

Research Article

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Stress and Coping Strategies Among Caregivers of Cancer Patients in a Tertiary Care Setting in Nepal

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Abstract

Background: Cancer represents a tremendous burden on patients, families, and society as it is the second leading cause of death worldwide. With patients going through disease-specific problems, their care providers also face a variety of challenges during and after their treatment. The main objective of this research was to assess the stress level and coping strategies adopted by caregivers of cancer patients attending B.P. Koirala Memorial Cancer Hospital in Nepal.

Methodology: The study used a cross-sectional design at B.P. Koirala Memorial Cancer Hospital in Bharatpur, Nepal. Participants were selected through purposive sampling and data collection was done using a pretested interview questionnaire schedule. Standardized Kingston caregiver stress scale and Brief COPE inventory were used. A chi-square test was done to analyze the data.

Results: More than half (56.5%) of the caregivers were found to have mild level of stress followed by 26.1% with moderate stress levels. Educational status, monthly income, relationship with patient were found to have significant association with stress level ($p < 0.05$). Major coping strategies adopted by caregivers were praying and meditation (35.5%), accepting reality (34.8%), and seeking emotional support (22.5%).

Conclusion: The study's findings revealed a notable prevalence of stress among caregivers of cancer patients. It highlights the need for targeted efforts to address caregiver stress, tailoring strategies based on income and education levels. Special attention should be given to caregivers who are first-degree relatives, as they may require unique support mechanisms

Keywords: Cancer, Caregiver, Stress, Coping Strategies, Nepal

Tweetable Abstract: A long-term illness like cancer not merely affects the patient but also on their caregivers, necessitating targeted efforts to address the caregiver stress.

Introduction

Cancer is the second leading cause of death globally where 1 in 6 deaths occur due to cancer worldwide [1]. Approximately, 70% of deaths from cancer occur in low and middle-income countries [2]. According to the Global Cancer Observatory, there were an estimated 26,184 new cancer cases and 19,413 cancer deaths in Nepal in 2018 [3]. Cancer contributed to 10% of total deaths and 5.6% of total DALYs in Nepal [4]. With a per capita income of a nominal amount of 600 dollars, the majority of Nepalese struggle to afford expensive cancer treatment leading to financial burden to the patient and their family [5].

Cancer caregivers mostly refer to individuals/close relatives/family members who assist cancer patients [6]. Cancer caregiving involves several practical concerns related to the patient's day-to-day physical needs, such as managing symptoms and adverse effects, transporting the patient to medical appointments, administering medication, handling insurance, financial burden while patient treatment [7]. In the process, they pertain to suffer from a term called caregiver stress which is a condition of exhaustion, anger, rage or guilt that results from unrelieved caring for a chronically ill

dependent [8]. A study in Australia mentioned that more than half of caregivers had their physical health directly affected by tiredness and exhaustion (54.5%), back, neck and shoulder problems (33.8%), stress-related illness (6.6%), blood pressure or heart problems (12.6%), arthritis (10%) [9]. In 2014, 69.2% of cancer caregivers were moderate to very stressed and over a quarter of caregivers reported caregiving as being very stressful in USA [10]. In 2015, 89% and 1% of cancer care givers had moderate and severe level of stress in India respectively [8].

Execution of stress coping strategies is mandatory for caregivers to ensure a positive psychological adjustment to cancer treatment and patient management respectively referring to healthy environments, responsive parenting, sense of belonging, health activities, coping, resilience and treatment of illness [11]. With crucial importance given to family bonding in countries like Nepal, family members hold great responsibilities as patient's physical and emotional care providers. Keeping this into account, the study aimed to assess the level of stress, it's associated factors and coping strategies among caregivers of cancer patients attending B.P.

Koirala Memorial Cancer Hospital in Nepal.

Materials and methods

Study design

A cross-sectional analytical study was conducted among caregivers of cancer patients in B.P. Koirala Memorial Cancer Hospital, which is a tertiary-level hospital exclusively for the treatment and management of all types of cancer in Nepal. The study method was quantitative, and the study was conducted from July to December 2018.

