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Maternal impacts of a physically disabled baby birth: A comparative study

Impactos maternos do nascimento de um bebê com deficiência física: um estudo comparativo

Diego Rodrigues Silva¹ , Luiza Amaral Trindade¹ , Rogério Lerner¹ 

¹ Universidade de São Paulo, Instituto de Psicologia, Departamento de Psicologia da Aprendizagem do Desenvolvimento da Personalidade. São Paulo, SP, Brasil. Correspondence to: D. R. SILVA. E-mail: <silva.diego@alumni.usp.br>.

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Abstract

Objective

This study aims to assess the emotional impacts of the baby's physical disability on the mother.

Method

It is an exploratory investigation carried on with two mother-infant dyads, only one of which gave birth to a physically disabled baby, both participating in a larger case-control investigation. The tools used included the Beck Anxiety and Depression Inventories, the Parental Reflective Functioning Questionnaire, the Ages and Stages Questionnaire as well as semi-structured interviews.

Results

Both mothers showed similar reports and parenting levels, but the one whose baby had a disability scored higher on anxiety and depression, in connection with the baby's low level of development.

Conclusion

It is concluded that, in order to achieve the same levels of a typical parenting condition, greater adaptation mechanisms are required.

Keywords: Emotions; Human development; Parent-child relationship.

Resumo

Objetivo

Este artigo tem como objetivo avaliar impactos emocionais da deficiência física do bebê na mãe.

Método

Trata-se de um estudo exploratório realizado com duas díades, uma composta um bebê com deficiência e sua mãe e outra por um bebê sem deficiência e sua mãe, provenientes de uma pesquisa

maior com desenho caso-control. Foram utilizados a Entrevista Semiestruturada, Inventários Beck de Ansiedade e Depressão, Questionário de Função Reflexiva Parental e Ages and Stages Questionnaire.

Resultados

As mães demonstraram relatos e níveis de parentalidade semelhantes, mas a do bebê com deficiência apresentou maiores scores para ansiedade e depressão, relacionados ao baixo nível de desenvolvimento do filho.

Conclusão

Conclui-se que mecanismos de adaptação são necessários para se obter os mesmos níveis de parentalidade de uma condição típica.

Palavras-chave: Emoções; Desenvolvimento humano; Relações pais-filho.

The human baby is fragile and dependent. His/her experience requires learning and depends on the help of loving parents. When healthy, comfortable, and well cared for, newborns demonstrate coherent intentional awareness, directed movement, selective perception, and the ability to assess affect. They are able to act expressively and in a highly sensitive manner to human presence (Trevarthen, 2011).

The exchanges between parents and babies occur spontaneously as part of the family routine (Wallon, 1941/2007). These exchanges are permeated by culture and have practical specifics that are characterized by their non-compulsory nature, rapid bonding and behavioral synchrony. Thus, parenting takes the form of a bond based on physical contact, more specifically under the parents' gaze, touch and voice. Characteristic behaviors are present, such as the expression of positive affections, high-pitched vocalizations, face-to-face contact and affective touch. Past events and future projects are an important mediator in the formation of bonds and go back to generational transmissions of bonding patterns (Abraham & Feldman, 2018; Feldman, 2016). On the other hand, current research has demonstrated how parenting can be impaired if the parents' emotional state is somehow compromised (Chen et al., 2019; Howell et al., 2021)

According to Franco (2015), the birth of a baby diagnosed with disability has a high chance of leading to a crisis situation: depression, anger and stress can compose the emotional reactions experienced in the face of the disability that causes the loss of what parents had imagined for their offspring. For the author, the experience of mourning at this time can affect the parents' hopes and expectations about their children in different ways.

