da notícia. Os dados foram coletados em um único encontro, individualmente, com duração aproximada de 30 minutos. Os resultados evidenciam que a presença de irmãos com desenvolvimento típico pode mudar a estrutura e a dinâmica familiar, porém, não de forma a influenciar a melhor QV, já que os relatos de ambos os grupos foram muito parecidos.

Palavras-chave: Síndrome de Down; qualidade de vida; cuidadores.

SÍNDROME DE DOWN: ¿HERMANOS HACEN DIFERENCIA EN LA CALIDAD DE VIDA DE LOS PADRES?

RESUMEN. El objetivo de este estudio fue evaluar y discutir la influencia de la presencia de hermanos con desarrollo típico en la calidad de vida (CV) de padres de adolescentes con síndrome de Down (SD). Se trata de un estudio cualitativo, transversal, descriptivo y exploratorio. La muestra fue formada por 25 familias representadas por un cuidador, con hijos en edad entre 10 y 19 años. Estas familias fueron divididas en dos grupos: a) grupo de padres con hijos únicos con SD (GSDU) y b) grupo de padres con hijos con SD y otro (s) hijo (s) con desarrollo típico (GSDI). Los participantes respondieron a la entrevista semiestructurada, cuyo itinerario enfocaba temas como la planificación familiar, presencia del hermano en la familia, relaciones entre los hermanos (para GSDI), el futuro del hijo con SD y aspectos referentes a los sentimientos de los padres ante el nacimiento del hijo y de las noticias. Los datos fueron recolectados en un solo encuentro, individualmente, con una duración de cerca de 30 minutos. Los resultados evidencian que la presencia de hermanos con desarrollo típico puede cambiar la estructura y la dinámica familiar, pero no para influir en una mejor CV, ya que los relatos de ambos grupos fueron muy parecidos.

Palabras clave: Síndrome de Down; calidad de vida; cuidadores.

Introduction

The diagnosis of a deficiency in the children is one of the most unexpected and perhaps sudden revelations, which changes parents and family lives (Chambers & Chambers, 2015). One side of the emotional impact is because of these children have an influence on family life, as they require extra care throughout their lives, which will be (more often) provided by their parents (Geok, Abdullah, & Kee, 2013).

The parents experience when receiving the news is variable. It depends on how it is carried out. At the time, it is very important the people who are involved, the place, the language used, and the information provided. When these aspects are inadequate, feelings contrary to the joy of the birth of a child are generated, making it difficult the process of linking with the newborn (Paul, Cerda, Correa, & Lizama, 2013).

The moment of discovery is more difficult for these families who may experience feelings and varied reactions. These can be influenced by indirect variables such as financial resources, child's disability type and social network of support. Regarding siblings without disabilities, these feelings can be ambivalent and contradictory, such as envy, jealousy, sadness, shame, happiness with behaviors of love and affection received by the disabled brother (Pereira-Silva & Almeida, 2014).

Having a child with developmental disorder can affect the family quality of life (QoL). QoL is a subjective feeling of the individual for the betterment of life as well as satisfaction and happiness in life. This includes the physical well-being, psychological state, social relations within and outside the family, environmental effects and beliefs (Tekinarslan, 2013).

To better understand the family dynamics, it is necessary to focus all the subsystems, including, besides parental and marital subsystems, the brother-brother and grandparents-grandchildren, considered relevant (Silva & Dessen, 2006). This system consists of reciprocal relationships in which the child is actively involved in this interaction; each member of the system influences and is influenced by all other (Dessen, 1997). Thus, any child at birth, changes the family relationships; after all, he is a new member who presents himself with his own characteristics and interferes directly in the environment he will live, imposing new roles (Pereira & Fernandes, 2010). So, the family should not be seen more as a separate set of dyads, and it is necessary to highlight how this child is inserted in the familiar system and how he accepts them (Dessen, 1997).

Historically, within the family sphere, care for people with some dependency is done essentially by their families, which is called as informal caregivers. This care may have different difficulties depending on the type of disability and dependence, causing impact on the family unit and can adversely affect the QoL of the main caregiver (Amendola, Oliveira, & Alvarenga, 2008).

The development of people with DS is more slowly and requires more dedication, especially from parents, which ultimately generate changes in routine, causing functional, structural and emotional changes in all family members and it may influence the QoL of them all. Most studies point out to the mother as the figure who most often plays the role of caregiver, who is responsible to provide physical, emotional, drug and sometimes financial assistances (Oliveira & Limongi, 2011).

According to King, Zwaigenbaum, Bates, Baxter and Rosenbaum (2012), several studies have focused on the negative aspects of raising a child with disabilities instead of the joys that this experience, although challenging, can provide. But there is a recent interest on the positive contributions that these children can bring to each family, especially in relation to psychological concepts. Considering the consulted literature, the aim of this study was to evaluate the influence of the presence of siblings with typical development in the QoL of DS teenagers' parents, discussing qualitatively the presence of siblings in the family in relation to the family planning and the future of the DS son.

Method

This study was designed as an exploratory, cross-sectional and descriptive in nature, in the qualitative investigation line. The research project was approved by the Research Ethics Committee of Paulista University - UNIP on June 8, 2017, under number 2109032.

