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Socio-demographic profile and burden on caregivers of cancer patients treated in a palliative care unit

Perfil socio-demográfico y sobrecarga del cuidador de pacientes oncológicos atendidos en una unidad de cuidados paliativos

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Abstract

The aim of this study was to determine the characteristics of caregivers associated with caregiver burden in the context of caring for cancer patients treated in a palliative care unit. The study was observational, correlational, and prospective. The study population consisted of 127 caregivers, all of whom were included in the study, so no sample was extracted. The average age of the caregivers was 41.28 years; 63.8% were women and 54.3% were single. In terms of educational level, 47.2% had higher education and 36.2% had secondary education. Regarding their relationship with the patient, 55.9% were children and 27.6% were other relatives, such as siblings, nephews, brothers-in-law, or grandchildren. Fifty-eight point three percent of caregivers showed some degree of overload; of these, 34 cases (26.8%) corresponded to mild overload and 40 cases (31.5%) to intense overload. The conclusions showed that there are characteristics associated with caregiver burden, including marital status and current employment. Both variables are significantly associated with caregiver burden. These results highlight the need for targeted interventions to improve the quality of life of caregivers and thereby reduce the burden on family caregivers of cancer patients.

Keywords: socio-demographic profile, caregiver burden, cancer patients

Resumen

En la presente investigación se propuso determinar las características del cuidador asociadas a la sobrecarga del mismo en el contexto del cuidado de pacientes oncológicos atendidos en una unidad de cuidados paliativos. El estudio fue observacional, correlacional y prospectivo. La población de estudio estuvo conformada por 127 cuidadores y se trabajó con ella en su totalidad, por lo que no se extrajo muestra. La edad promedio de los cuidadores fue de 41.28 años; el 63.8% eran mujeres y el 54.3% eran solteros. En cuanto al nivel educativo, el 47.2% tenía estudios superiores y el 36.2% contaba con estudios secundarios. Respecto a la relación con el paciente, el 55.9% eran hijos y el 27.6% eran otros familiares, como hermanos, sobrinos, cuñados o nietos. El 58.3% de los cuidadores presentaba algún grado de sobrecarga; de estos, 34 casos (26.8%) correspondían a una sobrecarga leve y 40 casos (31.5%) a una sobrecarga intensa. Las conclusiones evidenciaron que existen características asociadas a la sobrecarga del cuidador, entre ellas el estado civil y el trabajo actual del mismo. Ambas variables se asocian significativamente con la sobrecarga del cuidador. Estos resultados evidencian la necesidad de realizar intervenciones focalizadas a fin de mejorar la calidad de vida de los cuidadores y, con ello, reducir la carga en cuidadores familiares de pacientes oncológicos.

Palabras clave: perfil socio-demográfico, sobrecarga del cuidador, pacientes oncológicos

Introduction

The diagnosis of cancer enters abruptly into the lives of individuals, impacting not only those who experience physical and/or psychological decline but also their families and broader social contexts (Palma-Rivadeneira et al., 2022; Sánchez Ramírez & Silva Espín, 2024). The responsibility of caring for these patients often falls on a family member, who, motivated by love, tends to place their personal life on the back burner (Soriano Ursúa et al., 2022).

Palliative care is defined as “the comprehensive and active support of individuals of all ages with severe health-related suffering due to a serious illness, especially those nearing the end of life” (Radbruch et al., 2020). The primary goal is to enhance the quality of life for patients, their families, and caregivers through the early and

comprehensive identification, assessment, and management of biopsychosocial and spiritual suffering (Radbruch et al., 2020).

Globally, the demand for palliative care remains high (World Health Organization, 2023). Notably, the presence of a family caregiver is associated with an increased likelihood of receiving home-based palliative care (Kim et al., 2025). As articulated by the World Health Organization (2023), access to palliative care is critical for comprehensive healthcare and Universal Health Coverage; however, it remains insufficient or, in some cases, nonexistent in many parts of the world.

