




Mothers' perception of the neuropsychomotor development of their children liver diseases: a qualitative study

Percepção das mães em relação ao desenvolvimento neuropsicomotor de seus filhos com doenças hepáticas: um estudo qualitativo

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ABSTRACT | INTRODUCTION: Much is known about the impact of liver diseases on children's cognitive, motor, and social development. However, knowing what mothers think about their children's development and the aspects they consider most important are issues that have been little explored. **OBJECTIVE:** To investigate the perceptions of mothers of hepatopathy children about the development of their children. **METHOD:** This is a qualitative, descriptive-exploratory research conducted with 12 mothers of children (up to 6 years of age) with chronic liver diseases, followed by a reference center in Bahia, Brazil. A narrative interview was conducted to collect the data, later transcribed and processed according to Bardin's analysis of the category thematic content. The perception of mothers about the development of their children was compared with the results obtained in the evaluation with the Denver II screening test (TTDII) of their children. **RESULTS:** There is an agreement in most evaluation results for suspicion or risk of neuropsychomotor development, demonstrating that these mothers can identify typical and atypical behaviors. The maternal statements are of overprotection and softening of the disease process and self-confidence and superiority as an attitude of defense in an attempt to conceal the feeling of fragility in the face of the disease. **CONCLUSIONS:** The mothers' perception of their children's development was in line with the TDDII results. Mothers and children need multi-professional follow-up for better therapeutic management and neurodevelopment, as well as family support.

KEYWORDS: End Stage Liver Disease. Developmental Disabilities. Perception.

RESUMO | INTRODUÇÃO: Muito se sabe sobre o quanto as doenças hepáticas impactam no desenvolvimento cognitivo, motor e social infantil. Entretanto, saber o que as mães pensam sobre o desenvolvimento de seus filhos e os aspectos que elas consideram mais importantes constituem temas pouco explorados. **OBJETIVO:** Investigar as percepções das mães de crianças hepatopatas acerca do desenvolvimento de seus filhos. **MÉTODO:** Trata-se de uma pesquisa qualitativa, descritivo-exploratória, realizada com 12 mães de crianças (até 6 anos de idade) com hepatopatias crônicas, acompanhadas num centro de referência da Bahia. Realizou-se entrevista narrativa para coleta dos dados, que foram posteriormente transcritas e processadas conforme a análise de conteúdo temático categorial de Bardin. Foi comparado a percepção das mães acerca do desenvolvimento de seus filhos com os resultados obtidos na avaliação com o Teste de triagem de Denver II (TTDII) de suas crianças. **RESULTADOS:** Há concordância na maioria dos resultados da avaliação para suspeita ou risco do desenvolvimento neuropsicomotor, demonstrando que essas mães conseguem identificar comportamentos típicos e atípicos. As falas maternas são de superproteção e amenização do processo do adoecimento, bem como autoconfiança e superioridade como uma atitude de defesa, na tentativa de escamotear o sentimento de fragilidade frente a doença. **CONCLUSÕES:** A percepção das mães acerca do desenvolvimento de seus filhos foi convergente com os resultados do TDDII. As mães e as crianças precisam de acompanhamento multiprofissional para melhor manejo terapêutico e neurodesenvolvimento, bem como suporte familiar.

PALAVRAS-CHAVE: Doença Hepática Terminal. Deficiências do Desenvolvimento. Percepção

Introduction

Chronic diseases in children are known to have a long or indefinite course. Some may present periods of remission and exacerbation of symptoms, thus requiring continuous care¹, and may entail hospitalizations, invasive and exhausting treatments, besides the possibility of bringing physical and mental harms to children and family impact.² The diagnosis of chronic liver disease is no different, as it also requires a continuous treatment regimen, including uninterrupted use of medications, regular visits to physicians, and examinations for a lifetime.³ Liver disease is characterized by inflammatory lesions with a fibrotic appearance of the organ, with varying origin and levels of necrosis and hepatocellular inflammation, which can progress to cirrhosis.⁴ Its various clinical manifestations can impair development and growth at an early age.

