



## Prevalence of Burden, Family Dysfunction and Depression in Primary Caregiver of Pediatric Patients with Disabilities

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### Abstract

**Introduction:** Primary caregivers (PC) health and psychological well-being, in cases of children with disabilities must be studied for the high impact on life quality of both, caregivers and children. Our objective was to analyze the epidemiological profile of children with disabilities and their primary caregiver (PC), determine the presence and severity of depression in the PC, measures the burden degree of the PC and estimate the presence of family dysfunction.

**Patients and methods:** A total of 110 disabled children at the Pediatric Hospital of XXI Century National Medical Center were included. The degree of depression, the burden level in primary caregiver and the presence of family dysfunction was determined. The degree of disability (DS) and time of disease evolution were registered too.

**Results:** The median age of the PC was 37 years, 72.7% were mothers, 22.7% had depression, 43.6% had burden and 11.8% presented family dysfunction. Patients with DS had an average of 9 years old (3-17). Burden degree was associated with time of evolution ( $p = 0.048$  [95% CI, 1.1-13]), depression degree ( $p = 0.0001$  [95% CI 3.22-43.36]) and sensory impairment grade ( $p = 0.02$  [95% CI: 0.04 to 0.9]).

**Conclusions:** PC depression and burden should be investigated routinely in all cases of children with DS to ensure the physical, psychological and social well-being of the primary caregiver for the important consequences in his familiar and own health.

### Keywords

Disability, Caregiver burden, Depression, Primary caregiver

Disability is divided into four groups; *sensory and communication disabilities*: alteration of any of the senses; speech, sight, hearing. *Motor*: mobility impairment either partial or complete. *Mental*: cognitive or intellectual impairment. *Multiple*: to have two or more disabilities [4]. According to the degree of severity is classified as *mild*: the patient is independent, and can perform self-care activities without help, such as dressing, grooming, bathing, etc. *Moderate*: The patient is moderately independent, they can perform some self-care activities unassisted, but requires help with others. *Severe*: the patient is totally dependent [5-8].

The DS is present in approximately one billion people, 15% of the world population. The Global Burden of Disease estimates about 975 million people with DS (9.4%), of these, 95 million are children and 13 million have severe DS [2]. Low resources family children and those belonging to ethnic minority groups have greater risk of DS [3].

In Mexico there are 5,739,270 people with DS, 520,369 of these are children between 0-14 years old and 58.2% are boys. From the total, 58.3% have DS to walk and move, 27.2% visual DS, 12.1% hearing DS, 8.3% to talk or communicate DS, 5.5% is to attend personal care, 4.4% is to pay attention or learn and 8.5% is mental retardation [4,5].

Depression prevalence in Mexican mothers is about 66%, with primary caregivers between 31 to 40 years old accounting for 9.1% [9]. Mexico primary caregiver overloads of people with cognitive impairment was 58% [10]. Villanueva in 2015 in Mexico reports 48% of caregiver burden syndrome in relatives of geriatric patients in a secondary hospital [11].

Due to the conditions presented by the country, with an increase in children with disabilities, and then the care is provided by a family member in most cases; the purpose of this study was to identify the presence of depression in the PC of a disabled patient, the degree of overload, family functioning, epidemiological characteristics and if it is association with the type of disability.

### Introduction

Disability (DS) is a generic term that include deficiencies, activity limitations and participation restrictions in the interaction between illness people with other people and environmental factors [1-3].

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## Material and Methods

### Participants

This was a cross-sectional study developed in a reference Tertiary care Pediatric Medical Unit, located in the XXI Century National Medical Center from México, Distrito Federal 2013. Included patients were referred from south of the country, including patients in Genetics, Neurology, Otorhinolaryngology, Ophthalmology, Orthopedics, Rehabilitation and Urology services, presenting one or multiple DS.

A sample size for proportions was calculated with a 95% confidence interval and an 80% statistical power. The sample was conformed of 110 patients without previous burden, depression and family dysfunction.

