

# SYSTEMATIC REVIEW OF PARENTAL STRESS OUTBREAKS IN CAREGIVERS OF CHILDREN WITH DOWN SYNDROME<sup>1</sup>

## LEVANTAMENTO SISTEMÁTICO DOS FOCOS DE ESTRESSE PARENTAL EM CUIDADORES DE CRIANÇAS COM SÍNDROME DE DOWN

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**ABSTRACT:** The arrival of a child with Down Syndrome (DS) requires a family readaptation, demanding efforts in relation to daily care or therapeutic and school routines. The aims of this study were to understand what the main sources of parental stress in caregivers of children with DS are and identify who the main caregivers of these children are. This is a literature review of a qualitative approach that used a theoretical framework of empirical researches published as of 2010, found in the Google Scholar, Scielo and Psychology.PT portals, and in the journals: *Interação em Psicologia*, *CEPE UEG* e *Ata CIAIQ* 2016. Initially, 23 researches were identified, through the use of the descriptors Down syndrome, stress and caregivers. After filtering, five works were selected for a final review. The result shows that parental stress is related to three factors - disability, development of the child and the role of the caregiver. The main stress outbreaks were the impact of the following diagnosis; fear of discrimination and prejudice; lack of autonomy of the child; emotional overload of the caregiver; concern about sexuality; low paternal schooling; mothers who cannot work; and older children. Mothers had the highest levels of stress. A balanced family division in relation to childcare with DS, as well as family psychological counseling, are alternatives to reducing stress levels and guarantee physical and mental health to caregivers. It is concluded that parental stress outbreaks are diverse and cause emotional distress, difficulties of acceptance and family adaptation.

**KEYWORDS:** Special Education. Down Syndrome. Caregivers. Parental stress.

**RESUMO:** A chegada de uma criança com Síndrome de Down (SD) requer uma readaptação familiar, demandando esforços em relação aos cuidados diários ou às rotinas terapêuticas e escolares. Os objetivos deste estudo foram compreender quais são os principais focos de estresse parental em cuidadores de crianças com SD e identificar quem são os cuidadores principais dessas crianças. Trata-se de uma revisão de literatura de abordagem qualitativa, que utilizou como referencial teórico pesquisas empíricas publicadas a partir de 2010, encontradas nos portais Google Acadêmico, Scielo e Psicologia.PT, e nos periódicos: *Interação em Psicologia*, *CEPE UEG* e *Ata CIAIQ* 2016. Inicialmente, foram identificadas 23 pesquisas, utilizando-se os descritores Síndrome de Down, estresse e cuidadores. Após filtragem, cinco passaram para revisão final. O resultado evidencia que o estresse parental está relacionado a três fatores - à deficiência, ao desenvolvimento da criança e ao papel do cuidador. Os principais focos de estresse foram o impacto do diagnóstico; medo da discriminação e preconceito; falta de autonomia da criança; sobrecarga emocional do cuidador; preocupação com a sexualidade; baixa escolaridade paterna; mães que não podem trabalhar; e crianças mais velhas. As mães apresentaram os níveis mais elevados de estresse. A divisão familiar equilibrada em relação aos cuidados com a criança com SD, além de um acompanhamento psicológico familiar, são alternativas para reduzir os níveis de estresse e garantir saúde física e mental aos cuidadores. Conclui-se que os focos de estresse parental são diversos e causam abalo emocional, dificuldades de aceitação e adaptação familiar.

**PALAVRAS-CHAVE:** Educação Especial. Síndrome de Down. Cuidadores. Estresse parental.

## 1 INTRODUCTION

The birth of a child is always surrounded by expectations and, naturally, parents idealize their children from social patterns of acceptance. The diagnosis of a disability, in

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addition to the frustrating expectations of the parents, requires a permanent readaptation in family structure for the duration of life, because, apart from greater attention with daily care, medical monitoring is of fundamental importance (Cavalcanti, 2011). All the relevant studies state that the first reaction in the sense of acceptance of the disability is in some way related to the affliction. 'Tears are an effective part of affliction, as well as impotence and despair. If they are not repressed, the tears will cease and the rehabilitation process will begin' (Buscaglia, 2006, p. 13). In this sense, Cavalcanti (2011, p. 13) states that:

Another relevant aspect is the impact that the birth of a child with Down Syndrome can cause in the family, because at the moment of discovery, the parents can feel guilty; furthermore, family members may not accept this fact and fall into a state of deep denial, in which they attribute the diagnosis to a medical error.

