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Family Functionality: A Risk Factor for Tired Caregiver Syndrome

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Abstract

Background: The role of the caregiver of dependent people with disabilities exerts a significant influence on the quality of life and health of the care recipient. Furthermore, it has been demonstrated that this role can precipitate the development of "tired caregiver syndrome," a phenomenon that merits further investigation within the Ecuadorian context. The objective of this study is to analyze the relationship between tired caregiver syndrome and family functionality, as well as the dependence of people with cerebral palsy sequelae, in two different population areas. Methods: The analytical, associative, cross-sectional research with a qualitative-quantitative approach was conducted to assess the variables of family functionality, caregiver burden, emotional well-being, and patient dependence. The study population comprised 24 individuals residing in the suburban and urban areas of Quito, ranging in age from 35 to 50 years, who were caregivers for a family member with cerebral palsy for a duration ranging from 18 to 25 years. These individuals were assessed using the Zarit Burden Assessment Scale, a tool designed to evaluate the burden experienced by caregivers. The Results of this study indicated that the participants exhibited symptoms consistent with the caregiver overload syndrome. In the urban area, the caregiver's burden is intense, accompanied by a moderate dependence on the patient. In conclusion, caregivers in suburban areas reported a moderate patient dependence, accompanied by a relatively low caregiver burden. In suburban areas, caregivers maintain a relatively normal family function, exhibiting only mild fatigue in their caregiving roles. Conversely, in urban populations, caregivers experience a more pronounced burden, accompanied by mild family dysfunction.

Keywords: *Caregiver Syndrome, Cerebral Palsy, Family Functionality, Caregiver Dependence.*

Introduction

The impact of the family environment on individuals with cerebral palsy is contingent upon the degree of care required by the patient. In most cases, the primary responsibility for this care falls upon the mother of the family. The physical demands of caring for a person with CP can lead to significant emotional and psychological strain for the family, potentially altering their initial expectations for the birth of a baby (1)(2).

Even in the most severe cases of cerebral palsy, family members often harbor the hope that their children will achieve autonomy in walking and functioning in their daily lives, particularly in the event of parental death. The relationship between the mother and the father is affected by the adaptation to the new family situation, each one resolves their psychological grieving process, and sometimes this triggers couple conflicts. The transition to parenthood often entails a significant redistribution of a couple of times, with the mother assuming a more dominant role in childcare and the father experiencing a shift in his involvement. This transition can be particularly challenging for couples, potentially leading to decreased time spent together,

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feelings of jealousy, and, in some cases, marital dissolution (3).

In most cases, the father exits the family home, leaving the mother to assume primary responsibility for the family, including a child with CP. This dynamic aligns with the observations made in the population under study. Consequently, two consequences that the person responsible for caring for dependent children (or adults) with CP may experience are related to emotional interdependence and tired caregiver syndrome.

The manifestation of emotional interdependence is characterized by a persistent need for proximity to avert perceived threats, whether real or imagined. The caregiver may develop a sense of indispensability, manifesting in cognitive, behavioral, and emotional signs. Consequently, the caregiver may develop obsessive thoughts, such as the belief that no one understands them like they do. This phenomenon can be understood as a consequence of the caregiver's almost exclusive dedication to the care of the child, particularly in cases of severe dependence. The caregiver (often the mother) may become so engrossed in caring for the child that they neglect other aspects of their lives (4).

From an emotional standpoint, the interdependence between the individual with CP and the caregiver is characterized by feelings of anguish and depression. The phenomenon of "burnt out caregiver syndrome" has been identified as a potential outcome of the interdependence previously described. This phenomenon arises when the primary caregiver experiences profound physical and psychological fatigue resulting from their unwavering commitment to the care of their child. This phenomenon can be understood as a response to chronic stress, leading to a series of physical and psychological symptoms stemming from a sense of losing control in the face of adversity (5).

The role of the caregiver of a family member with a physical disability encompasses providing support in fundamental daily activities, including meal preparation and consumption, personal hygiene, selection of attire, and assistance with positional changes, among other responsibilities. The role of the caregiver of dependent people with disabilities exerts a significant influence on the quality of life and health of the caregiver and can serve as a catalyst for the onset of Caregiver Syndrome (Caregiver Burden Syndrome) (6).

Research conducted in multiple countries has revealed that caregivers of dependent individuals with disabilities constitute a highly vulnerable demographic, characterized by the utilization of suboptimal coping mechanisms that impede their adaptive processes. The predominant conditions are of an emotional nature, including anxiety and depression, and physical in nature, particularly lower back pathologies resulting from overexertion (7).

In countries analogous to Ecuador's circumstances, such as its neighboring nation, Colombia, a cross-sectional descriptive study was conducted, encompassing a sample of 2557 caregivers of individuals with severe disabilities across 19 localities in Bogotá. The study revealed that caregivers exhibited self-perceived health alterations, demonstrated a high dedication of time to informal care activities, and exhibited a multitude of responsibilities (5).