PC who assumed this role from the patient's diagnosis, with consultation in the previously mentioned services was included and informed consent signed. Patients with uncertain or fatal prognosis were excluded, considering the last as a confounding variable difficult to exclude.

PC with a month hospital stay in the previous three months, involved in a recent death situation, depression in the past year, job loss, recent divorce or PC disease were excluded too.

Informed consent signature was requested to the PC and sociodemographic data certificate.

### Procedures

**Ethical considerations:** All participants signed an informed consent to participate in the study and the pediatric hospital local investigation committee, in attachment to the current ethics regulations, authorized the research.

### Questionnaires

Four different instruments assessed questions about PC role:

1. Interview of Zarit of caregiver burden [12-14], from which the population was classified at zero charge (less than 23 points), mild burden (24-30 points) and severe burden (more than 41 points).

2. Self-administered questionnaire of depression. The Beck questionnaire evaluates different levels of depression or Dysthymia [15]. 1-16 points: absence; 17-20 points: mild; 21-30 points: moderate and > 31 points: severe. This scale was applied and validated in Mexican people with a Cronbach of 0,89 [16].

3. Zung questionnaire is an instrument of 20 self-applicable items with the same objective as Beck questionnaire with 25-49 points meaning absence, 50-59 points: mild, 60-69 points: moderate and > 70 points as severe [17].

4. Family APGAR (Adaptability, Partnership, Growth, Affection, Resolve [18] was designed to explore the familiar functionality [19], assesses five components (adaptability, cooperation, development, problem resolution and affective response capacity) measure both the emotional environment surrounding patients and household capacity to deal with various crises. It is validated in the Mexican population [19,20]. According to their score, family function is stratified into 7-10: absence of dysfunction, 4-6: mild dysfunction and 0-3: severe dysfunction.

The research group developed a three sections questionnaire. The first section includes PC demographic data, including age, gender, origin, education, marital status, occupation and relationship with DS children. The second section is the DS children data such as age, gender, DS time of evolution and origin of it. The last section includes the four instruments used, Zarit, Beck, Zung and Apgar which have been tested and validated in Mexican population.

### Data analysis

It was performed with SPSS version 21.0 for Windows. Measures

**Table 1:** Sociodemographic characterization of primary caregiver and pediatric patients with DS.

Variable	N	Extreme values or percentages
Primary caregiver		
Age in years (md)	37	18-72
Sex		
Female	93	84.5
Male	17	15.5
Marital status		
Single	12	10.9
Married	61	55.5
Cohabiting	22	20
Divorced	11	10
Widower	4	3.6
Relationship		
Mother	80	72.7
Father	17	15.5
Grandmother/Grandfather	11	10
Others	2	1.8
Pediatric patients with DS		
Age	9 years	3-17 years
Sex		
Female	60	54.5
Male	50	45.5
Disabilities type		
Sensory and communication	25	22.7
Motor	25	22.7
Mental	25	22.7
Multiple	35	31.8
Degree of disability		
Mild	35	31.8
Moderate	36	32.7
Severe	39	35.5
Time disability		
Less than one year	15	13.6
More or equal than one year	95	86.4

of central tendency and dispersion for continuous variables were determined. Hypothesis testing was performed by Chi [2] test and considered significant when  $p < 0.05$ . For disability groups, Fisher test was applied. The Pearson correlation was applied among variables, and concordance between two depressions scales were estimated by kappa index.

### Results

Table 1 shows the sociodemographic data of PC and patients with DS. PC age interval was between 18 and 72 years, with a median of 37 years. PC were females in 75.5%; 75.5% married and 20% cohabiting. The main PC was the mother in 72.7%.

DS patients age range between 3 and 17 years, with median of 9 years. In each type of DS except multiple, 25 patients were included. The degree of DS was mild in 31.8%, moderate in 32.7% and severe in 35.5%. As for the time of evolution of DS only 13.6% had less than one year diagnosis and 86.4% more than a year.