Study population

In the context of this study, “selected caregivers” denote individuals primarily engaged in providing practical care to cancer patients at B.P. Koirala Memorial Cancer Hospital. Practical care involves tasks such as assisting with daily activities, medication management, transportation to medical appointments, and coordinating healthcare services. Caregivers included in the study were chosen based on their active involvement in these practical caregiving responsibilities, their presence at the hospital during the study period, and their voluntary willingness to participate in the study.

The required sample size was calculated as 138 using the population proportion formula, with the following statistical assumptions: a 5% margin of error (0.05), a Z-value of 1.96 corresponding to a 95% confidence level, and a 90% prevalence of stress among caregivers in a study conducted in India [12]. Caregivers were selected through the purposive sampling method. In our study, logistical constraints like limited resources and time were significant factors. Also, not all caregivers were consistently present at the hospital, making it challenging to get a representative sample. Therefore, purposive sampling was considered a feasible approach as it allowed us to recruit caregivers already present at the hospital, managing resources better and accommodating their intermittent presence.

Among selected caregivers, 68 caregivers were from the medical department and 70 from the surgical department. Caregivers of patients attending outpatient service and those who refuse to participate in the interview were excluded from the study. Additionally, caregivers who did not meet the eligibility criteria, such as those not directly involved in providing care or those unable to comprehend the study procedures due to language barriers or cognitive impairments were excluded.

Clear and concise information about the study’s objectives and confidentiality measures was shared with caregivers. Timing for data collection was adjusted to accommodate participants’ schedules which helped ensure flexibility and convenience. Despite the refusal to participate being an exclusion criterion, none of the caregivers approached purposively declined their participation in the study.

Data collection tools and techniques

Kingston Caregiver Stress Scale (KCSS) was used to assess the stress level of the caregivers. KCSS consists of a set of ten questions grouped into three categories (caregiving, family, and financial issues) [13]. In this study, the KCSS scores ranged from a minimum of 0 to a maximum of 40. For subsequent analysis, scores between 0 and 7 indicated “no stress,” scores between 8 and 18 indicated “mild

stress,” scores between 19 and 29 indicated “moderate stress,” and scores between 30 and 40 indicated “extreme stress.” To examine the association between stress and other independent variables, “no stress” and “mild stress” categories were merged, and “moderate stress” and “extreme stress” categories were merged.

A brief Coping Inventory was used to measure the coping strategies. This is a 4-point scale with 1 being ‘I haven’t been doing this at all’, 2 being ‘I’ve been doing this a little bit’, 3 being ‘I’ve been doing this a medium amount’ and 4 being ‘I’ve been doing this a lot’ [14]. The Kingston Caregivers’ stress assessment tool had satisfactory validity (0.82) and reliability (0.85), while the Brief COPE inventory demonstrated validity (0.73) and reliability (0.68) within acceptable ranges [15]. Both of the tools were merged into a single questionnaire and further translated into the Nepali language for participant’s ease. The translation validity was ensured by translating the questionnaire back to English. Pre-testing of the tool was done among 10% of the estimated sample size. Self-administration and face-to-face interviews were used as study techniques for literate and illiterate participants respectively.

Study variables

In this study, the dependent variable of interest was the ‘Level of Stress,’ while a range of independent variables was examined for their association with stress level. These independent variables were categorized into two groups: sociodemographic variables, including age, gender, monthly income, occupation, and educational background; and cancer and caregiver-related variables, which included the degree of relationship between the patient and caregiver, the type of cancer, the duration of illness, and the duration of caregiving.

Data analysis

The collected data was entered in Epi-Data version 3.1 and exported to IBM SPSS software for further analysis. Descriptive statistics (frequency, percentage, mean) were computed to understand participant characteristics. Bivariate analysis (chi-square test) was employed to explore associations between dependent and independent variables. Associations were presented using odd ratios (OR) and their 95% confidence interval (95% CI). The value for statistical significance was set at 0.05.

Ethical considerations

Ethical approval was secured as permission from the Institutional Review Committee (IRC), Pokhara University, and authorization was obtained from the hospital’s administration. Informed written consent was obtained from each participant before data collection, providing information about the research project’s objectives, methodologies, confidentiality guarantees, and questionnaire content. Participants were informed of their right to withdraw from the study or decline to answer specific questions. Confidentiality was maintained, and the data was exclusively used for research purposes.

