

Sociodemographic Determinants of Burden and Resilience among Caregivers of Children Diagnosed with Cancer: A Cross-sectional Study

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ABSTRACT

Introduction: Caregiving encompasses various challenges and adversities, with resilience playing a crucial role in navigating these hurdles. However, resilience is influenced by individual characteristics, prompting an examination of how demographic variables impact resilience and caregiver burden among caregivers of cancer patients in India.

Aim: To investigate the relationship between demographic variables and resilience, as well as caregiver burden, among caregivers of cancer patients in India.

Materials and Methods: In this cross-sectional study, a clinical sample of 125 caregivers {males (46.4%) and females (53.6%)} from Indraprastha Apollo Hospital, New Delhi, India was assessed. Resilience was measured using the Connor-Davidson Resilience Scale (CD-RISC), while caregiver burden was evaluated using The Burden Assessment Schedule (BAS). Various demographic factors, including gender, age, qualification, socio-economic status, loss of work, number of children, travel for treatment, duration of treatment, type of illness, and employment status, were examined. T-tests and Analysis of Variance (ANOVA) were utilised for data analysis.

Results: The predominance was of female caregivers, comprising 67 (53.6%) individuals, primarily falling within the age bracket of 30-40 years demographic variables significantly influenced resilience levels among caregivers (p-value ranged from 0.001 to 0.86). However, caregiver burden was not significantly impacted by demographics overall (p-value ranged from 0.24 to 0.98), although certain sub-domains were affected. Notably, male caregivers demonstrated higher levels of resilience compared to females ($T=9.88$, $p=0.001$), with postgraduate qualifications correlating with increased resilience (mean: 17.02) and lower caregiver burden (mean: 81.53). Additionally, age did not significantly affect the results (effect size ranged from 0.10 to 0.86).

Conclusion: The study underscores the importance of tailored support strategies for caregivers, particularly focusing on enhancing resilience among female caregivers and addressing specific burden dimensions affected by demographic factors of socio-economic status and qualification. Overall, resilience was affected by gender, socio-economic status, number of children, travel, duration of treatment, and employment significantly, but caregiver burden was not significantly affected by any demographic variable.

Keywords: Cancer care facilities, Demographic analyses, Family caregiver, Psychological resilience

INTRODUCTION

Cancer remains a significant global health issue, affecting millions of individuals and their families each year. The most common types include Acute Lymphoblastic Leukaemia (ALL) (26%), brain and central nervous system tumours (21%), neuroblastoma (7%), and Non-Hodgkin's Lymphoma (NHL) (6%) [1]. A study by Arora RS et al., in 2021 estimated approximately 52,366 annual cases, far surpassing the previously projected 28,712 cases, with the number rising to 76,805 when including adolescents, indicating potential underdiagnosis. Despite medical advancements prolonging children's lives, caregiving profoundly impacts caregivers [2,3]. Families often provide comprehensive home care due to high hospital costs and a preference for shorter stays [4]. Caregivers manage daily activities, medication, and medical appointments, leading to a significant burden [5,6].

Caregiver burden refers to the stress that comes from caregiving duties, including physical, emotional, and financial challenges [7]. Research shows that caregivers' stress levels are influenced by patients' emotional symptoms and demographic factors such as gender, age, and treatment history [8]. Some caregivers, despite the demands, exhibit effective functioning, indicating resilience. Resilience, the ability to achieve positive outcomes despite adversity, emphasises strengths over weaknesses [9]. Insufficient resources can lead to adverse outcomes or increased caregiving challenges. Resilience involves

managing stressors and adapting to adversity, drawing on individual, environmental, and life resources [9]. Families thriving amid a child's illness often emphasise open communication, shared understanding, flexibility, attachment, and balance as coping mechanisms [10].

Several factors influence the severity of care burden in family caregivers, including socio-economic status, the number of caregivers, disease type and duration, and cancer stage [11,12]. Additional factors contributing to care burden include employment limitations, reduced family finances, and lack of support and training [13]. Educational status also affects caregiver resilience and burden, with higher education levels correlating with lower care burden [14], although some studies report conflicting findings [15,16]. Education may equip caregivers with better coping skills, while lower education levels may coincide with limited resources and increased socio-economic strain [17]. Gender does not significantly impact perceived caregiver resilience [18], yet women, often the primary caregivers, may experience higher care burden [19]. Income inadequacy exacerbates caregiver burden, especially with prolonged caregiving duration [20]. Resilience may be age-related, with older caregivers exhibiting higher resilience, although some studies report conflicting findings [21-23]. Younger caregivers may experience increased burden due to caregiving interference with personal and social activities [24]. Spousal caregivers often demonstrate higher resilience, although findings vary [22,25].