Several repercussions in the daily lives of families can occur. Pereira and Kohlsdorf (2014), in a study carried out with 27 parents, observed that, after being informed about the diagnosis, 19 parents reported having enhanced their care for their child. In one of the reports, the following can be found: "I don't leave her alone, because she is very dependent on me, and I'm afraid the worst may happen" (Pereira & Kohlsdorf, 2014, p. 42). According to Silva and Dessen (2014, p. 209), "in everyday life, feelings and simpler care, such as looking, holding in arms, feeding, can generate intense difficulty, both because of the child's limitations and also because of the emotional confusion experienced by the caregiver". The same is stated by Alaei et al. (2015) who demonstrated that the care provided by these parents can be crossed by a feeling of punishment, constant concern and a feeling of loneliness. Park and Kim (2020) found in a sample of 217 children with cerebral palsy and their parents that activity limitations and depression are a source of stress. Similar data are found in longitudinal studies (De Clercq, et al., 2021; Dieleman et al., 2021), which demonstrate how the child's limitations impact parents' motivation and satisfaction, so that the more externalizing problems are evidenced in the child, the more controlling is parenting.

Understanding the repercussions of a diagnosis of the baby's disability helps parents. The need to develop understanding that allows interventions favoring the parents' mental health is pointed out. The aim is that the bond between parents and children be the most favorable for the baby's development. That said, this article aims to assess the emotional impacts of the baby's physical disability on the mother.

Method

The partial results presented and discussed in this paper refer to the investigation "Suffering and parenting of babies with physical disabilities: implications for child development", approved by the Research Ethics Committee of the University Hospital of the University of São Paulo under CAAE: 12607218.2.0000.0076 and by the *Associação de Assistência à Criança Deficiente* under CAAE: 12607218.2.3002.0085. The investigation participants read and signed the free and informed consent form, being previously informed about all the procedures used and their potential risks of physical or emotional discomfort.

This is an exploratory investigation, as it seeks to identify variables, establish priorities or suggest statements (Sampieri et al., 2006). The case-control model selects participants who have a clinical condition and others who do not and assessing such participants' exposure to set factors (Schlesselman, 1982).

Participants

From the data collected in our study, we will discuss those in connection with two mothers: one who had a baby with unspecified cerebral palsy and the other with a baby without disabilities. Both babies were 10 months old. Their mothers suffered a previous abortion, were between 30 and 40 years old, had completed high school, were in a long-term marital or marital-like relationship, had a C1 socioeconomic level (Associação Brasileira de Empresas de Pesquisa, 2018) and had the same number of people in the household.

Instruments

The instruments used were the semi-structured Interview (Bleger, 2003) with the triggering question "How is your relationship with your child?"; the Beck Depression Inventory (BDI) and Beck Anxiety Inventory (BAI) (Cunha, 2001), both self-reported questionnaires based on the previous week; the Parental Reflective Functioning Questionnaire (PRFQ) (Luyten et al., 2017). In the Likert-type scale model, this allows measuring the ability of caregivers to perceive their thoughts and feelings also regarding their children, as well as their association with behavior. The PRFQ is divided into three subscales: Pre-Mentalization, Certainty about Mental States and Interests, and Curiosity; and the Ages and Stages Questionnaire – Brazil (ASQ-BR), a series of questionnaires divided into 20 intervals according to the baby's age. Five domains of child development are assessed: communication, gross motor coordination, fine motor coordination, problem solving, and personal/social. Each behavior is scored so that higher scores indicate better rates of development (Squires et al., 2009).

Procedures

Date collections were carried out in the health institutions where the babies were treated. Each visit lasted an average of 30 minutes and took place in a room ensuring confidential conditions to the participants.

Results

Table 1 below shows the description of the sample of each case. It contains the gender of the baby and his/her age at the time of data collection, as well as that of his/her caregiver. Further, schooling, marital status, socioeconomic status according to the *Associação Brasileira de Empresas de Pesquisa* (2018) definition, type of housing, area of São Paulo where they live, number of dwellers at the time of data collection, presence of siblings, personal and/or family history of anxiety/depression and psychological treatment.