In early childhood, fast neurodevelopment means that any injury during this phase can cause irreversible damages to the brain. Therefore, a child whose liver is dysfunctional may present developmental alterations due to the release of neurotoxic substance.⁵

Much is known about how liver disease impacts children's cognitive, motor, and social development.⁶ Nevertheless, knowing what mothers think about their children's development and the aspects they consider most important are topics that have been little explored. Anton and Piccinini¹⁰, when investigating the impact of chronic illness and liver transplantation on the emotional development of children with hepatopathy, created a category on development. The mothers reported that motor development before transplantation was delayed, but they observed improvement after the surgery. The mothers also described that their children were very communicative and intelligent, but most of them

were still dependent in some aspects, such as carrying out personal hygiene habits and the permanent desire to sleep with their parents.³ Since this was not a study with the main objective focused on the neurodevelopment of children with hepatopathy, it was sought to find other studies in the literature that related neuropsychomotor development scales with the mothers' reports in the context of these children, without obtaining any results. It is believed that mothers often underestimate and/or overprotect their offspring, especially in a situation of illness, or even manifest opposite attitudes towards the optimization of children's abilities. From this perspective, the objective of this study was to investigate the perceptions of mothers of children with hepatopathy about the neuropsychomotor development of these children, who were cared for in a reference center in the state of Bahia.

Methods

This is a qualitative, descriptive, and exploratory study, where twelve mothers and their children aged between 6 months and 6 years of both genders were selected. These children had chronic hepatopathy and were cared for in the Pediatric Center Professor Hosannah Oliveira - University Hospital Complex Professor Edgard Santos from the Federal University of Bahia (HUPES-UFBA, as per its Portuguese acronym), in the Pediatric Gastroenterology and Hepatology Outpatient Clinic, Salvador, Bahia.

Mothers whose children had neurological and psychiatric disorders or other chronic diseases, who had some genetic syndrome, children who were deaf or blind, with traumatic brain injury, hemodynamically unstable, and those whose parents or guardians did not sign the Free and Informed Consent Form (FICF) were excluded.

Data collection was performed from November 2019 to March 2020, and the interviews and the assessment of neuropsychomotor development were performed on the same day of consultation with a hepatologist – liver specialist – in a specific office for research. In the first contact with the mothers, the work was explained, with the reading of FICF, which was then accepted and signed. These procedures were followed by applying the sociodemographic questionnaire and the accomplishment of the narrative interview, with the following triggering question: “What do you think about your son or daughter’s development?” The interview was recorded on an iPhone 7s for later data transcription.

The authors analyzed and transcribed the interviews when it was possible to establish the relationships and common points among the interviewees’ speeches based on the content analysis proposed by Bardin.⁷ The categories that emerged from the mothers’ narratives were: “It is normal”: mothers’ perception about their children’s development,” and “It is... I think it is normal”: mothers’ perception regarding the liver disease.” The interviewed mothers were named only as mother 1 (M1), mother 2 (M2), mother 3 (M3), mother 4 (M4), and so on, thus preserving the confidentiality of their identity. The transcriptions of the speeches follow the way each mother made her report, with no adequacy or grammatical correction.

After the interview with the mothers, the Neuropsychomotor Development Assessment (NPMD) was performed with the children. The developmental assessment instrument used was the Denver Screening Test II (DDST-II), which a licensed physical therapist applied. This instrument is dichotomously classified into “suspected or risk for developmental delay” or “normal.” It contains 125 items, presented in four domains: personal-social, fine-adaptive motor, language, and gross motor.⁸ The assessment is not invasive, it is easy to apply, very similar to children’s daily play, and the application time lasts an average of 30 minutes.

When applying the test, the child’s age is calculated, and then a vertical line is drawn on the specific sheet of the instrument when the procedures for that age group are applied in all domains. The child is classified as normal when it presents no “delay” or, at most, a “caution” in all tests; if it presents one or more “caution” and (or) one or more “delay,” it is classified as suspected, with risk for NPMD alteration. All the steps (interviews with the mothers and NPMD assessment of the children) were carried out in an average time of 1 hour.