The main caregivers (mother and/or father) of adolescents with DS were selected from a convenience sample also using up-sampling technique by saturation. The study included 25 families represented by a caregiver, whose inclusion criterion was having a child with DS aged from 10 to 19 years old, male or female. These families were divided into two groups: a) a group of parents with single child with DS (GDSU) represented by 11 fathers or mothers and b) a group of parents with children with DS and other(s) with typical

development (GDSI), represented by 14 mothers. This age group is defined as adolescence by the World Health Organization [WHO] (2017). Exclusion criteria were the parents of institutionalized adolescents (residents in the institution care), hospitalized patients, children who presented any other associated comorbidities and families with other member with neurological disorder without any relation with DS.

The data collection location was an Institution of specialized care to persons with disabilities in the metropolitan region of São Paulo. The institution representative also signed a term authorizing the research in that place. The 20 participants from this Institution were invited by the researcher through an invitation letter with explanations of the work, as well as clarification on ethical procedures. Once it was accepted, meetings were scheduled for data collection, individually, in date and time convenient to the collaborators, in which they signed the terms of Informed Consent Form (ICF) and all doubts were answered. In order to complete the numbers of participants to the sample as it was necessary to have more 5 ones, it was contacted a Non-Governmental Organization (NGO), using the sampling method named snowball, which is not probabilistic and uses references chains.

Data were collected in a single meeting, individually, lasting approximately 30 minutes. Participants filled an identification sheet and afterwards they answered the semi-structured interview, whose script was focused on topics such as family planning, brethren's relationships, the future of the child with DS, as well as aspects related to the feelings of the parents in the face of the child's birth and other relevant facts that they wanted to report on the subject.

The data collected through semi-structured interviews were transcribed in full, read repeatedly and organized in thematic groups with development of five categories for further analysis.

Results and discussion

The total sample of participants consisted of 25 caregivers, 11 in the GDSU and 14 in the GDSI. All sample details are described in Table 1.

Table 1. Characterization of the GDSU / GDSI sample.

Variables	GDSU	GDSU	GDSI	GDSI
	Frequency	Percentage	Frequency	Percentage
Sex Caregiver				
Female	10	90,90	14	100,0
Male	1	9,09	0	0
Marital Status				
Married or living with a partner	7	63,63	7	50,0
Single, divorced or widowed	4	36,37	7	50,0
Level of Education				
Completed Elementary and High School Education	7	63,63	13	92,86
Completed Higher Education	4	36,37	1	7,14
Remunerated Activity				
Yes	6	54,00	2	15,00
No	5	46,00	12	85,00
Socioeconomic Status				
A	4	36,36	0	0
B	3	27,27	5	35,71
C and D	4	36,36	9	64,28
Son with DS				
Female	10	90,90	7	50,00
Male	1	9,09	7	50,00

Time of diagnosis and initial reaction

From all the caregivers of both groups, only two knew the diagnosis of children before birth, through the morphological ultrasound and had the confirmation with amniocentesis. The others, although they reported that underwent prenatal examinations monitoring, they only discovered after birth and, according to the following statements in a distressing way:

I only knew when he was born. The doctor said in cold and rough way: your daughter has DS and she will have a problem forever. They told me to look for APAE (institution who welcomes disorders people, especially children) where they would explain to me what it was this syndrome. I went into depression [...], it was very shocking, like a mourning of a child, you do not know and do not know what will be from then on (P10 - GDSI).

The diagnosis was only after the birth, he was born normal, he was just squishy, but I did not know much of newborn child, but it seemed like everyone was running from me, that everyone knew except me. The feeling was a lot of sadness, mourning, I cried a lot, I felt bad to have not noticed, I felt ashamed of myself... he was my son (P5 - GDSU).

The news that a child has a chronic condition is usually unexpected for parents and family. The diagnosis of DS can be done during the prenatal period, through the morphological ultrasound of the first trimester and can be confirmed by karyotype or amniocentesis. According to Paul et al. (2013), prenatal diagnosis allows to inform and guide

the families, however, especially in Latin American countries, it does not happen routinely, and most of the diagnoses occur after birth, which happened in most of the cases of this study, in line with the caregivers' reports. The authors state that parents whose diagnosis was made during the prenatal are four times more satisfied with the lived experience in relation to parents with post-natal diagnosis. Probably, this occurs due to the longer time they have to adapt themselves to the news and to elaborate the idea of the birth of a son with different characteristics from that imagined.

Cunha, Blascovi-Assis and Fiamenghi Jr. (2010) conducted a qualitative study on the impact of DS news for parents with participation of four couples. From these, three also received the news only after birth. They all reported a lack of more enlightening news and they reported a sense of mourning and loss of the idealized son. Similar results were observed in the present study, the sense of mourning reported by some mothers (reports set out above in P10 - GDSI and P5 - GDSU) when they 'lose' the perfect, idealized son, and need to open unexpectedly a room for an unknown reality, which causes fear and sadness. This feeling of mourning can be compounded by the sense of failure they may feel because they could not generate a perfect life. Another found condition refers to how the diagnosis was given, some mothers reported being alone at that time, which made the news more impactful. It is observed that in the following report of P6 - GDSU. Cunha et al. (2010) also add that there is a consensus among researchers who study the subject, that the news has to be given in the presence of both, father and mother.