Higher resilience scores among informal caregivers correlate with lower caregiver burden levels [26], while low resilience is associated with increased burden and decreased quality of life [27]. Family caregivers, predominantly patients' partners, experience varying levels of caregiver burden, with younger, highly educated caregivers reporting higher burden and lower resilience [24]. A scoping review consisting of 18 studies shows that demographic factors are of key importance in dealing with caregiving adversities of children diagnosed with cancer. The current body of research on caregiver burden and resilience among caregivers of children diagnosed with cancer lacks insights into the interplay of various socio-demographic factors within the Indian context. The present study is novel as it explores caregiver burden and resilience in relation to specific demographic variables such as age, gender, education, employment status, loss of work, types of cancer, siblings, and treatment duration. Moreover, most of the existing research focuses on Western contexts, leaving a significant gap in understanding these dynamics within the sociocultural framework of India. Understanding these relationships can provide valuable insights for developing targeted support systems and interventions tailored to the specific needs of caregivers. Additionally, this knowledge can inform policymakers and healthcare providers about the distinct challenges faced by caregivers, enhancing the overall care for children diagnosed with cancer [28].

MATERIALS AND METHODS

The present cross-sectional study, utilising a within-subject design, was conducted during the Coronavirus Disease-2019 (COVID-19) pandemic from June 2021 to July 2022. A total of 125 participants, serving as caregivers for children diagnosed with cancer, were recruited from the Department of Paediatric Oncology at Indraprastha Apollo Hospital in New Delhi, India. The study was conducted with the approval of the Institute's Ethics Committee (Reference No IAH-BMR-028/11-19 dated 14/12/2019). Informed written consent was obtained from all participants.

Inclusion and Exclusion criteria: Inclusion criteria stipulated that primary caregivers must have resided with and provided care for the child for a minimum of six months, be aged over 18 years, and possess proficiency in either Hindi and/or English. Exclusion criteria included professional or paid caregivers, those with significant medical or psychiatric illnesses, and caregivers whose care recipients resided in nursing homes.

Sample size calculation: A prior power analysis was conducted, suggesting a sample size of 99 participants to achieve 80% power with a 0.05 significance level using ANOVA. Based on this estimation, 125 participants were ultimately enrolled in the study.

Study Procedure

Participants were recruited by identifying eligible individuals at the hospital. The purpose of the study was thoroughly explained to potential participants, confidentiality was assured, and informed consent was obtained before administering the measures. Efforts were made to establish rapport with respondents, addressing any doubts or concerns about the study. Participants were instructed on the questionnaire procedures, emphasising the importance of completing all items and ensuring the confidentiality of their responses. It was reiterated that the information collected was solely for research purposes.

The study measured various parameters, including socio-demographic factors (age, gender, educational qualifications, employment status, loss of work, types of cancer, presence of siblings, and treatment duration), caregiver burden, and resilience. These parameters were assessed using validated questionnaires and scales, ensuring the reliability and validity of the data collected.

Measures: Resilience was evaluated using the CD-RISC, a measure designed to assess one's capacity to withstand various life stressors including change, personal challenges, illness, pressure, failure, and distressing perceptions [29]. Originally adapted by

Chinese scholars, the scale has demonstrated favourable reliability and validity [30,31]. In present study, the CD-RISC-10 [29], a condensed version derived from the original 25-item CD-RISC, was employed to evaluate mental resilience over the preceding month. This abbreviated assessment comprises 10 items, each prompting respondents to rate their level of agreement on a 5-point Likert scale, ranging from 0 (not true at all) to 4 (true nearly all the time). Subsequently, scale scores ranging from 0 to 40 were calculated by summing item ratings, with higher scores indicating a heightened capacity for resilience. Cronbach's alpha was 0.63.

The BAS was utilised to evaluate both subjective and objective measures of burden experienced by caregivers over the past month in present study. Originally developed for chronically ill mental patients, particularly those with schizophrenia, the BAS is a 40-item scale designed by Thara R et al., at the Schizophrenic Research Foundation (SCARF) [32]. It encompasses nine distinct domains assessing caregiver burden. Each item on the BAS is rated on a 3-point scale, yielding scores ranging from 40 to 120, with higher scores indicating greater burden. The scale demonstrates good internal consistency, with an alpha coefficient of 0.80, and its validity has been established through comparisons with the Family Burden Schedule (FBS) [33]. It evaluates burden across seven areas, including financial burden, patient behaviour, social relations, caregiver health, caregiver occupation, leisure, and emotional burden. The scale has been validated against the FBS, with correlations ranging from 0.71 to 0.82 for most items. Cronbach's alpha was found to be 0.94.

STATISTICAL ANALYSIS

Data analysis for present study was performed using Statistical Package for Social Sciences (SPSS) software version 28.0. Initial data processing included managing missing data, identifying outliers, and computing descriptive statistics to prepare for further analysis. Paired sample t-tests were utilised to compare caregiver burden and resilience scores before and after the specified period of care. ANOVA was employed to analyse mean differences across various demographic categories, such as age, gender, educational qualifications, employment status, types of cancer, presence of siblings, and treatment duration. Descriptive statistics were also used to summarise the socio-demographic characteristics of the participants.

RESULTS

Descriptive statistics: The sample demographics revealed a predominance of female caregivers, comprising 67 (53.6%) individuals, primarily falling within the age bracket of 30-40 years [Table/Fig-1]. Most caregivers possessed a graduate or postgraduate degree, accounting for 86 (68.8%) participants, with a significant portion hailing from middle socio-economic backgrounds 70 (56%) participants [Table/Fig-1].