Table 1
Sample characterization

Group	With disability	Without disability
Baby gender	M	F
Baby age (Months)	10	10
Caregiver gender	F	F
Caregiver age	40	30
Education	Complete High School	Incomplete College
Marital Status	Common Law Marriage	Married
Socioeconomic status	C1	C1
Housing	Apartment	House
Number of people in the household	3	3
Other children	Yes	No
History of Anxiety/Depression	Yes (diagnosed)	No
Previous psychological treatment	Yes	No

The interview was submitted to a content analysis (Bardin, 2011), addressing the categories Maternal Suffering, Parenting and Baby Resources.

In “Maternal Suffering”, there are concerns, difficulties and clinical complications reported by mothers, as can be seen in the excerpts below: “And I lost a pregnancy before this one, so he is the rainbow baby” (Mother of the disabled baby). “And since I, I, had... an... abortion before her” (Mother of the baby without a disability).

In “Parenting”, statements referring to maternal expectations are grouped together:

“Ah, we do everything together, he sticks to me like a chewing gum! Wherever I go, he is there with me. Everything... we play together, laugh together, watch television together, sleep together... it's my little chewing gum” (Mother of the disabled baby).

“I'm still rather attached, right? So I am that person who doesn't trust to leave my baby with someone else... I'm still in that phase, but trying to let it go, right? (...) our relationship is good, it's good, I think it's common” (Mother of the baby without disability).

In the “Baby Resources” category, there are statements referring to the baby's abilities. Only the mother of the baby without disability presented this category.

“Yeah, now she’s learning to walk so I’m teaching her to walk, holding on to things” (Mother of the baby without disability).

Table 2 below presents the results of the other instruments, in order to compare both mothers. The values referring to ASQ represent the sum of all domains.

Table 2

Child development outcomes, anxiety, depression, and parental reflective function

Instruments	With disability	Without disability
ASQ total	105	235
BAI score	12	5
BAI interpretation	Mild	Minimum
BDI score	30	19
BDI interpretation	Moderate	Mild
PRFQ Pre-Mentalization	1.7	1.0
PRFQ Certainty about Mental States	3.8	4.3
PRFQ Interest and Curiosity	4.8	4.2

Note: ASQ: Age and Stages Questionnaire; BAI: Beck Anxiety Inventory; BDI: Beck Depression Inventory; PRFQ: Parental Reflective Functioning Questionnaire.

In the mother of the baby with a physical disability, the BAI items marked as moderately stand out “Fear of worst happening”, “Heart pounding of racing”, “Nervous”, “Feelings of choking” and “Fear of losing control” stand out. And in the BDI stand out “I feel I have nothing to look forward to”, “As I look back on my life, all I can see is a lot of failures”, “I’m disappointed in myself”, “I cry all the time now I cannot stop it”, “I have lost all my interest in other people and do not care about them at all”, “I am less sure of myself now and try to put off making decisions” and “I feel less worthy when I compare myself to other people”. In the results of the mother of the baby without a disability, the statement “Unable to relax” was marked as moderate in the BAI. And, in the BDI, the items “As I look back on my life, all I can see is a lot of failures” and “I cannot make any decisions at all any more”.

Discussion

Both mothers have a similar socioeconomic profile: they are aged between 30 and 40 years, one with complete secondary education and the other with incomplete higher education. As for marital status, the first is married and the second is married under common law. Socioeconomic level was coincident (C1), as well as the number of people living in the household (three). The mothers reported an abortion prior to the birth of the child participating in the study. Likewise, they report a relationship in which closeness and mutual participation in everyday practices are highlighted: “Ah, we do everything together, he sticks to me like a chewing gum!” (mother of the disabled baby) and “I’m still rather attached, right?” (Mother of the baby without disability).

