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The influence of household environment on caregivers' overload of children with cerebral paralysis

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ABSTRACT. The environment is considered an extremely important factor in individuals' health promotion and life quality. The influence that the environment exerts on caregivers' lives is due to all the complications they have to experience. Current study investigates the influence of family environment on the overload of caregivers of children with cerebral paralysis. The research comprised 21 caregivers, whose overload intensity was assessed by three instruments: a caretaker characterization form, Zarit Caregiver Burden Interview (ZBI) and an environmental characterization protocol. Results showed that all caregivers revealed a certain level of overload (52.4% intense and 47.6% moderate). Physical modifications were observed in 52.4% of the residences under survey but none was undertaken by a professional in rehabilitation. A statistically significant correlation occurred in children's spatial movement ($p=0.031$). Research suggests that caregivers of children with cerebral paralysis are overburdened due to the health care activities and that the environment constitutes a risk factor.

Keywords: child care, risk factors, health promotion.

A influência do ambiente domiciliar na sobrecarga de cuidadores de crianças com paralisia cerebral

RESUMO. O ambiente é considerado fator de extrema importância na promoção de saúde e qualidade de vida dos indivíduos. Determinar a influência que o ambiente exerce na vida de cuidadores surge como uma necessidade diante de todas as dificuldades por eles enfrentadas. O objetivo deste estudo foi investigar a influência do ambiente familiar na sobrecarga dos cuidadores de criança com paralisia cerebral. A pesquisa contou com 21 sujeitos, cujo nível de sobrecarga foi levantado por meio de três instrumentos, um formulário de caracterização do cuidador, o inventário de sobrecarga de Zarit e um protocolo de caracterização do ambiente. Os resultados encontrados foram que todas as cuidadoras apresentavam sobrecarga (52,4% intensa e 47,6% leve). Observou-se a existência de adaptações em 52,4% dos domicílios estudados, no entanto nenhum deles tinha sido adaptado por um profissional de reabilitação. Foi encontrada uma correlação estatisticamente significativa com a existência de espaço para criança se locomover ($p = 0,031$). O trabalho sugere que cuidadoras de crianças com paralisia cerebral são sobrecarregadas em decorrência da atividade de cuidar, tendo o ambiente muitas vezes como fator de risco.

Palavras-chave: cuidado da criança, fatores de risco, promoção da saúde.

Introduction

The environment is a factor of great importance in promoting health and life quality of individuals, although concern is very recent in scientific studies. It was only in the 1970s and 1980s that the environment was introduced in health-related discussions. In fact, the 1986 Ottawa Charter for Health Promotion was the landmark that highlighted this phenomenon.

At present, environmental influences on health have caused increasing concern. The Ottawa Charter for Health Promotion and the 1972

Stockholm Declaration, another significant document on the environment as a direct object of health promotion, have triggered investigations within several perspectives to understand its manifestations on peoples' lives and on life quality in general (AUGUSTO, 2003).

Freitas (2005) has surveyed and analyzed the scientific production on the environmental theme in four major Brazilian scientific journals between 1992 and 2002 to understand the environmental stance incorporated in collective health issues. Results pointed to a concentrated scientific

production in institutions of the southeast region of Brazil that focused on the biological notions of health and environmental biophysics, with the predominance of diagnostic studies. However, only a few enquiries incorporated the search for solutions or the estimation on the contribution of different identities involved in environmental problems.

In spite of all the contemporary discussion about environmental influence on the population's health, studies about the health of the caretakers of children with cerebral paralysis are rare (LOPES et al., 2002; BITTENCOURT et al., 2008). Research works in the field generally deal on the concepts, etiology and treatment, among others items. Little has been reported on such important issues as the health of caregivers of sick people and studies are even scarcer when the environmental risks to caregivers' health are taken into account (RUBINSTEIN et al., 2002; RANDOVANOVIC et al., 2004).

Silva (2002) stated that environmental factors may influence the development of healthy babies and that this influence may be greater in babies with some kind of health complications. The author also reported that the families of premature infants have a key role in the development, potentiating and alleviation of the effects of possible neurological damage.