Demographics	Category	Frequency (n)	
Gender	Male	58	46.4
	Female	67	53.6
Age (years)	20-30	21	16.8
	30-40	76	60.6
	40-60	28	22.6
Qualification	Schooling	37	29.6
	Graduate	52	41.6
	Above graduation	36	28.8
Socio-economic status	Less than 30000	33	26.4
	30000-69000	70	56
	70000 plus	22	17.6
Loss of work	Yes	86	68.8
	No	39	31.2

Siblings	0	9	7.2
	1-2	92	73.6
	More than 2	24	19.2
Travel	Less than 10 km	12	9.6
	10-20 km	68	54.4
	More than 20 km	45	36
Duration of treatment	Initial phase	9	7.2
	Middle phase	63	50.4
	Terminal phase	53	42.4
Types of illness	Acute lymphoblastic leukaemia	49	39.2
	Non-hodgkin's lymphoma	28	22.4
	Sarcoma	09	7.2
	Wilms tumour	08	6.4
	Retinoblastoma	12	9.6
	Hepatoblastoma	19	15.2
Employment status	Yes	31	24.8
	No	94	75.2

[Table/Fig-1]: Sample demographics.

The types of illnesses among the paediatric patients encompassed a range of conditions, including hepatoblastoma, retinoblastoma, Wilms Tumour, Sarcoma, NHL, and ALL. The dataset was complete, with no instances of missing data, and outliers were not detected. For a comprehensive overview, descriptive statistics, including means and the number of participants for all variables [Table/Fig-2,3].

Results revealed that resilience was found to be significant for gender, socio-economic status, the number of children, travel for treatment, duration of treatment, and employment ($p < 0.001$). Overall, Caregiver Burden was insignificant for each demographic variable ($p > 0.05$), while some sub-dimensions of caregiver burden were significant for some demographics as detailed in [Table/Fig-2,3]. Patient (child) behaviour was significant for gender ($p < 0.05$). Socio-economic status was significant for patient (child) behaviour ($p < 0.05$), taking responsibility $\{f(122)=3.18, p < 0.05\}$, and other relations sub-dimensions $\{f(122)=4.08, p < 0.05\}$. The number of children was significant for patient (child) behaviour $\{f(122)=3.92, p < 0.05\}$, and other relations $\{f(122)=5.18, p < 0.01\}$. Travel was significant for other relations $\{f(122)=4.78, p < 0.01\}$, and physical and mental health burden $\{f(122)=4.17, p < 0.01\}$.

Further analyses suggested that fathers (mean; 20.14), aged 30-40 (mean; 15.93), with above PG qualifications (mean; 17.24), belonging to the upper class (mean; 24.18), not losing working hours due to caregiving (mean; 15.97), having only one child (cancer diagnosed patients) (mean; 26.33), traveling 10-20 km for treatment (mean; 19.47), having their children in the initial phase of treatment (mean; 22.56), diagnosed with Wilms tumour (mean; 17.29), while employed (mean; 23.26) showed the most resilience in their respective groups.

DISCUSSION

Caring for a child diagnosed with cancer poses significant challenges and stressors for caregivers. Understanding the role