We only knew about our baby two days after birth. I knew something was wrong, but no one told me anything. Then the nurse came in and said the baby wasn't feeling well and that he was in the ICU and they were suspecting of DS, it was out of the blue, and I was alone, my husband had just gone away. Could they not have wait for him? It looked like it was not happened to me, it was a story, it was the worst feeling in the world (P6 - GDSU).

Skotko (2005) conducted a research called 'Communicating the postnatal diagnosis of Down's syndrome: an international call for change', in which the reflections of 882 mothers in the United States and 422 mothers in Spain were analyzed. It was found that mothers in both countries rarely reported that the birth of their children was a positive experience because they were very frightened and anxious at the time of the discovery of the diagnosis. Mothers also agreed that the timing of the news would not be gloomy if doctors adopted some recommendations, and completed with suggestions of improvement for this moment, such as: 1) who gives the diagnosis should be the doctor; 2) the doctor should give the diagnosis with both parents together, whenever possible; 3) the diagnosis should be done in a private location; 4) the diagnosis has to be reported as soon as possible, as the doctor suspects; 5) sensitive language should be used; 6) the doctor must include the positive aspects of DS; 7) the doctors should not share his personal opinion; 8) parents should receive an updated printed material and 9) the doctor should provide the contact information of a local support group.

Family planning and relationship between the children (if any)

In GDSI group, children with DS were the youngest children. A unique mother had a child with typical development after the child with DS. However, she reported that the pregnancy of her second child had not been planned. All these mothers said they did not

want more children and no mother planned a son after having a child with DS. As for pregnancies of children with DS and of the oldest children, there was great variation between the pregnancy was planned or not. Most mothers reported that the relationship among the children is good, but some problems have appeared, especially in relation to jealousy.

Yes, the three pregnancies were planned. The relationship is good now, but at first my daughters were jealous because I go out with him every day, and I gave much attention to him [...] but today my oldest daughter is graduating in pedagogy. She wants to work with inclusion (P2 - GDSI).

Skotko, Levine and Goldstein (2011a) report that parents who have children with DS feel that their children without DS have a good relationship with the siblings. Most of the parents also felt that their children without the diagnosis are more sensitive and caring, attributing this attitude to having a brother with DS. Cuskelly and Gunn (2003) state that having a brother with DS can be benefited to the others. In comparison among siblings of people with DS to the control group (no sibling), the first demonstrated more positive interaction, increased tolerance to the different and more empathy and gentleness in respect to their siblings.

Skotko, Levine and Goldstein (2011b), in another study on the siblings' perspective about having a brother with DS it was found that most of the siblings of all ages love their brothers and, especially, the oldest ones, they are pride on their brothers with DS. A minority of the se said they felt sad, pity and / or shame of their brothers. But even with these feelings, almost 100% of the siblings said they would not exchange their brother with DS. The authors also mentioned that the minority of the siblings reported that feel that their parents give much more attention to their brother and not enough for them. Regarding this point, we found a difference in the perception of the mothers evaluated in this study, in which some mothers reported feeling that the otherchildren were jealous of the child with DS, especially for the attention given to him. This fact can be interpreted, if it is not just a perception alteration, as a sense of guilt of the mothers since they know that they give more attention to the child, although he really needs. What can be noted in there port cited above from the P2 mother - GDSI. Another hypothesis could be the possible embarrassment of the siblings when they assume they are jealous, because they are aware that the DS brothers really need more attention.

In the case of this research, it detected the narrative of the good relationship among the children for all caregivers of the GDSI group. The fact of they have not had more children after the child with DS was justified, sometimes by old age, by having other older children and/or the financial expense that another child would ask. Regarding the GDSU group, only four mothers reported they want more children, but they did not realize this desire by factors such as failed attempts, the age, the partner do not want to, separation, fear, concern about the financial situation and time division among the children. This indicates that in this sample as a whole, few mothers actually planned to have another child:

Today I do not plan any more children, but I tried hard before and I had two natural abortions and after talking a lot with doctors, we decided not to try again (P4 - GDSU).

I want another child, but the mother does not want because of her age [...] but I think it would be very important, because even if we want to fantasize that she is capable of doing things alone, we have to face the reality that alone maybe she can not support herself (P8 - GDSU).

Concern for the future of the child with DS and the absence of parents

A constant worry in parents of people with some developmental disorder is, what will be of my son when I die? Who will take care of him? Currently, this concern is more frequent due to the increase in life expectancy of people with DS. In the past, these individuals did not exceed adulthood due to complications that worsened throughout their lives. However, with advances in medicine, the longevity of these people has increased considerably.

The loss of parents, by the children, is natural considering the life cycle and aging. But for parents who have a child with DS or other disabilities, the imagination about this situation can generate anguish and restlessness by the concern for her son's dependence and who will care for their child in their absence, since few of them can effectively have independent living.