A child with Down Syndrome (DS) requires family changes and adaptations at all stages of the child's development (Franco, 2015). Down Syndrome is a genetic accident that occurs in the pair of chromosome 21, with the presence of an extra chromosome, that's why this syndrome is also called Trisomy 21. The extra presence of this chromosome has implications on intellectual development with a slight or moderate retardation, due to cerebral alterations (Castro & Pimentel, 2009). However, it is worth noting that this change in cognitive development does not necessarily imply a poor quality of life. 'As for the child, the development of language, motor ability, cognitive function, and the socialization and schooling process should all be prioritized' (Oliveira, Eduardo, Prudente, & Ribeiro, 2016, p. 2).

A child with DS requires more time, dedication and investment from the family, directly affecting the family dynamics and the difficulty of adaptation which can lead to stress. 'Stress is a phenomenon that can cause various harmful effects in the individual, whether in relation to health (physical and/or mental), or behaviour, reducing their quality of life and social well-being' (Brito & Faro, 2016, p. 64). When related to family functions, it is called parental stress (Ribeiro, Porto, & Vandenberghe, 2013; Minetto, 2012).

Parental stress can be defined as an imbalance that occurs when parents assess that the resources they have are insufficient to cope with the demands of their commitment to the parental role (Skreden, Skari, Malt, Pripp, Björk, Faugli, & Emblem, 2012). Stress, in addition to compromising the mental and physical health of the caregiver, can also negatively influence the relationship between the caregiver and the child. Parenting, due to the involvement of different movements - satisfaction, rewards, demands and overloads - can harm the physical, emotional, and social well-being of parents (Skreden et al., 2012).

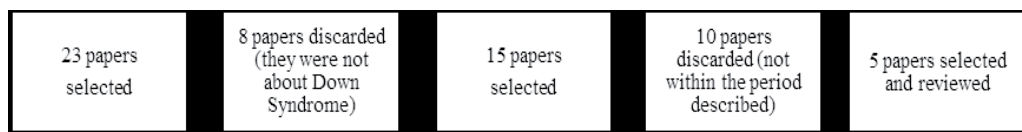
Parents are more likely to develop changes in physical and psychological health due to expectations and anguish in dealing with the dependency of the child with disability and difficulties in organizing their own time. 'In general, mothers spend more time with their children and are primarily responsible for the care activities. The prolonged task of caring, can become a continuous source of stress' (Ribeiro et al., 2013, p. 1706). On the one hand, high levels of stress can compromise and hamper family dynamics and have negative consequences for parents and children. On the other hand, reasonable levels of parental stress can be a stimulating factor for the performance of daily activities.

As a matter of extreme relevance, the objective of this study was to understand the main parental stress outbreaks in caregivers of children with DS and to identify who the main caregivers are.

## 2 CONSIDERATIONS ON THE RESEARCH DEVELOPMENT

This is an exploratory research, of literature review, carried out with empirical researches selected from two pre-established criteria: descriptors and temporal cut-off (2010-2017). The temporal cut-off of 2010 was due to interest in more recent publications. For the survey, we only used the descriptors, disability and parental stress. Initially, we searched on Google Scholar (<http://www.googleacademico.com.br/>) and Scielo (<http://www.scielo.br/>), Psicologia.PT, and the following journals: *Interação em Psicologia*, *CEPE UEG e Ata CIAIQ 2016*, in the month of July, 2017, and selected 23 researches.

Starting from this broader search, an initial filtering was performed (Figure 1), from which only the researches dealing specifically with parental stress in caregivers of people with Down Syndrome were selected. Eight papers were discarded as they were about other disabilities such as autism and cerebral palsy. From this, fifteen objects were selected. Then, a second filtering was performed, using as selection criterion of the following keywords: Down syndrome, stress and caregivers, with a publication date from 2010. Of the 15 pre-selected studies, ten were excluded because they were not within the period previously described, leaving five objects for final revision, three papers and two master's thesis.



**Figure 1.** Flowchart with the path of the bibliographic research and the criteria of selection and discarding of the reviewed researches

Source: Elaborated by the authors.

A qualitative analysis was performed. The data were organized into eight categories, according to qualitative content analysis (Bardin, 2011) and later described, analyzed and articulated with the researched literature, seeking to identify who the main caregivers of children with DS are and the main stress-related outbreaks of these caregivers.

## 3 EVALUATION OF THE REVIEWED RESEARCHES

### 3.1 CHARACTERIZATION OF THE RESEARCHES

The studies analyzed were published in the corresponding period between 2010 and 2016, and the main areas of research were Psychology, Physiotherapy and Speech Therapy, as shown in Table 1.