A study conducted by Kwadwo Anago, McFeely, Bayuo, Ngmenesegre Suglo, and Dueck Friesen (2025) concluded that caregiving is influenced by cultural expectations of family duty, often occurring in contexts marked by poverty and inadequate healthcare infrastructure. This scenario exposes caregivers to economic hardships, stress, physical health issues, and spiritual suffering. Despite these challenges, family members and friends remain willing to assist in caring for individuals with advanced cancer.

It is not uncommon for primary caregivers to develop a sense of burden, especially when the patient is in a terminal phase and death is imminent (Soriano Ursúa et al., 2022). Such individuals require complex palliative care interventions that alleviate clinical manifestations, bolster spiritual well-being, and enhance understanding of the illness and the dying process (Arias Tuapanta & Cusme Torres, 2021; Sánchez Ramírez & Silva Espín, 2024). This situation necessitates profound changes in the primary caregiver's life, who often sacrifices personal time and dedicates extensive hours to patient assistance, hindering their ability to balance caregiving with personal and social life (Amador Ahumada et al., 2020).

This imbalance negatively impacts caregivers' health, leading to psychological impairments such as stress, depression, and anxiety, along with feelings of helplessness, concentration difficulties, loss of interest in previously enjoyable activities, and sleep disturbances. Consequently, these issues deteriorate their quality of life and heighten feelings of despair. Additionally, this demographic often adopts harmful coping mechanisms, such as smoking and excessive drinking, as a means of escaping reality, particularly when financial resources dwindle due to job changes or healthcare costs (Miranda Do Vale et al., 2023; Sánchez Ramírez & Silva Espín, 2024).

Primary caregivers may also grapple with guilt stemming from negative emotions (anger, frustration, sadness, among others) associated with prolonged caregiving. The moral code often prevents them from expressing these feelings, leading caregivers to suffer in silence for fear of judgment or out of pride, even as they struggle to manage the burdens of their responsibilities (Miranda Do Vale et al., 2023; Sánchez Ramírez & Silva Espín, 2024).

Thus, it can be inferred that caregivers of oncology patients are vulnerable to experiencing caregiver burden, particularly when they take on caregiving roles without the necessary knowledge or skills (Amador Ahumada et al., 2020; Sánchez Ramírez & Silva Espín, 2024). Consequently, the scientific community has shifted its focus beyond patients to investigate the myriad variables influencing caregiver burden. This approach is essential for adequately identifying vulnerable populations (Hernández et al., 2024; Toffoletto & Reynaldos-Grandón, 2019) and for developing evidence-based policies or social programs that effectively address the true needs of this cohort (Sánchez Ramírez & Silva Espín, 2024).

Despite the growing interest in studies concerning caregiver burden among oncology patients, there remain significant limitations in the current body of evidence. Many studies focus on isolated aspects and fail to consider the multifaceted nature of the phenomenon, as well as the interplay between psychosocial, sociodemographic, and clinical variables (Semere et al., 2021). Furthermore, variability in research outcomes has hindered the generalization and application of effective interventions, underscoring the need for studies in more specific contexts and employing robust methodologies (Kavalieratos, Corbelli, & Zhang, 2016). While interventions have been designed to alleviate caregiver burden and have shown some improvements in quality of life and depression among caregivers, the impact on burden reduction remains inconsistent (Vun Kong & Chong Guan, 2019).

Yan et al. (2024) explored the efficacy of palliative care interventions aimed at addressing depression, quality of life, and caregiver burden among informal caregivers of patients with advanced cancer. Their findings indicated that while targeted palliative care interventions effectively improved informal caregivers' depression and quality of life, they did not significantly reduce their burden.

The available national and international evidence has thus far highlighted the sociodemographic and psychosocial characteristics of caregivers and the clinical conditions of patients as variables associated with caregiver burden. However, the multifactorial nature of the phenomenon and variability in outcomes (Amador Ahumada et al., 2020; Hernández et al., 2024; Sánchez Ramírez & Silva Espín, 2024; Toffoletto & Reynaldos-Grandón, 2019) necessitate the execution of a study aimed at accurately determining the caregiver characteristics associated with the burden faced by caregivers of oncology patients receiving care in a palliative care unit.