In the current study, all caregivers demonstrate concern for the future of their children specially with the possibility of the lack of them. A caution on this work was relevant to the sample of parents with teenagers, whose children and parents, are already older. This is the point where a brother with typical development, could make a difference, because parents who have more children feel some security, no matter how small it may be, when compared to parents with single child. Even if the presence of a brother is no guarantee for them that there will be someone to look after their children, a slight difference and safety can be seen in the reports of parents with more children.

I teach him to be independent, but he is very naive, he thinks the street people are equal the home people. I think my daughters would take care of him, the problem is that when I leave him with them, he is sulking, he does not ask for things if he wants something, he is not comfortable. I don't know if he will take care of himself in a right way and it's my biggest concern because we're not here forever (P2 - GDSI).

My other children say that I'm selfish because I say that when I go (die) I want he goes with me, and when he goes, I want to go with him. Because to say that I care and I love, I think it's easy, but each one takes care of his way, doesn't he?! And for everything in life it is necessary to have time and control [...] sometimes I get home when I go out alone and I ask him if he drank water and says no, it was all day long with cola and juice, do you believe?! (P14 - GDSI).

I imagine he will survive without me, he will have a wife, employment and he will continue to be a source of pride. I teach his brother to take care of him, if one day I will go out, it's important that one has the other (P4 - GDSI).

Returning to the study by Cuskelly and Gunn (2003), the authors mention that when parents plan for the future of their child with intellectual disability (ID) after their deaths, in most cases, this planning associate a brother as a successor of this care. The burden of care usually falls on the eldest brother, who takes greater domestic responsibility in relation to his peers, his siblings with DI.

The data of this study, combined with the results of Cuskelly and Gunn (2003) and Rosa, Alves and Faleiros (2015), indicates that having more children does not guarantee care for the brother with disabilities, but can bring greater security to parents, if at least some help that person will have. According to the reports, the mothers who have more children, talk about the possible care of siblings, but none shows to be so confident.

This is a situation that worsens in the report presented at GDSU, since, according to the reports which are highlighted below, many caregivers say that this is a very distressing

matter, so much concern and they prefer not to think about it. As a result of lack of a possible care, many parents talk about trying to raise the child as independent as possible. This was the time of the interview in which the relationship with religion has become more evident with utterances about faith.

I do not think about this, I cannot even think, there's no one, nor his father. It's just me and it upsets me very much, but I trust in God (P1 GDSU).

I prepare my daughter for the world. I try to give her every opportunity, that's what I can do for her [...] I do not think much about the time when I'm not here anymore, the future belongs to God (P3 GDSU).

I imagine a good future, peaceful, but if I am not here it will be difficult. What makes me worry and wonder is, and if she did not have neither her father nor me? I think she does not live even one month (P11 - GDSU).

In the paper by Rosa et al. (2015) entitled *Com quem ficará meu filho? Uma preocupação dos pais que estão envelhecendo e não têm com quem deixar seus filhos com SD, que também estão envelhecendo*, it was found that many families take time to accept the fact that people with DS age and that the loneliness and the guilt were recurrent feelings among families, for their dependent children require a lot of dedication, and they feel guilty just the thought that such responsibility may lie with the other children, possible caregivers in the future and how this transition and adaptation of siblings would be without them. This situation could be seen in the following report of P10 mother - GDSU, who says she never thought of transferring their responsibility in a child who does not exist yet:

You know, I'm going to take care of my daughter, People have asked me what will happen the day of my absence, and I think, I'll have to have another child to pass the buck on another child? My family has eight brothers, they will decide. I will not have a child to be born already with this responsibility, and that's no guarantee. You already know that nobody wants to take care of a child with DS and I do not know who goes first if it's me or her, tomorrow belongs to God and not me (P10- GDSU).

Nunes and Dupas (2011) also discuss this issue, and claim that in studies of siblings, usually they are responsible for the brother with DS, if necessary. Another strategy pointed out by parents refers to leave a financial support for the child to be able to enjoy after they die, but there is concern in achieving this goal before the current economic situation. They complement the study reporting the importance of religion and spirituality, as support for the family since they are a source of comfort and hope.

Belief in any religion or spirituality can provide peace of mind to people who are going through some sort of need or illness. The study by De La Longuiniere, Yarid and Silva (2018), argues that religiousness and spirituality influence in facing the adverse situations and cause positive impact on people QoL. They also claim that spirituality is a support for both the patient and the caregivers who recognize that they deal with it to cope with possible stressful experience.

In an article carried out on the experience of the Taiwanese men who take care for their siblings with DS, Kuo (2014) states that to have the responsibility for their brother's care was the most discussed topic among the evaluated subjects. In this case, there is a large cultural impact, because brothers are the obvious caregivers of DS brothers, mostly the older brothers, and this responsibility appeared as unquestionable in this population. Almost all participants mentioned the chaos they experienced during the transfer phase for the role as a primary caregiver, especially due to the lack of familiarity with this role. Cultural differences with the West are clear in this article, in which Western culture, most of the time,

assigns the role of caregiver to women. By isolating the cultural differences, an important factor to think about Kuo's study, would be, how to improve the process of transferring to the role of primary caregiver. The author says that parents need to involve the children, likely caregivers, in the lives of children with DS from the beginning, as this will increase the capacity and competence of the brothers to provide care and the proper help.