Authors	Title	Year of publication	Journal or portal	About the authors	Objects of research
Ribeiro, Santos, Campos, Gomes, Formiga, & Prudente	<i>Mães de crianças, adolescentes e adultos com Síndrome de Down: estresse e estratégias de enfrentamento</i> <sup>1</sup>	2016	ATAS CIAIQ 2016	Physiotherapist and Physiotherapy students	21 mothers of children with DS
Oliveira, Eduardo, Prudente, & Ribeiro	<i>Estresse geral e estresse parental em pais de crianças e adolescentes com Síndrome de Down</i> <sup>2</sup>	2016	CEPE UEG	Professor and Physiotherapy students	40 parents of children with DS
Barros, & Leonardo	<i>Estresse parental em mãe cuidadora de criança com Síndrome de Down: relato de caso clínico</i> <sup>3</sup>	2013	Psicologia. PT Portal	Speech Therapist and Psychology student	One mother of child with DS
Cavalcanti	<i>Estresse e qualidade de vida dos cuidadores de portadores de Síndrome de Down</i> <sup>4</sup>	2011	Scielo Portal	Clinical Psychology Master student	48 empirical papers
Cruz	<i>Caracterização do estresse parental de mães de crianças com Síndrome de Down</i> <sup>5</sup>	2010	Interação em Psicologia Journal	Psychology Master student	72 mothers

**Table 1.** Description of the empirical researches used

1 Mothers of children, adolescents and adults with Down Syndrome: stress and coping strategies.

2 General stress and parental stress in parents of children and adolescents with Down Syndrome.

3 Parental stress in caring mother of child with Down Syndrome: clinical case report.

4 Stress and quality of life of caregivers of Down Syndrome patients.

5 Characterization of parental stress of mothers of children with Down Syndrome.

Source: Elaborated by the authors.

### 3.2 IDENTIFICATION OF CAREGIVERS

The reviewed researches indicated the caregivers as the parents, the mothers, the uncles and the grandparents (Table 1). Among them, it is possible to affirm that mothers are the main caregivers of children with Down Syndrome. They are the ones who spend more time and attention on daily care and follow up on medical appointments and stimulus activities. Many of these mothers give up their schooling and their professional careers in order to dedicate themselves entirely to their children.

Some paternal difficulties were pointed out; however, they are specially related to financial, family planning issues, as well as family constraints and long-term care concerns in relation to their children (Oliveira et al., 2016).

### 3.3 PARENTAL STRESS DATA

Studies have shown various causes for parental stress, which are basically related to three main factors: disability, development and role of caregiver. Regarding disability, the moment at which the news is received, whether it is during gestational examinations or at the time of delivery, generates stress for the family. 'The mothers complained about the doctors' inability to inform the diagnosis of DS. They claim that doctors reinforce the negative aspects related to the Syndrome' (Ribeiro et al. 2016, p. 1399).

Concerns about development are due to the lack of knowledge about the Syndrome and the developmental potential of the child. In this sense, stress can arise from the frustrated expectation of caregivers when comparing children with DS with children with typical development. In this perspective, Cavalcanti (2011, p. 23) states that:

The person with Down Syndrome has limitations, and it is in childhood that motor delay becomes very expressed. It is at this stage that comparisons with other children begin. Often, the mother does not understand why her child still does not speak, does not walk with balance and why he/she has this delay.

Another relevant factor that generates parental stress is related to the role of the caregiver. 'Parental stress depends in part on how parents perceive themselves in relation to their maternal and paternal roles' (Silva & Dessen, 2006, p. 189). Caring for the child with DS continues throughout life and is largely associated with feelings of anxiety and uncertainty, and above all related to the need for long-term care and the impact this will have on the personal life of these caregivers.

### 3.3.1 MAIN PARENTAL STRESS OUTBREAKS

The following data shows the main stresses pointed out by the reviewed researches. In total, eight parental stress factors could be detected.

- *The impact of the diagnosis.*
- *Fear of discrimination and prejudice.*
- *Lack of autonomy of the child.*
- *Caregiver emotional overload.*
- *Concern about sexuality.*
- *Parents with a low level of schooling.*
- *Caregivers who cannot work.*
- *Older children.*

The analyzes of each stress factor listed in the revised studies are as follows:

- *The impact of the diagnosis*

Two studies have pointed out this factor as a potential generator of parental stress. Whether during pregnancy or after birth, informing the family about the child's disability requires preparation and should be done with caution and sensitivity to lessen the emotional impact. Parents prepare for the birth of children without disabilities, and the news contrary to this expectation can cause suffering, difficulties of acceptance and family disruption. Research indicates that denial of a disability is a way in which mothers escape reality or postpone coping with challenges (Ribeiro et al., 2016).