These data can be read under the PRFQ results’ light. According to the instrument (Luyten et al., 2017), interest and curiosity about the baby’s internal world contribute to the baby’s development. In this aspect, there was no relevant difference between the cases, which presented a score of 4.8 and 4.2, an indication of favorable parenting for the baby’s development. The pre-mentalization results were also similar (1.7 and 1) and considered favorable. Pre-mentalization refers to parenting with little openness and sensitivity to perceive and understand what is happening from the baby’s subjective point of view. Finally, certainty about mental states is highlighted and is understood as an indicator of limited and concrete parenting. While the mother is guided by certainty about what

is going on with the baby, she runs the risk of being excessive and intrusive, when not paranoid. In this item, both mothers obtained a similar score (4.8 and 4.2), a value considered high and harmful.

The similarities in the cases allow for a relevant comparison, insofar as the presence of the diagnosis of physical disability stands out as a salient difference. It can be conjectured that the similar results in the PRFQ may be related to these similarities (socioeconomic profile, previous abortion and dealing with the baby). However, the high level of certainty about mental states is noteworthy. To understand these data, it is necessary to observe the other results.

Although there are similarities, the cases differ in significant aspects for this research. The difference in relation to the quality of the baby's development is evident, since the comparison is made between a typical and an atypical case, diagnosed with unspecified cerebral palsy. The central difference is the level of functional resources present in babies, whose scores were, respectively, 105 and 235 for the participant with and without disabilities.

Differences in the anxiety and depression scales also stand out. In general, the results indicated more symptoms of anxiety and depression in the mother of the baby with a physical disability than in the mother of the baby without any disability. Even so, this is a Mild level of anxiety and Moderate depression, a result relatively similar to what is found in the current literature of parents of children with physical disabilities using the Beck scales (Malm-Buatsi et al., 2015; Türkoğlu et al., 2016; Yoo, 2016). It should be mentioned that the mother of the disabled baby was already diagnosed with depression and underwent psychotherapeutic and drug treatment, which should be considered in the discussion.

A qualitative observation about the data obtained through the BAI and BDI allows a deep understanding about the results found. When observing the items answered as "moderately", the mother of the baby with disability has a specific trait, more marked by neurovegetative symptoms (e.g. "Heart pounding of racing" and "Feelings of choking") and questions related to self-esteem and sensitivity (e.g. "As I look back on my life, all I can see is a lot of failures" and "I cry all the time now I cannot stop it") than the other mother.

This difference may be related to the severity of the condition of the baby with a disability, which impacts the caregiver available resources for daily activities, developing situations of dependence for locomotion and feeding, as well as for interaction with the caregiver. Regarding the first aspect, the review by Barreto et al. (2019) indicates that the situations specific to the care of these babies can act as factors that lead to mental health risk. The time spent with the baby impacts the hours of sleep and limits other activities. The report of the mother of the disabled baby was in line with this literature. As the aforementioned statement illustrates, child care takes up most of the family's time (Alaee et al., 2015). Routine events such as taking the child to school, physiotherapy and medical visits demand time, disposition and money from caregivers beyond what would be needed with a child without a physical disability (Kisler, 2014). Specifically caregivers who hesitate to leave children under the responsibility of other people are found in this population with the justification of lack of confidence, fear and concern that they would not be able to provide adequate care (Silva et al., 2010).

Even so, the need for third parties to help with care is described, often due to the need for physical strength, which can create a stressful condition both by establishing situations of dependency and by the absence of these people in the daily lives of some families. In this connection, there are numerous reports of parents who give up work to dedicate themselves to child care. Among the family arrangements, the mother is described most of the time as the one who places herself in this role (Alaee et al., 2015; Guillamón et al., 2013; Vadivelan, et al., 2020).