This last article brings reflections beyond the question of who will take care of the DS subjects in the future, that is, how this new caregiver should be prepared for it, how the transfer of that care will be, and the implicit responsibility inherited by this person often without being prepared for such a role. This concern appeared sometimes with mothers in this study, and few of them demonstrate worry in relation to the possible child caregiver, but only with their child with DS. However, according to Ardore and Regen (2014), concern for the future can become smaller if parents and children can talk about it and try to establish a life project. The authors also point out that questions such as "[...] who will take care of my brother when my parents die?" come to the siblings, but they have little afraid to talk to parents about it.

Although the care of that subject falls upon a close family member, there are some families that they do not count on for help, or they do not trust on the certainty of this care. Pinto and Simson (2012) state that in the 1988 Constitution, health and education are understood as a right of all and duty of the State. In it, the support for the elderly explicitly becomes the duty of the family, the state and society. In practice, however, the family remained the primary responsibility for this support. But here is a question: and when the family is no longer able to provide this support?

Rosa et al. (2015) argue that while the Brazilian legislation provides that the care of dependent family members should be the responsibility of the families, this should be reconsidered in that family are likely to die before, and they do not have the support of other family members to assume guardianship. In this context, one of the alternatives of non-family care, would be the long-term care institutions for the elderly, whether public or private. However, it is not a common practice in Brazilian society, especially when we think of older people with a disability.

The speeches reported in the current study corroborate with the searched literature when looking on the aging of that population, the feelings and concerns of these parents. These works address the fact of who will continue the support of their children when they die, but unfortunately, they did not conclude with suggestions or solutions on what to do when this occurs.

The therapeutics residential service, also known as therapeutic homes or assisted living facility, were instituted by decree number 106 of February 11, 2000 by the Ministry of Health with a view to the need for restructuring the care model to person with mental disorders, but which is found in the very ordinance is the exclusivity to people with mental disorder, which does not apply to people with ID and/or physical disabilities. Regarding the DS population, it is verified that this kind of housing or assistance is done only either by some NGOs that provide this institutional welcome or private institutions or non-profit ones.

The law number 13.146 of July 6, 2015, establishes the Brazilian Law of Inclusion of People with Disabilities (Person Statute with Disabilities), in Chapter Five, referring to the right to housing, says in Article 31 that "A person with disabilities has the right to decent housing, within the natural family either substitute with his/her spouse or partner or alone, or in housing for independent living of persons with disabilities, or even in an inclusive

residence". Hence, in practice and in the stories of many of the parents surveyed in this research, existing legislation is not always applied.

Parents Feeling and perception on the child with DS

A correlation was observed for this category in both groups. This uniformity is presented mainly in relation to the feeling of caregivers on: the ability to care for a child with DS the self-fulfillment, the choice and gift from God, the felt and received love, the protection, and the pride of the children with DS. There are few mothers who speeches on overload or pressure care.

As it has been said before, the time of the diagnosis or the birth of a child with DS can be a traumatic factor in the lives of couples and families. However, which was noted in this study is that, after the initial shock, caregivers face up to their child and all the issues surrounding the disease that comes with him, unconditionally. This is partly because of being mother or father, and the bond and dependence that exists in this relationship. The way of each mother will go easily through this process will depend on her philosophy of life, beliefs, mental harmony, emotional balance and social support with which she interacts.

In the current study, the evaluated caregivers, being adolescents' parents, have had enough time to overcome barriers and more difficult moments after the initial shock. These observations appear highlighted in the following reports:

Ah I feel very good, if God gave me her it is because I can take care of her, so it's great because she is a loving and healthy child and I feel I am very able to do this (P1 - GDSI).

I feel happy, I won a gift from God. One day I asked God for a pure, true love and he gave me my son [...] I remembered that another day. He is a blessing for everything, and everything that he needs I am here! (P14 - GDSI).

I feel I am an enlightened and capable person, I have him as a companion for life, and he is loving and cheerful (P6 - GDSU).

Following this route, an important point for discussion is the strategies of 'coping', which means to face, to deal with, to fight, and it can also be the way of coping strategies that these parents have to bear an unwanted situation. Some families find it easier to adapt to this situation than others, often more vulnerable. This difference depends on the family resilience level.

In the study of Rooke and Pereira-Silva (2016) the authors claim that the ID or DS cannot be considered as synonyms of suffering, sadness, stress and social isolation, as the literature of past decades pointed. They add saying that, despite reports indicate the DS as a bad event, the reaction of families to the diagnosis had more positive impact than negative. Regarding family resilience indicative, the results pointed out to the fact that these families, facing problems, organize themselves so that there is unity, dialogue with all the members seeking for co-operation, with closer ties among members and adoption of a perspective positive.

In the present study, the focus was not directed to the coping strategies that each family had in order to face the situation in a more friendly way, but with those obtained reports, it was observed that a greater strategy used was really the love that a mother has for a child, the affection received and the spiritual belief.