The study complied with the recommendations of CNS Resolution 466, dated December 12, 2012, for the development of research with human beings. All individuals who agreed to participate in the study signed the FICF document. This project was approved by the Research Ethics Committee of the Institute of Health Sciences (ICS/UFBA, as per its Portuguese acronym), under opinion nº 3.695.203.

Results and discussion

A total of 12 mothers of children with chronic liver diseases participated in the study. The mothers’ ages ranged from 22 to 45 years, and the children’s ages ranged from 6 months to 6 years. The income of 11 families was up to two minimum wages (classes C2 and D-E by the Brazilian Association of Research Companies [ABEP, as per its Portuguese acronym]). Most of the mothers had completed high school as the highest level of education in the sample, were single, and lived in the hinterland of Bahia. As for the children, eight were male, and seven had siblings.

Regarding hepatopathies, eight had preserved liver (native), and four underwent liver transplantation. According to DDST-II, seven children presented suspected or risk for neuropsychomotor development. There were five disagreements between the DDST-II results and the mothers’ perception (Table 1).

Table 1. Characterization of mothers and children aged 6 months to 6 years with chronic liver diseases

Name	Children's gender	City	ABEP Classification ¹	DDST-II	Mothers' report	Mothers' perceptions x DDST-II	Diagnosis	Siblings
Child (6Y) Mother 1	Male	Hinterland	C2 (R\$1,691)	Normal	Normal	Agreement	Native liver	1
Child (5Y) Mother 2	Male	Hinterland	C1 (R\$2,965)	Suspected or risk	Suspected	Agreement	Native liver	2
Child (4Y) Mother 3	Female	Hinterland	C2 (R\$1,691)	Normal	Normal	Agreement	Native liver	0
Child (4Y) Mother 4	Male	Salvador	D-E (R\$708)	Normal	Normal	Agreement	Native liver	1
Child (4Y) Mother 5	Female	Hinterland	C2 (R\$1,691)	Suspected or risk	Suspected	Agreement	Native liver	2
Child (5Y) Mother 6	Male	Hinterland	D-E (R\$708)	Suspected or risk	Normal	Disagreement	Native liver	1
Child (6M) Mother 7	Male	Others	D-E (R\$708)	Suspected or risk	Normal	Disagreement	Native liver	1
Child (5Y) Mother 8	Male	Salvador	B2 (R\$5,363)	Suspected or risk	Normal	Disagreement	Native liver	0
Child (2Y) Mother 9	Female	Hinterland	C2 (R\$1,691)	Suspected or risk	Normal	Disagreement	Transplanted liver	0
Child (3Y) Mother 10	Female	Hinterland	C2 (R\$1,691)	Suspected or risk	Normal	Disagreement	Transplanted liver	0
Child (16M) Mother 11	Male	Salvador	C2 (R\$1,691)	Normal	Normal	Agreement	Transplanted liver	0
Child (4Y) Mother 12	Male	Hinterland	D-E (R\$708)	Normal	Normal	Agreement	Transplanted liver	1

¹The minimum wage in Brazilian Reals (R\$) in 2020 had a value of R\$1,045.00. Y= years; M= months

“It is normal”: mothers’ perception about their children’s development”

Development is the ability a child needs to perform complex functions and activities increasingly; it is a dynamic process with physical, social, emotional, language, and cognitive alterations.⁹ In our study, 10 mothers reported that their children’s development was normal. However, it was observed that Mother 1 and Mother 9 overvalued the development of their children:

“It’s according to his age, very advanced sometimes, in the case so for his age.” (M1)

“Oh... her development was pretty good. I didn’t think it would be so fast because she was transplanted.” (M9)