This inquiry aims to illuminate significant factors contributing to caregiver burden within the context of palliative care in oncology and underscores the need for more precise investigations into the psychosocial and clinical variables contributing to this challenging reality. Therefore, the primary objective of this research is to identify the characteristics of caregivers associated with caregiver burden among oncology patients in a palliative care unit. This will provide clear evidence to inform the design of policies and new support programs tailored to the local realities of caregivers, ultimately contributing to improvements in the quality of life for both patients and their caregivers, thereby alleviating the burden they experience.

Methodology

The study employed an observational, correlational, and prospective design. The study population consisted of 127 caregivers of patients with oncological diseases receiving care at the Palliative Care Unit of the Regional Institute of Neoplastic Diseases (IREN) Center from July to December 2023. No sample size calculation was performed as the entire population was included. Caregivers over 18 years old of both sexes who consented to participate in the study were included, while those who declined were excluded.

Data collection was accomplished via survey using a questionnaire. The caregiver characteristics considered included age, sex, marital status, education level, and relationship to the patient. To assess caregiver burden, the Zarit Caregiver Burden Scale was utilized (Felipe Silva et al., 2021), which consists of 22 items evaluating three dimensions: care impact, interpersonal burden, and self-efficacy expectations. The scale demonstrated acceptable reliability (intraclass correlation coefficient (ICC) greater than 0.71 in its original study and various validations) and internal consistency (Cronbach's alpha greater than 0.85).

A database was established using SPSS version 25, which underwent a record consistency check—this involved the classification and cleaning of records for subsequent statistical analysis. Measures of central tendency (mean) and dispersion (standard deviation) were calculated for quantitative variables, while qualitative variables were represented by absolute and relative frequencies (%). The Chi-square test was employed to determine the relationship between caregiver characteristics and burden, using a significance level of 5%. Results were presented in simple and double tables, utilizing Microsoft Excel 2016.

Results

The findings reveal (in Table 1) that the average age of caregivers was 41.28 years, with 63.8% being female and 54.3% single. Regarding educational background, 47.2% reported having higher education, while 36.2% had completed secondary schooling. In terms of their relationship with the patient, 55.9% were children, and 27.6% were other relatives, such as siblings, nephews, in-laws, or grandchildren.

Table 1

Characteristics of caregivers for oncology patients treated in a palliative care unit.

Caregiver data	n	%
Age ($\bar{x}$ ± DS)	41.28 ± 11.9	
Sex		
Male	46	36.2%
Female	81	63.8%
Marital Status		
Single	69	54.3%
Married	25	19.7%
Divorced	12	9.4%
Widowed	4	3.1%
Cohabitant	17	13.4%
Education Level		
No Education	2	1.6%
Primary	19	15.0%
Secondary	46	36.2%
Higher	60	47.2%
Relationship to Patient		

Mother	2	1.6%
Father	3	2.4%
Child	71	55.9%
Spouse	14	11.0%
Private Nurse	2	1.6%
Other	35	27.6%
Current Employment		
Yes	78	61.4%
No	49	38.6%
Total	**127**	**100%**

Note. x̄ = Mean; DS = Standard Deviation

Regarding Table 2, it shows that 50.4% of caregivers experience some degree of burden. Among these, 36 cases (28.3%) report mild burden, and 28 cases (22.0%) indicate severe burden.

Table 2

Caregiver burden of oncology patients treated in a palliative care unit.

Caregiver burden	n	%
No burden	63	49.6%
Burden	64	50.4%
Mild burden	36	28.3%
Severe burden	28	22.0%
Total	**127**	**100%**

With respect to Table 3, it shows that marital status (p = 0.005) and current employment (p = 0.001) are significantly associated with caregiver burden.

Table 3

General characteristics associated with caregivers for oncology patients treated in a palliative care unit.