Late diagnosis may represent a negative factor in relation to the acceptance and adaptation of the family to the new reality. There is no ideal time for parents to learn that

their child has Down Syndrome or that they have any other disabilities. However, a diagnosis during pregnancy can provide the time needed to assimilate the news and prepare emotionally to receive the child, especially for the mother (Cavalcanti, 2011).

The timing of informing the family of the diagnosis is fundamental and a determinant for the acceptance of the child with DS. In order not to be late, parents need to be adequately informed and guided. However, what is observed is that professionals are not sensitized or humanized for this task, or do not pay attention to the psychological importance of that moment (Cavalcanti, 2011). The lack of a well-informed diagnosis by the medical team and the preparation of the relatives to receive the news causes deep and lasting marks and contributes to generating feelings of denial, disturbance and guilt, hindering the process of acceptance and weakening the first affective bonds between mother and child (Ribeiro et al., 2016). The information that parents receive should be sufficient to clarify doubts in relation to the child's development and necessary follow-ups, and at the same time, requires the professionals' sensitivity in understanding the emotional vulnerability that family members face at this time, namely delicate and painful.

- *Fear of discrimination and prejudice*

After the impact of the news, it is natural for parents of children with DS to deal with the fear of prejudice and discrimination that children will face throughout their lives. Of the five reviewed studies, two point out this problem. Lack of knowledge of society, in general, causes disability to be considered a chronic disease, a burden or a problem, subjecting families of children with disabilities to traumatic situations. It is in the family that the first manifestations of prejudice usually occur, even in a concealed way, and these are extended to society (Maciel, 2000).

Despite the advances and the confrontation in the fight against prejudice and the inclusion of people with disabilities, people have difficulties in dealing with differences and tend to express this in a very subtle and even unconscious way, through the way they isolate people, when they look in a disrespectful way or avoid contact with them (Buscaglia, 2006).

It is a recurrence for some families to deprive children with disabilities of a social life in an attempt to avoid feelings of suffering caused by situations of prejudice. Especially mothers who feel insecure, and fear that their children will suffer from stigmatization, discrimination or any other form of violence (Ribeiro et al., 2016).

- *Lack of autonomy of the child*

All the reviewed studies pointed to a lack of autonomy of the child as one of the most relevant factors in triggering parental stress. When the child gets older, clinical problems are usually already stabilized, and most children acquire motor independence. However, this evolution does not guarantee independence and autonomy like it does in children with typical development (Ribeiro et al., 2016).

Parents complain that their children grow up and continue to be dependent, including routine activities such as brushing their teeth, bathing, leaving home, among others. The perception of the degree of difficulty of the various tasks of childcare/education is positively associated with the parental stress experienced by the mothers of these children. In particular, the tasks related to hygiene and feeding are associated with stress due to the characteristics of both the child and the parental figure (domains of the child and parents). Hygiene is associated with more areas of stress, and is therefore the one area that will generate more intense stress for the mothers (Cruz, 2010).

- *Caregiver emotional overload*

The five reviewed studies point to this theme. The child with Down Syndrome needs care that usually rests on the family members, who end up being subjected to emotional overload (Barros & Leonardo, 2013). Mothers are challenged by the different demands of parental care required by their children and feel overwhelmed and helpless (Ribeiro et al., 2016).

The reviewed literature shows that the mothers are the ones who suffer most from emotional overload since they are the main caregivers of children with Down Syndrome (Oliveira et al., 2016). 'The demands are diverse and the mothers receive little or no support to meet the challenges; they suffer for not being able to take care of the other children and for not giving attention to the husband' (Ribeiro et al., 2016, p. 1400).

Another cause of emotional overload is due to the fact that mothers need to give up their studies and work, so they do not have time for personal activities, such as looking after their appearance or doing physical activities, as well as feeling tired due to the poor collaboration of other family members in relation to the care of the child. Mothers have difficulty getting back to their life plans. Most continue to live for their children even when they are teens or adults because they need to accompany and supervise them and do not feel secure in leaving them alone or with other caregivers (Ribeiro et al., 2016).

Although mothers are the primary caregivers of children with DS, the burden does not fall on them alone. Regarding the fathers, studies show that fathers of children with Down Syndrome have more overload in their daily lives than those of children without disabilities (Silva & Dessen, 2006).

- *Concern about sexuality*

Discussing sexuality is a stress-generating factor for parents of children with Down Syndrome. Different studies show that parents see their children with intellectual disabilities as asexual. This '[...] view is probably related to beliefs that they are unable to learn proper sexual behaviors, and that they have no form of sexual desire, which reinforces the idea of eternal children' (Galbes & Grossi, 2012). Such statements may justify the difficulty in facing this issue.