In 2016, a study of the emotional state of mothers with children with disabilities was conducted in the city of Cuenca (Ecuador). The Hamilton test was applied, and 87.8% of the participants exhibited anxiety. The Hamilton test was complemented by the application of the family APGAR, a method designed to evaluate family functionality. The study revealed that 86.6% of the caregivers who exhibited anxiety also demonstrated high levels of family functionality. However, a survey of primary research sources related to the field in the Ecuadorian context reveals a paucity of attention to other salient factors, including the examination of the relationship between caregiver fatigue and family functionality, as well as the dependency of individuals with sequelae of cerebral palsy across two distinct population groups. This oversight forms the foundation of the present research endeavor (8).

Methods

A cross-sectional study was conducted using a qualitative-quantitative approach, encompassing a total of 24 individuals between the ages of 35 and 50 (female) who were relatives of individuals with physical disabilities resulting from infantile cerebral palsy (dystonic diparesis, mixed diparesis, spastic diparesis, ataxic diparesis, athetotic diparesis, diplegia) from two communities within the city of Quito. The present study examined the experiences of family members who have provided care for individuals with physical disabilities between the ages of 18 and 25.

The following variables were investigated: type of population sector, family functionality, caregiver burden, emotional well-being, age, years of care, and dependence on the performance of the activities of daily life of the patients, in a northwestern suburban community and another urban community, located in the city of Quito, Republic of Ecuador.

The study worked with the population that met the following inclusion and exclusion criteria:

a) **Inclusion criteria:** caregiver of a family member with Cerebral Palsy, for a period between 18-25 years, who has Caregiver Overload syndrome in the Zarit test (score > to 46), and who agreed to participate, explicit in the Informed Consent.

b) **Exclusion criteria:** caregiver of a family member with another dependent illness. Caregiver of a family member with Cerebral Palsy, who did not present caregiver overload syndrome on the Zarit test (score < to 46), family members who have been a caregiver of a person with a physical disability for less than 18 years.

Data collection was carried out with the application of the following research instruments:

1) APGAR test that quantifies family functionality.

2) Zarit scale to measure the variable of Caregiver Burden.

3) Barthel test in order to quantify dependence on the performance of the activities of daily life of patients.

4) GQH 28 questionnaire to assess emotional well-being.

In the analysis of the data collected, descriptive statistics, cross-tables and associative chi-square tests were used using the *SPSS version 22* program. In this study, SPSS version 22 software was used to analyze data using descriptive statistics, cross-tabulation, and chi-square association tests. This program allowed the variables of family functionality, caregiver burden, emotional well-being, and patient dependency to be evaluated. In addition, ethical implications were included, and the project was presented to the bioethics committees of the Camilo José Cela University in Spain and the San Francisco University in Quito, Ecuador, where it was approved in June and August 2019, respectively.

Results

		Total Sample (24)	Suburban (12)	Urban (12)
Age (years)		48,25	47,92	48,58
Years of Care		20,13	19,83	20,42
Gender		Female	Female	Female
Anxiety	Presence	88,2%	74,6%	86,5%
	Absence	11,8%	25,4%	13,5%
Caregiver Charge	Intense	66,7%	41,7%	91,7%
	Light	33,3%	58,3%	8,3%

Table 1. Characteristics of the Sample of Caregivers

The study was carried out in two zonal groups (Table 1), a group in a suburban area, made up of 12 mothers of an average age of 47.92 years, caregivers of patients with cerebral palsy of an average of 19.83 years of care, 58.3% presented light load as caregivers of patients, while 41.7% had intense load.

The other group was made up of 12 mothers of an average age of 48.25 years, who reside in an urban area, caregivers of patients with cerebral palsy with an average of 20.13 years of care, who mostly (91.7%) presented intense burden as caregivers of patients in the Zarit test.

Both groups had levels of anxiety in the corresponding item of the GQH emotional well-being test 28 (88.2%).

		Total Sample (24)	Suburban (12)	Urban (12)
Age		20,13	19,83	20,42
Gender	Female	37,5%	16,7%	20,8%
	Male	62,5%	33,3%	29,2%
Degree of dependence (Barthel)	Dep. Moderate	54,2%	41,7%	66,7%
	Dep. Severe	45,8%	58,3%	33,3%

Table 2. Characteristics of Patients with Cerebral Palsy

Regarding the characteristics of patients in the care of their mothers (Table 2), in the suburban and urban groups, the male gender predominates 33.3% and 29.2%, respectively, 62.5% of the total of 24 people.

Population area				Family Function			Total
				Moderate	Lightweight	Normal	
Suburban	Caregiver Load	Intense		0%	41,7%	0%	
							41,7%

		Light		0%	0%	58,3%	58,3%
Urban	Caregiver Load	Intense					
				85,4%	6,3%	0%	91,7%
		Light					
				0%	8,3%	0%	8,3%

Table 3. Caregiver Burden and Family Function, According to Population Area

The average age of patients is 20 years and the degree of dependence in the urban sector is moderate (66.7%) and in the severe suburban sector (58.3%).

