Original Article

Overload of the Primary Caregiver of Patients with Terminal Cancer

Sobrecarga del cuidador primario de pacientes con cáncer terminal

Irving G. Soriano-Ursúa,* Ricardo Castrejón-Salgado,** Laura Ávila-Jiménez,*** Marco A. León-Mazón,**** Cairo D. Toledano-Jaimes,*****
Cidronio Albavera-Hernández,* Cinthya Nayeli Medina-Galicia,* Elena Espín-Paredes.*

Summary

Objective: to identify associated factors and level of primary caregiver overload in patients with terminal cancer. **Methods:** cross-sectional analytical study, 151 primary caregivers of patients with terminal cancer were assessed, from May to November 2018, attending the Regional General Hospital No. 1 with Family Medicine of the Mexican Institute of Social Security in Cuernavaca, Morelos, Mexico. Overload was assessed using the Zarit Scale. Frequencies, percentages, medians and limits were calculated for the analysis. Variables were compared using the χ^2 or Fisher's exact and the statistical Mann-Whitney U test. Inferential statistics were performed by fitting a logistic regression model. **Results:** 33.77% of the primary caregivers had overload. Urologic and gynecologic cancer were related to greater overload of the caregiver. In the multivariate analysis it was found that when the primary caregiver is a child, the possibility of overburden increases 4.45 times more, as well as the fact of being a second and third degree relative (4.37 times); basic-high school and bachelor's degree schooling reduce the possibility of overburden by 89% and 93%, respectively. **Conclusions:** a significant number of primary caregivers presented overload, the associated factor was kinship, such overburden decreases when there is a higher academic preparation.

Keywords: Terminally Ill; Stress Psychological; Psychological Distress; Caregivers

Correspondence:
Marco Antonio León Mazón
E-mail: marco.leonm@imss.gob.mx

Resumen

Objetivo: identificar factores asociados y nivel de sobrecarga del cuidador primario de pacientes con cáncer terminal. **Métodos:** estudio transversal analítico, se evaluaron 151 cuidadores primarios de pacientes con cáncer terminal, de mayo a noviembre de 2018, atendidos en el Hospital General Regional con Medicina Familiar No. 1 del Instituto Mexicano del Seguro Social en Cuernavaca, Morelos, México. La sobrecarga se evaluó mediante la Escala de Zarit. Para el análisis se calcularon frecuencias, porcentajes, medianas y límites. Para la comparación entre variables se utilizó la prueba estadística de χ^2 o exacta de Fisher y U de Mann Whitney. Se realizó estadística inferencial mediante ajuste de un modelo de regresión logística. **Resultados:** 33.77% tenía sobrecarga del cuidador primario. El cáncer urológico y ginecológico se relacionó con mayor sobrecarga. En el análisis multivariado se encontró que cuando el cuidador primario es un hijo, aumenta 4.45 veces más la posibilidad de sobrecarga, así como el hecho de ser familiar de segundo y tercer grado (4.37 veces); la escolaridad básica-preparatoria y licenciatura reduce la posibilidad de sobrecarga un 89% y 93%, respectivamente. **Conclusiones:** un número importante de cuidadores primarios presentó sobrecarga, el factor asociado fue el parentesco, dicha sobrecarga disminuye cuando hay una mayor preparación académica.

Palabras clave: enfermo terminal, estrés psicológico, agotamiento psicológico, cuidadores

Introduction

Metastases are the leading cause of death from cancer. Terminal cancer is an advanced, gradual and irreversible pathology, which does not answer to curative medical treatments.[1,2]

According to statistics from the World Health Organization (who), cancer is one of the leading causes of death worldwide; in 2020 alone, nearly ten million people died,[1] highlighting lung cancer with 1.79 million of deaths, followed by colorectal cancer with 935,173, liver cancer with 830,180 and more than one million deaths from stomach, breast and esophageal cancer; 70% of these deaths occurred in low- and middle-income countries.[3]

In Mexico, during 2019, according to the National Institute of Statistics and Geography (inegi), 88,683 deaths due to malignant tumors were registered, which affect men and women, with a death rate per hundred thousand inhabitants by age group ranging from 4.48 in men and 3.71 in women in ages zero to nine years, to 1,140 in men and 674 in women, in people over 80 years of age.[4]