Martins et al. (2004) made a prospective study related to population. Describing and identifying factors that might be associated with environmental quality in children in Pelotas, Rio Grande do Sul State, Brazil, the authors reported that 97 children (15%) were living in negative environments that affected their development. Another research on the environment was carried out by Barros et al. (2003) who indicated that the development of biologically healthy children might suffer negative influence from environmental risk factors. These difficulties were aggravated when children with cerebral paralysis were focused.

It may be noted that the environment is doubly linked to the children's care setting. In fact, it directly interferes in their development through the interaction or not of the child in favorable environments, and indirectly through the influence of the environment on the caregivers' health and life quality (RUBINSTEIN et al., 2002).

The environment, therefore, may contribute favorably and unfavorably in the development of CP children. Caregivers are tools that make easier the environment-children interaction. However, the interaction is performed correctly when an environment that helps the caregivers' activities with

the child is established (ANDRADE et al., 2005; MANCINI et al., 2004).

The assistance provided by the caregivers is, in itself, highly stressful and leads to different levels of overload. It is important to pay attention to the caregivers of children with severe illnesses have similar profile. A research by Frota et al. (2012) with 16 caregivers of children with acquired immune deficiency syndrome (AIDS) in Public Hospital in Fortaleza revealed that the profile of the respondents mostly were family mothers and grandmothers women, and have indicated that there was a need for better access to health services, and this humane environment with fun activities that allow creating bonds of affection between caregiver and health professionals.

Studies on the overload of caregivers to elderly people are highly illustrating (CALDAS, 2003; KARSCH, 2003; FLORIANI; SCHRAMM, 2006) and such a literature may be of help in researches on caregivers of CP children. Another point to be discussed is the lack of government policies to guide the health of caregivers dealing with patients suffering from chronic illnesses in general. Despite the government's attempt to integrate disabled people in society by promoting accessibility to public places and thereby reducing the time spent in the transport of children, very little has been done to ensure integration and accessibility of CP patients in their home environment. Moreover more formation and orientation programs to the children's families are needed (ALMEIDA et al., 2006; VILAÇA et al., 2005).

Although in 2007 the Brazilian Ministry of Health launched a practical guide for caregivers, limitations were rife since it was directed only to caregivers of elderly people. In fact, it forgot the large percentage of caregivers who take care of patients with many other chronic illnesses, including cerebral paralysis. However, the guidelines provided important information on the caregiver-environment-care interaction since they also focused on the need for environmental adaptations to facilitate the tasks and minimize damages in caregivers (BRASIL, 2008).

Studies on the home environment as an influence on the overload of caregivers of CP children will be of great help to solve effectively and practically the complications caused by caretaking. They will also optimize the children's development since the care provided to improve their health is closely linked to care quality.

Merely considering the needs of healing and rehabilitation of this pathology does not determine a

healthy life for the sick children. The environment, actually perceived as a health-promoting agent, may no longer be neglected. When its influence on health is made clear, intervention programs for families, covering environmental aspects that promote the welfare of children and their caregivers, will be developed and will facilitate the tasks undertaken. Current study investigates the influence of the family environment on the overload of caregivers of children with cerebral paralysis.

Material and methods

The analytic and observational investigation comprises a quantitative and qualitative study. All the children were clinically diagnosed with cerebral paralysis and treated at the Neuropediatric and Physiotherapy Rehabilitation Unit Leonor Barreto Franco, a health unit of the Tiradentes University Aracaju SE Brazil, which took part in the research. The Rehabilitation Center Leonor Barreto Franco is a reference center for physical rehabilitation in the industrial district of Aracaju. It features Physiotherapy in the fields of Trauma, Orthopedics, Respiratory diseases, Gynecological-Obstetrics, Neurology, Pediatrics and others. Patients with several diseases, including individuals with CP, are treated.

Research involved 53 caregivers of children with a clinical diagnosis of cerebral paralysis, out of whom 21 were selected according the following criterion: a caretaker of 1 to 12 year-old children who frequented the physiotherapy treatment. The exclusion criterion was the caregiver's non-consent to participate in the survey, after having been informed on the Term of Consent contents. Formal salaried caregivers engaged in the activity were also excluded. The about criterion was necessary so that the aim of the survey could be achieved, or rather, without the bias that the salary might represent. Moreover, caregivers who lived outside the territorial limits of Aracaju's Metropolitan Region were also excluded since home visits were required to conduct the research.