Results

Socio-demographic and socio-economic characteristics

The majority (61.6%) of participants were male as shown in Table 1. Among 138 caregivers, 62.3% of participants belonged to the age

group of 21-40 years followed by 26.8% of participants of age group 41-60 years. Almost 38.4% of participants were Janajati followed by 21.7% of Brahmin. Almost 79% of participants were married. More than half (58%) of them had attained secondary and above level of education. The majority of the cancer caregiver's occupations were in agriculture i.e. 34.8%, followed by services which were 25.4%. The majority (58%) of caregiver's monthly income was found to be less than NPR. 50,000. (Table 1)

Table 1: Socio-demographic characteristics of caregivers

Variables (n=138)	Frequency (n)	Percentage (%)
*Age (Mean ± S.D)	34.81 ± 11.559	
<20	12	8.7
21-40	86	62.3
≥41	40	29
Sex		
Male	85	61.6
Female	53	38.4
Ethnicity		
Janajati	53	38.4
Brahmin	30	21.7
Chhetri	21	15.2
Madhesi	13	9.4
Dalit	12	8.7
Others	8	5.8
Marital Status		
Married	109	79
Single	29	21
Education		
Illiterate	15	10.9
Up to primary level	43	31.2
Secondary and above	80	58
Monthly Income (n=131)		
< NRs 25,000	80	61.1
≥ NRs 25,000	51	38.9
Occupation		
Agriculture	48	34.8
Services	35	25.4
Business	19	13.8
Others	14	10.1
Labor	12	8.7
Foreign Labor	10	7.2

* Minimum age=16, Maximum Age=68

Level of stress among caregivers

Among 138 caregivers, more than half (56.5%) of caregivers were found to have mild stress followed by 26.1% with moderate stress and 0.7% with severe stress. (Figure 1)



Figure 1: Level of stress among caregivers

Association of variables with caregiver stress

Several variables namely educational status (p value= 0.027), income level (p value= 0.016) and relationship with care-giver (p-value= 0.023) were found to be significantly associated with caregiver stress. Other variables like type of occupation, type of cancer, duration of illness and caregiving did not show association with stress in the study. (Table 2)

Table 2: Association of variables with caregiver stress

Variables	Stress Level		Chi-square value	P-value
	No and mild stress	Moderate and Severe stress		
Sex				
Male	66(77.6%)	19(22.4%)	2.242	0.167
Female	35(66%)	19(34%)		
Marital Status				
Married	77(70.6%)	32(29.4%)	1.174	0.191
Single	24(82.8%)	5(17.2)		
Education				
Illiterate	7(46.7%)	8(53.3%)	7.16	0.027*
Up to primary	15(34.9%)	28(65.1%)		
Secondary and above	48 (60%)	32(40%)		
Age				
≤ 20	8(66.7%)	4(33.3%)	1.586	0.663
21 - 40	64(74.4%)	22(25.6%)		
≥ 41	29(70.3%)	11(29.7%)		
Income level				
Less than 25000	52(65%)	28(35%)	5.830	0.016*
More than 25000	43(84.3%)	8(15.7%)		

Variables	Stress Level		Chi-square value	P-value
	No and mild stress	Moderate and Severe stress		
Relationship with care giver				
1st degree	71(68.3%)	33(31.7%)	5.205	0.023*
2nd degree	30(88.2%)	4(11.8%)		
Illness Duration				
Less than 1 year	80 (71.4%)	32 (28.6%)	0.938	0.333
1 to 5 years	21 (80.8%)	5 (19.2%)		
Care giving duration				
Less than 10 days	60(80.0%)	15(20.0%)	4.539	0.103
11 to 20 days	17(70.8%)	7(29.2%)		
More than 20 days	24(61.5%)	15(38.5%)		
Cancer Type				
Blood Cancer	16(57.1%)	12(42.9%)	-	0.259
Cervical cancer	18(81.8%)	4(18.2%)		
Stomach Cancer	11(91.7%)	1(8.3%)		
Urinary tract	15(78.9%)	4(21.1%)		
Oral cancer	19(73.1%)	7(26.9%)		
More than 25000	43(84.3%)	8(15.7%)		

*Significant at 0.05 probability levels, aFisher’s Exact Test

Coping strategies adopted by caregivers

As shown in Table 3, the most frequently used coping strategies by cancer patient’s caregivers were praying and meditation (35.5%), accepting the reality of fact that has happened (34.8%), taking action to make the situation better, and taking emotional support (22.5%). Minimally used coping strategies were usage of alcohol and drugs or other substances (0.75%) blaming self for things that happened (2.9%) and making fun of the situation (6.5%).