For depression, burden and family dysfunction variables (Table 2) a 22.7% percentage of depression was obtained with Beck and Zung scale, with a correlation of 97% ( $Rho = 0.9$ ). The most frequent was mild depression in 12 PC. 56.4% of PC resulted without burden with Zarit questionnaire, and 30% resulted in intense burden. An 80.9% of PC was reported normo-functional according to the family Apgar and 11.8% with mild dysfunction.

Bivariate analysis was performed (Table 3) between depression, family burden and family dysfunction with DS time. Burden and time of DS was associated significantly ( $p = 0.048$  [95% CI, 1.1-13]). Bivariate analysis between depression and burden is significant too ( $p = 0.0001$  [95% CI 3.22-43.36]) (Table 4).

To assess the outcome variables impact and the type of DS T Student test was applied, since the Shapiro Wilk test revealed normal. In sensory DS prevalence of depression was observed with a statistically significant low frequency compared to other groups ( $p = 0.02$  [95% CI: 0.04 to 0.09]) (Table 5). The correlation between burden caregiver and depression level (beck and Zung) was  $r = 0.48$  p

**Table 2:** Questionnaires results.

Variable	N	Extreme values or percentages
BECK (Depression)		
Absence	85	77.3
Mild	12	10.9
Moderate	10	9.1
Severe	3	2.7
ZUNG (Depression)		
Absence	85	77.3
Mild	19	17.3
Moderate	6	5.5
Severe	0	0
ZARIT (Burden)		
No burden	62	56.4
Mild burden	15	13.6
Intense burden	33	30
APGAR (Family)		
Normo-functional	89	80.9
Mild dysfunction	13	11.8
Severe dysfunction	8	7.3

**Table 3:** Variables association.

Variable	Burden	No burden	p value [IC 95%]
*Disability time			
> 1 year	35	41	
< 1 year	11	11	0.09 [0.24-0.56]
*Depression			
Depression	19	4	
No depression	19	48	< 0.01 [0.24-0.5]
Family dysfunction			
With	12	3	
Without	26	49	< 0.01 [0.10-0.4]

\*Time of disability, depression and burden was taken as outcome variables.

**Table 4:** Association between depression and disability degree.

Disability Degree	Depression degree (ZUNG)				P
	No depression	Mild	Moderate	Severe	
Mild	30	4	1	0	0.386
Moderate	28	5	3	0	0.397
Severe	27	10	2	0	0.154

**Table 5:** Association between depression and disability type.

Variable	No depression N 85 (%)	Depression N 26 (%)	p value
Mixed	28 (33)	7 (27)	0.3
Motor	17 (20)	8 (31)	0.1
Mental	17 (20)	8 (31)	0.1
Sensory	23 (27)	2 (7)	0.02

Presence of depression was taken as outcome variable.

= 0.0001, with family dysfunction  $r = 0.34$   $p = 0.001$  (Table 6).

## Discussion

Health policies in Mexico have directed their efforts to determine the number of people with DS and their characteristics, but there are still areas of opportunity in the investigation of families of children with DS [6-8].

Most of the support comes from family or social networks. Relying only in informal support may have adverse consequences for caregivers, like psychological and emotional stress, isolation and loss of socio-economic opportunities. These difficulties increase, as the family members get older. In the United States, families of children with development DS, work fewer hours than other families, are more likely to lose their jobs, have more serious economic problems and are less likely to be incorporated into a new job [8].