I've already heard a lot: ah, you were chosen by God, it is not anyone who can have this responsibility and that I was also paying the price for all my sins. But I think that, if I have him, I have as a learning experience in my life and I feel happy because he is very loving. When I'm sad, he hugs me, he kisses me, he says that everything is going to be alright and he completes: Mom, you are my life (P2 - GDSI).

I feel myself as a special person, I have a lot of ability and patience, and sometimes I think that I protect him so much. But he's always there with me, he is loving, and it gives me assurance that he will not get involved with the wrong things, it is worse to have a drugged child than a child with the problem like mine (P12 - GDSI).

I'm proud to have a daughter like her, do you know why? Because today everything related to care children is very hard and this girl does not give me any work, she is very loving and a close companion (crying) (P10 - GDSU).

Another important point noted in this study was the excessive attachment between parents and their children, which is, undoubtedly, genuine by the nature of this relationship, but that can be amplified by the disability, by the remorse, by the feeling of sadness at the time of the identification of fetal chromosomal disorder and by the proximity in daily and intensive care, as well as by responsibility and by dependence.

Negative feelings and difficulties

At the end of the interviews, the interviewer noticed that the parents had not reported feelings or negative factors for the child with DS. So, she did a more objective question about any negative feeling about the care of children with DS and consequently more dependent. The answers are in the following reports:

I feel charged by anyone and it is very difficult because prejudice is very big, and I feel it. Because you are fear on what you do not know and I cannot judge people because I was in the same way. People already look with pity or judging, like, will he be somebody? The world is cruel (P4 - GDSI).

I think that the lack of trained people, mainly in schools is harmful. There is a lot of prejudice and it seems they are born with a prognosis to be a problem (P6 - GDSU).

Buscaglia (2006) in his book talks on the congenital or acquired deficiency issue. Here members that no one is free of possible irreparable disability. What all these families have in common is the confrontation with a new, unexpected and potentially devastating reality. A deficiency is never desirable and often cause pain, discomfort, tears, confusion and waste of time and money. However, although they may not realize it, the person who has a disability that incapacitates him, will be less limited by disability than the attitude of society towards him. That is, society, in most cases, will define disability as incapacity and the subject will suffer the consequences of such a definition. The author states that a child who has a physical or intellectual disability in our society is not incapable, he is just a disabled child. But the people who are around, even the closest and well-intentioned, will undertake to convince these people, or help them to learn that they are unable. This is the fear, ignorance and prejudice occurrence.

Social prejudice exists and it is opens wide in the society daily. Whether by race, color, economic status, religion and even political opinion. In the case of prejudice with disabilities people, it is no different, what has been observed previously in the story of

mothers P4- GDS I and P6 - GDSU. So many families limited to their homes and take refuge into their own housings, limiting further the physical, social, emotional and psychological development of people with disabilities.

Other variables that appeared during the following reports were on fatigue and dedication. Although the present study has been few reports on the fatigue of caring, it is very common in the literature that parents of people who needs extra care, they have a lower QoL and increased stress. A common point in the literature, which can be verified in this study, is the advantage of DS in relation to other diseases or syndromes, this happens very likely to be a common condition, thereby better known and, as seen enough in the mothers' reports, children are very caring, loving and concerned.

Sometimes I feel a little tired, because you must take more responsibility because he is special. Then, everything that happens it is me who is there to solve (P12 - GDSI).

A child with DS requires more dedication, it needs more engagement and stimulation and with a result that we never know what will be. It's a daily and tiring routine. For us and for them (P5 - GDSU).

Oliveira and Limonge (2011) mention advantages that can favor the DS in relation to other diagnoses, including: recognition of the clinical picture and early diagnosis; chromosomal origin, which would be external factor to parents; wide prevalence, being of event and common recognition; slow development, which would allow more time to adapt to changes in behavior and at the same time its course is predictable.

Corrice and Glidden (2009) state that mothers who have children with DS suffer less depression and stress than mothers who have children with ID of another etiology. There is also positive impact on parents' relationships, as the divorce rate of these families is smaller than in families with other disabilities, and better relationship between siblings.

The data presented here serve as a basis for reflections about family planning and the knowledge on parental concerns about their children with DS. More studies focusing on the mother-child relationship or parent-child should be performed in order to promote greater knowledge of the needs of these families and their ways of coping.

Final considerations

It was possible to evaluate and discuss, from the study group, the impact of the presence of the siblings in the young family with DS. Qualitative data helped to confirm that the investigated phenomenon could be understood through the verbal report of the principals caregivers involved in this search.

In the semi-structured interviews, the parents showed that the time of diagnosis was the hardest and most difficult time to cope, and all parents showed concern for the future of the child when in their absence. However, it was observed that the resilient behavior, the religiosity and the parental unconditional love were evidenced in the sample. It is fundamental to continue the studies in this field so that the needs of the families, who deal with DS children, are known from the therapeutic, the educational and the public policies point of view which are supposed to support people with special needs.

It was concluded that the presence of siblings with typical development can change the structure and the family dynamics, but they do not influence them to the point of getting a better QoL, since reports from both groups were very similar.