Data were collected by three instruments. First, the caregiver form, created exclusively for this research, was filled to obtain data on the identification of the caregiver and the child, socioeconomic status, schooling level, marital status, knowledge on the child's pathology, difficulties in daily activities, complaints related to the physical activity of care, the number of hours a day dedicated to child's care, occupation, workload, number of people living at home, use of facilitators, home

adaptations, the child's transport conditions, and others.

Second, Zarit Caregiver Overburden Inventory, a Brazilian version of the Zarit Burden Interview, evaluated the overload on caregivers of people with chronic diseases (TAUB et al., 2004; ZARIT; ZARIT, 1985). The inventory consists of 22 questions that scale-assess the impact of the caregivers' activities on physical, psychological and social fields (WESTPHAL et al., 2005; TAUB et al., 2004). Each question of the Zarit Burden Interview must be scored on a 5-point Likert scale ranging from – 'Never' to 'Nearly always present'. Total scores range from 0 (low burden) to 88 (high burden). The higher the final score, the higher the caregiver's overburden (TAUB et al., 2004, ZARIT; ZARIT, 1985). A reaching weighbridge proposed by Gonzáles et al. (2004) was employed, in which the following cut-off points: 0 - 22 (no overcharge), 23 - 44 (moderate overcharge), and over 44 (acute overcharge) were established.

Third, a protocol to characterize the environment and provide inform on the location in which the caregiver and the child were inserted so that the overload may be correlated to environmental conditions.

The term of consent was signed by the caretaker and data were collected. Only one researcher interviewed individually each participant using the above-mentioned forms. Previously scheduled home visits were undertaken to evaluate the environment and determine adaptations and facilitators. A Protocol of Environmental Characterization, in which the researcher noted the environmental characteristics, adaptations and facilitators of each household visited, was the next stage in the research.

After data collection, a descriptive analysis of the study with the socio-demographic and historical features of the caregivers, overload rates, functional and clinical history of patients and characterization of the environment, determinant factors and overburden levels were undertaken. Pearson's correlation test was applied to assess the correlation between the variables under analysis. Significance level was 95% ($p < 0.05$).

The project was approved by the Ethics and Research Control of the Universidade Tiradentes, protocol 450508.

Results and discussion

The 21 caregivers who participated in the survey were female, average age 31 years, 95.2% (20) were mothers and one (4.8%) was a grandmother. None

of the caregivers had formal employment and 90.5% (19) worked between 12 and 24 hours in caring activities for CP children.

The high workload devoted to CP children's care required that caretakers quitted their jobs and became exclusively dedicated to the task. This fact increased stress. The caretaker also experienced a process of social exclusion, frequently without the support of the other members of the family.

Caregivers presented a variable schooling level, or rather, 42.9% (9) had finished secondary school; 52.4% (11) finished high school; 4.8% (1) had a higher education certificate. Low schooling mirrored the familiar income. In fact, 81% (17) earned between one and two minimum wages current in Brazil.

All caregivers showed an overload related to caring activity. Overload levels evaluated by Zarit Caregiver Overburden Inventory showed that 52.4% (11) were classified as light and 47.6% (4) were classified as severe overload.

Overload levels could be perceived by caregivers when they answered the question whether they felt themselves overloaded by taking care of the child, demonstrated in Table 1.

Table 1. Frequency distribution of the perceived overload reported by caregivers of children with cerebral paralysis.

Overload level	Absolute frequency (n)	Percentage (%)
Moderately overloaded	15	71.4
heavily overloaded	2	9.5
Extremely overloaded	4	19.0
Total	21	100.0

The outcome of this analysis makes it clear that the caregivers of children with cerebral paralysis exhibit an overcharge resulting from the buildup of chores. As a rule, the caregivers distinguish an overcharge consistent with the Zarit Burden Inventory final quantified score.

Although 52.4% (11) of the homes had some kind of adaptation, none was built by a rehabilitation professional and none of the caregivers reported having any orientation in this matter. Adaptations were made according to needs encountered by each one to minimize the difficulties and/or to facilitate certain tasks in handling the child (Table 2).

House adaptations varied from a simple change in furniture disposition to physical adaptations in the house structure. Only one among the 21 visited houses had stairs, but a ramp was built to facilitate access. The bathrooms did not have may structure proper to handicapped people and only 14.3% (3) had adaptations such as anti-skidding floor tiles and wall bars.