Parameters	Category	N	Resilience (Total)	Spouse-related burden	Physical mental health burden	External support burden	Caregiver routine burden	Support of patient	Taking responsibility burden	Other relations	Child behaviour	Caregiver strategy	Caregiver burden (Total)
Gender	Male	58	20.14 (3.84)	10.16 (1.54)	12.28 (2.11)	9.41 (2.08)	9.78 (1.49)	5.16 (1.21)	8.78 (1.39)	8.93 (1.35)	8.19 (1.90)	8.64 (1.31)	81.16 (4.90)
	Female	67	12.03 (5.29)	10.13 (1.38)	12.58 (2.32)	9.15 (2.28)	9.52 (1.53)	5.55 (1.52)	8.54 (1.50)	8.73 (1.20)	8.78 (1.76)	8.46 (1.21)	81.13 (5.09)
p-value			0.001	0.93	0.44	0.50	0.35	0.11	0.36	0.83	0.04	0.44	0.98
Age(years)	20-30 y	21	15.43 (4.97)	10.19 (1.72)	12.19 (2.44)	9.05 (2.78)	9.48 (2.01)	5.29 (1.15)	8.81 (1.27)	8.71 (2.07)	8.24 (1.27)	8.76 (1.26)	80.43 (5.91)
	30-40 y	76	15.93 (6.24)	10.18 (1.46)	12.63 (2.10)	9.04 (2)	9.82 (1.39)	5.39 (1.36)	8.76 (1.18)	8.76 (1.74)	8.68 (1.18)	8.71 (1.33)	81.62 (4.67)
	40-50 y	24	15.29 (7.44)	9.92 (1.25)	12.21 (2.52)	9.88 (2.01)	9.38 (1.34)	5.25 (1.65)	8.13 (1.46)	8.96 (2.01)	8.17 (1.46)	8.08 (0.97)	79.79 (5.02)
	50-60 y	04	18 (2.71)	10.50 (1.29)	11.50 (1.29)	11.25 (2.22)	8.75 (1.50)	6 (2)	8.75 (1.89)	9.75 (1.29)	8.50 (1.89)	9 (.82)	84 (4.32)
p-value			0.86	0.83	0.62	0.10	0.34	0.78	0.28	0.44	0.58	0.21	0.24
Qualification	10 th	22	13.86 (6.32)	10.05 (1.49)	12.41 (2.17)	9.82 (2.06)	8.91 (1.82)	5 (1.51)	8.32 (1.96)	8.59 (1.42)	8.32 (1.96)	8.14 (1.42)	79.36 (5.32)
	12 th	15	14.53 (7.56)	10.13 (1.12)	13.60 (1.84)	8.13 (2.32)	9.67 (1.54)	5 (1.46)	8.27 (1.71)	8.80 (1.26)	8.93 (1.71)	9.20 (1.26)	81.33 (3.31)
	Graduate	52	15.87 (6.46)	10.19 (1.60)	12.54 (2.40)	9 (2.20)	9.69 (1.50)	5.71 (1.30)	8.75 (1.84)	8.79 (1.19)	8.58 (1.84)	8.58 (1.19)	81.63 (4.95)
	Postgraduate (PG)	34	17.24 (4.80)	10.21 (1.39)	11.82 (2.01)	9.94 (2)	9.97 (1.22)	5.26 (1.38)	8.91 (1.90)	8.97 (1.13)	8.35 (1.90)	8.38 (1.13)	81.53 (5.44)
	Above Postgraduate (PG)	2	20 (1.41)	9 (0)	12 (1.41)	7.50 (.71)	10.50 (.71)	5 (1.41)	8 (0)	10 (0)	8 (0)	10 (0)	80 (2.82)
p-value			0.24	0.84	0.14	0.03	0.11	0.19	0.42	0.57	0.83	0.04	0.46
Socioeconomic status(INR)	Less than 30000	33	7.88 (3.04)	10.42 (1.46)	12.97 (2.49)	8.82 (2.42)	9.55 (1.64)	5.88 (1.43)	8.09 (1.59)	8.33 (.95)	8.79 (1.82)	8.52 (1.20)	81.15 (4.78)
	30000-69000	70	16.89 (3.07)	10.16 (1.43)	12.40 (2.03)	8.46 (2.04)	9.60 (1.45)	5.21 (1.47)	8.76 (1.33)	8.93 (1.29)	8.69 (1.91)	8.51 (1.28)	81.43 (5.18)
	Above 70000	22	24.18 (2.08)	10.68 (1.46)	11.77 (2.27)	9.36 (2.31)	9.91 (1.54)	5.09 (.81)	9.14 (1.39)	9.23 (1.44)	7.50 (1.30)	8.68 (1.29)	80.23 (4.72)
p-value			0.001	0.18	0.14	0.38	0.64	0.04	0.02	0.02	0.02	0.85	0.62
Loss of work	Yes	86	15.17 (6.12)	10.27 (1.47)	12.15 (2.73)	9.49 (2.15)	9.81 (1.45)	5.36 (1.43)	8.57 (1.47)	8.72 (1.32)	8.33 (1.89)	8.50 (1.26)	80.97 (5.13)
	No	39	15.97 (6.40)	9.87 (1.40)	13.08 (1.98)	8.79 (2.21)	9.26 (1.58)	5.38 (1.31)	8.82 (1.39)	9.05 (1.15)	8.90 (1.67)	8.64 (1.24)	81.54 (4.67)

p-value			0.82	0.16	0.03	0.05	0.03	0.93	0.37	0.18	0.11	0.62	0.55
Employment	Yes	31	23.26 (2.28)	9.84 (1.52)	12.10 (2.31)	9 (2.27)	9.77 (1.50)	5.23 (.99)	8.97 (1.35)	9.06 (1.34)	7.87 (1.86)	8.68 (1.22)	80.42 (5.05)
	No	94	13.33 (4.96)	10.24 (1.46)	12.55 (2.19)	9.36 (2.16)	9.60 (1.52)	5.41 (1.51)	8.54 (1.47)	8.74 (1.24)	8.71 (1.79)	8.50 (1.27)	81.38 (4.97)
p-value			0.001	0.18	0.32	0.43	0.57	0.51	0.16	0.23	0.03	0.50	0.35
Total		125	15.79 (6.18)	10.14 (1.45)	12.44 (2.22)	9.27 (2.18)	9.64 (1.51)	5.37 (1.39)	8.65 (1.45)	8.82 (1.27)	8.50 (1.84)	8.54 (1.25)	81.14 (4.98)

[Table/Fig-2]: Descriptive and inferential statistics. Values presented as mean±Standard Deviation (SD)