Caregiver data	Caregiver burden						p*
	No burden		Mild burden		Severe burden		
	n	%	n	%	n	%	
Age (x̄ ± DS)	38.4 ± 11.9		43.2 ± 11.2		45.3 ± 11.7		
Sex							
Male	23	36.5%	12	33.3%	11	39.3%	0.884
Female	40	63.5%	24	66.7%	17	60.7%	
Marital Status							
Single	41	65.1%	16	44.4%	12	42.9%	
Married	3	4.8%	12	33.3%	10	35.7%	
Divorced	7	11.1%	1	2.8%	4	14.3%	**0.005**
Widowed	2	3.2%	2	5.6%	0	0.0%	
Cohabitant	10	15.9%	5	13.9%	2	7.1%	
Education Level							
No Education	2	3.2%	0	0.0%	0	0.0%	
Primary	6	9.5%	5	13.9%	8	28.6%	0.087
Secondary	19	30.2%	16	44.4%	11	39.3%	
Higher	36	57.1%	15	41.7%	9	32.1%	
Relationship to Patient							
Mother	1	1.6%	1	2.8%	0	0.0%	
Father	1	1.6%	1	2.8%	1	3.6%	
Child	35	55.6%	19	52.8%	17	60.7%	0.636
Spouse	5	7.9%	3	8.3%	6	21.4%	
Private Nurse	1	1.6%	1	2.8%	0	0.0%	
Other	20	31.7%	11	30.6%	4	14.3%	

Current Employment							
Yes	49	77.8%	16	44.4%	13	46.4%	**0.001**
No	14	22.2%	20	55.6%	15	53.6%	
Total	**63**	**100%**	**36**	**100%**	**28**	**100%**	

Note. x̄ = Mean; DS = Standard Deviation // * Chi-square Test

Regarding the general characteristics associated with the dimensions, the caregiver impact dimension revealed that associated characteristics included marital status (p = 0.031) and current employment (p = 0.000), as shown in Table 4.

Table 4

General characteristics associated with the caregiver impact dimension for oncology patients treated in a palliative care unit.

Caregiver data	Caregiver impact						p
	No burden		Mild burden		Severe burden		
	n	%	n	%	N	%	
Age (x̄ ± DS)	37.7 ± 11.5		42.5 ± 12.2		46.5 ± 10.4		
Sex							
Male	21	36.8%	19	47.5%	6	20.0%	0.06
Female	36	63.2%	21	52.5%	24	80.0%	
Marital Status							
Single	37	64.9%	18	45.0%	14	46.7%	
Married	3	5.3%	12	30.0%	10	33.3%	
Divorced	5	8.8%	5	12.5%	2	6.7%	**0.031**
Widowed	2	3.5%	1	2.5%	1	3.3%	
Cohabitant	10	17.5%	4	10.0%	3	10.0%	
Education Level							
No Education	2	3.5%	0	0.0%	0	0.0%	
Primary	4	7.0%	8	20.0%	7	23.3%	0.062
Secondary	18	31.6%	18	45.0%	10	33.3%	
Higher	33	57.9%	14	35.0%	13	43.3%	
Relationship to Patient							
Mother	0	0.0%	1	2.5%	1	3.3%	
Father	1	1.8%	1	2.5%	1	3.3%	
Child	31	54.4%	19	47.5%	21	70.0%	0.251
Spouse	4	7.0%	6	15.0%	4	13.3%	
Private Nurse	1	1.8%	1	2.5%	0	0.0%	
Other	20	35.1%	12	30.0%	3	10.0%	
Current Employment							
Yes	46	80.7%	21	52.5%	11	36.7%	**0.000**
No	11	19.3%	19	47.5%	19	63.3%	
Total	**57**	**100%**	**40**	**100%**	**30**	**100%**	

x̄ = Mean; DS = Standard Deviation // * Chi-square Test

Based on the general characteristics associated with the dimensions, the findings revealed that in the dimension of interpersonal relationships, the relevant characteristics included marital status (p=0.000), educational level (p=0.02), and current employment (p=0.013), as illustrated in Table 5.