References

- Amendola, F., Oliveira, M. A. C., & Alvarenga, M. R. M. (2008). Qualidade de vida dos cuidadores de pacientes dependentes no programa de saúde da família do município de São Paulo. *Texto & Contexto-Enfermagem*, 17(2), 266-272. Recuperado de: <http://www.scielo.br/pdf/tce/v17n2/07.pdf>. doi:10.1590/S0104-07072008000200007
- Ardore, M., & Regen, M. (2014). *Tenho um irmão diferente. Vamos falar sobre isto?* (4a ed.). São Paulo, SP: APAE
- Buscaglia, L. (2006). *Os deficientes e seus pais* (5a ed.). Rio de Janeiro, RJ: Record.
- Chambers, H. G., & Chambers, J. A. (2015). Effects of caregiving on the families of children and adults with disabilities. *Physical Medicine and Rehabilitation Clinics of North America*, 16(1), 1-19. Recuperado de: <https://www.sciencedirect.com/science/article/pii/S1047965114001016?via%3Dihub>. doi: 10.1016/j.pmr.2014.09.004
- Corrice, A. M., & Glidden, L. M. (2009). The Down syndrome advantage: fact or fiction? *American Journal on Intellectual and Developmental Disabilities*, 114(4), 254-268. Recuperado de: <https://www.ncbi.nlm.nih.gov/pubmed/19642708>. doi: 10.1352/1944-7558-114.4.254-268
- Cunha, A. M. F. V., Blascovi-Assis, S. M., & Fiamenghi Jr., G. A. (2010). Impacto da notícia da síndrome de Down para os pais: histórias de vida. *Ciência & Saúde Coletiva*, 15(2), 445-451. Recuperado de: http://www.scielo.br/scielo.php?script=sci_arttext&pid=S1413-81232010000200021. doi:10.1590/S1413-81232010000200021
- Cuskelly, M., & Gunn, P. (2003). Sibling relationships of children with Down syndrome: perspectives of mothers, fathers and siblings. *American Journal of Mental Retardation*, 108(4), 234-244. Recuperado de: <https://www.ncbi.nlm.nih.gov/pubmed/12780335>. doi:10.1352/0895-8017(2003)108<234:SROCWD>2.0.CO;2
- Desarrollo en la adolescencia. World Health Organization. [s.d.]. Disponível em <www.who.int/maternal_child_adolescent/topics/dev/es/>. Acesso em 10 ago. 2017.
- Dessen, M. A. (1997). Desenvolvimento familiar: transição de um sistema triádico para poliádico. *Temas em Psicologia*, 5(3). Recuperado de: <http://pepsic.bvsalud.org/pdf/tp/v5n3/v5n3a06.pdf>
- Geok, C. K., Abdullah, K. L., & Kee, L. H. (2013). Quality of life among Malaysian mothers with a child with Down syndrome. *International Journal of Nursing Practice*, 19(4), 381-389. Recuperado de: <https://www.ncbi.nlm.nih.gov/pubmed/23915407>. doi:10.1111/ijn.12083
- King, G., Zwaigenbaum, L., Bates, A., Baxter, D., & Rosenbaum, P. (2012). Parent views of the positive contributions of elementary and high school-aged children with autism spectrum disorders and Down syndrome. *Child Care Health and Development*, 38(6),

817-828. Recuperado de: <https://www.ncbi.nlm.nih.gov/pubmed/21916929>. doi: 10.1111/j.1365-2214.2011.01312.x

Kuo, Y. C. (2014). Brothers experiences caring for a sibling with Down syndrome. *Qualitative Health Research*, 24(8), 1102-1113. Recuperado de: <https://www.ncbi.nlm.nih.gov/pubmed/25023221>. doi: 10.1177/1049732314543110

La Longuinieri, A. C. F., Yarid, S. D., & Silva, E. C. S. (2018). Influência da espiritualidade/religiosidade do profissional de saúde no cuidado ao paciente crítico. *Revista Cuidarte*, 9(1), 1961-1972. Recuperado de: <https://periodicos.ufpe.br/revistas/revistaenfermagem/article/viewFile/23418/19096>. doi: 10.5205/reuol.9799-86079-1-RV.1106sup201704

Lei nº 13.146, de 6 de julho de 2015. (2015, 6 de julho). Institui a Lei Brasileira de Inclusão da Pessoa com Deficiência. *Diário Oficial da União, seção 1*.

Nunes, M. D. R., & Dupas, G. (2011). Independência da criança com síndrome de Down: a experiência da família. *Revista Latino-Americana de Enfermagem*, 9(4). Recuperado de: http://www.scielo.br/pdf/rlae/v19n4/es_18.pdf. doi: 10.1590/S0104-11692011000400018

Oliveira, E. F., & Limongi, S. C. O. (2011). Qualidade de vida de pais/cuidadores de crianças e adolescentes com síndrome de Down. *Jornal da Sociedade Brasileira de Fonoaudiologia*, 23(4), 321-327. Recuperado de: <http://www.scielo.br/pdf/jsbf/v23n4/v23n4a06.pdf>. doi: 10.1590/S2179-64912011000400006

Paul, M. A., Cerda, J., Correa, C., & Lizama, M. (2013). ¿Cómo reciben los padres la noticia del diagnóstico de su hijo con síndrome de Down?. *Revista médica de Chile*, 141(7). Recuperado de: <https://scielo.conicyt.cl/pdf/rmc/v141n7/art07.pdf>. doi:10.4067/S0034-98872013000700007