Dimensions	Category	n	Resilience (Total)	Spouse-related burden	Physical mental health burden	External support burden	Caregiver routine burden	Support of patient	Taking responsibility burden	Other relations	Child behaviour	Caregiver strategy	Caregiver burden (Total)
Children	Single child	9	26.33 (1.12)	10.22 (1.39)	11.44 (2.55)	9.67 (2.74)	10 (1.50)	5 (1.12)	8.56 (1.67)	9.33 (1.66)	6.89 (.93)	8.33 (1.50)	79.44 (6.31)
	1-2	92	17.20 (3.84)	10.05 (1.45)	12.45 (2.14)	8.43 (2.06)	9.62 (1.56)	5.26 (1.35)	8.82 (1.31)	8.96 (1.26)	8.62 (1.84)	8.58 (0.22)	81.46 (5.02)
	2+	24	6.46 (2.24)	10.46 (1.47)	12.79 (2.36)	8.67 (2.39)	9.58 (1.35)	5.92 (1.56)	8.04 (1.76)	8.13 (.90)	8.67 (1.83)	8.50 (1.32)	80.58 (4.28)
p-value			0.001	0.18	0.14	0.30	0.76	0.09	0.06	0.01	0.02	0.84	0.43
Travel	Less than 10 km	12	19.08 (6.67)	10.33 (1.15)	10.67 (1.56)	10.42 (2.11)	9.67 (1.43)	4.50 (.90)	9.08 (1.56)	9.17 (1.47)	7.50 (1.24)	8.75 (.96)	80 (2.56)
	10-20 km	68	19.47 (3.38)	9.99 (1.56)	12.50 (2.10)	9.16 (2.02)	9.71 (1.38)	5.35 (1.34)	8.91 (1.32)	9.04 (1.30)	8.59 (1.88)	8.60 (1.22)	81.59 (5.52)
	20+ km	45	9.36 (3.59)	10.33 (1.34)	12.82 (2.36)	9.15 (2.38)	9.53 (1.73)	5.62 (1.51)	8.13 (1.49)	8.40 (1.07)	8.64 (1.86)	8.40 (1.37)	80.78 (4.58)
p-value			0.001	0.41	0.01	0.16	0.84	0.04	0.01	0.01	0.14	0.59	0.50
Duration of Treatment	Initial	9	22.56 (7.83)	10 (1.50)	11 (2.29)	9.67 (3)	10.33 (1)	5.11 (1.05)	8.56 (1.74)	8.78 (1.39)	7.11 (2.15)	8.44 (1.59)	79 (7.07)
	Middle	63	19.08 (3.32)	9.95 (1.54)	12.43 (2.13)	9.43 (1.98)	9.67 (1.41)	5.14 (1.33)	8.78 (1.31)	9 (1.34)	8.54 (1.81)	8.62 (1.22)	81.32 (5.02)
	Terminal	53	10.74 (4.63)	10.40 (1.32)	12.70 (2.26)	9.02 (2.27)	9.49 (1.67)	5.68 (1.48)	8.51 (1.56)	8.62 (1.15)	8.70 (1.75)	8.47 (1.25)	81.30 (4.53)
p-value			0.001	0.25	0.10	0.51	0.30	0.10	0.60	0.28	0.05	0.80	0.41
Type of illness	ALL	50	16.26 (5.97)	10.12 (1.35)	12.50 (1.97)	9.14 (2.14)	9.68 (1.56)	5.38 (1.95)	8.68 (1.43)	9 (1.56)	8.30 (1.85)	8.32 (1.96)	80.74 (1.87)
	NHL	29	15.69 (6.45)	10.38 (1.45)	11.93 (2.26)	9.69 (2.39)	9.66 (1.09)	5.41 (1.84)	8.48 (1.48)	8.62 (1.85)	8.66 (1.98)	8.86 (1.67)	81.31 (2.56)
	Sarcoma	9	15.56 (7.20)	9.44 (1.74)	12.56 (2.83)	8.33 (2.34)	10.89 (1.56)	5.44 (1.94)	8.56 (1.52)	8.11 (2.56)	8.44 (1.83)	8.56 (2.76)	80.33 (4.87)
	Wilms tumour	14	17.29 (3.44)	10.57 (0.76)	12.57 (1.30)	10.14 (1.77)	8.93 (2.67)	5.43 (1.86)	8.71 (0.67)	9 (2.86)	8.36 (0.67)	8.57 (92.23)	82.29 (3.87)
	Hepatoplastoma	19	15.16 (4.56)	9.79 (1.55)	13.37 (2.39)	8.63 (2.14)	9.21 (1.65)	5.37 (2.76)	8.74 (3.67)	8.84 (1.98)	8.37 (1.47)	8.68 (1.56)	82 (3.64)
	Retinoblastoma	4	9 (6.58)	10.50 (1.72)	10.25 (2.24)	10 (1.90)	10.75 (1.96)	4.50 (2.45)	9 (1.24)	9 (1.64)	6.50 (2.65)	8.25 (1.98)	78.75 (4.87)
p-value			0.29	0.37	0.11	0.20	0.02	0.90	0.98	0.43	0.08	0.57	0.73

[Table/Fig-3]: Descriptive and inferential statistics.

of demographic variables in influencing resilience and caregiver burden among caregivers of paediatric cancer patients is crucial for developing targeted interventions and support systems. The present cross-sectional study aimed to explore the impact of various demographic factors on resilience and caregiver burden among caregivers in India.

The study found significant differences in resilience based on gender among caregivers of paediatric cancer patients. Male caregivers exhibited higher levels of resilience compared to female caregivers (M=20.14 vs. F=12.03, p<0.001). However, the effect size was substantial (d=1.73). This finding was in contrast with the findings of Toledano-Toledano F et al., and Street AF et al., who suggested that females were more resilient or that gender does not impact resilience [18,34]. Regarding caregiver burden dimensions, no significant differences were observed between male and female caregivers across most dimensions. However, there was a significant difference in the “child behaviour” dimension (p=0.04), where male caregivers reported lower burden compared to female caregivers, aligning with Schrank B et al., [19]. The effect

size for this difference was moderate (d=0.44). The analysis also indicated no significant differences in resilience levels or caregiver burden across different age groups of caregivers (p>0.05). This suggests that age does not appear to be a significant factor influencing either resilience or caregiver burden among caregivers of paediatric cancer patients, contrasting studies that suggest age does have an impact, such as Opsomer S et al., [23].

