STRESS IN CAREGIVERS OF CHILDREN WITH HYDROCEPHALUS (O ESTRESSE EM CUIDADORES DE CRIANÇAS PORTADORAS DE HIDROCEFALIA)

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ABSTRACT

Purpose: Hydrocephalus in children is – usually – a chronic disease and frequently it has no perfect treatment. Long periods of continuous care and supervisions of these children lead the caregivers to varied levels of stress. The main objective of this study is to evaluate the stress level in caregivers of children with hydrocephalus. **Methods**: A descriptive longitudinal and observational study, by using inventory to evaluate and scale the presence of stress in caregivers of children with hydrocephalus. **Results**: Stress symptoms were present in 95% of caregivers, especially in the phase known as resistance (51%). In 39%, these caregivers were diagnosed in almost exhaustion phase. **Conclusions**: Our results showed different degrees of stress in almost all caregivers of children with hydrocephalus, making essential to have a multidisciplinary approach in this group of patients and their caregivers, so, besides the child, parents and guardians also receive specific treatment.

Keywords: Hydrocephalus; Quality of life; Behavior therapy; Caregivers.

RESUMO

Objetivo: A hidrocefalia em crianças é geralmente uma doença crônica e muitas vezes não tem tratamento perfeito. Longos períodos de cuidados continuados e supervisões dessas crianças levam os cuidadores a variados níveis de estresse. O principal objetivo deste estudo é avaliar o nível de estresse em cuidadores de crianças portadoras de hidrocefalia. **Metodologia:** Estudo descritivo, por meio da aplicação de inventário para avaliar e dimensionar a presença de estresse em cuidadores de crianças com hidrocefalia. **Resultados:** Sintomas de estresse estavam presentes em 95% dos cuidadores, especialmente na fase conhecida como resistência (51%). Em 39%, os cuidadores foram diagnosticados em fase de quase exaustão. **Conclusões:** Nossos resultados mostraram diferentes graus de estresse em quase todos os cuidadores de crianças com hidrocefalia, tornando essencial ter uma abordagem multidisciplinar neste grupo de pacientes e seus cuidadores, para que além da criança, os cuidadores também recebem tratamento específico.

Palavras-chave: Hidrocefalia; Qualidade de vida; Terapia comportamental; Cuidadores.

1 INTRODUCTION

Hydrocephalus in children usually is a chronic disease, stigmatizing, especially if associated with macrocrania and neurological deficits. Several ways of treatment may be proposed, depending on its cause and classification, being the surgery the basis of treatment to relieve the intracranial pressure, either by ventricular drainages through shunts (especially for the peritoneum - VP shunts), or endoscopic third ventriculostomy (ETV).(1-5)

Although there are clinical reports about caregivers of certain neurological infant diseases, such as Down syndrome and cerebral palsy,(6-9) not much is known about the caregivers of children with hydrocephalus. The caregiver of a child with hydrocephalus has unique particularities, which makes it more prone to suffering and stress. The mothers are those who generally have the overload of the uncertainties and fears, grieving for her son "dreaming" to the harsh reality of a sick child, with the anguish coming from the diagnosis and treatment of a serious illness, sometimes with neurological disabilities.(6,7) In this perspective, this study intended to report the level of stress of caregivers of children with hydrocephalus.

2 **METHODOLOGY**

Descriptive study: Data collected from the ambulatory of Pediatric Neurosurgery of the Pediatric Hospital Martagão Gesteira, a public and philanthropic hospital, ranked as a reference by the Health Department of the State of Bahia, for care and treatment of children with congenital neurosurgical diseases.

Study sample:

Caregivers responsible for hydrocephalic children, regularly accompanied in the ambulatory of Pediatric Neurosurgery at the Pediatric Hospital Martagão Gesteira (Salvador da Bahia, Brazil), after placement of VP-shunt. We considered as main caregivers those who held the entire or the greater responsibility for the childcare at household level.(10)

Inclusion and exclusion criteria

One hundred children per month are regularly follow-up in the ambulatory of Pediatric Neurosurgery. The research included, in a consecutive way, all caregivers of children with hydrocephalus, which returned regularly to outpatient visit during the first quarter of 2013. In our service, especially in cases of congenital hydrocephalus, the VP-shunt is still considered as the treatment of choice, before the first year of life.(5) Were excluded from the final analysis the caregivers who refused to participate in the research, those who returned for outpatient visit outside the period described above, whose children were followed up at another hospital or if other technique, besides the VP-shunt, was used for ventricular drainage. Also were excluded cases of infant death.

The research was composed by a specific survey and The Parental Stress Inventory(11) was applied by a single interviewer. This interviewer was trained to implement the inventory by a licensed and trained psychologist, which subsequently has made the needed corrections. If after collecting inventory data, errors were identified by the psychologist, new contact was established with the caregiver, allowing the correction of this questionnaire. The psychologist who corrected the questionnaires did not know the ultimate goal of the research.