Table 2. Distribution of frequency of variables on the characterization of the environment in which the caregivers from the Rehabilitation Center Leonor Barreto Franco were inserted in the second half of 2008.

	Yes	No	Total (n / %)
Home adaptation	52.4% (11)	47.6% (10)	100.0% (21)
Space for future adaptations	81.0% (17)	19.0% (4)	100.0% (21)
Use of facilitators	52.4% (11)	47.6% (10)	100.0% (21)
Space for child's development	61.9% (13)	38.1% (8)	100.0% (21)
Space for child's locomotion	66.7% (14)	33.3% (7)	100.0% (21)
Use of appropriate transport for the child	23.8% (5)	76.2% (16)	100.0% (21)

These results demonstrate the shortcomings of services and/or programs geared to the orientation of the caretakers. The assistance given to children with Cerebral Paralysis by health professionals is limited to clinics and rehabilitation institutions and fails to see care as a *facilitating* agent in the children's treatment. A study carried out by Lopes et al. (2002) demonstrated that the effective participation of the parents is beneficial to the child's rehabilitation, avoided the physical stress that the activity demanded and prevented humor oscillations of the caretakers caused by overload.

Home visits provided more security to caregivers and made therapists more able to evaluate the family's emotional and social-economical conditions of the family, with orientations and adaptations more specifically directed to each patient. Moreover, they encouraged more participation by the family. Since more often than not only the mother was involved in the rehabilitation process, all the family members were counseled as to their responsibility (FELICIO et al., 2005).

When facilitators were taken into consideration, it was reported that 52.4% (11) of the mothers received these resources (Table 2). The information was not considered relevant since these facilitators, such as orthoses (47.6%), wheel chairs (38.1%) and positioning chairs (4.8%) were distributed free by the Brazilian National Health Service (SUS). The non-utilization of orthosis when necessary might be considerate a risk factor to overload caretakers of CP children since its use facilitated the maintenance of the appropriate body posture and a better functionality (CURY et al., 2006).

The utilization or not of materials and/or toys which stimulated the neural and psychical motor development of the child in the home environment was also surveyed. In fact, 71.4% (15) of the children had access to these materials. However, in spite of the existence of toys that stimulated their development, they were frequently incompatible to the children's age

or to their cognitive development. Incorrect usages of toys by people who should stimulate the children were also perceived. This may be explained by a lack of conscience-awareness and orientation on the importance of stimulating the children in their everyday activities and not solely during therapy.

The caregiver of CP children accumulates concerns with the health and welfare of the caregiver of handicapped people in other age groups and still has to help in their development, once they need more stimuli when compared to healthy children.

Pearson's correlation test evaluated overload and other relevant environmental items, such as the utilization of facilitator resources, adaptations, transport, space for child development in the home environment, space for child locomotion, utilization of materials to stimulate the neural and psychical motor development and others. The only information statistically significant referred to the existence of space for child locomotion ($p = 0.031$).

The literature points out that the task that physically demands more of the mothers is that related to child transportation (SOUSA; PIRES, 2003). The physical stress associated to the inexistence of an appropriate space for child locomotion may aggravate even more the mother's overload. This item reiterates the need for knowledge of the environment in which the mothers are inserted so that adaptations and orientations could be made and the damages caused by the caring activity would be minimized.

Research works focused on caregivers of CP children are scarce and are often based on studies for caregivers of elderly people. The relevance of this work lies in its uniqueness, since there is no study in the literature that correlates home environment and caregiver's health.

Current study is an asset to research on the health of caregivers of CP children. Further research work on the environment and its influence in caregivers' lives is required so that the existing gap on the topic could be emended.

Conclusion

Results show that caregivers of CP children are overloaded due to the caring activity and that the environment is constantly perceived as a risk factor. A significant correlation exists between the existence of space for children's movement and the overload of caregivers. Although some correlations between the mother's overload and the features of house environment are not statistically significant, results show that they mostly indicate an unfavorable environment in caring, corrected by boosting physical and / or psychological participants.

Data showed the urgent need for programs focused on the caregiver's health at the institution. Guidance on the best methods to carry out activities and home adaptations to facilitate the daily life of the family are simple measures that may limit the impact of caring on the health and life quality of mothers / caregivers.

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