Table 5

General characteristics associated with the interpersonal relationship dimension of caregivers for oncology patients treated in a palliative care unit.

Caregiver data	Interpersonal Relationship						p*
	No burden		Mild burden		Severe burden		
	N	%	n	%	n	%	
Age (x̄ ± DS)	37.3 ± 11.6		44.1 ± 10.8		45.5 ± 11.7		

Sex							
Male	20	33.9%	14	37.8%	12	38.7%	0.877
Female	39	66.1%	23	62.2%	19	61.3%	
Marital Status							
Single	38	64.4%	20	54.1%	11	35.5%	
Married	2	3.4%	9	24.3%	14	45.2%	
Divorced	5	8.5%	4	10.8%	3	9.7%	**0.000**
Widowed	4	6.8%	0	0.0%	0	0.0%	
Cohabitant	10	16.9%	4	10.8%	3	9.7%	
Education Level							
No Education	0	0.0%	1	2.7%	1	3.2%	
Primary	6	10.2%	7	18.9%	6	19.4%	**0.020**
Secondary	15	25.4%	16	43.2%	15	48.4%	
Higher	38	64.4%	13	35.1%	9	29.0%	
Relationship to Patient							
Mother	1	1.7%	1	2.7%	0	0.0%	
Father	1	1.7%	0	0.0%	2	6.5%	
Child	37	62.7%	17	45.9%	17	54.8%	0.558
Spouse	5	8.5%	5	13.5%	4	12.9%	
Private Nurse	1	1.7%	1	2.7%	0	0.0%	
Other	14	23.7%	13	35.1%	8	25.8%	
Current Employment							
Yes	44	74.6%	20	54.1%	14	45.2%	**0.013**
No	15	25.4%	17	45.9%	17	54.8%	
Total	**59**	**100%**	**37**	**100%**	**31**	**100%**	

Note. x̄ = Mean; DS = Standard Deviation // * Chi-square Test

Regarding the dimension of self-efficacy expectations, no association was found with the caregiver characteristics, as the p-value exceeded 0.05, as shown in Table 6.

Table 6

General characteristics associated with the self-efficacy expectations dimension of caregivers for oncology patients treated in a palliative care unit.

Caregiver data	**Self-Efficacy Expectations**						
	No burden		**Mild burden**		**Severe burden**		p*
	n	%	N	%	n	%	
Age (x̄ ± DS)	41.1 ± 11.5		39.5 ± 12.3		44.8± 12.2		
Sex							
Male	19	31.1%	16	38.1%	11	45.8%	0.427
Female	42	68.9%	26	61.9%	13	54.2%	
Marital Status							
Single	33	54.1%	25	59.5%	11	45.8%	
Married	8	13.1%	8	19.0%	9	37.5%	
Divorced	8	13.1%	2	4.8%	2	8.3%	0.274
Widowed	3	4.9%	1	2.4%	0	0.0%	
Cohabitant	9	14.8%	6	14.3%	2	8.3%	
Education Level							
No Education	2	3.3%	0	0.0%	0	0.0%	
Primary	6	9.8%	7	16.7%	6	25.0%	0.278
Secondary	20	32.8%	18	42.9%	8	33.3%	
Higher	33	54.1%	17	40.5%	10	41.7%	
Relationship to Patient							
Mother	2	3.3%	0	0.0%	0	0.0%	0.099

Father	1	1.6%	2	4.8%	0	0.0%	
Child	29	47.5%	23	54.8%	19	79.2%	
Spouse	7	11.5%	4	9.5%	3	12.5%	
Private Nurse	0	0.0%	2	4.8%	0	0.0%	
Other	22	36.1%	11	26.2%	2	8.3%	
Current Employment							
Yes	40	65.6%	27	64.3%	11	45.8%	0.218
No	21	34.4%	15	35.7%	13	54.2%	
Total	**61**	**100%**	**42**	**100%**	**24**	**100%**	

Nota. x̄ = Mean; DS = Standard Deviation // * Chi-square Test

Discussion

Oncology patients receiving care in palliative settings require continuous support from family members, who must adjust their daily routines to meet the health needs of the patient. Generally, this role is assumed by children, parents, or partners, who, motivated by love, take on caregiving responsibilities without proper preparation, professional guidance, or support networks. It is therefore not surprising that a significant proportion of informal caregivers experience “burden” (Felipe Silva et al., 2021; Villa Clavijo et al., 2023).