The analysis revealed a significant effect of caregivers’ educational qualifications on resilience (p=0.03) and caregiver burden (p=0.04). Specifically, caregivers with postgraduate qualifications demonstrated the highest resilience scores (M=17.24) and relatively lower caregiver burden scores (M=81.53) compared to other educational groups. Conversely, caregivers with qualifications below the postgraduate level exhibited lower resilience scores and higher caregiver burden scores. These findings suggest an association between higher educational attainment and better resilience, aligning with the findings of Arab M et al., as well as reduced caregiver burden among caregivers of paediatric cancer patients [15].

The present study revealed a significant effect of socio-economic status on resilience ($p=0.001$) and certain dimensions of caregiver burden. Specifically, caregivers from above-middle-class backgrounds exhibited the highest resilience scores ($M=24.18$), while those from below-poverty backgrounds had the lowest resilience scores ($M=7.88$). Furthermore, dimensions such as external support burden, caregiver routine burden, support of the patient, and taking responsibility burden showed significant differences across socio-economic groups ($p<0.05$). These findings suggest that socio-economic status plays a crucial role in determining resilience levels and various aspects of caregiver burden among caregivers of paediatric cancer patients, aligning with the findings of Nemati S et al., [20].

The present study indicated that the loss of work due to caregiving responsibilities did not significantly affect overall resilience levels among caregivers ($p=0.82$). However, it had a significant impact on certain dimensions of caregiver burden, including physical and mental health burden, external support burden, and taking responsibility burden ($p<0.05$). Specifically, caregivers who reported experiencing work loss demonstrated higher scores in these burden dimensions compared to those who did not experience work loss. This suggests that while the loss of work may not directly influence resilience levels, it does contribute to increased caregiver burden in specific areas, aligning with the findings of Bialon LN and Coke S, [13].

The findings of present study suggested that caregivers' resilience levels significantly varied based on the number of children they had, with caregivers of a single child showing the highest resilience. This may be attributed to the more focused distribution of their emotional and physical resources, allowing for better coping mechanisms and support. Conversely, caregivers with multiple children might face more divided attention and resources, reducing their resilience as suggested by Theng B et al., [35]. Interestingly, the number of children did not significantly impact most aspects of caregiver burden, except for "other relations" and "child behaviour." Caregivers with 1-2 children reported slightly higher burden scores in these areas, potentially due to the additional demands of managing relationships and the behaviour of multiple children simultaneously, contradicting Adib-Hajbaghery M and Ahmadi B, who suggested that the number of children significantly affects caregiver burden [14]. This suggests that while the overall caregiver burden may not be heavily influenced by the number of children, specific relational and behavioural stressors are more pronounced for those with more children.

The present study also indicated a significant link between the duration of travel for treatment and both caregiver resilience and

burden. Caregivers traveling over 20 kilometers for treatment experienced higher levels of burden in areas such as physical and mental health, external support, and taking responsibility. This heightened burden could be due to the increased time, energy, and financial resources required for long-distance travel, which can intensify stress and reduce available support as suggested by Sav A et al., [36].

The present study revealed that the duration of treatment significantly impacted both caregiver resilience and burden. Caregivers of patients in the initial phase of treatment experienced lower burden levels, likely reflecting the initial availability of energy and resources, as well as the potential optimism at the start of treatment as suggested by Sav A et al., [36]. As treatment progresses into the middle phase, the cumulative stress, extended caregiving responsibilities, and possible escalation of the patient's condition contribute to higher burden scores. This suggests that the ongoing and intensifying demands of caregiving over time lead to increased stress and decreased resilience, as per Kimura NRS et al., [16]. Conversely, the type of illness did not show a significant impact on these outcomes, indicating that the stage of treatment is a more critical factor in determining caregiver burden and resilience. These findings highlight the necessity for stage-specific support interventions to address the evolving needs of caregivers throughout the treatment process.

The present study showed that employment status significantly influenced caregiver burden and resilience, with employed caregivers demonstrating higher resilience and lower burden in areas such as spouse-related and physical and mental health burdens. Employment might act as a protective factor by providing a sense of routine, purpose, and social interaction, which can buffer against stress and enhance coping mechanisms, as suggested by Warner EL et al., [37]. Furthermore, the financial stability associated with employment may reduce stressors related to caregiving. However, employment status did not significantly impact other dimensions, such as external support burden and taking responsibility burden, which suggests that these aspects of caregiver stress may be influenced more by external factors and intrinsic caregiving responsibilities than by employment status alone, as per Kimura NRS et al., [16]. A comparison and summary of similar studies are provided in [Table/Fig-4] [13,15,18,19,21,23,34]. These findings underscore the complex interplay between employment status and caregiver experiences, highlighting the need for comprehensive support strategies tailored to the individual needs of caregivers.