Moving on to the second point, the baby's functional difficulties (or even impossibilities) may affect the resources needed to attract and maintain a relationship/exchange with the caregiver. The literature allows sustaining that atypical patterns of behavior, the perceptibility of anatomical and functional differences and the difficulties of accepting the diagnosis impact on parenting. The problems can be summarized as lack of knowledge and vulnerability of the caregivers. Items marked by the mother of the baby with disability as "moderate" point in this direction ("Fear of losing control", "As I look back on my life, all I can see is a lot of failures", "I'm disappointed in myself", "I am less sure of myself now and try to put off making decisions" and "I feel less worthy when I compare myself to other people").

For this sample, caregiver anxiety and depression impact parenting. Anxious and depressive caregivers have more negative affect, intrusion and criticism compared to mothers without these diagnoses. They demonstrate less sensitivity and synchrony with the child, look more often at their child, but with short intervals and offer faster or slower touches than required in the relationship. Indeed, associated with these results are children with behavioral problems, less social engagement and greater activation of the stress response compared to children in the control group (Granat et al., 2017; Priel et al., 2019; Ulmer-Yaniv et al., 2018).

Observing the results found, only the certainty about the mental states pointed to difficulties in the exercise of parenting in the manner presented. Comparing the mothers, no salient differences were noted. We return to the hypothesis that the cases have similar characteristics, but it should be added that the only instrument used to assess parenting was the self-report, which is sensitive to the mother's unique understanding of her practical performance with the baby.

In any case, what draws attention when comparing a baby with a disability and a random case without disability is the lack of significant differences in parenting. These data indicate that, for this sample, disability can impact the mother's mental health, but without intensely affecting parenting. In this case, it is necessary to consider that there will be more work for the mother of the baby with disability in order to offer the same quality of care compared to the other mother, albeit with a more serious emotional condition. A path is opened here towards the processes of adaptation and elaboration proposed by Franco (2016), which provide a key to understanding what is needed from the caregivers of these babies and how professionals can help in this process.

Conclusion

This article aimed to assess the emotional impacts of the baby's physical disability on the mother. The mothers involved in the study presented socioeconomic data, life history events and similar outcomes. The only differences found were the levels of anxiety and depression between the mothers and the baby's functional resources.

With fewer resources, babies with physical disabilities are more dependent on the caregiver. This care is based on the bond established between the caregiver and the baby, depending on how both will behave and interpret each other's behavior. Added to the atypical patterns of behavior and to the greater suffering of this caregiver, it is pointed out that there is a potential difficulty when there is a physical disability: if the baby has fewer resources, caregivers need to have greater observation, attention and understanding to interact. Delays in this interaction, in turn, can affect development, enhancing existing functional difficulties, creating a pattern that will increasingly demand from these parents if adaptation and preparation work fails.

It is understood that a baby's disability does not go unaffected. As seen, human parenting is engendered around physical contact, gaze, touch and voice, factors impacted by the different pathologies that cause physical disability. However, parenting is also conditioned to culture, past events and future projects, inserting a subjective variable that should be considered. For this reason, it can be expected that, even in the face of a baby's disabling condition, caregivers can still engage favorably with their offspring. We point out here to the clinical aspect that goes beyond the levels of anxiety and depression, but to the nature of this suffering, more specifically the unique meanings attributed to the experiences.

As noted, there are similarities between the cases: both report a previous miscarriage, but the mother of the disabled baby uses the expression "Rainbow baby", with a whole underlying elucubration. This solution can help explain the mother's resources to sustain parenting even in the face of more significant difficulties. This clinical aspect could be better explored in future investigation.

This study was limited by the use of a small sample and supported only by self-report instruments. Without observational instruments for comparison, there may be a risk of information contamination from one instrument to another. Also, the presence of a mother with diagnosed and treated depression can impact the results. Further studies are required, with more controlled samples and other instruments to verify the hypotheses raised here.

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Contributors

D. R. SILVA was responsible for the conception and design, analysis and interpretation of data and discussion of results. L. A. TRINDADE was responsible for the analysis and interpretation of data and discussion of results. R. LERNER was responsible for the Analysis and interpretation of data and discussion of results and review and approval of the final version of the article.