The impact that a chronic illness can bring to the family is well known. Change of daily routine, with constant visits to the physician, administration of medications, examinations, hospital admissions, reduced social participation in schools and communities – all this can undermine the neuropsychomotor development of the child in several spheres.¹⁰ It was observed that the child of Mother 9 presented, according to DDST-II, suspected or risk for NPMD, i.e., there was disagreement with the mother’s perception, who did not see any alteration in her child. It is believed that this mother attributed a good development to her child by thinking about the biological aspect of the fatal disease and the severity of undergoing a complex procedure such as liver transplantation. She, in a way, observed improvements in her development after this procedure. Another issue that may have influenced the mother’s optimistic view would be that she had a comparison of the child pre- and post-transplantation. The literature indicates improved neuromotor skills after liver transplantation, although these children remain below the recommended average for their age.^{11,12}

Mothers 6, 7, 8 and 10 were also discordant about the developments of their children when compared to DDST-II:

“He is normal, in terms of our vision, we give him objects, he follows the sound when the noise is too loud, it bothers him, he already rolls on the bed; he rolls on the bed yet. We have to pay attention to him, and I think his development is normal.” (M7)

Mother 7 showed that she followed the motor development of her son, who was less than a year old since the report came with information about this domain. This child’s DDST-II showed “caution and attention” in the personal-social and language domains, which shows the mother’s limited view of development as a whole. For Hanton et al., parents tend to deny the possibility of negative aspects that the disease can bring to their children as a defense attempt.¹³ Therefore, there may be a valorization by this mother of the skill that the child performs well to the detriment of others, which are not compatible with the child’s age.

In their speeches, two mothers (4 and 10) brought an association of development with cognitive aspects:

“Sometimes, I find him inattentive in some things; but, for the most part, he has very good perception. From a very early age, he knew his mouth, nose, and so on. He learned colors very fast. So, in relation to this, I think he draws pretty well. When he is lazy, he crosses everything out just like that; but, just now, he had a little sheet, which [...]” (M4)

“I think she is developing in a way that is compatible with her age. At school, she is doing very well, she writes her full name. Moreover, the evaluation that the teacher and the school give me is that she is developing well.” (M10)

School and the consequent cognitive and social learning can work as a milestone for these parents because it is an environment of confrontation with more rigid standards of performance, where children will be exposed, outside the family environment, to the inevitable comparisons with their peers.¹⁴ This makes us think that these mothers feel contemplated about the development when their children learn and show learning daily, as well as when they follow their schoolmates.

Anton & Augusto³ investigated the mothers' perception about the development of children aged 4 to 8 years old in the context of liver transplantation. In this sample, mothers reported the negative impact of pre-transplantation hepatopathy and the improvement, over time, and the success of the transplantation on physical development and social communication.³ Similar results were found in our study when analyzing the speech issued by mother 11:

"It was delayed because of the transplantation; but, after the transplantation, it started to take off." (M11)

Another variable analyzed in the above study was the fabled test, which revealed emotional conflicts and impairment in emotional development greater than what the interviewed mothers perceived. That is, there were disagreements between data from one test and the parents' perception.³ In the current study, in the case of children with suspected or risk for NPMD through DDST-II, 5/7 mothers did not perceive alterations in development, also revealing a disagreement between a test and their maternal perception. Although this disagreement has not prevailed in most cases, these families need to be assisted since these mothers overvalue their children's development can have implications, thus depriving these children of timely interventions to minimize the risks to their full development.

"It is... I think it is normal": mothers' perception regarding the liver disease"

Children with chronic liver disease are delayed in several spheres of neuropsychomotor development.^{6,15} The underlying disease, which undermines the multiple functions of the liver, often causes malnutrition (which leads to loss of muscle mass and weakness), presence of ascites, recurrent hospital admissions, and clearly decreases the opportunities to perform the neuromotor experiences that are fundamental to achieving good development, thus impairing functional capacity at home and at school.⁶ The report of Mother 5 brings content on how hepatopathy influences the execution of a child's daily skills:

"So, normal, normal, it doesn't get to be normal, right? Because her belly is very big, it bothers her a lot, right? And sometimes it's disturbing, but she does everything that a normal child does: she plays, jumps, sometimes she throws herself, falls on her belly on the floor, and

I get worried all the time. She doesn't stop quiet and she feels a lot of pain; practically, every day, she feels pain and says 'it's hurting me', and then she takes medication. Lately, she has started to feel pain in her legs. Now, every single day, she complains of pain in her legs. Nonetheless, I don't know if it has something to do with it, because she started feeling it a month ago. So, I don't know [...] But apart from that...". (M5)

In this speech, one can observe that the mother makes correlations between her daughter's development and the liver disease, which limits the child in her plays, as if the NPMD delays were in the background, according to this mother's point of view. For this mother, the most important thing is the biological and fatal component of the pathology. Mother 2 also presented uncertainty in her report. It is believed that, in those children with greater severity and greater manifestations of chronic illness, the development of human kinetics, as well as of language, social and cognitive skills, was not very important for their caregivers. This fact makes us reflect that, for these mothers, hepatopathy can have a fatal outcome, while deviations in the children's development would not lead to death.

"He is apparently normal, he is normal. However, he has to be observed because of his blood sugar, he has decreased blood sugar. Therefore, he has to eat right, at the right time, he can't miss the schedule, everything is going pretty well. I monitor his blood glucose three times a day, twice when needed". (M2)

The DDST-II results of the children of mothers 2 and 5, who showed suspected or risk for NPMD, agreed with the caregivers' reports. Several aspects may have influenced the fact that 58% of the current sample presented deviations in the Denver II, such as low family income, because the higher the socioeconomic status, the greater opportunities these children have to be stimulated. Our sample had a predominant family income of 2 minimum wages.¹⁶ As for the parents' level of education, the literature shows that the higher the parents' education (college degree or higher), the better the cognitive scores of their children.¹⁷ It is known how socio-environmental risk factors can influence the acquisition of neurodevelopmental skills and that children need a favorable environment for this benefit. Therefore, when biological and socioeconomic risk factors are associated, the harms to development become clear.

The data from this research, qualitative in nature, has low generalization power because it deals with subjective aspects of the perception of mothers of children with hepatopathy about the development of these children. The interpretation of the data is related to the subjectivity of the researcher, i.e., the way he/she interprets what he/she was told, based on his/her history, as well as on previous understandings. Our data can be used to warn the multidisciplinary team that follows up these children and their family cycle about the possible neurodevelopment outcomes so that the patients are better assisted and their relatives. Rehabilitation programs with neuropsychologists, physical therapists, nutritionists, and other professionals should be instituted; because, with increased survival, it will be more common to find patients at risk for developing illness in various spheres.

Conclusions

In general, the mothers' perception about their children's development coincided with the DDST-II results, thus showing that these mothers can identify typical and atypical behaviors. Chronic liver disease can bring physical consequences and emotional ones since it is a pathology that requires many changes in the family environment. It was also possible to observe maternal speeches loaded with overprotection and softening of the disease process, as well as reports of self-confidence and superiority; such behaviors may configure an attitude of defense in an attempt to hide the feeling of fragility that the disease causes.

It is also worth underlining that most children in this study presented a potential risk for NPMD delay warns us of the need for further testing for diagnostic confirmation since DDST-II is a screening tool. The study highlights that these mothers and their children need multidisciplinary follow-up so that the therapeutic approach is conducted without significant burden to the neuropsychological development of children and their families.

Authors' contributions

SantosJC, Barreto NMPV, Santana HS, Sá SMP e Silva LR participated in the project design, collection, analysis, and interpretation of data, writing the article, and relevant critical review of the intellectual content. All authors approved the final version.

Conflicts of interest

No financial, legal or political conflicts involving third parties (government, companies and private foundations, etc.) have been declared for any aspect of the submitted work (including, but not limited to grants and funding, advisory board participation, study design, preparation manuscript, statistical analysis, etc.).

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