S no.	Author's name	Place of study	Objective	Parameters assessed	Conclusion
1	Street AF et al., 2010 [34]	Victoria	To investigate the psychosocial adjustment of female partners living with men diagnosed with either localised or metastatic prostate cancer	Resilience	Female performed well
2	Toledano-Toledano F et al., 2021 [18]	Mexico	To identify sociodemographic variables for resilient prediction	Resilience	No gender role
3	Schrank B et al., 2015 [19]	Austria	Correlates of caregiver burden	Caregiver burden	Male caregivers reported lower burden compared to female caregivers
4	Opsomer S et al., 2019 [23]	Belgium	Correlates of resilience	Resilience	Age does not effect
5	Arab M et al., 2019 [15]	Iran	Association between social support and caregiver burden	Caregiver burden	Caregivers with qualifications below postgraduate level exhibited lower resilience scores and higher caregiver burden scores
6	Hayman KJ et al., 2017 [21]	New Zealand	Resilience and sociodemographic variables	Resilience	Socioeconomic status plays a crucial role in determining resilience levels
7	Bialon LN and Coke S, 2012 [13]	USA	Factors affecting caregiver burden	Caregiver burden	This suggests that while the loss of work may not directly influence resilience levels, it does contribute to increased caregiver burden in specific areas
8	Present study	India	To investigate the relationship between demographic variables and resilience, as well as caregiver burden, among caregivers of cancer patients in India.	Resilience and caregiver burden	The study found that most of the sociodemographic variables played a role in association with resilience but not with caregiver burden. Detailed findings are discussed above.

[Table/Fig-4]: Summary and comparison of findings[13,15,18,19,21,23,34].

Limitation(s)

One limitation of present research is the reliance on self-reported data, which may introduce response biases and inaccuracies. Additionally, the study's cross-sectional design limits the ability to establish causality between employment status, resilience, and caregiver burden. Longitudinal studies tracking caregivers over time would provide a more comprehensive understanding of the dynamic relationship between employment and caregiver outcomes. Furthermore, the sample size and demographic characteristics of the study population may limit the generalisability of the findings to broader caregiver populations. Future research should aim to include more diverse caregiver samples to ensure the representativeness of the findings across different demographic groups.

CONCLUSION(S)

Caring for a child with cancer significantly impacts caregivers, with demographic variables such as gender, education, socio-economic status, and employment status influencing their resilience and burden. Employment status shows clear associations with both resilience and burden, while family size and the type of illness do not. Tailored support strategies are essential to address the unique challenges faced by caregivers, enhancing their resilience and alleviating caregiver burden effectively.