Table 3: Coping strategies adopted by caregivers

Characteristics	Frequency (Percentage %)			
	No practice	Low level of practice	Medium level of practice	Extreme level of practice
Turning work or other activities to take mind off	50 (36.2%)	27 (19.6%)	52 (37.7%)	9 (6.5%)
Alcohol or other drug	124 (89.9%)	10 (7.2%)	3 (2.2%)	1 (0.7%)
Emotional support to make	16 (11.6%)	33 (23.9%)	58 (42%)	31 (22.5%)

Characteristics	Frequency (Percentage %)			
	No practice	Low level of practice	Medium level of practice	Extreme level of practice
Deal with it	108 (78.3%)	13 (9.4%)	15 (10.9%)	2 (1.4%)
Make joke about it	44 (31.9%)	15 (10.9%)	49 (35.5%)	30 (21.7%)
Movies, watching TV, reading, day dreaming, sleeping and shopping	49 (35.5%)	29 (21%)	39 (28.3%)	21 (15.2%)
Accepting the reality	20 (14.5%)	5 (3.6%)	65 (47.1%)	48 (34.8%)
Expressing negative feeling	82 (59.4%)	22 (15.9%)	20 (14.5%)	14 (10.1%)
Trying to get advice or help from other people	17 (12.3%)	26 (18.8%)	59 (42.8%)	36 (26.1%)
Thinking hard about what step to take	32 (23.2%)	28 (20.3%)	58 (42%)	20 (14.5%)
Blaming myself for things that happened	119 (86.2%)	6 (4.3%)	9 (6.5%)	4 (2.9%)
Praying and meditation	23 (16.7%)	24 (17.4%)	42 (30.4%)	49 (35.5%)
Make fun of the situation	75 (54.3%)	35 (25.4%)	19 (13.8%)	9 (6.5%)

Discussion

Mental health remains a relatively underexplored topic in Nepal, particularly concerning caregivers of cancer patients. Our study provides insights regarding the stress experienced by this specific group, addressing a domain with limited prior research. Furthermore, by examining the coping strategies already employed by caregivers, our study not only adds to the understanding of the current scenario but also provides practical implications for intervention and support. The findings of our study showed the prevalence of mild stress among caregivers of cancer patients to be 56.5%, moderate stress to be 26.1%, severe stress to be minimal (0.7%) and 16.7% had no stress as such. These figures are consistent with prior research in India, which indicated that 82% of participants experienced moderate stress [16]. Comparatively, a study conducted in Mangalore, India, demonstrated a higher proportion, with 89% reporting moderate stress, 9% mild stress, and 1% severe stress [8]. Similarly, a study in Karad, Maharashtra, found that 55% of caregivers experienced moderate stress, while 35% grappled with se-

vere stress [6]. A study conducted in Saudi Arabia observed a stress prevalence rate of 65.5% among cancer caregivers [17]. Likewise, in the United States, the study showed 69.2% reporting moderate stress and 28% experiencing extreme stress [10].

The variation in stress levels among caregivers of cancer patients may be attributed to cultural, structural, and individual factors, including differences in societal norms, support systems, caregiving demands, personal coping mechanisms, and the utilization of diverse stress measuring tools across studies. Despite variations in stress prevalence across countries and continents, a significant prevalence of stress is evident in each study.

In our study, education level showed significant association with the level of stress. This was in alignment with a study conducted in Hong Kong where caregivers who had less education were at higher risk of developing stress ($p < 0.01$) [18]. Studies conducted in India and Saudi Arabia also showed a significant association between education and stress level [6,19]. The significant association between education status and stress levels among cancer caregivers may be due to differences in health literacy regarding the intensity of cancer, its curability, and preventability of further complications. Educated caregivers tend to have better ability to navigate complex medical information making them relatively more aware of the existing health condition of the cancer patient.