Terminal cancer affects both the patient and the family, and their environment, with physical, mental and socioeconomic repercussions.[5] Generally, it is only one person within the family group who takes or is assigned the role of primary caregiver.[6] The who defines primary caregiver as the person responsible for the patient, who makes decisions on behalf of the patient, covering the patient's needs, even neglecting his or her own interests, and health.[7] Therefore, it is possible for these caregivers to develop overload, which can be objective and subjective.[8] Objective overload refers to the concrete and visible negative results of the caregiver's role, while subjective overload refers to the feelings that the caregiver triggers, that is, the personal evaluation of the primary caregiver.[9]

It has been identified that overburden causes psychological morbidity in caregivers; sleep disorders are frequent in up to 72% of cases,[5,8] however, some authors point out that the degree of resilience in caregivers is a determining factor in their development.[6] Likewise, there are studies that show that personality traits also play an important role in the identification of caregivers at high risk of presenting overload; it has been reported that depressive traits and neurosis are associated with a greater possibility of presenting caregiver overload.[10] It has also been noted that the spiritual dimension is important.[11] Given this, caregivers need significant support, education about the disease and mental health care, as they are a key element for the patient.[12] Given this context, the aim of the present study was to evaluate the associated factors and the overload level of the primary caregiver of patients with terminal cancer.

Methods

Analytical cross-sectional study from May to November 2018, primary caregivers of patients with terminal cancer who were attended at the Regional General Hospital No. 1 with Family Medicine, of the Mexican Institute of Social Security (imss) in Cuernavaca, Morelos, Mexico participated. The study was conducted after voluntary acceptance and signing an informed consent. Primary caregivers over eighteen years of age, who were in charge of a patient with a diagnosis of terminal cancer and who was referred to the palliative care consultation, were included. Caregivers caring for two or more patients and caregivers caring for a patient with terminal cancer concurrent with another long-standing chronic degenerative disease were excluded. Reports

of those caregivers who decided to with-draw before completing the survey were eliminated. The sample size calculation was performed using the formula for the finite population existing in the census of 250 patients attending the palliative care consultation with a diagnosis of terminal cancer and a primary caregiver burden ratio of 47%, obtaining a total of 151 caregivers as the final sample. Participants were approached in the waiting area of the palliative care outpatient clinic and a non-probabilistic quota sampling was performed.

The Zarit primary caregiver burden scale was applied, an instrument with linguistic validation for the Mexican population with an internal consistency of up to 0.90 Cronbach's alpha;[13,14] with scores ranging from 22 to 110, with the following cut-off points: ≤ 46 points absence of overload; from 47 to 55 mild overload and ≥ 56 intense overload. The instrument is self-applied and consists of 29 items with five response options; each participant had thirty minutes to answer it, in an office where he/she remained, accompanied only by the applicator to solve doubts, without intervening in the participants' responses. The clinical and sociodemographic data, type of patient's cancer and time in charge of the primary caregiver were analyzed with the statistical package Stata v.13. Univariate analysis was performed to characterize the care-givers by means of qualitative variables using frequency and percentages, and for quantitative variables, median, and lower and upper limits. Bivariate analysis was used for quantitative variables with the Mann Whitney U test, and for qualitative variables, χ^2 and its equivalent for small samples Fisher's exact test, in all cases a p value < 0.05 was considered significant. A multiple logistic regression model was ad-justed with the predictors of the bivariate analysis. The present study was approved by the IMSS research ethics committee.

Results

According to the Zarit Scale, of the 151 primary caregivers, approximately one third were overburdened and two thirds were not overburdened, 63.58% of the caregivers lived with their partner, three out of ten participants were men. Overall, 21.85% reported caring for a patient with gastrointestinal and 32.45% with gyne-cologic cancers, the rest were distributed among other cancers. The average age of the primary caregiver was 45 years, the

Table 1. Sociodemographic and Clinical Characteristics of the Primary Caregivers of the Study

Variable	Frequency (n=151)	%
Primary Caregiver Load		
With overload	51	33.77
Without overload	100	66.23
Lives with a partner		
Yes	96	63.58
No	55	36.42
Gender		
Man	47	31.13
Woman	104	68.87
Schooling		
Illiterate	10	6.62
Basic	128	84.77
Higher Education	13	8.61
Kinship with the patient		
Spouse	56	37.09
Child	76	50.33
2nd and 3rd Degree Relative	19	12.58
Comorbidities		
Yes	57	37.75
No	94	61.25
Cancer Type		
Hematopoietic	21	13.91
Gastrointestinal	33	21.85
Gynecological	49	32.45
Urologic	24	15.89
Others	24	15.89

Variable	Median	Lower limit - Upper limit
Age, in years	45	18 - 89
Age of the patients, in years	62	3 - 92
Time of care , in months*	12	1 - 120

*Time served as primary caregiver for the terminally ill cancer patient.

average age of the terminally ill patient under care was 62, the median length of time in their care was 12 months (range 1-120 months), see Table 1.