REFERENCES

- Ward E, DeSantis C, Robbins A, Kohler B, Jemal A. Childhood and adolescent cancer statistics, 2014. *CA A Cancer J Clinicians*. 2014;64(2):83-103.
- Arora RS, Bagai P, Bhakta N. Estimated national and state level incidence of childhood and adolescent cancer in India. *Indian Pediatrics*. 2021;58(5):417-23.
- Mahendran R, Lim HA, Tan JYS, Ng HY, Chua J, Lim SE, et al. Evaluation of a brief pilot psychoeducational support group intervention for family caregivers of cancer patients: A quasi-experimental mixed-methods study. *Health Qual Life Outcomes*. 2017;15(1):17.
- De Souza JA, Hunt B, Asirwa FC, Adebamowo C, Lopes G. Global health equity: Cancer care outcome disparities in high-, middle-, and low-income countries. *Journal of Clinical Oncology*. 2016;34(1):6.
- Wolff JL, Spillman BC, Freedman VA, Kasper JD. A national profile of family and unpaid caregivers who assist older adults with health care activities. *JAMA Internal Medicine*. 2016;176(3):372-79.
- Hailu G, Abdelkader M, Meles H, Teklu T. Understanding the support needs and challenges faced by family caregivers in the care of their older adults at home-A qualitative study. *Clin Interv Aging*. 2024;19:481-90.
- Liu Z, Heffernan C, Tan J. Caregiver burden: A concept analysis. *International Journal of Nursing Sciences*. 2020;7(4):438-45.
- Johansen S, Cvancarova M, Ruland C. The effect of cancer patients' and their family caregivers' physical and emotional symptoms on caregiver burden. *Cancer Nursing*. 2018;41(2):91-99.
- Windle G. What is resilience? A review and concept analysis. *Rev in Clin Gerontol*. 2011;21(2):152-69.
- Brody AC, Simmons LA. Family resiliency during childhood cancer: The father's perspective. *J Pediatr Oncol Nurs*. 2007;24(3):152-65.
- Choi-Kwon S, Kim HS, Kwon SU, Kim JS. Factors affecting the burden on caregivers of stroke survivors in South Korea. *Arch Phys M Reh*. 2005;86(5):1043-48.
- Kahriman F, Zaybak A. Caregiver burden and perceived social support among caregivers of patients with cancer. *Asian Pac J Cancer Prev*. 2015;16(8):3313-17.
- Bialon LN, Coke S. A study on caregiver burden: Stressors, challenges, and possible solutions. *Am J Hosp Palliat Care*. 2012;29(3):210-18.
- Adib-Hajbagheri M, Ahmadi B. Caregiver burden and its associated factors in caregivers of children and adolescents with chronic conditions. *Int J Community Based Nurs Midwifery*. 2019;7(4):258.
- Arab M, Bernstein C, Haghshenas A, Ranjbar H. Factors associated with caregiver burden for mothers of children undergoing Acute Lymphocytic Leukaemia (ALL) treatment. *Palliat Support Care*. 2020;18(4):405-12.
- Kimura NRS, Baptista MAT, Dourado MCN. Differences in the predictors of the resilience between carers of people with young- and late-onset dementia: A comparative study. *Dement Neuropsychol*. 2022;16(3):292-99.
- Ahmadi M, Rassouli M, Karami M, Abasszadeh A, Poormansouri S. Care burden and its related factors in parents of children with cancer. *Iran Journal of Nursing*. 2018;31(111):40-51. Available from: https://www.researchgate.net/publication/326429473_Care_burden_and_its_Related_Factors_in_Parents_of_Children_with_Cancer.
- Toledano-Toledano F, Luna D, Moral de la Rubia J, Martinez Valverde S, Bermudez Moron CA, Salazar Garcia M, et al. Psychosocial factors predicting resilience in family caregivers of children with cancer: A cross-sectional study. *Int J Environ Res Public Health*. 2021;18(2):748.
- Schrank B, Ebert-Vogel A, Amering M, Masel EK, Neubauer M, Watzke H, et al. Gender differences in caregiver burden and its determinants in family members of terminally ill cancer patients. *Psycho-Oncology*. 2016;25(7):808-14.
- Nemati S, Rassouli M, Ilkhani M, Baghestani AR. Perceptions of family caregivers of cancer patients about the challenges of caregiving: A qualitative study. *Scand J Caring Sci*. 2018;32(1):309-16.
- Hayman KJ, Kerse N, Condesine NS. Resilience in context: The special case of advanced age. *Aging & Mental Health*. 2017;21(6):577-85.
- Simpson GK, Dall'Armi L, Roydhouse JK, Forstner D, Daher M, Simpson T, et al. Does resilience mediate carer distress after head and neck cancer? *Cancer Nursing*. 2015;38(6):E30-36.
- Opsomer S, Pype P, Lauwerier E, De Lepeleire J. Resilience in middle-aged partners of patients diagnosed with incurable cancer: A thematic analysis. *PLoS One*. 2019;14(8):e0221096.
- Van Roij J, Brom L, Sommeijer D, Van De Poll-Franse L, Raijmakers N, on behalf of the eQuiPe study group. Self-care, resilience, and caregiver burden in relatives of patients with advanced cancer: Results from the eQuiPe study. *Support Care Cancer*. 2021;29(12):7975-84.
- Cassidy T. Benefit finding through caring: The cancer caregiver experience. *Psychology & Health*. 2013;28(3):250-66.
- Úzar-Özçetin YS, Dursun SI. Quality of life, caregiver burden, and resilience among the family caregivers of cancer survivors. *Eur J Oncol Nurs*. 2020;48:101832.
- Li Y, Wang K, Yin Y, Li Y, Li S. Relationships between family resilience, breast cancer survivors' individual resilience, and caregiver burden: A cross-sectional study. *Int J Nurs Stud*. 2018;88:79-84.
- Tumanggor FRS, Dewi NS, Anggorowati. Resilience of parents who have children with cancer. *SJIK*. 2023;12(1):12-27.
- Campbell-Sills L, Stein MB. Psychometric analysis and refinement of the connor-davidson resilience scale (CD-RISC): Validation of a 10-item measure of resilience. *J Trauma Stress*. 2007;20(6):1019-28.
- Wang L, Shi Z, Zhang Y, Zhang Z. Psychometric properties of the 10-item Connor-Davidson Resilience Scale in Chinese earthquake victims. *Psychiatry Clin Neurosci*. 2010;64(5):499-504.
- Ye ZJ, Qiu HZ, Li PF, Chen P, Liang MZ, Liu ML, et al. Validation and application of the Chinese version of the 10-item Connor-Davidson Resilience Scale (CD-RISC-10) among parents of children with cancer diagnosis. *Eur J Oncol Nurs*. 2017;27:36-44.
- Thara R, Padmavati R, Kumar S, Srinivasan L. Instrument to assess burden on caregivers of chronic mentally ill. *Indian J Psychiatry*. 1998;40(1):21-29.
- Pai S, Kapur RL. The burden on the family of a psychiatric patient: Development of an interview schedule. *Br J Psychiatry*. 1981;138(4):332-35.
- Street AF, Couper JW, Love AW, Bloch S, Kissane DW, Street BC. Psychosocial adaptation in female partners of men with prostate cancer. *Eur J Cancer Care*. 2010;19(2):234-42.
- Theng B, Tran JT, Serag H, Raji M, Tzeng HM, Shih M. Understanding caregiver challenges: A comprehensive exploration of available resources to alleviate caregiving burdens. *Cureus* 2023;15(8):e43052. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10480575/>.
- Sav A, Kendall E, McMillan SS, Kelly F, Whitty JA, King MA, et al. 'You say treatment, I say hard work': Treatment burden among people with chronic illness and their carers in Australia. *Health Soc Care Community*. 2013;21(6):665-74.
- Warner EL, Kirchoff AC, Nam GE, Fluchel M. Financial burden of pediatric cancer for patients and their families. *J Oncol Pract*. 2015;11(1):12-18.

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