The Parental Stress Inventory (PSI).(11)

It takes approximately ten minutes to apply the PSI. It is composed of three categories that are related to the four stages of stress. In the *alert* phase (first phase), the body is trying to regain balance, using healthy adaptations. The resistance phase (second phase) is characterized by the persistence of the stressing factor, causing the sensation of waste, when parents start to manifest psychological symptoms. All phases are responsible for bring suffering to the caregiver, and then they bring discomfort to the other people around the stressed person, who is habitually angry, anxious, pessimistic and full of poorly characterized fears.(8,12) The third stage is known as near exhaustion, and occurs when the individual no longer can adapt to the stress, getting weak, and may also get sick. The fourth and last phase is the exhaustion.(8,11,12)

At the moment of data collection, after medical care of their children, caregivers were directed to a private room at the hospital in scope to prevent their exposure or the exposure of their children. After reading and signing the consent form, in clear and understandable language, it was started the answering of the questions. Although the original inventory predict reading and response performed by the caregiver,(8,11,12) for this research we opted for oral question and response marking of the answers by the interviewer, due to the low educational level of the sample analyzed, as previously observed in our hospital population.(5) The application of the Inventory strictly followed the procedures described and socioeconomic status was measured by the criteria of the Brazilian Association of Research Companies.(13)

2.1 Variables Analyzed

Dependents: levels of stress in caregivers of hydrocephalic children.

Independent: age and gender of the child and caregiver, caregiver educational level and socioeconomic level of the family. Etiology of hydrocephalus, presence of epilepsy in the child, infection, need of changes or revisions of VP-shunt.

Statistical Analysis and Ethical Aspects

The statistical analysis was realized by the using SPSS (Statistical Package for Social Sciences – Version 9.0) software. Descriptive statistics and correlation tests were used for the analysis to compare the four phases of stress and their ranks, with the independent variables. The Phi correlation was applied to nominal variables among themselves, and Rho correlation (Spearman) for nominal variables with ordinal. It was considered an error of 5% and a confidence interval (CI) of 90% to accept the alternative hypothesis. The research began with the consent of the hospital, based on Resolution No. 196 of October 1996 which deals with legal aspects related to human research, as well as approval by the Ethics Committee in Research (register number 10658312.1.0000.0048).

3 RESULTS

Among the 41 children included for analysis, 58% were male. At the time of the interview with their caregivers, 51% had more than 02 years of follow-up after VP-shunt. In 66% of cases the diagnosis of hydrocephalus was made after the child's birth (postnatal), and 49% were classified as congenital, 10% after cerebral hemorrhage occurred due to prematurity (preterm babies) and 2% after inflammatory and infectious processes of the central nervous system (infections occurring during intrauterine or postnatal period). In 39% this categorization was not possible (unknown etiology). In 54% of these children VP-shunt was performed during the first 3 months of life. Regarding complications related to the surgery, there were reports of infection or mechanical malfunction of shunt with the need to change the system in 24% of cases (Table 1).

Table 1 - Epidemiological characteristics of 41 children with hydrocephalus submitted to ventricular peritoneal shunt-VP-shunt (Salvador da Bahia, Brazil, 2013)

General characteristcs	n (%)

Male	24 (58)
Child's age at the moment of VP-shunt	
< 3 month	22 (54)
3-6 month	10 (24)
> 6 month	09 (22)
Diagnosis of hydrocephalus	
Congenital	20 (49)
Posthemorrhagic [a]	04 (10)
Post infection [b]	01 (2)
Unknown	16 (39)
VP-shunt complications [c]	10 (24)

a. Cerebral hemorrhage associated with prematurity (preterm babies).
b. Hydrocephalus secondary to infectious or inflammatory diseases of the central nervous system, occurring in the intrauterine period (congenital infections) or postnatal.
c. Surgical complication by infection or mechanical malfunction of the VP-shunt with the need to change the system.

Concerning the epidemiological characteristics of parents or caregivers, 34% were younger than 25 years at the moment of the interview, and mothers were responsible for the care of these children in 85% of cases, followed by their relatives in 10% of the time (grandmothers or aunts) Regarding the educational level, 20% of caregivers were illiterate or with low education and 90% classified as low economic class, according to Brazilian norms and criteria.

At the moment of interview, 95% of caregivers presented signs of stress, and 51% were in the resistance stage, followed by almost exhaustion phase (39%) (Table 2), predominating the grievances concerning the psychological disorders in 64% of times. There was no relation between the diagnosis of stress with the age of the caregiver (Rho = 0:26, p = 0.1), time of the child's illness (Rho = 0:24, p = 0.1) or socioeconomic level of the family (Rho = -0.14, p = 0.3). None of the complications evaluated after the VP-shunt, such as infections (10%; Phi = 0:13, p = 0.7) and the need of frequent changes of shunts (24%; Phi = 0:21, p = 0.4), or presence of epilepsy (30%; Phi = 0:24, p = 0.3), influenced the frequency or severity of stress on the caregiver. Since practically all the interviewees demonstrated the presence of stress (95%), it was not possible to compare this group with those with absence of stress.