Once classified by the Zarit Scale, the explored characteristics were contrasted between the group with overload and those without overload, finding that schooling had statistically significant differences when comparing these groups, caregivers with higher levels of education were less likely to have overload, as opposed to caregivers with lower levels of schooling.

Gender, kinship with the patient, presence or absence of comorbidities of the caregiver, type of cancer of the patient were not observed with statistically significant differences, urological cancer was the type of cancer that presented a higher proportion in the group with overload compared to the group without overload.

The medians of caregiver age, patient age and patient care time did not present statistically significant differences, see Table 2.

To identify whether there was an association between the variables, a logistic regression model was fitted for the association between caregiver overload, age, gender, schooling and kinship, these data are shown in Table 3; a statistically significant association was observed with the variables basic schooling, high school OR=0.11 (95% CI; 0.02-0.65, p=0.01) and higher education OR=0.07 (95% CI=0.007-0.64, p=0.01), the latter with a lower possibility of presenting the caregiver overload. Being a child OR=4.45 (95% CI; 1.53-12.93, p=0.005) or being a second- and third-degree relative OR=4.37 (95% CI; 1.12-16.98 p=0. 03) of the person with terminal cancer was significantly associated with an increased likelihood of caregiver overload after

adjusting for age, gender, schooling, kinship, personal pathological history of the caregiver, type of cancer and time of care by the primary caregiver, while the rest of the adjusted variables did not show statistically significant results.

Discussion

The primary caregiver has to put his or her needs first to meet those of the dependent person, which often affects his or her quality of life and emotional well-being.[2] It is documented that primary caregivers who present mental or emotional stress may be more likely to die from any cause, compared to those who are not primary caregivers, so it is essential to take care of the health not only of the sick but also of the caregivers.[15] In recent years the population of

Table 2. Sociodemographic and Clinical Characteristics of Primary Caregivers

Variable	Without overload n=100 n (%)	With overload n=51 n (%)	p Value*
Gender			
Man	34 (34)	13 (25.5)	0.285[Y]
Woman	66 (66)	38 (74.5)	
Schooling			
Illiterate	3 (3)	7 (13.7)	**0.048[y]**
Elementary, Junior High-School and High-School	87 (87)	41 (80.4)	
Higher Education	10 (10)	3 (5.9)	
Kinship			
Spouse	41 (41)	15 (29.4)	0.344[Y]
Child	48 (48)	28 (54.9)	
2nd and 3rd Degree Relatives	11 (11)	8 (15.6)	
Comorbidities			
No	87 (87)	44 (86.3)	0.901[Y]
Yes	13 (13)	7 (13.7)	
Cancer Type			
Hematopoietic	13 (13)	8 (15.7)	0.083[Y]
Gastrointestinal	27 (27)	6 (11.7)	
Gynecological	33 (33)	16 (31.4)	
Urologic	11 (11)	13 (25.5)	
Others	16 (16)	8 (15.7)	
Variable	Median (Lower limit - Upper limit)	Median (Lower limit – Upper limit)	p Value*
Age, in years	43 (19-89)	50 (18-79)	0.436[§]
Age of the patient, in years	62 (3-92)	62 (28-87)	0.890[§]
Time of care, in months*	12 (1-120)	18 (1-120)	0.215[§]

*Time served as primary caregiver for the terminally ill cancer patient
Abbreviations PPH: Personal Pathological History
Y Statistical test χ, Fisher's Exact, Mann-Whitney U test

the elderly has increased and this trend is expected to continue in Latin American countries, which has led to an increase in non-communicable diseases and the consequent need for more caregivers.[16-18] The identification of factors associated with primary caregiver overload can help decision-makers, based on scientific literature, to establish intervention measures in primary prevention and prevent

this phenomenon from occurring or from being quickly identified and its complications prevented.

It was observed in this study that one out of three primary caregivers presented overload, results similar to those of Valencia et al.,[19] who report a proportion of 31% in a study conducted in Nigeria, with 46.2% of intense and 36.2% mild overload,[20] these values vary

up to 60%;[21,22] in all the works referred to, overload was evaluated with the Zarit Scale; all are countries with different customs, traditions and health systems, which could explain the discordance in terms of prevalence.

