

# Loading the primary caregiver of paediatric cancer patients in the Cuban Institute of Oncology and Radiobiology

Mariuska Forteza Sáez<sup>1\*</sup>, Dra María del Carmen Llanta<sup>2</sup>, Jorge A Grau Abalo<sup>2</sup>, Débora García Socarrás<sup>1</sup> and Dra Migdalia Pérez Trejo<sup>1</sup>

<sup>1</sup>Department of Oncopedia, National Institute of Oncology and Radiobiology, Cuba

<sup>2</sup>Department of Psychology, National Institute of Oncology and Radiobiology, Cuba

## Abstract

**Introduction:** Cancer is a disease of high incidence among children and the patients need a caregiver during the treatment.

**Objective:** To describe the sociodemographic and clinical variables and assess the burden of the primary caregiver of children and adolescents hospitalized in the service Onco paediatrics the National Institute of Oncology and Radiobiology of Cuba (INOR) cancer.

**Materials and methods:** Exploratory, observational-descriptive study during January to December 2016 in the INOR. The universe consisted of all primary caregivers of paediatric patients who were admitted in the mentioned period, an intentional sample (248 caregivers) depending on the availability to participate in the investigation was taken. Summary measures for qualitative variables were used: absolute and relative frequencies and for evaluating the objective burden Zarit method was used. The analysis was performed with SPSS, version 21.0.

**Results:** There was a predominance of women with college degree education by caregivers. An intense overload mostly related to physical overload of carers in 90% was obtained.

**Conclusions:** Overloading may be closely related to both the impact of care, the complexity of the actions, time care, coping resources, physical and emotional state of the caregiver

## Introduction

Malignant neoplasms account for 2 to 5% of cancers in the world, the second cause of death in the subgroup from 0 to 4 years and the third in the group of 5 to 18 years, depending on the diagnosis. Worldwide, figures of 68% are reported for all cancer sites in children [1,2].

In Cuba, between 400 and 450 new cases are presented annually, according to the National Cancer Registry. Cancer patients have prolonged and complex treatments. They are based, mainly, on the administration of treatments such as chemotherapy and surgery independently, or combined among them, in the function of histology, clinical stage and the functional status of each patient [3,4].

With the diagnosis of a serious or prolonged illness, not only the patient has important changes in his life, but also the whole family dynamic has been affected by the physical and psychic repercussions of the disease. Its impact on the family can lead to painful and devastating effects. When the disease is cancer, the situation worsens, it is an entity that stigmatizes and is feared by the population, in virtue of the suffering it causes the patient and the family [5]. Hospitalization represents a crisis for the whole family. It is evident that the deprivation of daily activities, such as the function of hospitalization, the modification of the sensitive and relevant form of the behaviour of the patient and their closest relatives [6].

This situation in turn affects the risk of caregivers of physical and emotional problems. Many of them have the feeling of feeling physically and emotionally trapped, including feelings of guilt that can lead to claudication or inability to continue to meet the demands of their sick family member [7,8].

Caregivers are related to the physical, psychological and socioeconomic order, and the whole with stress and interference in the management of the disease.

It is why the authors of this research were given the task of evaluating the burden of primary caregivers; in the period from January 2014 to June 2015, in the Paediatrics Room of the Institute of Oncology and Radiobiology.

## General objectives

To describe the socio-demographic and clinical variables and to evaluate the burden of the primary caregiver of children and adolescents with cancer hospitalized in the Oncopedia service of the National Institute of Oncology and Radiobiology of Cuba (INOR).

## Patients and methods

An exploratory, observational-descriptive and cross-sectional study was conducted in the period from January 2014 to June 2015 in the Oncopedia service of the National Institute of Oncology and Radiobiology of Cuba.

**\*Correspondence to:** Dra Mariuska Forteza Sáez, Department of Oncopedia, National Institute of Oncology and Radiobiology, Cuba, E-mail: mforteza8324@gmail.com

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The universe was constituted by all the primary caregivers of pediatric patients who were admitted in the mentioned period, an intentional sample was taken (448 caregivers) according to the availability to participate in the research.

**Eligibility criteria were:** All primary caregivers of hospitalized cancer patients. That they agreed to participate in the study (informed consent).

**The exclusion criteria were :** Primary caregivers who did not want to participate in the study. That they did not have informed consent.

### Statistical methods

In the research, a survey prepared by the researchers of the subject was used to characterize the sociodemographic and clinical variables (age, sex, education, histological diagnosis, treatment used), and to evaluate the objective load the Zarit method was used. Summary measures were used for qualitative variables: absolute and relative frequencies. The analysis was performed with SPSS, version 21.0.

### Ethical aspects of the study

The consent of each caregiver who participated in the study was requested in written and verbal form, clarifying that their participation was totally voluntary and that they could stop answering the instrument at the time they considered it. The completion of the instrument was

done anonymously, using a file number only known by the authors of the investigation. The investigative tasks executed did not imply physical or psychic affectations to the participants.

### Results

A total of 448 primary caregivers of pediatric patients with malignant diseases in the selected period were evaluated; Of these, 118 presented a diagnosis of tumors of the central nervous system, followed by lymphomas and bone tumors, with an average time of disease progression of 1.7 years. The most used treatment modality was chemotherapy and 30% of patients received palliative care. Table 1.