The World Health Organization in 1999, defines the primary caregiver (PC) as "a person of the environment of a patient who voluntarily assumes the role of responsible for it in a broad sense without remuneration for their services; [1]. This individual is willing

**Table 6:** Association of variables according to the type of disability.

	Sensory	Motor	Cognitive	Mixed	p*
Caregiver data					
Caregiver age <sup>†</sup>	37.3 ± 10.7	37 ± 8.6	36.7 ± 8.8	41.3 ± 11.6	0.06
Sex					
Male	0	5	3	5	0.1
Female	20	14	16	27	
Relationship					
Mother	19	13	14	20	0.02
Other	1	6	5	12	
Civil status					
Married / cohabiting	13	13	14	26	0.5
single	6	6	5	6	
Support networks					
Yes	3	1	3	21	0.00
No	17	18	16	11	
Another child in care					
Yes	7	8	18	16	0.004
No	13	11	1	16	
Patient data					
Child age					
Patient sex					
Male	10	8	8	13	0.55
Female	10	11	11	19	
Disability degree					
Severe	1	6	2	28	0.001
Moderate	2	10	9	4	
Mild	17	3	8	0	
Disability time					
More than one year	19	17	12	28	0.03
Less than one year	1	2	7	4	
Zung questionnaire					
Moderate depression	0	1	3	1	0.13
Mild depression	2	6	5	5	
CP burden					
Intense	3	7	6	9	0.6
mild	3	1	4	5	
Family APGAR					
severe dysfunction mild	0	2	2	1	0.6
dysfunction	2	3	2	3	
no dysfunction	12	14	15	28	
Beck questionnaire					
Severe	0	1	1	0	0.4
Moderate	1	3	3	2	
Mild	1	3	4	4	

<sup>†</sup>Student T test \*Chi square

to make decisions for the patient, addressing the basic needs of the same, either directly or indirectly [21].

Being PC has an impact on the degree of physical and mental stress of this person [22-25]. The presence of depression in PC varies from 46 to 59%, three times higher than the rest of the population [26-28], higher as more time is spent, sacrifice their own resources and activities [29], realize or supervise the work of the home and, in an increasing number, working out of home [4]. Greater overload impairs mental, social and physical health of the caregiver, most often presenting anxiety disorders and depression, more social isolation, family worsening economic situation, greater overall morbidity and included higher mortality than comparable population not overloaded disorders [30]. The presence of these events as the DS in families are classified as Para normative crises which requires that family roles are flexible and adapt to the conditions of the family member with DS, which affects changes in family functionality.

Knowledge of children with disabilities primary caregivers mental health, allows health systems to improve services and develop strategies to support the PC in their vital roles. Although in many societies the phenomenon of disability in children is common [1] there are few studies that explain the presence of depressive disorders and their relationship with burden in the children with disabilities PC, primarily the search for explanations related to the presence of family dysfunction is an emergent research topic in Mexico, mainly in the north [5].

DS children are a doubly vulnerable group, age and disease require ongoing monitoring and support of a PC who is exposed to

suffer emotional distress, depression, feeling of burden and even the possibility of developing familiar dysfunction [31-34], three situations that directly impact the quality of care that children with DS receive [35-37]. The role of the mother in the family *per se* is considered like a PC.

Globally these studies has focused mainly on elder caregivers, children with asthma or neurological disability, our study includes population of all socioeconomic strata and from different regions of Mexico to be performed in a Third level Concentration Hospital, plus it includes all types of disability so the findings are reproducible for different populations.

PC features are similar to other female studies, DS child mother [38-40], with couple, working age, which means that they have other responsibilities that could be affected by the need to care a DS patient [22,40]. The DS degree has a very similar distribution among the three groups, which is not consistent with that reported in the literature [4,40]. A total of 86% of patients have more than one year, this is because the median of age is 9 years and acute disease period was exceeded, in addition to the study group it is part of a captive population of outpatients of different specialties. In the depression diagnosis as a control measure for selection bias two questionnaires were applied and it was found a strong correlation between the Beck and Zung questionnaires ( $Kappa = 0.97$ ) [37,40], the Zung questionnaire puts more weight on the behavioral component. Depression was present in 22.7% of PC, which differs from reported in PC of patients with some form of DS [13-15] affecting PC of patients with motor and mental DS and less frequent in the group of sensory DS.