Regarding the gender of the caregivers, in this study 68% were women, who accounted for 75% of the caregivers with overload; this is a constant in different parts of the world.[5,6] It is observed that despite cultural diversity on a global scale, women are the most common primary caregivers; within the Mexican context, women have represented in the traditional family the pillar of most of the basic family functions (care and protection, reproduction, affection and socialization), the overload as primary caregiver in women can represent the loss of their physical and emotional well-being, and can trigger family dysfunctionality, so it is important to identify this condition in the first level family care consultation and emphasize the formation of support networks and the distribution of work in families, as well as strengthening resilience mechanisms, role changes, among others.

In our results, gender, age, living or not with a partner, pathological history of the caregiver, type of cancer and time of care were not determining factors for overburden. It was found that if the caregiver takes care of a patient with urological cancer there is a greater possibility of overload; in the consulted literature no studies with similar results were reported. This study showed that if the primary caregiver is the child, the possibility of overburden increases 4.45 times more and that being a second- or third-degree relative where it increases 4.37 times more, this is similar to that reported by Chua et al.[23] who report that

Table 3. Associated Factors with the Caregiver Overload

Variable	OR adjusted	p Value	CI 95%
Age			
18-34	1	-	-
35-41	0.31	0.07	(0.08, 1.13)
42-52	1.56	0.46	(0.46, 5.21)
53-60	2.14	0.24	(0.59, 7.78)
61-89	1.29	0.72	(0.31, 5.34)
Gender			
Man	1	-	-
Woman	0.93	0.88	(0.36, 2.36)
Schooling			
Illiterate	1	-	-
Basic and High-School	0.11	**0.01**	(0.02, 0.65)
Higher Education	0.07	**0.01**	(0.007, 0.64)
Kinship			
Spouse	1	-	-
Child	4.45	**0.006**	(1.53, 12.93)
2nd and 3rd Degree Relative	4.37	**0.03**	(1.12, 16.98)
Comorbidities			
Yes	1	-	-
No	0.89	0.86	(0.27, 2.98)
Type of Cancer			
Hematopoietic	1	-	-
Gastrointestinal	0.79	0.74	(0.19, 3.21)
Gynecological	0.29	0.08	(0.07, 1.15)
Urologic	1.15	0.81	(0.35, 3.70)
Others	2.7	0.15	(0.68, 10.74)
Time of care, in months	0.99	0.304	(0.97, 1.00)

Multiple logistic regression model mutually adjusted for the variables expressed in the table.

most of those who presented overburden were children, with 43.8%. However, in the study by Kim et al.[10] being a spouse was related to greater overburden. With regard to schooling, it was determined that the higher the level of schooling, the lower the possibility of presenting overload. It has been considered in other studies that resilience, emotional state and support networks may influence overload.[6,22]

In our study, the age of the caregivers and the time spent in caregiving were not significantly different between the groups that presented overload and those that did not, it is noteworthy that there was no association since these are determining factors in the development of overload.

This study identified some limitations, including the inclusion of participants from a specific geographic area of the state of Morelos and a small sample size, which could limit the external validity of our findings. On the other hand, although some sociodemographic factors and history of the caregiver and the terminally ill patient were adjusted, it was unable to fit for other unmeasured confounding factors, such as the use of undeclared drugs, psychiatric disorders, and the presence of undiagnosed chronic diseases, among others.

Conclusions

It was observed that a significant number of primary caregivers presented overload. The associated factor with a greater possibility of suffering from caregiver overburden was being related to a child and having higher education was the protective factor. The results found suggest possible associations between primary caregiver overload, kinship with the sick patient and level of schooling; however, studies with greater methodological strength are needed to allow us to evaluate causality between these variables.