The caregivers' average age was 35 years. Caregivers were mostly women (64%) and married (75.0%). Most of them had some college, college degree or higher (91.6%), did not receive help from other people for care (20.5%), Table 2.

Regarding the level of overload, it is observed that most of the caregivers showed an intense overload of 78.7%, while the remaining 20% perceive the light load, the most frequent relationship of the primary caregivers with the patient was the mother (63.2 %), followed by the father 27.2%, and the uncles by 4%. While the mother and father accounted for 63.2% and 27.2% respectively of the study population. Therefore, there is a direct relationship of overload with parents. Table 3.

**Table 1.** Histological diagnosis of paediatric patients and time of evolution of the disease

Histological diagnosis	No	%	Treatment			Time of evolution of the disease in years
			Chemotherapy	Radiotherapy	Surgery	
SNC tumours	118	26	100	118	90	1
Non-Hodgkin lymphoma	99	22	99	17	0	1,6
Hodgkin lymphoma	91	20	91	56	0	2
Osteosarcoma	54	12	54	0	54	1,8
Ewing's sarcoma	48	11	48	19	48	1,
Wilms' Tumour	20	5	20	6	20	3
Germ cell tumour	15	3,3	15	1	15	1,6
Neuroblastoma	3	0,7	3	0	3	2
Total	448	100	430	217	230	1,7

**Table 2.** Parent Demographics (N=448 families)

Caregiver characteristics	(n=448)
Age: (years)	35 (23-47)
Gender	
Female	287 (64%)
Male	161 (36%)
Employment situation	
Housewife	279(62.3%)
Employed	135(30.1%)
Unemployed	34(7.6%)
Education	
Less than high school diploma	6(1.3%)
High school diploma	32(7.1%)
Some college	246(54.9%)
College degree or higher	164(36.7%)
Marital status	
Married	336 (75.0%)
Divorced/widowed	55(12.4%)
Single	57 (12.7%)
Received help to take care of the child	
No	92 (20.5%)
Yes	356 (79.5%)

**Table 3.** Overload level according to kinship

Overload level	Relationship								Total
	Father %	Mother %	Brothers %		Uncles %		Stepmother %	Stepfather %	
No overload (22-46 points)	1 (0,2)	0 (0)	2	0,4	1	0,2	1	0,2	1 0,2 6(1.3)
Overload mild (47-55 points)	15 (3,3)	68 (15,2)	4	0,9	0	0	3	0,7	2 0,4 92(20)
Overload Intense (56-110 points)	106 (23,6)	215 (48)	0	0	17	3,8	0	0	12 2,7 350(78,3)
Total	122 (27,2)	283 (63,2)	6	1,3	18	4	4	0,9	15 3,3 448(100)

## Discussion

The present study results permit a broad discussion on how the cancer diagnosis and treatment in children affect caregivers' lives. The caregivers' average age (35 years) bordered on the age demonstrated in different studies of caregivers to children with cancer, as well as caregivers to children with tumors of the central nervous system, followed by lymphomas [9].

Among caregivers, women predominated, specifically the mother, compatible with other studies, in which female caregivers exceeded 70% [10-12].

In general, the mother believes that "nobody can rise up to her to take care, protect and see to her child's needs. Most caregivers (79.7%) were married/had a fixed partner – lower than for caregivers of children with brain tumor (93.3%) [13,14]. This lower rate can be due to the fact that, according to the Cuban Institute of Demographic and Statistics, the number of separations and divorces has been increasing in Cuba: in 2014, for every four weddings, one dissolution was registered [15,16].

As for employment, 62.3% did housework and 7.6% were unemployed, totaling 69.9% of caregivers without monthly income. Studies demonstrate that, when one of the children has cancer, employment contracts are broken due to the need for organization for child care and treatment, compromising family income [11]; many caregivers end up losing their job after the diagnosis, due to the difficulty to reconcile care and work activities [14]. Based on these data, the report on the caregivers' lack of need to remain absent from work is understandable (69.9%), as most informed they were housewives or unemployed. Despite the distancing mentioned in literature between other family members and the caregiver, caregivers also develop other activities, as most of them have other children, like in the present study with an average 2.7 children [17]. Also, 20.5% of caregivers did not receive help to take care of the sick child or see to treatment demands (resources, including time and money) [18].

Our findings regarding the existing correlation between the caregiver's average burden, are similar to findings of researchers who looked at symptoms/disorders in mothers to children recently diagnosed with cancer regarding their adjustment trajectory and concluded that symptoms/disorders are common among parents to children with cancer during treatment, and that psychosocial interventions should be used to enhance parents and children's long-term wellbeing.

It should be highlighted that mental health alone was responsible for 25.55% of this burden observed that mental health was also the domain that most collaborated with the care burden (24.0%).

## Conclusions

There was a predominance of females in caregivers, with a university level of education, and an age range between 30 and 45 years. The percentage of levels of overload in the caregivers reported that

most of them experienced intense overload. The analysis of overload according to kinship reveals that mothers and fathers experience mild and intense overload. The overload could be closely related to the impact dimension of care, the complexity of the actions, the time of care, the coping resources, the physical and emotional state of the caregiver.

## Conflicts of interest

No potential conflict of interest exists.

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