In this context, it is crucial to establish the sociodemographic profile of these caregivers in order to delineate at-risk populations and implement evidence-based interventions. In our study, 50.4% of caregivers reported experiencing some form of burden (28.3% mild and 22% severe) despite the implementation of the National Comprehensive Cancer Care Plan 2020-2024, which includes objectives related to the creation and dissemination of training programs for families and caregivers (National Comprehensive Cancer Care Plan, 2021).

Toffoletto and Reynaldos-Grandón (2019) reported similar findings among family caregivers of oncology patients in Chile, where 58.8% experienced some degree of burden, particularly intense burden (37.5%). This predominance is attributed to the systematic labor involved in caregiving and a lack of regulation, impeding personal projections and diminishing quality of life. Soriano-Ursúa et al. (2022) in Mexico and Hernández et al. (2024) in Colombia found lower frequencies of caregiver burden, at 33.7% and 35.1%, respectively. All studies employed the Zarit Burden Scale to assess caregiver burden, suggesting that discrepancies in percentages may be influenced by health culture, healthcare assistance systems, customs, and traditions of different countries, as well as the presence of a secondary caregiver.

Regarding the sociodemographic profile, marital status and current employment were significantly associated with caregivers experiencing burden. A predominance was noted among single caregivers and those who are economically active. This may be due to a lack of experience in household organization and caregiving, coupled with the demands of dual roles (Hernández, Muñoz, & Sánchez, 2024; Felipe, J., Partezani, & Pecchi, 2021). Many studies differ from these findings; for instance, Soriano-Ursúa et al. (2022) and Hernández et al. (2024) disputed the correlation between variables, identifying age, socioeconomic status, origin, and education level as factors linked to caregiver burden in informal caregivers of patients with advanced cancer.

Additionally, the association between sociodemographic profile and dimensions of caregiver burden was assessed. Current employment was related to the dimension “impact of caregiving on the caregiver,” while marital status, education level, and current employment were associated with the dimension “interpersonal relationship.” No variables were linked to the dimension “caretaker self-efficacy expectations.” The first association is grounded in the changes caregiving entails for work dynamics, often leading to imbalances that adversely affect both physical and mental health. The subsequent associations are rooted in the quest for support networks and the lack of teamwork; typically, one individual bears the entire responsibility, which limits time for self-care and improvements in quality of life (Arias-Rojas et al., 2021).

Single caregivers with lower levels of education may not seek support from their social environment or institutions due to a lack of knowledge, ego, or fear of judgment (Felipe Silva et al., 2021; Miranda do Vale et al., 2023; Sánchez Ramírez & Silva Espín, 2024). Furthermore, having a job restricts the time available to build such connections or initiate the search for caregiver training programs and support services (Arias-Rojas et al., 2021; Hernández et al., 2024.

Conclusions

The results indicate that the burden among family caregivers of oncology patients in palliative care at the Instituto de Enfermedades Neoplásicas de Nivel II-E Junín, Peru, is significant and is primarily associated with sociodemographic factors such as marital status and the caregiver's employment condition. Understanding these characteristics allows for more precise identification of at-risk populations and the development of appropriate support strategies tailored to their needs.

It is important to note that this research is not free from limitations, as no studies linking sociodemographic profiles with dimensions of caregiver burden were found. This lack of existing literature should not be seen as a barrier but rather as an opportunity to highlight the needs for future research. Additionally, it is crucial to clarify that the associations presented do not imply causality, and the findings should not be generalized to other contexts and populations, as they only represent the studied cohort.

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