Table 2 - Presence of stress symptoms and severity level, in 41 caregivers of children with hydrocephalus (Salvador da Bahia, Brazil, 2013)

Presence of stress symptoms	n (%)
Non attendant	2 (5)
Attendant	39 (95)
Phase 01 (Alert)	01 (2)
Phase 02 (Resistence)	20 (51)
Phase 03 (Almost exaustion)	15 (39)
Phase 04 (Exaustion)	3 (8)

4 DISCUSSION

Congenital hydrocephalus (CH) occurs in approximately 1:1,000 live births, being this proportion higher in developing countries, such as in Brazil, reaching rates of 3.16: 1.000.(14,15) An early diagnosis is fundamental and can be done since the second trimester of pregnancy, highlighting the importance of regular prenatal care.(1,5,16) The hydrocephalus stand out as one of the diseases most frequently treated by pediatric neurosurgeons, which shows the importance of its understanding, from the epidemiological profile, through diagnosis, treatment options, and knowledge of its complications.(1,2,17,18) The same epidemiological characteristics described in this study were observed in our case series previously published, showing that the diagnosis of hydrocephalus in children of certain regions of northeastern Brazil is usually done in the postnatal period, predominantly in boys, and commonly operated in the first three months of age.(5) Regarding the higher rates of postoperative complications of VP-shunt, described in this study, in comparison to the series previously described(5) it can probably be justified by the longer follow-up period of these children (51% with follow-up longer than 2 years), and have been included all patients treated and followed at our outpatient clinic, independent of the hospital where they were operated.

Regarding the socio-economic level of families and schooling, similar results were previously published(5) and are probably associated with the profile of patients treated at the hospital (a public and philanthropic hospital). The care act rests, mostly on women, especially for caregivers of children with chronic diseases.(9,19) These data corroborate to our results, where almost all children with hydrocephalus included in the study (95%) are cared for by their mothers or their female family members. The importance of recognizing in caregivers stress caused due to the illness of their children, may help the neurosurgeon to understand some attitudes of caregivers, which in turn will influence the handling of these children throughout their lives and the mother-child relationship. The fact of being young mothers, probably inexperienced, with low income and schooling levels, further emphasizes the need for greater involvement of the pediatric neurosurgeon with family, for better understanding of disease by the caregivers.

The neurosurgeon must keep in mind that the consultation should not be restricted to the examination of the child, but also include the knowledge of the maternal difficulties in relation to understand the child's disease, attempting to minimize these doubts, difficulties and concerns. The assistance of qualified professionals capable to recognize this stress on caregivers reduces this overload on them,(20-22) considering that the medical team communication with family members is fundamental on assistance to reduction of anxiety and stress. For caregivers, the complexity in having a child with hydrocephalus, by itself, is already considered as a stress factor, as evidenced by the results shown here, where practically the entire samples analyzed (95%) was within the diagnoses criteria of stress. Other studies confirm this data, where is described that caregivers of sick children often suffer from stress symptoms.(6,23,24) Considering the four stages of stress,(8,11,12) most caregivers in the current sample are in the resistance phase (51%), characterized by the persistence of the stress factor (in this case, the chronic illness of the child) creating the sensation of waste and manifestations of psychological symptoms, followed by almost exhaustion phase (39%).

If the health team involved in the treatment and monitoring of these children is not be able to notice the risk of developing stress symptoms in this group of mothers, the tendency is to evolving for the later phases, culminating in phase 4 or exhaustion. In this phase, the caregiver also becomes sick. Achieving the stage of exhaustion, we question the quality of assistance of the caregiver to follow medical instructions, as well as the capacity of caregivers to observe smaller, but important, signs and symptoms for the treatment of these children.(8,11,12) Among all independent variables analyzed, this study was not able to identify a factor of greater significance in triggering the stress in this group of caregivers. Stress is not a disease, but a triggering factor for diseases, so there are no specific treatments. There are measures that can contribute positively to the reduction of the stress level and may help facing this.

5 **CONCLUSIONS**

By the large number of caregivers of hydrocephalic children, with diagnosis of stress, it becomes essential continual improvement of communication from the medical team with the patient and their family, exposing in a clear and comprehensible way, information for the understanding of the disease, and possible complications of the treatments. Probably, these orientations may help to lower the stress level of mothers that are caregivers of children with hydrocephalus. The multidisciplinary team of health must be aware of the health status of caregivers of children with hydrocephalus, not only to relieve their suffering by understanding the disease, surgical procedures and risks, as well as to refer to early treatment and psychological support. The actual results will be forwarded to the State Health Department of Bahia, with the aim of adding a psychologist to attend, exclusively, the unit of Pediatric Neurosurgery.

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