Pereira, A. P. A., & Fernandes, K. F. (2010). A visão que o irmão mais velho de uma criança diagnosticada com síndrome de Down possui da dinâmica da sua família. *Estudos e Pesquisas em Psicologia*, 10(2), 507-529. Recuperado de: <http://www.redalyc.org/articulo.oa?id=451844632014>. doi: 10.12957/2010.8980

Pereira-Silva, N. L., & Almeida, B. R. (2014). Reações, sentimentos e expectativas de famílias de pessoas com necessidades educacionais especiais. *Psicologia Argumento*, 32(79), 111-122. Recuperado de: <https://www.researchgate.net/publication/279750795>. doi: 10.7213/psicol..argum.32.s02.AO10

Pinto, S. P. L. C., & Simson, O. R. M. V. (2012). Instituições de Longa Permanência para Idosos no Brasil: Sumário da Legislação. *Revista Brasileira de Geriatria e Gerontologia*, 15(1), 169-174. Recuperado de: <http://www.scielo.br/pdf/rbgg/v15n1/18.pdf>. doi:10.1590/S1809-98232012000100018

Rooke, M. I., & Pereira-Silva, N. L. (2016). Indicativos de resiliência familiar em famílias de crianças com síndrome de Down. *Estudos de Psicologia*, 33(1). Recuperado de:

<http://www.scielo.br/pdf/estpsi/v33n1/0103-166X-estpsi-33-01-00117.pdf>.
doi:10.1590/1982-027520160001000012

- Rosa, E. R. A., Alves, V. P., & Faleiros, V. P. (2015). Com quem ficará meu filho? Uma preocupação dos pais que estão envelhecendo e não têm com quem deixar seus filhos com SD, que também estão envelhecendo. *Revista Kairós Gerontologia*, 18(3), 109-121. Recuperado de: <https://revistas.pucsp.br/index.php/kairos/article/view/26474>
- Silva, N. L. P., & Dessen, M. A. (2006). Padrões de interação geitores-crianças com e sem síndrome de Down. *Psicologia : Reflexão e Crítica*, 19(2). Recuperado de: <http://www.scielo.br/pdf/prc/v19n2/a15v19n2.pdf>. doi: 10.1590/S0102-79722006000200015
- Skotko, B. G. (2005). Communicating the postnatal diagnosis of Down's syndrome: an international call for change. *Italian Journal of Pediatrics*, 31, 237-243. Recuperado de: <https://pdfs.semanticscholar.org/58fc/0c6ad7412e5471376d0fe720f380c80524c0.pdf>
- Skotko, B. G., Levine, S. P., & Goldstein, R. (2011a). Having a brother or sister with Down syndrome: perspectives from siblings. *American Journal of Medical Genetics*, 155A(10), 2348-2359. Recuperado de: <https://www.ncbi.nlm.nih.gov/pubmed/21910244>. doi:10.1002/ajmg.a.34228
- Skotko, B. G., Levine, S. P., & Goldstein, R. (2011b). Having a son or daughter with Down Syndrome: Perspectives from Mothers and Fathers. *American Journal of Medical Genetics*, 155A(10), 2335-2347. Recuperado de: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3353148/>. doi:10.1002/ajmg.a.34293
- Tekinarslan, I. C. A. (2013). Comparison study of depression and quality of life in Turkish mothers of children with Down syndrome, cerebral palsy, and autism spectrum disorder. *Psychological Reports*, 112(1), 266-287. Recuperado de: <https://www.ncbi.nlm.nih.gov/pubmed/23654042>. doi:10.2466/21.02.15.PR0.112.1.266-287
- World Health Organization [WHO]. *Desarrollo en la adolescencia*. 2017. Recuperado de: www.who.int/maternal_child_adolescent/topics/dev/es/

Received: Aug. 24, 2018
Approved: Dec. 12, 2018

Roberta Pasqualucci Ronca: Physiotherapist, Master in Development Disorders by Universidade Presbiteriana Mackenzie, teacher at Physiotherapy Course of Universidade Paulista, São Paulo.

Marina Monzani Rocha: Psychologist, PhD in Clinical Psychology by Universidade São Paulo (USP), acts as a clinical psychologist and an assistant professor of the Post-Graduation Program in Developmental Disorders at Universidade Presbiteriana Mackenzie.

Denise Campos Pozzi: Physiotherapist, PhD in Biomedical Sciences by the Neurology Department - FCM/Unicamp and teacher at Physiotherapy Course at Faculdade Anhanguera de Campinas-SP.

Raquel Cymrot: graduated in Statistics and a Masters in Statistics by Universidade de São Paulo. She is currently full-time Professor at Universidade Presbiteriana Mackenzie, where she participates of various interdisciplinaries researches.

Silvana Maria Blascovi-Assis: Physiotherapist, PhD in Physical Education by Unicamp, Professor of Physical Therapy Course and Post-Graduation Program in Developmental Disorders at Universidade Presbiteriana Mackenzie, São Paulo.