References

1. Organizacion Mundial de la Salud. Cancer: Datos y cifras Ginebra: 2021. [Internet]. [Citado 2021 Nov 22]. Disponible en: https://www.who.int/es/news-room/fact-sheets/detail/cancer
2. Caqueo-Urízar A, Segovia-Lagos P, Urrutia-Urritia U, Castillo C, Navarro-Lechuga E. Impacto de la relación de ayuda de cuidadores primarios en la calidad de vida de pacientes con cáncer avanzado. Psicooncología. 2013;10(1)(1696-7240):95-108.
3. International Agency for Research on Cancer. Cancer Today Francia 2020 [Internet]. [Citado 2021 Nov 22]. Disponible en: https://gco.iarc.fr/today/home
4. Instituto Nacional de Estadística y Geografía. Estadísticas a propósito del día mundial contra el Cáncer. [Internet]. [Citado 2021 Nov 22]. Disponible en: https://www.inegi.org.mx/contenidos/saladeprensa/aproposito/2021/cancer2021_Nal.pdf
5. Areia NP, Fonseca G, Major S, Relvas AP. Psychological morbidity in family caregivers of people living with terminal cancer: Prevalence and predictors. Palliative & supportive care. 2019;17(3):286-93.
6. Palacio C, Krikorian A, Limonero JT. The influence of psychological factors on the burden of caregivers of patients with advanced cancer: Resiliency and caregiver burden. Palliative & supportive care. 2018;16(3):269-77.
7. Galindo-Vázquez Ó, Meneses-Garcia A, Herrera-Gomez A, Caballero-Tinoco MdR, Aguilar-Ponce J. Escala Hospitalaria de Ansiedad y Depresión (HADS) en cuidadores primarios informales de pacientes con cáncer: propiedades psicométricas. Psicooncología. 2015;10(2-3):383-292.
8. Maltby KF, Sanderson CR, Lobb EA, Phillips JL. Sleep disturbances in caregivers of patients with advanced cancer: A systematic review. Palliative and Supportive Care. 2017;15(1):125-40.
9. St-Onge M, Lavoie F. The Experience of Caregiving Among Mothers of Adults Suffering from Psychotic Disorders: Factors Associated with Their Psychological Distress. American Journal of Community Psychology. 1997;25(1):73-94.
10. Kim H-H, Kim S-Y, Kim J-M, Kim S-W, Shin I-S, Shim H-J, et al. Influence of caregiver personality on the burden of family caregivers of termi-

nally ill cancer patients. Palliative and Supportive Care. 2016;14(1):5-12.
11. Spatuzzi R, Giulietti MV, Ricciuti M, Merico F, Fabbietti P, Raucci L, et al. Exploring the associations between spiritual well-being, burden, and quality of life in family caregivers of cancer patients. Palliative and Supportive Care. 2019;17(3):294-9.
12. Covarrubias Gomez Alfredo et al. Atención paliativa al final de la vida. Corporativo Intermédica, Ciudad de México, 2014.
13. Ramírez VJA. Validez de la Entrevista de Carga de Zarit en una muestra de cuidadores primarios informales. Psicología y salud. 2008;18:10-17.
14. Aguilar-Navarro SG, Mimenza-Alvarado AJ, Palacios-García AA, Samudio-Cruz A, Gutiérrez-Gutiérrez LA, Ávila-Funes JA. Validez y confiabilidad del MoCA (Montreal Cognitive Assessment) para el tamizaje del deterioro cognoscitivo en México. Revista Colombiana de Psiquiatría. 2018;47(4):237-43.
15. Schulz R, Beach SR. Caregiving as a risk factor for mortality: the Caregiver Health Effects Study. JAMA. 1999;282(23):2215-9.
16. Partida Bush V. La transición demográfica y el proceso de envejecimiento en México. Papeles de población. 2005;11:9-27.
17. Arredondo Garcia J, Carranza Rodríguez N, Vázquez Cruz M. Transicion epidemiológica. Acta Pediatr Mex. 2003;24(1):46-56.
18. Vera Bolaños M. Revisión crítica a la teoría de la transición epidemiológica. Papeles de población. 2000;6:179-206.
19. Valencia M, Meza O, Peéez C, Cortés C, Hernández O, Hernández P. Factores que interviene en la sobrecarga del cuidador primario del paciente con cáncer. Rev Calid Asist. 2017;32(4):221-5.
20. Akpan-Idiok PA, Anarado AN. Perceptions of burden of caregiving by informal caregivers of cancer patients attending University of Calabar Teaching Hospital, Calabar, Nigeria. Pan Afr Med J. 2014;18:159.
21. Yeh PM, Chang Y. Use of Zarit Burden Interview in analysis of family caregivers' perception among Taiwanese caring with hospitalized relatives. International journal of nursing practice. 2015;21(5):622-34.
22. Gonzalez Guerra A, Fonseca Fernandez M, Valladares Gonzalez A, López Angulo L. Factores moduladores de resiliencia y sobrecarga en cuidadores principales de pacientes oncológicos avanzados. Revista Finlay. 2017;7:26-32.
23. Chua CK, Wu JT, Wong YY, Qu L, Tan YY, Neo PS, et al. Caregiving and Its Resulting Effects-The Care Study to Evaluate the Effects of Caregiving on Caregivers of Patients with Advanced Cancer in Singapore. Cancers. 2016;8(11):105.