Two studies pointed to the maternal concern in dealing with the sexuality of the children. The mothers do not know how to act and complain that they are little guided by



the professionals who collaborate in the rehabilitation of the children in how to proceed, and because the topic is misconducted, it becomes controversial (Ribeiro et al., 2016). Since they are not well-oriented on the subject, it is natural for mothers to ignore and overprotect their children in an attempt to escape the problem. Without guidance, the most often used strategy by mothers is to encourage their childishness as a trick to escape or try to postpone discussion as a way of coping with the problem (Ribeiro et al, 2016). The mothers justify this controlling behaviour because their children do not have maturity. Looking at a broader analysis, the topic of sexuality is uncomfortable for parents in general when dealing with this issue with their children, and even more so for those with atypical development, as in the case of this study.

- *Parents with a low level of schooling*

One of the studies considered only the parents of children with DS and divided them into two groups: one group with parents of children with DS and another group with parents of adolescents with DS. The results show that older parents have lower levels of schooling and this group has the highest parental stress index. There was a significant difference between the two groups in terms of schooling, 75.90% of the parents of young children are High School or Higher Education graduates, and for the group of parents with adolescents, the proportion is 27.30%. The correlation between the data shows that the lower the parental schooling, the higher the level of stress (Oliveira et al., 2016).

The lower level of schooling was verified as a strong influencing factor in the representation of higher levels of stress experienced by parents. This statement is due to the fact that the lower level of schooling is usually related to a lower financial income. From the revised literature, it can be affirmed that parents develop higher levels of stress due to a concern with family financial issues, associated with the occurrence of the Syndrome in the offspring.

- *Caregivers who cannot work*

In one of the reviewed studies, Cavalcanti (2011) states that among non-working caregivers, stress levels were higher in comparison to those who performed paid work. Thus, working can bring some enjoyment that reduces the daily stress of the caregiver and in addition, improves the financial situation of the family which directly impacts on the quality of life.

Reconciling work with care for a child with DS could be considered another stress factor due to the accumulation of tasks. However, the revised studies emphasize that giving up work to focus exclusively on the child can contribute to raising parental stress levels. On the one hand, the decision for some caregivers to abandon their working life and, at the same time, reduce family income results in a sensation of incapacity. On the other hand, performing activities in which they have affinities should bring them some satisfaction, which will benefit the caregiver (Cavalcanti, 2011).



- *Older children*

One of the researches states that the parental stress of mothers of children with DS varies according to the age of the child, with higher levels of stress experienced in the mothers of the older children (aged 4-12 years) (Cruz, 2010). This statement may be related to the fact that mothers create expectations regarding the development of their children and, as they grow and do not reach these expectations, there is frustration on the part of these mothers, besides the physical and emotional exhaustion related to daily care.

The review of this literature states that parents of adolescents with DS have a greater proportion of parental stress when compared to the parents of younger children, evaluating the parents' perceptions of their children to the compatibility of their own expectations. 'The presence of stress suggests that parents have difficulties interacting with their child, and their expectations are not satisfactory' (Oliveira et al., 2016, p. 7).

#### **4 FINAL CONSIDERATIONS**

This research sought to understand the main sources of parental stress in caregivers of people with Down Syndrome, and to identify who their main caregivers are. Although it is a subject of great relevance, the bibliography on the subject is limited, which made the construction of this research difficult. Thus, complementary studies are necessary to inform and corroborate in the sense of thinking and coping strategies that assist parents in their role as caregivers of a child with DS.

The parental stress outbreaks reviewed in this study were numerous, along with potential causes of emotional overload and difficulties of acceptance and family adaptation, especially in the main caregivers - the mothers. In addition to interfering in the physical, mental and social dimensions, they directly influence the relationship between the caregiver and the offspring, and may interfere with their development.

The expectation regarding the development of the child and the lack of knowledge of the caregivers in relation to the future contribute to the elevated levels of stress. Although there is a familiar collaboration in the care of children, it is still the maternal figure that is mainly responsible for the daily care and follow-up of the medical treatment of children with DS. Most of the time these mothers give up their studies and work to dedicate themselves exclusively to children with disabilities, stating that they are the ones who complain the most about emotional overload. Thus, a balanced family division in relation to the care of children with DS as well as family psychological counseling are alternatives to reducing stress levels and guarantee physical and mental health to caregivers.

We hope that this research will help to elucidate the main parental stress outbreaks in families of children with DS and reinforce the interest in the continuity of researches in the family area.

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