In our study, there was also a significant association between income and level of stress. This was in alignment with a study conducted in Saudi Arabia which showed income level had a significant association with stress level [19]. This observed association may be due to the financial constraints experienced by individuals with lower incomes. Limited financial resources could impact access to support services, healthcare facilities, and coping mechanisms, thereby increasing the stress burden on caregivers. Similarly, married caregivers were found to have more stress as compared to unmarried and divorced caregivers as per a study conducted in Taiwan whereas in this study there was no significant association of marital status with stress [20].

Relationship type with the cancer patient and stress being significantly associated ($p=0.023$) depicts how nature of bonding has to be sensitively considered while developing coping interventions for the caregivers. This is supported by a study in Maharashtra which showed relationship to the patient of caregiver to have significant association to the stress [6]. The responsibility and burden of taking care of the cancer patient is inevitably higher among immediate family members i.e. first degree caregivers that might eventually predispose them to higher intensity of stress within themselves. Various studies have shown that the presence of a sick or disabled family member is known to create burdens for both caregivers and other family members, affecting various aspects of their lives including physical and emotional well-being, as well as their overall quality of life [21-24]. Similar to a study in Tamilnadu, relationship with the patient and stress ($P = 0.004$) implicates that immediate family members of countries of eastern civilization like Nepal, India are evidently close and dependent of one another [25].

In our study, most frequently used stress coping activities constituted healthy practices such as praying and meditation, trying to seek external assistance, accepting reality, taking actions of betterment and getting emotional support. Studies have shown

that religious coping provides support during challenging times, helping individuals manage stress, while fostering acceptance and well-being [26-28].

Alignment of Nepalese societies towards religious faith for cure of the diseased might shape their behaviour during stress coping. Unity and support within family members can have a supporting role while they deal with the induced stress. The least used coping strategies here, were use of alcohol and drugs use, try to deal with it and make fun of the situation. In contrast, Turkish family caregivers predominantly favoured effective coping attitudes like active planning, acceptance, cognitive restructuring, seeking external aid, and religious solace, while also demonstrating some reliance on ineffective strategies such as avoidance isolation [29]. Meanwhile, a mixed-methods research study conducted in India uncovered a diverse array of coping mechanisms among caregivers. In addition to denial, substance use, behavioural disengagement, self-blame, venting, and self-distraction, positive coping strategies such as humour, religion, instrumental support, planning, emotional support, positive reframing, acceptance, and active coping were prevalent [16]. Coping strategies can be planned and tailored based on caregiver's preference relative to generic intervention styles in this context.

The variations in stress coping strategies across different studies may have been influenced by diverse cultural contexts such as cultural norms, social support structures, etc. Considering the positive outcomes of coping skills interventions observed in a randomized controlled trial, it is recommended to explore the incorporation of coping skills interventions into caregiver support programs, aiming to enhance overall well-being and alleviate the burdens associated with caregiving tasks [30]. It is also evident that providing family members with coherent, consistent, and sustained information from clinicians is instrumental in mitigating the stress accompanying caregiving duties during hospital stays [31].

Our study has several limitations. As the study design was cross-sectional, we couldn't capture the dynamic nature of caregiver stress over time. A chi-square test was done to explore associations. While this approach provided meaningful preliminary findings, it did not account for potential interactions or confounding effects between variables. In addition, the use of purposive sampling may have introduced potential selection bias, as the chosen participants may not have fully represented the broader population of cancer caregivers. These limitations emphasize the need for caution in generalizing our findings and highlight the importance of future research using longitudinal designs, robust statistical analysis, and more representative sampling strategies.

Conclusion

A long-term disease such as cancer not merely affects the patient but expands its diverse effects on their caregivers. In our study, majority of caregivers (56.5%) had experienced mild stress followed by moderate stress (26.1%) of inpatient cancer patients of B.P. Koirala Memorial Cancer Hospital, Bharatpur, Nepal. Factors such as educational status, economic status, and relationship with cancer patients were significantly associated with stress among participants. Most of them adopted praying and meditation and actualization of the situation as major coping strategies. Programs related to stress management is recommended to be conducted among

the inpatient care givers of the cancer hospital. There should be provision of free cancer treatment facilities to poor and marginal group of people and provision of support groups offering individual counselling to cancer caregivers. Additionally, essential training in decision-making and problem-solving for caregivers is crucial for comprehensive care.

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Disclosure

The authors declare no conflicts of interest in this work.

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