Familiar_Function		Value	Gl	Asymptotic sig. (2 faces)	Exact Significance (2 Faces)	Exact Significance (1 Side)
	Pearson's Chi-square	9,882	1	0,002		
	Reason for plausibility	12,674	1	0,000		
	Fisher's Exact Test				0,005	0,002

Table 4. Chi-square tests of Family Function and Caregiver Burden

In the urban population area, the intense caregiver burden predominates (91.7%) (Table 5), although patient dependence is moderate (58.3%), in the suburban area severe patient dependence predominates (58.3%), with a light caregiver burden (41.7%).

Population Zone				Degree of Dependency		Total
				Moderate	Severe	
Suburban	Caregiver_Burden	Intense	Recount	0	5	5
			% of total	0,0%	41,7%	41,7%
		Light	Recount	5	2	7
			% of total	41,7%	16,7%	58,3%
	Total		Recount	5	7	12
			% of total	41,7%	58,3%	100,0%
Urban	Caregiver_Burden	Intense	Recount	7	4	11
			% of total	58,3%	33,3%	91,7%
		Light	Recount	1	0	1
			% of total	8,3%	0,0%	8,3%
	Total		Recount	8	4	12
			% of total	66,7%	33,3%	100,0%
Total	Caregiver_Burden	Intense	Recount	7	9	16
			% of total	29,2%	37,5%	66,7%
		Light	Recount	6	2	8
			% of total	25,0%	8,3%	33,3%

	Total	Recount	13	11	24
		% of total	54,2%	45,8%	100,0%

Table 5. Caregiver Burden and Dependency of The Patient with Sequelae of Cerebral Palsy, According to Population Area

When analyzing the variables of the degree of Caregiver Burden and patient dependence (Table 6), no association with statistical significance was found (p=0.148 Chi-square and p=0.156 Fisher's exact 1-sided test).

Patient Dependence		Value	Gl	Asymptotic sig. (2 faces)	Exact Significance (2 Faces)	Exact Significance (1 Side)
	Pearson's Chi-square	2,098	1	0,148		
	Fisher's Exact Test				0,211	0,156

Table 6. Chi-square tests of Caregiver Burden and Patient Dependence

Discussion

In the international literature there are multiple studies of the Tired Caregiver Syndrome in relatives of older adults, mostly in the female gender, who fulfill this role of informal family caregiver, although in the Ecuadorian environment it has not been possible to verify works that analyze in depth the national characteristics (9).

In the present study, the entire sample is female, and it was found that family functionality was a risk factor for tired caregiver syndrome in patients with cerebral palsy. The degree of patient dependence on the caregiver was not a risk factor in this study.

Research in the neighboring country of Colombia coincides that caregivers of older adults did not show a correlation between the degree of dependence of the patient and the burden of the caregiver. Another study in Latin America coincides with the results of this study, mentioning that family functioning is a risk factor for Caregiver Burnout Syndrome in daughters of elderly patients (10)(11).

Research shows that another risk factor for Burnt Out Caregiver Syndrome is the time spent in the role of caregiver, when intense overload occurs in those who care for their elderly family member for a period of 6 to 10 years. In the present research, the two study groups that have Tired Caregiver Syndrome, according to the urban and suburban population area, present the same time (mean of 19 years) of caregiver performance of the family member with cerebral palsy (12).

There are several studies on Caregiver Syndrome, which show that emotional health is affected, as indicated in Gallegos, Cuentas, Canaza, and Rodríguez. As in the present study, intense overload and anxiety were found in caregivers (13).

As people with cerebral palsy sequelae were between 18 and 25 years old, the main concern was the future of the family member cared for, the dependence of the person with physical disability on the caregiver, which was reflected in the answers with the highest weighting (4 almost always) in questions 7, 8, 14, 16 of the Zarit test.

The care of a person with a physical disability must be shared with the whole family, because the burden and costs it causes are very high and can only be borne with the organization of family work in an equal and equitable manner (14).

The study ratifies the need to implement strategies to support the caregiver of people with dependency in Ecuador, mainly in the aspects of physical and emotional health, as well as to design an education plan for the dependent patient, for which the experiences in Latin American countries that have School for Caregivers programs can serve as a theoretical and methodological basis. support from community and government institutions for the care of family members who face anxiety and depression in this population, most of whom are of low socioeconomic resources (15).

Final Considerations

A correlation has been identified between family dysfunction and Tired Caregiver Syndrome. In urban areas, the predominant pattern is characterized by a significant caregiving burden and mild to moderate family dysfunction. Conversely, in suburban areas, the predominant pattern is characterized by a less substantial caregiving burden and normal to mild family dysfunction. Furthermore, the patient's degree of dependence does not correlate with the development of Tired Caregiver Syndrome.

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Conflicts of Interest

The authors state that there were no conflicts of interest.

Author Contribution

Ana Cristina Díaz: Project management, statistics, writing; Teresa García Pastor: Methodological advice; Diana Ruiz Vicente: Methodological advice.

Informed Consent

All participants were informed about the research objectives and Written informed consent was obtained from all participants.

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