Furthermore the DS patient PC senses a burden on itself, and their capabilities to cope with care. We found that the majority (56%) consider not overwhelmed by the situation, while in the literature a higher level of overload is reported [27-30,37], and it is reflected in the homogeneity percentage in various types of DS (30-45%). This finding could be explained by the strong attachment and strength of mothers to the children problems, which makes them have great tolerance and temperance to the theoretical burden of caring for a DS child, but may also be due to the idiosyncrasies of Mexican race where the social role of the PC mother in any state of child health [36].

Family functioning was assessed using a questionnaire called the acronym APGAR [23]. In the study group, 81% were rated as normal functioning families and motor DS was the one with the highest percentage of family dysfunction by 27% without significant differences with other disabilities, which may account for the families flexibility of this sample to fit a member with a disability and carry out its basic functions without affecting the roles that members assume within the family system [32].

Although one might think that parents who besides the patient with disability had another child in their care, submit increased risk for depression, burden or family dysfunction, this association was not demonstrated; ( $p > 0.05$ ) neither the presence or absence of support networks, a factor influencing the presentation of depression, family dysfunction or burden and contrasting way in children with multiple DS, higher percentage of support networks was presented compared with the rest, coupled with lower frequency of depression, a situation which corroborates the theory of families with adequate functionality in Mexican society where support networks for patients with DS can overcome the presence of some Para normative crisis, being understood that this crisis is presented in an extraordinary way of the vital cycle of the family [28].

The time in which the family has been carrying DS patient determines a statistically significant estimated risk ( $p < 0.05$ ) for the presence of burden when it has been more than one year, not in that way for depression. It is necessary emphasize the presence of depression is associated with burden, which is consistent with literature which states that the mood disorder is found associated with the activity of care in general and a greater perception of burden [37-40]. This relationship still provides research opportunities in Mexico

and in the world within the population of children with DS, since it has prioritized questions on this subject in geriatric population or children with neurological diseases [32,33,36].

In the group with motor DS frequently exist less support networks, which could explain the higher frequency of family dysfunction, although it is not statistically significant ( $p > 0.05$ ). It does have clinical significance. Also the care of these patients warrants further physical exertion, it can hinder the transfer and attachment to the activities of support networks and encourage the abandonment of these. In the group with mental DS, evolution time was lower in relation to other disabilities, probably is associated to pathologies in our population (for example consequences of head injuries, neuroinfections, etc).

Sensory DS has a lower frequency compared to the other groups in the prevalence of depression, which could be explained as not all people with DS have the same disadvantages, and generally children with sensory DS are more independent from children with other DS [26].

While it is forthright that primary caregivers of children with sensory DS have less depression, it is clear that despite the manifestations of multiple DS are more severe, the family members have less depression than those who care for children with pure motor and mental disorders, most likely because they have more support, in contrast with surveys reported by the WHO [26].

As for the bivariate analysis between the degree of depression according to the Zung scale and degree of disability, no statistically significance was found, which is probably explained by a type 2 error. The type of disability relates to burden presence ( $p < 0.05$ ). Burden levels in Mexican population agrees with previous studies, 44% have some degree of charge, the most common of these is the intense burden 68%, which is consistent with previous studies in children with infantile paralysis [26,37].

The present study demonstrates that motor DS is associated with the presence of depression and burden on primary caregivers. Families with children with DS are able to adapt to these Para normative crises and recover their family roles.

## Financing

Own resources.

## Conflicts of Interest

The authors declare no conflict of interest.

## What is known about?

Studies about burden on informal caregivers have been conducted mainly in elder caregivers, children with asthma and neurological diseases.

Depression is three times more common in caregivers.

Family function tends to get lost in Para normative crises.

## What brings the Study?

The detection of depression, burden, and family function should be done routinely to all caregivers of patients in general. Motor disability determines a higher frequency of burden and depression. Families of children with DS tend to adapt better and regain their family function.

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